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Palliative Care

Core Skills and Clinical Competencies

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Dedication

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"The last stages of life should not be seen as defeat, but rather as life's fulfillment. It is not merely a time of negation but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and to expect this."

Cicely Saunders, 1965
–First published in American Journal of Nursing;
republished in Cicely Saunders: selected writings *by David Clark*
Oxford University Press, 2006

We dedicate this book to the memory of Dame Cicely Saunders. In its pages, we have sought to provide for the core skills that a clinician needs in order to make it possible for every man, woman and child that, when dying is necessary, it becomes life's fulfillment.

Linda Emanuel, S. Lawrence Librach, 2007

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Palliative Care in Developing Countries

Foreword

> *We emerge deserving of little credit, we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced. (1)*
>
> *John Hinton*

THE ROOTS OF HOSPICE/PALLIATIVE CARE

With these searing words, British psychiatrist John Hinton proclaimed the societal neglect and deficiency in end-of-life care that he documented in his research during the 1960s. As a champion for change, he was not alone. Cicely Saunders, an Oxford trained nurse, had also noted the plight of the dying and, in particular, the need for improved pain control. Her commitment was unswerving. When a back injury ended her nursing career, she became an almoner (social worker) and finally, on the advice of a medical mentor ("*Go read Medicine. It's the doctors who desert the dying.*" [2]), she 'read Medicine', qualifying as a doctor in 1957 at the age of 39. With this she became a one-person interdisciplinary team, a breadth of perspective that was to serve her well (3, 4).

Cicely Saunders brought a unique spectrum of personal qualities, including unstoppable determination, to the task of redressing the care of those with far advanced disease. Her published 1959–1999 correspondence (5) sheds light on the many reasons for her success as a health care reformer: her keen intellect, an inquiring mind given to attention to detail; an articulate tongue, capable of infectious persuasiveness; a tendency to consult wisely and widely with world authorities on each successive issue under the scrutiny of her "beady eye"; personal warmth, coupled with confident humility; and natural leadership skills of epic proportions!

The result of this providential mix was St. Christopher's Hospice in London, the first center of academic excellence in end-of-life care. Dame Cicely saw St. Christopher's as being "*founded on patients*" (6). The evolution of her dream was painfully slow. David Tasma, a young Polish cancer patient whom she had nursed in February 1948, had famously remarked to her, "*I only want what is in your mind and in your heart,*" (7) thus indicating to Cicely's discerning ear the twin

pillars on which she would construct her refined approach to whole person care. There must be all the diagnostic and therapeutic skills of the mind, but also an empathic, caring, presence of the heart, a presence that is willing to accompany into the uncertain terrain where both sufferer and caregiver may learn that *"there is great strength in weakness accepted"* (8).

Dame Cicely recognized that, as healthcare providers, we don't always 'make it all better.' Indeed, we don't *ever* make it all better. As she expressed it, *"However much we can ease distress, however much we can help the patients to find a new meaning in what is happening, there will always be the place where we will have to stop and know that we are really helpless."* She continued, *"It would be very wrong indeed if, at that point, we tried to forget that this was so and to pass by. It would be wrong if we tried to cover it up, to deny it and to delude ourselves that we are always successful. Even when we feel that we can do absolutely nothing, we will still have to be prepared to stay. 'Watch with me' means, above all, just be there"* (8).

Nineteen long years of careful planning, fund raising, and the evolving clarity of her vision passed between David Tasma's prophetic comment and the admission of the first patient to St. Christopher's in June 1967. Dame Cicely was leading global health care into a paradigm shift: from disease to illness (9); from quantity of life to a broader perspective that included quality of life; from the reductionism of the biomedical model, to Engel's biopsychosocial model (10), and beyond, to include consideration of the determinants of suffering and the existential / spiritual issues implicit in 'Total Pain,' (11) whole person care and healing.

THE LEGACY AND THE CHALLENGE

Now, four decades later, we marvel at the wisdom of Cicely Saunders' planning and the richness of her legacy. At this writing, St. Christopher's addresses the needs of 1,600 patients and families per year with its 48 beds, 500 patients per day on the Home Care Service, and 20 patients per day in the Day Care Centre. Their education and research programs continue in Cicely's fine tradition of excellence. They host 2,000 visitors and convene 80 conferences and workshops on an annual basis. But her legacy reaches far beyond South East London; she has been the critical catalyst for the international modern hospice movement, with the creation to date of at least 8,000 hospice and palliative care programs in more than 100 countries and the academic field of palliative medicine.

The progress in palliative care diagnosis and therapeutics over the decades since 1967 has been remarkable (12). With our increasing sophistication as 'symptomatologists' (13) and the trend toward specialization, however, are we in palliative care in danger of losing touch with Dame Cicely's challenge to see our mandate as '*a characteristic mixture of tough clinical science and compassion*' (14)? Do we see palliative medicine as going *"beyond symptom control to creating conditions where healing at a deep personal level may occur for the individual patient,"* (15) or are we progressively less effective as we attempt to stretch our perspective from *biomedical model*, to *biopsychosocial model*, to *whole person care* with its notion of 'healing'(16)? Each practitioner must answer this question for him- or herself.

Our answer to that question is important. The *whole person* approach to understanding the patient's needs is gaining increasing credibility as research

repeatedly identifies major pieces of evidence of its validity. It is becoming clear that *the whole person care model* has greater explanatory power than either the biomedical or the biopsychosocial models alone. For instance, there is now evidence to support the following:

- The existential/spiritual domain is a significant determinant of quality of life (QOL) throughout the disease trajectory in cancer patients (17, 18) and is the most important QOL determinant once patients with Human Immunodeficiency Virus (HIV) have Acquired Immune Deficiency Syndrome (AIDS) (19).
- Cognitive processing of loss that leads to increased perception of meaning is associated with increased CD4 counts and enhanced survival among grieving men with HIV — the first study to show a link between meaning and mortality; the first to report an association between meaning and physical health indexes that does not appear to be mediated by health behaviors (20).
- QOL is not dependent on the physical domain alone. For example, 2 out of 3 cancer patients who were aware of their diagnosis (and most were on active therapy at the time) assessed their own health to be "very healthy" — including 12 who died during the study (21). Similarly, in a study of emotional well being, persons with malignant melanoma had emotional well being levels similar to the general population (22). Furthermore, in a study of life satisfaction, seriously disabled persons, including some who were paralyzed following trauma, had life satisfaction levels equal to the general population (23).
- Telomere shortening compatible with cellular aging of a full decade has been found in premenopausal women with chronic stress (24).
- Those able to find equanimity in the face of impending death are distinguished from those with anguish and suffering by several themes. They commonly experience: a sense of 'healing connection' to self, others, the phenomenal world experienced through the five senses, or ultimate meaning as perceived by that person; a sense of meaning in the context of their suffering; a capacity to enter the present moment; a sympathetic connection to the cause of their suffering; an openness to finding potential in the moment that is greater than their need for control (25).

Clinicians must, it would seem, take seriously Kearney's insightful observation that we need to aim "*beyond symptom control to creating conditions where healing at a deep personal level may occur for the individual patient,*" (26) and do so with a growing understanding of the potential involved. If human life is, as the world's great Wisdom Traditions remind us, body, mind, and spirit, and the agreed goal of palliative care is to improve the quality of life, how can we *possibly* do this without considering the whole person?

Today, the multiplicity of challenges that face those who would follow in Dame Cicely's footsteps are as varied as the cultural, geopolitical, and economic realities that frame the communities they work in. How different the demands and constraints in the isolated communities of the Canadian Arctic and the teeming cities of India. Yet the root causes of suffering are the same. This book is offered in the hope that a well referenced, reader-friendly guide to palliative care principles and practices in a wide range of clinical settings will be of assistance to you.

As you provide your patients with palliative care, keep the whole person care model in mind and create care plans that truly integrate the comprehensive assessment that it demands. Offer care that reaches for perfection in symptom

management and in care for the psychosocial and spiritual forms of suffering that life-limiting and serious illnesses entail, and consider ways of working with the innate healing potential which resides within each individual, and which, paradoxically, appears to be catalyzed by approaching death (27). Whether you are a surgeon in a tertiary care center (as I have been), or a nurse or social worker (both of which Dame Cicely Saunders was before she became a doctor), or any other healthcare provider, may you find in the following pages what you need to accomplish the noble task of caring for the seriously ill person and his or her family '*with tough clinical science and compassion.*'

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Preface

Palliative care comprises at least half of medicine. It is the art and science of providing relief from illness-related suffering. Every medical declaration binds medical professionals not only to cure when it is possible, but to care always. Alleviation of suffering is needed for all who have a curable illness as well as those who have an incurable illness, and it is certainly needed for those with chronic, serious illnesses. Palliative care developed in the modern era as a set of skills for care of those near the end of life. This hospice movement's achievements have provided much. It afforded dignity and comfort to those who were dying and to the families of the dying and, with the cognitive and technical skill set that has developed within hospice, it is now augmenting the quality of care provided by all disciplines and specialties within medicine.

Never in the history of medicine has our knowledge and technical capacity to manage symptoms and address other forms of suffering been so sophisticated. Palliative care combines a growing understanding of the molecular, physiological, and psychological mechanisms of suffering at the end of life with interventions that are increasingly subjected to rigorous evaluations. These care interventions are provided with interdisciplinary care delivery models that are humanly-centered (rather than technology- or pathophysiology-centered) and grounded in a network of community-specific, therapeutic relationships that take into account the whole picture of the origins of the patient's suffering and its consequences.

Palliative care can provide something else that society sorely needs; the ability to make life transitions and sustain tragedies without being entirely decimated. By accepting the concept of a good death, palliative care can focus on the journey at the end of life and the possibilities for continuing contributions of the patient to his or her family and society. By managing symptoms and attending to mental health, spiritual well-being, and social needs, palliative care allows the patient to continue living life to the fullest extent possible for the longest possible time. It allows the patient to stay out of the dependent, sick role and continue in the role of a productive member of society, including staying in the work force if it is helpful to do so, for as long as possible. Palliative care also supports the caregiver and, after the patient's death, the bereaved. Caregivers can perform better and sustain their prior roles better with this type of support. Bereaved families can grieve and learn to go on without their loved one in a healthier, more viable way if they have the type of preparation and support that palliative care offers. These

approaches combine to provide potentially tremendous improvement in what is known in medical economics as the realm of indirect costs. As such, societies ravaged by tragedies such as the current HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) epidemic or other sources of widespread loss may need palliative care for societal survival and future well-being.

It is hoped that the present textbook will help spread the practices of palliative care to those areas of medical care and regions of the world that need it. The first section provides a practical rendition of the framework philosophy and core skills — cognitive and technical — of palliative care. The second section provides a chapter on how palliative care can be integrated into some of the major illness categories that encompass chronically disabling and life-shortening conditions. The third section is about care delivery; palliative care can be delivered in settings that range from specialty consultation services to home care and each has its own common and unique challenges. Finally, the fourth section sets out some features of the range of social settings in which palliative care must be delivered and considers some of the policy options that impact palliative care and, in turn, the social impact that palliative care can have.

The content of this book has been gathered from pioneers of palliative care and is offered to all of those who serve their fellow human beings with care: professionals, policy makers, service delivery administrators, and family and community members.

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SECTION I

Palliative Care: Core Skills

A GENERAL FOUNDATIONS

1 Palliative Care

A Quiet Revolution in Patient Care

Linda L. Emanuel and S. Lawrence Librach

> *In some respects, this century's scientific and medical advances have made living easier and dying harder. (1)*

CHAPTER OUTLINE

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INTRODUCTION

The above quoted accurate observation by the Institute of Medicine stands in stark contrast to the reality that dying can be the last great time of living. Sadly, multiple studies have confirmed the poor quality of end-of-life care in North America (2, 3, 4). If medicine is part of what stands between people and their ability to access the potential qualities of that time of life, medicine needs to ask: What happened? Part of the answer comes from the fact that the way people die has changed over the last hundred years. Most people now die with one or more chronic illnesses and demonstrate a predictable, slow decline in function (5). Another part of the answer must note that the emphasis in medical care has been on technology, cure, and life prolongation, and some societal expectations have also been youth oriented and similarly disinclined to afford mortality its place. The medical and social cultures offered little that was appropriate for those who were dying. Therefore, these patients stayed in the sick role rather than entering the dying role, and received interventions designed for cure and recovery.

Both medicine and society have great capacity to react, however, and a set of countermovement initiatives began. In a parallel to the home birthing movement, which was a reaction to the intense focus on technology in obstetrics, people facing the other end of life also began to seek control over their dying. Some pushed for assisted suicide, whereas others sought and found ways to protect the human meaning that could be found in dying; this approach was supplied by hospice, and more people began to seek home hospice care at the end of life (6, 7). The pioneers and leaders of hospice and palliative care constructed a coherent analysis of what needed to be fixed. It was a radical list, as the Foreword by Mount describes. Hospice and palliative care developed rapidly in a movement that made *hospice* a household word and *palliative care* a type of care that people now know they can demand from their health care delivery organization. Looking back at 3 decades of progress, it seems fair to say that the early decades of hospice and palliative care can be understood as a successful call to action to address the observed deficiencies in end-of-life care that had come to characterize the modern North American health care systems (8).

This chapter delineates what constitutes palliative care and how to aid quality of life for the dying. It illustrates how palliative care seeks to change the norms of medical care so palliative care can be integrated into all of medicine, summarizes some remaining challenges in palliative care for both the practicing clinician and the health care system, and explores challenges for palliative care in the global setting.

This textbook goes on to outline the following: the core competencies of end-of-life care, which can now be taught to future generations of clinicians; essential palliative care skills for specialty settings, which can now be taught in specialty training programs; and service delivery features in palliative care that should be essential knowledge for all health care administrators and community practitioners of all professions. The textbook ends with a broad overview of the social setting in which palliative care is still facing major challenges, including a hard look at the role of financial devastation in the illness experience and a look at global challenges. Finally, the Appendix offers a drug formulary, information on the practicalities of reimbursement for clinicians in the United States, further resources for professionals, and further resources for patients and their informal caregivers.

DEFINITION OF PALLIATIVE CARE

The terms *hospice* or *end-of-life care* can be seen as synonyms for *palliative care.* Although each term has distinguishing features, for simplicity we use *palliative care* throughout this textbook to denote either or both.

The World Health Organization (WHO) has defined palliative care as follows (9):

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

The attributes of palliative care have been articulated in a consensus document from Canada (10). These attributes support the WHO definition and guide all aspects of care at the end of life; they are as follows:

1. *Patient Family Focused.* Because patients are typically part of a family, when care is provided, the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs, and practices, their developmental state, and their preparedness to deal with the dying process.
2. *High Quality.* All hospice palliative care activities are guided by the following: the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth telling and confidentiality; standards of practice that are based on nationally accepted principles and norms of practice and standards of professional conduct for each discipline; policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines; and data collection and documentation guidelines that are based on validated measurement tools.
3. *Safe and Effective.* All hospice palliative care activities are conducted in a manner that is collaborative; ensures confidentiality and privacy; is without coercion, discrimination, harassment or prejudice: ensures safety and security for all participants; ensures continuity and accountability; aims to minimize unnecessary duplication and repetition; and complies with laws, regulations and policies in effect within the jurisdiction, host, and palliative care organizations.

4. *Accessible.* All patients and families have equal access to hospice palliative care services wherever they live at home, or within a reasonable distance from their home, in a timely manner.
5. *Adequately Resourced.* The financial, human, information, physical, and community resources are sufficient to sustain the organization's activities and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.
6. *Collaborative.* Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.
7. *Knowledge Based.* Ongoing education of all patients, families, caregivers, staff, and stakeholders is integral to the provision and advancement of high-quality hospice palliative care.
8. *Advocacy Based.* Regular interaction with legislators, regulators, policy makers, health care funders, other palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and to develop, palliative care activities and the resources that support them. All advocacy is based on nationally accepted norms of practice.
9. *Research Based.* The development, dissemination, and integration of new knowledge are critical to the advancement of high-quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations in effect within the jurisdiction that govern research and the involvement of human subjects.

CONCEPTS OF QUALITY OF LIFE AND QUALITY OF DYING

As palliative care made its case and consolidated its progress, it had to respond to those who saw no need and asked: Why should care be changed? It also had to respond to the skeptics who asked: Is it possible to have a quality of life at the end of life or a quality of dying? For those who wanted change but needed direction, it had to respond to the question: What are those issues that are important to patients and families at the end of life? The following studies, among others, identify guiding answers to these questions.

One study interviewed 385 US residents in 32 cities using a qualitative interview and focus group–based method. Those who were interviewed were not yet facing a terminal illness and reflected mixed demographics, including age, race, culture, and religion. These persons articulated their concerns, hopes, and beliefs about the process of dying (10). They feared being hooked up to machines at the end of life and preferred a natural death with loved ones in familiar surroundings. They did not believe that the current health care system supported their ideal concept of dying, and although they thought it was important to plan for dying and death, they were uncomfortable with the topic and resisted taking action. They said that family consideration was their primary concern in making end-of-life decisions. Finally, they reported that the current planning options did not support the way they wanted to manage dying and the death experience.

In another study (11), 126 patients from 3 groups (patients undergoing dialysis, patients with human immunodeficiency virus [HIV] disease, and chronic care

patients) were interviewed to explore their views about what constitutes good end-of-life care. A qualitative analysis was done, and certain themes were identified. These included receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.

Similarly, in another study (12), a cross-sectional, stratified, random, national survey conducted in March through August 1999 among seriously ill patients (n = 340), recently bereaved family (n = 332), physicians (n = 361), and other care providers (nurses, social workers, chaplains, and hospice volunteers; n = 429) found similar themes. The investigators also identified items that were consistently rated as important (>70% responded that the item is important) across all four groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a "whole person." Eight items received strong importance ratings from patients but were not rated as highly by physicians ($P < .001$). These items included being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God. Ten items had broad variation within, as well as among, the four groups, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Participants ranked freedom from pain most important and dying at home least important among nine major attributes.

PALLIATIVE CARE AS A REVOLUTION

The palliative care movement has been revolutionary in that it insisted on a return to the professional values of medical care that seemed to have been too much overlooked at the time. The changes required were applicable to most settings of medical care. So perhaps it is ironic that it began as a fringe movement, providing hospice care as a charity. Palliative care is based on a clear and coherent philosophy of care that Dame Cicely Saunders first articulated as *care of the whole person* (13). This comprehensive model of care was interprofessional from the beginning in that it recognized the need to meet physical, psychological, social, and spiritual needs of dying patients and their families. An important goal in palliative care is to educate the patient and family about dying and death. Another goal is to integrate care across the continuum of care stages, even when the doctors or sites of care change; palliative care seeks to bridge these changes by communicating and transferring the patient's goals of care and resultant care plans from one team to another. Care is also extended beyond the patient's death to reflect a concern for the grief outcomes of family members.

In this new model of care, death is not seen as the "enemy" but rather as an acceptable outcome. The dying are seen as having an important role, complete with tasks and expectations, that is different from the sick role when recovery is expectable (14). The goal is not to prolong or shorten life; rather, the process of dying is to be freed of as much unnecessary suffering as possible. The inevitable dimensions of suffering that do accompany dying and death can be mollified by finding meaning and purpose in the life lived and by enhancing quality of life and the quality of the dying process. The model is not technology based, but it does accept

technology when it reduces suffering. The model is based on a comprehensive, humanistic approach to suffering and dying. It attempts to make end-of-life care as comprehensive and important as care at the beginning of life. The philosophy of palliative care is remarkably similar throughout many countries; this reality may be understood as evidence for the fundamental need and place of palliative care in medicine and medicine's mandate to care for people who face illness-related suffering.

Palliative care has grown progressively as an international movement and has many national and international organizations that promote better care for the dying across all continents. Specialists have developed in all health care professions, and a large volunteer component has emerged to support care for patients and families. There has been a tremendous growth in knowledge about dying and death in our society, and research is now taking on a level of sophistication that parallels any other area in medicine. The public, especially in developed nations but also those that are resource constrained, has become more aware of the option of palliative care. For professionals, many new text and Web resources, comprehensive education programs, research efforts, and specialty journals are devoted to enhancing end-of-life care.

CHALLENGES FOR THE PRACTICING CLINICIAN

The palliative care movement has seen dramatic progress, and in this sense, as characterized earlier, the call to action has been successful. However, major challenges remain, some of which are listed and discussed here.

Developing Competencies

Much still has to be done to incorporate competencies in end-of-life care into curricula of undergraduate and postgraduate professional training programs. All practicing clinicians must have at least basic competence in this area, with support from specialists as necessary. Continuing professional development in palliative care needs to be more in evidence in conferences and other professional development activities.

Dealing with One's Own Dispositions

Death anxiety among professionals appears to play a strong role in the way clinicians interact with dying patients (15, 16). This probably results, in part, from training that emphasized death as the enemy. When clinicians see patients and families suffer greatly and feel helpless to intervene, it is powerfully compelling to walk away if these health care professionals have had no training in how to deal with their own (in part, transferred) suffering. If clinicians cannot access their intuitive capacities for empathic healing through presence, it may be impossible to offer the kind "being there" that Mount describes in the Foreword of this book as one of Dame Cicely Saunders' founding insights and premises for palliative care. Better training and care are necessary.

Providing Palliative Care for All Life-Limiting Illnesses

Cancer is only one cause of death, and although the prevalence of cancer is increasing, other illnesses such as heart disease, lung disease, and Alzheimer's disease account for a larger proportion of deaths. Palliative care has grown up in the midst of cancer care; more attention must now be paid to providing palliative care to patients dying of other diseases too.

Palliative care needs to be integrated into the care of all chronic, progressive illnesses and some acute illnesses in which the prognosis is quite poor. This integration should take place much earlier in the course of the illness than it currently does. Patients and families need to deal with many issues from diagnosis on and not only after some magic line is crossed into acknowledged dying. Clinicians can integrate palliative care into any disease management guideline as described in Chapter III-6. Clinicians also need to be aware that reducing palliative care into symptom management alone avoids the desired comprehensive, humanistic approach to dying patients and their families.

When to Involve a Palliative Care Specialist

The knowledge base in palliative care has grown progressively. Specialists who focus on complex issues in end-of-life care have emerged in all health care professions. These professionals have provided necessary research, education, and advocacy, but this should not mitigate the need for every professional to have some basic competencies in end-of-life care. Palliative care specialists are not needed for every patient, and these specialists will never be able to meet the increasing need for care for the dying. Moreover, specialized palliative care should not be confined to free-standing hospices or palliative care units; rather, it must be present across the continuum of the health care system, in part to avoid the abrogation of others in providing better care.

Maintaining the Interprofessional Nature of the Work

No one profession or discipline can provide all the care necessary to meet the physical, psychological, functional, social, and spiritual needs of a dying patient and family. Interprofessional teamwork is essential both for the patient and family and for the professionals.

CHALLENGES FOR THE HEALTH CARE SYSTEM

The challenges that still face the palliative care movement are not limited to those that must be shouldered by individual clinicians. The health care systems, and those who design, manage, advise, and influence them also face challenges. Some are listed and discussed here.

Developing Standards and Quality Improvement Processes

The standards for palliative care set out by National Consensus Project for Quality Palliative Care (17) in the United States and the norms of practice developed in Canada have started to set standards for palliative care organizations. Certification

of practitioners in palliative care is evolving rapidly in the United States, so fellowship requirements for specialty board certification, which will occur through the American Board of Medical Specialties, will be in place over the next few years. In addition, there are guidelines in palliative care and recommendations on how to incorporate palliative care into other disease management guidelines (18, 19). A need exists, however, for accreditation standards and quality improvement strategies for all organizations and agencies involved in end-of-life care, whether they be acute care hospitals, cancer centers, long-term care facilities, home health agencies, or others. The Joint Accreditation Commission of Healthcare Organizations' standards for hospitals have been examined by the Center to Advance Palliative Care, and a detailed cross-walk has been provided so facilities can build according to established standards (20). In Canada, the Canadian Council on Health Services Accreditation, the agency that accredits almost every health care organization and agency, has developed a palliative care section in their accreditation instrument. Implementation may spur the development of high-quality end-of-life care across the spectrum of health care. For the health care system in general, attention to at least the following areas is necessary.

Support for Formal Interdisciplinary Teams

All palliative care organizations, whether national, regional, or local, recognize the need for interdisciplinary formal teams. However, the challenge is for the system to recognize and support formal teams (organized interdisciplinary teams devoted to palliative care), rather than relying on the informal teams that form around a patient and family but that have no consistent existence or commitment to work as a team with palliative care expertise and focus.

Many palliative care services already rely on nursing care to a greater extent than other specialties. Over the long term, it may be necessary to adjust the ratio of professionals involved since much more counseling is needed than can be provided by the current workforce of social workers and pastors in most medical service delivery systems.

Support for Education at All Levels

Across the care continuum, there is a need for basic competencies in end-of-life care for all who work with terminally ill patients and their families. This includes not only health care professionals, but also volunteers, health care aides, personal support workers, and administrative personnel who come into direct contact with palliative care patients and their families. The Canadian Strategy on Palliative and End of Life Care Education Work Group has developed a list of six basic, common competencies for any professional:

1. Address and manage pain and symptoms.
2. Address psychosocial and spiritual needs.
3. Address end-of-life decision making and planning.
4. Attend to suffering.
5. Communicate effectively.
6. Collaborate as a member of an interdisciplinary team.

This framework has been used to develop a national education program for medical students and postgraduate trainees in Canada. Health care curricula in North America must incorporate such competencies and must ensure that they are taught and evaluated in the clinical milieu. Health care organizations need to incorporate palliative care into orientation sessions for new employees and new care providers. Continuing professional development in palliative care is also important. Organizations such as the Education in Palliative and End-of-Life Care Project in the United States and the PALLIUM Project in Canada have been leaders in developing comprehensive, basic education materials and educational and high-quality train-the-trainer programs. In some jurisdictions (e.g., California), palliative care professional development is required for renewal of medical licensure.

Support for Research

Although much research is done on curative or life-prolonging treatments, many agencies that support research have not devoted funding to end-of-life care research until recently. The recently formed National Center for Palliative Care Research in the United States is a promising development.

There are a number of challenges that need special support in order for palliative care research to progress. One challenge arose when commentators questioned whether palliative care patients who are often quite ill can participate in research ethically. Others argued that it was a right and essential for progress that palliative care patients be included in research. The ensuing debate made it is clear that such research can be ethical as long as the basic precepts of autonomy, informed consent, privacy, confidentiality, and justice are observed. It has been observed that patients and families are frequently very open to participating in research in palliative care environments because they are often very grateful for the care they have received.

Another challenge arose from the practical realities involved in doing research on people who are so sick that they often cannot participate in research for long. Special methods for collecting and analyzing data are needed to mitigate this problem (21).

Further, research in symptom management aspects of palliative care is challenged by the reality that palliative care patients have a wide diversity of illnesses and usually have multi-system failure and multiple symptoms.

Moreover, palliative care needs to go beyond medical interventions in pain and symptom management to include research on the psychosocial and spiritual needs of patients and families. Much of the necessary research in those areas requires social and behavioral research techniques that are often qualitative or ethnographic or economic, research types not well represented in health care environments and often not adequately supported by national health care research funding agencies. Interdisciplinary research networks and partnerships need to be developed that include experienced researchers from those areas as well as medical, nursing, social worker, pastoral and pharmaceutical researchers. This will reflect the diverse needs of patients and the interdisciplinary care that characterizes high-quality end-of-life care.

Finally, to foster the development of education research in end-of-life care and the training of required personnel, palliative care must become part of research at academic institutions. Centers, units, or departments must be fostered.

Integrating Palliative Care Throughout Health Care Services

Palliative care should not be seen as a transfer of care out of the usual care system. Palliative care can be successfully integrated much earlier into the course of patients with progressive, life-threatening illness without any negative effects on patients and families. The commonly held view, that patients will give up hope and "stop fighting" their illness, is wrong and often prevents or delays high-quality end-of-life care until just a few weeks or days before death. This short period of intervention may mean that patients and families suffer unnecessarily for months. Diagrammatic care models (e.g., that provided in Figure I-19-1 of Chapter I-19, by Ferris and associates) and models of adjustment (e.g., those described by Knight and Emanuel in Chapter I-14) have been developed to demonstrate how transitions can happen effectively, enhance patient and family satisfaction, and lead to outcomes such as better quality of life during the process of dying and, for families, after death has occurred.

Transitions between services remains a challenge. Constraints on the provision of palliative care exist in some jurisdictions in the United States and Canada; they are inherently harmful and without scientific basis. These and other challenges can be met through local and national initiatives of government, accreditation bodies, health care organizations and agencies, academic institutions, professional organizations, and research funding agencies.

PALLIATIVE CARE AND THE GLOBAL SETTING

The threat of future pandemics, the current pandemic of HIV disease, and the health consequences of poverty and violence that have plagued populations through the ages show no sign of abatement, and all pose considerable challenges, the response to which must include providing better palliative care.

In resource-limited nations, family members, community volunteers, or health care workers are often not available in sufficient numbers to provide adequate care without overburdening individual caregivers. However, palliative care is potentially the kind of low-cost, high-impact approach to maximizing function until inevitable death that resource-limited countries need. Ideally, a mix of family, volunteers and health care workers will be used, perhaps with hospital- or clinic-based health care workers providing initial teaching to families and volunteers who can follow-up with most of the care in the home. Palliative care should be included in the curriculum of medical, nursing, and other health professional students to ensure that health care workers are sufficiently prepared to care in all settings and are able to train family members and community volunteers (22).

Good palliative care also requires that standards, policies, and guidelines be in place at the system and institutional level to ensure that adequate palliative care is integrated into health care systems. In many countries, especially resource-constrained countries, restrictive regulations regarding the use of morphine and other opioids constitute obstacles to pain control. Even in the United States, where

palliative care is relatively well developed, some jurisdictions have regulations (e.g., triplicate prescriptions for opioids) that inhibit physicians from prescribing these analgesics for terminally ill patients. In both resource-constrained and wealthier environments, good palliative care can be cost-effective and can result in fewer hospital days, more home care, and fewer high-technology investigative and treatment interventions, with responsibility of care given to an interdisciplinary care team that includes volunteers.

PEARLS

- The goal of palliative care is quality of life for the dying and their families.
- Palliative care is well defined, has clear content areas, and has well-specified guidelines.
- Palliative care demands sophisticated skills that have warranted its acceptance as a full specialty in medicine in the United States.
- Challenges to implementing high-quality palliative care involve internal barriers within the clinician as well as system barriers.

PITFALLS

- Palliative care is not a soft discipline.
- Lack of competence in the area is a barrier to high-quality palliative care.
- Lack of training and lack of adjustment to the clinician's own mortality are barriers to high-quality palliative care.
- Lack of institutional support for palliative care makes it difficult to provide high-quality care to the dying.

SUMMARY

The accurate observation of the Institute of Medicine that "in some respects, this century's scientific and medical advances have made living easier and dying harder" has a silver lining. The fundamental humanity in members of society and the ability of the medical system to see the need for change have fostered a rebalancing movement that has made significant progress in returning to high-quality health care for the dying. Palliative care is now a component of health services, and it is replete with skill sets and the capacity to deliver its desired outcomes. The remaining chapters of this textbook outline the following: the core competencies of end-of-life care, which can now be taught to future generations of clinicians; essential palliative care skills for specialty settings, which can now be taught in specialty training programs; and service delivery features in palliative care that should be essential knowledge for all health care administrators and community practitioners of all professions. The textbook ends with a broad overview of the social setting in which palliative care is still facing major challenges, including a hard look at the role of financial devastation in the illness experience and a look at global challenges. Finally, the Appendix offers a drug formulary, information on the practicalities of reimbursement for clinicians in the United States, further resources for professionals, and further resources for patients and their informal caregivers.

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Suffering

The Hundred Little Deaths before Dying

2

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CHAPTER OUTLINE

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INTRODUCTION

The inclusion of a discussion of suffering in the general foundations section of a palliative care textbook surprises and encourages me, more so when it is given consideration as a core skill of palliative care. I concur in the discussion that follows: a deep knowledge of suffering and an ability to suffer are both mandatory skills for the provision of good palliative care. I go on to offer the view that the suffering known as grief is also very much a skill of living and a skill that a dying person is inevitably called on to learn and practice. The challenge to do so is compounded significantly when the person is dying in a death-phobic and grief-illiterate culture and when the person is attended by helping professionals whose self-appointed tasks include the management and containment of suffering. The discussion concludes with the suggestion that it is in a shared understanding of suffering that the palliative care provider and patient and family find the kinship necessary for making a good dying.

DEMANDING TO LIVE: DEATH PHOBIA CAUSES SUFFERING

A man I know who had lived with Mayan people in Central America for years observed in passing one day, apropos of nothing in particular: "It is very strange where you come from." Brevity tends to be a highly valued skill in many indigenous cultures, and I respect it. For a host of reasons, I readily agreed with his assessment—and still do—although I hoped that he might elaborate. At length, and

with some encouragement, he did. With a shrug that showed more bewilderment than judgment, he said, "It seems that people where you are wake up every day expecting to live." And with that he had exhausted the subject to his satisfaction.

I continue to believe that one should listen particularly well to the observations of those outside one's culture. By doing so, one can taste the difference and re-experience one's own culture and its edicts as something less than inevitable and universal, and so I have contemplated that man's oblique observation for years. He seemed to say that where he had lived people woke up every day in some other fashion, with a different kind of expectation and a different understanding of why they were in the world and a different sense of how much life was enough life, and that it was perfectly possible and natural and good to do so. He was suggesting, of course, that people there woke up every day expecting in some way to die. In his brevity was subtlety: I believe he meant that, among his people, death—and their own personal death—was their more or less constant companion throughout their lives and was a known thing for them.

Many people who work in the helping professions would not rest until something had been done to relieve people of having to rise each day in that fashion, with that kind of death familiarity. These workers would do so because it is not possible in the dominant culture of North America to imagine a people who would willingly choose such an orientation to life or who would knowingly perpetrate it on their young people. The assumption of their personal and professional culture would be that people with a chronic, unrelieved expectation of death must be afflicted with a depressive, fatalistic malaise, the only rational explanation for something so strange, so unproductive, and so lacking in positivism and unbridled faith in a limitless future. This last element is important for our discussion: The inability to imagine a future inherently better than the present—a tangible, enduring consequence of the immigrant experience that has done so much to shape contemporary North America—is a cornerstone in the dominant culture's understanding of suffering.

I have been to the village where this man lived, and I can report that although those people certainly had their share, or more, of death of all kinds—relentless infant mortality, death by treatable minor illness or preventable accident, generations of politically motivated assassinations, a life expectancy slightly more than half that among North Americans—they did not appear to have their commensurate share of depression. On the other hand, if waking up each day expecting to live were a sure sign of emotional health, we should expect that depression in North America would be a minor event, afflicting primarily those people who had exhausted that expectation. People in the helping professions, and many others, know that this is not so. They know further that depression is abundant, particularly in those places where people exercise this expectation to live. And so on this thin thread I would hang the following proposition: Getting up every day expecting to live and depression may have a causal connection, and palliative care is one area in which this connection shows itself plainly.

Expecting to live in a culture that has massive medical and technical prowess is not often subtle, nor is it without consequence. Expecting to live is not content to remain an expectation for long: Sooner or later, it becomes a demand. The practice of medicine in North America is generally in thrall to this demand to live. We could not expect any culture wedded to this demand to live, or its medical system to make significant room for any death acknowledgment in its priority list, and

so palliative care occupies the liminal status it does. A children's hospital with a mission statement that every child be a healthy child will not readily allow palliative care a high profile in its public relations, for example. In a culture that resolutely demands to live, dying is not part of any definition of health, nor does it occupy a significant place in the life plan of most individuals.

The demand to live is at war with life—the dying part of life. Its advocates hold that living and dying are opposites. The demand to live is not, as it might seem, a life-affirming sentiment, unless your understanding of life does not include intractable limitation, diminishment of all kinds, and death. Although traded on and invoked constantly, the demand to live in the dominant culture of contemporary North America is generally invisible because it passes for legitimate and universal common sense and is believed to reflect a healthy, positive outlook. It often takes an outsider, or someone who does not share the conviction that death is an intrusion in the natural order of things, to see it. In the context of end-of-life care, however, it is naked and adamant. The demand to live shows itself in all its raging glory when it meets with an irreducible limit on what living can be or whether it may continue. Stories abound of how health care practitioners and families with a seriously ill member will advocate without rest for every available and conceivable medical intervention. The question "Should we?" is now frequently answered by the question "Can we?". The wretched excess that boiled up around the recent Schiavo case in the United States traded on this unchallenged and unacknowledged demand to live. Night after night for weeks, television viewers were treated to an overwrought, vicarious tragedy. At the end of life, where the ethical uncertainties often reign in the very places where medical technology proliferates, it is no longer a question of what to do, but of what not to do; not how to intervene, but how to stop intervening. With little or no preparation or guidance, families are now routinely in the position of having to withdraw the very technology that helped keep their loved one alive, in order to achieve something like a good death. Demanding to live obliges everyone to exhaust all the possibilities, instead of teaching everyone how to find the sign that says "Enough," when enough means ample, sufficient, as in good enough. In an age that demands to live, what does enough life look like?

Palliative care decision making is routinely obliged to deal with the consequences of prior medical interventions, interventions made with little or no recourse to palliative care input or consideration. Some years ago, I was asked to become involved in the case of a 31-year-old man, recently married and the father of a 7-month-old child, who had end-stage lung cancer. He had confided to the physician on our palliative care team that he was beyond the limit of his endurance and wanted his hydration and ventilation withdrawn, but he was unable to tell his wife of his wishes because of the intensity of her religious beliefs about the omnipotent redemptive powers of the Almighty. My assignment: to help his wife to consider withdrawal of the technology that was extending her husband's days. This couple lived in a two-room second-story walk-up apartment, with the baby in one room and the husband in the other. I asked his wife what she knew of her husband's prognosis and wishes. She allowed that he was seriously ill, but that he was still alive because God wanted him to live. We discussed the decision-making process that had gone on throughout her husband's illness, and we talked about who had initiated the curative and then palliative treatment of her husband's cancer, who had provided the hydration and ventilation, and whether her husband

showed any improvement in his health, mobility, energy, or outlook as a result of the technology. I suggested to her that we could no longer be sure of God's will—if we ever could have been sure of it—because we had intervened so thoroughly in her husband's disease process and life that whatever was meant to be had been irretrievably obscured by what we meant to be. She was immovable on this point, and there was no feeling of relief or vindication on the palliative care team when her husband died several days later, ventilator and hydration in place. In this case, his wife's appeal to and assessment of the will of the Divine was so consistent with the culture-bound demand she made of her husband to live that they were, for her, indistinguishable.

The dominant cultures of North America and Europe, and perhaps beyond, are death-phobic cultures. The professions that are underwritten and are highly valued by those cultures—medicine among them—are likely to have some vestige of death phobia, and it may be that the status they enjoy requires them to sustain that phobia. Like all phobias, death phobia has grown more pervasive and persistent as the direct experience of being in the conscious presence of dying has grown rarer and rarer, as the explicit realities of dying have faded to rumour. The prevailing aversion to death and to speaking of death comes not from the experience of living and working closely with death, but from the scarcity of that experience and from intolerance of that experience. The proliferation of palliative care services in North America, if there is a proliferation, is not a sign of the ebbing of death phobia. It is the ghettoizing of dying, making a cloister for the unacceptable, that masquerades as acceptance. It is as if we were to mistake the proliferation of old folks' homes as a sign of the veneration of age.

Death phobia, we could agree, is not an adequate preparation for experiencing or treating terminal illness. With so few culturally sanctioned opportunities to experience death directly, it is harder to make the case that the dread associated with dying comes from knowledge of the experience of dying. As technological interventionism becomes a more compelling option, and as the demand to live is championed as a life-affirming moral imperative, it is more necessary to make the case that death phobia is a primary cause of suffering: It is not dying, but the feeling of being insulted and demeaned and arbitrarily victimized by the finality of death, that makes much of the suffering associated with death. Any medical or psychosocial approach to serious illness that inadvertently embraces or serves the demand to live has an iatrogenic culpability in patient and family suffering at the end of life.

THE OLD NIGHTMARE AND THE NEW

I am not old enough to remember the days when unmanaged pain and rampaging symptoms and cobalt treatments and the like were commonplace, and those who worked with dying people did what they could, hoped for the best, and planned for the worst. I have heard stories, but much of it sounds like the travail of another age and place, much as a grandparent's stories sound remote and half-imagined or exaggerated to younger people. Clearly, there was a lot of suffering, and those working in the field must have shared in it. My generation of palliative care practitioners has inherited some of the dread of the limited treatment options of

those times, and so, for us, patient access to advanced pain and symptom management has been a holy grail of end-of-life care. Good pain and symptom management is currently honored as both an art and a science. It is also offered up in our time as the prime prerequisite for a good death.

The phrase *pain and symptom management* itself seems to carry some of that old dread, however. It is clear enough that most palliative care practice models and standards of care are predicated on the conviction that management, containment, and problem-solving strategies are the sanest, most self-evidently effective, and most rewarding professional responses to most medical and nonmedical aspects of dying. Coping and management have been enlisted in the repertoire of palliative care theory at all levels, and their utilization is designed in part to give practitioners a sense of being able to do *something* in the face of circumscribed options. Coping strategies are certainly a cornerstone of psychosocial training and practice, just as problem solving (e.g., brief, solution-focused therapy), along with antidepressants, is the principal psychotherapeutic approach to grief and death anxiety in palliative care patients and their families. The old nightmare scenario to which these strategies are responding is the occasion of unexpected pain and unanticipated death in the context of severe technical constraints on the practitioner. The presumption may be that unanticipated pain and death are the root causes of suffering at the end of life.

Pain and symptom management has come of age during a period of intense and seemingly inevitable advancement in medical technology and therapeutic application, and that is no coincidence. The Western world's deep fascination with the redemptive possibilities and powers of technology is long standing, and nowhere is it more pervasive and persistent than in its medical incarnation. If there is any sense of remoteness from medical research and development experienced by general practitioners of medicine and related front-line professions, it has done little to dissuade many from a faith in the inevitability of advancement in medical research and development. The popular imagination has made a home for this fascination as well. I have been beseeched by many end-stage palliative care patients to help keep them alive long enough to be treated and cured by the next new and improved drug or procedure that is inevitably coming down the pipe and into the laboratory or pharmacy.

Good pain management is, in many respects, a reality. It is now more the rule than the exception that people are dying with their symptoms somewhat well cared for and their pain for the most part well anticipated and managed, depending on professional competence in generic end-of-life care, patient compliance, and drug availability. Good deaths should abound, but it is managed death that abounds instead. The old nightmare of palliative care has been replaced by a new nightmare: Many patients' symptoms are under some control, the pain is well managed, and they move through their last days in vague and underrecognized panic and terror and dread.

The standard understanding of palliative care usually offered up by practitioners is a sequence of compassion-informed and medically and psychologically skillful comfort-giving measures: harm reduction, pain management, symptom control, psychotherapy, antidepression. Go down the list of subjects in any palliative care textbook: multisymptom management, management of anxiety, depression, delirium, management of constipation and diarrhea, coping with loss, resolving grief. In our focus on pain and symptom management, and our prevail-

ing practice of managing death, we seem to have missed something about our manner of dying.

People who have been diagnosed as having life-threatening illness are typically offered several treatment regimens. The ostensible goals of these options are to pursue a cure and to relieve symptoms. Their subtler purpose is to obey the cultural imperative to do *something* or try *everything* available. Their fundamental purpose is to buy or borrow or steal more time. If the person is remarkably adroit in the consultation session and is not overwhelmed by the diagnosis and the proffered treatment options, he or she may inquire of their diagnostic professional: "If I submit myself to the harsh protocols of treatment you offer, and if we win, and if I gain the 'more time' we are bargaining for, what am I to do with it? What is this 'more time' for?" The diagnostic professional in response may indicate that this is not really his or her field, but he or she would be happy to make a referral to the offices of social work, psychiatry, chaplaincy, or psychology, which are down the hall. If we find any absurdity, shortsightedness, ingratitude, or self-absorption in the question "What am I to do with the 'more time' I win?", it may come from the fact that we believe utterly that more time means more life, and that more life is inherently and self-evidently efficacious and a good thing, with its own payoff and its own owner's manual. If people win their heart's desire, by way of supplicating prayer or adroit medical intervention, or both, surely they will know how to live it when it comes to call.

The massive achievements in medical technology over the last 30 years have simply not been accompanied by any comparable advancement in the practice wisdom needed to guide their application or to respond well to their consequences. A fundamental consequence of extending a person's life through the application of medical technology in a palliative care context is that that person's death is also extended. Most palliative patients have had their lives extended by treatment, and that extended life is conducted in the palpable presence of their impending death. This is a new and permanent attribute of the "more time" that has been secured for them. "How am I to live?" is a confounding enough and rarely considered question at times when one is healthy and feeling competent. It is far more than confounding and relentlessly persistent when one is sick, diminished, fearful, and, because of the changes in what family, friends, and doctors and counsellors now say and do not say, no longer sure about one's citizenship in the land of the living.

Living in the presence of one's death is not a lifestyle choice or a matter of conjecture or philosophical reflection for palliative patients. It is an existential, spiritual, psychological, and corporeal fact. If it is rare to have some kind of companionship with and understanding of death throughout one's life, then there is no reason to presume that one will know how to live at the end stage of a terminal illness, regardless of whether medical intervention wins more time. It is probably a far more common occurrence than has been thought in the palliative care field that it is a prolonged dying—a *lived* thing—rather than fear about dying—an *imagined* thing—that results in that panic and terror and dread that accompany the end of life for many palliative care patients. Unanticipated death is now relatively rare in palliative care, as (thankfully) is rampant and untreatable pain. Patients and practitioners in the present decade are contending instead with an unanticipated and often vaguely articulated wish to die that comes not from the experience of pain but from the experience of continuing to live and that is not

obviated by improved pain management or antidepressants or persuasions about quality of life.

This unanticipated, seriously expressed wish to die is not an inevitable part of the disease trajectory, nor is it any more usefully understood as situational depression. Rather, it often accompanies the life/death extension that medical innovation has engineered. The official palliative care program of pain and symptom management of dying inadvertently *makes* suffering for patients and families. Fundamentally, this is because palliative care seems to have accepted the dominant culture's understanding of death as something that is random, chaotic, apocalyptic, and senseless. The deep responsibility of people who have special expertise in end-of-life care is to challenge especially those unspoken fears about dying that contribute so enormously to suffering. Instead, palliative care practitioners inherit and assume the culturewide dread of dying when they resort to a "management and control" agenda. A culture that is death phobic and technology reliant wages war on the random and the chaotic and the unpredictable, and management and control are strategies of containment. Medicated patients whose pain is at low ebb may lose track of their dread for prolonged periods. Dispensing antidepressants is likely to reduce the *expression* of the wish to die, but it will not touch the untenable dilemma of winning the more time bargain while being obliged to live that more time in a death-phobic place and time. More time for palliative patients means, irreducibly, more death. Patients and families need strategies of wonder to give them some kind of option to death phobia when in the palliative stage of their illness. Palliative care practice cannot—must not—be seduced by a patient's deep ambivalence at wanting to know about dying into a default function of symptom management and trafficking in euphemism.

LONG LIFE, QUICK DEATH?

So, how best to understand suffering? Most Indo-European languages give their users this way of asking the question: "What *is* suffering?" But this "is" is elusive. The static, immutable, definition-driven way of understanding things does not work where suffering is concerned, just as it is a hopeless way of understanding dying. There is no verb "to be" in many other linguistic families, and so their users have to ask: "Suffering makes what happen?" or "Suffering belongs to whom, and where, and when?" The quest for essence, in other words, has to be flavoured in the complicating caldron of relation: Things mean what they mean not unto themselves, but as they are with each other.

I read a story some years ago of a Western tourist who found his way to a small town in Tibet during the early days of the thaw of the Chinese embargo on foreigners traveling there. It happened that he was on the main road on market day when Chinese army trucks came headlong down the road and drove through the middle of the throng of buyers and sellers. Everyone except one man escaped the path of the trucks, and when the dust began to clear, he lay crumpled and clearly dead in the roadway. The shock fixated everyone there, until an older, rough-looking man stepped from the crowd and knelt over the dead man and began whispering in his ear. He did so with obvious force of purpose for several minutes until the dead man's extremities began to twitch and tremble. The older

man continued the whispering and gesturing until the twitching and trembling subsided and then stopped altogether. Four or 5 more minutes had gone by. The older man slipped into the crowd, and the dead man was dead again in the road.

When the Westerner returned home, he headed straight for the nearest Buddhist temple and asked the abbot about the mysterious event. He was told that the older man was a priest, classically and esoterically trained, and an outlaw in Chinese-occupied Tibet. The priest, at considerable risk to his own life and limb, had dragged the dead man's shocked and aimless spirit back into his broken body to give him the chance to die well, something he was robbed of by the truck that ran him over. He had used his training to oblige the dead man to suffer dying a second time, so as not to be taken unawares. Dying well, in that part of the world, meant being given the chance to know death before dying.

As the average lifespan lengthens a little with each passing decade now, most people in North America will live long enough to outgrow their former certainty that they will live forever. No surprise, it is not often an entirely welcome realization. In most people, it results, more or less inevitably and increasingly as their lives proceed, in imagining, picturing, and probably having to decide about their own dying. Given all this, ask what most people wish for in themselves and the answer is most likely to contain some version of a good, longish life and a quick death. This wish is perfectly reasonable and understandable and, in our time, increasingly impossible.

Consider those people you have known who have slipped past the transitional stage of "getting old" and entered, however reluctantly, into the tribe called "old." Their numbers are increasing with each decade. Consider the look that is often seen in their eyes. Consider where it comes from, and imagine that more than loneliness resides there. These people have lived long enough to see personal and public catastrophes of all kinds. They have seen the passing away of the entire generation of their grandparents, and then their parents. They have seen the passing away of most or all of their contemporaries, and the passing away of many who were younger than they. They probably have lived long enough to be the last one they know who remembers many of the things they remember and to be alone enough in that remembering. These people have lived with that most inevitable of life's companions, their own dying, long enough that they cannot be surprised by it, so it will not, and cannot, happen quickly. They have known that they will die for some time, regardless of the state of their health. The look that can sometimes be seen in the eyes of the old is the look of knowing about dying and no longer being able to die quickly. Regardless of their age, many patients in the palliative stage of their illness—many of whom will neither live long nor die quickly—have a similar look and for the same reason.

So if we can agree that it is not really possible to live long and die quickly, then what is being longed for in this simple and unattainable wish? I think it is more than a wish not to linger in pain and pointlessness. You may say: It is a wish to die unawares, without knowing that you are dying. Or you may say: It is a wish to die without having to die. In an age that has affection for self-direction, autonomy, and feeling in control bordering on mania, the wish for a quick death surprisingly expresses a wish to be on the receiving end of something sudden, unforeseen, and involuntary. English grammatical rules can help to clarify this a bit. The verb "to die" can be used only in the active voice. There is no way to say "dying" passively. How can we make a passive voice verb that has the same end result as

the verb "to die"? We have to use the verb "to be killed." Our grammar makes us choose: Either "I die" or "I am being killed."

That is what I think is lingering in the wish for a quick death: It is a wish to be killed. The differences between the two are not only grammatical or semantic. Dying irreducibly is something you do; being killed irreducibly is something done to you. A death-phobic culture believes that knowing you are dying makes suffering, that being obliged to live in the shadow of your impending death makes suffering. A death-phobic culture that wakes up every day expecting to live and prescribes management and control as its bromide for the immense challenges that come with the end of life delivers itself from the inevitable suffering that such phobia brings during the process of extended dying by opting for sedation over sorrow, ignorance over moral intelligence, euphemism over age-appropriate candor: being killed over dying. That is where the unanticipated wish to die (in the absence of uncontrolled pain) and the suffering that gives it urgency come from. They do not come from dying, but from hating death. They are not life affirming; they demand a life without dying. A debate on physician-assisted death that doesn't include an awareness of this tension is not useful to anyone.

For all its diagnostic and jurisprudential sophistication, the dominant culture in North America continues to struggle with coming to some acceptable and legitimate clarity and consensus as to when life begins. We haven't achieved much more with answering the question: "When do we begin to die?" My contention is that, regardless of biochemical processes and what computed tomography scans show, one begins to die when one begins to suspect that one is dying. Sorrow and suffering come with that suspicion and with its confirmation. At that point, people face a simple, momentous decision that their lives rarely prepare them for: "*Shall* I die?" Dying is a bundle of tasks that terminally ill people either take up or leave undone, including making decisions about what one's life meant, and why life is as it is, and what one's way of dying will do and mean to one's loved ones in the days and years after one's death. How people die and how palliative care providers help dying people have enormous consequence for family, community, and culture because these experiences give others some living example on which they will draw when their turn comes. "Dying" and "being killed" may both end at the end of life, but they have fundamentally different outcomes. A person wishing to be killed foments death phobia in the generations that survive his or her passing, a phobia that is unnecessary and indefensible, whereas one who takes on the tasks of dying as doable tasks gives the survivors one tangible living example of what such an endeavour looks like that will serve them well when their turn comes. Dying well therefore is not only a *right* of all people. It is also a moral, mythic, social, and existential *obligation* of all people. Informed awareness is a prerequisite for dying well, comparable in rank with good pain and symptom management.

This brings me finally to say something about the job description of palliative care providers. I see enormous tension among us between acting on what we know of dying and death and proceeding according to what patients and families seem comfortable with or capable of. The feeling of being obligated to maintain hope and a positive outlook—a cornerstone of palliation—is a common element in this tension. Often the result is that we opt for defining palliative care as the amelioration of suffering through comfort. What makes comfort-giving measures comforting, ultimately? The recipient of those measures feels comforted by them,

without which no meaningful comfort has been given. What is required to experience comfort? The measures rendered are consistent with a person's prior experience of comfort. In other words, the measures must conform to what has been familiar and comforting in the past. Given that most people no longer have much direct experience with dying—comforting or otherwise—before their own, it is not obvious that comfort uninformed by the realities of dying can be useful at the end of life.

If palliative care exists because dying happens, then palliative care at its core must be formed around the realities of a patient who is dying in a particular culture at a particular time, in the midst of a particular family or community, as a particular person. Palliative care must be a culturally attuned endeavor. If practiced in a culture where death is a failure, a tragedy, a violation of personal autonomy, a punishment for not eating right or allowing too much stress in one's life, the ultimate in a series of random cruelties, inevitable and wrong all at once—death-hating and limit-hating attitudes at their core, all of which are suffering-inducing stances—then palliative care's fundamental responsibility to the patient, the family, the community, and the practitioners is not to manage or reduce a patient's exposure or reaction to dying but to expose those attitudes as root causes of intractable suffering. The palliative care practitioner's deep responsibility is to challenge—even subvert—those cultural norms that contribute to patient suffering at the end of life, even when patients and families themselves identify heavily with those norms. We do not give patients what they want because they want it, or because they say it is good for them, when it comes to prescriptions or assisted suicide. Why do we do so when it comes to euphemizing death, or complying with obfuscation, or agreeing that talking about dying with dying people who are unwilling to do so itself makes suffering?

Under all the subspecialties and the medical and nonmedical distinctions in palliative care, our job is to teach people how to die or how to live as if what is happening is happening. Helping them die is part of it, yes, but the essential function is to advocate dying by teaching what the work of dying is. This is a sane alternative to the common preference for avoiding the work of dying by being killed. Being qualified and feeling qualified to teach the work of dying are other matters, but I am persuaded that it is teachable, learnable, doable, and crucially necessary. It is true that there is little or no demand among palliative care patients or in the broader culture to learn the skills of dying. The burden of the work lies in trying to teach something knowable but generally unknown and probably to help create some kind of felt need for it. We are forever selling what no one wants, and there is some suffering in that for us.

At its core, the work of dying centers around learning and growing the skill of grieving. In a death-phobic culture, grief is understood to cause suffering. A death-phobic culture is a grief-illiterate culture that contains suffering by limiting, resolving, medicating, or banishing grief. Ask, and most people will tell you that the opposite of grief is joy or happiness. For them, being happy requires that grief be very scarce. I remember once reading how Carl Jung remarked toward the end of his life that, if forced to choose, he would rather be whole than be good. And so I wondered for years: Where does the ability to be good come from? Jung's genius was to answer that it does not come from the absence of "bad" in one's life or character, but from a deeper life skill of being whole. Wholeness includes all of one's experiences, flaws, sorrows, and achievements: The ability to be good is

rooted in all of them and not in the absence of some. Grief is a life skill: Its only opposite is the inability or refusal or failure to grieve. It cannot be taught by problem solvers, but by grievers.

The ability to know happiness is rooted in the ability to grieve, and vice versa. Grief has equal parts of sorrow over loss and a love of being alive, and one does not cancel the intensity of the other. It deepens the other. Consider earth. What is it made of? The detritus of all that has lived before. Combine botany and grief, and you answer the question this way: All that grows is rooted in and fed by all that failed to live forever. The architecture of life shows us resolutely that living is rooted in dying, that knowing life is rooted in knowing death, that the ability to love being alive is rooted in knowing the grief of not living. In a death-phobic culture, grief is far from inevitable, but for that more utterly necessary. The inability to grieve compounds suffering. The inability to grieve is a root condition for depression, and so we may seriously consider prescribing grief to treat depression. Teaching the skill of grief helps dying people give their suffering its rightful place at the banquet table of their life's end.

Our job is extraordinarily difficult for three fundamental reasons. First, we work in the continued presence of the suffering of the people we try to help. Subsequently, when we do our work well, we participate in that suffering to some degree, both as perpetrators and as co-sufferers. Finally, we practice death knowledge in a culture that is death phobic. So we are like that monk who appeared at the dead man's ear in Tibet, keepers of an orphan wisdom, looking for willing recipients for some of life's great and valuable secrets. We whisper about what dying can and should be to people who instead long already to be on the other side of it. We oblige people to taste deeply the sorrow of the passing of their lives, to give suffering a rightful place and portion in their lives.

What, if anything, could qualify someone to do such a job? In a book entitled *Under the Mountain Wall*, I remember Peter Matthiessen telling a story of sitting in Borneo in the 1950s with an old man who gestured to a hill a mile or two from his village and told him that despite how closely situated they were, he could not speak with the people of the village on that hill. Matthiessen asked the old man whether this made the other villagers enemies. No, the old man told him, they are our relatives. Matthiessen asked how they could be relatives when they did not even speak the same language. The old man told him, "they die the same kind of death as we do."

PEARLS

- An understanding of suffering, coupled with a deep capacity to suffer, is a core skill of palliative care provision.
- Death phobia is better understood and responded to as a cultural norm, not a personal idiosyncrasy.
- Palliative care providers must encourage a patient's active participation in his or her dying.

PITFALLS

- Suffering is not an intrapsychic problem and thus cannot be solved.

- Life extension is typically death extension in palliative care, and few patients are provided any guidance commensurate with the sophistication of the technology that has extended their days.
- Reinforcing a patient's refusal to die in the guise of patient-centered practice is disastrous for the patient, the palliative care provider, and the communities in which they live.

SUMMARY

The demonization of suffering and death phobia, widespread as these things are, do not make for good kinship with the dying people with whom we work. Knowledge and experience of suffering are what give us our kinship with the people we are honoured to serve, whether we speak the same language or not, and that kinship is probably our most reliable qualification to do the work. Professional development in palliative care should include a reconsideration of what our job is regarding patient suffering, and we should not accept as inevitably beneficial the management of suffering—the patient's or our own—as we have accepted the management of pain and symptoms.

Comprehensive Assessment

3

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INTRODUCTION

Medical care depends on the traditional patient history and physical examination, an approach to patient assessment that has developed gradually over the course of the modern medical era. Variants that emphasize diverse aspects of a person's

situation are used in different disciplines in medicine, such as nursing, social work, and pastoral assessments. Furthermore, different specialties (e.g., family medicine, rehabilitation medicine, cardiology, and infectious disease) also use their own variants that emphasize different aspects of a person's situation. Many components of patient assessment have been evaluated for efficacy. As a whole, however, the assessment has received sparse attention in research, and its variants are often not well codified or researched. Palliative care has adopted its own distinctive approach based on the whole-patient assessment. Early in the evolution of the discipline, the palliative care assessment was founded on its specific purposes and soon thereafter on research.

Palliative care aims at improving the quality of both life and dying by ameliorating or relieving physical symptoms and psychological, social, and existential suffering for the patient and family within the community context. This comprehensive care is demanding in that it depends on global information. Palliative care professionals also assert that it is important to have some meaningful human interaction during the assessment, yet the practicalities of real-life care depend on efficient collection of concise information. Although these demands also characterize other areas of medicine, palliative care in particular emphasizes the global picture of human meaning in the setting of serious and terminal illness. In addition, palliative care tries to minimize uncomfortable physical examinations and inconvenient, expensive, or invasive tests by avoiding those that are unlikely to change the management plan. Because palliative care also specifies an interdisciplinary approach that can respond to a comprehensive assessment of needs, its assessments should be conducted in such a way that they can link directly to the interdisciplinary team's care plan.

Palliative care has recently engaged in some of the research necessary to bring rigor to this comprehensive assessment of patients with advanced, life-limiting illnesses. This rigor has been made possible in part because palliative care is based on an articulated philosophy and framework of care that identifies domains of need. In what follows, the framework is described, followed by a description of how to approach comprehensive assessment in palliative care. The approach is based on both experience among the discipline's experts and supportive evidence from research of its efficacy.

It may require two or more visits to complete the initial comprehensive assessment for the seriously ill patient because persons in this circumstance may have limited ability to interact, at least until the most consuming sources of suffering are controlled. Once the complete assessment is accomplished, it will need to be revisited with brief screening question and a review of active concerns on a regular basis so the whole picture is always retained as the most important guide to the continuously updated and tailored care plan.

FRAMEWORK

The existence of a clear framework and of identified domains of experience in which suffering can occur has allowed systematic identification of areas that need assessment. The first study of the dying was conducted by William Oser at the turn of the twentieth century (1). These studies were to be of great interest to

Cicely Saunders,[1] who later circumscribed the domains of need for the first decades of the modern hospice and palliative care movement. She defined the field as attending to what could become "total pain," or pain in the physical, mental, social, and spiritual domains of experience. Beginning in the late 1990s, palliative care researchers began again to empirically to identify domains of illness-related suffering, and areas within them, that constitute the components of the palliative care framework.

These empirical identifications were grounded in rigorously researched experiences of patients and family caregivers. They therefore differed from the origins of the traditional medical history, which evolved over time, mostly from the insights of physicians about the origin of illness, and in the modern era emphasized the biomedical aspects of the causes of illness. These palliative care studies were conducted on populations with serious and advanced illness, so they tend to apply more appropriately to patients facing the end of life than to those with better prognoses. Although differences existed among findings, they all confirmed that patient and family illness-related experiences were consistent with the whole-person, full-picture approach (2–5). More recent standards of care and clinical guidelines provide another source for identifying the content areas that should be included in a comprehensive assessment. These also use the whole-person, full-picture approach (6, 7). Most recently, some research has become available on the feasibility, validity, and efficacy of systematic instruments to guide assessment. Those instruments that are validated for specific areas can be used if an overall evaluation so indicates. Some instruments also provide for an initial overall approach to guide more specific evaluations.

THE UNFOLDING APPROACH: SCREENING QUERIES GUIDE EVALUATIVE QUESTIONS

In all general assessments, the key is first to ask sensitive screening questions that will reveal the existence of needs in a general domain. This first step allows the clinician to judge whether an indication of need exists so additional time will not be wasted by asking further questions to which a negative answer is almost ensured. Conversely, if need is indicated, more evaluative questions are posed that become progressively more specific for a set of conditions that are among the possibilities raised by the detected need. Enough screening questions must be asked so, as often as possible, no relevant or important need is left undetected and yet no needless negative inquiry of a specific, evaluative kind is prompted. Decision sciences have underscored the reality that testing for something that is unlikely commonly leads to false-positive results. Poorly applied screening questions divert attention away from the real needs and require the expenditure of time, energy, and resources in populations that have little to spare, all in pursuit of irrelevant matters and possibly producing their own negative side effects.

The first systematic, comprehensive palliative care assessment was provided by Higginson (8). Originally named for its use as an outcomes scale, it is also offered as an assessment instrument and has shown acceptable reliability and validity as

[1] Personal communication from Paul Mueller, December 2006.

both a clinical assessment tool and an outcomes measure. Known as the Palliative care Outcomes Scale, or P.O.S., this instrument is a list of survey-type questions.

The next step in systematic, comprehensive assessment approaches involved the creation of a nested guide to the use of sensitive screening items that, when responded to in a way that indicates a need, lead to further, more specific, evaluative items for needs in the screened area. This approach was first reported in the field of geriatrics, another discipline that has promoted the comprehensive assessment, in the form of the nursing home Resident Assessment Instrument (RAI). In a parallel line of thinking in palliative care, the Needs at the End of life Screening Test (NEST) was developed (9). A palliative care version of the RAI followed: the RAI-PC (10). Other instruments are less comprehensive (11, 12).

Linear survey-type approaches to caregiver comprehensive assessment are available (13), in addition to numerous caregiver outcomes assessment instruments that evaluate areas such as burden and gratification. An unfolding approach is under development in the form of the Multidimensional Aspect Related to Caregiving Experience (MARCE) (14). MARCE also links to NEST, thus allowing coordinated assessments for the patient and caregiver with purpose-designed, partner instruments.

Because of their brevity, brief forms such as the POS or the initial screening questions from an unfolding instrument such as NEST or RAI-PC can be used not only for the patient intake comprehensive assessment, but also for continuous assessment. A brief assessment for caregivers, such as that developed by Glajchen and associates or the MARCE (13, 14), can be used for intake and update assessment of family caregivers.

CONDUCTING THE COMPREHENSIVE ASSESSMENT FOR THE PATIENT

In starting a therapeutic relationship, the clinician should greet the patient and caregiver respectfully and should introduce himself or herself and use formal titles for all present. Although more a matter of suitable courtesy, the introduction can also provide something of a rapid screen for norms of communication, whether personal, family, or cultural norms, that should be observed to optimize the therapeutic alliance. The clinician can then ask "Is there a different way you like to be addressed, or is [Mr/s ___] fine with you?" This inquiry can make future communication about how to discuss subsequent, more specific issues more comfortable.

The palliative care clinician should then learn about the disease, the history, and the clinical management approaches taken to date, including who has provided care and where it was provided. To make the process efficient, this information should be gathered from previous records whenever possible. However, a point should be made of asking the patient and family members what they know about the illness, its significance to them, and what they see as the issues that need attention. This will provide an initial insight into their understanding and how to communicate with them, and it may also indicate their priorities. It also communicates to them that their perceptions are important in guiding care. Overall, the face-time component of this start to comprehensive assessment can be brief,

even for long-standing illnesses; the main goal of this phase of an initial palliative care assessment is to begin the relationship on a good footing, orient to the medical background, and ascertain the perceived situation.

Needs in the Social Domain

For efficiency, it can be helpful to ask screening questions in all the main areas before going to more specific evaluation questions. Both screening queries and deeper questions can be taken from the NEST or the RAI-PC. The clinician may want to start by memorizing the areas and questions. Eventually, the questions will flow smoothly as part of a give-and-take interaction between the patient or family member and the clinician.

Functional and Caregiving Needs

Asking about day-to-day functioning and caregiving needs is a reasonable area in which to start an assessment. It is neither too personal nor too technical, and it naturally affirms the nature of the therapeutic alliance, namely, to help meet their needs.

It is often fairly clear from a first visual impression of a person's condition the level of assistance that will be needed with activities of daily living. A question such as "When you need help, how often can you count on someone for house cleaning, groceries, or a ride?" (15) can screen for instrumental needs. A follow-up question such as "When you need assistance in bathing, eating, dressing, transfer, or toileting, how often can you count on someone being there for you?" can screen for needs with basic activities of daily living. This question may be asked in the past tense ("When you needed help, how often could you count on someone...?") for patients who are in the hospital and are not expected to leave, because it will provide a gauge of how much stress existed in this area before the hospitalization. For patients who are expected to return home and who are being visited in another setting, asking them to describe their home will give further clues to functional and practical issues.

Isolation

From this point in the assessment, and especially if family members are not present, the atmosphere may be comfortable enough to screen for isolation with a question such as "How much do you have the sense of being acknowledged and appreciated?" (9) or "In the last two weeks, how often would you say someone let you know they care about you?" (16).

Economic and Access Needs

The question "How much of an economic or financial hardship is the cost of your illness and medical care for you or your family?" screens sensitively for financial needs. Asking "How much of a problem have you had getting to see a specialist?" screens reasonably well for difficulty in accessing care. If it feels premature to ask these questions on a first visit, the clinician should follow his or her intuition; it

will probably be seen as prying or too personal to the patient or family member as well. The question should be saved for another visit.

Needs in the Existential Domain

All people have a spiritual dimension in that we all relate in some fashion to the universe beyond us and have a reaction to knowing that we are mortal. Susceptibility to life-threatening illness is obvious to most patients in need of palliative care, and existential issues may have taken on new urgency. Approaches that worked for the patient while he or she was in good health may not be adequate for coping during serious illness. "How much does a spiritual or religious community help in your personal spiritual journey?" is a good screening question, both for unmet needs in that area and for the importance of spirituality to the person. The question "How much does your relationship with God contribute to your sense of well-being?" may seem not obviously relevant for nontheists, but nonetheless a negative answer, on empirical evaluation among patients in the United States near the end of life, appears to correlate with spiritual distress.

In addition, the question "How much have you settled your personal relationships with the people close to you?" screens for a sense of equanimity and a feeling of peace that people value highly near the end of life. The absence of such feelings may indicate need. The counterpart question "Since your illness, how much do you live life with a special sense of purpose?" screens for a sense of having a meaningful role in the current situation. This can be heightened rather than diminished near the end of life. A negative answer may also indicate need.

Symptom Management Needs

Physical and Mental Symptoms

A general question such as "How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, and bowel or urination problems?" can screen for any physical suffering. Asking "How often do you feel confused or anxious or depressed?" can screen for mental suffering. Because some patients tend to not report symptoms unless asked about the specific symptom, it is wise also to screen for the most common symptoms directly, at least until such point as a routine expectation allows the clinician to be confident that the patient will identify symptoms with a general prompt.

For a patient who is unlikely to be symptom free, it makes sense to skip directly to symptom-specific questions. The Edmonton Symptom Assessment Scale (ESAS) provides quick and sensitive screening questions for the 10 most common physical and mental symptoms among palliative care patients. This scale, designed for patients to fill out themselves, can be a time-saving approach if the patient is given the form ahead of time. If incorporating the ESAS into the verbal interview, the clinician should ask the patient to rate how he or she feels about each symptom on a scale of 0 to 10 (with 10 being the worst possible) and list the symptoms: painful, tired, nauseated, depressed, anxious, drowsy, (lost) appetite, (lost) feeling of well-being, and shortness of breath. At the end of the interview, the patient should be asked if there are any other physical symptoms.

The Therapeutic Alliance

Goals of Care

No amount of understanding of a person's needs will result in an optimal care plan if that person's goals for care are not understood. The clinician should screen right away, and then on a continuous basis, for any mismatch between goals and actual care, so the care can be progressively adjusted to meet the patient's goals as much as possible. The clinician should ask a question such as "How much do you feel that the medical care you are getting fits with your goals?" If the answer is not the equivalent of "Completely," then he or she should probe for and settle on realistic goals that are compatible with medical care so the team can consider how to adjust the care to meet the patient's goals (see Chapter I–5). Goals change over time, depending on the physical realities and the mental, spiritual, and social circumstances of the patient.

Therapeutic Relationships

As patients and caregivers become more dependent on medical care, the professional team becomes more and more a part of their personal day-to-day life. These relationships can have a profound impact on quality of life. Needs in this area should be screened for with questions that ask about the relationship such as "How much do you feel your doctors and nurses respect you as an individual?" and about their information needs by using a question such as "How clear is the information from the medical team about what to expect regarding your illness?"

Probing Issues Raised on Screening

A focused inquiry begins once issues have been identified on screening. Selection of questions that have steadily increasing specificity while retaining as much sensitivity as possible will allow the clinician to zero in on the evaluation without missing related issues along the way. For instance, if a patient with abdominal pain is presented with questions related to cholecystitis, but not questions related to adherence to the bowel regimen prescribed to go along with opioid use for bone pain, the clinician may miss the possibility of constipation. Similarly, consider a patient who responds to the screening question that his or her relationship with God does not contribute to his or her sense of well-being. If the clinician immediately infers that the patient needs a visit from the hospital chaplain, the clinician may miss something important, merely for lack of a suitable follow-up question. For example, a question about what does help may reveal that members of a local religious community can be of much greater help in identifying and fostering a resolution to, say, a ruptured family relationship that has been blocking spiritual peace. Similarly, for mental health symptoms and social needs, such poorly chosen questions can lead to wasted time and effort and possibly to negative impact from the ill-fitting diagnoses and interventions.

The unfolding screening-evaluation approach can be illustrated for any area, but it is described here in the area of symptom management. The general approach is as follows. Starting with the first layer of screening questions from an instrument such as NEST or RAI-PC, suppose that the clinician identifies symptoms that need further evaluation. The clinician therefore follows with questions taken from

ESAS. Once a symptom has been clearly identified, the clinician can follow the recommendations for symptom evaluation outlined in specific chapters of this textbook and other palliative care resources. The Memorial Symptom Assessment Scale Short Form (MSAS-SF) covers 32 symptoms (17). After evaluation is complete and management is under way, the palliative care clinician can use the relevant MSAS questions for monitoring progress in symptom management over time.

To illustrate this point with specific questions, consider a patient who responds to the initial screening question for mental symptoms "How often do you feel confused or anxious or depressed?" with "Most of the time." The clinician can go on to ask each mental symptom question in the ESAS. If the patient's responses indicate no problem except in relation to the question "How would you describe your feelings of depression during the last 3 days?" to which he or she answers "Very depressed," then the clinician will continue to probe the history and possible sources of depression. In this situation, the clinician will also gather baseline answers to the questions in the MSAS-SF, by asking, for instance, "In the last week, how often have you felt sad? Rarely, occasionally, frequently, or almost constantly?" and then "How severe was it usually? Slight, moderate, severe, or very severe?" and, finally, "How much did it distress or bother you? Not at all, a little bit, somewhat, quite a bit, or very much?". After treatment has begun, the clinician may repeat the last set of the MSAS-SF questions periodically to monitor the symptom and the efficacy of treatment. Analogous progression can be used for any physical or mental symptom. In sum, by using this approach, the clinician will have efficiently moved from (a) the shortest available screening question set (e.g., from the NEST or the RAI-PC) to (b) intermediate questions (e.g., from the ESAS), then (c) in-depth evaluation questions and tests as needed, and finally to (d) a specific validated scale (e.g., the MSAS) for monitoring the progression of the symptom and its management.

CONTENT AREAS FOR FAMILY CAREGIVER COMPREHENSIVE ASSESSMENT

Proxy Perspectives about the Patient

An interview with the family caregiver can provide a second perspective on the needs of the patient. This interview can be the sole source of information other than the medical record for patients who are unable to respond to questions. Questions posed to the caregiver are largely the same as those posed to the patient, except all are framed in the third person, to ask the caregiver's perception of the patient's circumstance and experience.

Family caregiver perspectives tend to differ from those of the patient. Some differences are relatively predictable. For instance, caregivers tend to underemphasize the burden to themselves relative to the patient's report and to overemphasize patient pain relative to the patient's report (18). Other differences are less predictable, and all individual patient-family caregiver dyads differ, so clinicians need to take proxy perspective as relevant but less certain to represent the patient's perspective than patient-provided information.

Family Caregiver Assessment

A second, equally important function of the family caregiver interview is to find out how the caregiver himself or herself is doing. Because caregiver well-being appears to correlate strongly with patient well-being (19) and with the future health of the caregiver, and because the caregiver is an essential member of the whole care team, and because intolerable caregiving burdens tend to have an adverse impact on other members of the family and even on the community (20), it is also crucial to interview the family caregiver about himself or herself.

Some areas of need in the patient interview should lead the clinician to probe more deeply in the family caregiver interview. For instance, needs in the social domain of the patient interview are especially likely to indicate needs for the family caregiver. In addition, the caregiver often starts out with a brave face, in keeping with the role of providing for needs rather than seeking help. The caregiver may not admit to needs unless he or she is reassured that it is important to take care of his or her needs as well as those of the patient.

The areas of evaluation that go into a caregiver assessment are not as well established as those that comprise the patient assessment. One researcher recommended seven possible areas to evaluate, as follows: preparedness for the tasks of the role; competence or performance quality in the role; rewards of the role; social support; self-efficacy or belief that he or she can manage the situation; reactions to caregiving, whether by sense of burden or gratification; and optimism. The MARCE suggests use of slightly different areas, which are roughly followed here.

Burden/Gratification of the Caregiving Role

An early sense of how the family caregiver is doing in the role can be ascertained by asking whether the patient needs more help with nursing care than the caregiver can provide. The family caregiver's comfort level with the role seems to be fairly well indicated by being able to talk with the patient about how to handle the patient's physical care needs.

Care Skills and Understanding Illness Information

Caregiving by family members requires some special skills and an understanding of the illness. Research indicates that patients are often bewildered by the medical system and do not know how to access the information or resources they need. The health care provider should ask questions such as "Do you get help from us in knowing what [patient name] needs?" or "Do you get enough clear information from us about what to expect regarding [patient name's] illness and outcome?" or "... about the risks and side effects of [patient name's] treatment?". Responses to these questions allow the clinician to determine whether the caregiver is receiving enough comprehensible information and assistance from the clinical team to perform the role and can guide the clinician to fill any gaps in needed understanding or skill.

Psychological Issues, Including Adaptation to Losses

Family caregivers face many losses, including perhaps loss of their hopes for the future, loss of their own activities in favor of caregiving tasks, loss of aspects of the patient who may well have been different before the illness, and, eventually, loss

of the patient to death. Family caregivers need to employ many skills of adaptation and creative reintegration to maintain a quality of life, and these challenges often overwhelm their personal resources and result in depression. The clinician can ask how well they are adapting and can screen for anxiety and depression with questions such as "How often have you felt downhearted and blue in the last weeks?".

Social Issues

Family caregivers are at risk for isolation. The clinician should ask whether "other family members provide help with caring for [patient's name]" and whether he or she sometimes feels "alone or abandoned." If it has not been covered earlier in the interview as described above, then as soon as feels reasonable, it is important to ask about economic stresses and difficulties in accessing medical services, especially if the family caregiver has had to cut back on work or stop working to care for the patient.

Probing Issues Raised on Screening

A progressive approach to probing issues can be used for caregivers and patients alike. However, the clinician's obligation to diagnose and therapeutically intervene for the caregiver is more limited because no patient-clinician fiduciary therapeutic relationship is in place; the caregiver has not sought medical care. Nonetheless, some probing is reasonable and necessary to allow the care team to provide suitable information and skills to the caregiver, as well as recommendations for care. Therefore, it is reasonable that the clinician follow the progression over time once the early screening and deeper evaluation questions have identified an issue. The clinician can do this by using items from validated scales to assess an area more quantitatively. Numerous instruments for caregiver assessment have been studied and have achieved standards for validity (21).

CONNECTING THE ASSESSMENT TO AN INTERDISCIPLINARY TEAM'S CARE PLAN

A comprehensive assessment is of some independent worth if the patient and family caregiver receive therapeutic effect from being heard and from the empathic exchange of the interaction. However, most of the potential impact depends on effective translation of detected needs into a care plan for those needs. Several issues are important in making this an effective translation.

Patient and Family as Part of the Team

Confidentiality Issues

Palliative care seeks to include the family. At the same time, the patient is the key figure in the situation, and his or her confidentiality needs to be honored to the greatest extent possible. The patient should be asked at the outset how he or she likes to have information shared with family members.

Ensuring Accessibility for the Patient and Family

Even taking into account the variations among people, patients and families tend to do well if they feel a sense of choice and control over their care options. Drawing them into the comprehensive assessment and its connection to the care team's deliberated plan of care, to whatever level is suitable for the particular patient and family, is one mechanism that can help to provide the best balance for them.

Different Sources and How Information Is Gathered and Recorded

The approach to comprehensive assessment that relies on the interdisciplinary team and on the inclusion of the patient and family in the total care team has both strengths and hazards. In many systems of care, multiple professionals take their own version of the comprehensive assessment. The strength of this method of care delivery is derived from the full picture that multiple sources of information provide. However, the burden involved in information gathering and the potential to lose track of much of that information or to favor one source over another when the findings are disparate also need to be considered. Approaches such as that used by the NEST instrument, which is designed for use by anyone, provide a mechanism by which all members of the interdisciplinary team and the family caregiver can derive the same full picture of the patient's needs. In some service delivery situations, this may provide improved coordination and quality of care.

Team Meetings

The interdisciplinary team is distinct from the multidisciplinary team, in which interactions among the perspectives of each are less clearly emphasized. Palliative care has strongly emphasized the interdisciplinary team, and most palliative care services honor this by holding regular interdisciplinary team meetings. A chance to share perspectives is essential in translating the comprehensive assessment into high-quality care. The family meeting may also be a setting in which valuable perspectives and exchanges can occur so that the assessment is both comprehensive and, to whatever level is appropriate, shared by all relevant parties.

Continuously Adjusted Plans of Care

As noted earlier, the situation of seriously ill patients tends to change rapidly. The comprehensive assessment therefore needs to be periodically administered and reviewed by the team for an adjusted care plan.

SPECIAL ISSUES

Difficult Families, Difficult Patients

Some families and some patients seem intent on avoiding the difficult realities of serious illness. Others have emotional reactions that can be hard for clinicians,

patients, and families. Simple, genuine acknowledgment of the difficult nature of the situation and the feelings it causes can help the clinician to form a productive relationship with the patient and family. If this fails, it can be difficult to collect the needed information and to translate it into an effective care plan; seek help from colleagues.

Patients with Cognitive Impairment

Cognitive impairment need not preempt all aspects of a comprehensive assessment. Direct inquiry of the patient with as many of the screening and specific evaluation questions as possible should be attempted. Cognitive impairments may be quite variable, and some ability to give useful information can be retained even when other aspects of cognitive function are lost. Family caregivers can provide proxy information, although, as discussed earlier, the clinician must take into account that proxy information tends to be inaccurately correlated with patients' reports.

Language and Cultural Barriers

When language is a barrier, the services of a medical translator should be employed. The clinician should pay attention to the physical location of the translator, who should be seated to the side of the clinician and patient so the clinician and patient can make eye contact and the translator does not "get in between." If the translator starts to add supplemental explanations or to ask questions him or herself, the clinician should ask for a full translation, so nothing is assumed and inaccurate extrapolations or inferences are prevented.

Open acknowledgment of cultural differences can help the clinician to ask the patient or family caregiver about his or her expectations for health care and communication and about those expectations that may have already had a poor (or good) outcome. The clinician should assure the patient and the caregiver that the goal is to meet all possible expectations and to try to close the gap if some expectations have not been met. Because only the patient and family know their unique culture, they should be asked to help the care team honor it by sharing information about it.

OUTCOME MEASURES IN PALLIATIVE CARE

Many of the assessment questions used for screening and evaluation are in a format that elicits a scaled response and are also valid for use as outcomes measures. These questions are often sufficient for the practicing clinician. Individual assessment questions that can double as outcomes measures are useful not only in chronicling the progress of individual patients but also for research and continuous quality improvement activities.

In addition, for researchers, specific areas may have not only validated outcome measures but also large databases that contain data from those instruments. A compendium of approximately 160 assessment and outcomes instruments is found in the End-of-Life Care Toolkit, and a recent compilation of areas of relevant

information in palliative care and database sources for that information has been provided by the Institute of Medicine (22, 23).

INFORMATION TECHNOLOGY IN COMPREHENSIVE ASSESSMENT

The comprehensive assessment is well suited to a form of computer-assisted technology that has been developed in the field of educational assessment. Computer-assisted testing (CAT) in education examinations uses item response theory to select test items that progressively assess the respondent's knowledge or capacity. If the respondent evidences superior knowledge in response to a difficult item, the easier items are skipped, and more difficult items are given. Conversely, if the respondent fails to answer an item correctly, the computer selects easier items to determine what the respondent does know. A similar approach to sensitive screening items followed by specific, deeper evaluation items as described in the unfolding approach in this chapter can be programmed into a CAT system. Such a system could allow for completion of assessments by a range of clinicians and by patients and caregivers. Tablet-based self-response assessments have proven effective in some settings (24). Comprehensive information management systems that connect patients and caregivers with clinical teams across distances could be set up using such CAT-based assessments (25), and clinicians should expect that such progress may occur rapidly.

PEARLS

- A good comprehensive assessment is the foundation of high-quality palliative care. Devote effort to developing and honing the needed skills.
- To make comprehensive assessment efficient, start by asking screening questions for the major areas of illness-related suffering: physical, mental, social, and spiritual.
- If need be, take more than one session to complete a comprehensive assessment.
- After the initial comprehensive assessment, periodic reassessment is essential because things change rapidly with seriously ill patients. Make a point of asking screening questions on a regular basis.
- Use validated questions for screening whenever possible.

PITFALLS

- Omitting any major area of a comprehensive assessment is a mistake. Diagnoses may be misguided as a result.
- Do not try to cover everything in detail at one session. The patient may loose stamina and, eventually, so will you.
- Do not avoid areas of inquiry that you find difficult. Ask yourself why it is difficult for you; talk about it with a friend, a colleague, or a counselor.
- When taking a patient transfer from a colleague, do not accept assessments that are not comprehensive. Ask questions about what he or she should have investigated.

SUMMARY

Comprehensive assessments in palliative care are the cornerstone of high-quality care. However, they are demanding by their nature, requiring as they do rapid but accurate assessment of a very broad range of sensitive issues that vary widely among people. Nonetheless, use of a systematic method that covers established domains with questions that have been selected for the ability to screen sensitively for problems, followed by more specific items to identify and evaluate the issues, provides for an efficient and reliable approach. Information technology may soon allow for computer-assisted approaches that will make comprehensive assessments even more efficient.

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Communication Skills

4

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CHAPTER OUTLINE

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SUMMARY

INTRODUCTION: THE ROLE OF COMMUNICATION IN PALLIATIVE CARE

Palliative care is all about the relief of suffering; most tangibly, palliative care aims to relieve the symptoms associated with terminal illness. Symptoms are complex entities that the patient experiences. In other words, symptoms, like all experiences, unpleasant or pleasant, require processing by the brain (or, more precisely, by its main function, the mind). Assessing symptoms is therefore crucially different from assessing an objectifiable disease process. Whereas a disease process such as a bone metastasis can be visualized objectively and measured on a radiograph or in a computed tomography scan, the pain provoked by that metastasis can be assessed only by talking to the patient and finding out how much it hurts. As has often been said, "There is no blood test that measures pain." Hence, to assess the patient's symptoms (and subsequently the effect of treatment on those symptoms), the health care professional must have good communication skills. It is through communication that we assess how the patient is feeling and whether our interventions for symptom control are effective. However, in addition to assessing the patient's symptoms and the effects of therapy, communication also has a therapeutic benefit of its own. Almost invariably, the act of communication is an important part of therapy in its widest sense: occasionally, it is the only constituent. Communication usually requires greater thought and planning than a drug prescription and is unfortunately commonly administered in subtherapeutic doses.

The problem is that very little published material gives busy clinicians simple, practical guidelines. There is no lack of published literature concerning the emotional and psychosocial needs of the dying patient and the important role that communication plays in the delivery of all medical care, particularly palliative care. Some published work is also available on the obstacles to, and the deficiencies in, communication between the dying patient and the health care professional. However, the general medical literature does not provide much detailed practical advice to help improve the communication skills of palliative care practitioners. The major objective of this chapter is to remedy that omission by providing an intelligible and coherent approach to communication between professionals and patients in the palliative care setting. Experienced health care professionals may be familiar with much of this material, but very little of it has been previously published or documented. The objectives of this chapter are therefore practical and pragmatic, and its somewhat unusual structure and style reflect that emphasis.

This chapter has five parts: (a) a brief discussion of the main obstacles to talking about dying, including the factors that make dying a near-taboo subject and an exploration of the origins of those factors (in society, in the patient, and in ourselves); (b) basic communication skills (the CLASS strategy); (c) a six-point strategy, the SPIKES protocol, for the specific task of breaking bad news; (d) a summary of the important elements in therapeutic or supportive dialogue; and, finally, (e) some guidelines for communicating with other people, such as family, physicians, and other professionals.

SOURCES OF DIFFICULTY IN COMMUNICATION WITH DYING PATIENTS

In our society, discussing death and dying can be awkward, perhaps even more so when the discussion takes place between a doctor and a patient. Some of that awkwardness is social and stems from the way in which society currently views death. Some awkwardness originates from the individual patient, but some also originates from the professional. This is because our professional training prepares us to treat sick people but, paradoxically, also leads us to lose touch with our own human skills when the curative treatment of the disease process fails. A conversation with a dying patient also causes some degree of discomfort or awkwardness, even for the most experienced health care provider. It is important to recognize that this discomfort is universal and is not the product of any personal fault or deficiency of the health care professional. The major causes of this sense of unease originate long before the individual patient and the individual doctor begin the conversation. What follows is a board overview of these issues.

The sources of difficulty can be divided into three groups: first, those related to society (the social causes); second, those related to the individual patients; and third, those related to the health care professional that arise from our own social background and also from our training (e.g., in medical school or nursing college).

The Social Denial of Death

Contemporary society is going through (and just beginning to emerge from) a phase of virtual denial of death (1). Such attitudes are probably cyclical, and we may now be seeing this denial phase beginning to fade. However, the current attitude of denial or avoidance carries a price, a price paid by the person whose life is threatened and who faces death, as well as by those who look after and support that person—the family and the professionals. The major social roots of the contemporary fear of dying are discussed in the following subsections.

Lack of Experience of Death in the Family

Most adults today have not witnessed the death of a family member in the home at a time when they themselves were young and still forming their overall view of life. Although the number varies with regional demographics, for the last few decades more than 65% of deaths have occurred in hospitals or institutions. By contrast, a century ago approximately 90% of deaths occurred in the home. This shift is associated with a change in family structure as the norm evolved from that of the extended family to that of the nuclear family. Thus, elderly people are less likely to be living with their grandchildren and usually do not have young, fit relatives available to support them at the time of their last illness. By the same token, in contemporary society, a normal childhood and adolescence do not include the personal experience of a family death that occurs in the home.

Other factors that determine the place of most deaths are the growth and range of modern health services and the increased facilities and treatments they

offer. Although these services undoubtedly offer medical and nursing care advantages for the person who is dying in an institution, family support for the patient is disrupted, and surviving relatives are deprived of the experience and understanding of the dying process.

This is not to imply that witnessing a death at home in the past was always a serene or tranquil experience. Although a death at home may not have been a pleasant event, a child who grew up in such a home would be imprinted with a sense of the continuity of life, the process of aging, and the natural inevitability of death ("when you are older you look like dad, when you are much older you look like granddad, when you are very, very old you die"). As the extended family has disappeared, dying has become the province of the health care professional or institution; most people have lost that sense of continuity and now regard the process of dying as intrinsically alien and divorced from the business of living.

High Expectations of Health and Life

Advances in medical sciences are often overreported in the media and hailed as major breakthroughs. The constant bombardment of the public with news of apparently miraculous advances in the fight against disease not only subconsciously raises expectations of health, it also appears to offer tantalizing hopes of immortality. Thus, it becomes even harder for an individual to face the fact that he or she will not be cured despite the many miracles seen on television or in the newspapers.

Materialism

It is beyond the scope of a textbook to assess the materialist values of the modern world, except to point out that our society routinely evaluates a person's worth in terms of material and tangible values. This is our current social system of values, and it is neither good nor bad. However, it is universally accepted in our society that dying means being parted from material possessions. Hence, a society that places a high and almost exclusive value on the material possessions of its members implicitly increases the penalty of dying.

The Changing Role of Religion

The role of religion changed in the twentieth century. In North America and in much of Europe the previously near-universal view of a single, exterior God became fragmented and individualized. More individual philosophical stances became possible than in earlier centuries, and it is no longer possible to assume that everyone shares the same idea of a God or of an afterlife. Whereas a Victorian physician in England could have said to a patient, "Your soul will be with its Maker by the ebb-tide" and may have genuinely meant it as a statement of fact and consolation, nowadays we cannot assume that such a statement will bring relief to all, or even most, patients.

For all these reasons, then, our society is passing through a phase of development in which the process of dying is often perceived as alien and fearsome and the dying person is separated and divided from the living. This situation increases the uncertainty that surrounds any conversation about dying.

Table I–4–1 ■ Common Fears about Dying

Fears about Physical Illness
Physical symptoms (e.g., pain, nausea)
Disability (e.g., paralysis or loss of mobility)
Fears about Mental Effects
Not being able to cope
"Breakdown" or "losing one's mind"
Dementia
Fears about Dying
Existential issues
Religious concerns
Fears about Treatment
Side effects (e.g., baldness, pain)
Surgery (e.g., pain, mutilation)
Altered body image (e.g., surgery, colostomy, mastectomy)
Fears about Family and Friends
Loss of sexual relations
Being a burden
Loss of family role
Fears about Finances, Social Status, and Job
Loss of job (breadwinner)
Possible loss of medical insurance
Expenses of treatment
Being out of the mainstream

Patients' Fears of Dying

The fear of dying is not a single emotion. It can be composed of any or all of many individual fears, and every human when faced with the prospect of dying probably has a different and unique combination of fears and concerns. Some of these fears are illustrated in Table I–4–1. This concept of the patient's fear of dying has important implications for communication in palliative care. First, recognizing that fear of dying is not a single monolithic emotion should prompt the professional to elicit from the patient those particular aspects of terminal illness that are uppermost in his or her mind. Thus, a patient's statement that he or she is afraid of dying should begin dialogue, not end it. Second, an awareness of the many different aspects of dying that cause fear should prompt the professional to initiate a discussion of what triggers the patient's feelings. It is the recognition of and ensuing familiarity with the causes of fear that often enhance the professional's ability to empathize with the patient, thus increasing the value of the professional's support.

Factors that Originate in the Health Care Professional

Professionals in any health care discipline are subject to several sources of pressure that add to the discomfort of talking about dying. Some of these factors arise simply because, although we are professionals whose behavior has been ostensibly modified by training, we are human beings in the presence of another person, the patient, who is in distress. Others factors may be the product of our training

or experience. The major constituents are noted in the following subsections; fuller discussions are published elsewhere (2).

Sympathetic Pain

We are likely to experience considerable discomfort simply by being in the same room as a person who is going through the distress of facing death. This sympathetic pain may seem so patently obvious that it does not need to be stated, but it is often the case that professionals feel distressed by a painful interview and markedly underestimate the intensity of feeling that has originated from the patient. Particularly with trainees and junior staff, the degree of stress experienced by a health care professional is proportional to the intensity of the patient's distress. Until this is openly acknowledged, the professional may not seek the support that he or she needs and may continue to experience feelings of personal inadequacy and guilt, thus creating another set of factors that block good communication.

Fear of Being Blamed

As professionals, our fear of being blamed is partly justified. This fear has two main components. First, as the bearer of bad news, we are likely to be blamed for that news (blaming the messenger for the message). This is probably a basic human reaction to bad news and one with which we are all familiar in daily life (e.g., blaming a traffic warden for writing out a parking ticket), so we are somewhat justified in expecting it when it is our role to bring bad news. Furthermore, many of the trappings of our profession (e.g., uniforms, jargon, ward rounds) help to support the concept that we are in control of the situation. This concept may be valuable when the patient's condition is improving, but the same trappings increase the likelihood that we will become targets of blame when the patient's clinical condition begins to deteriorate.

Second, the notion that someone must be at fault when a patient deteriorates or dies is a concept imbued in us during our training. This attitude is strongly reinforced by medicolegal practice in which monetary sums are attached to a deterioration in health. Medical school training inadvertently reinforces this feeling in physicians. Medical school education prepares doctors (appropriately) to deal with the myriad of reversible or treatable conditions, whether common or rare. Until recently, however, there has been little or no teaching on the subject of what to do when the disease cannot be reversed (hence the need for this textbook). Palliative medicine has not previously been included in the undergraduate curriculum of medical school, and, as a result, most medical students evolve into physicians who are keen to treat the curable conditions but who have little training in how to deal with chronic, irreversible diseases. This omission makes it even more difficult for the physician to deal with his or her own sense of therapeutic failure when communicating with a dying patient (3).

Fear of the Untaught

We also fear talking to a dying patient if we do not know how to do it properly. In all professional training, trainees are rewarded for doing a particular task "properly." In essence, this means following conventional procedures and avoiding deviations from standard practice. Although this is the accepted and justifiable norm for any procedure for which guidelines have been established, if no guidelines exist (as is the case in communicating with the dying) the professional will naturally feel ill at ease and will tend to avoid the area entirely.

Fear of Eliciting a Reaction

In the same way that professionals dislike doing tasks for which they have not been trained, they also avoid the side effects or reactions caused by any intervention unless they have been taught how to cope with them (4). It is an axiom of medical practice that we "don't do any thing unless you know what to do if it goes wrong." If there has been no effective training in talking to patients about dying and death, there will also have been no training in how to deal with complications or side effects of such conversations (e.g., the patient's becoming angry or bursting into tears). Not knowing how to cope with these reactions further increases the aversion an untrained person feels when communicating with a dying patient.

Furthermore, interviews in which patients show emotional reactions may earn discouraging responses from other professionals. Although it is now less common than a few years ago, some senior physicians and senior nurses still think that it is a bad thing to "get the patient all upset." It should be obvious (but it is often ignored) that if a patient bursts into tears during a discussion about the gravity of his or her illness, it is the medical situation, not the discussion, that has caused the tears.

Fear of Saying "I Don't Know"

No matter the training or discipline, health care professionals are never rewarded for saying "I don't know." In all training, and particularly when being tested, we expect that our standing will be diminished if we confess that we do not know all the answers. In everyday clinical practice, by contrast, honesty shown by the professional strengthens the relationship, increases trust, and, in return, encourages honesty from the patient. Conversely, attempts to "flannel" or "snow" the patient, to disguise ignorance, or to pretend greater knowledge or experience weaken the bond between the patient and the doctor or nurse and discourage honest dialogue. Thus, our fears of displaying our ignorance—normal in tests but not appropriate in clinical practice—make communication increasingly difficult when the answers are unknown and, often, unknowable.

Fear of Expressing Emotions

We are also encouraged and trained to hide and suppress our own emotions (this may be truer of medical students than of nursing students or trainees in other disciplines). It is, of course, essential for truly professional behavior that we modulate emotions such as irritation or panic. However, this training inadvertently encourages us to envisage the ideal doctor as one who never shows any emotions and is consistently calm and brave. Although that is not necessarily a bad paradigm for a doctor who is dealing with emergencies or reversible crises, it is unhelpful in the palliative care setting. When a patient is facing death, a professional who expresses no emotions is likely to be perceived as cold or insensitive.

Ambiguity of the Phrase "I'm Sorry"

Even when we want to show human sympathy, the moment we begin do to so, linguistic problems threaten to create further difficulties. Most of us do not realize that the word *sorry* has two quite distinct meanings. It can be a form of sympathy ("I am sorry for you"), and it can also be a form of apology when accepting responsibility for an action ("I am sorry that I did this"). Unfortunately, both

meanings are customarily abbreviated to "I am sorry." This reflex abbreviation can commonly lead to misunderstanding. For example:

A. "...and then my mother was brought into hospital as an emergency."

B. "Oh, I am sorry."

A. "You've got nothing to be sorry for."

The first speaker is so used to hearing the word *sorry* as an apology that she or he responds with a reflex reply to an apology before realizing that it was not an apology that was offered, but an expression of sympathy. This has relevance to all of us as professionals. Not only is it difficult for us to overcome some of our trained responses to express our own emotions of sympathy and empathy, the moment we try to do so we fall into a linguistic slip and appear to be accepting responsibility (with the associated medicolegal implications) instead of offering support. The solution to this ambiguity lies in paying careful attention to your own speech patterns: rather than saying "I am sorry," you can use the specific words "I am sorry that happened to you."

Our Own Fears of Illness and Death

As professionals, most of us have some degree of fear about our own deaths, perhaps even more so than the general population. In fact, some psychologists would suggest that the desire to deny one's own mortality and vulnerability to illness is a component of the desire to be a doctor, nurse, or other health care professional. This is sometimes called *counterphobic behavior* and, in real terms, means that each time we have an encounter with a sick person and emerge from the encounter unharmed, we are reinforcing our own illusions of immortality and invulnerability. If this is indeed a major constituent of the desire to be a health care professional, then it may lead to avoidance of those situations in which these illusions are challenged (5). Hence the professional's own fear of dying can lead to avoidance or blocking of any communication with the dying patient.

Fear of the Medical Hierarchy

Finally, there is the discomforting fact that not all professionals think of these issues as important, perhaps because of their own fears of illness and death or fears of the untaught, and so on. Thus, when trying to have a conversation with a patient about dying, a junior member of a medical team may be under pressure from a senior staff member. In more old-fashioned hierarchical systems (e.g., in the United Kingdom in the 1960s), it was quite possible for a senior physician to state: "No patient of mine is ever to be told that he or she has cancer." Nowadays, for ethical and legal reasons, that stance is less tenable, but occasional instances of this attitude can still make it difficult to respond to the patient's desire for information and support. This problem sometimes has a solution when a hierarchy of care exists in which the patient's questions, reactions, knowledge, or suspicions can be transmitted upward to the senior person concerned.

BASIC COMMUNICATION SKILLS: THE CLASS PROTOCOL

As stated earlier, communication in palliative care is important from the moment that the patient first meets a palliative care professional until the last moment of life.

Most significant conversations in palliative care comprise two major elements: one in which medical information is transmitted to the patient (*bearing the news*), and the other in which the dialogue centers on the patient's feelings and emotions and in which the dialogue itself is a therapeutic action (*therapeutic or supportive dialogue*). In practice, most conversations are a mixture of the two, although commonly there is more medical information transmitted in the earlier conversations shortly after starting palliative care, and there is usually a greater need for therapeutic dialogue in the later stages.

Let us start by discussing the basic and central elements of effective communication, particularly as they are important in therapeutic dialogue. Although there are many ways to summarize and simplify medical interviews, few are practical and easy to remember. The five-step basic protocol for medical communication set out here and bearing the acronym CLASS, has the virtue of being easy to remember and easy to use. Furthermore, it offers a straightforward technique-directed method for dealing with emotions. This is of crucial importance because a recent study showed that most (>85%) oncologists feel that dealing with emotions is the most difficult part of any clinical interview (6).

In brief, the CLASS protocol identifies five main components of the medical interview as essential and crucial. They are **C**ontext (the physical context or setting), **L**istening skills, **A**cknowledgment of the patient's emotions, **S**trategy for clinical management, and **S**ummary.

C: Context (or Setting)

The context of the interview means the physical context or setting and includes five major components: arranging the space optimally, body language, eye contact, touch, and introductions. A few seconds spent establishing these features of the initial setup of the interview may save many minutes of frustration and misunderstanding later (for both the professional and the patient). These rules are not complex, but they are easy to forget in the heat of the moment.

Spatial Arrangements

Try to ensure privacy. In a hospital setting, draw the curtains around the bed if a side room is not available. In an office setting, shut the door. Next, move any physical objects out of the way. Move any bedside tables, trays, or other impediments out of the line between you and the patient. Ask that any televisions or radios to be turned off for a few minutes. If you are in an office or room, move your chair so you are next to the patient, not across the desk. Evidence indicates that conversations across a corner occur three times more frequently than conversations across the full width of a table. Clear any clutter and papers from the area of desk that is nearest to the patient. If you have the patient's chart open, make sure you look up from it and do not talk to the patient while reading the chart. If you find any of these actions awkward, state what you are doing ("It may be easier for us to talk if I move the table/if you turn the television off for a moment").

Then, arguably the most important component of organizing the physical context, sit down. This is an almost inviolable guideline. It is virtually impossible to assure a patient that she or he has your undivided attention and that you intend to listen seriously if you remain standing. Only if it is absolutely impossible to sit should you try to hold a medical interview while standing. Anecdotal impressions

suggest that when the doctor sits down, the patient perceives the period of time spent at the bedside as longer than if the doctor remains standing. Thus, not only does the act of sitting down indicate to the patient that he or she has control and that you are there to listen, but it also saves time and increases efficiency. Before starting the interview, take care to get the patient organized if necessary. If you have just finished examining the patient, allow or help him or her to dress and to restore a sense of personal modesty.

It is also important to be seated at a comfortable distance from the patient. This distance (sometimes called the *body buffer zone*) seems to vary from culture to culture, but a distance of 2 to 3 feet between you will usually serve for the purpose of intimate and personal conversation. This is another reason that the doctor who remains standing at the end of the bed seems remote and aloof.

The height at which you sit can also be important; normally, your eyes should be approximately level with the patient's. If the patient is already upset or angry, a useful technique is to sit so you are below the patient, with your eyes at a lower level. This position often decreases the anger.

Whenever possible, make sure that you are seated closest to the patient and that any friends or relatives are on the other side of the patient. Sometimes relatives try to dominate the interview, and it may be important for you to send a clear signal that the patient has primacy.

In almost all oncology settings, it is important to have a box of tissues nearby. If the patient or a relative begins to cry, it is important to offer tissues. This act not only gives overt permission to cry but also allows the person to feel less vulnerable when crying.

Body Language

Body language makes a difference (7, 8). Try to move and talk in an unhurried fashion to convey that the person to whom you are relating matters. To achieve an air of relaxation, sit down comfortably with both your feet flat on the floor. Let your shoulders relax and drop. Undo your coat or jacket if you are wearing one, and rest your hands on your knees (this is often termed in psychotherapy the *neutral position*).

Eye Contact

Maintain eye contact for most of the time that the patient is talking. If the interview becomes intense or emotionally charged, particularly if the patient is crying or is very angry, it will be helpful to the patient for you to look away (to break eye contact) at that point.

Touching the Patient

Touch may also be helpful during the interview if (a) a nonthreatening area is touched such as a hand or forearm, (b) you are comfortable with touch, and (c) the patient appreciates touch and does not withdraw. Most of us have not been taught specific details of clinical touch at any time in our training (3, 9). We are therefore likely to be ill at ease with touching as an interview technique until we have had some practice. Nevertheless, considerable evidence (although the data are somewhat "soft") suggests that touching the patient (particularly above the patient's waist, to avoid misinterpretation) is of benefit during a medical interview.

It seems likely that touching is a significant action at times of distress and should be encouraged, with the proviso that the professional should be sensitive to the patient's reaction. If the patient is comforted by the contact, continue; if the patient is uncomfortable, stop. Touch can mean different things and can be misinterpreted (e.g., as lasciviousness, aggression, or dominance), so be aware that touching is an interviewing skill that requires extra self-regulation.

Commencing the Interview

Ensure that the patient knows who you are and what you do. Many practitioners, including myself, make a point of shaking the patient's hand at the outset, although this is a matter of personal preference. Often the handshake tells you something about the family dynamics as well as about the patient. The patient's spouse will frequently also extend his or her hand. It is worthwhile to make sure that you shake the patient's hand before that of the spouse (even if the spouse is nearer), to demonstrate that the patient comes first and the spouse (although an important member of the team) comes second.

L: Listening Skills

As dialogue begins, the professional should show that she or he is in *listening mode*. The four most essential points are listed in the following subsections. They are the use of open questions, facilitation techniques, the use of clarification, and the handling of time and interruptions.

Open Questions

Open questions are ones that can be answered in any way or manner. The question does not direct the respondent or require that he or she make a choice from a specific range of answers. In taking the medical history, of course, most of the questions are, appropriately, closed questions (e.g., "Do you have any difficulty with fine hand movements?" "Do you have any areas of numbness or tingling?"). In therapeutic dialogue, when the clinician is trying to be part of the patient's support system, open questions are an essential way of finding out what the patient is experiencing, to tailor support to the patient. Hence open questions ("What did you think the diagnosis was?" "How did you feel when you were told that?" "What did that make you feel?") are a mandatory part of the "nonhistory" therapeutic dialogue.

Silence

The first and most important technique in facilitating dialogue between patient and clinician is the use of silence. If the patient is speaking, do not overlap your speech by talking over her or him. Wait for the patient to stop speaking before you start your next sentence. This, the simplest rule of all, is the most often ignored and is most likely to give the patient the impression that the doctor is not listening (10).

Silences also have other significance: they can, and often do, reveal the patient's state of mind. Patients often fall silent when they have feelings that are too intense to express in words. A silence therefore means that the patient is thinking or feeling something important, not that he or she has stopped thinking. If the clinician can tolerate a pause or silence, the patient may well express the thought in words a moment later. If you have to break the silence, a helpful way to do so may be to

say "What were you thinking about just then?" or "What is it that's making you pause?" or words to that effect.

Evident Hearing

Once you have encouraged the patient to speak, it is valuable to demonstrate that you are hearing what is being said. Hence, in addition to silence, dialogue may be facilitated by using any of these facilitation techniques: nodding, pausing, smiling, and using responses such as "Yes," "Mmm hmm," "Tell me more." In addition, it is often valuable to use repetition as a conscious and deliberate facilitation technique. To demonstrate that you are really hearing what the patient is saying, employ one or two key words from the patient's last sentence in your own first sentence. For instance, if the patient says, "I just feel so lousy most of the time," begin your response with, "Tell me what you mean by feeling lousy." Reiteration means repeating what the patient has told you, but in your words, not the patient's: "Since I started those new tablets, I've been feeling sleepy" "'So you're getting some drowsiness from the new tablets?" Both repetition and reiteration confirm to the patient that you have heard what has been said.

Clarifying

As the patient talks, it is very tempting for the clinician to go along with what the patient is saying, even if the exact meaning or implication is unclear. This may quickly lead to serious obstacles in the dialogue. Hence it is important to be honest when you have not understood what the patient means. Several different phrases can be used ("I'm sorry—I'm not quite sure what you meant when you said..." "When you say...do you mean that...?"). Clarification gives the patient an opportunity to expand on the previous statement and to amplify some aspect of the statement, now that the clinician has shown interest in the topic.

Handling Time and Interruptions

Clinicians seem to have a poor reputation for handling interruptions, whether caused by phone, pager, or other people. We may often appear to ignore the patient we have been speaking with abruptly to respond immediately to a phone call, a page, or a colleague. Even though it may be inadvertent, the patient frequently interprets this as a snub or an insult. If it is not possible to hold all calls or to turn off the pager, then it is at least worthwhile to indicate to the patient that you are sorry about the interruption and will resume the interview shortly ("Sorry, this is another doctor that I must speak to very briefly. I'll be back in a moment." Or "This is something quite urgent about another patient—I won't be more than a few minutes."). The same is true of time constraints ("I'm afraid I have to go to the E.R. now, but this is an important conversation. We need to continue this tomorrow morning on the ward round...").

A: Acknowledgment (and Exploration) of Emotions

The Empathic Response

The empathic response is an extremely useful technique in an emotionally charged interview, yet it is frequently misunderstood by students and trainees. The empathic

response need not relate to your own personal feelings: if the patient feels sad, you are not required to feel sad yourself. It can be a technique of acknowledgment, showing the patient that you have observed the emotion he or she is experiencing. Empathic response consists of three steps:

1. Identifying the emotion that the patient is experiencing.
2. Identifying the origin and root cause of that emotion.
3. Responding in a way that tells the patient that you have made the connection between 1 and 2.

Often the most effective empathic responses follow the format of "You seem to be. . "or "It must be..."; for example, "It must be very distressing for you to know that all that therapy didn't give you a long remission" or even, "This must be awful for you." The objective of the empathic response is to demonstrate that you have identified and acknowledged the emotion that the patient is experiencing and by doing so you are giving it legitimacy as an item on the patient's agenda. In fact, if the patient is experiencing a strong emotion (e.g., rage or crying), you must acknowledge the existence of that emotion, or all further attempts at communication will fail. If strong emotions are not acknowledged in some way, you will be perceived as insensitive, and this will render the rest of the interaction useless.

To stress it once more then, the empathic response is your acknowledgment of what the other person is experiencing. It need have nothing to do with your own personal view or judgment of the situation or how you yourself would react if you were facing these circumstances. You do not have to feel the same emotion that the patient is experiencing, nor do you even have to agree with the patient's viewpoint. You are simply observing what the other person is feeling and bringing that emotion into the dialogue between the two of you.

S: Management Strategy

Several techniques are useful to help ensure that you construct a management plan that the patient will concur with and will follow. The following are helpful guidelines:

1. Determine what you judge to be the optimal medical strategy. Define the ideal management plan (in your mind or out loud).
2. Assess, in your own mind or by asking the patient, the patient's own expectations of condition, treatment, and outcome. You can summarize this in your mind or clarify and summarize aloud if needed. Be aware if there is a marked mismatch between the patient's view of the situation and the medical facts. You are going to have to work harder to make the plan appear logical and acceptable to the patient if there is significant discordance between the patient's view and reality.
   Propose a strategy. Bearing in mind your conclusions from step 1 and step 2, propose your strategy. As you explain it to the patient, constantly. . .
3. Assess the patient's response. For example, make note of the patient's progress in forming an action plan (these stages are often defined as precontemplation, contemplation, and implementation or reinforcement). Acknowledge the patient's emotions as they occur and continue in a contractual fashion until you arrive at a plan that the patient can "buy into" and will follow.

S: Summary

The summary is the closure of the interview. In oncology, the relationship with the patient is likely to be a continuing one and a major component of the patient's treatment. The closure of the interview is an important time to emphasize that point.

It is relatively straightforward to cover three areas in the summary. Provide:

1. a precis or reiteration of the main points covered in the dialogue.
2. an invitation for the patient to ask questions, and
3. a clear arrangement for the next interaction (a clear contract for contact). This particular part of the interview is not necessarily long, but it does require considerable focus and concentration.

BREAKING BAD NEWS: THE SPIKES PROTOCOL

In palliative care, there are many occasions when new medical information needs to be discussed. Hence it is essential to have a logical and systematic approach to sharing medical information (11). The following protocol has been detailed at greater length elsewhere (2). In practice, it has been found useful in all interviews concerning bad news, whether or not the patient and the professional know each other well. However, formal studies of this protocol (or any other) have not been carried out, and even the design of such investigations poses major difficulties (12). It consists of six steps or phases.

S: Setting (Physical Context)

The physical context of the interview has already been reviewed. It is of even greater importance for the interview in which bad news will be shared.

P: Perception (Finding out How Much the Patient Knows or Suspects)

Before providing further information, it is always important to determine what the patient knows about the medical condition and its effect on the future. In fact, sharing information may be awkward, superfluous, or even impossible without first knowing what the patient already knows. In all cases, you should try to establish what the patient knows about the impact of the illness on his or her future and not focus on the fine details of basic pathology or nomenclature of the diagnosis. This information can be gathered in many ways. Some of the questions that may be useful include the following:

"What have you made of the illness so far?"
"What did the previous doctors tell you about the illness/operation, etc.?"
"Have you been worried about yourself?"
"When you first had [symptom X], what did you think it might be?"
"What did [Dr. X] tell you when he sent you here?"
"Did you think something serious was going on when [...]?"

As the patient replies, analyze the response. Important information can be obtained from three major features of the reply.

Factual Content of the Patient's Statements

It must be established how much the patient has understood and how close that impression is to the medical reality. At this point, some patients may say that they have been told nothing at all, and this may or may not be true. Even if you know it to be false, accept the patient's statement as a symptom of denial and do not force a confrontation immediately. First, the patient may be about to request information from you and may, in part deliberately, deny previous information to see whether you will tell the same story. Second, if the patient has been given information previously and is in denial, you are unlikely to appear supportive by forcing an immediate confrontation.

In fact, a patient who denies receiving previous information quite often precipitates anger or resentment on the part of the professional (e.g., "My goodness, doesn't Dr. Smythe tell his patients what he found at the operation!"). If you find yourself feeling this, pause and think. You may be seeing a patient in denial, and this may be causing you to suffer from the professional syndrome known as the "nobody-ever-tells-their-patients-anything-until-I-do" syndrome. It is very common when patients are sick and the emotional atmosphere is highly charged.

Style of the Patient's Statements

Much can be gleaned from the patient's emotional state, educational level, and articulation skills. Listen to the vocabulary, the kind of words being said, and the kind of words being avoided. Note the style, so when it is your turn to speak, you can start at the right level.

You should, however, ignore the patient's occupation in making this assessment, particularly if he or she happens to be a member of a health care profession because, far too often, you will find yourself making assumptions. Even a physician, as a patient, may not be an expert in a particular disease and may not understand a phrase such as "It's only a stage II but I don't like the mitotic index."

Emotional Content of the Patient's Statements

The two major sources of emotional content are verbal and nonverbal. Both may yield information about the patient's state, and discordance between the two may give valuable signals regarding state and motivation. For instance, a patient may speak in a calm manner, but the body language may reveal major anxiety.

I: Invitation (Finding out How Much the Patient Wants to Know)

This is the single most crucial step in any information-giving discussion. It is far easier to proceed with giving the news if there is a clear invitation from the patient to do so. Conversely, although it is universally acknowledged that in contemporary society patients have a right to truth and information, it is often impossible to predict which patients will want to hear the truth and which will not (13). (For fuller reviews, see Billings and Reiser [14, 15].) The exact proportion of patients who do want full disclosure varies from study to study, but current figures range from 50% to 98.5%, depending on patient demographics and the diagnosis suspected (13). (For a detailed review, see McIntosh [16].) Because no characteristics predict whether a patient desires disclosure (17), it seems logical simply to ask. The way

in which this important and sensitive question is phrased is largely a matter of personal style. Some examples are as follows:

"Are you the kind of person who likes to know exactly what's going on?"
"Would you like me to tell you the full details of the diagnosis?"
"Are you the kind of person who likes to have full information on what's wrong or would you prefer just to hear about the treatment plan?"
"Do you like to know exactly what's going on or would you prefer me to give you the outline only?"
"Would you like me to tell you everything relevant about your condition or is there somebody else you'd like me to talk to?"

Note that in all these approaches, if the patient does not want to hear the full details, you have not cut off all lines of communication. You are saying overtly that you will maintain contact and communication (e.g., about the treatment plan) but not about the details of the disease. If the patient does not want to hear the information, you should add that if, at any time in the future, the patient changes her or his mind and wants further information, you will provide it. The phrase "...the sort of person who" is particularly valuable because it suggests to the patient that many patients are like him or her and that if he or she prefers not to discuss the information, this is neither unique nor a sign of extraordinary feebleness or lack of courage.

K: Knowledge (Sharing Medical Information)

The process by which medical information is transmitted can be thought of as consisting of two crucial steps.

Aligning

At this point in the interview, you have already heard how much the patient knows about the situation and have learned something of the vocabulary used to express the knowledge. This is the starting point for sharing the information. Reinforce those parts that are correct (using the patient's words if possible) and proceed from there. This gives the patient a great deal of confidence in himself or herself (as well as in you) to realize that his or her view of the situation has been heard and is being taken seriously (even if it is being modified or corrected).

This process has been called *aligning*, a useful term to describe the process by which you line up the information you wish to impart on the baseline of the patient's current knowledge (11, 18). (Maynard uses the word *aligning* to describe one particular style of doctor-patient communication. The meaning has been extended in this schema to describe the first part of the information-sharing process.)

Educating

In the next phase of the interview, having begun from the patient's starting point (i.e., having aligned your information with the patient's original position), you now have to bring the patient's perception of the situation closer to the medical facts as you know them. No word in current usage fully describes this part of the

interview, but *educating* is perhaps the closest. The process of sharing information should be a gradual one in which the patient's perception is steadily shifted until it is in close approximation to the medical reality. This part of the interview can usefully be compared with steering an oil tanker. You cannot make sudden lurches and expect the patient's perception to change instantly. You have to apply slow and steady guidance over the direction of the interview and observe the responses as you do so. In the process, you build on those responses from the patient that are bringing him or her closer to the facts and emphasize the relevant medical information if it becomes apparent that the patient is moving away from an accurate perception of the situation. The key ingredients are steady observation and continued gentle guidance of the direction of the interview rather than sudden lurches.

Give Information in Small Amounts: The Warning Shot. Medical information is hard for patients to digest and more so if it concerns a grave prognosis or threat of death. Recall of information is poor at the best of times and is likely to be very poor if medical facts are grim ("The moment you said 'cancer', doctor, I couldn't remember a thing from then on..."). The rule is therefore to give the information in small amounts.

One of the most useful principles is the idea of the "warning shot." If there is clearly a large gap between the patient's expectations and the reality of the situation, you can facilitate understanding by giving a warning that things are more serious than they appear ("Well, the situation was more serious than that...") and then grading the information, gradually introducing the more serious prognostic points and waiting for the patient to respond at each stage.

Use Plain Language. Technical jargon ("medspeak") is an efficient language for transmitting codified information in a short time. Because it takes many years to learn, it is also comforting to the professional. Patients, however, have not learned to speak this language and cannot express their emotions in it. Hence, it reinforces the barrier between patient and professional and is most likely to make the patient feel angry, belittled, and isolated. We should avoid jargon if we are trying to support the patient at a difficult time.

Check Reception Frequently. Check that your message is being received, and check frequently. You can use any phrase that feels comfortable, anything to break the monologue. Examples are as follows:

"Am I making sense?"
"Do you follow what I'm saying?"
"This must be a bit bewildering, but do you follow roughly what I'm saying?"
"Do you see what I mean?"

These interjections serve several important functions: (a) they demonstrate that it matters to you if the patient does not understand what you are saying, (b) they allow the patient to speak (many patients feel so bewildered or shocked that their voices seem to seize up and they need encouragement and prompting to speak), (c) they allow the patient to feel an element of control over the interview, and (d) they validate the patient's feelings and make them legitimate subjects for discussion between the two of you. You should also check that you are transmitting the information at the same intellectual level as the patient is receiving it, by ensuring that your vocabulary and that of the patient are similar.

Reinforce. You can reinforce what you are telling the patient in several ways:

1. Have the patient repeat the general drift of what you have been saying.
2. Repeat important points yourself. Because it is difficult to retain information, particularly if the news is serious, and even more so if denial is operating, you may have to repeat crucial points several times. Accept this as a fact of life when looking after seriously ill patients (you can cover this with a phrase such as "I know it's difficult to remember all this stuff at one go...").
3. Use diagrams and written messages. A few simple scribbles on the back of an envelope or a scrap of paper may serve as a useful aide-mémoire.

Blend Your Agenda with that of the Patient. When transmitting information to the patient, it is important to elicit his or her agenda, or "shopping list" of concerns and anxieties, so further information can be tailored to answer major problems. The following are useful guidelines.

Elicit the "Shopping List". Quite often the patient's major concerns are not the same as those of the professional. For instance, patients may be more worried about severe pain or loss of mental functioning than about the primary disease itself (see earlier). You do not necessarily have to deal with the items at that particular moment, but you should indicate that you understand what the patient is talking about and will return to it in a moment. ("I know you're very worried about drowsiness, and I'll come to that in a moment, but can I first cover the reasons that we recommend increasing the painkillers in the first place?").

Listen for the Buried Question. Deep personal worries may not emerge easily. Sometimes the patient asks questions while you are talking. These questions ("buried questions") are often highly significant to the patient. When the patient does this, finish your own sentence and then ask the patient what he or she was saying. Be prepared to follow that train of thought from the patient; it is quite likely to be important. Ask another question, such as "Did you have something in mind that triggered that question?".

Be Prepared to Be Led. Quite often you may draw an interview to a close and then find that the patient wants to start part of it again. This is not simply contrary behavior. It often stems from fear and insecurity; by restarting the interview, the patient may be exerting some measure of control, or perhaps he or she has recalled something important. Try to accommodate or at least promise time at the next meeting.

E: Emotions and Empathic Responses (Responding to the Patient's Feelings)

In many respects, the patient's reactions to his or her medical condition and the professional's response to those reactions define their relationship and determine whether it offers support for the patient. Hence the professional's ability to understand and respond sensitively to the emotions expressed by the patient is central to all communication in palliative care. In essence, this part of the communication becomes therapeutic (or supportive) dialogue.

In the short space of this chapter, it is not possible to illustrate the wide range of patients' reactions to dying or to bad news in general. However, a detailed

analysis has been published elsewhere (2), together with several options available to the professional in each situation. The central components of the professional's response are (a) assessment of the patient's response and (b) empathic responses from the professional. For the sake of convenience, these two topics are discussed later, in the section on therapeutic dialogue.

S: Strategy and Summary

Organizing and Planning

The sixth and final step in the protocol for breaking bad news is the stage at which the professional summarizes the situation and makes an operational plan and a contract for the future. This process is of great importance to the patient, and it should conclude every interview with a palliative care patient, not just an interview in which bad news is discussed.

Frequently, after hearing news that is new or distressing, the patient may feel bewildered, dispirited, and disorganized. Although the professional should be sensitive to those emotions and be capable of empathy, our responsibilities consist of more than simply reflecting the patient's emotions. The patient is looking to us to make sense of any confusion and to offer plans for the future. At this point in the interview, it is therefore important to try to put together what is known of the patient's agenda, the medical situation, the plan of management, and a contract for the future. This process can be logically divided into six tasks.

Demonstrate an Understanding of the Patient's Problem List. If the interview has been effective so far, you have been achieving an understanding of the patient's problem list since the beginning. From the outset, you have demonstrated that you have heard what most bothers the patient, and a brief "headline" reference to the patient's major concerns will reinforce the fact that you have been listening.

Indicate that You Can Distinguish the Fixable from the Unfixable. With both medical problems and psychosocial problems, some are "fixable" and some are not. I discuss this further in relation to the patient's responses in the next section, but it is a pragmatic step without which your support will appear to be less effective. If the interview becomes stuck or bogged down as the patient explores her or his problems, it is often helpful to try to enumerate the problems in list form by having the patient arrange them in order of priority. You can then begin to set your own agenda by stating which problems you are going to tackle first. This leads logically to the next step.

Make a Plan or Strategy and Explain It. When making a plan for the future, it is quite permissible for that plan to include many uncertainties, "don't knows," and choices (e.g., "If the dizziness doesn't get better, then we'll..."), acknowledging that uncertainty is often a painful and difficult state with which to cope (19). What you are actually doing is presenting a decision tree or algorithm. Patients need to know that you have some plan in mind, even if it consists of little more than dealing with each problem as it arises, because it implies that you will not abandon the patient. The act of making a plan and explaining it to the patient is part of what the patient sees as support. It defines the immediate future of your relationship with this particular patient, reinforces the individuality of this person, and explains what you are going to do for him or her.

Identify Coping Strategies of the Patient and Reinforce Them. Strong emphasis is placed in our training on what we do to patients or for patients. Obviously, in acute emergencies, the professionals have to do all the work. However, this attitude of "we will do it all for you" can influence the professional's approach to all patients in every situation, particularly if the patient is feeling overwhelmed and helpless in the presence of bad news. This may be bad for the patient and also bad for us because we may later become overwhelmed by our responsibilities. At this point in the interview, then, it is important to look at the resources available to the patient, both internally and externally (20). We cannot, and should not, live the patient's life for him or her. Hence, as the problem list and the plan begin to take shape, the professional should begin to help the patient evaluate what he or she can do for himself or herself. This part of the process involves helping the patient identify his or her own coping strategies. It is a continuous process, not usually completed in one interview. It also leads logically to the next component.

Identify Other Sources of Support for the Patient and Incorporate Them. Not only do we tend to forget that the patient has capabilities of his or her own, we also tend to forget that there may be someone outside the professional-patient relationship who can assist. Most people have at least one or two friends or relatives who are close and can offer support. For those patients who have no social supports of their own, it will be necessary to enroll and coordinate the other available services.

Summary and Conclusion. The final part of the interview is the summary and contract for the future. The summary (which also requires a great deal of thought) should show the patient that you have been listening and that you have picked up on the main concerns and issues. It is not a particularly easy task, but you should try to give an overview of the two agendas involved: yours and the patient's. It need not be a long statement and often consists of no more than one or two sentences.

Having summarized the main points, you should then ask: "Are there any (other) questions that you'd like to ask me now?". The patient may have been bottling up concerns over some issue that simply has not arisen or over an aspect of the treatment or the disease that you have merely touched on, so this part of the interview is as important as the question period after a lecture. It is the time when any unresolved issues can be discussed.

Finally, you should make a contract for the future. Even though this may be as simple as a statement (e.g., "I'll see you at the next visit in 2 weeks" or "We'll try the new antisickness medicine and I'll see you tomorrow on the ward rounds"), without it patients may leave the interview feeling that there will be no future contact.

THERAPEUTIC (OR SUPPORTIVE) DIALOGUE

Many physicians underrate the value of therapeutic dialogue because it is not included in the curricula of most medical schools and thus they are unfamiliar with its use. Supportive communication is obviously central to psychiatric and psychotherapeutic practice, but it is generally not taught to medical or nursing students outside those disciplines (21). Hence, it often seems an alien idea that a

doctor or nurse can achieve anything by simply listening to the patient and acknowledging the existence of that individual's emotions.

Nevertheless, supportive dialogue during any stage of palliative care is an exceptionally valuable resource and may be the most important (and sometimes the only) ingredient in a patient's care. The central principle of effective therapeutic dialogue is that the patient should perceive that his or her emotions have been heard and acknowledged by the professional. It may then become apparent that there are problems that can be solved, emotions that can be resolved, and needs that can be met. Even if that is not the case, the simple act of supportive dialogue can reduce distress.

The empathic response is of prime importance in achieving the main objective of acknowledging the patient's emotions, although it cannot be the only component of the professional's side of the dialogue. Obviously, a single technique cannot create an entire relationship. Nevertheless, many professionals are unfairly perceived as insensitive or unsupportive simply because they do not know how to demonstrate their abilities as listeners. The empathic response is one of the most reliable methods of demonstrating effective listening. In addition to responding in this way, the professional should also attempt to assess the nature and value of the patient's coping responses, disentangle the emotions that have been raised by the discussion, and try to resolve any conflicts that may arise.

Assessment of the Patient's Responses

Although this chapter has not detailed all the possible reactions that a patient may experience, it is possible to offer some brief guidelines to assess those emotions so the professional will know which emotions are best reinforced and which require intervention. In essence, three criteria are used to assess a patient's responses.

Acceptability

First, a patient's reactions must meet the broadest definitions of socially acceptable behavior. These definitions vary from culture to culture (and some of the gravest misunderstandings arise from misinterpretation because behavior that is normal in one culture may be seen as aberrant in another). In the context of palliative care, however, interpretation of socially acceptable should be very wide. The professional should err on the side of generosity, and assistance should be sought only if extreme behavior is a genuine danger to the patient, staff, other patients, or family members. With the exception of these very rare cases, the professional should accept the behavior, even if he or she does not like it, and assess it on the other two criteria: does it help the patient, and, if it does not, can it be improved by intervention?

Distinguishing the Adaptive from the Maladaptive

Second, facing the end of life usually induces major stress and distress: An individual's response to that distress may either help the person to reduce it (an *adaptive response*) or may increase it (a *maladaptive response*). It is frequently difficult to distinguish one from the other at the first interview, and several interviews over

Table I–4–2 ■ Some Adaptive and Maladaptive Responses

Possibly Adaptive	Possibly Maladaptive
Humor	Guilt
Denial	Pathologic denial
Abstract anger	
Anger against disease	Anger against helpers
Crying	Collapse
Fear	Anxiety
Fulfilling an ambition	The impossible quest
Realistic hope	Unrealistic hope
Sexual drive, healthily fulfilled	Despair
Bargaining	Manipulation

a longer period may be required to decide whether a patient is adapting to the medical circumstances.

It is not easy to be dogmatic about which responses are always maladaptive, but some guidelines are shown in Table I–4–2. The consensus seems to be, for example, a feeling of guilt is always maladaptive and cannot help a patient. It may be somewhat more controversial, but still helpful, to regard denial in the early stages as an adaptive response that allows the patient to adjust in small "bites" to what would otherwise be an overwhelming threat. Moreover, some responses can buy the patient an immediate short-term decrease in distress, but they can also cause additional problems later. For instance, denial that is prolonged and prevents a patient from making decisions with which he or she is comfortable ("We won't even think about that...") may later increase distress. In some cases, only the professional's clinical experience and the passage of time can define the situation.

Distinguishing the "Fixable" from the "Unfixable"

The third criterion by which responses may be assessed is what may be termed *fixability*. If a problem is increasing the patient's distress or obstructing adaptation, can it be remedied? This is largely a matter of clinical experience, and it depends on the professional's confidence and competence in addressing psychosocial problems. Two points, however, are worth stressing. First, the chance of damage is higher when the professional feels that he or she can fix a problem and then perseveres without seeking help than it is when a professional knows his or her own limitations. Second, if a problem appears to be unfixable, it is even more important to seek a second opinion, preferably from a psychologist or psychiatrist. In up to two thirds of cases, problems that the medical team considers to be unfixable can be improved by psychological intervention (22).

Distinguishing Your Emotions from Those of the Patient

Another task that must often be undertaken during therapeutic dialogue is the disentangling of the emotions experienced by both the patient and the professional during the interview. We have already seen that strong emotions cannot be ignored

Table I–4–3 ■ In the Event of Conflict

1. Try to take a step back.
2. Identify your own emotions and try to describe them, not display them.
3. Try to define the area of conflict that is unresolved.
4. Try to obtain agreement on that area of difference, even if it cannot be resolved.
5. Find a colleague and talk about it.

without jeopardizing all communication. We should also try to be aware of our own emotions when dealing with an individual person who is dying. We may experience strong emotions because of our own previous experience (countertransference), or we may be moved, attracted, or irritated and intolerant as a result of the patient's behavior patterns. In any event, when emotions arise, it is essential to try to take a step back and ask yourself what you are feeling and where that feeling comes from. If the professional can recognize a strong emotion in himself or herself, that recognition will partly negate the effect of the emotion on judgment and communication. The emotion is far more likely to produce damage if it goes unrecognized.

Dealing with Conflict

We all want to do our best for the patient, but we also have our limits. Sometimes we simply cannot ease a patient's distress, sometimes a patient does not wish to be relieved, and sometimes the patient appears to have a need for antagonism or conflict to give himself or herself definition or some other gain.

Despite pretences to the contrary, at some time all of us feel exhausted, frustrated, and intolerant. This is unavoidable. However, a few guidelines may reduce the impact of those feelings in our professional life (23). The most useful are shown in Table I–4–3.

In summary, the single most useful tool of therapeutic dialogue is the empathic response that indicates to the patient that the emotional content of his or her reaction is being heard and is legitimized. In addition, the professional should attempt to assess the patient's response, disentangle his or her emotions from those of the patient, and try to resolve conflict. These, then, are some of the most important aspects of communicating with the dying patient. Other parties are almost always involved, however, and the next section deals with communication issues that concern the family and other health care disciplines.

COMMUNICATION WITH OTHER PEOPLE

All efforts in palliative care are directed at ameliorating the situation of the patient. However, other parties are involved who may assist or hinder efforts at effective communication (for a major review of communication issues with patients with cancer, their families, and professionals, see Northouse and Northouse [24]). Only a few broad guidelines can be offered in this limited space, but attention to even these simple issues can noticeably improve quality of care.

Communication with Friends and Family

The responses of friends and family to the imminent death of a patient may be as varied as those of the patient. Similarly, they may assist the patient and be of support, or they may be counterproductive and contribute to the patient's problems rather than being part of the solution. Responses from others may resemble the patient's responses, or they may be qualitatively different. Even when they are the same as those of the patient, they may be asynchronous with the patient's responses; for example, the patient may have resolved his or her anger and may have come to accept death while the family is still angry or in denial. Just as the patient's responses may be considered adaptive or maladaptive, so the family's responses may also serve to decrease or increase the patient's distress and to increase or decrease support.

When a patient's treatment is palliative, some effort should always be made to identify the leading members of his or her support systems (friends and family). When communicating with the family, however, two principles may at first seem mutually exclusive.

The Patient Has Primacy

A mentally competent patient has the ethical and legal right to determine who should be informed about his or her medical condition. All rights of friends or family are subordinate to this. If a patient decides to not share information with anyone else, although that may be an aggressive and vengeful action, it cannot be countermanded by the professional at the family's request. Similarly, however well intentioned, a relative's statement that "the patient is not to be told" does not have primacy over the patient's wishes if the patient wishes full disclosure.

The Family's Feelings Have Validity

Despite the secondary rank of the family's feelings, those feelings have validity and must be acknowledged even if the professional cannot accede to their wishes or instructions. The wishes of the family often arise from a desire to show that they are good and caring sons or daughters (e.g., rationalizing their own feelings, as in "If I cannot stop mother from becoming ill, I can at least stop her from finding out too much about it."). It is important for the professional to identify the family's emotions and to acknowledge them. For this purpose, the empathic response is of great value.

Communication Between Physicians

Doctors are notoriously bad at communicating with each other. We do not do it frequently enough and, more important, when we do communicate with each other, it is often disorganized and unfocused. Perhaps the most dangerous gaps in doctor-doctor communication occur when a patient moves from one care setting to another, for example from a hospital or home into a palliative care unit.

It is difficult to give useful guidelines about something as ill defined as interspecialty communication, but perhaps the key principles are that all communication should be task oriented and should clearly define frontiers of responsibility. This means that communications should be related to those aspects of the patients

situation that may have an impact on his or her care. On analysis, much of what is discussed between doctors is simply opinion or conjecture. Although there is nothing wrong with this in and of itself, we often feel that we have thoroughly discussed the case when, in fact, vital management issues have not been discussed at all.

The five-point checklist that follows may be of some value when considering a letter or telephone call to another physician about a palliative care patient.

1. Am I addressing the right person? (For instance, does the patient know the family practitioner well? Have I asked the patient whom he or she wished me to contact?)
2. What do I know about this patient that the other person should know? (And what do I want to know from the other person?)
3. What does this mean for the patient's future care?
4. Who is going to do what? Who is now "the doctor" for this patient?
5. How shall we communicate again if things are not going well?

Even if communications are limited to these five points, they will be more effective than many of the current communications between doctors, not because we are negligent or malevolent, but because we are often too polite and too afraid of stepping on each other's toes in making suggestions for the patient's benefit.

Communication Between Physicians and Nurses

By definition, professionals belong to different teams because they have special expertise and training that is identified with that discipline. This is essential for good patient care. However, there is a side effect, namely, that we each speak a different language, and we all tend to believe that our particular language is the only one truly relevant to the patient's care. As a result, different aspects of the patient's problems are often poorly integrated, and large gaps in communication are often apparent between the teams. Because of the way the jobs interrelate, the most common gaps occur between doctors and nurses.

One of the greatest paradoxes (and perhaps one of the greatest losses) in the recent evolution of the nursing profession has been the diminishing of the ward round as the standard method for exchanging information among patient, doctor, and nurse. Although this idea that the ward round is essential in patient care is controversial, it is a view that is now receiving increasing support from all disciplines as well as from patients and families. The days of the 3-hour ward round, during which four patients are reviewed, are over. Nursing time is at a premium, and nursing tasks have increased greatly in number and complexity, However, without the trinity of patient-doctor-nurse present in the same place at the same time, inpatient care is rendered unnecessarily complex and incomplete. In hospitals or hospices where time is limited, it is often possible to agree on time limits (e.g., an average of 10 minutes per patient can enable the team to accomplish almost all the necessary exchanges).

In our own unit, we ensure that the three following points are addressed during the minimum 10-minute period allotted for discussion of each patient:

1. The medical game plan: What is known about the patient's medical status, what measures are planned or being considered? What is the prognosis?

2. Nursing concerns: What are the main difficulties in the day-to-day care of the patient?
3. What does the patient know, and what are the patient's major concerns? For instance, does the patient have strong views about the type of therapy or the location for treatment?

It is surprising how efficient communication can be if all concerned are aware that time is limited and that these three main areas should be covered in the discussion.

PEARLS

- Talking about matters of dying can be difficult for all concerned.
- Take time to consider your own relationship with mortality; you cannot guide others unless you have some maturity in this matter.
- Talk about it with friends, family, colleagues, or a counselor.
- Consider the following common fears among professionals:
  - Discomfort at feeling the patient's suffering
  - Fear of being blamed
  - Fear of the untaught
  - Fear of eliciting a reaction
  - Fear of saying "I don't know"
  - Fear of expressing emotions
  - Our own fears of illness and death
  - Fear of medical hierarchy
- In general, use CLASS skills in communication:
  - Prepare for the interview (**C**ontext); review the information, determine who will be present, and arrange the setting.
  - Use **L**istening skills; use opening questions, use silence as appropriate; facilitate questions, and clarify understandings.
  - **A**cknowledge the perspectives of the patient and the family.
  - **S**trategically manage the medical care plan, its outcomes, and the expectations of the patient and the family.
  - **S**ummarize the interview, invite the patient to ask questions, and arrange for the next interaction.
- Specifically, when delivering important information, use the SPIKES protocol:
  - Get the **S**etting right.
  - Make sure you know the patient's **P**erspective.
  - **I**nvite the patient to tell you how he or she wants to receive the information.
  - Share the **K**nowledge.
  - Acknowledge the **E**motions and be empathic.
  - Share the **S**trategy for the next steps.

PITFALLS

- Avoidance of one's own issues is hazardous. Remember, others can tell when this is the case, so do not imagine that avoidance works.
- Avoidance of patients who are suffering or dying feels like abandonment to them and their families. Do not do it.

- Blunt delivery of information without follow through leaves a patient and family with harsh new realities without offering support or an opportunity to review information. This feels cruel to the patient and family. Allow time for follow through, and stick to the CLASS and SPIKES protocols or a similar protocol.

SUMMARY

In palliative care, everything starts with the patient, including every aspect of symptom relief and every aspect of communication. There is no doubt that we all want to do our best, but major challenges in palliative care often arise because we do not know how to approach the problem. Nowhere is this truer than in communication. A professional who feels ill equipped and inept at communication will become part of the problem instead of part of the solution. The act of following relatively straightforward guidelines, however simplistic they may appear, will at least give us a feeling of competence and will enhance our ability to learn as we practice.

An expert in palliative care is not a person who gets it right all the time. An expert is someone who gets it wrong less often and is better at concealing or coping with his or her fluster and embarrassment. We are, after all, only human beings.

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5

Negotiating Goals of Care: Changing Goals along the Trajectory of Illness

Annette M. Vollrath and Charles F. von Gunten

> *"Human dignity, I feel, rests on choice."*
> *Max Frisch, Swiss writer, 1911–1991*

CHAPTER OUTLINE

INTRODUCTION
DISCUSSING GOALS OF CARE
SIX-STEP PROTOCOL
1. Prepare and Establish an Appropriate Setting for the Discussion
2. Ask the Patient and Family What They Understand
3. Find out What They Expect Will Happen
4. Discuss Overall Goals and Specific Options
5. Respond to Emotions
6. Establish and Implement the Plan

CASE STUDY
PEARLS
PITFALLS
SUMMARY

Negotiating goals of care is an example of patient-centered medical decision making that differs significantly from the problem-oriented method practiced commonly in health care in the United States. A patient-centered approach to medical decisions has proven particularly useful in the setting of advanced or serious illness. This chapter discusses a six-step approach to the goals-of-care discussion including examples of how the steps can be used, including in a case study. Pearls and common pitfalls are highlighted.

INTRODUCTION

Health care in general aims at preventing or curing disease. When you fracture a bone, you go to the hospital to get it fixed. When you acquire bacterial pneumonia, you take an antibiotic to cure it. However, many diseases cannot be "fixed." Rather, they are managed; examples are hypertension, diabetes, and congestive heart

failure. For most diseases that must be managed, increasing longevity, reducing disease-related symptoms, and maintaining function and quality of life for a maximum period of time until the patient's death are the objects of medical care.

As a patient's disease progresses, medical decisions are influenced more and more not just by medical information, but also by the patient's underlying values and priorities. For patients living with chronic or life-threatening disease, medical decisions are often not as straightforward as they are for simple problems that can be fixed. Rather, these patients face several options that may all be reasonable within the breadth of accepted medical practice.

It is therefore crucial for the health care professional who cares for patients with chronic diseases to be able to elicit underlying values and priorities, to set overall goals for care. Mutually agreed on goals will then lead to appropriate decisions to achieve those goals. It is expected that, as the patient progresses along his or her trajectory of illness, goals may change. For example, in the patient whose case study opens this chapter, the initial goal was to cure the cancer, then to shrink it, then to keep it from growing too fast. Another goal may be to be as comfortable and functional as possible regardless of the state of the cancer.

Along the trajectory of illness, several trigger situations invite the patient and health care provider to reflect on and discuss goals of care. These include general advance care planning, a new diagnosis, a change in therapy, the transfer to a new health care provider or institution, and, probably most commonly, the point along the disease trajectory when interventions to cure or control the disease are no longer effective or desired. One reason for this may be that the treatment-associated burden seems to outweigh its benefit.

Patients are open to such discussions. Studies show that between 85% and 95% of patients want to have honest discussions with their health care providers regarding life-threatening diseases (1). Health care providers do not adequately meet this need. Studies have shown that doctors and nurses underestimate cancer patients' concerns, do not elicit the goals and values of seriously ill patients or include them in treatment decisions, and generally fail to address their patients' emotional concerns (2–4).

The three chief reasons that doctors do poorly in communicating honestly with patients and families are as follows:

1. Medical education does not devote much time or attention to the development of good communication skills, and medical students see few role models (5).
2. The culture of medicine in the Western world focuses on organ systems rather than on whole-patient care.
3. The physicians' own attitudes and underlying emotions regarding death and dying also interfere with adequate goals-of-care discussions (6).

The importance of good communication has been well recognized in the field of palliative medicine. Major educational initiatives such as Education for Physicians on End-of-life Care (EPEC) and End-of-Life Nursing Education Consortium (ELNEC) devote significant time on skills training in this area. Communication is a learnable skill that, like many other skills, requires ongoing practice. Brief educational interventions are likely not sufficient to change physician behavior (7). Intensive communication skills training, however, has been shown in a randomized trial to improve physician communication skills in practice (8).

For those physicians interested in skills training regarding the negotiation of goals of care, this chapter summarizes a six-step protocol that can be used as a framework anywhere along the disease trajectory such as advance care planning, discussing treatment options or resuscitation orders, or introducing hospice care. This protocol was adapted from a widely used communication model for the delivery of bad news (9). It is based on the American Medical Association's EPEC project and has been described in multiple settings such as the discussion of resuscitation orders or when introducing hospice.

The protocol uses the general principle of shared decision making. This principle is considered the current standard of care of medical decision making in the United States (10). Shared decision making as a process puts great emphasis on patient autonomy while acknowledging the physician's responsibility to make treatment recommendations that are based both on the patient's stated overall goals of care and the physician's medical expertise. The protocol for goals-of-care discussions described here not only reflects common communication styles in the United States, but is also strongly influenced by its current bioethical value system. Health care professionals balance the underlying ethical principles of autonomy, beneficence, nonmalfeasance, and justice with a strong emphasis on autonomy.

Studies of health care decision making in other parts of the world show that different cultures prioritize these ethical values differently. It seems most common to place less emphasis on autonomy in favor of beneficence and nonmalfeasance. For example, although more than 90% of US physicians share a new diagnosis of cancer with their patients, only 44.5% of competent patients were informed of their prognosis by their physician in a study from southern France. Studies from China indicate that patients there are rarely informed of a new diagnosis of cancer. In African countries such as Nigeria, Egypt, and South Africa, the type and amount of information shared seem to depend on patient factors such as level of education or socioeconomic status. Bruera and colleagues elicited an additional point when studying attitudes and beliefs of palliative care specialists in Canada, South America, and French-speaking Europe. In this study, all clinicians wanted to be told the truth about their own terminal illnesses, but physician predictions about their patients' wishes differed significantly: whereas 93% of Canadian physicians thought their patients would wish to know the truth, only 26% of their European and 18% of their South American colleagues thought that most of their patients would want to know about their diagnosis (11). These results invite the question regarding the degree to which the perceived differences reflect biases of local health care cultures rather than actual differences in patient preferences.

Attitudes toward truth telling also clearly change over time. In 1961, more than 90% of US surgeons did not share a new diagnosis of cancer with their patients. This finding clearly contrasts with today's practice.

These trends demonstrate that medical decision making and information sharing are processes guided by values and underlying ethical principles that are influenced by culture and will change over time. The element of the protocol proposed here that helps to assess this is the step of asking the patient how much he or she wants to know. This permits the professional to adjust the approach for a given individual. Over time and according to the needs of individual patients and health care providers in different parts of the world, overall patterns may also change.

DISCUSSING GOALS OF CARE

The protocol for discussing goals of care suggested here relies on common techniques of verbal and nonverbal communication. Great emphasis is placed on empathic listening, a highly underestimated skill in medical practice. In a patient-doctor interaction, fewer than 25% of patients are provided the opportunity to complete their opening statement of concerns; all others are interrupted in less than 20 seconds. Physicians then tend to focus on closed-ended questions in an attempt to retrieve information as fast as possible. This approach risks that patients never have the chance to address their major concerns. As a matter of fact, most patients leave the office without ever having their concerns addressed. Because eliciting patient preferences is at the center of goals-of-care discussions, it is especially important to start out the conversation with an open-ended question, followed by active listening. This allows the patient to focus on his or her major concerns and sets the stage for patient-centered care. Active or empathic listening then includes nonverbal communication skills that show full attention such as good eye contact and leaning toward the patient as well as verbal empathic listening techniques such as reflection, paraphrasing, and validation.

When conveying medical information, it is generally recommended that the information be given in small pieces. The physician should use words that the patient can understand and should pause frequently to check for the patient's responses. The higher the emotional impact of the given information on the patient, the less likely the patient is to hear what is being said (12). It may therefore be necessary to repeat the information at a later time. Stone and colleagues suggested always preparing and having difficult conversations at three levels: facts, emotions, and identity issues involved (13). An example of this triad regarding goals-of-care discussions would be to spend some time discussing the different clinical options such as further chemotherapy versus hospice care, then looking for and validating the patient's emotional responses such as fear, worry, and sadness. Last, but not least, the physician would reflect on what the discussed options would mean for the patient's and health care provider's identity. Examples of identity issues that influence goals-of-care discussions are as follows: "I have always been a fighter and now you're asking me to give up?" or "I am not someone who just gives up on a patient." Awareness of and addressing the emotional and identity issues underlying difficult conversations such as goals-of-care discussions are thought to facilitate better discussion outcomes by helping all parties involved to gain a better understanding of the different perspectives and thereby decrease the potential for adversarial interactions. Examples of the communication techniques used in this protocol are given under each step.

SIX-STEP PROTOCOL

A stepwise approach to goals-of-care discussions helps to remind the clinician to include all major components of the discussion. This is particularly true for those who are inexperienced or early in their training, in which this skill has generally not been demonstrated (14). The six steps include preparing and establishing an appropriate setting for the discussion, asking the patient and family what they

understand about the patient's health situation, finding out what they expect will happen in the future, discussing overall goals and treatment options, responding to emotions, and establishing and implementing a plan (Table I–5–1).

1. Prepare and Establish an Appropriate Setting for the Discussion

You should enter a goals-of-care discussion with a clear understanding of the purpose of the meeting and be prepared to discuss information that the patient and family will need to learn. An example could be the outcomes of different treatment options such as chemotherapy, cardiopulmonary resuscitation survival data, and common treatment side effects. In general, patients are more interested in outcomes ("Life is not worth living if I won't be able to speak") than in the details of interventions ("That means that we would have to put a tube down your throat that is about as thick as your finger") (15).

In addition to medical information, it can be helpful before entering the discussion to reflect on expected emotional responses and possible identity issues that may arise for the patient. This approach allows you to gain more insight into the patient's and family's perspective and to feel prepared, especially when their perspective seems "unrealistic."

Arrange to have the meeting itself in a private and comfortable place where everyone participating can sit at eye level. The atmosphere should be unhurried and undisturbed. After general introductions, the purpose of the meeting should be made clear. You can introduce the subject by phrases such as the following:

"I'd like to talk to you about your overall goals of care."
"I'd like to review where we are and make plans for the future."
"I'd like to discuss something today that I discuss with all my patients."

This is a good opportunity to address cultural or personal priorities regarding medical decision making. Ask whether your patient wants to have this discussion with you or prefers to defer it to someone else such as a family member or designated medical decision maker. Also see whether anyone else should be present. If so, be prepared to postpone the meeting accordingly. You can word your questions like this:

"Some patients like all the information, others like me to speak with someone else in the family. I wonder what is true for you."
"Tell me how you like to receive medical information."
"It there anyone else you would like to have present for our discussion?"

Table I–5–1 ■ Six Steps for the Discussion of Goals of Care

1. Prepare and establish an appropriate setting for the discussion.
2. Ask the patient and family what they understand.
3. Find out what they expect will happen.
4. Discuss overall goals and specific options.
5. Respond to emotions.
6. Establish and implement the plan.

2. Ask the Patient and Family What They Understand

Start out with an open-ended question to elicit what the patient understands about his or her current health situation. This is an important question and one that many clinicians skip. If the doctor is doing all the talking, the rest of the conversation is unlikely to go well. You could start with phrases such as the following:

"What do you understand about your current health situation?"
"Tell me how you see your health."
"What do you understand from what the doctors have told you?"

Starting with these questions not only helps to establish trust and set the tone for patient-centered decision making, it also helps to address misconceptions and conflicting or missing information and allows you a quick glimpse into the patient's emotional response to his or her current health state such as fear, anger, or acceptance. More time may be needed to clarify the current situation before the patient is able to address future medical decisions.

3. Find out What They Expect Will Happen

For patients who have a good understanding of the status of their disease, the third step is to ask them to consider their future. Examples of how you could start are as follows:

"What do you expect in the future?"
"Have you ever thought about how you want things to be if you were much more ill?"
"What are you hoping for?"

This step allows you to listen while the patient has the opportunity to contemplate and verbalize his or her goals, hopes, and fears. This step creates an opportunity for you to clarify what is likely or unlikely to happen. You may need to ask follow-up questions to understand the patient's vision of the future as well as his or her values and priorities more clearly. If there is a significant discontinuity between what you expect and what the patient expects from the future, this is the time to discover it.

4. Discuss Overall Goals and Specific Options

Now that you have set the stage for a joint understanding of the patient's present and future, you can discuss overall goals of care and specific options. Allowing the patient to reflect on goals that may still be realistic despite reduced functional abilities and a limited life expectancy can be a very effective tool to maintain hope. Your insight into the patient's values and priorities should then structure the conversation of medical options and should guide your expert opinion. Use language that the patient can understand, and give information in small pieces. As discussed earlier, you should focus the discussion on treatment outcomes rather than on details of medical interventions (15, 16). Stop frequently to check for emotional reactions, to ask for clarifications, and to clarify misunderstandings.

It is often helpful to summarize the patient's stated overall goals and priorities as an introduction to the specific options. Following the principle of shared

decision making, after the discussion of the available options, you should make clear recommendations that are based both on the patient's stated overall goals of care and on your medical expertise. For example:

"You have told me that being at home with your family is your number 1 priority and that the frequent trips to the hospital have become very bothersome for you. You do have three options at this point (....). Getting hospice care involved seems to be the option that best helps you to realize your goals."
"If I heard you correctly, your first priority is to live to participate in your granddaughter's wedding in June. Taking that into account, it may be best to continue the current therapy and try to treat your nausea with a stronger regimen."
"I heard you say that you are particularly concerned about being a burden to your children. By getting the hospice team involved, your family could get extra support from the nurse, chaplain, and social worker who would come to see you at the house."
"It is clear you want to pursue all options to extend your life as long as possible. That includes being cared for in an intensive care setting with maximal support. However, if you are unable to communicate, and there is no reasonable chance of recovery, you want life support to be stopped."

Starting out the discussion of treatment options from the patient's perspective and evaluating treatment options according to their potential to achieve the patient's realistic overall goals can be a great help in building trust between the patient and the health care provider and in maintaining hope.

5. Respond to Emotions

Patients, families, and health care providers may experience profound emotions in response to an exploration of goals of care. It should not be surprising that patients, when considering the end of their life, may cry. Parents of children with life-threatening diseases are especially likely to be emotional and need extra support from the health care team. In contrast to common worries in the health care community, however, emotional responses tend to be brief. Respond sympathetically. The most profound initial response a physician can make may be silence and offering a facial tissue. Consider using phrases such as the following:

"I can see this makes you sad."
"Tell me more about how you are feeling."
"People in your situation often get angry. I wonder what you are feeling right now."
"I notice you are silent. Will you tell me what you are thinking?"
"Many people experience strong emotions. I wonder whether that is true for you."

A common barrier to this step is the physician's fear to precipitate overwhelming emotional outbursts that they may not be able to handle. Therefore, conversations between physicians and their patients remain in the cognitive realm where emotions are not addressed (17). The best way to overcome this barrier is to learn how to respond to patient emotions empathically and to learn to be comfortable with silence. Most patients are embarrassed by being emotional and keep their

discussions brief. This is because most patients have adequate coping skills and appreciate the presence of a doctor while they work through the experience and their emotions. As with most aspects of being a physician, a sense of competence then leads to a willingness to engage in the challenge.

6. Establish and Implement the Plan

The last step of the goals-of-care discussion protocol involves the establishment and implementation of a plan on which that the patient, family members, and physician have agreed. You should verbalize a plan that is clear and well understood by everyone involved. Consider using language such as the following:

"You said that it is most important for you to continue to live independently for as long as possible. Because you are doing so well right now and need your current breathing machine only at night, we will continue what we are doing. However, when your breathing becomes worse, you do not want to be placed on a continuous breathing machine. We will then focus on keeping you comfortable with medicines to making sure that you do not feel short of breath."

"The different regimens we have used to fight your cancer are not working. There is no other anticancer therapy that is known to be effective. We discussed your options at this point including getting a second opinion from one of my oncology colleagues or asking a hospice program to get involved in your care. In light of what you told me about your worries about being a burden to your family, you thought that hospice care may be the best option at this point because you would get extra help at home from the hospice team members that come to see you at your house. I am going to call the hospice team today and arrange for them to call you in the morning so they can see you and explain more about what they offer. We can talk more after you see them."

It is often helpful to ask patients or family members to summarize the plan and underlying reasoning in their own words to ensure understanding. Especially for emotionally overwhelmed patients, good continuity of care is important. Ensuring this continuity, for example by arranging for follow-up appointments, speaking to the referring physician, or writing the appropriate orders, is part of the physician's responsibility.

CASE STUDY

Case Study ■

T. S. is a fully independent 53-year-old woman with breast cancer, metastatic to bone. Stage II breast cancer was diagnosed 10 years ago (premenopausal) and was treated with lumpectomy, radiation, and cyclophosphamide-methotrexate–5-fluorouracil chemotherapy. She has received two cycles of doxorubicin (Adriamycin) and paclitaxel chemotherapy. She has multiple bothersome symptoms including neuropathic pain and nausea. During a follow-up visit, T. S. asks you about continuing the chemotherapy.

You recognize T. S.' question as an opportunity to assist her and the health care team to define the goals of care. After inviting T. S. and her husband into a meeting room, you ask what she understands about her current situation. T. S. is able to describe that her cancer has spread to her bones and wonders whether this means that she will die soon. Her husband knows the cancer cannot be cured. In response to a question about her goals, she says she hopes the cancer will go into "remission." T. S. starts to cry and grabs her husband's hand. "I will be a grandmother soon, I want to see that child grow up, spend time with my family—there is so much we never had time for." Her husband says he does not want her to continue chemotherapy if it is not going to help or if the suffering will be too great. After a moment of silence, you reflect on how difficult all this must be for them and how much you hope that she will be able to reach her goals. T. S. has had several chemotherapy-associated side effects including persistent delayed nausea and neuropathic pain that is likely related to the chemotherapy. You clarify that it is too soon to know whether this chemotherapy is going to work, but there are things that can be done to help with the nausea and pain. You recommend that continued anticancer treatment is the option most consistent with her goals at this point if the side effects of further chemotherapy are tolerable. You make some suggestions about symptom control and volunteer to telephone her oncologist to confirm your role in the overall plan and to communicate your suggestions. After confirming the patient's understanding of the plan by asking her to repeat it in her own words, you reassure her and her husband that you will revisit goals each time you get together and that you and the oncologist will remain in close touch.

PEARLS

- **Start with the "big picture."** Many health care providers skip steps 2 and 3 (finding out what the patient understands and expects to happen) and lunge straight into detailed descriptions of medical interventions. These two simple questions set the stage. They show that you are interested in the patient and his or her experience and want to support the patient to achieve his or her goals. Starting from the patient's perspective is not only an invaluable tool to establish trust and a feeling of safety for the patient, but it also makes giving recommendations much easier for you later. When the "big picture" goals are clearly understood, the discussion of specific medical interventions most commonly falls quickly into place.
- **Pay attention to nonverbal language.** Much of the communication between people happens nonverbally. You can use that to your advantage by using simple nonverbal communication tools suggested earlier. Keep in mind that everyone is sensitive to nonverbal language; if you are not truly paying attention, you risk coming across as not authentic. Paying attention to nonverbal cues in yourself as well as in the patient or family member also allows you to access underlying emotions that influence the discussion.
- **Deferring autonomy is an act of autonomy.** We often come across situations in which a concerned family member asks us not to disclose health care information to our patient. This can make us very uneasy because it

interferes with our understanding of patient autonomy; conversely, do we not want to be accused of "truth dumping." You can solve this "dilemma" by first verbalizing understanding for the family member's concern and then conveying that you will need to double check with the patient if this is how he or she would like to proceed (if you have not done that already). When you see the patient alone, ask how he or she would like to handle medical information and decision making. You can use words such as these: "Some people want to know all medical information as we find it and discuss all options with the doctor. Others would rather have their children make decisions and do not want to have to deal with the medical information. Where do you stand?"

- **Cultural competence.** In a multicultural society such as the United States, physicians are prone to care for patients and families from many different backgrounds. The term *culture* is used here in the broad sense and includes ethnic, religious, social, and professional cultures such as the culture of the local hospital or another specialty. Each of these cultures has its own values and language. Sensitivity to differences in cultural background helps to facilitate communication and understanding. When inquiring about cultural backgrounds, you can use sentences such as: "People from different backgrounds handle death and dying very differently. Is there anything that we should be aware of regarding your care?"
- **Validate "unrealistic" or conflicting goals.** Physicians are sometimes frustrated by their patients' "unrealistic" goals. "They just don't get it" is a common reason for palliative care consultation requests. Reflecting on our own goals in life, most of us have some hopes that may not be very realistic ("I wish I could win the lottery") but still valid. The great difference lies in how we handle these hopes: Are we leading our life counting on what seems an unrealistic hope? An often cited example of this is a terminally ill parent who is unable to make the necessary arrangements for his or her minor children. A useful strategy to support hope, but at the same time assist in making appropriate plans for the future, is the "plan B" approach: "Although we hope for plan A, lets also prepare for plan B, just in case." Another useful way to validate your patient's hope is the "I wish" statement. An example could sound like this: "I wish this will come true for you. Whatever happens we will be there for you." It is often similarly distressing to health care providers when patients verbalize conflicting goals over time. Just as in the previous case, it helps to acknowledge that we, too, often have conflicting goals ("I wish I could eat ice cream three times a day and still be as slim as I was when I was 20."). In end-of-life care especially, intermittent denial of terminal prognoses verbalized as unrealistic hopes can be a proficient way of coping and should be accepted as such.
- **Pay attention to emotions and identity issues.** Paying attention to emotional reactions and to identity issues underlying goals-of-care discussions is an invaluable tool to promote understanding, comfort, trust, and thereby successful discussion and decision making. Emotional awareness is at the core of empathic health care and allows for a true and authentic relationship between you and your patient.

PITFALLS

Preparation

- **Having an agenda.** If you find yourself entering the room with your own agenda (e.g., to "get the DNR" or to "stop this futile treatment"), you may be headed for trouble. Try to understand patient values and priorities, first, to assist you in making appropriate medical recommendations that are most likely to achieve the patient's goals. An awareness of possible agendas of all parties involved in a goals-of-care discussion such as yourself, patients and families, consultants, or hospital administrators assists in understanding the different perspectives and prevents adversarial outcomes.
- **Stakeholders not identified.** You may have facilitated a picture-perfect goals-of-care discussion and thought that everyone agreed on a reasonable plan only to find out that the "cousin from out of town" flew in last night and threw over the whole plan. Before starting a goals-of-care discussion, always make sure that all stakeholders are physically present, included over the phone, or otherwise represented to the extent possible. Stakeholders also include other health care providers involved in the patient's care.
- **Homework not done.** Be prepared to answer questions regarding the outcomes and evidence of discussion interventions such as resuscitation survival data, prognosis, and side effects of treatments. Just as in any other informed consent discussion, patients need accurate information to make good decisions.

Discussion of Overall Goals and Specific Options

- **Inadequate information giving.** Each person handles information differently. Although some patients want to understand the numerical probability of success or failure of specific interventions, others do not comprehend statistical information. Many clinicians share an excessive amount of medical details (because it is familiar or interesting to the physician) using language that the patient cannot understand. Tailor the actual information giving to your patient's needs. It may be helpful to ask the patient to repeat the information back to you using his or her own words. When discussing options, avoid using diffuse language such as "heroic interventions," "comfort care," or "good quality of life" because everyone has a different understanding of what these mean.

Shared Decision Making, Informed Consent, and Decision-Making Capacity

- **The person does not have or is inappropriately denied decision-making capacity.** Before asking someone to make a decision regarding goals of care, ask yourself whether that person has decision-making capacity. This is usually the case if a person can summarize the decision in his or her own words including appropriate underlying reasoning. Patients with delirium, dementia, depression, or other mental health problems may be able to demonstrate decision-making capacity. Because decision-making capacity is specific for each decision, and at a specific point in time, patients may very

well be able to make consistent decisions regarding their care. This right should not be taken away from them inappropriately.

- **"Restaurant-menu medicine."** The process of shared decision making strongly values patient autonomy, but it also recognizes the duty of the health care provider to make recommendations based on his or her medical expertise that are most likely to achieve the patient's stated goals. Many physicians skip this step. It leaves the patient feeling lost and themselves often frustrated as the "waiter" offering different medical options as if they were items on a restaurant menu for the patient to choose.

SUMMARY

Addressing goals-of-care periodically over the course of a patient's illness is an important part of patient-centered care and has been shown to increase patient satisfaction and to decrease patient stress and anxiety (18, 19). The outcome of goals-of-care discussions should guide our therapy and will assist us in supporting our patients through stressful life transitions. In this chapter, we have discussed a simple, six-step protocol that can be used to facilitate these types of discussions. It is intended as a road map, highlighting the key components of successful negotiations. It is well known that communication is an important part of medial care. As any other skill, good communication skills are learned with practice over time. The techniques used in this model can be applied to may other fields of patient care and personal interaction in general.

Resources

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B PHYSICAL AND PSYCHOLOGICAL SYMPTOMS

6 Multiple Symptoms and Multiple Illnesses

S. Lawrence Librach

CHAPTER OUTLINE

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INTRODUCTION

The term *comorbidity* has been defined as follows:

The presence of coexisting or additional diseases with reference to an initial diagnosis or with reference to the index condition that is the subject of study. Comorbidity may affect the ability of affected individuals to function and also their survival; it may be used as a prognostic indicator for length of hospital stay, cost factors, and outcome or survival (3).

In the past, the term was not used to define the interplay of specific diseases and multiple symptoms. Here, the term is used to encompass both.

Patients who have advanced, progressive illness and those who are at the end of life rarely present with just one illness or symptom. Many of us will die with or of two or more chronic illnesses. In 1999, 65% of elderly persons in the United States had two or more types of chronic illnesses (1). Elderly patients comprise most of those in need of palliative and end-of-life care. In 2002, three fourths of the deaths in the United States occurred in persons aged 65 years and older. Five of the six leading causes of death in this age group were chronic illnesses, including cancer, neurodegenerative diseases such as Alzheimer's disease, and organ (particularly cardiac) or system failure. The frequency and mortality rate of cancer increase with advancing years. The incidence of neurodegenerative diseases and advanced pulmonary, cardiovascular, and renal diseases also increases dramatically with age. Patients with diagnoses other than cancer often have less predictable and longer illness trajectories (2). As a result, accurate prognostication, goals of care, and therapies are more difficult, and the issues of comorbidity are more prevalent.

Many patients who are at the end of life are also elderly persons who have experienced considerable changes in their function, drug pharmacokinetics, and social situations that also complicate management. Moreover, many clinical research studies exclude patients with significant comorbidities, thus making the application of the results of these studies less effective in the palliative care population. Underreporting of symptoms is a well-documented phenomenon in the elderly that makes symptom management difficult. Concern about being a burden on one's family may be one reason that symptoms are underreported.

Comorbid illnesses and symptoms may make prognosticating that much more difficult, may drastically change the prognosis of an illness such as cancer, may interfere with responses to therapy, and may pose a significant, independent threat to high-quality end-of-life care. Patients with comorbid conditions also have a variety of lifestyles, economic capabilities, families, and other psychosocial and spiritual issues that they bring with them into the terminal phase of their illnesses, and these factors can affect suffering and management of the illnesses.

The cost of care is also considerably affected by comorbid conditions. In one study of congestive heart failure, costs increased with each comorbid condition, especially diabetes and renal failure (4). In 1999, 65% of the US elderly population had two or more types of chronic medical conditions. Per capita annual expenditures were $1154 for those with one type, $2394 for those with two types, $4701 for those with three, and $13,973 for those with four or more chronic medical conditions (5).

Superimposed on this multiple illness background and the age factor is the prevalence of many symptoms produced by these illnesses in addition to a superadded terminal illness such as cancer. Pain as a symptom has been the major focus of attention in palliative and end-of-life care. Poor pain treatment continues to be documented. Uncontrolled pain can add to suffering in multiple ways, and compliance with therapeutic regimens may decrease. Depression, loss of function, anxiety, and family problems may result. Pain management that also overlooks the need to manage its common adverse effects such as constipation, sedation, and decreased concentration or cognitive dysfunction can end up adding to suffering rather than reducing it.

Pain is rarely the only symptom, however. Other physical symptoms are common in patients near the end of life and are often not assessed adequately. This deficiency contributes substantially to suffering in terminally-ill patients. One large study of hospice patients used a standardized tool, the Memorial Symptom Assessment Scale, to assess the prevalence of symptoms (6). The results are detailed in Table I–6–1.

A systematic search of medical databases and textbooks identified 64 original studies reporting the prevalence of 11 common symptoms among patients with end-stage cancer, acquired immunodeficiency syndrome, heart disease, chronic obstructive pulmonary disease, or renal disease. This review consistently showed a high prevalence of almost all considered symptoms: pain, confusion, delirium, cognitive failure, depression, low mood, sadness, anxiety, dyspnea, fatigue, weakness, anorexia, nausea, diarrhea, constipation, insomnia, and poor sleeping.

Table I–6–1 ■ Prevalence of Symptoms in End-of-Life Care (348 patients)

Symptoms	Prevalence (%)
Lack of energy	83
Pain	76
Lack of appetite	63
Drowsiness	61
Difficulty concentrating	60
Feeling sad	51
Shortness of breath	48
Agitation	48
Worrying	43
Cough	42
Nervousness	42
Constipation	39
Irritability	38
Swelling of arms or legs	36
Difficulty sleeping	35
Weight loss	35
Dry mouth	34
Difficulty swallowing	30
Plus 15 other symptoms of variable frequency	

From Kutner JS, Kassner CT, Nowels DE: Symptom burden at the end of life: Hospice providers' perceptions. *J Pain Symptom Manage* 2001;21:473–480.

Most symptoms were found in one third or more of patients, and multiple symptoms occurred for all five diseases. However, two symptoms, pain and fatigue, were common in all five diseases, occurring in 34% to 96% and 32% to 90%, respectively. Breathlessness was common in most conditions, but it was most consistently found among patients with chronic obstructive pulmonary disease (minimum, 90%) and heart disease (minimum, 60%) (7).

Another recent study reviewed the prevalence of symptoms in 90 older US adults. In this group, 42% had a diagnosis of chronic obstructive pulmonary disease, 37% had a diagnosis of congestive heart failure, and 21% had a diagnosis of cancer. The prevalence of symptoms, as measured by the Edmonton Symptom Assessment Scale, ranged from 13% to 87%. Limited activity, fatigue, physical discomfort, shortness of breath, pain, lack of well-being, and problems with appetite were experienced by the majority (>50%) of participants. Smaller proportions of participants experienced feelings of depression (36%), anxiety (32%), and nausea (13%) (8).

The prevalence of these symptoms in palliative care patients varied widely in other reports and depended on the trajectory of the patients' illnesses, the assessment tools used, and the selection of patients. These symptoms are often either undertreated or not recognized across care settings. More systematic assessments using multiple tools will uncover more symptoms, but options for effective treatment of these symptoms may be limited and often require numerous medications that can pose significant risks and added suffering because of adverse drug effects and interactions.

There is growing literature around the issues of multiple symptoms and clusters of symptoms. Research on symptoms has generally been focused on single symptoms. Symptom clusters such as pain, depression, and fatigue seem to be linked clinically and may have similar interdependent, pathophysiological processes (9). Initial data seem to suggest that patients with cancer who have multiple symptoms have worse outcomes. Palliative care has traditionally understood the need to address multiple issues, but the comorbidities engendered by these multiple symptoms, comorbid illnesses, and multiple care systems provide new challenges in management.

ILLUSTRATIVE CASE STUDIES

Case Study I-6-1 ■

Albert is a 62-year-old man with advanced, non–small cell lung cancer with liver and bone metastases. He also has a 30-year history of diabetes mellitus and is insulin dependent. Diabetic complications include increased creatinine (175 mg/L), peripheral neuropathy, hypertension, hyperlipidemia, and mild macular degeneration. He was quite obese (at least 20 kg overweight) until recently and has severe osteoarthritis in one knee. He has developed increased, burning pain in both feet since undergoing chemotherapy. His bone pain and knee pain have been difficult to control with opioids (oxycodone), and he has had two episodes of toxicity from his opioids. Other symptoms include decreased appetite with a weight loss of 10 kg, several hypoglycemic episodes, a sacral ulcer (stage 2), and generalized weakness. He is taking multiple medications, including atorvastatin, ramipril, insulin, sustained-release oxycodone, immediate-release oxycodone, desipramine, sennosides, and lactulose. He was referred to the palliative care service for pain management.

Case Discussion

Even without considering his psychosocial and spiritual issues, this patient's management is made very complex because of the interplay of his diseases, symptoms, and functional disability. Considering his impaired renal function, pain management with oxycodone is a relatively good choice, despite some reports of toxicity in patients with renal failure. Morphine and hydromorphone are not good choices for patients with renal impairment because of the risk of buildup of active metabolites of these drugs. Methadone and transdermal fentanyl may be better choices, but methadone may have significant interactions with some of his other drugs, such as lorazepam and desipramine. The patient's episodes of toxicity occurred when his knee was very painful and he took more than six breakthrough doses over a nighttime period. One episode of toxicity occurred when he used sustained-release oxycodone as breakthrough medication because he was unable to read the label properly at night as a result of his macular degeneration. He had to stop his nonsteroidal anti-inflammatory drug because of his increasing creatinine level. His renal impairment also limits the doses of other neuropathic pain adjuvants such as gabapentin.

This patient's weakness and the limited walking ability caused by his osteoarthritic knee have been cofactors in the development of a painful, stage 2 sacral ulcer. He is not able to monitor his blood glucose very effectively because he is more tired and sleeps for long periods of time. He is more susceptible to hypoglycemic episodes because of decreased and sporadic food intake. Therefore, his insulin dose should be decreased, and his blood glucose should be allowed to remain in a higher range. Tight blood glucose control leaves him open to significant risk. He should be monitored on a weekly basis by his home care nurses, and control of his diabetes should be supervised by one physician to minimize communication problems.

A medication review is definitely in order. The risk of rhabdomyolysis is greater in patients with renal impairment. Even though he is on a low dose, the hyperlipidemia is the least of his worries at this time. A full medication review should be done on patients with advancing disease. The need for antihypertensive, lipid-lowering drugs (among others) should be assessed regularly, and drugs should be discontinued if benefits are not significant, if multiple drugs complicate care, or if drug discontinuation does not add to patient discomfort.

Case Study I-6-2 ■

Antonia is a 54-year-old woman with advanced colon cancer. She was relatively healthy until 5 months ago, when she presented with a bowel obstruction. She was found to have obstructing ascending colon cancer with peritoneal seeding and para-aortic lymph node, sacral, and liver metastases. She had a bowel resection, but she had multiple episodes of partial bowel obstruction over the ensuing months that necessitated multiple hospitalizations. She has a number of persistent symptoms: moderate to severe abdominal pain, severe neuropathic pain in an S1 distribution in the right lower limb, nausea and occasional vomiting, intermittent diarrhea, anorexia, generalized weakness and fatigue, dry and sore mouth, difficulty concentrating, and anxiety panic attacks. This patient is receiving chemotherapy, but each session seems to increase all her symptoms for a few days. She was referred for symptom control. She is currently taking sustained-release morphine, 90 mg twice daily, with 10 mg every hour as necessary for breakthrough. This has helped her abdominal pain a little, but her leg pain is quite severe. She takes some dimenhydrinate for nausea, and is taking ondansetron for chemotherapy-related nausea.

Case Discussion

On interviewing the patient, it was obvious that her leg pain was the most distressing symptom. She was not receiving any neuropathic pain adjuvants, and it was decided that she would start one. The question of drug choice for neuropathic pain depends on a number of factors. Tricyclic antidepressants would expose her to adverse effects that could be problematic. She was already experiencing dry mouth, and a tricyclic antidepressant would worsen that symptom. Constipation, another common side effect of tricyclic antidepressants, could be problematic in a person prone to bowel obstruction. Carbamazepine may also be contraindicated because of the common side effects of nausea and sedation and also because of her ongoing liver disease. Gabapentin may be the best choice because its only usual side effect is sedation. She was started on that drug and was titrated to a dose of 900 mg/day. This provided a moderate amount of relief for her neuropathic pain, but attempts to increase the medication further were met with greater and intolerable sedation, as well as an increase in anorexia.

The use of sustained-release morphine tablets in this patient needs some review. This patient's shortened large bowel and the intermittent attacks of diarrhea may interfere with absorption of the morphine because of enhanced transit time through the bowel. She was switched to a transdermal fentanyl patch and was titrated to a dose of 125 μg/hour. The switch to the transdermal route also avoided the need to find alternative routes of morphine administration when she had more severe episodes of nausea and vomiting associated with intermittent bowel obstruction.

The patient was initially prescribed prochlorperazine for her nausea, but this caused too much sedation and some dystonic reaction. Octreotide was started in hospital and seemed to control her symptoms of nausea better, but she could not afford the cost of this medication. She was referred to a palliative home care program that covered her drug costs and the need for twice-daily injections.

Case Study I-6-3 ■

George is a 44-year-old man with human immunodeficiency virus disease. He has been positive for the virus for 8 years and has been on a regimen of drugs that have been successful in controlling all his disease markers such as CD4 count and viral load. He had been followed every 3 months by his primary care physician, but he missed the last appointment. He was admitted to hospital with severe pneumonia, and his markers have now worsened significantly. He was admitted to the critical care unit because of respiratory failure and is now on a ventilator. His condition is quite unstable because he is severely hypoxic. His brother is the substitute decision maker and provided more information to the critical care unit team and palliative care consultant in the critical care unit.

His brother stated that he has had some increasing concern about George's health for the last 2 months. George has seemed quite pale and ill, and he has also been quite depressed. His partner of 10 years left him about 4 months ago and moved to another city. George has had to change jobs and take a significant salary cut because of downsizing of the technology company for which he has worked. When George's brother was asked to bring in his brother's current medications, he brought in pill bottles of antiretrovirals that were full and had obviously been untouched for several months. He also brought his brother's journal, in which George had chronicled his decision to withdraw medication and his wish to die.

George's condition began to improve, and he was taken off the ventilator after 2 weeks. He was able to communicate and said that he just wished to die. An assessment indicated that he was depressed, but he refused treatment for his depression. The psychiatrist felt that George was competent to make such a decision, even in the presence of depression.

Case Discussion

Psychological issues, particularly depression, can be significant complicating features in end-of-life care. This patient had a long-term, chronic illness that was relatively stable until depression and social disruption led to his noncompliance with therapy. Depression can be a significant comorbidity that can lead to diminished quality of life, withdrawal from socialization, and noncompliance with medications and medical surveillance. In. this case, the patient's depression was manifested as a wish to die by not complying with treatment.

Case Study I-6-4 ■

Brenda is an 86-year-old woman who presented to the emergency department with delirium. Her daughter accompanied her. She was a resident in a senior home. She had a history of congestive heart failure several years ago, atrial fibrillation, hypertension, mild renal failure, and ischemic heart disease. She also had increasing problems with forgetfulness. Her medication list included the following drugs: digoxin, 0.125 mg once daily; furosemide, 20 mg once daily; ramipril, 10 mg once daily; atorvastatin, 20 mg once daily; nitroglycerin spray; paroxetine, 10 mg at bedtime; lorazepam, 1 mg at bedtime; donepezil, 5 mg once daily; acetaminophen with codeine, four to six tablets daily; omeprazole, 20 mg daily; risperidone, 0.5 mg once daily; sennoside tablets, 8.6 mg, two tablets once daily; ginkgo biloba tablets, twice daily; and a multivitamin.

On examination in the emergency department, the patient was quite agitated and confused. Her mucous membranes were dry, and her skin turgor was poor. Her blood pressure was 78/46 mm Hg, and her pulse was 90 and irregularly irregular. She had no edema. She had a loud diastolic murmur, and her liver was quite enlarged and nodular. She had a hard, fixed mass in the left lower quadrant. Her electrocardiogram showed a prolonged QT interval, and her digoxin level was in the toxic range. Her creatinine was 225 mg/L, and her urea was double the normal range. Her hemoglobin was only 90 g/L. All her liver function tests were elevated except for bilirubin, which was normal.

When asked for more information, Brenda's daughter said that her mother lived alone in a senior residence. There is a nurse present during the day in this home, but Brenda has rarely needed her assistance. Brenda's daughter had been away on vacation for the last 4 weeks, and when she returned home 2 days ago, she found her mother significantly changed. The doctor on call for the home prescribed risperidone because of Brenda's agitation, but no one examined her. Brenda's appetite had decreased markedly, and therefore her food and fluid intake have been very limited. No one remembers seeing her at meals in the residence for the last 2 days. Brenda had been responsible for administering her own medications, but her daughter found pills all over the small apartment.

Case Discussion

With a background of long-term cardiac disease and some memory problems that may have signaled early Alzheimer's disease, Brenda had become acutely ill. Although imaging had not been done yet, the likelihood that Brenda had cancer was evidenced by her liver findings and by the abdominal mass. In all likelihood, this added to her confusion, weakness, and anorexia.

One of her problems, the prolongation of her QT interval, was potentially life-threatening and was likely the result of a drug interaction between paroxetine and the recently added drug risperidone. Her severely disturbed liver function and its impact on drug metabolism may account for the adverse effects, particularly her confusion. Her confusion has added to her problems, as evidenced by the pills lying around her apartment. Could she have taken too much digoxin, as evidenced by her toxic levels of digoxin? Could her increasing confusion be a result of presumed cancer plus or minus progression of her dementia?

Numerous systems issues have contributed to her problems. No one was designated to keep an eye on Brenda while her daughter was on vacation. The supervision in the residence is limited, and patients in such settings can often go unmonitored for some time. Although dining room staff noted Brenda's absence from the dining room over the last 2 days, it was not reported to the nurse or to the administration. The on-call physician who prescribed the risperidone did not ask about other drugs and was not aware of the number of possible, significant drug interactions.

FACTORS THAT AFFECT MORBIDITY AND SUFFERING

Factors that affect morbidity and cause suffering are shown in Table I–6–2. Each type of factor is then described.

Disease Factors

Organ failure, especially renal failure, can be a major factor in comorbidity. Poor renal clearance is often seen in elderly patients and can alter the pharmacokinetics of drugs. This may lead to enhanced effects and adverse effects. Examples of drugs used in palliative care include morphine and gabapentin.

Cognitive problems induced by primary brain diseases, such as Alzheimer's disease, or secondary disease, such as brain metastases and metabolic changes, have numerous effects. Patients who are quite ill often also have poor ability to concentrate. Therefore, their ability to be educated and retain information may be severely impaired, and their decision-making capacity may be quite limited. An example of this occurs frequently in intensive care unit settings. Decision making may be substantially affected, yet substitute decision makers may not have obtained enough information to guide decision making. Reports of symptoms

Table I–6–2 ■ Factors That Affect Morbidity and Suffering

Disease factors
Multiple symptoms: physical
Multiple symptoms: psychological and spiritual
Age
Multiple drugs and drug interactions
Social factors
System issues

may be inaccurate or impossible to obtain except by indirect means. Confusion may result in poor compliance with drugs and treatment and may lead to inadvertent overdoses.

Physical functioning may be limited by disease. This affects the ability to perform multiple tasks, such as taking medication, visiting offices for appointments, taking food and fluids, and personal care. Occasionally, the symptoms or conditions of one illness exacerbate those of a second illness. For instance, antiemetic drugs (e.g., prochlorperazine) or major tranquilizers may cause increased symptoms in patients who have preexisting Parkinson's disease.

Multiple Physical Symptoms

Symptoms do more than cause suffering directly; they complicate other aspects of the patient's condition. For instance, pain often interferes with care in a number of ways. It may be such a focus for the patient and family that reports of other symptoms and issues will be suppressed. Pain and other symptoms cause emotional and spiritual distress that may lead to poor compliance, decreased interactions with family and care providers, and poor decision making. Nausea and vomiting interfere with the ability to take medications, food, and fluid and can lead to complications such as dehydration and poor disease control. Dyspnea may interfere with physical functioning to such an extent that it impedes the ability of patients to attend appointments or to participate in any rehabilitation.

Multiple Psychological and Spiritual Symptoms

Anxiety and depression may interfere with patient education and retention of information, and they may contribute to limited communication and compliance. Spiritual angst may lead to poor decision making and disregard of pain.

Age

Physiologically, the very young and the very old handle drugs in different ways, and they may therefore be more susceptible to drug adverse effects and interactions. Adjustment of drug dosing is essential.

Multiple Drugs and Drug Interactions

The more drugs a patient is prescribed, the greater is the likelihood of major drug interactions. All these can add to suffering. Many patients use alternative treatments, such as herbal remedies. These may cause adverse effects or may promote drug interactions that can lead to toxicity. For example, St. John's wort, which is commonly used for depression, may cause methadone toxicity when these agents are coadministered.

Social Factors

Family support is an important factor in compliance with therapeutic regimens. When support is lacking in dysfunctional families or in families who are not coping, this may cause significant problems that enhance patient suffering.

Patients with limited funding may not be able to afford medications. In this situation, compliance may become an issue, and symptoms such as pain may not be treated effectively. Poor living conditions may affect the delivery of care in the home.

Care System Issues

The limited availability of palliative care programs and consultants and late referrals may cause unnecessary suffering related to physical, psychological, and spiritual issues. For patients who are being cared for at home, a lack of home care resources may result in clinicians' unawareness of issues such as compliance, poor living conditions, family problems, and other situations.

AN APPROACH TO MANAGEMENT

Do a Comprehensive Assessment, Look for All the Potential Factors

Whole-patient assessment requires time, input from family and patient, and interdisciplinary collaboration to obtain a complete picture of all the factors and dimensions of comorbidity. Whenever possible, the clinician should use standardized assessment tools such as the Edmonton Symptom Assessment Tool (ESAS) and the Rotterdam Symptom Checklist for symptoms. The Needs Near the End of Life Care Screening Tool (NEST) allows for broad and precise assessment (see Chapter I–3)(10), or a broader assessment of spiritual and social needs. These standardized tools can make assessment more systematic and comparable across care settings. None of these assessment tools can define the totality of suffering, however, and they may be difficult to administer as the patient's illness progresses. Psychological and social issues or symptoms are the most likely to be assessed on a limited basis, thus leading to unaddressed suffering. If a patient is to be discharged home, an assessment directly in the home will reveal valuable information about the social factors of comorbidity.

The clinician should define for the patient and family the multiple dimensions of suffering that must be addressed to relieve the suffering that is associated with the human experience of dying. This educational process about the relief of suffering should be integrated into the holistic care plan from the time a terminal illness is diagnosed until death. Assessment is a dynamic, not static, process.

Review Medications Frequently

Many seriously ill patients have long medication lists that need review. Unnecessary medications should be stopped. Examples include lipid-lowering drugs and other drugs that may no longer be a priority in that phase of the illness trajectory. The health care provider should inform the original, prescribing physician (if he or she is still involved in that patient's care) which medications are being discontinued. As a preventive approach, a drug interaction program should always be

Table I–6–3 ■ Common Drug Interactions in Palliative Care Practice

Drugs	Interactions
Tricyclic antidepressants and carbamazepine	Cardiac toxicity from tricyclic antidepressants
Methadone and SSRIs and tricyclic antidepressants	Increased methadone levels and potential sedation and cardiac toxicity
Tricyclics and fluconazole and SSRIs	Cardiac toxicity from tricyclic antidepressants, serotonin syndrome
Benzodiazepines and methadone	Increased sedation and risk of respiratory depression

SSRIs, selective serotonin reuptake inhibitors.

ordered for patients taking multiple medications before a new medication is added. On-line resources for this can be downloaded onto personal digital assistants (Epocrates, Pepid) and are often incorporated into electronic medical records. Many of the medications frequently used for controlling symptoms are very interactive. Some of these are detailed in Table I–6–3. Routine screening for drug interactions should be standard for any patient being prescribed methadone or any of the neuropathic pain adjuvants. It is also important to recognize that some common herbal remedies (e.g., St. John's wort) and foods (e.g., grapefruit) can have a major impact on drug pharmacodynamics and pharmacokinetics.

Family involvement in monitoring medications can be very helpful. Dispensing aids such as Dosett containers or blister packs to organize medications should be used in elderly patients. Home care resources should be used to monitor patient compliance and adverse effects. Functional disabilities, such as vision or hearing disabilities and physical handicaps that could impede aspects of management, should be assessed. Chronic family and psychological dysfunction should also be assessed because it may interfere with medication compliance. Local pharmacists should be involved in the monitoring and education of patients and their families.

Accept Some Risk in Prescribing

If there is a potential for drug interaction, the clinician should weigh the severity of the risk. If the risk is low to moderate, then the drug should be prescribed, but the patient should be monitored frequently for adverse effects. Time trials should be done and ineffective medications stopped as soon as it is clear that they are not helpful. For example, nonsteroidal anti-inflammatory drugs and neuropathic pain adjuvants should show an effect within 2 or 3 weeks. In approaching a particular symptom, such as nausea, one could consider a trial with increasing doses of one drug or using multiple drugs, particularly if the symptom is quite severe. High doses of one drug may be associated with more frequent and more severe adverse effects, whereas smaller doses of multiple drugs with different pharmacodynamics may be preferable. Multiple drugs do expose the patient to increased possibilities of drug interactions. More research is needed on the multiple drug approach to a symptom, and, at this time, the choice is empirical.

Educate and Counsel about the Goals of Care

Priorities in management should be identified for the care team and for the patient and family. Care and compliance will be enhanced if the patient and family understand the goals of care and the way in which multiple issues and factors of comorbidity affect the outcomes of the care plan. This educational process should also include information on how members of the team can be contacted, and it should reassure patients and family about accessibility 24 hours per day. The clinician should recommend Internet resource sites for patient and family education on issues in end-of-life care. Patient and family re-education is necessary when goals of care change. Patient and family education about prognosis should include consideration of how significant comorbid conditions affect outcomes because this may influence treatment choices.

Communication with Others Involved in Care

It is essential to communicate the goals of care and the care plan regularly to other care providers who are still involved in the patient's care. It is hoped that this will minimize conflicting therapeutic regimens, drug interactions, and confusion for the patient and family. Information technology should be used to support decision making and communication. Confidentiality must be ensured.

Monitor Patients Frequently When Changing Therapies

Patient monitoring in this situation is a team responsibility. The care team must be accessible and responsive 24 hours per day for urgent issues.

Refer to Palliative Care Teams Early for Complex Cases

Palliative care professionals are very oriented to dealing with multiple symptom issues and should be consulted for patients with complex cases. Early consultation can limit unnecessary suffering.

Advocate for Social Supports

Referral for palliative care can be an important component in the ability to address issues of comorbidity. Adequate funding of care support and maximal utilization of community resources may relieve the family of financial burden and may avoid the all too common complications of bankruptcy and job loss.

PEARLS

- Comorbid illnesses and multiple symptoms are common in the population we serve (i.e., the elderly and chronically ill) and affect both prognosis and treatment.
- Medication review is important in managing comorbidity. It is important to discontinue unnecessary medications and perform drug interaction reviews.

- A comprehensive approach that includes patient and family education, communication with other care providers, and regular review may prevent and minimize problems.

PITFALLS

- Failure to consider the impact of multiple comorbid illnesses and symptoms may lead to increased suffering for patients and families.

SUMMARY

It makes sense that suffering increases with multiple disease and symptom burden. By using a biopsychosocial model to address the issues of comorbidity, clinicians will be able to understand how suffering, disease, and illness are affected by multiple factors from the physical to system issues and to understand how the patient's subjective experience is an essential contributor to accurate diagnosis, treatment regimens, health outcomes, and humane care.

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Pain

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7

CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

Pain is a complex biopsychosocial event. Studies have shown that all types of pain (acute, chronic, and cancer pain) are undertreated, and poorly controlled pain has been identified consistently as one of the major problems in end-of-life care. In North America, pain is a major reason for referral to palliative care programs.

However, adequate pain control can be achieved in most patients at the end of life by using a comprehensive approach that includes analgesics, adjuvants, education, support, and monitoring.

PAIN CLASSIFICATION

Pain can generally be classified as nociceptive or neuropathic.

Nociceptive Pain

Nociceptive pain is caused by the activation of nociceptive nerve fibers by physical tissue destruction or by chemical, pressure, or thermal processes.

Nociceptive somatic pain can result from injury to skin, muscle, soft tissue, or bone and can have a strong incident- or movement-related component. It is usually well localized, can be constant or intermittent, and is often described as gnawing or aching pain that may become sharp with movement.

Nociceptive visceral pain is typically less well localized, is usually constant, and may be referred (e.g., diaphragmatic pain may be manifested as shoulder pain). It is described by a variety of terms, such as aching, squeezing, and cramping. Pain arising from liver metastases is an example of nociceptive visceral pain.

Neuropathic Pain

Neuropathic pain is caused by injury to nerve tissue, including the central or peripheral nervous system and even the autonomic system. Neuropathic pain is frequently described as burning and often radiates along nerves or nerve roots. It can also be associated with dysesthesia (numbness and tingling), hyperalgesia (exaggerated response to a painful stimulus), lancinating pain, and allodynia (pain experienced from a stimulus that does not normally produce pain).

As knowledge about pain has advanced, health care professionals have become increasingly aware of the need to develop a more mechanism-based approach to pain control. Pain is often a combination of physical and inflammatory processes. Cancer pain is an example of pain that may result from tissue damage and destruction and stimulation of nerves by inflammatory mediators that are produced by the tumor and also by the body in response to tumors. The clinical usefulness of pain classification relates to the use of certain adjuvant medications for specific pains, particularly for neuropathic pain.

ASSESSMENT OF PAIN

Pain is a subjective sensation, and there is no truly objective method for measuring it. Understanding the multidimensional nature of the physical, psychosocial, and spiritual components of pain is integral to the assessment of pain. Pain assessment should include a detailed history, relevant psychosocial and spiritual evaluation,

physical examination, and relevant investigations. It is useful to assess pain in the physical, psychological, and social domains in sequence.

Physical Domain

Features of the pain include the following:

- Location
- Pattern of occurrence
- Quality; sharp, dull, burning
- Aggravating or relieving factors
- Radiation of the pain
- Severity and variation in severity
- Interference with activities of daily living that may reflect the degree of severity of pain
- Report of skin hypersensitivity or numbness, for example, that may suggest an underlying neuropathic component of the pain
- Pain treatment and analgesic history: what worked and what failed, dosage, side effects

A suggested tool that can be used to quantify pain is the Brief Pain Inventory (1), or, alternatively, a visual, verbal, or numerical analog scale can also be used (Fig. I–7–1).

A history of present and past medical conditions is useful because some conditions complicate pain expression and subsequent management. Inquiry should cover the following:

- Presence of underlying delirium, cognitive failure, or dementia that could alter pain expression and the accuracy of pain history
- Presence of preexisting chronic pain or previous pain history, such as osteoarthritis or diabetic neuropathy
- Previous exposure to neurotoxic antineoplastic agents
- Presence of complicated cancer pain syndromes, such as malignant leptomeningeal spread, plexus involvement, or pathological fractures
- Location of tumors, such as large retroperitoneal lymph nodes that cause back pain
- Presence of concomitant infection or abscess that causes pain

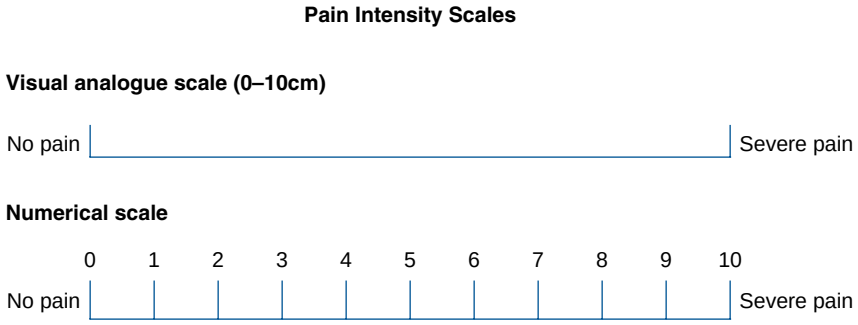

Figure I–7–1 ■ Pain intensity scales.

- Presence of general medical conditions that could affect management and analgesic dosing, such as significant hepatic or renal impairment
- Current medications that may interact with analgesics or adjuvants

Psychological Domain

An assessment of psychological factors adds to the understanding of a patient's suffering and pain expression. Issues in these domains that could affect pain assessment and management include the following:

- Depression and anxiety
- Limited understanding of the illness
- Patient's fears of opioid use
- Anger toward the health care system or health care workers
- Underlying personality disorder or psychiatric disorder
- Loss of body image related to various surgical procedures
- Poor coping mechanisms
- Patient denial

Social Domain

An assessment of the social factors that may have a bearing on the patient's pain expression is also useful. Some factors include the following:

- Fears of opioids
- Family discord and dysfunction
- Guilt within the family
- The family's lack of knowledge and understanding of the disease and prognosis
- Denial or unrealistic expectations of the family
- Financial issues
- Cultural and religious factors
- Drug addiction

PRINCIPLES OF PAIN MANAGEMENT

Educate the Patient and Family

It is essential to explain to the family and the patient the origin of the pain, the type of pain, the initial management plan (including the role of titration), expected adverse effects and how they will be managed, how the pain will be monitored, and how to access the professional care team. Fears concerning opioid use also need to be addressed.

Prevent and Minimize Adverse Effects

Common adverse effects such as sedation, constipation, and nausea should be anticipated and prevented through a combination of education and the regular use of

drugs that will address these issues. By minimizing adverse effects, additional patient suffering can be avoided, compliance may be enhanced, and anxiety reduced.

Match Pain Severity to Analgesic Potency

The three-stepladder approach for pain control by the World Health Organization (WHO) is now being questioned. Evidence indicates that, for mild to moderate pain, nonopioid analgesics are effective either alone or in combination with weak opioids. For moderate pain, the recommendation is to start with small doses of strong opioids. For severe pain, strong opioids are the initial drug of choice. The use of adjuvant drugs is recommended for all types of pain. For a summary of prescribing principles, see Table I–7–1.

Titrate to Pain Control

Each patient has different analgesic requirements, depending on the source of the pain and as a result of pharmacokinetic and pharmacodynamic differences among patients and the interplay of other factors in producing the "total pain" experience. Thus, dosages have to be tailored and titrated to the patient's individual pain needs.

Prescribe Around-the-Clock Dosing

Patients with constant pain require around-the-clock dosing at regular intervals to suppress the pain. There is rarely a role for "as necessary" administration of medication for constant pain except as breakthrough dosing.

Prescribe Rescue Doses

Pain is rarely completely stable, and extra pain should be treated with breakthrough or rescue doses. Always prescribe rescue dosing.

Table I–7–1 ■ Type of Pain and Analgesics

Type	Typical Analgesics	Adjuvant Analgesics
Nociceptive pain: mild	Non-opioids +/− weak opioids	NSAIDs brief trial
Nociceptive pain: moderate to severe	Strong opioids	NSAIDs Radiotherapy Surgery
Neuropathic pain: mild	May not be indicated	Tricyclic antidepressants Typical and atypical anticonvulsants
Neuropathic pain: moderate to severe	Strong opioids	Tricyclic antidepressants Typical and atypical anticonvulsants Radiation Surgery

Always Consider Using Adjuvants

For neuropathic pain, consider starting adjuvant analgesics before opioids for mild pain, or at the same time as opioids for moderate or severe pain. For bone pain from cancer, the option of radiotherapy must always be explored. For all types of pain, non-opioids such as acetaminophen and non-steroidal anti-inflammatory drugs may be helpful. Brief trials of these non-opioids along with opioids may prove to be beneficial to some patients. Surgery may also be indicated for bone pain and for neuropathic pain. These points are summarized in Table I–7–1.

Monitor Continuously

Constant and frequent review of the patient's response to the prescribed regimen of analgesics, adjuvants, and other interventions is important. The patient's medical status needs to be monitored for conditions that could affect the dose of the analgesic regimen, such as the development of renal failure. Patients and family members can all be involved in this process.

ADDICTION, DIVERSION, PHYSICAL DEPENDENCE, AND TOLERANCE

Physicians who prescribe opioids need to differentiate the issues of physical dependence, drug abuse and diversion, addiction, and tolerance. However, a history of substance abuse does not exclude someone from having pain. Definitions of addiction, physical dependence, tolerance, and pseudoaddiction are listed in Table I–7–2 (2, 3).

Some of the issues concerning opioid prescription for pain in a person with a history of substance abuse are as follows:

- Patients who have abused and developed tolerance to opioids may require higher than usual doses of opioids for pain control.
- Patients who are at higher risk of substance abuse can be identified, and questionnaires such as the CAGE may indicate abuse potential (4).
- Common abuse behaviors include reports of "lost" or "stolen" prescriptions, a history of multiple prescribers, obtaining prescription drugs from nonmedical sources, and repeated dose escalations or similar instances of noncompliance despite multiple warnings (2).
- Emotional, social, and even spiritual issues complicate and magnify pain expression.
- The patient's behavior may contribute to the difficulty in treating pain, and mistrust between the patient and the health care provider can be a barrier.
- Simple strategies to prevent abuse may include dispensing a limited amount of opioids at a time, having only one designated prescriber and one designated pharmacy to fill the prescription, and allowing no refills for "lost" or "stolen" prescriptions.
- Consider using opioids that have less street value (this can vary in different geographic locations).
- Be aware of analgesic combinations that have potentially hepatotoxic components, such as acetaminophen in drug abusers, who are at high risk of liver damage.

Table 1–7–2 ■ Definitions of Addiction, Physical Dependence, Tolerance, and Pseudoaddiction

Addiction	A primary, chronic neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: • Impaired control over drug use • Compulsive use • Continued use despite harm • Craving
Physical dependence	A state of adaptation manifested by a drug class-specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist
Tolerance	A state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time
Pseudoaddiction	Syndrome of behavioral symptoms that mimic those seen with psychological dependence, including an overwhelming and compulsive interest in the acquisition and use of opioid analgesics. Unlike true psychological dependence, pseudoaddiction is an iatrogenic syndrome caused by the undermedication of pain. Symptoms and aberrant behaviors resolve once pain is effectively controlled.

Data from American Academy of Pain Medicine, American Pain Society, and American Society of Addiction Medicine (ASAM): Definitions Related to the Use of Opioids for the Treatment of Pain. Public policy statement, 2001. Available at http://www.asam.org; and Weissman DE, Hadox DJ: Opioid pseudoaddiction: An iatrogenic syndrome. Pain 1989;36:363–366.

PHARMACOLOGICAL OPTIONS FOR PAIN MANAGEMENT

Analgesics drugs can be classified as follows:

- Nonopioid analgesics
- Opioid analgesics
- Adjuvant drugs

Nonopioid Analgesics

These drugs are appropriate as single agents for mild pain.

Acetaminophen

Acetaminophen is the most common over-the-counter analgesic drug. Its exact mechanism of action is not totally clear, but it does have peripheral and central actions. Dosage is limited to less than 4 g/day, to minimize potential hepatotoxicity. This drug should be used with caution in patients with active hepatitis or hepatic dysfunction, in patients who abuse alcohol, and in those with jaundice. It may also be effective as an adjuvant when added to strong opioids (5).

Acetaminophen is often combined with codeine or oxycodone. This combination may prove useful in patients who have mild to moderate pain, but the amount of acetaminophen limits the titration dosages.

Nonsteroidal Anti-inflammatory Drugs

Nonsteroidal anti-inflammatory drugs (NSAIDs) have peripheral and central actions perhaps related but not totally limited to inhibition of cyclooxygenase enzymes (COX-1 and -2). There are concerns of gastrointestinal and renal toxicity with NSAIDs. Some of the newer, specific COX-2 inhibitors may have less severe or fewer gastrointestinal and renal side effects. However, more recent information on the increased cardiovascular risk associated with these COX-2 inhibitors caused both rofecoxib and valdecoxib to be withdrawn from the market.

Considerations in the use of NSAIDs mainly in nociceptive pain include the following:

- For various reasons, many patients with advanced illnesses are often taking corticosteroids. Some may also be taking anticoagulants for deep vein thrombosis or may even have coagulopathy secondary to hepatic impairment. The use of NSAIDs in these patients puts them at high risk of upper gastrointestinal bleeding.
- Clearance of the first-line strong opioids such as morphine and hydromorphone depends on kidney function. NSAIDs may affect renal function and may lead to decreased renal clearance and an increased risk of opioid toxicity.
- Gastric protection with misoprostol and proton pump inhibitors such as omeprazole can be considered for high-risk patients.
- No clear evidence indicates that one NSAID is superior to another.
- If the patient has no clear response to an NSAID, the drug should be discontinued. This applies whether the drug is used alone or as an adjuvant.

Tramadol

Tramadol is a unique, synthetic, centrally acting analgesic with both opioid and nonopioid properties. It has some action at the μ opioid receptor, but it also has other actions, including possible anti-inflammatory effects. In addition, it stimulates neuronal serotonin release and inhibits the presynaptic reuptake of both norepinephrine and serotonin at synapses. Naloxone only partially reverses the analgesic effect of tramadol. Its bioavailability is twice that of codeine. It is a pro-drug and relies in part on an active metabolite for its analgesia. It is converted in the liver in the cytochrome P450 system to *O*-desmethyltramadol, which is itself an active substance, two to four times more potent than tramadol. Further biotransformation results in inactive metabolites that are excreted by the kidneys. Five to 10% of the population lacks the isoenzyme to metabolize tramadol, and in such persons tramadol has little or no analgesic effect. CYP 2D6 inhibitors (e.g., chlorpromazine, delavirdine, fluoxetine, miconazole, paroxetine, pergolide, quinidine, quinine, ritonavir, and ropinirole) may decrease the effects of tramadol. Carbamazepine decreases the half-life of tramadol by 33% to 50%. The concomitant use of monoamine oxidase inhibitors is contraindicated. Tramadol must be used with caution with any central nervous system depressant such as phenothiazines and barbiturates. By injection, tramadol is one tenth as potent as parenteral morphine. Orally, because of much better bioavailability, it is one fifth as potent. Tramadol can be regarded as double-strength codeine.

Tramadol is available in the United States and in Canada, but in Canada it is available only in a fixed combination with acetaminophen. There is a ceiling dose. The most common adverse effect is constipation, but this seems to occur less often than with equianalgesic doses of morphine. There is a risk of increased seizures, and therefore tramadol should probably not be used in patients with seizures.

Opioids

Opioids are the mainstay of pain management in palliative care.

General Properties

1. Opioids are variably absorbed from the gastrointestinal tract. Morphine and codeine are absorbed relatively poorly (30% to 50%), and methadone has a good oral bioavailability of about 80% (ranges from 41% to 99%). Bioavailability is further reduced by metabolism in the gut wall and the liver (the first-pass effect). Absorption may be genetically determined and may decrease with increasing age.
2. All opioids are bound to plasma proteins, generally to albumin and α_1-acid glycoprotein. However, the extent of binding varies from less than 10% for codeine to 80% to 86% for fentanyl. Morphine is about 20% to 35% protein bound.
3. Most opioids have a large volume of distribution, depending on the lipophilicity of the parent compound and metabolites. Fentanyl and methadone are the most lipophilic.
4. Opioids are metabolized to more hydrophilic compounds, predominantly by glucuronidation in the liver, although some extrahepatic metabolism may occur. Most of the metabolites are less active than the parent opioid and may not have much clinically relevant pharmacological action. However, some metabolites are as potent or more potent opioid agonists than the parent drug (e.g., morphine as a metabolite of codeine, morphine-6-glucuronide derived from morphine). Some metabolic byproducts, particularly morphine-3-glucuronide, hydromorphone-3-glucuronide, and normorphine, may be responsible for the neurotoxic side effects of confusion and myoclonus. Because they are excreted by the kidneys, these metabolites accumulate in patients with renal failure. Methadone is the exception because it is metabolized in the liver through the cytochrome P450 system, and the major route of excretion is fecal. Methadone is therefore more prone to drug interactions with agents that affect that metabolic system. Oxycodone, fentanyl, and methadone have no active final metabolites.
5. Opioids bind to opioid receptors that are spread throughout the body. In the central nervous system, they are concentrated in the thalamus, the periaqueductal gray matter, and the dorsal horn of the spinal cord. Receptors are also present in the lungs, the myenteric plexuses of the gastrointestinal tract, and in other areas where their exact function remains unclear. The μ receptor is the one most strongly associated with analgesia. Other receptors include κ and δ receptors. Recent work on opioid receptors suggests that genetic polymorphism may be responsible for the varied interindividual response to the same doses of an opioid.
6. Opioids can be divided into pure agonist, partial agonists, mixed agonist, and antagonists (Table I–7–3) based on their interactions with the various receptor subtypes (μ, κ, and δ). Partial agonists (e.g., buprenorphine) and the mixed agonists and antagonists (e.g., butorphanol and pentazocine) have the disadvan-

Table I–7–3 ■ Classification of Opioid Analgesics by Receptor Interactions

Agonists	Partial Agonists
Weak	Buprenorphine
Codeine	
Propoxyphene	
Hydrocodone	
Dihydrocodeine	
Strong	
Morphine	***Agonist/Antagonists***
Oxycodone	Pentazocine
Hydromorphone	Butorphanol
Methadone	Nalbuphine
Fentanyl	
Diamorphine (heroin)	
Oxymorphone	
Meperidine	
Levorphanol	
Sufentanil	
Alfentanil	

tage of a ceiling effect. The mixed agonist and antagonists are noted to have psychotomimetic side effects and partial agonists have the potential to cause withdrawal problems when added to pure opioid agonists. Hence, the pure agonist opioids are the most useful medications in the management of pain.

Adverse Effects

Common Effects

- *Sedation.* Almost every patient has some sedation from opioids, especially on initial dosing. This sedation often resolves in 3 to 4 days unless the dosage is too high. If mild sedation persists, methylphenidate may be helpful.
- *Constipation.* This is an almost universal phenomenon with opioids, especially in patients with advanced disease (6). The effect of opioids on bowel myenteric plexuses results in decreased propulsion of stool and increased transit times, causing increased fluid absorption that results in hard, infrequent stools. Combined with other factors such as weakness, decreased food intake, and other drug effects in patients with advanced illness, constipation can become a major problem. The approach should be preventive, and every patient should be receiving a stimulant laxative such as senna or bisacodyl and an osmotic laxative such as lactulose or milk of magnesia. Patients should be monitored carefully for constipation.
- *Nausea and vomiting.* Approximately 70% of the population may develop some nausea with opioids, particularly on initiation of an opioid. Again, the approach should be preventive. Patient education is important because patients who are warned of the possibility of nausea may tolerate the usual, minimal nausea that occurs, and they are less likely to request additional medication for the nausea. Antiemetics (especially those that bind to dopaminergic receptors, such as haloperidol, metoclopramide, and prochlorperazine) are most effective. Antihistamine

agents such as dimenhydrinate are less effective. Prolonged nausea and vomiting are rare, and most patients tolerate this nausea within a few days, although with titration there is the possibility of some recurrence of nausea. Severe nausea and vomiting may occur rarely with even small doses of opioids. Those patients may tolerate transdermal or parenteral administration or a significantly smaller starting dose and gentler titration.

Less Common Adverse Effects

- Urinary retention
- Pruritus resulting from histamine release in the skin
- Mild cognitive problems, including poorer memory, decreased ability to concentrate, and bad dreams
- Mild confusion
- Myoclonic jerks

Rare Adverse Effects

- Allergy to opioids (except for codeine)
- Respiratory depression (rare except in circumstances of overdose)

Special Issues

Driving While Taking Opioids. After an initial period of adjustment to opioids and when sedation is not present, patients may be allowed to drive. However, other factors in their disease process, such as generalized weakness and other symptoms, may preclude driving. Each case should be considered individually.

The Issue of Opioid Toxicity. Some patients may develop opioid toxicity. This may relate to overdosage (with rapid titration, overenthusiastic dosing, medication errors, poor compliance, and other factors), renal failure and other metabolic problems, and sepsis. Patients initially present with increased sedation and then delirium with confusion, hallucinations, agitation, and frequent myoclonus. Severe toxicity may result in coma and respiratory depression, although these are relatively rare. In the case of opioid toxicity, the opioid can be withheld or significantly reduced or rotated to another opioid, and the patient should be monitored carefully and given fluids if necessary.

Practical Tips

- The starting dose for opioid-naive patients can be 5 to 10 mg of morphine equivalent every 4 hours. Dosage can be initiated with sustained release preparations, but immediate-release preparations may provide more careful titration.
- Immediate-release and sustained-release opioids should be prescribed regularly around the clock.
- Initial breakthrough (rescue) doses should be prescribed up to every hour as needed. Breakthrough doses are generally 10% to 15% of the total daily dose of the same opioid.
- If the patient is very elderly or frail, the initial dose should be smaller, and titration should be done more slowly.
- The oral and parenteral doses of opioids are not equivalent. The dose of parenteral opioids (subcutaneous or intravenous) is usually one half to one third of the oral dose.

- Suggested equianalgesic ratios are listed in the formulary. Equianalgesic ratios are guidelines only, and the final doses have to be individualized according to the patient's needs (7).
- Patients with acute or poorly controlled pain should be given immediate-release formulations to achieve a quicker response and to allow more rapid titration. The controlled-release opioid formulations are more appropriate for palliative care patients who have achieved fairly stable pain control and relatively stable dosages and for patients with chronic pain not related to cancer.
- The initial dose can be titrated or adjusted every 24 to 48 hours. As a general rule, the use of four or more breakthrough doses in a day may warrant a dose increase of the regular opioid. In most cases, the breakthrough doses can be added to the total daily dosage, and the new regular daily dosage can be recalculated on a 24-hour basis in divided doses. If this regimen causes sedation or nausea and the patient does not need breakthrough doses, this may indicate the need to decrease the total daily dose.
- Meperidine should not be used on a long-term basis because of the risk of neurotoxicity (confusion, seizures) from its toxic metabolite, normeperidine, which tends to accumulate with repeated use.
- The oral route is most preferable for all opioids except fentanyl. If the oral route is not suitable, subcutaneous (intermittent or continuous), rectal, and intravenous routes can be considered. Generally, the intramuscular route is not recommended because this route is more painful and is usually unnecessary.
- Transmucosal fentanyl and sufentanil are available for patients who need a fast-acting medication for incident pain.
- If the patient is experiencing symptoms of opioid toxicity, the following should be done:
  - Check for precipitating factors, such as dehydration, renal failure, and infection.
  - If the pain is well controlled, consider holding or decreasing the dose of opioid until the patient is more alert or becomes less confused.
  - Consider rotating to another opioid.
  - Augment pain control with adjuvant analgesics.
- Transdermal fentanyl should be considered for patients who have difficulty swallowing, who experience nausea with the oral route of opioid administration, or who a have a preference for this type of analgesic delivery. However, therapeutic levels from the fentanyl transdermal patch are reached only after 6 to 12 hours, and it may take up to 36 to 48 hours to achieve a steady state. Transdermal fentanyl patches should be used cautiously on opioid-naive patients. After the removal of a transdermal fentanyl patch, fentanyl will still be released from the subcutaneous depot for the next 8 to 12 hours. Hence when switching from transdermal fentanyl to another opioid, it is prudent to wait for about 8 to 12 hours before instituting the new opioid regimen. The patient can use breakthrough doses of another opioid temporarily. If the patient is in severe pain, however, it may be necessary to start the new regimen of opioids, including the transdermal patch, earlier.
- If the patient is using escalating doses of breakthrough opioids, certain issues may impede patient judgment, and pain assessment or other factors should be considered, such as imminent fractures, spinal cord compression, and delirium.
- Opioids are generally not contraindicated in moderate liver disease. In the presence of liver failure, the dose of opioid can be reduced and the frequency of administration decreased.

- In renal failure, the frequency and dose of opioids that have active, renally excreted metabolites (morphine, hydromorphone) may need adjustment (8). An alternative is to switch to a drug with no known active metabolites, such as methadone, fentanyl, or oxycodone.

Opioid Rotation. If there are concerns about tolerance (which may be manifested by ever-increasing doses without response) or issues of adverse effects or opioid toxicity, rotation of opioids may be considered (9,10). Rotation can be done by taking the morphine equianalgesic dose of the first opioid and reducing it by 20% to 30% for incomplete cross-tolerance and then calculating the equivalent dose for the second opioid. For example, to rotate from oxycodone to hydromorphone in a patient receiving oral oxycodone 10 mg every 4 hours, the total daily dose is about 75 mg of morphine equivalent (taking an equivalency factor of 1.5). Doing a dose reduction of about 30%, the new morphine equivalent dose is about 52.5 mg/day, and the oral hydromorphone equivalent dose is about 10.5 mg/day (taking a factor of 5). The final regular dose of oral hydromorphone could be approximately 2 mg every 4 hours. Rotation to transdermal fentanyl is more difficult, and rotation to methadone requires special care.

Methadone

Methadone is a synthetic opioid that has gained renewed interest as an analgesic because of its low cost and potential activity in neuropathic pain syndromes (11). It is a μ opioid receptor agonist, possibly a δ opioid receptor agonist, and an N-methyl-D-aspartate (NMDA) receptor channel blocker. In general, methadone is recommended for use by experienced prescribers. It is a very lipophilic drug and is well absorbed by the gastrointestinal tract, with a bioavailability of approximately 80%. This is better than the bioavailability of oral morphine and other opioids.

Methadone binds extensively to α_1-acid glycoprotein. Initial rapid and extensive distribution occurs within 2 to 3 hours, and a subsequent and slower elimination phase lasts for 15 to 60 hours. This half-life does not seem to correlate with the observed duration of analgesia (6 to 12 hours) after steady state is reached.

Methadone is metabolized mainly by type 1 cytochrome P450 enzymes, namely, by CYP 3A4 (which can be induced or inhibited) and, to a lesser degree, by CYP 1A2 (which can also be induced or inhibited) and CYP 2D6 (this level depends on genetic polymorphism). Methadone therefore has more interaction with other drugs than some opioids because of the potential for inhibiting or enhancing these cytochrome P450 pathways. A drug interaction program should be used with every patient considered for methadone therapy and when any new drug is added to the regimen of a patient receiving methadone.

Some medications can decrease methadone levels. Among these are some antiretroviral drugs (e.g., nevirapine, ritonavir), phenytoin and carbamazepine, risperidone, rifampicin, and fusidic acid. Long-term alcohol ingestion and cigarette smoking can also reduce serum methadone levels. Some of the medications that can increase methadone levels are tricyclic antidepressants (TCAs), ketoconazole and fluconazole, selective serotonin reuptake inhibitors, erythromycin, and metronidazole.

Approximately 60% of methadone is eliminated by nonrenal routes, primarily fecal, and renal excretion depends on urinary pH. However, methadone does not seem to accumulate significantly in patients with renal failure.

The main concerns when using methadone are the unpredictable half-life and the associated risk of delayed overdose. Hence careful dose titration and individualized dosing are needed. Equianalgesic dose ratios depend on the patient's opioid requirements, and various guidelines are available for the administration and titration of methadone.

The simultaneous use of benzodiazepines and methadone may increase the potential for serious respiratory depression and sedation. The complex and highly individualized pharmacokinetic properties of methadone dictate the need for experienced physicians to administer methadone and monitor its effects.

Adjuvant Analgesics

Certain drugs can be used as adjuvants in combination with opioids. These include corticosteroids, TCAs, anticonvulsants, bisphosphonates, muscle relaxants, anesthetic agents, and antiarrhythmic drugs. These adjuvants may be used with opioids to complement pain relief. However, the problem of polypharmacy with problematic drug interactions and adverse effects has to be considered and weighed against the potential analgesic benefits.

Corticosteroids

Corticosteroids are sometimes used for their anti-inflammatory effects in bone pain, to reduce pain from increased intracranial pressure, and as an adjuvant for recent-onset neuropathic pain from spinal cord compression or peripheral nerve compression or destruction (12). Adverse effects include immune suppression, hyperglycemia, hypertension, accelerating osteoporosis, psychotropic side effects such as depression or overstimulation, proximal myopathy, and adrenal suppression. Dexamethasone is often used. Starting doses vary from 4 to 24 mg/day in divided doses. Short-term use and tapering to the lowest effective dose is generally recommended. The drug should be discontinued if pain does not respond quickly.

Tricyclic Antidepressants

This class of medications can be used for neuropathic pain (13). Most of the evidence for use of TCAs is in patients with non–cancer-related chronic neuropathic pain, and the best evidence available is for the drug amitriptyline. The dosage required is normally in the usual antidepressant dose range. It may take up to 4 weeks for a response, and the drug should be discontinued if there is little response.

Relative contraindications for use of TCAs in pain include the following:

- Anticholinergic side effects of the drug may worsen or cause urinary retention or glaucoma. Nortriptyline and desipramine (other members of this class of drugs) have fewer of these adverse effects but are not entirely free of them.
- Coexisting cardiac problems (e.g., heart block, underlying cardiac disease with significant cardiac arrhythmias, significant postural hypotension) are relative contraindications to the use of TCAs.
- Frail elderly patients are more sensitive to the adverse effects of TCAs.

The role of other antidepressants, such as the selective serotonin reuptake inhibitors, in neuropathic pain requires further evaluation and research.

Anticonvulsants

Anticonvulsants have been used for many years in the management of neuropathic pain. Numerous drugs are available, including the typical anticonvulsants such as carbamazepine, phenytoin, valproate and oxcarbazepine and atypical anticonvulsants such as gabapentin, pregabalin, topiramate and lamotrigine, and clonazepam (14).

Considerations in the use of the anticonvulsants include the following:

- The doses used are the same as the usual anticonvulsant doses.
- Response may take 2 to 4 weeks. In the presence of little or no response, these drugs should be discontinued.
- Some of the anticonvulsants (e.g., carbamazepine and valproate) may be contraindicated in patients with bone marrow suppression.
- The presence of drowsiness, a common side effect of anticonvulsants, may require slower titration of these drugs.
- Superimposed drug-induced hepatitis from anticonvulsants such as carbamazepine and valproate may worsen the liver function in patients with preexisting hepatic impairment.

Bisphosphonates

Bisphosphonates may be of value in treating malignant hypercalcemia and in reducing skeletal-related events such as pathological fractures and cancer-associated bone pain. Evidence of a significant effect on bone pain in patients with advanced disease is limited (15).

Conditions that favor the use of bisphosphonates for bone pain include the following:

- Presence of concomitant hypercalcemia
- Presence of significant osteoporosis with previous fracture
- Diffuse nature of symptomatic bone pain
- Patients with multiple myeloma and breast cancer

A relative contraindication for the use of bisphosphonates is the presence of renal impairment. If use of these drugs is necessary despite renal impairment, patients will require dose adjustment as well as a slower infusion rate. If the subcutaneous route is required, clodronate can be used. Pamidronate and zoledronic acid are given intravenously. If there is no decrease in pain and no other concomitant conditions require bisphosphonate, the drug should be stopped. The high costs of these agents may be an issue.

Muscle Relaxants

This group of medications has been used very frequently for acute pain from musculoskeletal injuries and for muscle spasm. The disadvantages of these medications are sedation and their anticholinergic side effect profile. Their effect on pain has not been proven. Some examples of these medications are baclofen, orphenadrine, methocarbamol, and cyclobenzaprine.

Anesthetics

Ketamine can be given orally, subcutaneously (16), or even as "burst ketamine" (18), in which it is given in incremental doses subcutaneously. The main disadvantage of ketamine is the psychotomimetic adverse effects, with hallucinations and confusion.

Other drugs, such as lidocaine, have been used transdermally, intravenously, and subcutaneously (17). Oral mexiletine and flecainide have also been tried. However, the prime concerns in the use of these drugs are central nervous system toxicity, which can cause ataxia, tremors, or even confusion, and potential cardiotoxicity, which may induce fatal cardiac arrhythmias.

NONPHARMACOLOGICAL MANAGEMENT

Radiation Therapy

Radiation therapy is often very useful in controlling localized cancer-related bone pain, tumor growth, and infiltration. More than 40% of patients can expect at least a 50% reduction in pain, and slightly fewer than 30% can expect complete pain relief at 1 month (19).

The speed of onset of pain relief is variable. However, because of problematic incident pain associated with bone metastases, radiation therapy is an important adjunct to pain control. Bone metastases can often be treated with a single dose of radiation. On a practical note, there is also the problem of daily transport of a very ill patient for outpatient radiation therapy. Radiation toxicity to the adjacent anatomical structures and radiation-induced fatigue are some side effects of radiation therapy.

Relaxation Therapy

Relaxation and distraction may be useful techniques to help some patients cope with pain and manage psychological factors (particularly anxiety) that could increase the pain experience.

Physical and Occupational Therapy

Physical therapy and occupational therapy are useful adjuncts to the overall management of pain control, especially in patients with contractures and fractures that require various orthopedic devices and supports.

Transcutaneous Electrical Nerve Stimulation

In experienced hands, transcutaneous electrical nerve stimulation can also be considered as an adjuvant for pain, particularly in limbs and for back pain. It may make neuropathic pain a little worse, however.

Acupuncture

The mechanism of action of acupuncture may be through the enhancement of the body's production of endogenous opioids. Acupuncture appears to be more effective in musculoskeletal-related pain, and multiple treatments may be necessary (20).

Interventional Methods for Pain Management

According to the WHO, only 15% to 20% of patients with cancer require invasive methods of pain relief. In the immediate postinjection period, peripheral nerve blocks can lead to pain relief in about 66% of patients with neurogenic pain and 64% of patients with nociceptive pain (21). However, long-term pain relief after local anesthetic blocks is usually not observed in palliative care patients.

Epidural and intrathecal infusions of analgesics can also be used. One survey reported that only 16 of 1205 (i.e., 1.33%) patients with cancer required intraspinal therapy (22). There is wide variation in the practice patterns in this approach. Opioids and local anesthetics can be given.

Intrathecal administration of drugs requires less medication than epidural administration. Epidural doses are also smaller compared with parenteral doses. The calculation for intrathecal opioids requires specialized anesthesiology services, and treatment becomes even more complex when intraspinal anesthetics are given together with intraspinal opioids. Intrathecal and epidural medications can be given through a pump. Concerns about infections and the cost-to-benefit ratio must be considered. Some of the devices are very expensive and require specialized expertise (23). Another consideration is whether enough experienced personnel are available to support this technique at the local institution or home care system. Intraspinal analgesia should be considered for patients with refractory pain syndromes.

PEARLS

- Pain is a complex biopsychosocial event that requires a comprehensive, interdisciplinary assessment for management to have the most chance of success.
- Pain, particularly cancer pain, is often multifactorial in causation.
- Attention to basic principles of pain management leads to consistent results in pain management.
- Opioids are the mainstay of treatment of pain.
- Every patient should be offered appropriate multiple modes of adjuvant therapy.
- Adverse effects of opioids, particularly constipation, which is the most common side effect, can be prevented for the most part.

PITFALLS

- Although the WHO ladder can be very helpful, remember to begin with the analgesic whose potency best matches the severity of the pain.
- Failure to deal with the fears of patients and families about opioids may impede good pain control.

- Failure to prevent or minimize adverse effects of opioids will also inhibit the achievement of good pain control.
- Failure to monitor pain and the patient's response to treatment adequately may lead to delays in achieving good pain control.

SUMMARY

Pain is a complex phenomenon. Adequate pain control can be achieved in most, but not all, patients at the end of life. The approach to management involves comprehensive, interdisciplinary assessment, the effective use of opioids and adjuvants, and constant monitoring. In some situations, the average physician will require the expertise and support of palliative or pain management specialists and multidisciplinary pain management programs.

Pain is a multidimensional, complex symptom expression that requires careful evaluation. The use of opioids and nonopioids requires thorough consideration, and the risk-to-benefit ratio must be taken into account. Improper titration leads to poor pain control and frustration for health care professionals, patients, and families.

Resources

Internet Resources

AIDS Info: This web site provides all the US Department of Health and Human Services human immunodeficiency virus treatment guidelines, updated as new data become available. Available at www.aidsinfo.nih.gov/

American Academy of Pain Medicine (AAPM): AAPM promotes quality of care for patients with pain through research, education, and advocacy. Available at www.painmed.org/

American College of Physicians Home Care Guide for Advanced Cancer: This guide is for family members, hospice workers, and caregivers who are caring for patients with advanced cancer. Information is offered on respite, pain management, symptoms, helping younger people, and grieving. Available at www.acponline.org/public/h_care/index.html

Edmonton Palliative Care Program: Available at www.palliative.org

Medical College of Wisconsin: Fast Facts at End of Life/Palliative Education Resource Center. Available at www.eperc.mcw.edu

International AIDS Society USA: This not-for-profit continuing medical education organization offers up-to-date information for physicians who are actively involved in the care of people living with human immunodeficiency virus/acquired immunodeficiency syndrome. Information is disseminated through continuing medical education courses around the United States, the publication *Topics in HIV Medicine,* and the development of treatment guidelines. Available at www.iasusa.org/

International Association for the Study of Pain: Available at www.iasp-pain.org

National Cancer Institute, National Institutes of Health Physician Data Query. Available at www.nci.nih.gov/cancertopics/pdq

World Health Organization (WHO): WHO Cancer Pain Relief, 2nd ed, 1996. This publication provides a proposed method for pain relief and includes information on how pain medications are available internationally. Available at www.who.int/ncd/cancer/publications/books/cancer_pain_ relief.html

Non-Internet Resources

Alberta Palliative Care Resource: A project of the Alberta Cancer Board, supported by the Alberta Cancer Foundation (Original content compiled by Drs. Jose Pereira and Eduardo Bruera.)

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Guidelines

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Nausea/Vomiting, Anorexia/Cachexia, and Fatigue

8

Stephen L. Berger and Ann M. Berger

CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

Nausea/vomiting, anorexia/cachexia, and fatigue are several of the most common symptoms experienced by palliative care patients. These interrelated symptoms can be associated with a broad array of physical, psychological, social, and spiritual problems, including decreased physical activity, mood and sleep disturbances, changes in social roles, and questions about the meaning of life. They can also potentially interfere with the treatment process and can hasten the course of the primary illness. Although research on these symptoms is in its infancy, enough is known for assessment and development of a comprehensive, individualized plan that will improve quality of life for the patient and family.

The constitutional disorders associated with illness—nausea, vomiting, anorexia, cachexia, and fatigue—represent common problems in palliative care. Although each of the five disorders is clinically distinct, they almost invariably overlap in origin, onset, and treatment. Indeed, in clinical practice it is often useful to think of these five disorders as a symptom cluster with variable manifestations in different individuals. Most patients with advanced cancer or other palliative care illnesses develop multiple, devastating physical and psychosocial symptoms for weeks to months before death (1). Ultimately, the goal of the palliative care

physician is to provide relief of all these symptoms, and this requires an understanding of the individual symptoms and their complex relations.

NAUSEA AND VOMITING

Incidence

Nausea is the patient-defined sensation of wanting to vomit. *Vomiting* is defined as forcefully bringing up ingested food. *Retching,* the attempt to vomit without actually expelling stomach contents, is similar to vomiting in cause and treatment. Collectively, these phenomena are known as *emesis.* Along with alopecia, nausea and vomiting are consistently reported to be among the top three most feared effects of cancer chemotherapy (2). Side effects of nausea and vomiting, such as loss of appetite, weight loss, and decreased thirst, are also commonly reported by palliative care patients. The emetic syndromes are physically and psychosocially distressing to the palliative care patient and can potentially lead to metabolic disturbances, changes in the treatment of the underlying disorder, and shifts in social roles.

Assessment

When assessing nausea and vomiting, the clinician needs to ascertain the cause of the problem. The most important consideration is whether the nausea and vomiting are caused by the disease process itself, by side effects of medications, by complications of the disease process or treatment for the disease, by complications of other treatments, or by psychosocial and spiritual factors.

Patients with life-threatening palliative care illnesses can have nausea and vomiting for many different reasons. The most readily appreciated example of emesis is chemotherapy-induced nausea and vomiting (CINV) seen in patients with cancer, but multiple other potent causes of the nausea/vomiting syndrome exist (Table I–8–1).

In the evaluation of nausea and vomiting, the two symptoms should be assessed separately. It is recommended to ask questions about the specific details of the symptoms, including both qualitative and quantitative measures that may be useful for diagnosis and treatment. When assessing nausea, for example, the patient should be questioned about the severity and duration of the episodes, the time of day when it occurs, and possible other mitigating factors (e.g., do the episodes seem to be triggered by movement or by smells?). When assessing emesis, information on the number of episodes, duration of vomiting, and contents and color of the vomitus (e.g., pills, whole undigested food, coffee ground, bilious) can be very helpful. Because a patient's inability to keep down other oral therapy, such as pain medication, compounds how terrible he or she is feeling from the nausea and vomiting, alternate routes for administration of medication may need to be discussed until the nausea and vomiting are better controlled.

Pathophysiology

Despite the wide variety of clinical presentations of the nausea/vomiting syndrome, all cases of emesis share similar general pathophysiologic features. A physiologic

Table I–8–1 ▪ Causes of Nausea and Vomiting

Cause	Examples
Medications	Chemotherapy
	Opioids
	Antibiotics
	Antifungals
	Anticholinergic drugs
Metabolic causes	Uremia
	Liver failure
	Hypercalcemia
Gastrointestinal causes	Gastritis
	Gastric or duodenal ulcers
	Bowel obstruction
	Constipation
	Motility problems
Infections: bacterial or viral	Sepsis
	Hepatitis
Vestibular problems	Auditory nerve tumors
	Motion sickness
Increased intracranial pressure	Brain tumors
	Infections
Psychological conditions	Anxiety
	Fear
	Grief
Radiation therapy	

or psychological trigger activates the central nervous system's innate pathways for emesis, culminating in the so-called *vomiting center* (VC) in the brainstem. Often, a patient has multiple triggers that act simultaneously. The proper treatment of emesis depends on determining the triggers and pathways of emesis in the individual patient.

Emesis can generally be classified into two categories, central and peripheral, based on the origin of the triggers for emesis. Three primary types of central emesis are recognized. First, the chemoreceptor trigger zone (CTZ) located in the medulla is able to detect toxins in the blood and cerebrospinal fluid directly and to relay that information to the VC. The CTZ is primarily activated in CINV, as well as in cases of food poisoning, hypercalcemia, and liver and renal failure and by a variety of medications. This type of emesis may be intermittent or constant. Second, the vestibular center integrates and interprets information on balance from the inner ear, peripheral receptors (e.g., nociceptors), and the visual system and sends signals to the VC to activate emesis associated with dizziness, loss of balance, motion sickness, and other vestibular disorders. Third, cortical signals can activate the VC. This is seen in anticipatory nausea associated with the memory of a past trigger such as cancer treatment, anxiety, and other emotional triggers, as well as in the recognition of certain sights or smells that cause emesis in some individuals. Additionally, a traumatic brain injury, a tumor, or a central nervous infection such as meningitis can directly affect these regions and can trigger central nausea.

Peripheral emesis is associated with a complex system of afferent (ascending) nerves that induce or inhibit the emesis response in the CTZ or the VC. Chemoreceptors and baroreceptors in the gut send signals to the brain through the vagus

nerve and autonomic nervous system in response to irritation of the tissues of the gut, including intestinal smooth muscle and the peritoneum. These tissues may be irritated by drugs, toxins, viral or bacterial infection, or ulcers. Additionally, full or partial bowel obstruction and tumor growths in the gut, celiac plexus, and liver often trigger emesis. When the clinician is making a diagnosis in cases of peripheral emesis, diarrhea and constipation should be considered along with the emetic symptoms.

Neurotransmitters and Receptors

In trying to understand the pathophysiology and neurotransmitters involved in nausea and vomiting, one can look to CINV as the prototype. Numerous neurotransmitters are known to have a role in CINV. These include serotonin (5-hydroxytryptamine [5-HT_3]), substance P, histamine, dopamine, acetylcholine, γ-aminobutyric acid (GABA), and enkephalins (3). Either one or a combination of these transmitters may induce vomiting. Other enzymes that are active in or near the CTZ, such as adenosine triphosphatase, monoamine oxidase, cholinesterase, and catecholamines, may also be involved in CINV, althouth their physiologic role is currently unknown.

In the past, the neurotransmitter that appeared to be the most clearly responsible for CINV was dopamine. Many effective antiemetics are dopamine antagonists that may bind specifically to the D_2 receptor. However, there is a high degree of variation in dopamine receptor binding affinity by these drugs. It is known that not all the important receptors in the CTZ are dopaminergic because the effect of dopamine antagonists is not equal to surgical ablation of the CTZ. Investigators have noted that the degree of antiemetic activity of high-dose metoclopramide cannot be explained solely on the basis of dopamine blockade. Metoclopramide is a weak antagonist of peripheral 5-HT_3 receptors and can stimulate gastrointestinal (GI) motility by increasing acetylcholine release from the cholinergic nerves of the GI tract (4).

The 5-HT_3 receptor pathway and the substance P–natural killer-1 (NK-1) receptor pathway play major roles in the modulation of CINV and perhaps in other conditions such as opiate-induced nausea and vomiting, as well as postsurgical nausea and vomiting. The introduction of 5-HT_3 receptor antagonists offered an improved treatment option for CINV. The precise mechanism of action is unknown, but the primary mechanism of action appears to be peripheral.

Substance P (mediated by NK-1 receptors) is known to modulate nociception. High-density NK-1 receptors are located in the regions of the brain implicated in the emetic reflex. The primary mechanism of NK-1 receptor blockade appears to be central, and antagonists of these receptors are effective for both acute and delayed events. NK-1 antagonists augment the antiemetic activity of 5-HT_3 receptor antagonists and corticosteroid in the prevention and treatment of CINV.

Cannabinoid receptors are located throughout the central and peripheral nervous systems. They are especially localized in the brainstem, basal ganglia, amygdala, and several cortical regions. Most cannabinoid receptors have an inhibitory effect on neurotransmission, and some evidence indicates that they may inhibit emesis. Cannabinoids and cannabinoid agonists (including dronabinol, a synthetic tetrahydrocannabinol, nabilone, and levonantradol) may be indicated for some patients who are receiving mildly emetogenic chemotherapy.

Histamine (H_1 and H_2) receptors are found in abundance in the CTZ; however, H_2 antagonists do not work well as antiemetics. H_1 antagonists help to alleviate nausea and vomiting induced by vestibular disorders and motion sickness. Opiate receptors are also found in the CTZ. It is known that opioids have mixed emetic and antiemetic effects that are blocked by naloxone. Naloxone also has emetic properties. These facts have led to the proposal to use certain opioids and enkephalins as antiemetics (5).

Other Mechanisms

Other mechanisms that may be involved in nausea and vomiting are direct or indirect effects on the cerebral cortex, olfactory or gustatory stimuli, and effects on the vestibular system. Animal studies have shown that nitrogen mustard partially causes emesis via direct stimulation of the cerebral cortex. Other evidence indicates that indirect psychological effects can mediate the symptom. For example, the risk of nausea and vomiting increases for a patient if a roommate is experiencing nausea or vomiting, and the amount of time a patient sleeps before receiving chemotherapy may influence whether that patient will develop CINV.

The importance of taste and odor perception in relation to enhancement of gag, nausea, and vomiting is well appreciated, although the exact mechanism is unknown. Women who have suffered from hyperemesis during pregnancy show taste damage (6). In addition to indirect effects on taste, some chemotherapeutic agents can be tasted. In a study of patients with breast cancer who received cyclophosphamide, methotrexate, and 5-fluorouracil, 36% reported a bitter taste in the mouth. One third of the patients believed that this bitter taste led to vomiting. Clearly, changes in taste secondary to infection or medications may contribute to both nausea and vomiting, as well as to anorexia.

Chemotherapeutic agents, many other types of medications, and infection can also cause nausea and vomiting by influencing the vestibular system. It is known that patients who have a history of motion sickness or vertigo experience greater severity, frequency, and duration of CINV than patients who do not experience motion sickness or vertigo. Once again, the mechanism by which the vestibular system may lead to nausea and vomiting is unknown.

Patient Risk Factors

An appreciation of the risk factors for developing CINV is important because it most likely relates to nausea and vomiting secondary to any medications such as opioids, antibiotics, and antifungals. Risk factors for developing CINV include those that are intrinsic to the patient, the chemotherapy, or the tumor.

Patient characteristics that may affect antiemetic control include prior experience with chemotherapy, alcohol intake history, age, and gender. Previous experience with chemotherapy very often sets the stage for success or failure in controlling emesis with future chemotherapy courses.

Other patient-specific risk factors exist. Alcohol intake greater than 100 g of ethanol, or five mixed drinks per day (i.e., chronic and heavy alcohol intake), whether past or current history, has been shown to affect the control of emesis positively. This implies that someone who is sensitive to the effects of drinking alcohol (e.g., feeling warm, drowsy, nauseous) and has a history of relatively light and rare intake may have a higher chance of CINV.

As a prognostic indicator, age cannot reliably predict a patient's response to CINV. However, the general trend is for younger patients to be more violently emetic. Gender is another patient factor in considering risk for CINV. For unknown reasons, control of emesis is poorer in women receiving treatment for various malignant diseases. Other contributing factors that may affect the control of emesis include fatigue, low social functioning, personal history of motion sickness, hyperemesis with pregnancy, anxiety, and prechemotherapy nausea (7).

Treatment

The goals of therapy in the management of nausea and vomiting are to enhance the patient's quality of life, to prevent or eliminate nausea and vomiting, to provide convenient care, to reduce hospital and clinic time, and to reduce treatment costs.

Preventive Management

The principal strategy for the management of nausea and vomiting is prevention. A goal of prevention reduces morbidity and medical complications and is cost effective.

1. Give the appropriate antiemetic medication as part of the palliative care plan when it is known that emesis may occur.
2. Prevent constipation with medications.
3. Ensure that patients have antiemetics when they start emetogenic medications such as opioids.
4. Respond rapidly to nausea and vomiting.

Pharmacologic Management

It is important to be aware of the antiemetic agents and their proper use, to prevent and treat nausea and vomiting. There is a growing diversity of antiemetic classes. It is also critical to review the potential causes, including the pathophysiology and neurotransmitters, to choose the appropriate medication.

Most pharmacologic management of emesis is based on interference with the neurotransmitters associated with the syndrome (Table I–8–2). Because diagnosis of the precise mechanism of emesis may be difficult for some patients, and because multiple medications are available for each type of neurotransmitter or receptor, the empirical approach is most effective for the patient and the physician. Adjusting medications and dosages over time should help the patient reach at least a tolerable level of symptoms, if not a total cure.

General principles of pharmacologic management include the following:

- Ensure that the antiemetic is given regularly, rather than on an as-needed basis.
- Use one antiemetic first and go to maximum doses before switching or adding a second medication. If the first agent is only mildly helpful, try a different class of antiemetic.
- A combination of antiemetics may be necessary to help relieve the nausea and vomiting.

The neurons of the CTZ use dopamine and 5-HT_3 to excite an emetic response. Dopamine antagonists (e.g., metoclopramide, haloperidol, trifluoperazine, and

Table I–8–2 ▪ General Antiemetic Dosing Chart*

Medication	Suggested Dose and Route	Side Effects	Comments
Serotonin Antagonists			
Ondansetron	8 mg IV or 0.15 mg/kg IV q3h × 3 12–24 mg PO qd or 8 mg PO bid	Mild headache Constipation Lightheadedness Diarrhea Mild sedation Asymptomatic liver Transaminase elevation Rarely EPS	First dose 30 min before chemotherapy; no renal adjustment
Granisetron	2 mg PO qd or 1 mg PO q12h 0.01 mg/kg IV over 5 min	See above; Taste changes	PO first dose <1 hr before chemotherapy; IV first Dose <30 min before chemotherapy; no renal adjustment
Dolasetron	100 mg PO or IV 1.8 mg/kg IV	See above	See above
Palonosetron	No oral form; 0.25 mg IV	Headache Constipation QT prolongation	Give 30 min before chemotherapy; 40-hr half-life; no renal adjustment
Dopamine Antagonists			
Metoclopramide	5–20 mg PO/IV q6h 4–8 mg PO bid	EPS (greater risk if younger)	Pretreat with diphenhydramine to decrease EPS when using to prevent/treat CINV; prolonged half-life with renal failure; >10-mg dose should be given IVPB; avoid in bowel obstruction
Chlorpromazine	10–25 mg PO q4h 25–50 mg IV/IM q4h 50–100 mg PR q6h	Sedation Tardive dyskinesia Hypotension NMS	May use for intractable hiccups

Table continued on following page

Table I–8–2 ▪ General Antiemetic Dosing Chart* (Continued)

Medication	Suggested Dose and Route	Side Effects	Comments
Haloperidol	0.5–5 mg PO, SC, IV q 8h (max 100 mg in 24 hr)	NMS EPS Tardive dyskinesia Drowsiness Anticholinergic effects Gynecomastia	Half-life~20 hr; usual max 30 mg/day
Prochlorperazine	5–10 mg PO/IM q6h 2.5–10 mg IV q3h 25 mg PR bid	Drowsiness NMS Tardive dyskinesia Dry mouth Constipation Urinary retention	Multiple adverse reaction risks; max 40 mg/day
Neurokinin Antagonists			
Aprepitant	See specific CINV prevention and treatment guidelines	Diarrhea Fatigue Hiccups Constipation Rarely neutropenia	Contraindicated with cisapride and pimozide (for QT prolongation risk)
Steroid (1)			
Dexamethasone	4–8 mg PO bid 8–20 mg IV qd 0.5–0.6 mg/kg divided q12h	Mood swings Insomnia Peptic ulcer Appetite increase	Increase dose as needed; often dosed empirically
Methylprednisolone	See CINV guideline for dosing	See above	Used as a substitute for dexamethasone in CINV prevention and treatment
Antihistamine			
Diphenhydramine	25–50 mg PO q4h 10–50 mg IV q2h	Drowsiness Dry mouth Urinary retention Confusion See above: for Diphenhydramine	Max 400 mg/day; EPS treatment dose is 50 mg

Hydroxyzine	25–100 mg PO/IM q6h	Bitter taste Headache	Max 600 mg/day
Meclizine	25–50 mg PO q2h	Drowsiness Dry mouth Confusion Nausea/vomiting Tachycardia	
Anticholinergic			
Scopolamine	1.5-mg patch q72 hr 0.6–1 mg IV/SC q4h	Dry mouth Blurred vision Urinary retention Tachycardia	In palliative care, used for excess secretions and with intestinal obstruction
Glycopyrrolate	1–2 mg PO bid 0.1–0.2 mg IM/IV q6h	Constipation Dry mouth Urinary retention	In palliative care, used for excess secretions and with intestinal obstruction
Cannabinoid			
Dronabinol	2.5–5 mg PO q6h (max 20 mg/day)	Dysphoria Somnolence Difficulty concentrating	Generally better tolerated in younger patients
Benzodiazepine			
Lorazepam	0.5–2 mg PO, SL, IV q6h	Sedation Amnesia	Not intrinsically an antiemetic; Very useful as an adjunct; See CINV guidelines
Miscellaneous			
Octreotide	50–300 g SC bid; (max 1500 g/day)	Diarrhea Dizziness Biliary tract abnormalities Fatigue Fever	Start at 50 and titrate up based on response; used in palliative medicine for nausea/vomiting resulting from complete bowel obstruction; Decreases secretions

*These dosing guidelines are not meant to replace US Food and Drug Administration guidelines or clinical judgment.

bid, twice daily; EPS, extrapyramidal symptoms; CINV, chemotherapy-induced nausea and vomiting; IM, intramuscularly; IV, intravenously; IVPB, by intravenous piggyback; NMS, neuroleptic malignant syndrome; PO, orally; PR, rectally, qd, once daily; SC, subcutaneously; SL, sublingually.

From Berger A, Berger S: Introduction. In Berger A (ed): Prevention of Chemotherapy-Induced Nausea and Vomiting. Manhasset, NY: CMP Healthcare Media, 2004, pp ix–xiii.

domperidone) and 5-HT_3 antagonists (e.g., ondansetron, granisetron, dolasetron, tropisetron, and palonosetron) block these pathways. Metoclopramide, a prokinetic agent, is often useful because of its combination of central and gastric-emptying effects. Certain antihistamines, including meclizine and cyclizine, are indicated for vestibular-induced nausea. Scopolamine, which is an M_1-muscarinic (cholinergic) receptor antagonist, is also indicated for vestibular-induced emesis. Cortical-associated emesis is generally associated with the neurotransmitters 5-HT_3 and GABA. Therefore, the 5-HT_3 antagonists, as well as GABA agonists such as lorazepam, may be helpful. Other medications such as cannabinoids and corticosteroids (e.g., dexamethasone) may also be effective in treating nausea and vomiting and cortical-associated emesis or emesis associated with increased intracranial pressure. Dexamethasone, given in combination with metoclopramide, can be especially useful in the treatment of nausea and vomiting. Both medications can be given subcutaneously (8). Lorazepam and other benzodiazepines are particularly helpful in anxiety-induced emesis.

Nonpharmacologic Techniques

Nonpharmaceutical techniques are also appropriate for the management of emetic syndromes. Relaxation therapy, guided imagery, and hypnosis are especially effective for anxiety-induced emesis and other cortical emetic syndromes (9). Acupuncture and acupressure may relieve some of the symptoms of nausea (10). Ginger, given orally or as a drink (soda or tea), is useful to help treat nausea and vomiting (11). Regulating the patient's food intake and working with a nutritionist to discover and avoid trigger foods or smells are also recommended, especially for patients with chronic nausea and vomiting.

ANOREXIA AND CACHEXIA

Incidence

The anorexia-cachexia syndrome is a major cause of morbidity and mortality in cancer, human immunodeficiency virus (HIV) disease, and other long-term illnesses. *Anorexia* is defined as a loss of normal appetite; *cachexia* is the associated nutritional deficiencies and weight loss. The anorexia/cachexia syndrome, characterized by progressive nutritional changes, weakness, and wasting, is often debilitating and potentially life-threatening over a lengthy period. The catabolism of lipid stores and proteins, especially muscle tissue, coupled with defects in anabolism, severely affects the patient's quality of life and may render the patient bedridden and unable to perform even the most basic activities of daily living. Patients and families report the physical and social consequences associated with anorexia and cachexia to be among the most psychologically distressing of their disease.

Anorexia and cachexia must be viewed as part of a larger set of GI and constitutional disorders associated with long-term illness. They are most frequently seen in the later stages of HIV and acquired immunodeficiency syndrome (AIDS), dementia, cancer, especially tumors of the GI tract, pancreas, and lungs, and other advanced noncancer illnesses such as Alzheimer's disease and end-stage renal failure. Unsurprisingly, anorexia and cachexia often result from nausea and

vomiting and may be closely related to the latter in pathophysiology and treatment. Other GI symptoms such as dry mouth, early satiety, constipation, dysphagia, and changes in taste or olfaction are also risk factors. Finally, pain and psychological factors, including depression or anxiety (especially when related to the disease or treatment process), may contribute to anorexia and cachexia.

Pathophysiology

Anorexia and cachexia represent significant and widespread changes in the normal functioning of the body. The causes of anorexia and cachexia may lie in the central nervous system, in metabolic and hormonal derangements, in failures of the normal digestive system, or, frequently, in a combination of all three. A complete understanding of the specific causes of a patient's anorexia and cachexia is necessary for the effective treatment of the disorders.

Appetite is ordinarily under the control of a feedback system between two regions of the hypothalamus: the feeding center in the lateral hypothalamic nucleus and the satiety center in the ventromedial hypothalamic nucleus. These two regions interact with nervous and hormonal signals from the gustatory and olfactory systems, the upper GI tract, and the liver. The GI tract relays information about pressure changes caused by the presence or absence of a bolus of food. The GI tract is also responsible for secreting hormones such as gastrin, secretin, glucagon, and cholecystokinin, and the latter two implicated in the abnormally low appetite characteristic of anorexia. The feeding center and the satiety center integrate information from multiple sources to balance the timing, duration, and degree of appetite. High amounts of dopamine, 5-HT_3, and tryptophan in these regions are associated with a decrease in appetite, and the latter two especially are implicated in the abnormally low appetite characteristic of anorexia.

In anorexia and cachexia, the normal appetite response is suppressed. Appetite suppressors include many pharmaceuticals such as cancer chemotherapeutic agents, amphetamines, and antibiotics, as well as radiation therapy. Appetite is indirectly suppressed by dry mouth and other oral or dental problems, nausea, vomiting, constipation and dysmotility, fever, and alterations in taste or smell, many of which are caused directly by various drugs. Metabolic derangements including hypercalcemia may also play a role, although it can be difficult to determine whether these derangements are a cause of, or an effect of, anorexia/cachexia. Abnormal activity of cytokines, including interleukin-1, interleukin-6, tumor necrosis factor-α, and interferon-γ, seems to be involved, but the role of these cytokines is not well understood. Psychosocial concerns cannot be discounted by the clinician. Depression, anxiety, and fear about the disease process, treatment, dying, family dysfunction, or suffering in general can lead to anorexia and ultimately cachexia. The anorexia related to chronic or terminal illness should be distinguished, however, from anorexia nervosa, which is strictly psychological in origin.

Cachexia can be diagnosed when the weight loss leads to significant shifts in the metabolism of the individual, that is, when the body begins to catabolize its own tissues. Anorexia and cachexia ultimately lead to a vicious cycle of continued weight loss and accumulating negative effects on the body, especially loss of adipose tissue and skeletal muscle. A unique aspect of anorexia/cachexia associated with cancer is the effect on glucose synthesis via overactivation of the Cori cycle:

anaerobic consumption of glucose by the tumor produces large amounts of lactic acid, which is converted back to glucose in the liver, thus creating a futile cycle of energy consumption. Changes in glucose metabolism are seen in most patients with anorexia/cachexia, regardless of cause; these include abnormal glucose turnover associated with the Cori cycle and an abnormal insulin response resulting in glucose intolerance.

Treatment

The treatment of anorexia/cachexia focuses mainly on alleviating the causative factors associated with the syndrome if possible. The successful treatment of nausea and vomiting, constipation, infection, or other contributing symptoms may improve anorexia and cachexia, depending on the disease trajectory.

The stimulation of appetite is one of the primary goals of treating anorexia and cachexia. The "gold standard" of anorexia and cachexia treatment is still megestrol acetate (a progestogen), and newer pharmaceuticals are measured against it for efficacy. Cannabinoids and corticosteroids are useful, but the latter drugs tend not to result in weight gain. Thalidomide has been shown to be effective in reversing cachexia associated with HIV/AIDS, most likely by inhibiting the production of tumor necrosis factor, although its use in cancer treatment is still unproven. Cyproheptadine, hydrazine sulfate, and pentoxifylline are of limited efficacy in the treatment of anorexia and cachexia. Metoclopramide, a prokinetic agent, has been studied in its use to treat early satiety. Emerging drugs for the treatment of anorexia/cachexia include melatonin, omega-3 fatty acids, anabolic agents such as growth hormone and insulin-like growth hormone-I, anabolic androgens, antioxidant agents, and nonsteroidal anti-inflammatory drugs (12). None of these treatments has been associated with significant life prolongation.

Nonpharmaceutical methods may also be effective in the treatment of anorexia. Modification of the types of food eaten and the times they are consumed may increase the patient's desire to eat; by working with a dietitian, the most benefit can be achieved from each meal. Decreasing the portion size and making the patient's favorite foods and drinks readily available at all times can be helpful. Nutritional supplements and multivitamins may also be indicated earlier in the disease trajectory. Psychosocial counseling, management of non-GI symptoms, and proper oral and dental care will also often improve appetite.

Enteral or parenteral nutrition may be useful for some patients. However, no randomized controlled trials have addressed the potential symptomatic and survival benefits of artificial nutrition at the end of life. Furthermore, nutritional support in the cachectic patient tends to increase lipid stores, as opposed to protein or muscle mass. Generally, the anorexia and cachexia are caused by the underlying disorder itself and not by malnutrition. Patients and their families should be educated that simply loading the patient with calories will often not lead to weight gain and may even cause additional distress to the patient who is physically unable to eat a lot of calories. It should be emphasized as well that anorexia and cachexia are expected to some extent at the end of life, and much of the treatment plan should be palliative. It is clear that the decision regarding hydration needs to be personalized for each patient after discussion of potential risks and benefits with the patient and family.

FATIGUE

Incidence

Fatigue is a common symptom in patients with chronic progressive disease. It is especially prevalent among patients with cancer; between 70% and 100% of patients receiving cancer chemotherapy or radiation therapy identify fatigue as a major impediment to daily functioning and quality of life. Fatigue is associated with a broad array of physical, psychosocial, and spiritual consequences, including decreased physical activity, mood and sleep disturbances, changes in social roles, and questions about the meaning of life.

In 2000, Winningham reviewed the history of the word *fatigue* (13). In 700 AD, the word used for fatigue was *tire*. From 1100 to 1400, fatigue was associated with the words *sleepy, weakness,* and *inefficient*. From 1500 to 1800, the words used for fatigue included *debilitated, forced, exhausted, stressed, enervated,* and *cachectic;* the word *fatigue* first appeared in 1669. From 1800 to 2000, words used for fatigue included *energetics, myasthenia* (muscular weakness), *neurasthenia* (psychic and emotional stress from exhaustion of the nervous system), *life force, vital signs,* and *stressors*. These different words used for fatigue reveal the difficulty of defining a complex concept that even today often eludes medical science.

Fatigue is a complex, multifaceted symptom frequently associated with nausea/vomiting as well as anorexia/cachexia. Fatigue may be directly associated with the disease or its therapy, or it may be related to a spectrum of disorders including anemia, depression, chronic pain, sleep disturbances, electrolyte disturbances, infection, malnutrition, deconditioning, immune dysfunction, or the use of centrally acting drugs. The treatment plan needs to be personalized for each individual patient because fatigue usually has several different causes in one patient.

Assessment

The assessment of fatigue presents a dilemma for the palliative care physician. Although fatigue is an inherently subjective condition, unique but nonetheless real for each patient, modern evidence-based medicine demands its measurement and categorization. Fatigue is multidimensional and abstract, and it manifests differently in each patient. Some patients may complain of a loss of efficiency, whereas others mention disproportionate exertion or an excessive need for rest. The key to diagnosis of fatigue is to assess accurately both objective laboratory and clinical tests and the patient's subjective reports about how he or she feels.

The effect of fatigue on the patient's quality of life is the cornerstone of the patient's description of the symptom, and it can give valuable clues for diagnosis and treatment. Often the effects of fatigue on a patient's ability to perform activities of daily living, his or her family life, sex life, or professional career, or its negative impact on self-esteem and social roles, can all result from and contribute to the all-encompassing effects of fatigue. Many of these effects may be registered semiquantitatively on a battery of self-report assessment tools used to measure fatigue. These questionnaires often assign scores to various answers to give a combined measure of multidimensional fatigue. Other holistic measures of fatigue include assessment of related factors such as patterns of activity and rest,

depression or changes in mood, sleep patterns, and related symptoms including anemia and pain.

Numerous physiologic measures of fatigue are equally important for the clinician. The general criteria for these measures are the intensity of fatigue, the change of fatigue over time, and the accompanying physical, psychological, and social sequelae of the fatigue. Measures of anaerobic metabolism, oxidative metabolism, and caloric metabolism can provide a reliable indicator of fatigue on the cellular and subcellular level, but, in general, they are not recommended for patients with end-stage disease. Changes in body mass, especially muscle mass, are especially useful in patients who have reported fatigue for a lengthy period or who experience fatigue alongside other symptoms such as anorexia and cachexia. Measures of energy reserve, functional capacity, and exertion or stress tests can indicate the extent of fatigue as well. Quantitative tests of muscle function, such as a walk test or in some cases cardiac function and output, may also be indicated to test for deconditioning, depending again on where the patient is in the disease trajectory and the goals of care.

Pathophysiology

Like other constitutional disorders, fatigue has several physiologic causes. Advanced disease of any type may cause fatigue, although the exact mechanisms are not totally understood. Dehydration, electrolyte imbalance, and thyroid deficiency may all contribute to fatigue but can be easily remedied with standard fluid and electrolyte treatment or, in the case of thyroid deficiency, hormone replacement. Anemia of various causes, including blood loss, tumor infiltration of bone marrow, or anemia associated with chronic disease such as HIV/AIDS or kidney disease, may also play a role.

Another key aspect of the pathophysiology of fatigue is depression, which is frequently underdiagnosed by both patient and physician. Situational depression and major depressive disorder can both contribute to the onset of fatigue or can exacerbate the existing symptoms while complicating the treatment. Significant overlap exists between the symptoms of fatigue and those of depression, and, therefore careful analysis is necessary for the effective treatment of both. Depression can lead to symptoms of fatigue, and fatigue can lead to feelings of depression. Other potential causes of fatigue include poor sleep hygiene, pain, and malnutrition.

Treatment

In some cases, treatment of an underlying disorder greatly improves symptoms of fatigue. The treatment of anemia is a well-documented example, especially in patients with cancer. Erythrocyte transfusions are indicated for severe, acute anemia (hemoglobin, <8). Erythropoietic agents are potentially indicated, especially in the earlier stages of anemia (hemoglobin, <11 to 12). Epoetin alfa is currently indicated for patients with anemia related to chronic renal failure, in HIV/AIDS, in some surgical patients, and in patients receiving cancer chemotherapy that lasts for more than 2 months. Darbepoetin alfa is especially useful in chemotherapy-induced anemia. Besides effectively increasing and maintaining hemoglobin,

studies with both erythropoietic agents have shown that they increase energy and activity levels as well as quality of life, but not in late disease (14).

Corticosteroids are clinically useful for fatigue in patients with advanced cancer, usually during end-of-life hospice care (15). One of the reasons for this somewhat limited use is that steroids have many complications. Giving patients steroids for extended lengths of time, even 4 to 5 months, may lead to the development of proximal myopathy with muscle weakness that may further limit patient activity. This inactivity increases fatigue; therefore, most clinicians reserve the use of steroids as a last option, and most of the case-controlled trials have involved hospice patients. When steroids are used, therapy is usually with dexamethasone, 1 to 2 mg twice a day, or prednisone, 5 to 10 mg twice a day.

Another class of medications used clinically with no controlled trials includes the psychostimulants methylphenidate, dextroamphetamine, and modafinil. Many anecdotal clinical reports of this class of drugs note that it is helpful for depression in medically ill and elderly patients, as well as in treatment of opioid-related cognitive impairment. The largest experience has been with methylphenidate and if there are no contraindications, enough anecdotal evidence exists to warrant a trial. Modafinil has been used in a variety of clinical models, including narcolepsy, Parkinson's disease, obstructive sleep apnea, and multiple sclerosis. For patients who are unresponsive to other treatments, amantadine has been useful for fatigue related to multiple sclerosis (16). Clearly, further research is needed on all these medications.

Fatigue is clearly related to many other syndromes of chronic disease. Anorexia and cachexia are frequently reported in relation to fatigue, and the successful treatment of these symptoms (outlined earlier) often alleviates accompanying symptoms of fatigue. Both the metabolic derangements caused by anorexia and cachexia and the associated psychosocial crises may contribute simultaneously to fatigue. Both these aspects of anorexia/cachexia must be addressed. Dehydration is a related concern. Studies have shown that dehydration leads to muscle weakness, confusion, and fatigue. In addition, other symptoms such as diarrhea, nausea, and pain can increase dehydration.

Pain, especially chronic pain, can also lead to increased fatigue. Pain is emotionally and physically draining for a patient, by disrupting sleep and decreasing movement and exercise. Therefore, optimal pain management is necessary.

A key element of the treatment of fatigue is nonpharmacologic management. Patients must be educated about what to expect and how better to deal with the symptom. It is clear that providing information decreases anxiety and improves quality of life. Education about fatigue for both the patient and the caregiver allows them to assist with activities of daily living, set limits on exertion when necessary, and lessens the chance that they will become anxious when fatigue and depression occur. It is critical for the patient to understand that fatigue is not a character flaw.

Education can also play a role in modifying the patient's lifestyle to conserve energy best and thereby to maximize the patient's ability to function normally. Energy conservation involves prioritizing, planning, eliminating, delegating, modifying, and pacing. By working with the health care team and the caregiver, the patient can set reasonable and healthy goals (17). Working with a rehabilitation medicine professional can assist in developing appropriate coping strategies for activities of daily living.

Fatigue associated with deconditioning is a problem for many individuals with cancer and other palliative care illnesses. Appropriate activity usually includes aerobic exercise such as walking or cycling; such exercise has been shown to help some patients with fatigue (18).

Therapy of various types may also be indicated to alleviate both fatigue and the psychological sequelae associated with it. Cognitive-behavioral therapy, performed in groups or individually, helps the patient to develop strategies for coping with various problem situations. Coping skills and individual psychotherapy help the patient to deal with the trauma of illness and its effects on their daily lives. Support from organized groups and from caregivers is another important aspect of this treatment. Consultation with a mental health professional and, potentially, a trial of antidepressants or psychostimulants such as methylphenidate, dextroamphetamine, and pemoline may be helpful in treating both depression and fatigue (19).

The management of sleep is crucial for the fatigued patient. It is important to educate the patient about the erroneous but popular myth that a diagnosis of fatigue means that the patient needs more sleep. More sleep in a fatigued patient may actually lead to poorer health and insomnia. Rather, fatigued patients must carefully monitor and adjust their sleep habits to ensure that they receive 6 to 8 hours of sleep a day, arise at a regular time, limit naps, and avoid stimulants such as caffeine.

Various complementary and alternative approaches have value in treating fatigue and related symptoms. Acupuncture, mind-body techniques such as relaxation and hypnosis, biofeedback, music and art therapy, massage, spiritual ministry, and elements of energy medicine such as therapeutic touch and Reiki can be performed by trained professionals as part of a palliative care team.

Equally important in the evaluation and treatment of palliative care patients is concern about fatigue in the caregiver. Caring for a loved one with a life-threatening illness is extremely difficult and challenging for the family. In addition to conducting his or her routine role, the caregiver may need to take on new family responsibilities, including some of the patient's roles. Additionally, the caregiver may need act as an extension of the medical team by administering medications such as for pain and by assessing treatment. Unfortunately, this usually leaves little time for the caregiver to focus on his or her own needs.

Some ways of dealing with caregiver fatigue include taking quality time away from the situation, even if it is only half a day. Ask other family members and friends for help and suggest specific tasks that can be done; educate the caregiver about the loved one's illness, and encourage the caregiver to use resources in the community such as transportation services and home health aides. The social worker may be able to help with these resources; help the caregiver acknowledge his or her feelings and suggest techniques such as relaxation and diversion to relieve stress; teach the caregiver to give himself or herself credit for all they do; and, most importantly, encourage communication.

PEARLS AND PITFALLS

Nausea/Vomiting

- It is important to determine whether the nausea and vomiting are related to central, vestibular, taste/smell, peripheral, or psychological causes.

- The key aspect of treating nausea and vomiting is prevention rather than interventional or salvage therapy.

Anorexia/Cachexia

- Anorexia and cachexia are constant reminders of the extent of the patient's advanced illness.
- The cultural and social aspects of food and eating are significant issues for the anorexic or cachectic patient and the family.

Fatigue

- Fatigue is a complex, multifaceted symptom that makes assessment difficult.
- The effect of fatigue on the patient's quality of life is the cornerstone of the patient's description of the symptom, and it can give valuable clues for diagnosis and treatment.

SUMMARY

The management of nausea/vomiting, anorexia/cachexia, and fatigue is a commonly encountered issue in palliative care practice. These symptoms have a great impact on quality of life for the patient and family and are often detrimental to the treatment of the underlying disease. The multifactorial origin of these constitutional disorders presents a challenge for the patient, the family, and the clinician and requires careful assessment and a personalized treatment plan. Emerging pharmaceuticals and nonpharmacologic approaches, combined with improved understanding of the complex pathophysiology of these disorders, will aid the clinician in their alleviation.

Resources

American Academy of Hospice and Palliative Medicine (USA): 4700 West Lake Avenue, Glenview, IL 60025; (847) 375–4712. Available at www.aahpm.org

National Hospice and Palliative Care Organization (USA): 1700 Diagonal Road, Suite 625, Alexandria, VA 22314; (703) 837–1500. Available at www.nhpco.org

World Health Organization: Avenue Appia 20, 1211 Geneva 27, Switzerland; (+ 41 22) 791 21 11. Available at www.who.int

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Depression, Anxiety, and Delirium

9

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INTRODUCTION

As major advances in the understanding and treatment of human illness have occurred, a more determined and compassionate approach to the care of the dying has emerged. Sickness and death will always be features of the human condition, however, and despite the wonders of progress in medicine, they will continue to be part of the reality of everyday clinical practice. Success in alleviating the multiple, diverse, and difficult manifestations of disease becomes the overriding imperative for the clinician treating those patients who are facing death. Patients and their loved ones are most concerned about the immediate, practical needs and problems of everyday life. The manner and process of caregiving, along with the whole spectrum of possible outcomes and satisfaction measurements of this care, are intimately connected. There is also an ongoing battle in the patient's mind as he or she attempts to enjoy the intimate, random thoughts of daily living while at the same time having to accommodate the constant torment and burden of facing the loss of self. The dying person takes on a special status that separates him or her from those who are seen as well and is therefore often in a state of crisis: fragile, fearful, vulnerable, wounded, dependent, time bound, and, above all, distressed.

It is the anticipation of the dying process and of death itself that heralds enormous apprehension among the sick. Being seriously ill and time bound is a frightening experience that involves loss, pain, disability, disfigurement, and dependency. The precise language of the scientist accurately details the biology of disease, but it does not offer the words necessary to comfort the sick. What is often promised to patients is seldom delivered. Forty percent of dying patients who were surveyed had distress, yet fewer than 10% of such patients are referred for any level of emotional help (1). Patients rarely talk about their deeply personal experiences—fears, anxieties, spiritual loss—and clinicians may not be equipped to listen or to have the time required to address these important concerns. Because of progressive mental and physical issues, patients are less likely or unable to report their worries. More important to patients is the issue of "meaning," that is, what the specific signs and symptoms of the illness symbolize for them. Two very sick patients may report the same severity, duration, and frequency of a specific symptom, yet one will describe it as less distressful. In the setting of advancing illness, these important relationships among psychodevelopmental factors, personality traits, and psychopathology are poorly understood. An interesting model suggests that some patients may have a hyperactive, stressed, pro-inflammatory cytokine system that predisposes them to a mood disorder with a "sickness syndrome" presentation (2).

Somatic complaints such as pain, dyspnea, nausea, and diarrhea are easy to recognize. Unfortunately, psychological symptoms such as psychic pain, depression, anxiety, and cognitive loss are not as obvious and may be managed with indifference, apathy, negligence, and even incompetence. Emotional symptoms are seen as a "normal" part of the clinical picture. Distressed patients make for distressed families, and this often hinders the ability to deliver adequate medical care. Physicians and other professional care providers may lack familiarity with common psychiatric syndromes and psychotropic medications, and many patients and families are reluctant to accept emotional and pharmacological help, which they associate with the stigma of mental illness and weakness of character. In a study of 215 patients with cancer, 33% adjusted well to the stresses of the illness, but 47% had obvious psychiatric problems. Sixty-eight percent of this latter group had adjustment disorders associated with depressed or anxious mood, 13% with major depression, and 8% with delirium. As the disease progresses, this population becomes more vulnerable; up to 85% of hospitalized patients who are dying of cancer suffer from delirium, especially when they are close to death (3).

In the United States, the National Comprehensive Cancer Network has developed practice guidelines regarding management of distress (4). The term *distress* was chosen to address the psychological component of cancer care because it is more acceptable to patients and less stigmatizing than alternative terms such as *psychiatric* or *emotional.* The term distress is also commonly applied to normal reactions and may escalate across a continuum, finally to meet the criteria for a psychiatric disorder. These guidelines ensure that patients are recognized by the health care team when a level of distress obligates documentation, monitoring, and treatment. Therefore, screening for distress in all patients is necessary, especially in those who clearly display any sadness, fear, unclear thinking, despair, or excessive worry. Screening opens communication among all interdisciplinary care providers, patients, and families. Depending on the nature and intensity of the clinical picture, a psychiatrist, expert counselor, support group, and psychopharmacology may be used to help the patient cope better as the clinical situation worsens.

The World Health Organization forecasts that 15 million people annually, around the globe, will develop cancer by the year 2020 (5). This number represents only the oncology aspect of people in industrialized countries who will have a disease with a high mortality rate. People will die at an older age and live for a longer time with the pain and progressive symptoms of the illness. The emotional adjustment to serious illness needs to be better understood, and effective therapies need to be developed that target mood and anxiety disorders. Health care teams are frequently better able to diagnose the symptoms of anxiety than the depressive symptoms of their patients. However, anxiety is sometimes presumed in patients who say they are not distressed. Hospice nurses document only one third of the psychological issues that patients report (6).

Nurses, more than physicians, appear to diagnosis patients who are not distressed as being anxious and depressed. The oncologists who take care of dying patients have not been adequately trained to evaluate and manage complex psychological symptoms and syndromes. Even experienced, bedside clinicians experience discomfort that stems from conflicting roles, goals, and unrealistic expectations of themselves, the patients, and their families. Factors that exacerbate this stress may include fear of dying, inadequate training, poor communication skills, conflicts in knowing goals of care, and uncertainty of treatment outcomes.

DEPRESSION

Normal Responses Versus Clinical Depression

It is a common misconception that depression is a normal response in patients who are dying. A typical patient with cancer (or perhaps another terminal illness), usually undergoes six discrete phases: time of diagnosis, disease-free interval, recurrence or progression, treatment for advancing illness and increasing disability, comfort care only, and, finally, the last days and hours of life. In a normal patient, both sadness and depressed mood may be normal responses to being seriously ill or dying. We "allow" people to grieve with a wide range of reactions to their situation. The community of family and friends embraces and supports the person's response to the loss because it is a common bond of humankind to share the distress and suffering. However, psychological help is needed if the intensity or duration of the response crosses a line of inappropriate behavior and includes expressions of guilt, suicidal ideation, functional paralysis, or clinical signs of depression.

It can be difficult to distinguish which symptoms are manifestations of a psychological diagnosis and which are caused by the primary medical illness, physical symptoms, or treatment. Some may argue that it is a rational reaction for a dying patient to express a wish to die or to have suicidal thoughts. The helplessness and hopelessness of the situation may be reflected by the clinician, who may also feel frustrated and helpless. Clinicians cannot, however, act helpless, nor can they abandon good clinical judgment. Indeed, the clinical team must be astute and vigilant to these themes.

Depression is a well-defined psychiatric illness characterized by the presence of depressed mood or loss of enjoyment, interest, or pleasure for at least 2 weeks, along with the presence of five specific criteria (four or fewer indicate minor depression). These criteria include the following:

1. Appetite disturbance with weight loss or gain of at least 5% in 1 month
2. Sleep disturbance
3. Motor agitation or retardation
4. Fatigue or loss of energy
5. Excessive guilt or feelings of worthlessness
6. Indecisiveness and trouble concentrating
7. Recurrent thoughts of death

Prevalence and Risk Factors

Major depression is common in the United States; the lifetime prevalence is approximately 15% (7). No ethnic differences have been observed, but women have twice the risk of major depression as men. Depressive disorders have the following factors: a patient's genetic makeup, psychosocial stresses, physical disability, pain, and serious medical illness. Twenty-five percent of patients with cancer are clinically depressed, but the prevalence rates vary with the specific malignant process and stage of disease (1.5% in acute leukemia patients awaiting bone marrow transplantation, 21% in women following mastectomy, 15% in recurrent colon cancer, 50% in pancreatic cancer) (8). The Medical Outcomes Study found that approximately two thirds of depressed patients seen in the mental health sector had at least one of eight chronic medical conditions, including hypertension, gastrointestinal disorders, chronic lung problems, and arthritis, and the depressed medically ill had a mean of 1.8 physical diagnoses (9). Similarly, studies have found that 10% to 14% of outpatients in general medical settings have major depression, with a higher prevalence of subsyndromal conditions (10).

The important factors that influence the risk of psychiatric morbidity and help clinicians to make a diagnosis of depression include the following: past medical history, personal and family histories, past history of adjusting to life crisis, alcoholism, other substance abuse, sexual abuse and family abuse, and anxiety disorders. The patient's family may add important clues about the patient's behavior, such as forgetfulness, unusual quietness, irritability, preoccupation with physical complaints, or obvious behavioral missteps such as missing medical appointments. Depression impairs life. It enhances disability, increases dysfunction, and adds to overall suffering. Making the correct diagnosis and treating depression are therefore important, because treatment improves quality of life, increases compliance with the primary medical condition, improves independence, affects length of hospitalizations, and may ultimately affect survival.

Diagnosis

In advanced, progressive disease, the diagnosis of depression, anxiety, or delirium is made when a set of threshold events or symptoms demands attention. As the illness progresses, the clinical team's approach can be less rigid in diagnosing depression. There is less need to distinguish the physical problems of the illness from the somatic symptoms caused by depression. One can choose an *exclusive system* of diagnostic criteria for depression that removes all the physical symptoms. For example, the common symptoms of anorexia and fatigue would not be included. Although this approach may be useful in research settings, an *inclusive system* may be the better choice for palliative care because all symptoms would be

considered (whether attributable to the disease process or its treatment), and underdiagnosis of depression would be less likely. If the symptoms of depression are not severe, then the distinction between a clinical diagnosis of depression and the primary medical disease and its treatment is more problematic. Clinical judgment requires an assessment of several factors, including mood, hopelessness, suicidal ideation, irritability, cognition, and concentration. There is lack of uniformity in the screening tools for depression, along with variability of the thresholds necessary for making a diagnosis. Although, certain commonly used tools for the assessment of depression (e.g., Hamilton Depression Rating Scale, Beck Depression Inventory) measure the severity of depression, a single question such as, "Are you depressed?" may be the best and most reliable tool (11).

Other common, basic questions that are frequently asked include the following:

- "How are you doing?"
- "How are you feeling now?"
- "How are your spirits?"
- "Do you find yourself crying for no reason?"
- "If so, how often?"
- "Have you felt this way before?"
- "What do you see for yourself in the future?"
- "Do you feel in control of things?"
- "Do you feel helpless?"
- "Are you feeling guilty?"
- "Do you feel like a burden?"
- "Do you think you would be better off dead?"
- "Do you have any thoughts of hurting yourself?"
- "When do you go to bed? Do you need naps during the day? How long are your naps?"
- "Are you able to fall asleep fast?"
- "Do you awaken early?"
- "Do you feel refreshed when you wake up?"
- "Do you look forward to eating?"
- "Do you find pleasure eating foods you usually like?"
- "Has your weight fluctuated these past few weeks?"
- "Are you able to concentrate?"
- "Are you irritable or restless?"

The differential diagnosis may be more challenging once depressive symptoms are recognized. Comorbid medical conditions and a diverse group of medications have both been implicated in altering a patient's mood. Some medical conditions (e.g., cerebral vascular disease, Parkinson's disease, cancer, hypercalcemia, hyponatremia, and adrenal insufficiency) can add to the risk for depression. Uncontrolled pain adds to a depressed mood and causes anxiety. Depression may occasionally have psychotic features, with delusions, cognitive impairment, and, rarely, hallucinations. Psychotic symptoms usually imply that the patient has an organic brain syndrome (delirium), and an underlying cause should be sought, rather than assuming a diagnosis of depression with psychotic features. Finally, when facing stressors such as a diagnosis or recurrence of cancer, patients may have an adjustment disorder rather than a major depressive syndrome. There is a lack of clarity in distinguishing depression from the mood disturbance of an adjustment disorder.

One of the obvious pitfalls is trying to describe accurately that which is qualitatively abnormal, excessive behavior in individuals with an illness such as terminal cancer. Adjustment disorders are usually associated with both emotional and behavioral symptoms that could progress to major depression. However, once successful adaptation occurs or the stressor is eased, the symptoms clear.

Treatment

Pharmacological intervention is commonly offered to patients with moderate to severe depression. Improvement of symptoms can occur as early as 2 weeks, although a period of 4 weeks is usually required to achieve a full response. Therapy is designed to restore the neurotransmitter system. The choice of antidepressant is based on the clinical picture, the nature of symptoms (e.g., anxiety, insomnia), and the adverse side effect profile of the specific agent. Maintaining an adequate dose for a period sufficient to observe a response is a key component for success. The antidepressant is too often withdrawn prematurely, thus causing a relapse of depressive symptoms. These drugs should always be withdrawn slowly.

The monamine oxidase inhibitors have significant drug interactions and serious adverse effects such as central nervous system hyperstimulation, hypotension, and hepatic and hematologic consequences. They are rarely used in palliative care and end-of-life settings. These drugs are more appropriate for the management of atypical depression (e.g., compulsions) or as third-line agents in patients with refractory depression.

The selective serotonin reuptake inhibitors (SSRIs) are the first choice of many clinicians. These drugs are generally well tolerated for both short-term and long-term management of depression, and they appear to have a therapeutic effect close to the starting dose. Most SSRIs are highly protein bound and have half-lives that range from a few hours to 9 days or longer. They have no cholinergic, histaminergic, or adrenergic side effects. The most commonly prescribed SSRIs include fluoxetine, sertraline, paroxetine, citalopram, fluvoxamine, and escitalopram. These drugs are potent inhibitors of the cytochrome P450 isoenzyme systems, and the intensity of drug interactions varies depending on the dose of the SSRI, half-life, and duration of use. These drugs should not be combined with tricyclic antidepressants (TCAs) because a serious interaction, a serotonin syndrome, may result. Patients taking an SSRI should avoid alcohol consumption and dextromethorphan. Because SSRIs are highly bound to plasma proteins, drug interactions can arise with other commonly prescribed agents such as anticonvulsants, digoxin, and warfarin. Sertraline, citalopram, and escitalopram may be better choices if patients are prescribed other medications. The SSRIs with short or intermediate half-lives relative to fluoxetine are less problematic with other co-administered drugs. Because of its long half-life, fluoxetine can still influence other agents 4 to 6 weeks after it is discontinued. The most likely side effects of SSRIs include gastrointestinal discomfort, nausea, headache, dizziness, agitation, insomnia, somnolence, and sexual dysfunction. Weight gain is most often associated with paroxetine. St. John's wort, an herbal remedy promoted for use in depression, can also cause a potential problem when it is used simultaneously with the SSRIs; this combination can produce the serotonin syndrome with hyperthermia, diaphoresis, and hypotension. Patients are susceptible to a flulike syndrome when an SSRI is suddenly withdrawn. Because of the long half-life, fluoxetine is less likely to cause these complications. For those

patients who are unable to swallow pills, both paroxetine and fluoxetine are available as a liquid substitute.

The TCAs remain important options. These compounds are highly bound to plasma proteins, are water soluble, and have a mean half-life of 24 hours. They are often used as adjuncts in the management neuropathic pain, and they probably act by mediating the neurotransmitters norepinephrine and serotonin.

The choice of a TCA depends on the general medical condition of the patient and the acceptability of the side effect profile. Side effects that are too bothersome affect compliance, as well as the patient's quality of life. Problems are related to the anticholinergic effects and include dry mouth, constipation, urinary retention, and blurred vision. Acute glaucoma precipitation is a risk, and because of their mydriatic actions, TCAs are contraindicated in patients with narrow-angle glaucoma. Elderly patients may be particularly at risk for adverse reactions. Sedation can be a concern, but the use of amitriptyline may be beneficial in the agitated patient who needs sleep. The anticholinergic cardiovascular effects may require monitoring, and desipramine and nortriptyline are the safer agents to prescribe for patients with a history of cardiac disease. Neuropsychiatric adverse effects can appear in 5% to 15% of patients taking TCAs and can include nightmares, agitation, confusion, and even hallucinations. These drugs can also enhance central nervous system depression if they are combined with sedatives such as benzodiazepines or alcohol. Amitriptyline and imipramine may be given as an elixir in patients who have difficulty with pills.

The heterocyclic agent trazodone is occasionally prescribed. It lacks anticholinergic properties and is used in patients to minimize the risk of cardiac side effects. Its absorption is enhanced dramatically when it is taken with food. In high doses, trazodone can induce priapism in younger men.

Atypical, newer-generation antidepressants including duloxetine, venlafaxine, nefazodone, mirtazapine, and bupropion can be appropriate in the treatment plan of particular patients. Duloxetine may offer benefit to individuals with prominent symptoms of anxiety or pain. This drug has dual reuptake inhibition of serotonin and norepinephrine with a dose range from 40 to 60 mg/day. It appears to have an excellent safety profile and has proven beneficial in patients with urinary stress incontinence. Venlafaxine has a mechanism of action similar to that of duloxetine, and it does not affect α-adrenergic, histaminergic, or cholinergic receptors. It has few drug interactions because of its low protein binding and lack of cytochrome P450 inhibition. Common side effects include nausea, dry mouth, constipation, nervousness, anorexia, and sweating. Some patients have reported cognitive, short-term memory problems while taking venlafaxine. Nefazodone is a good option because of its low incidence of sexual dysfunction and unique effects in improving insomnia and anxiety. Mirtazapine enhances both noradrenergic and serotonergic transmission and blocks serotonin ($5\text{-}HT_2$ and $5\text{-}HT_3$) receptors. If the starting dose of 15 mg is increased, the noradrenergic activation will cause less sedation and paradoxical arousal. This drug can enhance appetite as well as weight gain. Because of its low drug interaction profile, mirtazapine is good option in patients who are taking multiple medications. Mirtazapine has a half-life of 35 hours, allowing for once-daily dosing. Bupropion is a novel agent whose mechanism of action relates to norepinephrine and dopamine reuptake inhibition or enhancement. It is commonly used as a second-line agent for resistant depression. It can cause insomnia, headache, and gastrointestinal discomfort and is

contraindicated in patients with seizure disorders. It is rapidly absorbed and has a half-life of 8 to 15 hours. The extended-release form can be given once daily. Cautious dose titration is necessary in debilitated and elderly patients.

Because approximately 10% to 15% of patients are resistant to antidepressant medication, potentiation or augmentation may be considered. Lithium may potentiate a response by 50%, but it would not be prudent to initiate this drug in patients who are seriously ill, dehydrated, or frail. However, patients who take lithium for bipolar disease should be maintained on this drug. Psychostimulants can augment alertness and appetite, especially early in the course of treatment before a response to other antidepressant medications can be observed. Methylphenidate, dextroamphetamine, and modafinil are drugs that may be worth considering in selected patients. Methylphenidate should be started slowly, and side effects are uncommon. Headaches have been a problem with modafinil.

Although the pharmacological approach is frequently used to treat depression, other strategies can enhance the overall outcome. For almost all patients, some level of psychological support is helpful. The clinician should consider recommending counseling to address suffering, individual and family counseling, patient and family education, social interaction, spiritual consultation, group therapy, and cognitive-behavioral therapy. All these interventions can foster a sense of support in both the patient and the family and can allow the patient to feel less alone and abandoned. These efforts can also foster improvement of coping skills that, it is hoped, would allow individuals to see themselves more positively, particularly in thinking beyond their predicament.

Suicide

Although depression is common in patients with cancer, having cancer is not a mandate for depression or suicide (9). However, the risk that patients with cancer will end their lives is twice that of the general population. Multiple risk factors for suicide have been well documented. Although a clear relationship exists between depression and suicide, a patient's sense of hopelessness is an even stronger risk. Patients tune into this fatal option as a measure of getting back some level of control because they feel that the illness has stolen their autonomy. There is no evidence that raising the issue of suicide with a patient encourages that patient to act in a self-destructive manner. Psychiatric consultation is required when the risk for suicide is deemed high. The clinical team needs to be aware of past attempts, aborted actions, family history, and other experiences with deliberate intent for self-harm. Religious and cultural beliefs regarding suicide may make the patient reluctant to discuss this topic. Documentation of communication with family members can be meaningful, and it is necessary to foster support and give practical suggestions about what to look for and what to do if the patient is at risk. The rarity of suicide (10.7 suicides per 100,000 persons), even in high-risk populations, adds to the difficulty of prediction (10).

Special Populations

Patients with significant medical disability, pain, disfigurement, and poorly controlled physical symptoms are the population seen in hospice and palliative care settings. It is a considerable challenge to the clinician when clinical depression

is ruled out and terminally ill patients maintain the capacity to make their own decisions but are persistent in their wish to die. The most common, pressing questions are as follows: "Can the symptoms and pain be better managed? Are the adverse effect profiles of medications or procedures too much of a burden? Are there issues about money and loss that are not being discussed? Does the patient feel abandoned by family, friends, children, and physicians? Is there suffering that is not or cannot be addressed?"

Aging, terminally ill patients offer unique challenges. With the added burden of progressive illness, pain, and physical symptoms, the elderly patient may have to face further significant losses—the disabilities of aging, loss of a spouse, retirement, loss of independence, and loss of the home. The somatic symptoms may make it much more difficult to distinguish between the terminal illness and the depression. In the older patient, depressive symptoms usually improve as the primary illness improves. Changes in cognition may be secondary to neurological illness (e.g., stroke, Parkinson's disease, early dementia), the primary medical condition, or depression alone. Because tricyclic and heterocyclic medications are primarily metabolized by the cytochrome P450 system, which is diminished with aging, lower doses are necessary. α-Adrenergic blockade makes the older patient prone to orthostatic hypotension and subsequent falls. If TCAs are chosen, the secondary amine TCAs desipramine and nortriptyline may be better options. When SSRIs are selected, fluoxetine and sertraline may offer some advantage. Psychostimulants, such as methylphenidate in doses of 5 to 40 mg/day, have been used effectively and safely in the elderly population, especially when apathy or motivational problems seem to predominate. Antidepressants are as effective in elderly patients as they are in younger patients. However, caution should be exercised in both drug choice and dosage.

Which drug to choose? If the patient had a good experience in the past with a specific antidepressant, it may be reasonable to return to that same drug. However, a longer trial may be required before adequate response is achieved. The performance status of the patient, nearness of death, social setting, medical problems, and physical symptoms all play a role in the final choice of a drug. For example, if anxiety, insomnia, and weight loss are issues, mirtazapine may be a good option.

ANXIETY

Normal Response Versus Treatable Anxiety

Anxiety is the normal human response to a threat. It may represent a symptom, a syndrome, a disorder, or it may play a significant role in other psychiatric conditions such as major depression. After a patient is diagnosed with a life-threatening disease, anxiety may not be viewed as an issue because it is anticipated as a "normal" response in dying patients. Symptoms of anxiety may arise from many potential causes, including tension, nervousness, insomnia, hyperactivity, hypervigilance, apprehension, fear, shortness of breath, palpitations, or tremor. Interventions may be necessary when these symptoms appear bothersome or are beyond the level of threat.

In the palliative care and hospice setting, behavior, family reaction to this behavior, and the patient's own level of distress should be evaluated to determine whether treatment is necessary and to ascertain whether the anxiety is related to the medical condition, is a complication of the illness or medication, or is caused

by the withdrawal of some substance or drug. In a frail patient, dehydration, metabolic abnormalities, liver or renal failure, central nervous systems metastasis, hypoxia, sepsis, pulmonary emboli, and impending death can cause symptoms of anxiety. Patients who are receiving chemotherapy and radiation may actually experience increased treatment apprehension after therapy is completed because medical contact is decreased; these patients may fear that the cancer will get out of control. Patients can have very reasonable concerns such as fear of disfigurement, loss of bodily function, dependency, financial ruin, and death. When the future appears to hold only negative outcomes, patients may begin to draw conclusions that are at odds with the available data; that is, they overgeneralize, and catastrophizing is common.

Treatment

Psychiatric evaluation is reported in approximately 15% of patients with cancer (11). Behavioral interventions that may be helpful include meditation, biofeedback relaxation techniques, massage therapy, music therapy, and hypnosis. Cognitive therapy may help patients to develop alternative thinking patterns and better means of coping. The therapist's task is to dismantle the frozen cognitive paradigm established by the patient and allow the patient to discover alternative meanings.

Patients with anxiety associated with dementia, delirium, disinterest, or serious psychiatric illness are not likely to respond to psychological approaches. However, those patients who have failed in their efforts to control the situation by other means may benefit from psychological intervention. The severity and duration of anxiety will likely determine the chance of response. Group therapy has also been successful in reducing apprehension in some patients.

For patients with mild reactions to their illness, behavioral intervention may be sufficient. However, patients with sustained, bothersome symptoms of nervousness, apprehension, or anxiety may benefit from the use of benzodiazepines. These agents are best introduced for short-term relief of the general symptoms of anxiety and can also be of benefit in treating insomnia. Benzodiazepines have different pharmacokinetic profiles, are completely absorbed orally, and are 85% to 90% bound to plasma proteins. They have antidepressant effects and are useful for patients with panic attacks. Clonazepam is helpful if patients require treatment for a prolonged period because it has a half-life of 18 to 60 hours. Lorazepam, oxazepam, and alprazolam have no important active metabolites, but they must be cautiously administered if liver function is abnormal. Asians and African Americans appear to metabolize some benzodiazepines more slowly. Dependency can occur if the patient is at risk for substance abuse. Tolerance and physical dependence are more likely to occur with the use of high-potency, short-acting agents such as alprazolam and lorazepam, so these medications should never be discontinued abruptly. Alprazolam, in particular, can induce severe withdrawal with dysphoric reactions and overt delirium. Dosages of alprazolam should be tapered slowly at approximately 0.5 mg/week. Patients can sometimes be switched to an equipotent dose of long-acting clonazepam. Over-the-counter medications can elevate levels of benzodiazepines, and alcohol should be avoided.

Sedation may be a disturbing side effect of benzodiazepines, and it may be more severe in the elderly, especially in patients with central nervous system or liver impairment. Elderly patients who are receiving opioids and antidepressants

may be at increased risk for falling and may also be vulnerable to agitation and aggressive behavior if benzodiazepines are added. In those patients who are actively dying, in whom sedation is a goal, it may be difficult to distinguish the symptoms of anxiety from the adverse effects of benzodiazepines. Elderly patients can be challenging, especially if they are being cared for at home by an already stressed family, and this is often a reason for seeking hospitalization.

Buspirone belongs to a different chemical subgroup and is not a benzodiazepine. It does not have the sedation and muscle relaxant properties of the benzodiazepines and thus may be a good choice in elderly patients. It lacks the abuse potential of benzodiazepines and appears safe when used with other medications, with the exception of monamine oxidase inhibitors and haloperidol. However, symptoms improve more slowly, and a full response may require as long as 6 weeks. Because of this delay, some patients may become impatient and may want to switch to a different drug. Buspirone will not prevent the withdrawal syndrome in patients who are taking benzodiazepines.

DELIRIUM

The clinical features of *delirium* include alterations in consciousness, attention, cognition, and perception. This condition is characterized by an acute onset (hours to days), waxing and waning during the course of the day. Delirium can be induced by complications of the general medical condition or by medications, or it can have multiple, simultaneous causes. The cause may not be found in 10% of patients with this condition. Prevalence rates in the terminally ill have a wide range, from 20% to 90%, depending on how near death the patient is (12). Accurate statistics on the prevalence of this condition are difficult because of the variability in following strict diagnostic criteria, but it is widely accepted that delirium is underdiagnosed. Many patients have prodromal symptoms days before the onset of overt agitation and confusion. These symptoms may include insomnia, distractibility, irritability, and restlessness, and they can last from less than 1 week to more than 2 months.

Delirium is associated with increased morbidity (e.g., falls and pneumonia) that generates longer hospitalizations, disability, and increased costs, especially in elderly patients. It hinders patient communication with physicians and loved ones at a time when communication is so valuable. Seizures can be a component of delirium in withdrawal states, head trauma, hypoglycemia, and strokes. The acute onset, as well as the fluctuations commonly witnessed during a 24-hour period, help to distinguish delirium from dementia. Consciousness is altered, but stupor and coma are not seen. Patients demonstrate attention disturbance and distractibility. Cognition is poor, with disorientation to time and place, but disorientation to self is rare. Short-term memory is hampered. Delusions and hallucinations are common. Patients are commonly seen going through the motions, doing their "old" jobs (e.g., sewing a dress), or calling out to parents or lost loved ones they believe they see at the foot of the bed.

Delirium is known to have multiple medical causes. It is rare to find a single cause of delirium, and no cause is found in 10% of cases (13). Some of the underlying medical conditions associated with delirium include cerebral vascular accident, uremia, hypoxemia, hypoglycemia, endocrine alterations, electrolyte imbalance, dehydration, congestive heart failure, infection, withdrawal state, sensory

deprivation, limbic encephalitis, leptomeningeal metastases, and disseminated intravascular coagulation. Medications that have been implicated include opioids, sedatives, hypnotics, corticosteroids, and various chemotherapy drugs (vincristine, procarbazine, asparaginase, cisplatin, amphotericin, acyclovir, interleukin-2). The intensive care unit has been accused of being an environmental cause of delirium. Tools such as the Mini-Mental State Examination can be useful in alerting staff to changes in a patient's condition and behavior. It can be helpful to review the chart of a patient with a history of confusion and agitation that occurred during treatment with particular medications. Talking with family members will also fill the gaps needed to clarify the diagnosis, to identify dementia, and help to determine the cause. Depending on the patient's overall state of terminal illness, investigations may be helpful. Brain imaging may be indicated in individuals with a history of head trauma, focal neurological findings, or cancer. The obvious clinical state of the patient dictates how aggressive the clinician should be in determining the diagnosis.

The first step in the management of delirium is to determine the cause. Nonessential medications should be stopped, and opioids should be decreased, stopped, or given only as necessary, especially if the patient has myoclonus. Reversible causes should be sought. When delirium is present, it is important to monitor and ensure patient safety, to avoid falls and to evaluate the potential risk for suicide and impulsivity. The patient should not be left alone until the delirium has cleared. Physical and chemical restraints should be used only when necessary. Communication with family members is important and can help alleviate their concerns, guilt, and grief. Frequent nursing observations should be made during these periods of agitation, and the patient's mental state, medications, and clinical course should be thoroughly documented.

Delirium is a reversible condition in the majority of patients. However, cognitive impairment may persist in elderly patients who had unrecognized, prior dementia. Patients who are in the last 24 to 48 hours of life may never recover. Sedation may be required to treat the severe agitation or hyperawake state of the actively dying patient.

Pharmacological management is designed to alleviate the agitation and to lessen uncomfortable dysphoric episodes in delirious patients, and haloperidol is the drug of choice. Haloperidol is a potent dopamine blocker with sedative properties, yet it has a low risk for causing hypotension. Droperidol has the advantage of having a more rapid onset and a shorter half-life than haloperidol, but it is more sedating and can cause hypotension and serious cardiac side effects. There have been no good clinical trials comparing these drugs, so clinicians must rely on their own experience with the medications they have used successfully in the past. Haloperidol is versatile and can be administrated by the oral, intramuscular, intravenous, or subcutaneous route. It has a half-life of 14 to 20 hours. The oral route is easy and effective for mild delirium. If the patient is extremely agitated, however, the intravenous route is often necessary. Haloperidol is twice as potent when given parenterally, and the effects can be seen within 30 minutes and can last up to 4 to 8 hours. Doses can be given at 1 to 5 mg intravenously, depending on the severity of the agitation, and repeated every 20 to 30 minutes if necessary. Small, oral doses of 0.25 to 0.5 mg every 4 to 6 hours may be helpful in frail, elderly patients. Higher intravenous doses have been documented to cause fatal cardiac arrhythmias and sudden death. The seizure threshold also can be lowered with this agent. A wide range of dosages can be used during the first hour, but the maintenance dose is less than 2 to 4 mg/day.

Benzodiazepines may have a role in therapeutic sedation and comfort care of the dying patient during the last hours of life, when improving alertness is less meaningful. Lorazepam is usually the drug of choice, given orally or sublingually in doses of 1 to 3 mg or at 0.5 to 2 mg parenterally for those who need more sedation. Midazolam is another option in the end-of-life setting. Initial doses are usually between 20–100 mg over 24 hours. However, midazolam is not a good drug for prolonged use in patients with liver failure because plasma levels may rise. Olanzapine can be given as a dissolvable oral wafer, and this may be helpful in a hospice setting if a patient can no longer swallow and the parenteral route is not available. Risperidone and phenothiazines such as methotrimeprazine may also be effective.

PEARLS

- Patients and families are concerned about immediate, practical problems of everyday life.
- Patients fear both the dying process and death
- Forty percent of dying people are distressed.
- Somatic complaints are easy to recognize, but emotional symptoms are often not so easily recognized.
- Distressed patients make for distressed families and hinder the ability to deliver adequate care.
- The term *distress* is more acceptable than *emotional* or *psychiatric.*
- Standards should ensure that distressed patients are recognized and that necessary resources are employed (e.g., psychiatrists, social workers, pastoral counselors).

PITFALLS

- The dying patient is in a state of crisis: fearful, fragile, and distressed.
- Physicians lack familiarity with common psychiatric syndromes and psychotropic medications.
- Physicians exacerbate stress because of inadequate training, poor communication skills, their own fear of dying, unrealistic expectations, and conflicting roles.

Depression

Pearls

- Depression is a well-defined psychiatric illness characterized by depressed mood and loss of enjoyment.
- Psychological intervention is required when the severity of symptoms of depression leads to inappropriate behavior.
- Depressive disorders have common conceptual themes: genetics, psychological stressors, pain, physical disability, and serious illness.
- Depression impairs life, enhances disability, increases dysfunction, and diminishes quality of life.
- The SSRIs are the choice of clinicians who prescribe antidepressants and include fluoxetine, sertraline, paroxetine, citalopram, fluvoxamine, and escitalopram.
- Patients with significant medical disability, pain, disfigurement, or delirium are at risk for suicide.

PITFALLS

- It is a common misconception that depression is a normal response to dying.
- The clinician may feel helpless and frustrated but must not act helpless or abandon good clinical judgment.
- Pharmacological therapy is often withdrawn prematurely, before a response is realized, thus causing a relapse of the depression.
- SSRIs should not be stopped abruptly.
- Because elderly patients are often taking numerous medications, it is important to know the side effects of the antidepressants as well as those of the co-administered drugs.

Anxiety

PEARLS

- Anxiety is a normal response to a threat.
- Symptoms of anxiety include nervousness, fear, hypervigilance, shortness of breath, palpitations, and insomnia.
- Benzodiazepines are the drugs of choice to treat anxiety and include alprazolam, lorazepam, clonazepam, and oxazepam.
- Clonazepam is useful for the prolonged treatment of anxiety.
- Buspirone may be a better choice in elderly patients because it is less sedating.

PITFALLS

- Sedation is a disturbing side effect of the benzodiazepines.
- Tolerance and physical dependence are more likely with short-acting medications such as alprazolam and lorazepam.
- Alprazolam can induce a severe withdrawal syndrome if it is stopped abruptly.
- Precautions against falling may be necessary in the older patient.

Delirium

PEARLS

- Delirium is a clinical condition characterized by alterations in consciousness, attention, cognition, and perception.
- Up to 85% of terminal care patients will have delirium.
- Elderly patients may have a more prolonged course.
- Haloperidol is the drug of choice for delirium in the medical patient.

PITFALLS

- Delirium is often caused by prescribed medications such as opioids, sedatives, hypnotics, or steroids.
- Many patients have subclinical symptoms for days before exhibiting overt confusion and agitation.
- Benzodiazepines given for delirium rarely clear cognition and may add to sedation and confusion in the dying patient.

- Cognitive impairment may persist in elderly patients who had unrecognized dementia.
- Patient safety is crucial: Watch for falls, pneumonia, suicide, and impulsive behavior.

SUMMARY

Somatic symptoms such as pain, fatigue, fever, and nausea are common, recognized problems of seriously ill patients. Unfortunately, psychiatric symptoms and psychic pain (depression, anxiety, and distress) are not so widely recognized. Patients suffer needlessly because of this lack of familiarity with common psychological syndromes and psychotropic drugs, and this affects their medical care, decreases their quality of life, and adds to the distress of their loved ones. Each clinician approaches the dying with his or her own unique, lifelong collection of feelings, prejudices, and attitudes about sickness, loss, and death. Clinicians must be open to their own feelings to be better caregivers to those in need.

Resources

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Constipation

10

S. Lawrence Librach

CHAPTER OUTLINE

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MANAGEMENT
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Nonpharmacological Measures
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Enemas
Manual Disimpaction
The Paraplegic Patient
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SUMMARY

INTRODUCTION

Constipation is sometimes regarded as a minor symptom by care providers. However, this is not the case with palliative care patients. The prevalence of constipation in the overall population varies from 2% to 28% in population surveys, and it is more prevalent in elderly patients. It is a very prevalent symptom in patients who have advanced, progressive illnesses and is a significant source of suffering. Prevalence rates for constipation are approximately 25% to 50% for those with any type of terminal illnesses (1, 2). One study indicated that laxatives were administered to 87% of terminally ill patients with cancer (3). From my personal, on-call experience in a large, home-based palliative care practice, constipation ranks as one of the major reasons for accessing the on-call service after hours. The approach to managing constipation is similar to that of other symptoms: start with a comprehensive assessment, consider pharmacologic and nonpharmacologic management, follow through with careful monitoring, and be sure to educate the patient, family, and other care providers about the issues and the management.

DEFINITION

Infrequent defecation (fewer than three bowel movements per week) has generally been regarded as the most important marker of constipation. However, other

symptoms, such as excessive straining, hard stools, and a feeling of incomplete evacuation, have recently been recognized as equally important and perhaps more common (4). More formal definitions used in research studies do exist, but they are not very useful in the clinical situation (5). Constipation may be associated with other symptoms and may be the major cause of nausea and vomiting, confusion, agitation, intermittent diarrhea, bloating, and abdominal pain. Rarely, severe constipation can be associated with bowel perforation and sepsis.

ETIOLOGY

Constipation has a multifactorial origin, as do other symptoms commonly seen near the end of life. The normal physiology of defecation is complex and involves the central and peripheral nervous system, hormones, and reflexes that are unique to the gastrointestinal system. The peripheral sympathetic and parasympathetic nervous system controls colonic motility, colonic reflexes such as the gastrocolic reflex, and relaxation and contraction of the anal sphincter. The urge to defecate and the process of defecation itself are mediated by the central nervous system and require contraction of skeletal muscles to increase abdominal pressure to facilitate evacuation. Adrenergic, opioid, muscarinic, and dopaminergic receptors all have a role in gut motility. Gastrointestinal hormone physiology is controlled by the endocrine and paracrine systems, as well as by neural pathways (6). Problems in any one or a number of these systems may lead to constipation.

Opioid-induced constipation is one of the more common problems seen in palliative care. It results from decreased intestinal motility; poor propulsive action leads to prolonged intestinal transit time, increased fluid absorption in the colon, and hard stools. Opioids may also increase anal sphincter tone and may reduce awareness of a full rectum.

Contributing factors, both reversible and irreversible, to constipation in palliative care patients include the following:

1. Preexisting constipation. Elderly patients, in particular, have decreased bowel motility for various reasons. Long-term constipation is a problem seen in the general population, especially in women (8). These patients may also suffer from having taken laxatives for many years, a practice that can result in constipation.
2. Neurological abnormalities. These conditions include spinal cord lesions and autonomic dysfunction or neuropathy seen in diabetes and in cancer.
3. Metabolic causes. Conditions include dehydration, uremia, hypokalemia, hypercalcemia, hypothyroidism, and diabetes mellitus.
4. Structural obstruction. Conditions include fibrosis from radiation, adhesions, and bowel obstruction from tumors.
5. Decreased food, fiber, and fluid intake. Anorexia is a common symptom in many terminally ill patients. It is important to realize that 50% of stool weight is derived from cells, mucus, and bacteria, so even patients who eat very little will produce significant amounts of stool.
6. Uncontrolled pain. Uncontrolled pain may limit mobility and the patient's ability to strain at stool.

7. Medications frequently used in palliative care patients, such as certain chemotherapy drugs, opioids, antidepressants, nonsteroidal anti-inflammatory drugs, and others. Even vitamins and minerals commonly taken by patients can add to constipation. All opioids are associated with constipation.
8. Limited mobility.
9. Generalized weakness. Patients may not be able to sit or develop the increased abdominal pressure needed to evacuate the rectum.
10. Hypomotility disorders secondary to diabetes, advanced age, and paraneoplastic problems. These disorders cause increased transit time and ineffective propulsion of stool in the colon.
11. Environmental issues. These issues include lack of privacy, change in care setting, the use of bedpans, and inconveniently located washrooms.
12. Care provider neglect. Unfortunately, in the hustle and bustle of care, constipation may be overlooked, and protocols to address assessment and management may not be in place. Constipation may be seen as a minor problem and may not be addressed by physicians in particular.
13. Patient issues. Patients may be too embarrassed to discuss constipation or may feel that it is a minor symptom. Cultural issues may also hinder a discussion of constipation.

ASSESSMENT

A history of decreased frequency and description of hard bowel movements are the key indicators of constipation. Color, odor, and size of stools should be determined. However, other symptoms that result from constipation (e.g., nausea or vomiting, generalized malaise, headache, intermittent diarrhea, stool and urine incontinence, abdominal pain, and bloating) may be presenting problems. Nursing records in institutions often monitor the frequency of bowel movements. A thorough medication history uncovers factors in constipation, including inappropriate or inadequate laxative regimens. A long history of recurring problems of constipation refractory to dietary measures or laxatives often suggests a functional colorectal disorder. An assessment of physical functioning may reveal significant weakness and inability to access washroom facilities. Physical examination may reveal abdominal distention and palpable abdominal masses, fecal and other. Neurological examination may be required if a spinal cord lesion or brain lesion is suspected.

A gentle rectal examination is essential. Perineal sensation can be checked. The rectal examination can assess anal sphincter tone, the presence of hemorrhoids and anal fissures, the presence and consistency of stool in the rectum, or the absence of stool and rectal dilatation. A lack of stool in the rectum associated with rectal dilatation may indicate constipation higher in the left side of the colon or colonic obstruction.

Plain upright radiographic films of the abdomen may be needed when the diagnosis is not very evident. A classification system can be used by the radiologist to quantify the degree of constipation, but this is rarely reported or used (7).

MANAGEMENT

General Management Issues

Preventive management is always better than responsive management. For palliative care patients who tend to be sedentary and often on opioids, a bowel regimen to prevent constipation should be a routine consideration.

1. Correct reversible causes when possible. In most patients, the cause of constipation is multifactorial, so simple changes rarely produce significant change in the problem of constipation. Stopping opioids may, in fact, leave the patient in severe pain. Alternatives to opioids in patients with moderate to severe pain are very limited.
2. Prevent constipation. For instance, opioids almost always cause constipation. When opioids are prescribed, a laxative regimen using bowel stimulants and osmotic laxatives should be started immediately, before serious constipation develops. Constipation is one of the most feared adverse effects of opioids. A preventive approach should also be taken with other drugs that commonly cause constipation, such as tricyclic antidepressants.
3. Educate the patient, family, and other care providers about the cause of and management plan for constipation. Stress the importance of preventing constipation, thereby avoiding other symptoms and unnecessary suffering. Inquiry about constipation and frank discussions may not be possible in certain cultures. Avoid the cycles of alternating constipation and diarrhea by setting clear protocols for patients and their care providers.
4. Create realistic expectations. Although some patients would prefer to have a daily bowel movement, a soft, easy to pass movement every 2 days may be the best result.
5. Monitor the patient frequently. Pain diaries should also chart bowel movements. Protocols should be in place in all care settings to monitor patients at high risk of developing constipation, that is, most palliative care patients.

Nonpharmacological Measures

Increase fluid intake if possible. Intake of 2 to 3 L/day is recommended. Too much coffee or tea should be avoided, however, because of the diuretic properties of these fluids. Increase physical activity if possible. Patients may maintain higher levels of function early in the course of a progressive illness. Exercise improves bowel motility. A high-fiber diet increases stool weight and accelerates colonic transit time. Daily fiber intake must increase by 450% to increase stool frequency by 50% (9). A high-fiber diet does not benefit all patients with constipation. Increasing dietary fiber in the palliative care population is often not possible or practical in light of the high prevalence of anorexia, food preferences, and poor intestinal motility, and to do so may actually cause more constipation. Use wheeled bedside commodes to bring patients into washrooms. Ensure adequate privacy for patients. Use of drapes and screens is recommended for patients who cannot be wheeled in a bedside commode to toilet facilities. Avoid the use of bedpans for bowel movements because they are uncomfortable for many patients. Try to ease patients into a regular

Table I–10–1 ■ Sample Protocol

Set up regular dosing of laxatives	Sennosides: two to four tablets at bedtime Lactulose: 30 mL at bedtime
If no bowel movement by day 2	Increase sennosides by two tablets (can be given in two doses and increase lactulose to 30 mL twice daily) Monitor daily
If no bowel movement by day 3	Do a rectal examination If stool in rectum, use phosphate enema or bisacodyl suppository If no stool in rectum and no contraindication, give oil enema followed by saline or tap water enema to clear Increase regular laxatives
If continued problems	Switch stimulant laxative Use regular enemas

routine of having a bowel movement at a certain time of the day, usually following some food intake.

Laxatives

For palliative care patients, the use of laxatives, often in combination, is an effective way to manage constipation (10). See Tables I–10–1 and I–10–2 for specifics; see also the formulary in the Appendix. Titrate laxatives to effect. Many palliative care patients require large doses of laxatives, such as six to eight tablets of sennosides (Senokot) per day, much more than the usual recommended doses. Set up effective protocols that give day-by-day instructions for the family caregiver or nurse. A sample protocol is shown in Table I–10–1.

Enemas

Enemas can be used for fecal impaction. They induce bowel movements by softening hard stool and by stimulating colonic muscle contraction in response to rectal and colonic distention. An oil retention enema (120 mL vegetable oil), followed by a tap water enema (500 mL/day), is generally preferable to salt-containing enemas (phosphate and soapsuds enemas) because oil and water are less irritating to the rectal mucosa. Bisacodyl suppositories or phosphate enemas may also be used to empty the rectum if the stool is relatively soft. If the stool is very hard then a small volume (60ml) rectal oil enema may be used first. Enemas should be used cautiously in patients with a history of bowel stricture or recent lower bowel surgery. Gentle, low-volume enemas can be used through colostomies by experienced nurses.

Manual Disimpaction

Manual disimpaction may occasionally be necessary for low rectal impaction. Use a low bowel oil enema in small volume to soften and lubricate the stools first. Appropriate sedation and analgesics are usually required to make the procedure

Table I–10–2 ■ Laxatives

Laxative Class	Examples	Mechanisms of Action	Special Issues
Bulk-forming	Psyllium preparations Soluble fiber	Increase fiber	May increase bloating Should be avoided in weak patients and those with opioid-induced constipation
Lubricant	Mineral oil	Soften and lubricate passage of stools	Risk of aspiration causing lipoid pneumonia Long-term use will decrease absorption of fat-soluble vitamins May be good choice in significant bowel stricture or subacute obstruction
Osmotic	Magnesium hydroxide Lactulose Sorbitol Magnesium citrate Sodium phosphate	Draw fluid into the bowel lumen	Magnesium and sodium salts contraindicated in patients with renal insufficiency May cause cramping and bloating Lactulose and sorbitol may be associated with increased gas
Stimulant	Senna Bisacodyl Cascara	Increase motility in colon	May cause cramping and gas Bisacodyl available as suppository
Detergent	Dioctyl sodium sulfosuccinate (docusate sodium)	Stimulate fluid secretion May soften outside of stool mass	Introduced as stool softeners, but further study of its efficacy needed Although frequently used as a "softener," clinical evidence for effect very limited (10)
Opioid antagonist	Naloxone Naltrexone	Counteract opioid-induced effects on colon	May cause opioid withdrawal Other compounds now in research trials

comfortable. Manual disimpaction should not be needed often. Regular enemas should be sufficient to manage cases of recurrent, severe constipation.

The Paraplegic Patient

Constipation is a frequent issue for paraplegic patients and may be associated with stool incontinence. Setting up a regular regimen of enemas is essential and often avoids incontinence.

PEARLS

- Constipation is a very prevalent problem for palliative care patients and may manifest as a variety of other problems.

- A rectal examination is essential in assessing problematic constipation.
- Education of patients, families, and health care providers is important in addressing the problem of constipation.
- Constipation protocols are necessary.

PITFALLS

- Failure to address constipation vigorously can lead to significant suffering.
- Prescription of opioids without a bowel regimen is almost always a mistake.

SUMMARY

Constipation is one of the most common symptoms in palliative care. If it is not addressed carefully, it can lead to more suffering. Constipation is multifactorial, and not all factors can be addressed in all patients. Careful history and physical examination will provide important clues to the cause and to appropriate management. Combinations of laxatives and careful monitoring are key ingredients in the care plan.

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Urinary Incontinence

11

S. Lawrence Librach

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INTRODUCTION

Urinary incontinence is a relatively common problem seen in patients at the end of life, but the exact prevalence is not clear. Studies of symptom prevalence at the end of life often do not mention urinary incontinence at all (1, 2), yet most patients who receive palliative care are also elderly, and this population is often affected by urinary incontinence. In fact, urinary incontinence affects 15% to 35% of community-dwelling, older adults and more than 50% of nursing home residents (3). There is a general reluctance for patients and families to discuss urinary incontinence. It may be that care providers assume that urinary incontinence is not a symptom in the ordinary sense, but rather a common, although less serious, problem at the end of life.

Urinary incontinence can have a significant impact on quality of life. In its various forms, urinary incontinence may limit patients' mobility and social interactions. Elderly patients with urinary incontinence are more likely to be placed

in a nursing home. Those with limited, economic resources struggle to cope with the costs of seeking investigations and treatment. Urinary incontinence may also lead to depression. The impact of urinary incontinence on the place of care or on other aspects palliative care is not reported. If not properly managed, however, urinary incontinence may add to the suffering of these patients. Neglected urinary incontinence may lead to systemic infections, skin problems, and skin wounds, thus introducing other significant physical morbidity to patients who are already dealing with numerous symptoms at the end of life.

One study showed that men are more likely than women to develop sexual dysfunction in association with urinary incontinence (4). Another study indicated that, among heterosexual couples, urinary incontinence correlates with interference of sexual satisfaction (5).

Cultural attitudes toward urinary incontinence vary significantly. In North American culture, urinary incontinence is gaining recognition as a medical illness and is discussed more openly, even in television commercials. In other societies, however, urinary incontinence is still traditionally viewed as evidence of self-neglect, being unclean, having poor self-discipline, or being socially incompetent. Patients with urinary incontinence who live in such societies may manage their symptoms in isolation and secrecy (6). The onset of urinary incontinence may adversely affect self-esteem.

PHYSIOLOGY AND PATHOPHYSIOLOGY

Micturition, the process of voiding urine from the bladder, is a complex process that involves the interplay of involuntary smooth muscle, voluntary striated muscle, the autonomic and somatic nervous systems, and the brain, as well as a cognitive aspect.

The components of the system include the following (7):

- The bladder wall is composed of a mesh of smooth muscle fibers.
- An internal, involuntary sphincter is composed of layers of smooth muscle at the bladder neck that surrounds the urethral orifice, known as the detrusor muscle.
- The outer layer of this smooth muscle continues in a circular fashion along the full length of the urethra in girls and women and to the distal prostate in boys and men, to forming the involuntary urethral sphincter.
- An external, voluntary sphincter made up of striated muscle interdigitating with smooth muscle is located between the layers of the urogenital diaphragm. In boys and men, these fibers are concentrated at the distal aspect of the prostate; in girls and women, they are found mainly in relation to the middle third of the urethra.

The innervation of the system is complex. The bladder receives its principal nerve supply from one paired somatic and two paired autonomic nerves. The hypogastric nerves (arising from lumbar spinal segments L1 and 2) mediate sympathetic activity, whereas the pelvic nerves (derived from S2-S4) contain parasympathetic fibers. The pudendal nerves (S2-S4) are primarily somatic fibers innervating the striated, voluntary sphincter. With distention of the bladder wall, stretch receptors trigger

parasympathetic pelvic nerve fibers that, unless inhibited by higher centers, lead to a parasympathetic motor response and bladder contraction. In micturition, the detrusor muscle contracts, thus drawing the bladder downward, and the external sphincter, under voluntary control, relaxes. Micturition is inhibited by sympathetic nervous system stimulation. All are coordinated by higher centers to initiate or inhibit bladder emptying. Therefore, problems can arise at one or more levels: the physical structure of the bladder, the enervation of the bladder and urethra, and the cognitive function of the patient. Each may result in or may be a factor in urinary incontinence.

Other factors may be involved in producing urinary incontinence. Estrogens may be associated with increased prevalence of urinary incontinence. Benzodiazepines and selective serotonin reuptake inhibitors are also associated with an increase in the frequency of urinary incontinence. Another factor in urinary incontinence needs to be mentioned here: urinary incontinence may result from failure by the care provider to manage reversible causes, such as urinary tract infections.

TYPES OF URINARY INCONTINENCE

Overactive Bladder Syndrome

Overactive bladder (OAB) is characterized by urgency, a sudden compelling desire to pass urine that is difficult to defer. It is usually accompanied by frequency and nocturia, and it may occur with urge urinary incontinence. The exact cause of OAB is not entirely known, but it is both myogenic and neurogenic. OAB affects about 16% of the adult population, and the prevalence increases with age. OAB can have a negative impact on health, ability to function, and quality of life. Elderly patients with urge urinary incontinence are also more likely to be admitted to nursing homes (8). Patients, families, and physicians may treat OAB as a normal consequence of aging, an attitude that results in underdiagnosis and undertreatment of this condition. In the typical population requiring palliative care, namely elderly patients, preexisting OAB can lead to urinary incontinence. As palliative care patients become weaker or have significant pain, it is more difficult for them to reach the washroom in time, and the result is urgency urinary incontinence.

Other Forms of Urgency Incontinence

Inflammation of the bladder, tumors at or near the internal urethral orifice, urinary infections, inflammation secondary to radiation, and some neurological disorders may also result in an urgency type of urinary incontinence.

Stress Incontinence

Stress urinary incontinence consists of involuntary urethral loss of urine associated with increased intra-abdominal pressure from coughing, sneezing, jumping, laughing, or, in severe cases, even walking. It is associated with faulty urethral support that results in abnormal sphincter function and an inability to resist increased

bladder pressure. It is more common in women, but it can be present in men, especially those who have had prostate or bladder neck surgery. In female patients, parity, pelvic surgery, obesity, menopause, and smoking are also cofactors in the development of stress urinary incontinence. In palliative care, preexisting stress urinary incontinence may be made worse by symptoms such as poorly controlled coughing or nausea. New stress urinary incontinence may be caused by surgery to the bladder neck, radiation-induced inflammation and fibrosis, tumors external to the bladder that cause increased intravesical pressure, and spinal cord damage.

Overflow Incontinence

The continuous urinary leakage seen with overflow urinary incontinence is mostly the result of overflow with chronic urinary retention secondary to urethral stricture or blockage. The bladder remains palpable and percussible, considerable residual urine is present, and the condition is nonpainful. Benign or malignant prostatic disease, spinal nerve damage, and urethral obstruction from tumors are common causes of this problem in palliative care.

Incontinence Secondary to Neurological Dysfunction

Spinal cord damage from any cause, sacral tumors, pelvic surgery, and pelvic tumors that invade the nerve supply to the bladder may result in partial or total urinary incontinence.

Incontinence Associated with Cognitive Failure

Patients who suffer from significant dementia or delirium are almost always incontinent.

ASSESSMENT

An initial evaluation should include the following:

1. A good history. Ask about the following: urinary frequency; the presence of the sensation of urgency; leakage; the influence of activities that increase intra-abdominal pressure; a pattern of urinary incontinence (occasional, continual); neurogenic symptoms such as paresthesia, dysesthesia, anesthesia, motor weakness, or lack of sensation of bladder fullness; pain; and the presence of hematuria or dysuria.
2. A review of the patient's disease process and treatments.
3. A review of previous imaging to look for sources of neurogenic urinary incontinence and pelvic masses. New imaging may be required, depending on the stage of the patient's illness and whether this will change management.
4. Patient, caregiver, or care provider monitoring for at least 2 days. Ask for a voiding diary, which should record urinary frequency, urgency, volume of urine, relation to other symptoms (if any), and the presence of pain on urination.
5. A targeted physical examination. Ask for the following: an abdominal examination to exclude a distended bladder; a neurological assessment of the perineum and

lower extremities; a pelvic examination in women, if warranted; a genital and prostate examination in men, if warranted; and a rectal examination to assess for pelvic masses and anal sphincter tone. This may include a bulbocavernosus reflex. Both are tests of nerve function to the area.

6. Urinalysis. Reagent strip testing of urine is a sensitive and inexpensive screening method that can be supplemented with urine microscopy and culture.
7. Depending on the patient's illness stage, further investigations such as residual urine determination, urodynamic studies, and cystoscopy may be indicated if they can help with the management of urinary incontinence. Consultation with a urologist can be very helpful.

MANAGEMENT

The management of urinary incontinence starts with evaluation for and treatment of reversible causes. Infections should be treated after urine has been obtained for a culture. Some change may need to be made once the organism's sensitivity to antibiotics is determined. Prostatic obstruction may require surgical intervention, again depending on the stage of the illness. Urethral stricture may require dilation. Obviously, spinal cord compression must be dealt with in the usual fashion. For most palliative care patients, however, the conditions leading to urinary incontinence are not reversible, and a palliative approach must be taken.

One of the most important steps in managing patients with nonreversible urinary incontinence is to educate the patient (when possible) and the family about the cause of the urinary incontinence and the various aspects of the treatment. Patients may need counseling to deal with their grief over this particular issue because it is often equated with the need for institutional care. The benefits of appropriate treatment need to be emphasized.

Behavioral Therapy

Behavioral therapy includes techniques such as bladder training, timed or prompted voiding, pelvic muscle exercises, and biofeedback. Behavioral therapy may improve bladder control by changing the incontinent patient's voiding habits and teaching skills for preventing urine loss (9). However, because of the multitude of issues facing palliative care patients, these techniques may be applicable only in the early palliative stages.

Pharmacologic Therapy

Overactive Bladder

First-line therapy of OAB involves the use of anticholinergic drugs aimed at decreasing the urgency from detrusor muscle contractions. Commonly used agents include oral oxybutynin hydrochloride, tolterodine tartrate, and flavoxate hydrochloride. Controlled-release oxybutynin and transdermal oxybutynin are clearly effective in reducing episodes of urinary incontinence and are superior to placebo. Tolterodine, at a dose of at least 2 mg, is similarly effective in reducing episodes of

urinary incontinence. Direct comparisons between oxybutynin and tolterodine show little treatment effect difference between the two drugs (10).

Newer drugs have been marketed for the treatment of OAB. Trospium chloride has efficacy equivalent to twice-daily immediate-release oxybutynin and a lower incidence of dry mouth. Both darifenacin and solifenacin have proven efficacy and are available in once-daily formulations. Whether these agents have a distinct advantage over other anticholinergic drugs has yet to be determined, although they are marketed as having fewer side effects. Tricyclic antidepressant agents, often used as adjuvants for neuropathic pain, may be used for their anticholinergic effects.

Pharmacologic treatment is problematic, however. Many patients do not improve much and may experience only a small reduction in episodes of urinary incontinence, and many experience no improvement. Complete continence is rarely achieved. Although this may be important for some patients, if urinary incontinence continues despite treatment, it produces a continued burden and frustration with quality of life. Because the benefits are unpredictable and have not been studied well in the palliative care patient (in whom OAB may be related to tumors and treatments), patients should be offered a brief trial of these anticholinergic agents.

The most difficult part of taking these drugs may be the significant, adverse effects associated with their anticholinergic properties. Dry mouth is frequent, often occurring in the majority of patients. Palliative care patients frequently already have dry mouth because of oral candidiasis, chemotherapy and radiation treatments, and other medications, particularly opioids. The addition of further xerostomia from these agents may be intolerable to these patients. Constipation, already a very common problem in palliative care patients, may also be increased. These drugs should be used cautiously in patients with gastric or intestinal hypomotility because they enhance those problems. Anticholinergic drugs should also be avoided in patients with significantly impaired renal or hepatic function. Patients with cardiac arrhythmias cannot take these drugs. Major side effects, such as ventricular arrhythmias or sudden death, are not associated with anticholinergic drugs. Few central nervous system effects are observed in clinical trials of the specific agents, but these drugs may be associated with sedation, hallucinations, and confusion, particularly in elderly patients. Again, palliative care patient populations have not been studied.

Stress Incontinence

α-Adrenergic and β-adrenergic agonists, such as phenylpropanolamine hydrochloride, midodrine, and pseudoephedrine, increase the internal sphincter tone and bladder outflow resistance. β-Adrenergic agonists may also have some effect. α-Adrenergic receptors are widespread in the cardiovascular system, however, which is the mechanism for systemic cardiovascular side effects such as arrhythmia and hypertension. A meta-analysis of the effects of the adrenergic agonist drugs phenylpropanolamine and midodrine suggests that an adrenergic agonist drug is more effective than placebo in reducing the number of pad changes and episodes of urinary incontinence and in improving subjective symptoms (11). Patients who use adrenergic agonists usually experience minor side effects that rarely result in discontinuation of treatment. These include dizziness, palpitations, excitability,

and sleep disturbance. Rare but serious side effects, such as cardiac arrhythmias and hypertension, may occur.

Overflow Incontinence

For the overflow urinary incontinence that results from benign prostatic hypertrophy, the relief of outflow obstruction using α-blocker therapy is based on the hypothesis that clinical, prostatic hypertrophy is caused partly by α_1-adrenergic–mediated contraction of prostatic, smooth muscle that results in bladder outlet obstruction. Treatment options for symptomatic patients include α-adrenergic antagonists such as alfuzosin, doxazosin, tamsulosin, and terazosin. The data suggest that these agents are equally effective. Data are insufficient to support a recommendation for the use of prazosin hydrochloride. Adverse effects of these drugs include nasal congestion, hypotension, fatigue, ejaculatory problems, cardiac arrhythmias, headaches, and edema (12).

The 5-α-reductase inhibitors finasteride and dutasteride are effective for patients who have demonstrable prostatic enlargement, but these are long-term treatments. Patients who have symptomatic prostatic enlargement but no symptoms can be offered a 5-α-reductase inhibitor to retard progression of the disease, but response is limited. The benefit of these drugs in palliative care patients is not clear.

Use of Diapers

Diaper or pad technology has advanced rapidly. Diapers are now more absorbent, suppress odors better, and are more fitted, thus reducing the possibility of leakage. The cost may be significant, but it is offset by reduction in care provider time, the need to launder bedding, the ability to keep someone at home, and the reduced stress of family caregivers. Diapers need to be changed frequently. Family members who are caring for the patient at home should be educated about how to apply the diapers so minimal lifting is required. Patients can be dressed and still wear a diaper. Diapers may be problematic in the patient with severe incident pain, however, so urinary catheters should be considered in these patients. Incontinence pads are probably overused and are not very effective in absorbing large quantities of urine.

Skin Care

Urinary incontinence that is not adequately treated can lead to skin problems. Skin maceration and irritation can be minimized by frequent diaper changes, the treatment of skin candidiasis and intertrigo, and the use of barrier creams that usually contain silicone or zinc oxide to protect the skin. Skin that is irritated is much more likely to develop wounds, and wound prevention strategies must be employed.

Urinary Urethral Catheters

Urinary catheters are often seen as a last resort for patients with urinary incontinence. The major problem with catheters relates to the development of infections

with long-term use. Although urinary catheters are used with relative frequency in palliative care settings, few reviews have been done.

A urinary catheter should be considered for incontinent patients if behavioral changes, nursing care, special clothes, special bed clothes, and medication changes are unsuccessful. Indications for the use of a urinary catheter in palliative care patients include the following (13):

1. Management or prevention of decubitus ulcers and other skin wounds
2. Painful, physical movements that preclude frequent changes of clothes and bed linen
3. A decision by the patient and family that dryness and comfort outweigh the risks of catheterization
4. Overflow urinary incontinence associated with obstruction
5. Urine retention that is not surgically correctable
6. Continuous bladder irrigation in patients with hemorrhage from bladder tumors
7. An explicit request from the patient or family (primarily for patients at the end of life)

External, condom catheters have been used for a long time in men. They are poorly accepted by patients, are often difficult to apply and maintain in place, and are uncomfortable. They are associated with skin irritation and ulceration, urinary infections, and (rarely) penile gangrene from inappropriate fitting and neglect. Unless they are preferred by patients, it is probably best to avoid the use of these devices in palliative care.

Indwelling urinary catheters can be made of material such as rubber or silicone and may be impregnated with antibacterial chemicals. Complications of indwelling catheters include bladder and urethral infections, pyelonephritis, septicemia, bladder spasm, and hemorrhage from the bladder. It has not been determined whether palliative care patients are more susceptible to these problems because of their cachexia and reduced immune function.

Most patients with catheters and asymptomatic bacteriuria should not receive antimicrobial therapy (14). The rationale for this recommendation includes the following:

1. The risk of complications from asymptomatic bacteriuria is low.
2. Treatment does not prevent bacteriuria from recurring.
3. Treatment may lead to the presence of antimicrobial-resistant bacteria that are more challenging to treat.

Most experts recommend against using antimicrobial agents to eradicate bacteriuria in asymptomatic patients unless the patient has an abnormal urinary tract or will soon undergo genitourinary tract manipulation or instrumentation.

The introduction of the closed-drainage indwelling catheter system is an extremely important advance in the prevention of urinary catheter-related infections. The use of a presealed, urinary catheter junction (as delivered in most catheter sets these days) is important. Aseptic insertion techniques and careful maintenance of the catheter and drainage bag are essential. The collection bag should remain below the level of the bladder to prevent reflux of urine into the bladder, and the drainage tube should be checked for kinking. The drainage bag should be emptied at least

twice daily. Finally, glove use and proper hand hygiene practices are important in preventing the acquisition of pathogens.

Several different types of urethral catheters with anti-infective properties have been developed and evaluated. One such anti-infective catheter uses silver, an effective antibacterial substance, in the form of silver alloy. Results of one meta-analysis indicate that silver alloy catheters are likely to prevent bacteriuria (15), but the effect of these catheters on the more important clinical outcomes (e.g., bacteremia) remains to be determined. Although silver alloy catheters are more expensive, they seem economically efficient when they are used in patients who receive indwelling catheterization for 2 to 10 days (16). Catheters impregnated with antibiotics are now being evaluated, although they may be problematic because of the induction of antibiotic-resistant organisms.

Intermittent catheterization is a common method of urinary collection in patients with overflow urinary incontinence, especially from spinal cord damage. Inserting and removing a sterile or clean urinary catheter several times daily may reduce the risk of bacteriuria (compared with an indwelling catheter), and the technique can be taught to patients and family members. Suprapubic catheters may be required in patients with urethral obstruction from tumors.

Other Behavioral Techniques

It may be possible to prevent urgency urinary incontinence by prompting the patient to void frequently and to suppress the urge initially by tightening the voluntary sphincter. In institutions, the patient must be brought to toileting facilities before the urge becomes too great. If the patient is bed bound, ready access to urine bottles for men or to slipper-type bedpans for women may avoid embarrassing urinary incontinence. Reduced cognitive abilities may, however, make these interventions ineffective.

PEARLS

- Urinary incontinence has important negative effects on quality of life.
- Careful assessment to determine the type of urinary incontinence may lead to specific but limited pharmacologic treatment.
- Indwelling urinary catheters can be used effectively in palliative care patients when indicated.

PITFALLS

- Ignoring urinary incontinence will increase patients' suffering and will decrease quality of life.
- Unless managed properly with aseptic technique, indwelling catheters can become a source of infection.

SUMMARY

Urinary incontinence is a relatively frequent occurrence in palliative care patients, and it is a sensitive issue for patients and family. Management requires

careful assessment, education and counseling, and a variety of medications. It often requires instrumentation such as catheters, especially in the last few days of life.

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Sexuality

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12

CHAPTER OUTLINE

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INTRODUCTION

Sexuality is a universal human phenomenon. It is an integral part of the lives of most people and is a fundamental aspect of their quality of life. A terminal illness does not and should not preclude all sexual activity. Although much has been written on human sexuality in the last 50 years, little has been written about sexuality in end-of-life care.

Sexual dysfunction at the end of life has not been studied. The exact incidence and prevalence are not known and are likely to be highly dependent on the illness, the disabilities incurred, the side effects of treatment, and comorbid medical conditions. Cancer or treatments that directly affect the sexual organs (e.g., prostate, testes, cervix, ovaries, vagina, bladder, or rectum) can lead to significant hormonal, local, and mechanical problems. Other malignant diseases and advanced, progressive illnesses of any type may also greatly impair sexual function because of symptoms and disabilities such as fatigue, pain, dyspnea, altered body image (e.g., head and neck disfigurement or mastectomies), the presence of ostomies, lack of flexibility related to limitation of movement, chronic wounds, lack of desire, or other physical and psychological distress. For men with cancer, it appears that the major problems

with sexual dysfunction are erectile dysfunction, diminished desire, and fatigue. For women, dyspareunia, lack of desire, vaginal dryness, the inability to achieve an orgasm, fatigue, and altered body image are the predominant concerns.

The taboos of sexuality have been eroding slowly; many health care providers still feel uncomfortable assessing this area. Patient surveys suggest that many would appreciate a discussion of sexuality from their health care providers (1, 2). One study suggested that cancer patients were significantly more eager to discuss their sexual lives than were control participants, and even though cancer patients had lower strength and frequency of sexual activity, they reported no less sexual satisfaction than did control participants (3).

Another small, qualitative study investigated the meaning of sexuality to patients in a palliative care program (4). Several themes emerged. First, sexuality continues to be important at the end of life, and all patients in this study felt that their health care providers should have discussed sexuality as part of their assessment, yet only 1 in 10 did so. Second, emotional connection to others was reported to be an integral component of sexuality, taking precedence over physical expressions. Finally, lack of privacy, shared rooms, staff intrusion, and single beds were considered barriers to expressing sexuality in hospital and hospice settings. The whole-person approach to providing high-quality, end-of-life care must therefore address issues of sexuality as part of the assessment and care plan (Table 1–12–1).

Table I–12–1 ■ Patient Factors that Interfere with Sexual Function or the Expression of Sexuality

Physical	Symptoms such as pain, fatigue, dyspnea, and nausea
	Ostomies of various types
	Erectile dysfunction secondary to pelvic or prostate surgery
	Surgery on genital areas leading to problems such as vaginal fibrosis or stenosis
	Open wounds
	Amputations
	Lumpectomy or mastectomy for breast cancer
	Paralysis
	Brain tumors
	Previous erectile dysfunction
	Arthritis and diminished flexibility
Medications	Hormonal or antihormonal therapy
	Erectile dysfunction secondary to medications
Radiation therapy	Skin reactions or burns
	Destruction of neurovascular pathways and arterial vascular beds
	Fatigue, nausea, vomiting, and diarrhea
	Vaginal dryness, stenosis, and fibrosis
	Erectile dysfunction
Psychological issues	Anxiety and depression
	Couple or family dysfunction
	Body image issues
	Partner aversion to sex
	Grief
	Hopelessness and loss of meaning

DEFINITION

Sexuality can be defined as the quality or state of being sexual. Sexuality can be expressed in ways other than sexual intercourse. It may quite often be expressed through close, physical contact, caressing, and other touching. A patient at the end of life needs and often seeks physical and emotional closeness with others; sexuality with a partner can be part of this closeness. As with other needs at the end of life, sexuality has a number of components: biological, physical, psychological, social, cultural, and moral. Understanding sexuality in palliative care patients involves comprehensive assessment of each of these components and recognizing how they interact.

SEXUALITY AND PALLIATIVE CARE

These issues represent the complex interaction of all the components of sexuality as described earlier.

Patient and Family Issues

When people develop a serious, life-limiting illness, they may appear to lose interest in sex as they adjust to dealing with the illness and its treatment. Many patients have a poor understanding of their own sexual needs and ways of expressing those needs in the setting of illness. They may be very reluctant to raise the issue of sexual function or to discuss issues of sexuality with their physicians because many patients expect their physician to initiate the discussion. Some cultures may not allow patients to discuss sexual concerns, even with professional health care providers.

A patient's physical disabilities, symptoms, medications, surgery, treatment regimens, and associated psychological issues (e.g., anxiety and depression) may affect the desire for sexual expression and the physical ability to have such contact. Patients may worry that their partner may no longer be sexually attracted to them because of the changes in their body and the fact that they have cancer or another serious illness. Serious illness puts a great strain on partner and family relationships. This stress may cause problems in the relationship between partners and may disturb usual sexual function. The partner may feel guilty for having sexual feelings at a time when the patient is coping with the illness and associated problems. Similarly, the sexual partner may also be affected by the illness and may feel that sexual expression is not possible or even appropriate or may even be less attracted to his or her partner because of changes in appearance. This may be manifested by sexual dysfunction in the partner, such as erectile dysfunction or lack of arousal in either partner.

Aging Patients

Many patients who need palliative care are elderly. The Masters and Johnson's four stages of human sexual response (excitement/arousal, plateau, orgasm, and resolution) are all affected by the aging process. Nonetheless, elderly men and women can

continue to enjoy fulfilling sexual experiences (5). Therefore, elderly patients should also have sexual assessments as part of their comprehensive assessment. The clinician should also be cognizant of the possibility of preexisting sexual dysfunction that often has never been addressed.

Physiological changes that should be taken into account include the following: more and longer direct stimulation of the penis may be required to achieve erection in older men; erections are usually not as full and may occur less frequently; the plateau phase is prolonged, resulting in better control of ejaculation, compared with that of younger men; during orgasm, both the force of ejaculation and the number of contractions with each ejaculation are reduced, but the subjective feeling of pleasure is not diminished; older men who lose an erection before orgasm may not be able to achieve another because they experience a longer refractory period before another erection can begin.

Women also experience changes in sexual functioning with age. Most of these changes probably result from the decline in estrogen production that occurs with the onset of menopause. The reduced estrogen stimulation causes many changes in anatomy, including thinning of the vaginal mucosa, shrinking of the uterus, and replacement of breast glandular tissue by fat. Sexual arousal in older women requires more and longer direct stimulation. Vaginal lubrication is reduced, and the vaginal opening expands less fully. During the succeeding plateau phase, older women experience less vasocongestion and tenting of the vagina. With orgasm, fewer uterine contractions occur and, during resolution, clitoral tumescence is lost more rapidly than in younger women.

Health Care Provider Issues

Poor knowledge and attitudes about sexual function and dysfunction are still issues with many health care providers. Curricula in this area and clinical teaching experience in assessing and managing sexuality may be lacking. This means that skills in assessing and managing issues of sexuality are likely to be suboptimal among most clinicians.

The health care provider's reluctance to assess a patient's sexuality and to deal with related issues often stems from the provider's own sensitivity to discussing this very intimate function. This reticence can occur even if the patient wishes to discuss the issue of sexuality. Health care providers may be reluctant to ask questions about their patients' sexual functioning because they themselves are embarrassed and not comfortable with their own sexuality, they may not believe that sexuality is part of the presenting problem, or they may feel that they are not trained adequately to deal with sexual concerns (6).

In considering all the issues for patients at the end of life, health care providers may feel that sexuality must have a low priority. Health care providers often wait for the patient to initiate discussion, yet most patients want and expect the physician to initiate the conversation (7–9). The cultural and religious background of the health care provider may also inhibit such discussion of sexuality, especially if there is a significant difference between the health care provider's beliefs and those of the patient. Some health care providers have significant difficulties dealing with patients whose sexual orientation and practices may be very different from their own, and these difficulties provide yet another barrier for effective patient care and evaluation.

In such cases, clinicians must recognize and acknowledge their own beliefs and be willing to refer their patients to others who are better equipped to help.

System Issues

The structure of health care institutions presents another barrier to sexuality for those patients who reside in the facility. Simple items, such as the use of single beds, inhibit the ability of partners to experience sexual relations. Privacy is in short supply in most health care settings. Multipatient rooms are not conducive to intimate exchanges between and patient and partner. Even private rooms may not have doors or locks, so anyone can enter without notice, and this creates an environment that is not conducive to sexual intimacy (10). In addition, patient's lives are often discussed freely among the staff, a situation that leaves no sense of privacy. Many institutions still are reluctant to endorse a policy in which sexual contact or activity is allowed on site. Patients may be confined to the facility and may not have access to items such as condoms that would allow for safe sex practices. Institutions must develop policies that will allow patients access to such items and must develop systems that allow for the private and safe conduct of sexual activity for its residents.

ASSESSMENT

The best way to assess issues in sexuality is to address them through direct and frank communication with the patient and/or partner. The process of acquiring information about sexual needs and function requires some careful consideration in light of the sensitivities around this subject:

1. Written assessment forms that are filled in by patients or health care providers seem ubiquitous in palliative care. However, they are not a good way to collect information about sexuality. Patients rarely want to write this information down and may be a little suspicious if they see a health care provider check off boxes or write down comments as the subject is discussed. This is not an appropriate situation for the use of visual analog scales!
2. Privacy and confidentiality must be ensured both in discussions and in recording information in the medical record. It may be best to share limited information in the written medical record, especially if that information is sensitive (e.g., sexual preferences, sexual orientation, practices, dysfunction, or sexual abuse).

If one senses that patients are reluctant to discuss psychosocial issues, it may be wise to build up a relationship of trust before beginning to probe the area of sexuality. It may take several interviews before patients, particularly men, are willing to explore this area. The clinician should explore the patient's background, culture, and religion because the patient's beliefs may preclude the discussion of sexual function. It may be possible to learn culturally sensitive and appropriate methods to broach the subject from a spiritual leader in the community. The health care provider who is not confident in his or her own ability to take a history in this area should bring in someone who is knowledgeable and who can provide feedback on the process of obtaining information.

The health care provider should begin with open-ended questions in the third person such as the following:

- "For many people with your condition, sexual function is an important part of the quality of life. Is this something you would be willing to discuss with me or another member of the team?"
- "Many people who are ill have difficulty finding time alone with the ones closest to them. Have you been able to find time to be close and intimate with your partner? Is this something that would be important for you?"
- "Sometimes people who have had this type of surgery find it difficult to be intimate with their partner? Is this something you would like to discuss? Can we talk about how things are going so far?"

If the patient gives a positive response, the health care provider can begin the process of obtaining a more detailed history of sexual function. A sexual history may include topics and questions such as the following:

- How important is sexual intimacy to the patient? To the partner?
- What are the partner's issues and attitudes?
- Previous functioning and current changes in pattern and abilities
- Have the patient and partner discussed their feelings and changes in sexual function?
- Have they discussed or thought about any alternative ways to express intimacy?
- Interfering or inhibiting issues
- If there has been dysfunction, what has been tried?
- Previous sexual dysfunction and causes, if known
- Perceived wishes in this area of sexuality

At some point, if the patient consents, it is important to take information from the partner.

COUNSELING

The PLISSIT model of sexual counseling presents an easily remembered framework for addressing the needs of a patient and his or her partner (11). Table I–12–2 details the model and possibilities for counseling the palliative care patient.

SURGICAL TECHNIQUES

In recent years, modification of certain surgical procedures (particularly pelvic surgery) has led to better preservation of sexual function. For men with prostate cancer, nerve sparing at the time of complete prostatectomy has led to less impotence (13). Similar results have been seen in nerve-sparing cystectomy (14). Preservation of the neurovascular bundles has retained clitoral arousal and has preserved better sexual function in women who have undergone pelvic surgery for cancer (15). These techniques are not infallible, however, and sexual dysfunction may still occur.

Table I–12–2 ■ PLISSIT Model of Sexual Counseling

Permission

Get permission for determining the patient's or couple's interest in discussing sexual intimacy and permission to ask questions and discuss the issues openly without fear of being judged in any way.

Transmit a perception of the normalcy of sexual needs even at the end of life.

Limited Information

Describe how the specific illness and its treatment may limit sexual activity, and offer ideas for adapting or facilitating sexual activity.

Discuss the impact of illness on self-image and self-esteem, and emphasize the need to be honest with each other.

Provide an opportunity to educate the patient and partner about sexuality and other possibilities for intimacy if intercourse is not possible. Discuss the importance of touching and fondling.

Issues around safe sex need to be addressed, particularly in light of potential serious infections such as with human immunodeficiency virus.

Offer to provide names of specific health care providers for more detailed discussion.

Recommend available literature.

Specific Suggestions

Specific suggestions may include pacing activity to accommodate tolerance, positions that facilitate comfort, and medications that may enhance comfort or sexual performance (12).

Intimacy can be achieved through cuddling, fondling, and kissing if intercourse is not physically possible or if there is too much pain.

Privacy can be requested, even in institutions.

Specific suggestions for aids and medications can be given.

Intensive Therapy

This is rarely appropriate for patients close to the end of life. However, it may be relevant early in the course of the illness.

It may be necessary to refer partners with major problems to qualified sexual counselors before or after the patient's death.

In addition, sexual practices that seem quite "abnormal" may require consultation with sexual counseling experts.

OTHER INTERVENTIONS

Treatments for Male Impotence

Multiple forms of treatment for male impotence now exist. These include vacuum constriction devices, intracorporeal injections, intraurethral alprostadil, and oral medications (sildenafil and others). Vacuum constriction devices are effective for impotence that results from many different etiologies. Success rates vary from 60% to 80%, with the majority able to achieve vaginal penetration and intercourse. Compliance does tend to decrease with time, and the device can be somewhat difficult to use.

Intracorporeal injections have the advantage of bypassing neural pathways and are thus effective in patients who have nerve damage or a vascular cause of erectile dysfunction. Papaverine, phentolamine, and alprostadil are each individually effective, but combinations tend to work better and can decrease the side effects. A commercial preparation of all three drugs known as Tri-mix is available. Although intracorporeal injections can be highly effective ($\leq$85%), many men discontinue their use because of pain, penile fibrosis, corporal plaque, or unsatisfactory erections.

Intraurethral prostaglandin places a pellet of alprostadil into the urethra that is subsequently absorbed by the corpus cavernosa. Low success rates, coupled with local discomfort, significantly limit the usability of this therapy, but it remains one viable option for some patients.

Oral phosphodiesterase-5 inhibitors have recently become the treatment of choice for most cases of erectile dysfunction. Three drugs are now commercially available: sildenafil, vardenafil, and tadalafil. Phosphodiesterase-5 inhibitors work by increasing intracavernosal cyclic guanosine monophosphate levels, thereby restoring erectile function. These drugs should be used with caution or not at all in patients with cardiac disease or hypotension, in men who are using nitrates, or in patients who are concurrently taking CYP 3A4–inducing drugs such as rifampin and phenytoin. Although all three drugs are effective in men following radical prostatectomy, side effects can vary, and a randomized trial (16) showed that 60% of men chose a drug based on side effects, but only 40% chose a drug based on efficacy.

Female Sexual Dysfunction

Early intervention and education can be very helpful for women who undergo therapy for pelvic cancer. Early education in sexual rehabilitation can decrease the negative impact of gynecologic operations (17). Newer, nerve-sparing operations (analogous to those in prostate operations) may help to decrease female sexual side effects further. Otherwise, current treatment options for improving female sexual function following cancer therapy are limited by a lack of systematic studies and concerns about side effects of certain treatments.

Hormonal therapy is often contraindicated in many women with breast or other hormonally sensitive tumors. Estrogens can improve clitoral and vaginal sensitivity, lubrication, and sexual desire (18). Androgens can also improve sexual arousal and clitoral sensitivity (19), but many women do not tolerate the masculinizing side effects. Randomized, controlled trials of testosterone therapy have been done in postmenopausal women with decreased libido. These trials showed that the use of testosterone increased libido, but all trials excluded women with cancer, and all trials maintained women on estrogen replacement therapy (20, 21). A randomized, placebo-controlled trial of testosterone alone, without concomitant estrogen therapy, in 132 women with a history of breast cancer and diminished libido showed that, contrary to the previously noted trials in postmenopausal women, there was no effect of testosterone on libido in these women (22). Thus, it may be that testosterone alone is insufficient to improve libido, and because estrogen replacement therapy may be contraindicated in women with certain cancer types, this strategy may not be beneficial.

Phosphodiesterase-5 inhibitors are being studied in female sexual function, but their exact role remains undefined at this time. Early data suggest that these agents do improve clitoral sensation and vaginal lubrication (23). If lubrication is an issue, the use of vaginal lubricants is indicated.

Environmental Changes

Institutions should allow conjugal visits and should provide double beds if necessary. “Do Not Disturb” signs on doors to bedrooms at home or in institutions may be needed. The staff should be educated about the sexual needs of patients.

Condoms should be provided. Institutions and community agencies should try to provide cosmetic and hair styling opportunities for patients who feel physically unattractive. It may be possible to obtain these services through volunteers.

PEARLS

- Sexuality is important to patients and their partners at the end of life.
- Patients expect physicians to address sexuality.
- Discussions of sexuality must be sensitive and culturally appropriate.
- The PLISSIT Model of sexual counseling is an easy and effective way to initiate counseling.
- Sexuality can be expressed by ways other than intercourse.
- Education of other health care providers about patient sexual needs is advised.
- Specific interventions are possible for male and female sexual dysfunction.

PITFALLS

- Ignoring sexual needs of patients may enhance their suffering.
- Not providing privacy for patients and partners can add to sexual dysfunction.
- Lack of education in taking a sexual history increases physicians' distress and decreases the likelihood that the topic will be addressed.

SUMMARY

Sexuality in palliative care patients is an issue that needs to be raised with sensitivity, approached in a matter-of-fact manner without being judgemental, and attended to with the goal of optimizing quality of life for patients and their families. Methods that include counseling, medical, and technical techniques, as well as environmental arrangements, can provide effective intervention. Policies and procedures must be developed in chronic care facilities that will allow patients to express their sexuality in a private and safe environment to maximize quality of life at the end of life.

Resources

About.Com-Health and Fitness Section. Available at http://sexuality.about.com/od/seniorsexuality
Sexual Information and Education Council of Canada. Available at http://www.sieccan.org
Sexual Information and Education Council of the United States. Available at http://www.siecus.org
Shibley Hyde JS, DeLamater J: Understanding Human Sexuality, 8th ed. New York: McGraw-Hill, 2003.
Society for Human Sexuality. Available at http://www.sexuality.org

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Dyspnea

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CHAPTER OUTLINE

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INTRODUCTION

Dyspnea, an uncomfortable awareness of breathing, is a common symptom in people with advanced disease who are approaching the end of life. The presence of dyspnea is associated with significant functional and social limitations and psychological distress that impair quality of life and contribute to suffering. Good palliative care requires knowledge and skill in the management of dyspnea.

DEFINITION

Dyspnea has been defined by the American Thoracic Society as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (1). Dyspnea, like pain, is a subjective experience involving many factors that modulate both the quality and the intensity of its perception. Distinct sensations of breathing are produced by stimulation of various neurophysiological pathways, the conscious perception of the stimuli, and the interpretation in the context of lifelong previous experience and learning (Fig. I–13–1).

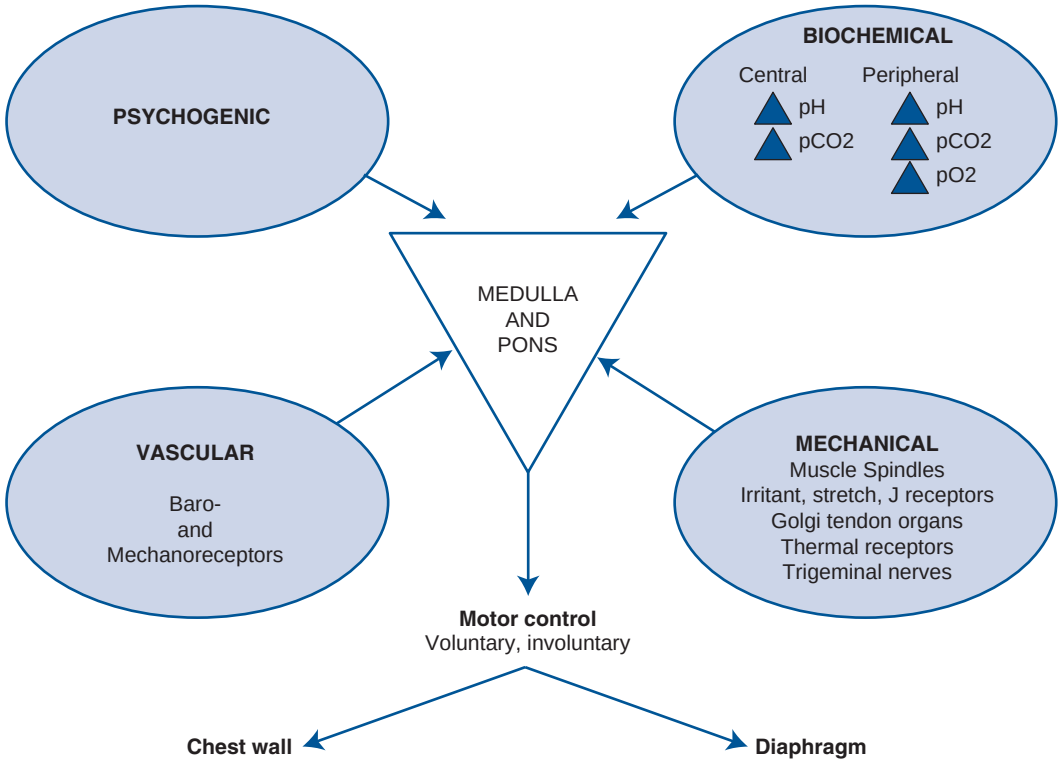

Figure I–13–1 ■ The psychogenic, vascular, biochemical and mechanical pathways of breathing. Distinct sensations of breathing are produced by stimulation of various neurophysiological pathways, the conscious perception of the stimuli, and the interpretation in the context of lifelong previous experience and learning.

PREVALENCE AND IMPACT

The prevalence of dyspnea varies depending on the stage and type of underlying disease. In a general outpatient population of patients with cancer, approximately 50% of patients describe some dyspnea (2), and the prevalence rises to 70% in the terminal phases of cancer (3). In patients with lung cancer, dyspnea is more common, approaching 90% just before death (4). Many patients with cerebrovascular accidents or end-stage heart and neurological diseases also experience dyspnea in the last years of life: cerebrovascular accident, 37% (5); congestive heart failure (CHF), 61% (6); amyotrophic lateral sclerosis, 47% to 50%; and dementia, 70% (7). Patients with end-stage chronic obstructive pulmonary disease (COPD) commonly experience extreme breathlessness and note it as their most distressing and debilitating symptom (8). Dyspnea is often present for prolonged periods, frequently exceeding 3 months in patients with late-stage cancer (9) and 6 months in patients with CHF (6) or cerebrovascular accidents (5), thus compounding suffering.

Patients with advanced disease typically experience chronic shortness of breath with intermittent acute episodes. The acute attacks of breathlessness frequently contribute to feelings of anxiety, fear, and panic for both the patient and family members and, when severe enough, a sensation of impending death for the patient. Many dying patients are terrified of waking in the middle of the night with intense air hunger (10).

Dyspnea severely impairs the quality of life by limiting functional ability and by interfering with mood, relationships, and enjoyment of life. In a study of patients living with end-stage COPD, 98% were unable to perform strenuous activities, 87% were unable to take a short walk around the house, and 57% required help with washing, dressing, and reaching the toilet (8). In patients with advanced cancer, dyspnea was intensified with climbing stairs (95.6%), walking slowly (47.8%), getting dressed (52.2%), and talking or eating (56.5%); approximately 26% of the patients were dyspneic even at rest (9). Patients universally respond by decreasing their activity to whatever degree relieves the breathlessness. Patients also socially isolate themselves from friends and outside contacts to cope with dyspnea (8). As a result, depression, fatigue, generalized dissatisfaction with life, and a high degree of emotional distress are very common.

In terminally ill patients with cancer, as death approached, the will to live was found to be directly related to the severity of breathlessness (11). The presence of dyspnea prompted the use of terminal sedation in 25% to 53% of patients requiring sedation for uncontrolled symptoms (12). Dyspnea has been associated with increased severity of spiritual distress and weakness in patients and with more distress in caregivers and staff. Patients who experience breathlessness are also more likely to die in the hospital than at home.

Unfortunately, patients often receive no direct medical or nursing assistance with dyspnea and are left to cope with this debilitating symptom in isolation (9). They need health care providers who will anticipate their fears and provide symptomatic relief of their breathlessness and anxiety as these patients approach death (10).

PATHOPHYSIOLOGY

Management of dyspnea requires an understanding of its multidimensional nature and the pathophysiological mechanisms that cause this distressing symptom. The pathophysiological mechanisms of dyspnea can be categorized as increased ventilatory demand, impaired mechanical responses, or a combination of these two mechanisms. The effects of abnormalities of these mechanisms can also be additive.

Increased Ventilatory Demand

Ventilatory demand is increased because of increased physiological dead space resulting from reduction in the vascular bed, hypoxemia and severe deconditioning with early metabolic acidosis (with excessive hydrogen ion stimulation), alterations in carbon dioxide output (VCO_2) or in the arterial partial pressure of carbon dioxide (PCO_2) set point, and nonmetabolic sources such as increased neural reflex activity or psychological factors such as anxiety and depression.

Impaired Ventilation

Impaired mechanical responses result in restrictive and obstructive ventilatory deficits. A *restrictive ventilatory defect* is caused by decreased distensibility of the lung parenchyma, pleura, or chest wall (parenchymal disease or reduced chest compliance) or by a reduction in the maximum force exerted by the respiratory muscles (muscle weakness). An *obstructive ventilatory deficit* refers to impedance of the flow of air. Both structural (external compression or internal obstruction) and functional changes (bronchoconstriction) can lead to progressive narrowing of the airways. Patients may also have a mixed restrictive and obstructive disorder. Table I–13–1 outlines the pathophysiological mechanisms of dyspnea with potential clinical causes in persons with advanced cancer and other end-stage diseases.

Special End-of-Life Considerations

Asthenia and generalized muscle weakness are common in patients with advanced COPD and other end-stage diseases. Exercise capacity is limited by abnormalities in either endurance or weakness of the skeletal muscles in patients with CHF, COPD, and cancer (13). Both peripheral muscle and respiratory muscle strength are reduced in patients with cardiorespiratory diseases and cancer, and muscle strength is a significant contributor to the intensity of exercise-induced dyspnea (13). Patients with chronic heart failure have abnormal skeletal muscle metabolism during exercise and significant ultrastructural skeletal muscle abnormalities that affect both the respiratory and the peripheral muscles (13).

Cachexia is a common final presentation of several chronic conditions, including cancer, COPD, chronic heart failure, acquired immunodeficiency syndrome, and renal failure (13). Cachexia differs from simple nutritional imbalance because there are modifications in the metabolism of proteins, lipids, and carbohydrates, with a preferential loss of muscle tissue over fat, enhanced protein degradation, and unresponsiveness to nutritional interventions. Weakness of both respiratory and peripheral muscles can result from impaired nutritional status (13).

Table I–13–1 ■ Pathophysiological Mechanisms and Clinical Causes of Dyspnea in Patients with End-Stage Disease

Increased Ventilatory Demand

Increased Physiologic Dead Space
- Thromboemboli
- Tumor emboli
- Vascular obstruction
- Radiation therapy
- Chemotherapy
- Emphysema

Severe Deconditioning

Hypoxemia
- Anemia

Change in Carbon Dioxide Output or Arterial Carbon Dioxide Partial Pressure Set Point

Increased neural reflex activity

Psychological Factors
- Anxiety
- Depression

Impaired Ventilation

Restrictive Ventilatory Deficit

Pleural or Parenchymal Disease
- Primary or metastatic cancer
- Pleural effusion
- Pulmonary fibrosis
- Congestive heart failure
- Pneumonia

Reduced Movement of Diaphragm
- Ascites
- Hepatomegaly

Reduced Chest Wall Compliance
- Pain
- Hilar/mediastinal involvement
- Chest wall invasion with tumor
- Deconditioning
- Neuromuscular factors
- Neurohumoral factors

Respiratory Muscle Weakness
- Phrenic nerve paralysis
- Cachexia
- Electrolyte abnormalities
- Steroid use
- Deconditioning
- Asthenia
- Neuromuscular factors
- Paraneoplastic conditions

Obstructive Ventilatory Deficit

External or Internal
- Primary or metastatic cancer

Functional
- Asthma
- Chronic obstructive pulmonary disease

Mixed Obstructive/Restrictive Disease

Any Combination of Factors

Neurological paraneoplastic syndromes can contribute to the development of dyspnea in patients with cancer. Thirty percent of patients with malignant thymoma have myasthenia gravis that can weaken respiratory muscles and cause respiratory failure (13). Eaton-Lambert syndrome, associated with lung, rectal, kidney, breast, stomach, skin, and thymus cancers, can also produce respiratory muscle weakness and result in dyspnea (13).

For patients with advanced cancer and other end-stage diseases, psychological factors may also play a significant role in the perception of dyspnea. Anxiety has been found to correlate with intensity of breathlessness in patients with advanced cancer (14) and COPD (15). Depression may also be predictive of breathlessness (16). In general, anxious, obsessive, depressed, and dependent persons appear to experience dyspnea that is disproportionately severe relative to the extent of the pulmonary disease.

MULTIDIMENSIONAL ASSESSMENT

Patient Reports

Because dyspnea is a subjective experience, the key to assessment is the patient's report of dyspnea through the use of unidimensional instruments and descriptions related to effect on level of activity. Individuals with comparable degrees of functional lung impairment may experience considerable differences in how they perceive the intensity of dyspnea (17). Factors such as adaptation, differing physical characteristics, and psychological conditions can modulate both the quality and the intensity of the person's perception of breathlessness. Therefore, medical personnel must ask and accept the patient's assessment, often without measurable physical correlates.

To determine whether dyspnea is present, it is important to ask more than the question, "Are you short of breath?" Patients often respond in the negative to this simple question either because the activity that they are performing at that moment is not causing dyspnea or because they have limited their physical activity to ensure that they do not experience breathlessness. It is therefore important to ask about shortness of breath in relation to specific activities (e.g., walking at the same speed as someone else of your age, walking upstairs, or eating).

Qualitative Aspects of Dyspnea

Dyspnea is also not a single sensation. Clinical investigation suggests that the sensation of breathlessness encompasses several qualities that may, as in the assessment of pain, allow discrimination among the various causes (18). For example, in assessing pain, descriptors such as "burning" or "shooting" suggest neuropathic pain. Similarly, the descriptors "chest tightness," exhaustion," and "deep" have been associated with asthma, and "suffocating" with CHF. Research to date is limited, however, and it is unclear whether qualitative assessment of dyspnea in breathless patients facilitates the determination of specific diagnoses (19).

Clinical Assessment

Clinical assessment of dyspnea includes the patient's report and history of the symptom and a focused physical examination. The assessment directs management

and provides a baseline on which to evaluate the patient's response to treatment. Table I–13–2 outlines a general approach to the clinical assessment of dyspnea in palliative care patients.

The history includes the temporal onset (acute or chronic), pattern, severity and qualities of the symptom, associated symptoms, precipitating and relieving events or activities, and response to medications. A past history of smoking, underlying lung or cardiac disease, concurrent medical conditions, allergy history, and details of previous medications or treatments should be elicited. The physical, social, and emotional impact of the symptom on patient and family members and coping strategies are also important components of the history. The use of unidimensional instruments and clinical measures based on functional ability can assist in determining severity of dyspnea.

Table I–13–2 ■ Clinical Assessment of Dyspnea in Palliative Care Patients

Patient report	Presence in relation to daily activities
	Qualities/descriptors
	Severity (use clinical tools)
History	Temporal onset: chronic/acute
	Pattern (e.g., acute exacerbations)
	Precipitating factors (e.g., activities, pets, scents, smoking, anxiety)
	Relieving factors (e.g., positioning, medication)
	Associated symptoms (e.g., pain)
	History underlying /concurrent conditions
	Smoking history
	Allergy history
	Medication use and effect: prescribed, over the counter
	Other treatment use and effect (e.g., oxygen, complementary, continuous positive airway pressure, bilevel positive airway pressure)
	Impact: emotional, sleep, activities
	Coping strategies
Physical examination	Vital signs
	Cyanosis, skin tone, and color
	Use of accessory muscles, pursed lips, ability to speak
	Positioning (e.g., bed, chair, seated leaning forward)
	Chest auscultation
	Specific system examination based on history
	Cognitive assessment: mood, affect, ability to concentrate and solve problems
	Behavioral changes (e.g., agitation, restlessness)
Diagnostic tests*	Chest radiograph
	Electrocardiogram
	Pulmonary function tests
	Oxygen saturation
	Arterial blood gases
	Complete blood count
	Biochemistry (e.g., potassium, magnesium, phosphate)
	Other specific tests (e.g., echocardiography, computed tomography angiogram)

*Appropriate to stage of disease, prognosis, risk-to-benefit ratio, and the wishes of the patient and family.

The *Visual Analog Scale* is commonly used to measure perceived intensity of the dyspnea (17). This scale is usually a 100-mm vertical or horizontal line, anchored at either end with words such as, "not at all breathless" and "very breathless." Patients are asked to mark the line at the point that best describes the intensity of their breathlessness. The *Edmonton Symptom Assessment Scale* can also be used to measure perceived intensity of dyspnea. It uses a numeric 0 to 10 scale where 0 means "no breathlessness" and 10 means the "worst possible breathlessness." Patients are asked to indicate the number that corresponds to their present intensity of breathlessness.

The *Oxygen Cost Diagram* is a visual analog scale that consists of a 100-mm vertical line used to quantify severity of dyspnea (17). Everyday activities such as walking, shopping, and bed making are listed at various points along the line proportional to the oxygen cost, that is, the amount of oxygen needed to perform the activity. Patients are asked to identify the level of activity that he or she cannot perform because it causes too much dyspnea. As dyspnea worsens, the scores become lower.

The *Modified Borg Scale* is a scale with nonlinear spacing of verbal descriptors of severity of breathlessness (17). Patients are asked to pick the verbal descriptor that best represents their perceived exertion during exercise. The Borg Scale is usually used in conjunction with an exercise protocol with standardized power output or metabolic loads. When used in this manner, the slope of Borg/time is very reproducible and reliable, and it permits comparisons within individuals and across population groups.

The *Reading Numbers Aloud Test* is an objective measure of the activity-limiting effect of breathlessness in patients who are breathless at very low levels of exertion (20). The test involves asking patients to read a grid of numbers as quickly and clearly as possible for 60 seconds. The number of numbers read and the number read per breath are recorded.

The physical examination should be performed with focus on the possible underlying causes of dyspnea and details obtained from the history. Particular attention should be directed at signs linked with certain clinical syndromes associated with common causes of dyspnea in people who have the patient's particular underlying disease. For example, dullness to percussion, decreased tactile fremitus, and absent breath sounds are associated with pleural effusion in a person with lung cancer, and elevated jugular venous pressure, an audible third heart sound, and bilateral crackles audible on chest examination are associated with CHF.

Accessory muscle use has been suggested as a physical finding that may reflect the intensity of dyspnea. Patients with COPD who were experiencing high levels of dyspnea were found to have significant differences in the use of accessory muscles as compared with patients with low levels of dyspnea, although there were no significant differences in respiratory rate, depth of respiration, or peak expiratory flow rates (15).

The choice of appropriate diagnostic tests should be guided by the stage of the disease, the prognosis, the risk-to-benefit ratios of any proposed tests or interventions, and the desires of the patient and family. If the person is actively dying or wants no further investigations or invasive or disease-oriented interventions, it is appropriate to palliate the symptom without further testing. If the patient is at an earlier phase of illness, diagnostic tests helpful in determining the origin of dyspnea include chest radiography, electrocardiography, pulmonary function

tests, arterial blood gases, complete blood counts, serum potassium, magnesium, and phosphate levels, cardiopulmonary exercise testing, and tests specific for underlying pathologic conditions (e.g., computed tomography angiogram for pulmonary embolism).

MANAGEMENT

The optimal management of dyspnea is to treat the underlying disease and any reversible causes. For persons with advanced disease, this is often no longer possible or desirable, and palliation becomes the goal. As with choosing appropriate diagnostic tests, the choice of treating or not treating a particular underlying cause of breathlessness should be guided by the stage of disease, the prognosis, the burden and benefit to the patient, and the desire of the patient and family. Both nonpharmacological and pharmacological interventions are helpful in alleviating breathlessness without addressing the underlying cause, and, whenever possible, a team approach to management should be utilized. Social services, nursing, and family input will need to be increased as the patient's ability to care for himself or herself decreases.

Tables I–13–3 and I–13–4 provide guidelines for the management of dyspnea in palliative care patients. In applying the guidelines, clinical judgment should be used to determine the appropriateness for a specific patient.

Nonpharmacological Interventions

Patients can obtain relief of dyspnea with positioning techniques such as leaning forward while sitting and supporting the upper body and arms on a table. This position has demonstrated efficacy in patients with emphysema, probably because of increased efficiency of the diaphragm resulting from an improved length-tension state (21).

Breathing strategies such as pursed-lip or diaphragmatic breathing are beneficial in the management of acute shortness of breath (21). Pursed-lip breathing slows the respiratory rate and increases intra-airway pressures, thus decreasing small airway collapse during periods of increased dyspnea.

People who are short of breath often obtain relief by sitting near an open window or in front of a fan. Cold directed against the cheek and through the nose can alter ventilation patterns and can reduce the perception of breathlessness, perhaps by affecting receptors in the distribution of the trigeminal nerve that are responsive to both thermal and mechanical stimuli (21).

Planning for and pacing of activities, together with some reduction in level of activity, help to reduce the intensity of breathlessness. Some patients find that isolation from others helps them to gain control of their breathing and diminishes the social impact (21). Other patients use structured relaxation techniques, conscious attempts to calm down, and prayer and meditation (21). Avoidance of triggers and aggravating factors and self-adjustment of medication can also be of benefit (21).

Nursing actions thought to be helpful include a friendly attitude, empathy, providing physical support, presence at the bedside, and providing information about the possible cause of the breathlessness and interventions (22).

Table I–13–3 ■ Management of Dyspnea in Palliative Care Patients

Activity	Plan for and pace activities
	Encourage rest periods as needed
	Provide assistance with feeding, hygiene, toileting, and ambulation as needed
	Provide assistive devices (e.g., wheelchair, walker)
Environment	Provide a calm, clean, and orderly environment
	Avoid triggers (e.g., perfume, flowers, pets)
	Caution against smoking in patient's room/house
	Check with patient about opening of windows, curtains, doors
	Have essential supplies available at all times (e.g. medications, oxygen if needed)
	Have resource/contact numbers readily available
	Encourage short visits from other than immediate family and caregivers
Patient/family education	Educate/inform regarding progression of symptoms and disease
	Inform about signs and symptoms requiring medical assistance
	Identify and address patient/family fear and anxiety
	Ensure patient/family at home have resource and contact numbers and an emergency plan in place
	Provide information on medications and oxygen therapy
	Inform about importance of remaining calm
	Teach coping techniques (e.g., positioning, fan, relaxation)
	Identify triggers, control environmental irritants, smoking, pets
Treatment	Treat underlying conditions and reversible causes considering stage of disease, risk-to-benefit to patient, patient/family wishes
	Use fan or open window, door
	Use positioning techniques (e.g., use reclining chair with foot rest, overbed table, pillows)
	Use breathing strategies (e.g., pursed-lip)
	Use complementary therapies (e.g., acupuncture, imagery, massage, music, relaxation techniques)
Medications	See Table I–13–4

Patient and Family Education

The goals of patient and family education are maintenance of patient comfort and reduction of the frequency and severity of acute episodes. Health care providers should offer information and address questions and concerns regarding disease, expected progression of symptoms, and management plan. The patient and family should be taught how to identify and control environmental and psychological triggers, conserve energy, and prioritize activities. They should also be instructed to consider the use of a fan or open window. Medications should be reviewed to ensure that the patient and family understand their use and know how to maximize the effectiveness of these agents. The patient and family should be taught the signs and symptoms of an impending exacerbation and how to manage the situation. They should learn problem-solving techniques to prevent panic, positioning techniques, and breathing strategies. An emergency plan that details step-by-step interventions and lists contact numbers should be discussed.

Table I–13–4 ■ Dyspnea Management Guidelines for Palliative Care Patients*

Considerations

Identify and treat common exacerbating medical conditions underlying dyspnea or shortness of breath (e.g., chronic obstructive pulmonary disease, congestive heart failure, pneumonia) as appropriate.

Drug treatments listed are not intended to represent a comprehensive treatment. Other treatments should be considered such as a fan or an open window.

Evaluate the impact of anxiety and fear on dyspnea and treat appropriately.

Use the Edmonton Symptom Assessment Scale (ESAS) and the Oxygen Cost Diagram to measure outcome.

Level of Dyspnea	Treatment
Mild Dyspnea (ESAS 0–3)	
Usually can sit and lie quietly May be intermittent or persistent Worsening with exertion No anxiety or mild anxiety during shortness of breath Breathing not observed as labored No cyanosis	Ensure access to fresh air or use a fan directing cold air on the face. Start humidified oxygen prn if the patient is hypoxic (SaO_2 <92%) or if deemed helpful by the patient (6 L/min by nasal prongs). If the patient is **NOT** taking an opioid, initiate short-acting morphine 2.5–5.0 mg PO q4h and 2.5 mg PO q2h prn for breakthrough **OR** hydromorphone 0.5–1.0 mg PO q4h and 0.5 mg PO q2h prn for breakthrough. (If the SC route is needed, divide the PO dose by half.) Titrate up by 25% every three to five doses until dyspnea is relieved. If the patient is taking an opioid with q4h dosing, increase this dose by 25%. If the patient is taking a long-acting opioid, change back to q4h dosing and increase this dose by 25%; **alternatively**, increase both the long-acting and breakthrough dose by 25%. Titrate short-acting opioid by 25% every three to five doses until dyspnea is relieved. If significant opioid side effects are present (e.g., nausea, drowsiness, myoclonus), consider switching to another opioid and re-titrate.
Moderate Dyspnea (ESAS 4–6)	
Usually persistent May be new or chronic Shortness of breath worsening if walking or with exertion; settling partially with rest Pauses while talking every 30 sec Breathing mildly labored	Ensure access to fresh air or use a fan directing cold air on the face. Start humidified oxygen prn if the patient is hypoxic (SaO_2<92%) or if deemed helpful by the patient (6 L/min by nasal prongs). If the patient is **NOT** taking an opioid, initiate short-acting morphine 2.5–5.0 mg PO q4h and 2.5 mg PO q1h prn **OR** hydromorphone 0.5–1.0 mg PO q4h and 0.5 mg PO q1h prn. (If the SC route is needed, divide the PO dose by half, and the prn dose can be as frequent as q30min.) Titrate the dose by 25% every two to three doses until dyspnea is relieved.

Table continued on following page

Table I–13–4 ■ Dyspnea Management Guidelines for Palliative Care Patients* (Continued)

Level of Dyspnea	Treatment
	If the patient is taking an opioid with q4h dosing, increase the dose by 25% (this applies to SC or PO dosing) and continue with breakthrough dosing at 50% of the regular dose q1h prn (or q30min prn if it is SC). If the patient is taking a long-acting opioid, change back to q4h dosing and increase this dose by 25%; **alternatively,** increase both the long-acting and breakthrough doses by 25%. Give breakthrough q1h prn. Titrate the dose by 25% every two to three doses until dyspnea is relieved. If opioids provide only a limited effect, consider adding chlorpromazine 12.5 or 25 mg q4–6h PO or methotrimeprazine 2.5–5.0 mg PO/SC q4–6h as an adjuvant. If significant opioid side effects are present (e.g., nausea, drowsiness, myoclonus), consider switching to another opioid and re-titrate.
Progressive Severe Dyspnea (ESAS 7–10)	
Often acute or chronic Worsening over days/weeks Anxiety present Often awakening suddenly with shortness of breath With or without cyanosis With or without onset of confusion Labored breathing awake and asleep Pauses while talking every 5–15 sec	Start humidified oxygen, up to 6 L/min by nasal prongs or even higher flow rate with mask, as tolerated (even if not hypoxic). Consider nebulized saline 1–3 mL by mask prn. If the patient is **NOT** taking an opioid, initiate a short-acting opioid. Consider: **Oral:** Morphine 5–10 mg PO q4h and 5 mg PO q1h prn **OR** hydromorphone 1.0–2.0 mg PO q4h and 1.0 mg PO q1h prn **OR** **Subcutaneous:** Morphine 2.5–5 mg SC q4h and 2.5 mg SC q30min prn **OR** hydromorphone 0.5–1.0 mg SC q4h and 0.5 mg SC q30min prn. Titrate dose by 25% every one to two doses until dyspnea is relieved. If the patient is taking an opioid with q4h dosing, increase the regular and breakthrough doses by 25%. Change the frequency of the breakthrough dose to q1h prn if PO and q30min prn if SC. If the patient is taking a long-acting opioid, switch back to q4h dosing and increase this dose by 25%. **DO NOT** try to manage severe dyspnea with a long-acting opioid. Change the breakthrough dose to half of the regular dose, either q1h prn PO or q30min prn SC. Titrate the dose by 25% increments every one to two doses until dyspnea is relieved. If opioids provide a limited effect only, consider adding chlorpromazine 12.5 or 25 mg q4–6h PO or methotrimeprazine 2.5–5.0 mg PO/SC q4–6h as an adjuvant. If unmanageable opioid-limiting side effects are present (e.g., nausea, drowsiness, myoclonus), consider switching to another opioid and re-titrate.

Acute Exacerbation or Very Severe Dyspnea	
Sudden onset (minutes to hours) High anxiety and fear Agitation with very labored respirations Air hunger Pauses while talking or unable to speak Exhaustion Total concentration on breathing Cyanosis usually May be cold/clammy With or without respiratory congestion With or without acute chest pain With or without diaphoresis With or without confusion	Start humidified oxygen, up to 6L/min by nasal prongs or even higher flow rate with mask, face tent if tolerated (even if not hypoxic). **If the patient is NOT taking an opioid**: If IV access is present, stat morphine 5–10 mg IV q10min until settled. If **NO** IV access is available, stat morphine 5–10 mg SC q20–30 min until settled. When settled: Morphine 10–20 mg PO q4h and q1h prn **OR** morphine 5–10 mg SC or IV q4h and q 30 to 60 min prn and titrate vigilantly. **If the patient is taking an opioid and *has IV access***: Stat opioid administration, dosed as follows: If taking a PO opioid, give the same dose **IV**, and repeat q10min until settled (e.g., if on 15 mg PO q4h usually, then give 15 mg IV q10min until settled). If taking a SC opioid, give double the SC dose **IV**, as often as, q10min until settled. When settled: Continue q4h dosing with breakthrough q30–60min prn (will likely need a higher dose than previous) and titrate vigilantly. **If the patient is taking an opioid and *has no IV access***: Stat opioid administration, dosed as follows: If taking a PO opioid, give the usual PO dose SC q 20–30min until settled (e.g., if usually takes 15 mg PO q4h, then give 15 mg SC q20–30min until settled). If taking a SC opioid, give the usual dose (or double it) q20–30min until settled (e.g., if on 15 mg SC q4h usually, then give 15–30 mg SC q20–30min until settled). When settled: continue q4h dosing with breakthrough q30–60min prn (will likely need a higher dose than previous) and titrate vigilantly. To treat agitation: For all patients, **consider** methotrimeprazine 5 mg PO/SC q4–6h prn and titrate to a maximum of 25 mg q4–6h prn. For all patients, if significant anxiety is present, **consider** lorazepam 0.5–1.0 mg PO/IV/SC/SL q30min prn for anxiety. (Carefully!) If the patient is already taking a higher dose of lorazepam or another benzodiazepine, then dose appropriately. Monitor for paradoxical agitation or excessive somnolence. For all patients with very congested breathing, **consider** glycopyrrolate 0.1–0.2 mg SC q4h prn or scopolamine 0.3–0.6 mg SC q2–3h prn.

*These are meant as guidelines. Physicians need to use their own clinical judgment regarding the appropriateness of the intervention in an individual patient.

IV, intravenously; PO, orally; prn, as needed; SC, subcutaneously; SL, sublingually.

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Complementary Treatment

Acupuncture and acupressure have been found to relieve dyspnea in patients with moderate to severe COPD (21). Acupuncture has also provided marked symptomatic benefit in patients with cancer-related breathlessness (21). Patients with COPD noted a reduction in breathlessness when muscle relaxation was used with breathing retraining (21). In patients with advanced lung cancer, a combined approach with breathing retraining, exercise counseling, relaxation, and coping and adaptation strategies significantly improved breathlessness and the ability to perform activities of daily living (21). Guided imagery and therapeutic touch have resulted in significant improvements in quality of life and sense of well-being in COPD and patients with terminal cancer, respectively, without any significant improvement in breathlessness (21).

Oxygen

Not all terminally ill patients require oxygen. Supplemental oxygen has been documented to benefit hypoxic patients. In two studies of hypoxic patients with terminal cancer, patients' ratings of dyspnea, their respiratory rate, oxygen saturation, and respiratory effort all improved with oxygen (23). Oxygen supplementation improved survival, pulmonary hemodynamics, exercise capacity, and neuropsychological performance in a study of hypoxic patients with COPD (24). However, the role of oxygen supplementation in the treatment of nonhypoxic dyspneic patients is less clear. A study of nonhypoxic patients with cancer and dyspnea demonstrated no significant differences in dyspnea, fatigue, and distance walked between those who received oxygen and those who breathed room air during exercise (25), whereas a study of nonhypoxic patients with COPD found that oxygen not only reduced breathlessness but also increased the distance that the patients were able to walk (26). Therefore, most authorities currently recommend supplemental oxygen for the management of dyspnea in hypoxic patients, the goal being to achieve and maintain a partial arterial oxygen pressure (PAO_2) of 55 to 60 mm Hg and an oxygen saturation of 88% to 90%, even in the presence of increasing hypercapnia (24).

Noninvasive Ventilation

Noninvasive ventilation (NIV) uses a mask or other device to provide intermittent ventilatory support through the patient's upper airway without sedation or analgesia. NIV, unlike invasive ventilation, allows patients to eat and drink, to communicate verbally, and to maintain some mobility. Randomized controlled trials have shown that NIV reduces the need for intubation, decreases in-hospital mortality, and improves arterial blood gases, respiratory rate and dyspnea, but its role in terminal breathlessness is unclear. NIV may be appropriate in the management of dyspneic patients with end-stage disease to provide time to clarify the diagnosis or response to treatment, to enable patients to get well enough to return home, or to give patients and families extra time to come to terms with dying and achieve "closure."

Pharmacological Interventions

Opioids

A systematic review of the literature confirmed that oral and parenteral opioids are effective in relieving the sensation of breathlessness (27). The proposed

mechanisms for the effects of opioids on dyspnea include an alteration in the perception of breathlessness, a decrease in the ventilatory drive and response to stimuli such as hypoxia and hypercapnia, and a decrease in oxygen consumption at any level of exercise. The same review found no evidence to support the use of nebulized opioids and indicated that nebulized morphine was no more effective than nebulized saline for the relief of breathlessness (27). Therefore, it is difficult to justify the continued use of nebulized opioids.

Some health care professionals fear that the respiratory depressant effects of opioids will induce respiratory failure and will hasten death. The systematic review of opioids for the management of breathlessness identified 11 studies that contained information on blood gases or oxygen saturation after intervention with opioids (27). Only one study reported a significant increase in arterial carbon dioxide pressure ($PACO_2$), but it did not rise above 40 mm Hg (28). It is now known that the development of clinically significant hypoventilation and respiratory depression following opioid therapy depends on the history of previous exposure to opioids, on the rate of change of the opioid dose, and possibly on the route of administration. The early use of opioids can improve quality of life and can allow the utilization of lower doses while tolerance to the respiratory depressant effects develops. It has also been suggested that early use of morphine or another opioid, rather than hastening death in dyspneic patients, may actually prolong survival by reducing physical and psychological distress and exhaustion (29).

Opioids for dyspnea are given in doses similar to those used for pain relief. Patients should be started on a short-acting formulation of an oral opioid on a regular basis with a breakthrough dose on an as-needed basis. The dose is titrated upward according to need. Once dyspnea is well controlled on a stable dose, the opioid can be switched to a long-acting preparation, with a short-acting opioid maintained for breakthrough distress.

Sedatives and Tranquilizers

Current evidence supports the use of phenothiazines, such as chlorpromazine or promethazine (alone or in combination with morphine), for the treatment of dyspnea (30). Chlorpromazine decreases breathlessness without affecting ventilation or producing sedation in healthy subjects. It has also been found effective for relief of dyspnea in advanced cancer. Although promethazine reduced dyspnea and improved exercise tolerance in patients with severe COPD, it did not improve breathlessness in healthy people, nor did it benefit patients with stable COPD.

In a double-blind, placebo-controlled, randomized trial, the combination of morphine and promethazine significantly improved exercise tolerance without worsening dyspnea compared with placebo, morphine alone, or the combination of morphine and prochlorperazine (31). The combination of morphine and chlorpromazine has also been found to be effective.

Clinical trials to determine the effectiveness of anxiolytics for the treatment of breathlessness have had conflicting results, and at present there is little support for their use in the treatment of chronic breathlessness (30). However, one drug that warrants further study is buspirone, a nonbenzodiazepine anxiolytic. Although it had no effect on pulmonary function tests or arterial blood gases in patients with COPD, its use improved exercise tolerance and decreased dyspnea (32). Anecdotally, anxiolytic agents are useful for people who have acute, severe breathlessness.

Other Medications

Studies of the usefulness of indomethacin (33) and inhaled bupivacaine for relief of breathlessness have been contradictory. Inhaled lidocaine (34) and dextromethorphan (35) did not improve breathlessness. None of these medications can be recommended at this time for the treatment of dyspnea.

End-Stage Management

Withdrawal from Ventilation

Withdrawal of mechanical ventilation is viewed as more problematic than withdrawal of other interventions. It is recommended that the health care team discuss the procedure, strategies for assessing and ensuring comfort, and the patient's expected length of survival with the family and patient (if possible).

Once the decision has been made to discontinue ventilation, the patient can be extubated immediately, or ventilation can be reduced slowly, weaning the patient, before extubation. In either case, the patient's comfort and family support are essential. Protocols for ventilator withdrawal include the use of continuous infusions of opioids and at times benzodiazepines (36, 37). The intravenous route is preferred for administration of medications. If the patient is currently receiving an opioid, recommendations suggest starting a continuous hourly infusion of the same opioid at the same dose, with bolus doses of 50% to 100% of the hourly dose available on an as-needed basis. If the patient is opioid naive, a low-dose opioid, such as morphine, 1 mg/hour, would be an appropriate infusion. Initiation of a midazolam or lorazepam infusion before ventilator withdrawal can also be considered (37). Scopolamine, 0.6 mg, can be administered for bronchial secretions. If distress ensues, then aggressive and immediate symptom control combining the as-needed opioid and/or midazolam, 2 to 4 mg by intravenous push every 10 minutes until distress is relieved, is recommended (37). If symptoms are refractory to these measures, then pentobarbital, methotrimeprazine, or propofol should be initiated (37).

Severe Escalating Dyspnea

Patients may experience a severe escalation of dyspnea at the end of life. This often causes high anxiety and fear in both the patient and family. The goal is to control breathlessness rapidly while maintaining a calm and reassuring environment. High-flow oxygen is recommended, along with administration of parenteral opioid bolus doses until dyspnea settles (38). The preferred route of administration is intravenous, but if the patient has no intravenous access, the subcutaneous route can be used. In patients with significant anxiety, a benzodiazepine, such as lorazepam, can be considered, and for patients with agitation, methotrimeprazine is recommended (38).

PEARLS AND PITFALLS

- Dyspnea is a subjective experience, and the patient's report is key to its assessment.
- Tachypnea is not dyspnea.

- Unidimensional tools and instruments based on function assist in measuring the severity of breathlessness and should be used to guide management.
- Nonpharmacologic strategies are essential components in controlling dyspnea.
- Opioids are the mainstay of pharmacological management and should be commenced early.
- Health care providers can improve the quality of life and can reduce suffering in dyspneic palliative care patients.

SUMMARY

Dyspnea is a common symptom in patients with advanced disease. Studies have demonstrated that dyspnea severely impairs the quality of life and contributes significantly to patient and caregiver stress. Management of breathlessness in patients at the end of life requires expertise that includes an understanding and assessment of the multidimensional components of the symptom, knowledge of the pathophysiological mechanisms and clinical syndromes that are common in people with advanced disease, and the indications and limitations of available therapeutic approaches.

Resources

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C Personal Context

Loss, Bereavement, and Adaptation

14

Sara J. Knight and Linda L. Emanuel

CHAPTER OUTLINE

INTRODUCTION
BRIEF OVERVIEW OF ADAPTIVE PROCESSES
LOSSES FOR THE DYING PERSON
Comprehension
Creative Adaptation
Reintegration
Journey through the Processes
FACTORS THAT INFLUENCE ADJUSTMENT
LOSSES FOR THE BEREAVED SURVIVOR
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SUMMARY

INTRODUCTION

Although grief of bereaved survivors has been the focus of theoretical and empirical work, in clinical practice it is essential also to focus on the experiences of the dying person as losses occur in health, physical and mental function, and social roles and responsibilities. Without a conceptual framework for adaptation to

losses, it is difficult to know how to intervene effectively in palliative care. We therefore describe a reintegration model that includes comprehension, creative adaptation, and reintegration processes for adapting to losses at the end of life. We describe adjustment processes from the perspectives of the dying person and the bereaved survivor. For each, we consider the implications of adjustment processes for the palliative care team and for families and other significant relationships. We provide examples of how caregivers can use knowledge of adjustment processes to provide focused interventions aimed at improving decision making and the quality of care at the end of life (Table I–14–1).

BRIEF OVERVIEW OF ADAPTIVE PROCESSES

News about a terminal prognosis, the experience of functional decline, and an acute health crisis are among the losses commonly experienced by persons approaching the end of life. Significant others may experience the same news

Table I–14–1 ▪ Reintegration Model: Process, Experience, and Activities of Palliative Care

Process	Patient Experience	Key Activities of Palliative Care Team
Comprehension Realize the loss	Shock, numbness, sadness, anxiety Awareness of the loss Uncertain goals and values	Empathic listening Verbal and nonverbal support Discussion of the practical consequences of the loss Avoidance of premature decision making
Creative adaptation Explore ways of living without what was lost	Ambivalence, mixed emotions Exploration and experimentation through action and imagination with new or alternate ways of living without what was lost Changing values, goals, preferences	Discussion of alternatives for living Support for distress Tolerance for changing emotions and ambivalence Support for efforts to try adaptive behaviors Life review and legacy building Values clarification, if decisions need to be made Education for family members and significant others
Reintegration Consolidate revised self-concept and view of life without what was lost	Emotional equilibrium Consolidation of revised self-concept and new ways of living Stable values, goals, preferences	Encouragement and support for revised self-concept and new ways of living Re-evaluation of decisions for care made during comprehension and creative adaptation

and events as losses and they also experience the death, the funeral, and other rituals and face continuing in life without the deceased.

Losses that occur close to the end of life can precipitate great distress. Yet these losses have the potential to stimulate psychological growth. For both the person who is close to the end of life and the survivor, these experiences can provide opportunities to resolve conflict in relationships, heighten spiritual awareness, and offer new perspectives on living. In the following section we describe adjustment processes, comprehension, creative adaptation, and reintegration, from the perspectives of the dying person and the bereaved survivor. We present a conceptual framework, termed the *reintegration model,* to understand the adjustment processes of the dying person, and we consider relevant conceptual and empirical research on bereavement (1). For each, we discuss implications for palliative care.

LOSSES FOR THE DYING PERSON

The trajectory to death differs according to the type of illness or injury. For some patients, the path involves a rapid decline to death; others experience a series of acute crises followed by periods of relatively stable health; still others see a slow deterioration in function and well-being (2). Adjustment to the losses that occur along any of these trajectories begins when the dying person becomes aware of limitations in function, well-being, and life. Awareness of end-of-life loss can occur when a person observes an acute, noticeable deterioration in function or compares a gradual decline with a previous higher level of health. This awareness can also occur when a person receives news of a terminal prognosis from clinicians or a referral to hospice care. A significant characteristic of many end-of-life losses is that they are irreversible; the person will not recover the previous level of function or well-being. A related characteristic is that many losses close to the end of life are associated with awareness of impending death.

When a person becomes aware of an end-of-life loss, adjustment occurs across several domains. A person may adjust physically, as when a walker is used to compensate for weakness in the legs or unsteady gait. Other adjustments may be psychological, social, or spiritual. For example, a person who is unable to work because of advanced pulmonary disease may focus greater attention on those close relationships with family and friends. With the loss of work, self-concept may shift from an emphasis on oneself as a worker to views of oneself in other roles such as friend, partner, or parent. Purpose in life may be realized through one's relationships with family, humanity, nature, or a higher power rather than through contributions at work. With greater awareness of impending death, meaning may be found through leaving one's legacy to loved ones, through considering beliefs about what happens after death, and through awareness of spiritual connections. These physical, psychological, social, and existential or spiritual domains are consistent with those that Cicely Saunders identified some 3 decades ago at the outset of the hospice movement, and they have been incorporated into contemporary conceptual models of palliative care (3, 4). We describe three processes—comprehension, creative adaptation, reintegration—that occur across these four domains as people adjust to losses at the end of life, and we discuss how palliative care professionals can use understanding of these processes to improve end-of-life care.

Comprehension

Theories of coping with stress postulate that an appraisal process occurs after the onset of stress (5). Appraisal serves to evaluate the characteristics of the stressful situation and to assess the resources one has to cope with it. Similarly, when a person observes deterioration in health and function or receives "bad news" in terms of prognosis, we suggest that they engage in a process of *comprehension* that identifies the experience as an irreversible loss. To adapt, a person who experiences a functional decline has to interpret diminishing abilities as an irreversible loss. Some losses may be so gradual that they are not interpreted as such. Other losses may appear temporary. For example, a fall and a fractured hip may be interpreted as a temporary setback in life. Conversely, if this injury signifies a sequence of losses leading to death, the comprehension process for irreversible loss may be initiated.

The emotional experience associated with comprehension includes shock, numbness, sadness, and anxiety. However, it is possible for a person to experience a range of positive responses as well as negative affect. For example, a person may feel relieved when the loss eliminates responsibility that is no longer manageable. Regardless of the emotion, during comprehension, the loss itself is highly salient cognitively, and behaviors are directed toward determining that a loss has occurred (e.g., testing one's limits). Recognition of what will be missed and evaluation of the importance of what is lost to the person's identity, in turn, disrupt equilibrium across the core domains. For example, a loss in the physical domain, such as in congestive heart failure, initiates activity in the psychological domain about what this means in terms of ability to work or care for oneself, the ability to think of oneself as an independent person, the need for assistance from others, the relevance of the health prognoses of family members, and the meaning of heart disease in terms of one's religious or spiritual beliefs. These psychological activities contribute to further disruption in the social and existential domains. Especially when a loss is realized suddenly and is central to a person's self-concept, comprehension may be associated with acute stress responses in the physical domain. In addition, because of the effort needed to process the loss, a person may have little energy to contribute to social relationships, existential concerns, or decision making.

For seriously ill people, comprehending loss may be impeded by cognitive impairment related to medications or disease. Similarly, comprehension cannot be expected to occur if caregivers withhold prognostic news. In addition, the type of loss is an important factor that influences the comprehension process. Losses associated with shame or stigma may be particularly difficult to experience emotionally. For example, in many Western cultures where people take pride in independence, the process of becoming more dependent on others (e.g., needing assistance with dressing, bathing, and toileting) may make it difficult for a person to experience fully their feelings about the loss of independence, and this reluctance impedes comprehension.

Palliative care clinicians can support the person by allowing the time and space for comprehension processes to occur. Clinicians can provide opportunities for the person to think about the loss, to discuss their perception of the news, to ask questions about what the loss means in practical terms, and to confer with significant others. The onset of a loss often becomes a time when health care decisions need to be made about a new treatment approach or the start of hospice care. The person who is in the process of understanding the loss and what it means may not

have the cognitive capacity to evaluate alternatives and to make informed choices at this time. It may be useful for the clinician to allow comprehension to occur before engaging the person in clinical decision making. If a decision about care or living arrangements cannot be delayed, then it may be important to provide additional support to the person by involving significant others, focusing attention on most likely alternatives, and allowing the person to reevaluate the decision once he or she fully comprehends the loss and its implications.

Creative Adaptation

Once a loss is comprehended as something that cannot be restored completely, a person begins a transition to living without what has been lost. We term this process *creative adaptation*. The person may experiment, through action and imagination, with new ways of thinking about oneself and living without what has been lost. New relationships may be formed, or new ways of interacting and being in existing relationships may occur. For example, a person who has fatigue and functional decline that affects mobility may develop alternate means of maintaining important social relationships. The following case study illustrates the processes of adaptation.

Case Study I–14–1 ■

B. G. was a 58-year-old man who lived alone and started therapy for metastatic malignant melanoma, but he found that he did not have the energy, attention, or concentration to work full time in his job as a vice president of a publishing company. He scaled back his responsibilities and, with some difficulty, continued in his position. Although his part-time work schedule allowed him greater time to rest, he was no longer included in the decision making of the inner management of the firm. B. G. found this highly discouraging and told his doctors that he was considering ending therapy early, before he had received the recommended dose. His doctor listened to him express his frustration and his desire to discontinue treatment. They discussed options and described what they thought were the advantages and disadvantages of each. After serious consideration of the alternatives, B. G. decided to continue on his current course. He felt that his physician understood his situation and supported him in considering the possible options fully.

When his disease progressed following his initial treatment, B. G. started an alternate treatment course and left his position at the publishing company. At this time, B. G. was aware that his prognosis was poor and that he was not expected to live beyond the year. Most of his social relationships were with coworkers at his firm, and his few family members lived at some distance away. He felt lonely and dispirited on days at home, and as he thought about dying, he ruminated about what he had not been able to accomplish in his life. Initially, he attended a support group at his hospital, and although this offered connections to others, he missed the sense of importance that he had always found in his work. After a call from an old friend with whom he had lost touch, he started writing letters that reestablished closeness with friends he had not seen in more than a decade. The friends who knew B. G. before his success as a publisher reminded him of the many ways in which his life had mattered to them. Through the letters, he became engaged in telling his story, and he often illustrated his letters with line drawings and watercolors, activities that he had always enjoyed and that he could do even with reduced concentration. The renewed means of self-expression and his reaching out to others became a way that B. G. reestablished self-worth and identity apart from work roles and contributions. As B. G. reflected on his life, he was able to think of himself as someone who had made a difference to his friends and family. He came to think of his letters as part of his legacy.

The description of B. G. illustrates the creative adaptation process that started with losses in his ability to work and depicts the exploration of alternative ways of living and finding meaning that are characteristic of this process. As shown in this example, creative adaptation may involve struggles to maintain earlier roles and activities and unsuccessful attempts to find new ways of coping. At times, the struggle to find ways of coping with loss may result in conflict with others. In this example, the clinician caring for B. G. was able to avoid conflict by supporting B. G. in an exploration of what it could mean to discontinue treatment. For B. G., the creative adaptation process ultimately contributed to revisions in his self-concept that incorporated a past tense view of himself in a specific job and reaffirmed a broader image of himself as a writer and friend.

Although several theories have proposed that awareness of impending death is an important, if not necessary, stage of adjustment to dying, more recent work suggests that most people fluctuate in their awareness of death, and some never reach a state of complete awareness or avowal of impending death. It is not clear that awareness or acknowledgement of imminent death is necessary for good psychological adjustment during dying (6, 7). However, when a loss is interpreted as leading to death, the transition that occurs with creative adaptation incorporates the idea of dying and death. Some people may imagine what it is like to die, and many have fears as they envision this process. The process of dying and what happens at and after death may be considered with new awareness and immediacy.

An important aspect of the creative adaptation process is that it involves experimentation with novel thoughts and behaviors, as well as drawing on existing skills and abilities. This type of coping has been described previously in the literature on aging and in reports on studies of disability (8, 9). When losses occur close to the end of life, previous avenues of coping are no longer available, and ultimately when a person is close to death, few options for new behaviors or ways of relating to others may appear to be open. The only possibility for adaptation at these times may be to find new psychological or spiritual perspectives. This approach may involve leaving a legacy to loved ones, reviewing one's life, experiences, and accomplishments, or considering beliefs about what happens after death with an immediacy and urgency that was not possible before facing death so closely.

During the creative adaptation process, new self-perspectives emerge that transcend previous self-concepts (10). A person who focused earlier in life on work and the meaning in life that is derived from work contributions may have a renewed appreciation of family relationships and close friendships. The perspective of earlier roles and self-concepts becomes one of the past rather than the present (e.g., "I once was an engineer, and now I am..."). Although new perspectives develop during creative adaptation, this process is one of shifting affect, behavior, and self-concepts. A person's values, goals, and preferences are likely to be in flux at this time. During the time that new behaviors and perspectives are being tested, it may be difficult for the person to express stable preferences for activities or care.

Caregivers, including palliative care clinicians, can support a person during creative adaptation by accepting the person's ambivalence and shifts in emotions, by supporting the person's exploration of alternatives for living through empathic listening and focused discussion, and by allowing for changes in plans of action as the person's needs evolve. Creative adaptation can be distressing for the person as well as for significant others, and family members may have difficulty understanding

the person's ambivalence or changes in preferences and plans. It may be important for clinicians to provide emotional support and education during creative adaptation to reduce distress and to minimize potential sources of conflict. As avenues for new behaviors become severely curtailed close to the end of life, life review and legacy building activities may be important as a means of self-transcendence and strengthening of connections with others. Especially as the person develops greater awareness of dying, it becomes important to answer questions about the dying process and to provide opportunities to talk about what happens at death and after death. When decisions need to be made, values clarification may be important because core beliefs may be reevaluated during creative adaptation as the person adjusts to the loss.

Reintegration

Finally, a process of *reintegration* occurs that consolidates the new perspectives, adjustments in social relationships, and new behaviors. Whereas the comprehension and creative adaptation processes are characterized by realization of a loss, transition, and experimentation, reintegration rebuilds the stability of the revised self-concept, expectancies about the future, and goals. In contrast to the flux in preferences that occurs during creative adaptation as the person experiments with alternatives for living, there is continuity in values and goals during reintegration. With this continuity, the person experiences greater stability in relationships.

Reintegration allows for greater psychological and social stability, and a person in this process may feel more "settled." We see this as a process rather than as an outcome at the end of life for several reasons. First, the consolidation that occurs during reintegration is an ongoing activity, in contrast to a stable state, that involves the enactment and validation of the revised self-concept, world view, and new course of living. Second, in many situations of deteriorating health, it is likely that new losses will occur, resulting in reiterative cycles of comprehension, creative adaptation, and reintegration.

The palliative care team can support the person during reintegration by providing affirmation of the revised self-concept and new ways of living and by offering practical support that helps the person to stabilize function and well-being. Because values and preference change during creative adaptation and stabilize during reintegration, it may be important for palliative care clinicians to work with the person to reevaluate important decisions about care. Choices made during comprehension and creative adaptation may no longer be consistent with the revised self-concept and goals that emerge during reintegration.

Journey through the Processes

The successful adaptive processes can be thought of as generally progressive, in which the primary direction of movement is from comprehension to creative adaptation and from creative adaptation to reintegration. However, like other psychological and behavioral adaptations, this is often a recursive process that includes iterations. Similar recursive processes have been described in the literature on bereavement and in previous work on adaptation at the end of life (11, 12). Thus, during a process that is overall one of creative adaptation, a person may return to the comprehension

process (i.e., realization that the loss has occurred). Similarly, during reintegration, a person may return to the creative adaptation processes (i.e., experimentation with new possibilities for the future without what was lost). Return to an earlier aspect rather than unidirectional progression may occur when a person has not reached equilibrium or when that person's resources are not sufficient to handle the demands of processing the loss. It may also be possible to enter the creative adaptive process or even reintegration and then confront the comprehension process, perhaps little by little, later on. A dying person may not possess the psychological, social, existential, or physical resources needed to progress completely or linearly toward reintegration when multiple, significant losses are experienced in rapid succession. Alternatively, that person's sense of depletion may enhance his or her ability to let go and progress to departure-oriented adaptations. If the losses are compiled to such an extent that adaptation is overwhelmed and then blocked, complex or maladaptive responses may arise. These possibilities will require further investigations in the future.

The features of the comprehension, creative adaptation, and reintegration processes that are characteristic of dying may be characterized by the specific challenges, roles, tasks, and opportunities of the final life stage. For instance, people can attain a state of giving, and all the reciprocity that results from it, that may be dependent on knowing that there is no use gathering things or relationships or roles for themselves that can no longer be; or they may attain a spiritual state that is heightened by the imminent end of life; or they may discover relationships of dependence as a result of their physical state that give them unexpected difficulty or gratification. All these and other circumstances of end-of-life living may trigger personal growth that is often highly valued (10, 13).

The final dying process has some unique features in that the adaptation process involves a nonrecursive handing over to family, friends, and others. This process has been described as "leaving a legacy" (10, 14). However, we see this as part of a broader process sometimes described as *self-transcendence,* a diminishing emphasis on independent functioning as an individual as one loses physical capabilities, functional abilities, and social relationships, contrasted with an emerging emphasis on the creative use of dependence and spiritual connections. In the end-of-life experience, the patient may reach a point through comprehension processes that acknowledges death as imminent, and the patient may let go. Family members and friends may even be involved in giving permission, by telling the dying person that it is all right to die. Hospice and palliative care workers often describe a kind of withdrawal when the dying person may talk to dead relatives or friends and may seem less engaged in the living world (15). The creative adaptation and reintegration processes of the real-time world are left to the living as they transition into bereavement and carry forward the dying person's legacy as part of the final reintegration pathway.

FACTORS THAT INFLUENCE ADJUSTMENT

Various factors influence the course of adjustment to and quality of end-of-life losses. These range from the type of illness or injury to psychological and social factors, including developmental stage, previous experience with loss, personality, social support network, and spiritual beliefs and practices. For example, a person whose illness is characterized by a gradual decline in function may slowly become

aware of significant losses over time and may have little need to make major adjustments in quick succession. For this person, comprehension of losses may be gradual and associated with little distress. Creative adaptation may involve little exploration of new avenues for functioning, and reintegration may involve little change in self-concept. In contrast, a person who has rapidly progressing metastatic breast cancer may suddenly lose the ability to walk because of fractures and may experience a rapid cascade of other losses, including work and social activities. The loss of mobility, for this person, may require major shifts in her roles, responsibilities, and relationships. The ramifications of a sudden and significant loss may be difficult to realize and comprehend and may be accompanied by greater distress. Creative adaptation may involve a larger struggle to find new ways of functioning and meaning in life, and reintegration may require more time for consolidation of a revised self-concept once alternate ways of living are established.

Depression, anxiety, and other psychiatric disorders can limit a person's ability to engage in the adjustment processes. For example, a person with a severe major depression may not have the energy or cognitive flexibility to envision alternative ways of functioning as a part of creative adaptation. For seriously ill people, adjustment may be impeded by cognitive impairment, related medications, or disease. Moreover, failure to comprehend a loss is often discussed in the context of *denial*, a coping process that is thought to protect a person from information associated with intense, painful affect (16). In this sense, adaptation to a loss may vary according to a person's ability to be aware of and to process painful information.

LOSSES FOR THE BEREAVED SURVIVOR

Theoretical perspectives have offered frameworks for understanding why we grieve. Bowlby suggested that grief occurs when an attachment necessary to one's safety and security is disrupted (17). Others have conceived grief as a part of the healing process, reestablishing equilibrium in a person's life after the loss of a loved one. Most theories conceptualize grief as multidimensional, encompassing emotional (e.g., sadness, anxiety, anger), physical (e.g., loss of appetite, fatigue), cognitive (e.g., preoccupation, confusion), and behavioral (e.g., restlessness, searching) sensations and experiences. The type of loss and closeness of the relationship are significant factors in the intensity and duration of grief. For some losses, grief continues for 6 months to several years. Grief may continue longer in some situations, such as the death of a child. Other factors that determine the duration of grief include the mode of death (e.g., natural or traumatic), historical antecedents (e.g., depression, stress), personality variables (e.g., coping and resilience), and social and cultural context (e.g., traditions, rituals, social network).

Clinicians have long observed that thoughts, emotions, and behaviors evolve during the grief process. Kubler-Ross proposed that grief occurs in stages: denial, anger, bargaining, depression, and acceptance (18). Although this theory has been important in its recognition of grief as a multifaceted and developmental process, it has been criticized for its limitations. It does not appear that grief involves all these stages or that people progress linearly through the stages. However, a similar conceptual framework often cited as being clinically useful is that of Worden (19), who suggested four tasks of grief:

1. Accepting the reality of the loss
2. Experiencing the pain of grief
3. Adjusting to an environment in which the deceased is missing
4. Withdrawing emotional energy from the deceased and reinvesting in other relationships.

According to Worden's framework, immediately following the death of a loved one, it is critical for the bereaved to accept that the loss has occurred and that it is irreversible. The second task involves the bereaved's experiencing the pain of grief, such as sadness, anxiety, and anger. Although more recent work on bereavement suggests that the range of emotional response to the death of a loved one is wide, this model indicates that both cognitive processing and affective processing of a significant loss are important. The third task involves adjusting to an environment without the deceased. This task involves both practical accommodations and psychological adjustments. For example, the bereaved may need to find ways of meeting the responsibilities that had been previously handled by the deceased. The fourth and final task of grief involves disengaging from the relationship with the deceased and becoming involved in other relationships or endeavors.

Worden and others defined benchmarks from which to judge the resolution of grief process (19, 20). One indication is when the bereaved is able to talk about the deceased without intense, fresh feelings of loss. Another is when the survivor is able to invest energy in new relationships, roles, and responsibilities without the disabling guilt and feelings of disloyalty toward the deceased. Previous theories described processes, termed *masked grief* and *delayed grief,* characterized by the lack of experience or lack of expression of emotions in response to significant loss. These views raised concern that suppression or displacement of emotions associated with a loss would lead to subsequent depression. However, Bonanno and Kaltman found that psychological resilience is more common during bereavement than previously thought (21). This work suggested multiple trajectories for the grief process, including those that involve little intense, negative emotional experience throughout the course and those that involve psychological growth.

Interventions for the Bereaved

Clinicians can support a grieving person in several ways. Before the loss, clinicians can encourage significant others to spend time with their loved one who is dying and can acknowledge the importance of these relationships. Clinicians can show appreciation for the contributions of the significant others to caregiving and to the well-being of the dying person. Immediately following a loss, it is important to provide a time and place for the bereaved to express feelings. Clinicians can extend sympathy, support cultural rituals, encourage reminiscing, and listen to the bereaved talk about the deceased.

During the weeks and months preceding and following the death, clinicians can provide education and communicate that painful feelings about a loss, such as sadness and anxiety, are understandable. It may be valuable to confirm that ambivalent feelings (e.g., sorrow and anger, anxiety and relief) in grief are common because most relationships have difficult times as well as wonderful ones. It can alleviate guilt if the clinician clarifies that anticipatory grief (i.e., occurring in expectation of the loss) is a normal response. As the bereaved adjusts to life

without the deceased, clinicians can provide support in problem solving. This may involve discussing the survivor's new roles, helping the survivor to reorganize overwhelming tasks into small steps, and identifying sources of social support. Ultimately, when the bereaved is ready, clinicians can encourage investment in new relationships. Although many individuals do not need professional counseling for grief, they may benefit from opportunities to receive education about the grief process, to express emotions with others who have similar feelings, and to receive guidance with problem solving during adjustment to life without the deceased.

GRIEF AND CLINICAL DEPRESSION

Grief can occur without clinical depression. However, depression can develop during the grieving process, and preexisting depression can complicate grief. Because both grief and depression are associated with intense, low mood, difficulty with the experience of pleasure, sleep disturbance, and appetite loss, it may be difficult to distinguish between them. Although a full depressive reaction may accompany a normal grief response, grief typically does not include the loss of self-esteem, worthlessness, or overall sense of guilt that characterizes depression. The depressed person has consistently low mood or an absence of emotion, has little enthusiasm for previously enjoyable activities, and has little interest in others. In contrast, the grieving person has variable emotions and is likely to shift from being able to enjoy some activities to refusing activities and from wanting to be with others to preferring to be alone.

PEARLS

- Introduce the idea of loss and creative adaptation early in the course of illness, to assist people near the end of life and their loved ones with coping resources during each transition.
- During comprehension processes, allow time for the patient and family members to realize that a loss has occurred before they make final decisions about care.
- Acknowledge that a range of emotions (e.g., numbness, sadness, anger, anxiety, relief), some quite intense and variable, may follow awareness of loss for both the dying person and loved ones.
- Recognize that during creative adaptation processes, a patient's preferences for care may fluctuate as various adaptive strategies are considered.
- Revisit decisions about care during reintegration processes when adaptive strategies, self-concept, and preferences are relatively stable.
- Identify psychological, social, and spiritual distress.
- Involve a mental health professional early in the course of persistent depression, anxiety, and other distress symptoms.

PITFALLS

- Forcing final decisions about care before dying persons and their loved ones have fully comprehended a loss

- Failing to affirm the full range of emotions experienced by dying persons and their loved ones
- Difficulty accepting the fluctuating adaptive strategies and values of dying persons during the creative adaptation process
- Missing the opportunity during the reintegration process to confirm previous decisions
- Failing to recognize persistent psychological, social, and spiritual distress in dying persons and their loved ones
- Avoiding mental health needs of dying persons and their loved ones

SUMMARY

The losses of function, health, and well-being that occur at the end of life are among the most stressful of human experiences, and palliative care clinicians have little theoretical or empirical literature on which to base interventions. In this chapter, we describe adjustment to end-of-life losses from the perspective of the dying person. Awareness of a significant, irreversible loss, particularly one that signals a decline toward dying and death, can initiate adjustment processes that include comprehension, creative adaptation, and reintegration aspects. Clinicians can intervene more effectively in the care of the dying if their communications are guided by awareness of the adjustment process in which a person is engaged at a particular time. Worden's tasks of grief provide a similar framework for considering how best to provide support to the bereaved survivor.

Resources

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Endlink Resource for End of life Care Education: Available at http://www.endoflife.northwestern.edu

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Understanding and Respecting Cultural Differences

15

Kerry Bowman

CHAPTER OUTLINE

BACKGROUND AND SIGNIFICANCE
SOCIOCULTURAL DEVELOPMENT OF PALLIATIVE CARE
ELEMENTS THAT CAN LIMIT CULTURAL UNDERSTANDING
Marginalizing Ethnographic and Psychosocial Information
Secular Focus
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COMMUNICATION AND CONTEXT
HISPANIC PERSPECTIVES
Background
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SUMMARY

BACKGROUND AND SIGNIFICANCE

Although death is universal, dying is very much a culturally specific experience. *Culture* refers to learned patterns of behaviors, beliefs, and values shared by individuals in a particular social group. It provides humans with a sense of identity and belonging, and it gives us a framework for understanding experience. When referring to culture in its broadest sense, the term usually implies a group of people with similar ethnic background, language, religion, familial beliefs, and world view. Culture is a strong determinant of people's views of the very nature and meaning of illness and death. Culture also influences whether health-related or end-of-life-related decisions can or should be controlled, how bad news should be communicated, and how decisions (including end-of-life decisions) should be made.

As a result of profound demographic changes that affect many Western nations, physicians increasingly care for patients from diverse cultural backgrounds. Differences in beliefs, values, and traditional health care practices are of

profound relevance at the end of life. Culture shapes the expression and experience of dying and death as families prepare to lose a loved one. There is growing awareness that the care of the dying is deficient despite many advances in the field of medicine and multiple initiatives to improve this care. The burgeoning field of end-of-life care is receiving increased attention, and experts in the field are attempting to improve the care of the dying by clarifying priorities and establishing humane and respectful palliavtive care standards and practices. Simultaneously, Western nations are being transformed by rapidly changing demographics related to the growing numbers of immigrants from diverse backgrounds. Because culture provides the primary framework for understanding experience, it is critical to consider culture in relation to end-of-life care.

The heart of the problem is that health care providers, patients, and family members may have dissimilar beliefs about the meaning of illness or death, and they may not agree on which strategies are the most appropriate to alleviate pain and suffering or in planning for the end of life. Good palliative care may be compromised by disagreements between physicians and patients, by miscommunication, or by decisions or beliefs that are not understood or valued (1). Values that are ingrained in a physician may be alien to patients from different backgrounds. Because of the significant potential for misunderstanding, it is imperative that health care workers be cognizant of potential cultural differences and develop the skills necessary to identify such differences.

A way in which we often go wrong in medicine, and especially in palliative care, is that we see "cultural differences" as something rooted solely in the patient's perspectives. As health care workers, we also represent a "culture" in which perspectives on end of life have a social and cultural history. It is imperative therefore to recognize that working with patients new to our society represents the interface of two cultures: theirs and ours. It is naive and unrealistic to believe that differences in patient perspectives can be taken into account without first understanding the genesis of our own perspectives. To this end, we must explore the historic and contemporary perspectives on end-of-life care. The terms *Western* and *non-Western* are used in this chapter. This distinction is not geographic, but rather it is philosophical and anthropological. In the context of medicine, this distinction is grounded primarily in different beliefs about the primacy of the individual as well as the adherence to the biological views of health and illness.

SOCIOCULTURAL DEVELOPMENT OF PALLIATIVE CARE

An empirical and philosophical analysis of cultural differences in end-of-life care (2, 3) has started to identify significant differences in perspectives that are rooted in culture (4, 5). However, this limited analysis has not yet had a significant influence on the fundamental assumptions of end-of-life care. When considering culture and end-of-life care, it is important to note that, despite the broadening of perspectives in the field of end-of-life care, moral agency and individual autonomy remain at the heart of contemporary attitudes and may cause cultural conflicts. Many health care workers who deal with people at the end of life recognize the importance of culture, but they argue that despite significant cultural differences, fundamental, inherent, universal ethical principles can and should to be applied across cultures, nations, and all forms of human boundaries as death approaches.

The argument is founded in the belief that essential elements are embedded within the world's apparently diverse moral systems, such as *humanness* (defined as compassion for the pain and suffering of others) and recognition of the equal worth and basic autonomy of every human being.

These concepts of equal worth and autonomy stem from the European Enlightenment of the 18th century. Moral agency and individual autonomy were strongly expressed by Immanuel Kant, were later refined into the political philosophy of liberalism expressed by John Stuart Mill, and, in turn, were developed and refined by many subsequent philosophers. These concepts are fundamentally Western and may be truly foreign to many patients.

If these concepts are applied as universal and are seen as our guiding light in the face of death, what then, for example, of Asian philosophical traditions grounded in Taoism, Confucianism, or Buddhism, in which moral perspective and direction are illuminated by *interdependence* rather than independence? Such cultures are perplexing to most Westerners because they do not contain references to autonomy or self. We often believe that having an "open mind" and "taking our cues from patients" will ameliorate cross-culture misunderstanding. We must first acknowledge, however, that our deepest beliefs related to death and dying are also shaped by culture.

Table I–15–1 is developed from three paradigms from the social sciences: *cultural context,* as first described Edward Hall (6); *health locus of control*, described by Rotter (7); and *explanatory model of illness,* described by Kleinman (8). This table represents trends when dealing with individual patients and families at the end of life.

The following common clinical situation illustrates some of these conceptual differences in perspective. A patient who is in a cognitively incompetent state is brought into an intensive care unit (ICU). When the ICU team meets with the patient's family, they focus first on biomedical explanations of illness and the potential for brain death. They then ask whether the patient expressed any personal wishes about treatment before becoming incompetent and thus encourage an open and direct conversation about the severity of the situation and the potential for death. By exploring the patient's perspectives and values with the family, the team hopes to formulate the best plan for the medical care of the patient.

However, the focus on individual rights and choices, the direct and blunt verbal communication about such a personal and difficult situation, the introduction of the element of choice, and the focus on a purely biomedical explanation of illness and death may be so confusing for this family of non-Western origin that the result is a complete breakdown in communication. Inherent in this relatively standard approach is a belief in the Western definition of illness and death, a belief that the timing and circumstances of dying can and should be controlled. At the heart of each of these paradigms is the fundamental belief in the inherent value of respect for autonomy, even if the patient and the family are unaware of that concept.

ELEMENTS THAT CAN LIMIT CULTURAL UNDERSTANDING

Marginalizing Ethnographic and Psychosocial Information

Many medical approaches and bioethical models rely on comparative cases and examination of competing principles. Although these methods may be useful in

Table I–15–1 ▪ Trends in Dealing with Patients and Families at the End of Life

	Contemporary Medical Perspectives	Non-Western Perspectives	Clinical Approach
Beliefs about causation of death and dying	Death is biologically determined Dying occurs when medicine can no longer stave off, treat, or reverse illness. Death most often occurs in hospitals, and the declaration of death is ultimately in the hands of medical personnel.	Death may be seen in a broader and seemingly less tangible manner. It may be viewed as being linked to religious, social, spiritual, and environmental determinants. Some cultural groups may perceive illness and death as separate entities. Declaration of death is also socially and culturally determined.	Anticipate nonmedical perspectives on death. Allow cultural rituals. Allow flexibility with time spent with the dying or deceased. Explore perceptions about the causes of the critical illness, its treatment, and death.
Social structures	Equality Independence valued Strong acceptance and value given to autonomy	Hierarchy Moral value given to interdependence; family decision making	Allow patients and families to make collective decisions (in the absence of coercion).
Communication about dying with patients and others	Information explicitly communicated Moral obligation to truth telling because patient has right to know and must make autonomous decisions Information best overtly communicated	Moral duty to protect loved ones from negativity Cues taken from social context Frank communication about death often unacceptable Truth telling highly problematic	Ask the patient how much medical information he or she wishes. Ask how that information should be communicated.
Perception of a religiously/culturally meaningful death	Individual choice No direct association to medicine Can be an impediment to the acceptance of the futility of further treatment	May be the most critical aspect of death Greatly shapes the bereavement process	Allow rituals and flexibility with the number and timing of visitors. Accept nonmedical perspectives.
Perception of negotiating death (levels of negotiating treatment)	Patients are largely responsible for defining the "kind of death" they wish.	Suffering and death are largely a matter of fate and may hold profound spiritual meaning.	A trial of therapy allows patient outcomes to be determined more by "fate."
Timing of death	The timing and circumstances of death can and ought to be controlled as much as possible to respect a patient's autonomous choices.	The timing and circumstances of death and dying are preordained and a matter of fate.	Allow as natural a process as possible. If the patient is on life support, withdraw it gradually.
Nonverbal communication	Direct communication, even about difficult matters, is the most ethical approach.	Consider body language, and respect silences and rituals.	Listen more than speak. Consider body language. Allow and respect silences; consider their meaning.

defining some ethical issue, to understand end-of-life dilemmas fully, we must examine the social and cultural context within which the situation is embedded. Medical perspectives or comparative cases alone tend to marginalize many relevant factors such as culture or the personal and social meaning of a situation. Thus, the common effort to render end-of-life analyses as objective, rational, and unbiased by defining "value-neutral" concepts such as *futility* risks making end-of-life decisions socially and culturally neutral. Concepts such as futility and the lived experience of patients and families are separated by a substantial distance. Health care workers and medical literature often describe social and cultural factors as external "constraints" and frequently use the term *cultural barrier,* usually with the intent to analyze and clarify. However, the word "barrier" implies that culture blocks access to the resolution of the ethical issue, thus implying something *universal* on the other side of this barrier. Is there?

Secular Focus

Despite the significant Judeo-Christian contributions to end-of-life care and although many health care workers are aware of the profoundly religious and spiritual beliefs and contributions to end-of-life perspectives, health care in general continues to adhere to a largely secular perspective. This is understandable because a secular approach in medicine is a practical, political, and moral response that seeks to apply a unitary approach to the demands of complex and diverse cultures. Many would also endorse the idea that palliative care philosophy is emerging as a secular alternative to religious perspectives and is better able to serve a pluralistic, morally diverse society. However, by doing this we often isolate cultural issues from their spiritual and social context to achieve an institutionally sanctioned method of avoiding potential conflict. Unfortunately, our efforts to examine issues from a nonspiritual or nonreligious perspective make our approach limited, incomplete, and sometimes devoid of meaning and difficult to understand for many patients and families who are new to Western health care.

Focus on Individual Autonomy

Although challenges to the principle of autonomy are becoming increasingly apparent in medicine in general and in end-of-life care in particular (9), this awareness has not deeply affected standard medical practice. For example, much of the contemporary discourse in medical ethics equates autonomy with personhood, as though autonomy exists universally for all people independently of cultural perspectives. The extreme opposite of autonomy would be experienced by people who live in remote tribal societies where the concept of the individual is virtually nonexistent and holds little social relevance. Although we do not have people from remote tribal societies living in Western industrialized nations, this difference in perceptions of the self in relation to others illustrates the power and influence of culture. Despite this, the concept of autonomy remains the intellectual and moral foundation of Western medicine (10), and it is a direct manifestation of the Western concept of individualism: a belief in the importance, uniqueness, dignity, and sovereignty of each person and the sanctity of each individual life. According to this belief, every person is entitled to individual rights such as

autonomy of self, self-determination, and privacy. For most cultures, this focus on individuality neglects the vital role of personal interconnectedness and the social and moral meaning of these interrelationships.

Truth Telling, Negative Focus

Generally, Western medicine (and, in turn, end-of-life care) has responded to the cultural trends of placing a high value on truth telling. Yet in the presence of serious illness, many cultures believe that giving negative information may induce negative outcomes (11, 12). This belief reflects the considerable cultural differences concerning the interaction between mind and body. Some cultures are strongly protective of the critically ill and believe that ill loved ones require the same supervision and protection as well-loved children. Western medicine derives the physician's obligation to communicate the truth to patients from the rarely questioned belief in the patient's "right to know," which, when considered as unconditional, requires that patients must deal with the truth overtly and rationally. The belief is that patients will ultimately be better off, and this perspective is particularly powerful in oncology. Sometimes we meet the patient's refusal to accept the truth with impatience and believe they are in denial, a state that is understandable but generally considered unacceptable. From a Western perspective, we usually agree quickly about what the truth is as we anticipate outcomes based solely on medical perspectives, yet this view may mystify people of other cultural perspectives.

Attitudes toward truth telling are largely determined by culture. A qualitative study showed that Chinese seniors did not see truth telling as a moral absolute but instead believed that in many cases truth telling could produce more harm than good and should be dealt with in a cautious way that involved the family more than the patient (13). Another study that examined the attitudes of 200 seniors from four ethnic groups (African American, Korean American, Mexican American, and European American) found that Korean Americans and Mexican Americans were significantly less likely than European Americans and African Americans to believe that patients should be told about a diagnosis of metastatic cancer. A study of American Navajo perspectives concluded that the Navajo culture views medical information as harmful (14). In Taiwan, neither Western-oriented nor traditional Chinese doctors give information related to diagnosis and prognosis to patients who are facing life-threatening illness; instead, this information is given to family members, who, in turn, are expected to inform and support the patient. These findings have been supported by further studies involving Asian populations (15). Neither patients nor physicians view truth telling as an ethical issue. In the West, however, this practice would be considered a direct violation of the principle of autonomy.

Different Definitions of Death

Although many of us accept the standard medical determinations of death, there can be profound cultural variation in this area. The following example illustrates this variation. In Western health care, organ donation from brain-dead patients

may be seen as something positive and without a great deal of moral ambiguity. This is not the case from some non-Western perspectives. Japanese views of brain death and organ transplantation clearly illustrate such differences. One study, for example, suggested that in Japanese society, Shinto and Buddhism have strongly supported "natural" processes and approaches to dying (16). According to Buddhist belief, aging, illness, and death are inevitable once a person has entered the cycle of life. From a traditional Japanese perspective, a human being is the integration of body, mind, and spirit. After death, a person remains an integrated whole. The metaphorical center of the body, *kokoro,* has traditionally been located in the chest. Therefore, removal of an organ from a brain-dead human, especially from the chest, may be perceived as disturbing this integrated unit. The Japanese find a fragment of the deceased's mind and spirit in every part of a deceased person's body. It follows that the Japanese believe a dead person goes to the next world as a soul. Similar to a living person, this soul has its own body, senses, and feelings. The dead body must remain whole because if some parts are missing, the soul becomes unhappy in the next world. Such latent yet formative cultural views are not specific to the Japanese. For example, although not homogeneous in their views, many North American aboriginal people are profoundly uncomfortable with organ donation (17). In many non-Western cultures, death is viewed as a social event rather than a scientific phenomenon.

What are the cultural, historical, philosophical, and religious influences that have made certain ideas about death acceptable in the West? Perhaps it is because in the West, human beings have often been perceived as the blending of body and soul. Christianity has shaped the West just as Buddhism, Shinto, and Confucianism have shaped Japan. In Christianity, people are expected to respect the body after death because it was an essential part of the person during life; however, a body without a soul is no longer considered a person. With regard to organ procurement, many Christians perceive the donation of one's organs as an act of love and generosity (18). The spiritual value of nonreciprocal giving is central to Christian belief. This, in part, may have contributed to the widespread social acceptance of organ donation. In general terms, Western medicine and, in turn, end-of-life care, have accepted brain death as death and have embraced transplantation. Clearly, there are profound cultural differences in perceptions of validity of brain death and the moral value of organ transplantation; this cultural difference cannot be addressed by the often-stated need for better education of new immigrants.

COMMUNICATION AND CONTEXT

It is imperative to understand the influence of culture on communication. All cultures have verbal and nonverbal approaches to giving and receiving messages. Although we as health care providers working the realm of end-of-life care can easily acknowledge the medical and ethical complexities of end-of-life decisions, we have barely begun to acknowledge the psychological and sociocultural complexities. For many people new to scientifically advanced Western nations, several factors—including the absence of life-sustaining technology, a far shorter life expectancy, a higher child mortality rate, and a closer geographic proximity for many families—made death a more frequent, home-based experience that had little

Case Study I–15–1 ■ AN EXAMPLE: THE CARILLERO FAMILY

Mrs. Carillero is a 70-year-old Hispanic woman who was admitted to the ICU with metastatic bone disease from a primary site of breast cancer that has now spread to her lungs and possibly her brain. Mrs. Carillero has a large extended family that essentially never leaves her side. Earlier in the illness, the Carillero family had been asked to consider a palliative care facility in the future because of the possibility Mrs. Carillero's care could become complex and demanding, but the family steadfastly refused and asked that the topic not be brought up again. These family members have consistently advocated for full and aggressive treatment. The ICU rule of two visitors at a time is rarely being followed, and the ICU staff is becoming frustrated and upset. When visitors are asked whether they are immediate family, they fall silent.

Although the ICU staff assured the Carillero family that prayer was welcomed, the family is repeatedly having fairly loud ritualized prayer sessions. The ICU staff members now feel that these sessions have become disruptive to the unit and disturbing to the other patients and their families. In addition, the Carillero family had identified themselves as Catholics. A Roman Catholic nurse has stated she had, at first, joined them in prayer, but many elaborate rituals have been introduced, and many of the prayers are unfamiliar to her. She has openly questioned whether they are truly Roman Catholic and respectful of Catholic traditions.

Through negotiation, Mrs. Carillero's son Everett was chosen as spokesperson. When the physician told Everett about his mother's poor prognosis and the "futility" of further treatment, Everett appeared to not acknowledge the severity of the situation and insisted that his mother be fully treated. He told the doctor that he had the skill to do miracles. The health care team repeatedly asked Everett and other family members whether Mrs. Carillero had previously expressed wishes about what she would want if she were in her current circumstances. The family did not respond to this question. The team also asked: "If she could speak to us now, what would she tell us she wanted?" The Carillero family was again consistently silent on this question.

Everett says that he wishes to deal with things one day at a time and states that his mother's fate should be in God's hands, not determined by decisions made by either the doctors or the family. The family's unresponsiveness to these questions and their insistence on continued treatment have been interpreted by some as a means of focusing on their "agenda" rather than on Mrs. Carillero's wishes and best interests. The Carilleros told a patient relations officer that they are very upset by the constant staff changes; they said that they feel like they have no one really to talk to and they are feeling pressured to end Mrs. Carillero's life.

Everett has also demanded that should his mother regain consciousness even briefly, she not be told about her condition or asked questions about her wishes, because it would "kill her spirit." The physician explained to Everett that he had a legal and ethical obligation to inform his mother of her medical situation and to clarify her wishes should she become conscious and capable. Family members are now refusing to leave even when procedures are being done and state that they are afraid that medical staff will give up on their mother. Tension is growing, and the ICU team has deemed this case a serious ethical dilemma.

to do with choice. In Western nations, however, end-of-life decisions abound, and the stakes are high. These decisions involve life or death, views about the quality and meaning of life, high costs, moral principles, and legal rights. Not surprisingly, such decisions can generate intense emotions, particularly for those with no familiarity with the concepts involved, and can increase the potential for conflict.

Moreover, substantial differences in culture, combined with social class and education, often exist between physicians and families. What is known or valued by health care workers may be elusive or irrelevant to families. When differences exist, so too will perspectives on choices, and this disparity creates a greater opportunity

for conflict. Conflicting perspectives become increasingly obvious when major decisions must be made. Large health care teams with shifting and inconsistent members, each trained in specific professions with separate working cultures, often fracture communication and make for an environment that is not conducive to balanced discussion and negotiation. Furthermore, all these factors occur in the climate of continuing change that defines the contemporary health care system. For families, end-of-life decisions are not abstract philosophical questions or matters of clear-cut clinical judgment; rather, they are painful emotional experiences, greatly shaped by cultural and religious beliefs that can generate profound revelations about mortality and family relationships. As previously stated, rather than viewing culture as an integral part of a patient's identity and life, much of the health care literature depicts culture in terms of a barrier. Families, central to the end-of-life experience in most cultures, are frequently described by health care workers as being a help or a hindrance, as supportive or difficult (19). Furthermore, the cultural meaning of illness in the context of the family is often not identified and is poorly understood by health care workers. This patient-centered perspective in health care may be rooted in the strong focus on patient autonomy and the sanctity of the physician-patient relationship.

HISPANIC PERSPECTIVES

Background

Although cultural generalizations as a means of anticipating behavior are not useful and run the great risks of stereotyping and producing further conflict, exploring the general cultural trends outlined in Table I-15-1 can be a useful means of examining *existing* behavior (as opposed to prediction). The first point that must be considered when referring to Hispanics is that the term is a label of convenience for a cultural group with a common cultural heritage stemming from Spain's colonization of the Americas. Hispanics can be of any racial group (e.g., indigenous American, black, Asian, white, or of multiple racial ancestry). Hispanic immigration to most Western nations has been rising steadily and is particularly extensive in the United States, where the Hispanic population of 31 million will soon surpass African Americans as the largest minority group in the country. Although significant differences exist among Hispanic subgroups, virtually all share a common language, religion, traditional family structure, and several common values. In addition to differences in subgroups, they differ in terms of their level of acculturation or assimilation into mainstream culture. Language use is one very good example of these differences. For instance, although many Hispanics are bilingual, the degree to which they speak either Spanish or English varies considerably.

Cultural Features

Religion

One value shared by most Hispanics, as evident in the Carillero family, is religion. Although the degree of practice and church participation varies, most Hispanics are Christian, predominantly Roman Catholic. However, many Hispanics practice

other religious beliefs that they have incorporated into their Christianity, such as forms of ancestor worship with rituals dating back to pre-Columbian times among Central American Indians. For example, many Caribbean Hispanics practice *Santería*, a fusion of Catholicism and the Yoruba religion that was brought to Cuba by African slaves. Such rituals are described as *Espiritismo,* a belief in good and evil spirits that can affect health and well-being and that includes views on dying and death. The rituals performed by the Carillero family that others found loud and disruptive and the attending Roman Catholic nurse felt was not Catholic in nature were likely rooted in this cultural trend. As evident with the Carillero family, it is common to hold a continued vigil over an older family member with a terminal illness. These and other practices honor the loved one and form part of the bereavement ritual.

Lack of Focus on Individual Patient Perspectives and Large Number of Visitors

The large extended Carillero family network can be understood in a context of the strong role of family for many Hispanics, highlighted by powerful ties within an extended network of uncles, aunts, cousins, grandparents, and family friends. Included in this is the important role of the family in the concept of *familismo*, an emphasis on the welfare of the family over that of the individual, perhaps illustrated by the family's silence and reluctance to identify Mrs. Carillero's *independent* wishes.

Discomfort with Constant Staff Changes

The Carillero family informed a patient relations representative that they found the constant staff changes very disturbing at such a difficult time. This could possibly be attributed to the Hispanic concept of *personalismo,* a term that refers to trust building over time and is based on the display of mutual respect.

Reluctance to Partner with Physicians for Planning and Unrealistic Expectations

Everett's reluctance to discuss family issues and values with the physician as well as his potentially unrealistic expectations of physicians could be related to *jerarquismo,* a term that refers to respect for hierarchy.

Focusing on the Present and Avoiding Long-Term Plans

Everett's persistent wish to take things day by day may be tied to the concept of *presentismo,* a concept defined as maintaining important focus on the present instead of on the past or the future.

Avoiding End-of-Life Decisions

The family's fervent wish to avoid human influence in the timing of Mrs. Carillero's death may be seen as *fatalismo*, the belief that fate determines life outcomes, including health, and that fate is basically unbeatable.

Truth Telling and Advanced Medical Planning

In a study that compared beliefs of Mexican Americans, Korean Americans, African Americans, and European Americans on several issues related to patient autonomy,

researchers found that Mexican Americans and Korean Americans were less likely to believe that a patient should be told about a terminal diagnosis or make decisions about using life support. The researchers also found that Mexican American and Korean American elders were more likely than African American and European American elders to want family members to make these decisions (20).

Life-Prolonging Treatments

When it came to the issue of life-prolonging treatments at the end of life, Hispanic Americans and African Americans were more likely than non-Hispanic whites to report wanting their doctors to keep them alive regardless of how ill they were (42% and 37% versus 14%, respectively). Furthermore, only 59% of Hispanics and 63% of African Americans agreed to stop life-prolonging treatment, compared with 89% of non-Hispanic whites (21). It is possible that this trend reflects a mistrust of the system or religious beliefs related to not killing and the sanctity of life.

Palliative Care Perspectives

As seen in the Carillero family, some studies have suggested a significantly low use of palliative care services in Hispanic populations. Reasons may include unfamiliarity with palliative care, language barriers, and unpleasant experiences with or distrust of the health care system. Cultural factors may well be at play, however, and further research is required in this area.

How Could the Carillero Family Be Better Respected?

Because Hispanics have a significant demographic representation in our culture, it is wise to increase our knowledge about Hispanic culture by becoming familiar with the history of the subgroups we dealing with, as well as the family, social, and religious values associated with Hispanic culture. This will help providers to display respect and to build trust. The provider should include family members in discussions with the patient regarding treatment planning and palliative care. There may be situations in which the patient does not want to have the family included, and this wish, of course, should be respected.

Finally, it is important to have open and clear communication with the patient and family, because deference to and respect for the provider as a result of *jerarquismo* may lead the Hispanic patient to withhold information or to hesitate to communicate honestly. The provider must ascertain whether the patient understands the treatment being offered and whether he or she fully agrees with the treatment plan. This is particularly important when it comes to end-of-life decision making and advance directives, because several cultural factors discourage discussions of these topics. *Jerarquismo* may lead the patient and family to have unrealistic expectations about what conventional treatment can offer. The family may be expecting a miracle cure for the terminally ill patient and thus may refuse to consider palliative care treatment options. Appropriate religious representation is imperative to avoid perceived conflicts between the patient's religion and the withdrawal or withholding of treatment.

CROSS-CULTURAL AWARENESS IN PRACTICE

Keep in mind the following questions when working cross-culturally with patient:

- Does this patient value individuality and personal choice, or does he or she focus more on family and collective choices?
- Does he or she value open communication, or do they tend to draw cues from the context of the situation?
- Does he or she believe a person can and should influence his or her health or death?
- Does he or she believe in a Western explanation of illness, or do they hold an alternative culturally based view, and is this view blended with Western perspectives on illness?

PEARLS

- Cultural differences vary extensively. Do not assume; always ask.
- When working cross-culturally, there is a good chance that your patient and his or her family may not value individuality over interdependence. Ask your patient how he or she would like decisions to be made.
- Not everyone believes in Western medicine. To understand your patient's perspective better, ask: "What do you think is causing your illness and how should it best be treated?"
- Truth telling is often not valued when working cross-culturally. Accommodate for this possibility by asking how and to whom information should be given and how and with whom decisions should be made.

PITFALLS

- Be careful when assessing emotional reactions cross-culturally.
- Do not assume to know another's cultural views. Always ask.
- Do not assume that patients are aware or accepting of a Western biomedical view of illness. Inquire, give your perspectives, and negotiate a treatment plan.

SUMMARY

Cultures are maps of meaning through which people understand the world and interpret the things around them. When patients and health care workers have different cultural backgrounds, they frequently follow different "maps," and this can hinder effective communication.

As a result of profound immigration and the resultant demographic changes, health care workers increasingly care for patients from cultural backgrounds other than their own. Culturally constructed differences in beliefs, values, and traditional health care practices are of profound relevance at the end of life. Culture greatly determines the expression and experience of death and dying as patients and

families prepare to lose a loved one. As much as contemporary end-of-life care critiques and acknowledges cultural differences, it remains questionable whether we have truly explored the profound significance of the cultural differences of the values given to independence and interdependence, present or future orientation, intervention with the timing and circumstances of death, and the way in which families and patients understand the nature and meaning of death. Nor have we compensated for how greatly these factors lead to substantial differences in cognitive processes, perception, social structures, values, and beliefs in both patients and health care workers.

Those who work in the domain of end-of-life care must undertake a deeper exploration of those social and cultural realities that shape end-of-life experiences. Although end-of-life care increasingly identifies and values interrelationships with others, autonomy and, in turn, the individual, remain at the heart of end-of-life analysis. Our organizational and legal structures assume that the person experiencing the illness is the best person to make health care decisions. This raises profound questions about the adaptability of end-of-life care in a culturally pluralistic society. Because many cultures vest the family or community with the right to receive and disclose information, and to organize and make decisions about patient care, we must be constantly cognizant that the cross-cultural application of the concept of autonomy will mean accepting each person's terms of reference for their definition of self. Specifically, we should respect the autonomy of patients and families by incorporating their cultural values and beliefs into the decision-making process. Although this may sound straightforward, it is easy to lose sight of this principle in our busy practices.

Ultimately, the most effective way to address cultural differences in end-of-life decision making is through open and balanced communication. When health care workers are uncertain about how a patient or family perceives a situation, it is best simply to ask. Differences can frequently be negotiated easily. Many people now living in Western cultures already hold blended views of culture, illness, and death. The mere acknowledgment of such differences will usually lead to improved communication. In health care, we often assume that respect and acceptance of cultural diversity are givens, yet it is important for us to remember that despite our openness to other cultures, our attitudes toward end-of-life care are as much an effect of *our* cultural beliefs as they are of the many diverse cultures we see in practice. We must make a significant effort to raise our awareness and to alter our practices in this crucial area.

Resources

AT&T LanguageLine: The AT&T language bank does translation. These interpreters are not trained in medical interpretation. Further, because they are on the telephone, they do not have access to the visual information in the setting. The AT&T language bank (LanguageLine) can be reached at 1-800-752-0093 extension 196. Also available at www.languageline.com

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Xculture. This web site has a short and long glossary of medical terms in several languages. Available at www.xculture.org

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D Specific Situations and Skill Sets

16 Advance Care Planning

Helene Starks, Elizabeth K. Vig, and Robert A. Pearlman*

CHAPTER OUTLINE

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How Is Decisional Capacity Assessed?
When Should Conversations Occur?
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What Communication Strategies Are Most Helpful?
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PEARLS
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SUMMARY

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OVERVIEW

Advance care planning is a process that aims to align medical decisions with patient preferences in the event that the patient cannot communicate his or her preferences. In the context of palliative care, advance care planning discussions offer a framework for exploring a patient's current values and goals, as well as how these could change as the illness evolves. To facilitate the implementation of advance care planning in palliative care, this chapter explores the following questions.

1. Which patients should engage in advance care planning?
2. Can patients with cognitive impairments also have these conversations?
3. How is the ability to communicate preferences assessed?
4. When should conversations occur?
5. Who should initiate the conversation?
6. What communication strategies are most helpful?
7. How should the conversation be introduced?
8. What topics should be addressed?
9. What strategies can be used when patients and families are reluctant to discuss these issues?
10. How can clinicians bill for the time spent in advance care planning conversations?

Ideally, advance care planning should begin early in the clinical relationship and should be revisited periodically, especially when changes in health status or goals of care occur. When possible, family members, especially designated proxy decision makers, should be included in these conversations because it is important for them to be aware of any changes in the patient's values and preferences. Exploring the reasons behind any changes can be very helpful in bringing discordant views into alignment.

INTRODUCTION

Advance care planning is a process that aims to inform and facilitate medical decision making that reflects patients' preferences in the event that patients cannot communicate their wishes. This process is achieved in many ways, including conversations with patients and families, the use of written advance directives that document a patient's wishes, and the participation of surrogate decision makers who can represent a patient's interests, values, and preferences. In this chapter, we first define the terms advance care planning and advance directives and provide a review of the evolution of these terms and mechanisms in practice. We then explore how to practice advance care planning in the context of palliative care and include a set of questions that can be used to guide advance care planning discussions with patients and family members. Finally, we review ways that clinicians can be reimbursed for the time spent in lengthy advance care planning conversations with patients and families.

DEFINITIONS

The Institute of Medicine defined advance care planning as "not only the preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions (including decisions should sudden and unexpected critical medical problems arise), and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families" (1). As such, advance care planning is a process—not a single event—with two basic components: thinking about preferences and goals of care, and communicating these preferences to loved ones, surrogate decision makers, and health care providers (2). For the first component, a patient needs to consider the many factors that influence care preferences, including beliefs about suffering, the sanctity of life, withholding and withdrawing treatments, estimated life expectancy, current quality of life and the probability of achieving a desirable outcome if treatment is pursued, and the cost of treatment or nontreatment to the patient and family (in both monetary and nonmonetary terms). Ideally, the person who engages in this deliberation process will be able to identify a personal threshold of acceptability for the benefits and burdens of future treatment. For the second component of advance care planning, the patient must communicate preferences to those persons who will be involved in making decisions on his or her behalf. These surrogates could include a legally appointed proxy decision maker, family members, and intimate others. Values and preferences can be communicated through formal conversations about the person's wishes as well as through informal discussions about the serious illness or death of family members or friends or about current events in the news that represent undesirable health states. Communication also includes documenting the person's wishes through advance directives or other means, such as letters or video recordings.

Advance directives can be informal verbal agreements, health care providers' written summaries of patient values and preferences in the medical record, or formal, legal, written documents. The formal documents have the potential advantage of providing the "clear and convincing" evidentiary standard that is required in some states (e.g., New York and Missouri) as proof of the person's wishes in the event of a legal dispute. These documents have two forms: a *durable power of attorney for health care*, in which the person identifies a designated proxy decision maker (or decision makers), and an *instructional directive* (commonly known as a living will), which is a written statement of instructions to guide medical decision making. Living wills specify treatment preferences under conditions of terminal illness or a persistent vegetative state. The durable power of attorney for health care and the living will are recognized as legal mechanisms everywhere in the United States.

HISTORY AND CRITIQUE

Laws that allow advance directives to guide the nonuse (or use) of life-sustaining treatments were first drafted in the mid-1970s, about the same time as the sentinel

court case of Karen Ann Quinlan. This young woman was in a persistent vegetative state, and, when her physicians declined to remove her breathing tube, her parents petitioned the court to remove it. The Quinlans eventually won the case, thus setting a legal precedent for the right to refuse unwanted medical treatments. State laws to the same effect began to appear throughout the United States, and a similar case, that of Nancy Cruzan, was settled in favor of the same right in the United States Supreme Court. The legal effort continued with passage of the Patient Self-Determination Act in 1990, which required that all health care facilities receiving federal funds offer patients information about advance directives and inform them of their right to refuse unwanted medical treatments (3).

Since the 1970s, a great deal of work has been devoted to increasing the access, availability, usability, and completion of advance directives (4). This was complemented by research and interventions designed to increase the use of advance directives in health care systems and to simplify the language and process of documenting preferences. Additional community-based initiatives were developed to educate the public and to increase completion rates. Although there have been a few notable successes (5, 6), most of these efforts have had modest effects on the rate of directive completion. Currently, approximately 30% of US residents complete written advance directives, although the number of US residents who have discussed the issue may be larger. Yet even among those who have advance directives, some steps in the advance care planning process may not be complete. Providers may not know that a directive exists, the directive may not be located or brought in when a patient is admitted to the hospital, or it may be ignored or overruled during the hospital stay (7).

Recent critiques have described multiple aspects of living wills that make the application of these documents problematic in practice:

1. People must obtain and complete the forms.
2. They must predict their future assessments of quality of life and preferences for life-sustaining treatments.
3. They must state these preferences in writing.
4. The documents must be available for use when necessary.
5. The proxy decision makers, family members, and health care providers who interpret these documents must be able to understand them in the context of the current situation.
6. The surrogate decision makers must then follow the written instructions as originally intended (8).

Critics argue that these conditions are virtually impossible to meet and that society should abandon this approach to extending autonomy at the end of life. They advocate continued use of proxy decision makers and also endorse the general shift in focus away from the legalistic documents toward the iterative process of advance care planning, which emphasizes eliciting the patients' values and goals of care rather than specific treatment preferences.

In spite of the critique of living wills, there remains the need to document advance care planning discussions to facilitate the transfer of information between institutions, to provide evidence of the patient's wishes in the event of a dispute, and to guide and support proxy decision makers. Several authors have developed worksheets and workbooks to facilitate this documentation. These documents take

different forms (see the Resources section for links to these different types of documents). Some emphasize patient values (e.g., the Values History Form), and others offer a range of situations and treatment choices and allow for the identification of personal thresholds for medical intervention (e.g., Your Life, Your Choices and the Medical Directive). Another effort that has had positive effects on the outcomes and processes of care is the Physician Orders for Life-Sustaining Treatment (POLST) form. Technically, the POLST is not considered an advance directive because it is completed by a physician rather than by the person whose wishes it conveys. It was developed to provide standing physicians' orders for emergency medical personnel (who cannot legally follow advance directives in emergency situations) and to serve as a transportable document to guide health care decisions between and across health care institutions. Evaluations of the POLST have demonstrated that the document improves both identification of and compliance with patients' wishes in multiple settings (9).

ADVANCE CARE PLANNING IN PALLIATIVE CARE

In the context of palliative care, advance care planning discussions also offer a framework for exploring a patient's current values, goals, and treatment choices, as well as how these may change over the trajectory of illness. For example, early in the course of cancer, palliative care may primarily serve as complementary therapy, with the goal being to alleviate symptoms associated with curative treatments. As the cancer progresses and cure is no longer an option, palliative care can become the primary goal of care. Goals of care may shift toward staying at home, maximizing comfort regardless of how that affects participation in daily activities, or finding a balance between controlling pain and still maintaining cognitive function. To the extent that the patient is capable of participating in these discussions, these goals will be established and updated in real time, but these discussions also serve as advance care planning to guide care when the patient can no longer express his or her wishes.

Putting advance care planning into practice requires the consideration of several issues. These include determining which patients are appropriate, deciding when and how to introduce the discussion, selecting members of the health care team who are best suited to initiate these discussions, and establishing the specific areas to be covered.

Which Patients?

All older adults and all patients with chronic or serious illness could benefit from advance care planning discussions, especially those who are likely to experience exacerbations of the illness that could cause loss of decisional capacity and require emergency therapy. Advance care planning offers the opportunity to identify goals of care, to explore contingency plans, and to prepare patients with serious illness for the probable trajectory of the illness. All patients in transition to a terminal phase of illness are ideal candidates.

Can Cognitively Impaired Patients Participate?

Patients with dementia, delirium, and psychiatric illness present unique challenges for advance care planning, but they may still be capable of participating. Patients with dementia, especially those in the early stages, may be able to express preferences for aspects of care, such as their preferred surrogate decision maker. Keys to success include initiating the discussion when patients are doing their best and framing questions in simple terms. It is far better to try to elicit preferences and to assess how much is understood than to assume that persons with dementia cannot participate at all. Patients with psychiatric illness also may be able to participate in advance care planning. During periods of remission or when their illness is well controlled, they can express preferences for future situations of decisional incapacity. They may complete two kinds of directives: a living will to guide end-of-life care and a mental health advance directive to guide care during acute exacerbations of mental illness (see the Resources section for links to sample psychiatric directives).

How Is Decisional Capacity Assessed?

For their preferences to be legally and ethically valid, patients need to have intact decision-making capacity. However, it is not appropriate to use a diagnosis of dementia, delirium, or other psychiatric illness to connote decisional incapacity because patients with cognitive impairments or psychiatric diagnoses may be able to assess the risks and benefits of some decisions, but not others (10).

Decisional capacity to choose a medical treatment is also not the same as capacity to complete an advance directive. Voicing preferences in a directive is more complicated than choosing to receive or forego a recommended treatment in a contemporaneous situation. Formulating preferences for a directive requires a patient to consider a future time and hypothetical circumstances involving interactions between treatments and health states. Decisional capacity to execute an advance directive presupposes meaningful, comprehensive communication between the health care provider and the patient. Health care providers should try to ensure that the patient understands and appreciates that the choices articulated in a directive will be used in the future when the patient is no longer capable of participating in the decision-making process. Moreover, the health care provider should ensure that the patient understands that choices can involve medical treatments and the designation of a proxy, as well as the relative strengths and weaknesses of alternative approaches to advance directives. The patient should be able to understand that choices can change over time, and if they do, that he or she can and should change the directive.

When a patient's decision-making capacity is in doubt, clinicians should assess the elements of decisional capacity. For patients to make decisions about preferred future treatments, they need to have the capacity to:

1. Understand broadly that they are thinking about future situations in which life-sustaining treatment may be needed and what that treatment could entail.
2. Appreciate that these choices would be applicable in future situations in which they developed life-threatening illness.

3. Use their reasoning to reach an opinion about whether the benefits and burdens of having life-sustaining treatment would be acceptable to them.
4. Choose and voice a goal of care or treatment preference. Difficult cases can be referred for psychiatric or ethics consultation.

When Should Conversations Occur?

The best time for advance care planning discussions is before the patient becomes acutely ill. Many patients are willing to have these conversations but prefer that clinicians raise the topic. Ideally, these conversations should happen in an outpatient setting, before a crisis occurs that could impede the patient's ability to think through values and preferences carefully. Other opportune times are those that could be viewed as "teachable moments," for example, after a recent hospitalization or health crisis, when patients raise specific concerns about their care, or when they share stories about the death or serious illness of a close friend or family member. Such moments offer the opportunity to explore a patient's hopes and fears and the values that shape these feelings.

Many palliative care clinicians meet the patient for the first time in a hospital setting. The challenge then is first to determine whether or in what ways the patient is able to participate in discussions. Even when the patient is seriously ill, clinicians should attempt to include him or her in advance care planning discussions to the extent that he or she is able to participate. However, because more than 90% of patients in intensive care units are unable to communicate at the time decisions need to be made about withholding or withdrawing life-sustaining treatments, clinicians will need to identify the proxy decision maker(s) who will be able to assist with determining appropriate goals of care.

Who Should Initiate Conversation?

Any of the clinicians who establish a relationship with the patient and family can initiate advance care planning conversations. Physicians, nurses, and social workers each bring different expertise and points of entry. Because advance care planning is an iterative process, it can be enhanced when more members of the health care team participate. Physicians bring the perspective of medical facts and available treatment options to advance care planning conversations. Their knowledge of the patient's condition and probable trajectories of illness can help patients and families to understand the range of possible outcomes of future decisions. Regardless of who initiates the conversation, it is important to ensure physician involvement at some point in the process because physicians have the ultimate responsibility for implementing medical decisions and they can probe for inconsistencies in the patient's preferences. For example, some treatment preferences may not match with one another or with stated goals of care, such as, "I want CPR but do not want to be hospitalized."

Nurses bring their expertise in patient education and may be better suited to exploring the psychosocial aspects of the patient's life. In hospital settings, nurses frequently elicit patient and family values with respect to treatment goals. They often serve as information brokers, before and after advance care planning discussions, by answering additional questions, clarifying misunderstandings, explaining

details of medical treatments, and revisiting topics addressed in earlier advance care planning discussions.

Social workers can initiate advance care planning conversations by introducing the topic of advance directives and by helping patients and families complete legal documents. In their exploration of social support and service needs, social workers may uncover important values and beliefs that shape patient and family preferences. In addition, their understanding of family dynamics is very helpful when the need arises to negotiate differences of opinion or achieve family consensus about changing goals of care.

What Communication Strategies Are Most Helpful?

Research has identified that good communication skills are vital to the success of advance care planning discussions. Skills that are particularly valued include being able to listen without interrupting, being open to questions, being sensitive to when patients choose to engage and not to engage in these discussions, using plain and honest language, ensuring that patients and families understand what is being said, and appearing comfortable when talking about death and dying (11). Effective communication strategies that invite an open dialogue include using empathy to respond to the patient or family's emotion and using techniques such as "ask-tell-ask" and "tell me more" to ensure understanding and to elaborate on important values (12). In "ask-tell-ask," the clinician asks the patient and family to explain their understanding of the current situation, then tells them the objective for the conversation (e.g., to deliver bad news about prognosis or the need to revisit goals of care given the patient's change in condition), and then asks again for the patient and family to restate their understanding. "Tell-me-more" is a strategy that allows clinicians to determine whether patients and families need more information to understand the situation or the decisions that need to be made, how they are responding emotionally to the conversation, and what the conversation means to them. All of this is useful in deciding how to pace the conversation and what topics should be addressed.

How Should the Topic Be Introduced?

There are many ways to introduce the topic of advance care planning, and the choice depends on the clinician-patient relationship and the setting where the conversation takes place. Normalizing the topic and being comfortable discussing it help to put patients and families at ease. In outpatient settings, it is important to explain why the topic is being raised during this particular appointment. Box I–16–1 offers some possible scripts that could be used under different circumstances.

What Topics Should Be Addressed?

A range of topics can be addressed, depending on how willing the patient is to engage in the process. At a minimum, patients should be asked to identify the person or persons who should speak on their behalf if that becomes necessary. It is important to inform patients about state laws on the legal hierarchy of surrogates

BOX I–16–1 *SCRIPTS FOR INTRODUCING ADVANCE CARE PLANNING*

Routine Visit with No Recent Changes in Health Status

It looks like you are doing well right now, and I expect it to continue that way in the near future. I like to talk with all my patients about their preferences for care in case they get very sick and to determine who they would want to make decisions for them if they were too sick to make their own decisions. I think it's best to talk about these things when patients are feeling well and long before we have to react to a crisis. That gives both of us plenty of time to talk about what matters to you so that I can give you the kinds of care that match your goals. Would it be okay for us to talk about this today?

Episode of Acute Illness or Hospitalization

To make sure that we are working together while you are so sick, it is important that we talk about your goals for care at this time. I know it can be hard to think about these things when you are ill, but would it be okay for us to spend a little time talking about this right now?

Follow-up Visit after Illness Exacerbation

You were pretty sick last time I saw you. Are you feeling better now? It's times like this that I like to talk about goals of care to make sure that I'm up-to-date with what you would want in case you have another episode like that and others might have to make decisions for you. Would it be okay for us to talk about this now?

in the absence of a durable power of attorney. Typically, the hierarchy is as follows (although this should be verified against state laws): court-appointed guardian, durable power of attorney for health care, spouse, adult children, parents, adult siblings. These hierarchy laws may cause problems for some patients, particularly those with large families or nontraditional family relationships, such as common-law or same-sex partners. For example, many patients do not know that some state laws require consensus among multiple persons in a category (e.g., all adult children must agree) or that estranged spouses still have legal authority over others to make surrogate decisions. These patients should be encouraged to complete a durable power of attorney for health care to give their surrogate more legal standing as the preferred and legal decision maker.

Most patients are willing to identify a surrogate. Although cognitively impaired individuals may not be able to make decisions about treatment, they may still be capable of identifying which person they would prefer to make decisions on their behalf. Box I–16–2 provides a set of criteria for evaluating who would be the best candidates to act as a surrogate. After a surrogate has been identified, it may be best to end the first advance care planning conversation by encouraging the patient to have the surrogate attend the next visit to discuss preferences and goals of care.

When the surrogate is present, it is helpful to restate the goal of the advance care planning discussion and the role of the surrogate decision maker, including a reminder that the surrogate's authority as a decision maker takes effect only when the patient becomes decisionally incapacitated. The clinician can then review what is known about the patient's wishes and can give the patient an opportunity to expand on preferences and goals of care. Box I–16–3 lists questions that clinicians can use to discuss a patient's preferences and goals of care.

BOX I–16–2 RECOMMENDATIONS FOR CHOOSING A DURABLE POWER OF ATTORNEY FOR HEALTH CARE

The person chosen for the role:
- Meets the state legal criteria for durable power of attorney for health care.
- Would be willing to speak on behalf of the patient.
- Would be able to act on the patient's wishes and separate his or her own feelings.
- Lives close by or could travel if needed.
- Knows the patient well and understands what is important to him or her.
- Could handle the responsibility, physically and emotionally.
- Will talk with the patient now about sensitive issues.
- Would be available in the future if needed.
- Would be able to handle conflicting opinions among family members, friends, or medical personnel.

BOX I–16–3 SPECIFIC QUESTIONS TO ELICIT PREFERENCES AND GOALS OF CARE

Who should speak for you if you're too sick to speak for yourself?
What is your understanding of your current illness?
What are your hopes and fears about your illness and how it's going to affect you in the future?
Are there any situations you can think of in which it might be preferable to die rather than be kept alive with life-sustaining treatments? Why?
Are there any life-sustaining treatments that you would not want under any circumstances? Why?
When hearing about the illnesses or deaths of others, have you ever said to yourself, "I wouldn't want to live like that"? What is it about those situations that made you say that?
What are your past experiences caring for someone who is or was seriously ill? What did you learn from those experiences about how you want to be cared for?
Who do you count on for support? Is there anyone specifically that you would want to be involved in your care (including family, friends, and religious or spiritual advisers)?

Topics to explore include gaining an understanding of patient and family values and beliefs with respect to what makes life worth living. Sometimes this topic can be explored through a discussion of undesirable outcomes or situations in which the patient would prefer death over continued existence on life support. Patients frequently identify persistent vegetative states and other conditions as a "state worse than death." If they mention these states, it is important to explore what it is about them that they consider unacceptable, especially because patients frequently end up in situations that do not exactly match their conceptualizations. The term "vegetable" can mean many different things to different people. Therefore, it is important to have the patient define the term. In addition, some patients have strong feelings about "*never* being on machines." Again, it is important to explore the source of these feelings because they are frequently based on misunderstandings of what the treatment entails or because they do not know about the option of therapeutic trials that can be stopped after a short time. Discussions about specific treatments should always be framed around goals of care and how

those treatments will be used to reach the desired outcome, not the outcome in and of itself.

The patient and the surrogate should discuss the degree of interpretive leeway that can be exercised in adhering to the patients' previously expressed preferences. Research has documented that many patients are comfortable with allowing surrogates some leeway in decision making (13). Additionally, although autonomy is the major principle that guides advance care planning, some patients who still retain decision-making capacity prefer to defer to the judgment of their surrogates and acknowledge that the best outcome may be one that does not always maximize their personal autonomy. One reason that patients defer decision making and allow surrogates leeway in interpreting their preferences is to avoid burdening their loved ones and because they recognize that family members have—and should be able to consider—their own needs and interests.

It is important to determine whether the surrogate is comfortable with the plan and to discuss any anticipated difficulties (e.g., discomfort making the decision to withdraw life support) or fundamental differences in values (e.g., definition of acceptable quality of life). Surrogates often need support with coming to terms with their loved one's illness and impending death. Sometimes differences in values reflect surrogates' difficulty with letting go and may signal the need for help with anticipatory grief or with feeling overwhelmed by the responsibility for making life-and-death decisions. It can be helpful to reassure surrogates that the clinical team will be responsible for making treatment recommendations and treatment decisions about the withdrawal of life support. The surrogate's role will be to represent the patient's values and preferences with respect to the goals of care. This can help to relieve the surrogate's feelings of responsibility for causing the patient's death when, for example, decisions about withholding or withdrawing life-sustaining treatments need to be made.

For patients with chronic illness or those whose trajectory of decline is somewhat predictable, it is very useful to discuss contingency plans for how the patient and family may respond to acute exacerbations or other sudden changes in health status. Patients and families report that being prepared for the next steps on their illness journey is highly valued (11). Knowing who to call and where to go in an emergency helps patients and families to manage the uncertainties of illness and dying.

Some authors advocate discussing prognosis with patients as part of advance care planning, especially if the patient may die in the next 12 months. The benefits of discussing prognosis with those patients who are willing to do so is that it can help them and their families prioritize how they would like to spend their remaining time. In addition, a patient's preferences for life-sustaining treatment may be shaped by his or her understandings of the prognosis. For example, patients who are optimistic about their survival are more likely to choose more aggressive therapies, even those therapies that care providers consider futile. In contrast, patients who acknowledge a shorter life expectancy are more likely to accept hospice referrals and the shift in goals to palliative care (14).

What If Patients and Families Are Reluctant to Discuss These Issues?

Patients and family members have legitimate reasons to resist engaging in advance care planning discussions. These include cultural traditions that discourage discussing bad news to keep it from manifesting, a desire to avoid thinking about

death and dying as a coping mechanism, and an unwillingness to focus on future events either because it distracts from the present or because there is no point in speculating about events that cannot be controlled (15, 16). For all these reasons, it is a good idea to ask permission to discuss the topic before fully launching into the agenda. If the patient appears hesitant, the discussion should focus on appointing a surrogate decision maker. One way for the clinician to frame further exploration of preferences is to explain that this is a means of helping the patient hope for the best while preparing for the worst. The "ask-tell-ask" and "tell me more" strategies can be useful ways to explore the patient's hopes and fears. Responding to emotions allows for exploration of possible barriers to engaging in advance care planning discussions. If the patient is reluctant to talk about death and dying, exploring that reluctance may allow the health care provider to discover a way to approach the topic that feels more comfortable to the patient and family. Although they may be uncomfortable imagining themselves with life-threatening illness, some patients are willing to discuss the illnesses and deaths of people in their lives or in the media. Probing a patient's opinions about the situations of these other individuals can be an indirect way to obtain information about their preferences. If patients choose not to engage in the specifics of advance care planning discussions, it is reasonable to describe how future decisions likely will be made and by whom, so the patient is aware of the consequences of his or her choice.

How Can Clinicians Bill for Advance Care Planning?

Advance care planning discussions can be lengthy and time consuming. Clinicians can, however, be reimbursed for the time invested in these discussions if the visits are documented and coded appropriately. Current Procedural Terminology (CPT) codes are used to bill for the face-to-face contact between patients and clinicians. Previously published articles address ways to bill for the time spent providing palliative care in hospital, home, nursing home, and outpatient settings and contain useful tables listing the applicable CPT codes (17). Some important aspects in the context of outpatient care are reviewed here.

If more than 50% of a visit is spent counseling or giving information, then the clinician can use Evaluation and Management (E&M) codes to bill for the visit by time, not by the complexity of the medical decision making (see Table I–16–1 for a list of codes). The documentation for the visit should include a statement that indicates the length of the visit and documents that more than 50% of the visit was spent on counseling or giving information. If a visit lasts longer than the time allocated by the CPT codes, additional "prolonged service" codes can be used to account for this extra time. However, these prolonged service codes do not take effect until 30 minutes after the end of the first CPT code.

For example, if a total of 100 minutes of an established outpatient visit is spent discussing advance care planning, the first 40 minutes are billed using code 99215, the next 30 minutes are "free" and not billable, and the last 30 minutes are billed using code 99354. If the visit lasts longer than 100 minutes, then each subsequent 30-minute period would be reimbursed by using code 99355, which can be used multiple times. Codes also exist for contact with families when the patient is not present (i.e., 99358, 99359), but these codes routinely are not reimbursed. There

Table I–16–1 ■ Billing Codes for Advance Care Planning Discussions

New Office Visit	
Code	**Time**
99201	10 min
99202	20 min
99203	30 min
99204	45 min
99205	50 min
Established Office Visit	
Code	**Time**
99211	5 min
99212	10 min
99213	15 min
99214	25 min
99215	40 min
Prolonged Service	
Code	**Time**
99354	30 min
99355	Each subsequent 30 min

are no International Classification of Diseases (ICD) codes for advance care planning or palliative care. The ICD code assigned to the visit should reflect the patient's chronic illness or symptoms.

PEARLS

- Initiate advance care planning discussions as a component of early goal planning conversations because patients are often waiting for clinicians to raise this topic.
- Include surrogate decision makers in these discussions whenever possible to ensure shared understanding of goals of care among all stakeholders (patients, surrogates and other family members, and health care providers). If surrogates cannot participate, encourage patients to discuss their preferences, goals, values, and preferences with their surrogates and family members.
- Use the patient's (and family's) values and goals of care (rather than specific treatment preferences) to focus advance care planning discussions.
- Check in early and regularly throughout a patient's illness while he or she still is capable and, when clinical changes occur, to ascertain whether the patient's goals of care have changed.
- Use communication strategies that include lay language and invite open-ended dialogue to ensure that patients and family members understand what

is being said and to provide opportunities for patients to express their values and preferences.
- Know that with appropriate documentation and coding, you can be reimbursed for the time spent in advance care planning discussions.

PITFALLS

- Waiting until the patient is near death to engage in advance care planning conversations
- Equating advance care planning with completion of advance directives or a POLST form
- Assuming that patients with dementia cannot express their wishes
- Not checking with surrogates to see what help they may need in implementing the patient's care plan
- Forcing patients and families to engage in specific conversations when they are not ready or willing to discuss details about death and dying

SUMMARY

Advance care planning is an integral part of palliative care and is one way to monitor changing goals of care as the illness progresses. Because people continue to accommodate to new challenges presented by their illnesses, it is important to check periodically to ensure that earlier values and preferences continue to be relevant and applicable. Patients may be more or less willing to discuss details about their prospective preferences for future treatments. For this reason, we recommend that advance care planning focus on establishing goals of care, given the likely trajectory of the patient's illness, and the appointment of one or more designated proxy decision makers. When possible, these proxies should be present for any discussions about shifting goals of care because it is important for them to be aware of any changes in the patient's values and preferences. Exploring the reasons behind any preferences, including changes, can be helpful in bringing discordant views into alignment. This process can also identify areas in which family members may need support to help them manage anticipatory grief or closure with their loved one.

Resources

Advance Psychiatric Directives: Available at http://www.bazelon.org/issues/advancedirectives/
Balaban RB: A physician's guide to talking about end-of-life care. *J Gen Intern Med* 2000;15:195–200.
Center for Ethics in Healthcare POLST.org. Oregon Health Sciences University. Available at http://www.ohsu.edu/ethics/polst/
Medical Directive: Available at http://www.medicaldirective.org/current/index.asp
Pearlman R, Starks H, Cain K, et al: Your Life, Your Choices: Planning for Future Medical Decisions: How to Prepare a Personalized Living Will. Veterans Heath Care Administration. Available at http://www.hsrd.research.va.gov/publications/internal/ylyc.htm
Values History Form: Available at http://hsc.unm.edu/ethics/advdir/vhform_eng.shtml

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Responding to Requests for Euthanasia and Physician-Assisted Suicide

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CHAPTER OUTLINE

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INTRODUCTION

The palliative care movement has developed in response to concerns that care at the end of life had been badly done in the midst of the acute care and technological advances of 20th-century medicine. The goals of palliative care are to provide better medical care for pain and symptom control and to attend more appropriately to the personal, emotional, and spiritual issues at the end of life (1). Care at the end of life has been one of the traditional goals of medicine, so why the need to develop a special focus on the end of life in health care?

The need emerged not because of modern medicine's failures, but from its successes. Phenomenal advances in medical science and technology during the 20th century increased fears of dying and loss of control at the end of life to a sterile and terrifying technology. We had become not just a death-denying but a death-defying society with an almost limitless possibility of medical benefit where something *more* could always be done. Those same technologies that can save life can also prolong dying. Indeed, death increasingly comes in hospitals for individuals who are still undergoing aggressive treatment directed at finding a cure. The technological imperative, with its bias for interventions, dominates the thinking of the public and of health professionals alike.

Palliative care developed to reestablish the importance of the goal of assisting "in pursuit of a peaceful death." It has become an important component of health care in most developed nations. Although there are significant challenges to the recognition of the limits of medicine to cure and to the acknowledgment of dying, serious issues of access to high-quality palliative care and the need for research in the difficult symptoms at the end of life, palliative care has made significant improvements in the care of the dying. Despite the wonderful advances of palliative care, highly publicized cases of patients who die in intractable pain continue to dominate the public imagination. It is in this climate that a renewed interest in euthanasia and physician-assisted suicide (PAS) has emerged, thus presenting fundamental issues for medicine and posing urgent questions to the hospice and palliative care communities.

There is a long-standing prohibition in medicine against the intentional ending of life. Arguments have come and gone over time, but, with some notable exceptions, the prohibition has stood. The recent resurgence of interest in the legalization of PAS and euthanasia is related to many factors, including the centrality of patient autonomy in medical decision-making (including recognition of the competent patient's right to refuse care), the development of advance directives as a mechanism of promoting the patient's autonomy even when the patient is incompetent, limited access to palliative care, concerns about physician competence in the care of the dying (especially in the area of communication), and pain and symptom control.

Some of the heightened interest results from the finding that some physicians have admitted publicly to helping end a patient's life and have justified their actions as being compassionate. Legal changes in some jurisdictions have fueled the debate. In 2001, after a long series of judicial decisions, the Netherlands formally legalized both euthanasia and PAS, and the state of Oregon legalized PAS by lethal prescription in 1997. Empirical information on these practices is now available. In 1997, the United States Supreme Court upheld state prohibitions on PAS and argued that the prohibitions are justified by the state's interest in preserving life, preventing suicide, and protecting vulnerable populations. Thus far, only Oregon has legalized the practice. In late 2005, both the United Kingdom and Canada opened Parliamentary debate on assistance in dying.

Therefore, a heightened interest in this approach to dying does not seem to have been affected by advances in palliative care. However, changes in legal and social policy surrounding death will have profound effects on the practice of palliative care. It is crucial for palliative care practitioners to understand these issues and to reflect on their position with regard to PAS and euthanasia. A hallmark of palliative care has been its commitment neither to hasten death nor to prolong dying. With the renewed interest in the legalization of PAS, those committed to end-of-life care face some crucially important questions:

1. Is the renewed interest in euthanasia and PAS a consequence of the failure of palliative care, or is it related to issues other than end-of-life care?
2. Are requests for PAS an indication of inadequate physician skills at end of life or of inadequate access to palliative care?
3. Is physician PAS an essential tool in palliative care, or is PAS inherently contradictory to the philosophy and goals of palliative care?

Any approach to these questions requires reflection on the goals of palliative care, an understanding of the arguments supporting and rejecting PAS and euthanasia, and knowledge of available empirical data where such practices have been legalized. These questions will require individual responses from clinicians when requests for assistance in dying are made and communal responses from the hospice and palliative care communities after careful reflection on the implications of PAS and euthanasia on their commitments to the dying.

GOALS OF HOSPICE AND PALLIATIVE CARE

The origins of palliative care are crucial to judgments about the role of euthanasia and PAS. Palliative care emerged in the United Kingdom, the United States, and Canada during the 1950s. Several elements have been identified that paved the way for its emergence. A systematic analysis of the care of the dying person began to emerge in the medical literature, as well as a new openness to discussions about dying, and a desire to foster the dignity of dying persons in the context of modern health care became the cornerstones of palliative care (2).

With the enormous scientific and technological advances of the 1960s and early 1970s, critics began to warn of the medicalization of dying (e.g., use of the portable ventilator, renal dialysis, and cardiopulmonary resuscitation) and feared these interventions could lead to a loss of the capacity to accept death and dying as normal, a rejection of the importance of personal and family care at the end of life, a disregard for traditional religious and cultural rituals surrounding death and dying, and medical control of the dying person conceptualized as a patient until the end. These fears about the care of the dying were confirmed by the results of research on end-of-life care, notably the SUPPORT study (3), which revealed profound inadequacies in end-of-life care, in large part because of the failure to acknowledge that patients were dying. The research drew a vivid portrait of individuals dying in pain and suffering, caught up in medical technology driven by a logic of its own and more focused on the struggle to maintain vital functions than on human suffering and dignity. The power of modern medicine has created many of the dilemmas in the care of the dying. Technology now allows us to accomplish lifesaving as well as death-prolonging acts. Dying, previously seen as a natural matter of fate or personal faith, is seen now as a matter of personal choice.

A concern for fostering the dignity of dying persons and restoring the importance of care of the dying as a proper goal of medicine was the inspiration for the founders of the palliative care movement. The vision of Dame Cecily Saunders was actualized with the founding of St. Christopher's Hospice in the United Kingdom in 1967. The principles of palliative care could be practiced in a wide variety of settings. She developed the notion of *total pain,* which included physical, emotional, and spiritual components (4). The term *palliative care* was coined by the Canadian surgeon Balfour Mount (5) to describe the parallel development of medical expertise in end-of-life care. These movements demonstrated renewed commitment to the care of the dying and to improving pain and symptom control.

These approaches stress the multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness and the priority of working as a team to achieve the relief of suffering and the enhancement of

the last days of life. Supporting the patient, family, and loved ones as a unit became a hallmark of palliative care. The sense of medical abandonment of the dying, seen as a failure of medicine, was replaced by a return to the traditional medical goal of care for the dying. The idea of a "good death" has been central to palliative care. A *good death* has been described as one that is pain free, where dying is acknowledged and preferably occurs at home in the presence of family and friends, with the patient aware and alert so the unresolved business of life can be accomplished. A good death resonates with the person's values and therefore is different for different persons. There is great difficulty in having a good death in the midst of technology. Concerns are emerging that palliative care is becoming too technological and thus is losing the initial philosophy of normality and balance. An issue that continues to be debated is whether the term *palliative care* should refer to a discrete period at the end of life or whether it is a concept relevant wherever suffering accompanies illness. These are important elements in responding to questions about the role of euthanasia and PAS in palliative care. Palliative care practitioners will have to address concerns about end-of-life care that have emerged in the PAS debate. This is not just another debate about differences of opinion in a pluralistic society. It represents a profoundly important set of questions regarding a new form of legally sanctioned killing, the scope and limits of self-determination, and the role and duties of medicine in general and palliative care in particular.

SOME DEFINITIONS

Many different terms and concepts are used in the debate about euthanasia and PAS. Much of the confusion surrounding these issues has arisen because of a lack of clarity regarding the issues and concepts. This is not surprising because each term is related to a profoundly value-laden set of concepts and practices. Palliative care practitioners need to be clear in their understanding of the various important terms and concepts involved in the practice of palliative care.

The right of a competent patient to refuse medical interventions, based on his or her judgment of the benefits and burdens, is central to modern practice. Termination of life-sustaining treatments generally refers to the withholding or withdrawing of life-sustaining treatment at the request of a competent patient or that patient's representative, a proxy or surrogate. The broad consensus is that physicians are not only allowed to honor these requests, they are also legally and ethically bound to do so. Some literature has referred to these practices as *passive euthanasia.* This term serves only to increase confusion and is not used in this chapter.

The two practices that are the focus of debate are PAS and voluntary euthanasia. PAS involves the physician's providing the means for a patient to end life, usually by prescribing a lethal dose of a medication or furnishing information to enable the patient to perform the life-ending act. It requires a suicide, that is, the patient performs the act that causes death. In contrast to the agreement regarding the termination of treatment, there is no consensus on PAS. Most professional organizations oppose PAS on ethical grounds, and most jurisdictions have clear legal prohibitions. The debate questions whether these prohibitions should be lifted.

In contrast to PAS, euthanasia involves the physician's performing an intervention, usually a lethal injection, that will end the patient's life. Euthanasia is categorized as voluntary, involuntary, and nonvoluntary. *Voluntary euthanasia* is requested by the patient; *involuntary euthanasia* is performed despite the objections of the patient, and *nonvoluntary euthanasia* occurs when the patient's decision has not been sought or, as in the case of infants and young children, there is a lack of decisional capacity. Although the Dutch permit euthanasia, it is widely prohibited both ethically and legally.

These definitions maintain a distinction between PAS and euthanasia. Although these practices are logically distinct, this chapter refers to both practices because

...it is of greatest importance to consider that the distinction, in practice, between PAS and voluntary active euthanasia may already be bridged in the attitudes of physicians who support PAS. Legislation should reflect this consideration. If public policy cannot support the link between PAS and voluntary euthanasia, this should have significant implications for the passage of legislation, or, at the very least, the creation of safeguards against abuse that this legislation must contain (6).

Palliative care practitioners have developed intermediate practices such as aggressive pain management and terminal sedation that, for some, challenge the traditional distinction between forgoing treatment and actively assisting death.

An observer would be able to distinguish classic cases of forgoing treatment (say, by withdrawing artificial ventilation) from assisting suicide (say, by providing a lethal prescription). The claim, however, is that it would be harder to distinguish two practices from assisted suicide or euthanasia: first, pain relief that may suppress respiration and hasten death, and second, sedation combined with withdrawal of artificial nutrition (7).

Aggressive pain relief (which may rarely hasten death) is acceptable when there is no less dangerous way to provide pain relief, the competent patient is informed of the risks and benefits and gives consent, and the physician's intent is therapeutic, not to hasten death. There are debates over whether pain relief techniques do risk hastening death. If, as competent palliative care practice suggests, these measures do not hasten death, they can then be more easily distinguished from PAS and euthanasia. An extensive philosophical and ethical literature has debated these claims, but more research is clearly needed.

Terminal sedation raises other issues. Definitions differ, but the term usually means sedating a patient to unconsciousness while withholding artificial nutrition. If sedation to loss of consciousness is necessary to provide good pain or symptom relief and the patient agrees to it and to the withdrawal of artificial nutrition, this is considered acceptable practice. The primary goal of terminal sedation is effective relief of refractory symptoms. However, terminal sedation is used judiciously because it results in the loss of capacity for interaction, the other crucial goal of end-of-life care.

These two standard practices of palliative care are justified by the *principle of double effect,* meaning the following: the act must be good or morally neutral; only the good effect is intended, whereas the bad effect is merely foreseen; the bad effect

must not be the means to the good effect; and the good effect must outweigh the bad (8). The principle is not a simple mathematical formula but rather requires judgment regarding which effects are good or bad. Here, the intention of the doctor (to relieve pain and suffering, not to end the life of the patient) is crucially important.

ARGUMENTS FOR AND AGAINST EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE

Most palliative care practitioners have received requests for euthanasia or PAS. Patients may request assistance in dying because of intractable pain and other symptoms, fear of being a burden on loved ones, depression, fear of loss of dignity, or a belief in autonomy and control, particularly over the timing and manner of one's death. Why, despite vast improvements in the care of the dying, is there a revival of support for legislative and professional revisions to allow physician-assisted death and voluntary active euthanasia? It is important for palliative care physicians to understand, at least in a general way, the reasons put forward in support of PAS and euthanasia and the long-standing arguments against allowing physicians to end life intentionally. This is an area of deep and highly contested issues and values. One of the most interesting and yet confusing aspects of this debate is the use of the same language in arguments for and against PAS and euthanasia.

Arguments in favor of PAS include the principle of respect for the autonomy of competent persons, the duty of physicians to care for patients who are in pain and suffering, and rejection of the distinctions considered morally and ethically relevant in the current practice of palliative care, such as that between killing and letting someone die. Proponents believe that the practices can be regulated, and regulation is dealt with in the next section.

The central argument for PAS is based on patients' rights and on respect for autonomy in modern society and health care in particular. This would extend the right to make decisions to include the right to determine the course of one's own dying. Under this argument, no competent person should have to endure what they judge to be unbearable pain, suffering, loss of dignity, or loss of quality of life. The right is based on principles of dignity, respect, and autonomous choice. It is seen as a control on the unrestrained use of technology at the end of life. This reasoning rests on a conception of autonomy as "negative liberty," that is, the right to act in accordance with one's beliefs and choices without interference as long as that behavior does not harm others. Proponents of PAS argue that this right should include an individual's control over the timing and circumstances of death, up to and including assistance in dying. In this conception, PAS is a personal decision, an application of the right to self-determination that should be free from paternalistic interference from any source. It is seen as a type of rational suicide. The highly publicized case of Diane is a dramatic example of a request for PAS that came from a patient with cancer for whom it was "extraordinarily important...to maintain control over herself and her own dignity during the time remaining to her"(9).

Proponents see PAS as a necessary extension of the negative right of competent persons to refuse or withdraw medical interventions. They see that right as insufficient to give individuals real control over their dying and argue that

The right to refuse medical treatment can help only in a limited number of cases in which it leads to a swift and painless death. Most cancer patients, for instance, are not in this situation. ...That is why the desire of control over how we die...will not be satisfied by concessions to patient autonomy within the framework of (traditional) ethics (10).

Some arguments for PAS are based on the claim that physicians have a duty to provide assistance in dying if the patient's suffering cannot be relieved by standard care. This argument is based on understanding PAS as a compassionate response to medical failure. Others go farther and argue that a physician's refusal of requests by competent, terminally ill patients constitutes a kind of abandonment. Timothy Quill, one of the most articulate physician proponents of PAS, expresses this strongly:

The profession appears to turn its back in these horrible moments in order to keep its intentions pure. Doctors cannot intentionally facilitate death, even if death is the only way to relieve a patient's overwhelming suffering. ...Because so many family members and friends have witnessed such very troubling deaths, it appears that this experience also undermines the publics' trust that doctors will not abandon them if they are unfortunate enough to experience unbearable suffering prior to death (11).

These proponents indicate that the traditional prohibitions of the Hippocratic Oath, against abortion and surgery, for example, have changed in response to social situations. In this understanding, the Hippocratic tradition requires a physician to alleviate suffering, and this can include PAS if that is the only solution. Moreover, PAS is distinct from euthanasia in that it does not involve the ending of life by a physician. Rather, the person takes his or her own life.

Some argue that no principled difference exists between acceptable practices such as terminating life-sustaining treatment and aggressive pain control (omission) and euthanasia and PAS (commission) and also no meaningful distinction between letting die and killing. For some, any distinctions that could be clear become challenged by practices such as aggressive pain and symptom control that may hasten death and terminal sedation.

The main arguments against PAS and euthanasia are as follows: these procedures are contradictory to the physician's role, and rejection of such procedures is crucial to the integrity of medicine; they do not promote patient autonomy but further medicalize dying; allowing the procedures will lead to error and abuse, and the practice is not necessary for efficient and compassionate care at the end of life.

Although there were early debates about the practice, the Hippocratic prohibition against a physician's intentional ending of life is long standing. Today, with notable exceptions, most professional organizations (e.g., the American Medical Association) hold that euthanasia and PAS are incompatible with the physician's role as healer. Trust is central in the patient-doctor relationship, and it requires a clear commitment to restore and promote life. Violations of this trust are possible when death is a legitimate option. Some opponents believe this debate has put "the very soul of medicine is on trial" (12). The "false promise of beneficent killing" (13) unalterably changes the patient-doctor relationship in this view.

What are the physician's duties at the end of life? A physician must respect a competent patient's right to refuse potentially lifesaving treatment. However, this

does not translate into an obligation to end life, even at the patient's request. In addition, a physician who is caring for a patient at the end of life should provide adequate and effective pain and symptom control, even if doing so may hasten death.

Opponents argue that PAS and euthanasia do not promote patient autonomy but give more power and authority to the physician:

...physician-assisted suicide does not de-medicalize death; rather it medicalizes suicide. ...It transforms a private act (suicide) into a medical event. Indeed, physician-assisted suicide implies not a resistance to but an extension of medical power over life and death (14).

It has also been described as self-determination run wild. Respect for autonomy is important, but other interests and values are at stake. Even if voluntary euthanasia and PAS were accepted as instruments of personal autonomy, limits should be set for the sake of other goods.

The acceptance of euthanasia would sanction a view of autonomy holding that individuals may, in the name of their own private, idiosyncratic view of the good life, call upon others, including such institutions as medicine, to help them pursue that life, even at the risk of common good (15).

A paradox emerges here. PAS is seen as a radically individual manifestation of autonomy, but it requires the agreement and participation of physicians and society.

Whereas in suicide the individual "drops out" of the social order, in the context of physician-assisted suicide the individual "drops into" a system that recognizes and must even authorize this particular (ostensibly private) choice. In other words, displacing suicide from the private arena to bring it under medicine's stewardship means surrendering suicide to the (medical) "establishment" (15).

As long as PAS requires the assistance of others, it cannot be conceived of as solely an extension of individual autonomy. PAS is an impediment to an individual's autonomy rather than an extension of it. It medicalizes an act, a practice, and the social ethos of death and suicide. Ideally, the patient is not abandoned, so the physician must be present. PAS becomes a medical act.

Some arguments are based on concerns about error and abuse of PAS and euthanasia. Recognizing the prevalence of depression in the chronically and terminally ill and the tendency for doctors to underestimate depression, substantive concerns exist regarding the patient's competence to request PAS and euthanasia. In addition,

Some psychiatrists believe that "demoralization syndrome" is a diagnosable cognitive disorder characterized in its extreme form by morbid existential distress. If they are right, then it should be an important part of our thinking about end of life decision-making. A demoralized patient would be unable to think reliably about the remainder of her life and therefore be incompetent to decide to commit physician-assisted suicide" (16).

Diagnoses of depression and demoralization are important because treatment, if provided, could alter the request for PAS or euthanasia.

There are significant concerns for vulnerable populations, such as the disabled and chronically ill, who already experience subtle pressures to accept limits. There are special concerns for discrimination against women and children who can be perceived as burdensome. Because health care costs are a concern for many, especially those with no insurance coverage, these concerns about pressures and limits are real. Although proponents of PAS and euthanasia base their arguments on the free choice of competent adults to make decisions regarding their dying, there is grave concern for the "slippery slope" extension to practices involving others who have not made or who cannot make such choices.

Finally, opponents argue that euthanasia and PAS are not needed to provide good end-of-life care. Much of the public support for these practices is based on a belief that they are necessary in some circumstances of intractable pain, but advances in palliative care have made such circumstances extremely rare. Moreover, as long as doctors can provide aggressive pain relief, including terminal sedation if necessary, intractable pain is not a necessary or usual experience at the end of life. Most patients who request PAS or euthanasia do not experience intractable pain or other physical symptoms. Rather, they are concerned about loss of control, autonomy, and dignity (17). These are issues that extend far beyond the care of those who are at the end of life and those with terminal illness. They are issues that go beyond the medical to an array of social and emotional circumstances in which persons feel this kind of suffering.

REGULATION AND THE "SLIPPERY SLOPE"

Debate is vigorous over the effectiveness of regulating practices such as PAS and euthanasia. Opponents of euthanasia and PAS are concerned with the slippery slope. The slippery slope connotes a concern that some practices, once allowed for specific reasons, gradually slide from an acceptable to an unacceptable state. Therefore, the argument for these practices is made for the right of competent persons to determine the circumstances of their own death. However, once allowed for these persons, the practice slides to include others who have not requested assistance in dying and those who have no capacity to make such a request. If intentionally ending death is a good thing for rational persons, then it ought to be provided to others; this is how the slippery slope occurs. Philosophers and others argue that there is a logical and an empirical slippery slope and that reasons for allowing a practice at the top of the slope can be logically distinguished from reasons for allowing practice at the bottom of the slope. Regulation of these practices is based on the importance of such logical distinctions. The empirical slippery slope is complex as it relates to societal acceptance of practices that were never intended at the outset, but with which society becomes comfortable over time. The empirical evidence of a practice should assist us in judging whether the slide has actually occurred.

Some propose that it is better to regulate covert practice and believe that safeguards regarding the slippery slope are possible through legislation and professional regulation. Guidelines have been suggested to ensure that the request

is voluntary, the procedure is a last resort, and there is public accountability. Empirical data from the two jurisdictions with experience (Oregon and the Netherlands) have given rise to competing assessments of the effectiveness of regulations.

The Oregon Death with Dignity Act provides that a capable adult suffering from a terminal disease and who voluntarily expresses a wish to die may make a request for medication for the purpose of ending his or her life. Reports of the first 2 years of the Oregon experience (23 patients and 27 patients, respectively) cited the importance of autonomy and personal control, not intractable pain, as the primary reason for the request (18). All information is dependent on physician reporting. The studies and their conclusions have been criticized on methodological grounds because

Unless physicians are asked to report more than they are now required to under the law, and unless properly trained independent physicians can question the physicians and examine the data, we will not learn much from the Oregon experience. Nor will we be assured that patients who choose assisted suicide are receiving appropriate care at the end of life (19).

Thus, the Oregon experience seems to demonstrate that a tidal wave of PAS and euthanasia requests has not occurred. Without accurate reporting, however, valid judgments on the practice are impossible.

Interpretations of the Dutch experience are conflicting. The Netherlands implemented euthanasia and PAS before palliative care services were developed. Since 1973, courts in the Netherlands have dealt with cases of both PAS and euthanasia, and, in 2001, the Dutch Parliament legalized both practices. In the Netherlands, the family doctors who perform the procedures have an established relationship with their patients, and the population is very homogeneous.

Some conclude that there is a cautious use of PAS and euthanasia in a well-regulated practice. Opponents note substantial evidence of difficulty in regulating the practice and evidence of a slippery slope. In the past 2 decades, the Netherlands has moved to legalize PAS and euthanasia for those who are chronically ill or in psychological distress. Moreover, the Dutch experience of nonvoluntary euthanasia involving children and incompetent adults legitimizes the concern that euthanasia can be abused more readily than PAS. This finding reinforces concerns regarding the slippery slope. Further, data show that significant numbers of Dutch physicians do not comply with reporting requirements, and this issue raises serious questions regarding oversight.

Other empirical studies have included people who are terminally ill. The results of these studies reveal an increased interest in PAS and euthanasia in persons who experience a high level of depression and hopelessness, have inadequate social support, feel that suffering is inevitable, and perceive themselves as being a burden. Others have reviewed the physician's experience of PAS and euthanasia. In the Dutch experience, physicians believed that they had done the right thing but also believed that "ending a person's life was inherently an unnatural act and felt unacceptable" (20). Other data indicate that physicians are ambivalent about participating in euthanasia and PAS. Moreover, those physicians who have the least time and training with terminal illness are more willing to support PAS than those with knowledge of pain management, such as oncologists, and physicians with a conservative attitude toward resources have also been found to favor PAS.

IS THERE A ROLE FOR EUTHANASIA OR PHYSICIAN-ASSISTED SUICIDE IN PALLIATIVE CARE?

The debate over PAS is complex and requires attention to ethical, legal, professional, and empirical arguments. The debate has particular significance for those who provide hospice and palliative care. Throughout history, humans have feared the unknown of death; modern society appears to fear dying even more. It seems clear many different conceptions of a good death are recognized. Some want a quiet death with medical assistance provided only for pain and symptom control; others will pursue technology and cure until the last breath.

In the spirit of honest disclosure about attitudes and beliefs regarding end-of-life care, I acknowledge that I oppose the legalization of PAS and euthanasia. My opposition is based on my personal religious belief that life is sacred. As a physician, my opposition is based on a belief that these practices irrevocably compromise the role of the physician, principles of justice (especially protection of the vulnerable), and a judgment that the slippery slope has been well demonstrated thus far in attempts to legalize assisted death. It is crucial for the palliative care community to note that most requests for euthanasia and PAS are not related to pain and symptom control. These requests do strengthen the need for research into difficult symptoms at the end of life. They emphasize the need for education about excellent palliative care for patients, families, and health care professionals and present a compelling case for ensuring that high-quality palliative care is accessible for all.

There are two levels at which physicians involved in hospice and palliative care need to reflect on the appropriate response to the role of PAS and euthanasia. The first is at the bedside, when the clinician receives such a request. The second level is within the palliative care community.

A request for PAS or euthanasia may be a sign of unrelieved pain or suffering in a dying person, and physicians need to treat these requests seriously. Palliative care teams should explore the issues that underlie the request and should use scientific and other available resources to relieve those underlying causes. We have seen that requests for PAS often come from those who suffer some existential distress rather than refractory pain or other symptoms. Identifying and treating depression and demoralization are crucial. Despite the best efforts of the palliative care team, some patients will request PAS or euthanasia, not for intractable pain, but for control of the dying. How does a palliative care physician respond? This is an incredibly challenging situation, one that requires the support and advice of colleagues. Requests for assisted death have personal, ethical, and legal ramifications. Most requests are resolved by attending to the pain and suffering. In almost all jurisdictions, PAS is illegal. In declining a request for PAS, however, the commitment to the care of the patient remains unchanged.

What do the hospice and palliative care movements make of the role of PAS? For some, this may be an expression of autonomy and a means to liberate patients from pain and suffering. However, it does medicalize dying at both the professional and societal level. How would these practices affect the philosophy and ethics of palliative care? If legalized, euthanasia and PAS would become the prerogative of physicians. Does a new specialty develop? Is it a specialty of palliative care? Must the person be terminally ill? If loss of meaning and emotional and spiritual

suffering are reasons for requests, are we expanding the scope of medicine here to consider euthanasia and PAS for reasons unrelated to health status?

For many in hospice and palliative care, dignity is a core concept that conveys a particular respect for patients as they prepare for death. Loss of dignity is one of the most common reasons for requesting assistance in ending life. Even though both proponents and opponents of euthanasia and PAS use of the term *dignity in dying,* there is little clarity regarding a definition. In a landmark study, Chochinov and colleagues explored the meaning of dignity from the perspective of terminally ill patients. They identified critically important factors for the maintenance of a sense of dignity in terminal illness, including "illness-related concerns, a dignity conserving repertoire and a social dignity inventory" (17). This research has profound implications for hospice and palliative care because the loss of a sense of dignity is a crucial factor that underlies requests for assistance in dying. Attention to patient's identified illness-related concerns regarding independence and symptom distress, sensitivity to the policies and practices that either conserve or erode dignity, and the development of an inventory of the social concerns and relationship dynamics that enhance or erode a sense of dignity must now be part of the hospice and palliative care philosophy and practice. As the authors concluded:

Further empirical work is necessary to develop and evaluate interventions that promote dignity and the quality of life of dying patients. Whether lost dignity leads to a wish for hastened death, or merely explains the patient's compromised quality of life, understanding dignity offers an opportunity to respond more sensitively and purposefully to those nearing death (17).

A PRACTICAL APPROACH

Independent of the clinician's personal position on physician-assisted suicide or euthanasia, it is important that 'moralizing' does not make the situation worse. A clinician who comments that he or she opposes the practice on principle may make the person seeking assisted suicide or euthanasia feel judged, abandoned and even more diminished than he or she felt before. A clinician who says that he or she will be ready to provide assisted suicide or euthanasia may make the patient feel that the worthlessness of his or her life has been confirmed and he or she may feel diminished by this response as well. Therefore, clinicians should adopt an open-minded, practical posture as much as possible and should disclose their position rarely, and then only with simultaneous care to affirm the importance of the patient and the clinicians respect for him or her.

When a patient does ask for assisted suicide or euthanasia, respond with compassion. First, convey that patient's request is an important matter, and take the time to clarify what he or she has in mind. Second, assess carefully all the contributing underlying causes for the request. Pay particular attention to the possibility of inadequately treated depression and other reversible sources of psychosocial suffering since these are correlated with requests. Attend to physical suffering as well. Spiritual suffering may be particularly important. Fears may have become extreme and may be ameliorable. Third, acknowledge the patient's suffering and affirm your commitment to staying with the patient, and to alleviating everything you

can, including by consulting with others. Fourth, address all the sources of suffering. When fear of lost control is a prominent matter, as is common, explore sources of control such as advance care planning, refusal of life-sustaining interventions, plans for when death does occur, or other matters of personal importance to the patient such as ways to avoid being a burden or losing dignity. Fifth, discuss legal alternatives, including palliative sedation, and declining nutrition and hydration at some defined medical state. Finally, be sure to consult with colleagues. Assisted-suicide and euthanasia are grave matters that should not be acted on alone. If resolution does not seem to be possible, published institutional steps to reach resolution can be followed, including consultation with an ethics committee (21).

PEARLS AND PITFALLS

- It is important to understand that patients may request assistance in dying because of unrelieved pain or other symptoms, fear of being a burden, depression, or fear of loss of autonomy and control.
- Identifying and treating the underlying cause are crucial because most of these issues can be managed.
- Aggressive management of pain and other symptoms, including terminal sedation, with the intent of relieving suffering is ethically acceptable and is almost always effective in relieving intractable symptoms.
- PAS involves a physician's providing the means for a patient to end life, usually by prescribing a lethal dose of medication.
- Euthanasia involves the physician's performing an intervention, usually an injection, to end the patient's life.
- Most enduring requests for PAS and euthanasia arise not from inadequate pain and symptom control, but from a patient's beliefs about dignity, autonomy, and control over the circumstances of one's death.

SUMMARY

There is a clear imperative to improve care at the end of life. Palliative care research needs to be enhanced, access to palliative care expertise needs to be improved, and information on the effectiveness of palliative care needs to be disseminated more effectively. These initiatives can reduce the perceived need for euthanasia and PAS, although to what extent is unclear. The ethical, legal, and professional debates about PAS and euthanasia require ongoing empirical work, serious reflection on the philosophy of hospice and palliative care, and continual improvements in the care of the dying. Those committed to a philosophy of "neither hastening death nor prolonging dying" must make a renewed commitment to understanding and facilitating dignity at the end of life.

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18

Withholding and Withdrawing Life-Sustaining Therapies

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INTRODUCTION

In modern medicine, health care providers have many therapies at their disposal to sustain life; they are able to support vital functions through illnesses to which the patients would have succumbed only decades ago. The use of life-sustaining therapies in patients with reversible illness is rarely questioned, but it is not always clear how such therapies should be used in patients with incurable disease. Life-sustaining therapies are less effective in patients with chronic or terminal disease, but they can, at times, provide short-term benefit. However, the potential benefits of a treatment are not always great enough to justify the burdens the treatment imposes.

This may be because the patient feels that her or his current quality of life is low, the expected quality of life after treatment is too low, or the burden of treatment is too great. In these cases, treatments should be withheld or withdrawn. Because withholding or withdrawing life-sustaining therapies is at times the right decision for the patient, it is important that providers learn how to make that decision, how to discuss withholding or withdrawing therapy with patients and their families, and how to palliate symptoms that arise when therapies are withheld or withdrawn.

EPIDEMIOLOGY

Data from intensive care units (ICUs) and nursing homes indicate that withholding and withdrawing of life-sustaining therapy are common practice; 80% of deaths in ICUs in North America are preceded by limitation of therapy (1–3). There is considerable variation by region. In the United States, fewer ICU deaths are preceded forgoing therapy in New York and Missouri than in the Middle Atlantic and Midwest regions (1). Multicenter studies in France and Spain found that on average, 50% and 35% (respectively) of deaths in ICUs in those countries were preceded by a decision to limit therapy, with significant unit-to-unit variation (4, 5).

In the United States, the presence of chart orders to withhold cardiopulmonary resuscitation (CPR) for nursing-home residents varies from 30% in Texas to 70% in Oregon (6), for an average of 50%. A Finnish study found that 13% of patients in long-term care facilities in Finland had do-not-resuscitate (DNR) orders, with institutional variation between 0% and 92% (7). Withholding of CPR is more common in patients with cognitive impairment, and as many as 90% of such patients have DNR orders in some US states (6).

Forgoing life-sustaining treatment is not an all-or-nothing phenomenon. CPR is commonly withheld while other therapies are provided (1, 4); although DNR orders are common in nursing homes, fewer than 10% of patients have orders to forgo hospitalization or artificial nutrition (6). When multiple therapies are withdrawn in the ICU, they are withdrawn in a specific order (3). Blood products are withdrawn first, followed by hemodialysis, vasopressors, and mechanical ventilation. Antibiotics, nutrition, and hydration are withdrawn last.

ICU patients who have a poor prognosis for recovery and those whose future quality of life is compromised by the severe dysfunction of multiple organ systems are considered candidates for forgoing of life-sustaining therapies (2, 4, 5). Discussions about limiting therapy are usually initiated by physicians, and decisions to withhold or withdraw therapy are almost always made by a surrogate because the patient is too ill to participate (2, 4, 5). Only rarely do surrogates disagree with recommendations to withhold or withdraw therapy, although in some cases multiple meetings are held before a decision to withdraw therapy is made (2). Withdrawal is usually initiated within hours after the decision is made, and most patients die within a few hours, although a few survive to hospital discharge (2). Despite a surrogate's agreement with physician recommendations, conflict frequently occurs between families and medical staff. Families may feel they are not given enough information about the patient's condition, or they may disagree with the manner in which providers discuss withholding or withdrawing therapies (8).

ETHICAL CONSENSUS

An ethical consensus regarding withholding and withdrawing of treatment emerged as the use of life-sustaining therapies became more common in the latter half of the 20th century. The current consensus was crystallized in the 1983 report on forgoing life-sustaining treatment that was issued by the President's Commission, a group mandated by Congress to study ethical problems in medicine and research. The Commission examined who should decide whether to withhold or withdraw life-sustaining therapies and the criteria by which the decisions should be made. Although the decision to forgo life-sustaining therapy may have more serious implications than the decision to forgo other therapies, the Commission found no ethical difference. It also found that the same ethical process used to guide non–life-sustaining treatments could be applied to life-sustaining treatments. The Commission thus recommended that decisions to forgo life-sustaining therapies be made by the same process as other decisions about medical therapy, and that the same criteria be used regardless of whether the treatment was withdrawn or not started.

The primary factor driving the decision-making process should be patient self-determination, or autonomy. When patients lack the capacity to make decisions, a surrogate should make decisions for them. The surrogate's goal should be to replicate the decisions the patient would make, thus preserving the patient's autonomy. When the patient's wishes are not clear, surrogates should make decisions based on what they feel to be in the patient's best interest.

Patients or their surrogates and clinicians should engage in a shared decision-making process to promote the patient's health and autonomy. What constitutes health and quality of life is defined from the patient's perspective, and the physician's role is to recommend treatment consistent with the patient's goals and to describe the benefits and burdens of therapy. The patient or surrogate has the authority to accept or reject the treatment plan. Patients and surrogates do not have the right to specify which therapies they receive, and physicians are not obligated to offer treatment they believe would be ineffective or inconsistent with professional treatment standards.

The Commission also examined four moral distinctions that had traditionally been used to determine whether life-sustaining therapies should be forgone:

1. Whether death occurs as a result of an *action* on the part of the clinician as opposed to an *omission*
2. Whether a treatment is *withheld* as opposed to *withdrawn*
3. Whether a consequence of a treatment is *intended* or *unintended*
4. Whether treatment is *ordinary* (usual care) as opposed to *extraordinary* (heroic measures)

The Commission found that these approaches oversimplify clinical reality and the physician's moral responsibility and thus are not ultimately useful in guiding decision making.

LEGAL CONSENSUS

Legal Consensus in the United States

In the United States, a legal consensus has developed over the past 30 years regarding withholding and withdrawing of medical therapies (see Meisel and Cerminara). This consensus can be described as follows:

1. Patients have a right to refuse any medical treatment, even if the refusal results in their death.
2. There is no legal distinction between withholding and withdrawing of therapies.
3. Decisions to withhold or withdraw medical interventions are usually made in the clinical setting, and courts rarely need to be involved.
4. When patients die after they request that life-sustaining therapies be withheld or withdrawn, their death is considered neither homicide nor suicide, and their providers are not held liable.

Sources of the Right to Refuse Medical Therapy

The sources of the right to refuse medical treatment lie in the common law doctrine of battery and in the constitutional right to liberty. Battery is defined as the unwanted invasion of one's bodily integrity, and this includes undesired medical therapy. The law of battery provides legal recourse for persons whose bodily integrity has been violated against their will. A person found guilty of battery is subject to punishment by fines or imprisonment and, in the case of health care providers, by suspension or revocation of licensure. The US Supreme Court and other courts have suggested a constitutional basis for the right to be free from unwanted interference with bodily integrity, based on the protection of liberty contained in the 14th Amendment.

Limitations on the Right to Refuse Medical Therapy

The right of patients to refuse life-sustaining therapy has been repeatedly and consistently upheld. Most of the legal cases regarding withholding and withdrawing of therapies involve incompetent patients. Incompetent patients have the same right to forgo life-sustaining therapy as competent patients, but the required type and level of proof of an incompetent's wishes that life-sustaining therapy be withheld or withdrawn vary among states. This issue was brought to the US Supreme Court in the case of *Cruzan v Director* in 1990. Nancy Cruzan, a woman in her 30s, was in a persistent vegetative state, and her parents requested that her feeding tube be withdrawn. Her physicians and the state of Missouri, which operated the hospital that was caring for Nancy, asked that a court order be issued to stop feedings. Her case was eventually brought before the US Supreme Court, which upheld her right to refuse unwanted medical treatment but also ruled that states have a right to protect the interests of incompetent persons. States are thus are permitted, although not required, to specify the type and level of evidence required to document an incompetent person's wishes.

Withholding or Withdrawing Life-Sustaining Therapies from Incompetent Patients

Patients who are unable to consider their own medical situation and voice their wishes can have their autonomy preserved in the form of written directives and surrogate decision makers (see also Chapter 1–16). A patient may appoint a surrogate before becoming incompetent (durable power of attorney). If an incompetent patient has not designated a surrogate, the choice is guided by either state law or by the clinician's judgment regarding who best knew the patient. Written directives (also called living wills) are helpful in that they clearly document the patient's wishes. However, they may not address all clinical situations because it is difficult to anticipate all possible scenarios when writing the directive. Thus, a surrogate may still be needed in addition to the written directive.

Two standards are commonly used to establish the patient's wishes: *subjective judgment* and *substituted judgment*. The subjective standard requires the patient to have stated verbally or in writing what he or she would want done in a specific situation. The substituted judgment standard does not require that the patient's actual wishes be established, but rather that the designated surrogate be familiar enough with the patient's values and beliefs to infer what he or she would have decided. The subjective standard is preferred, because it believed to reflect the patient's wishes more closely. Because a patient's actual wishes are not always known, however, most states allow a substituted judgment standard. In some states, if the evidence of the patient's values and beliefs is insufficient to permit the use of a substituted judgment standard, a best-interest standard may be used. In such cases, the surrogate and physician make decisions about withholding or withdrawing therapies guided by what they feel to be the patient's best interest. Other states do not allow surrogates to forgo specific therapies based on the best-interest standard.

Laws of Withholding and Withdrawing Therapies in Other Countries

The comparative legal literature about withdrawing and withholding of therapies is limited. Mendelson and Jost studied Australia, Canada, France, Germany, Japan, the Netherlands, Poland, and the United Kingdom and found that, in all these countries, competent patients have the right to refuse any medical therapy, even if doing so may result in their death (9). However, the laws differ in the legality of withholding and withdrawing therapies from incompetent patients. A subjective or substitute judgment standard is employed in some countries, whereas others use a best-interest standard. In some countries, the patient's physician may act as the surrogate and may withhold or withdraw therapies on the basis of his or her evaluation of what is in the patient's best interest. Some courts have also found that life-support measures need not be continued for incompetent patients. A seminal case involving Anthony Bland, a young man in a persistent vegetative state who was sustained with a feeding tube, was decided in the United Kingdom in 1993. The House of Lords ruled that incompetent patients should be treated according to their best interests when their wishes are not known. Life-support measures, including artificial nutrition and hydration, are not in the best interest of a patient who cannot be returned to his previous state; thus, such treatments can be stopped.

DISCUSSIONS WITH PATIENTS AND FAMILIES

Many of the key points involved in discussing withholding and withdrawing of therapies are common to general communication (see Chapter I–4). A six-step protocol for discussing withholding and withdrawing of therapies, adapted from recommendations for communicating serious information, is presented in the following subsections (see also Table I–18–1). Depending on the patient's or surrogate's understanding and acceptance of the current situation and the clarity of overall goals of care, the following steps may be covered in one conversation or may require several discussions.

Step 1: Establish the Setting for the Discussion

Before the discussion, the clinician should review the pertinent parts of the patient's case, including the prognosis, the evidence for that prognosis (see Glare and Christakis), and the likely effects of the treatment in question. It is important to ensure that all people relevant to the decision are present: the patient's loved ones, nurses, social workers, and spiritual advisor, as appropriate. The discussion should take place in a location were everyone is able to sit comfortably and hear and see one another. After introducing everyone and explaining each person's relationship to the patient or the role in the patient's care, the clinician should begin the discussion with a general statement about the purpose of the meeting. The specific treatment in question can be introduced later, but the fact that the meeting is being held to discuss the next steps in the patient's care should be stated to focus the discussion.

Step 2: Review the Patient's Current Situation

Before withholding or withdrawing of therapies can be discussed, the patient or surrogate should understand the patient's medical situation, insofar as possible. This understanding should be elicited, and the clinician should provide education if necessary. The patient's prognosis is a key element of the current situation. Although not all patients desire prognostic information, many appreciate it and use it to make treatment decisions. Patients are less likely to request life-prolonging therapies if they know that their overall prognosis is poor (10).

Step 3: Review Overall Goals for Care

Decisions to withhold or withdraw life-sustaining therapies should be based on the benefits and burdens to the patient and the potential effectiveness of the treatment. Effectiveness can be evaluated only with respect to a specific goal, so the overall goals of therapy should be agreed on before specific therapies are discussed. Therapies may be aimed at curing disease (curative), slowing the progression of disease (life-prolonging), or alleviating symptoms (palliative) (see Chapter I–5). The goals of therapy are influenced by the patient's disease state, the available treatments, and the patient's values.

Table I–18–1 ■ Communicating Recommendations for Withholding or Withdrawing Therapy

1. Establish the Setting	
Review relevant information.	Patient's prognosis Outcome of therapy in question in this patient
Make sure the right people are there.	Patient's or surrogate's loved ones Staff
Find a comfortable, quiet location.	Places for everyone to sit Seclusion from others Ability of everyone to see and hear each other
Introduce everyone at the beginning.	"Could we start by introducing everyone?" "How are you related to Ms. Jones?"
Introduce the topic for discussion.	"I was hoping we could talk about the next steps in your care."
2. Review the Patient's Situation	
Elicit the patient's or surrogate's understanding.	"Can you tell me your understanding of what is going on with your medical situation?" "What have the other doctors told you about your dad's medical situation?"
Educate as needed.	"That's right, the cancer has spread. What that means is that although there are treatments to control your symptoms, we can't cure the cancer."
3. Review Overall Goals of Care	
Elicit goals from the patient or surrogate.	"Did you talk with Dr. Smith about what the goal of your treatments should be?"
Summarize to confirm.	"So it sounds like the most important thing is to make sure your father is comfortable."
4. Relate Your Recommendation for Withholding or Withdrawing Treatment	
Introduce the specific treatment to be discussed.	"Today I wanted to talk about what we should do if your breathing gets worse, including whether we should use a breathing machine."
Ask about previous experience with the intervention in question.	"Has anyone ever asked you about being on a breathing machine?"
Describe the intervention in question and its benefits and burdens for this patient.	"Based on what we've talked about—the fact that this cancer isn't curable—the chance of being able to come off the breathing machine would be very low."
State your recommendation.	"I recommend that if your breathing gets worse we don't put you on a breathing machine."
Describe how you feel your plans are consistent with the patient's overall goals.	"The reason I think we shouldn't is that you said you wouldn't want your life to be prolonged if there wasn't a good chance of recovering to where you are now."
Describe what treatments will be provided.	"We will use medicines to improve your breathing and comfort."
5. Respond to Patient or Surrogate Reaction	
Acknowledge emotions.	"Its hard getting to this point isn't it?"
Is the recommendation consistent with patient's values and goals?	"How does that plan sound to you?"
Answer questions.	"I'll be around if you think of things you want to ask me later, but are there questions can I answer now?"

Table continued on following page

Table I–18–1 ■ Communicating Recommendations for Withholding or Withdrawing Therapy (Continued)

6. Summary and Follow-Up	
Summarize.	"Good. So we'll keep the antibiotics going and give you medicines if the breathing gets worse, but we won't put you on a breathing machine."
Explain the next steps in treatment.	"We'll plan on keeping you here in the hospital for the next few days and see how things go."
Arrange for the next meeting.	"I'll see you tomorrow on rounds. Please have your nurse page me if you need anything before then."

To provide care consistent with the values of terminally ill patients, the clinician must determine how the patient defines prolonging life and palliating symptoms. Whether life should be prolonged depends on the patient's definition of quality of life, the kinds of burdens the patient feels are worth tolerating, and the chance of success that would make a treatment worthwhile (Table I–18–2).

Once the clinician has an understanding of the patient's values and preferences for medical care, this information can be used in combination with knowledge of the patient's prognosis and the effectiveness of specific therapies to formulate a treatment plan, including recommendations regarding whether to initiate or continue a specific therapy.

Step 4: Discuss Recommendations for Withholding or Withdrawing Therapy

Next, the specific treatment in question should be introduced. Asking about previous discussions of or experiences with the therapy can be a useful way to start. If the patient or surrogate has discussed the therapy, asking about her or his previous preference can expedite the conversation. In addition, previous experiences may have created biases that the physician needs to explore and consider when providing education. The treatment, its likely benefits and burdens for the patient, and the physician's recommendation should be stated clearly and concisely, avoiding medical language. Enough detail should be given so the patient can make an informed decision in agreeing or disagreeing with the recommendation. Because patients use the likelihood of success of a given therapy to make decisions (10), information about the effectiveness of the therapy in question should be included. It is useful to ask patients how much detail they want to hear about the treatment, because preferences differ. The physician should describe the reasons for the recommendation, specifically how it is consistent with the physician's understanding of the overall goals of care. It is also important to describe the withholding or withdrawing of treatment in the overall picture of the patient's care, by specifically

Table I–18–2 ■ Eliciting Definition of Quality of Life

Under what kinds of circumstances would life be worth living for you?
What if you weren't able to...
Take care of yourself?
Get up out of bed?
Talk with your family and friends?
Eat and drink on your own?
Be awake and aware of what was going on around you?
Eliciting Tolerance for Treatment Burden
If a treatment caused you discomfort and had a small chance of getting your health to the state you described as being worth living, would you want that treatment?
What if it had a good chance of getting your health to the state you described as being worth living?

describing what treatments *will* be given. The withholding or withdrawing of therapies is not an absence of treatment, but rather a tailoring of treatment to meet the patient's unique needs and goals.

Step 5: Respond to Patient or Surrogate Reaction

Conversations about limiting therapy are, by their nature, upsetting because they make those involved aware of the nearness of death. Emotional reactions are common and are to be expected. They should be acknowledged and responded to before attempting to proceed, because it is usually not possible to continue the conversation in an emotionally wrought situation. In addition, responding to the emotion shows that the clinician cares about the patient or surrogate. This can be as simple as acknowledging that the conversation is difficult ("It's hard to talk about this, isn't it?"), or allowing time for the emotion to lessen. Emotions that do not subside after simple steps are taken may require more attention and exploration (see Chapter I–4).

Finally, the patient's or surrogate's opinion of the plan should be elicited and any questions answered. Lack of immediate agreement is not a failure on the part of the clinician, the patient, or the surrogate; it is a signal that further discussion is required. Conflict between providers and families is common when the withholding or withdrawing of therapies is considered, so it is important to learn how to respond constructively (see Back and Arnold). Most conflict relates to communication issues (8), and multiple meetings are often required before a decision is reached (2), so focusing on communication and allowing time are usually all that is needed. If time is truly of the essence and a plan has not been agreed on, treatment should be given, with the understanding that it can be withdrawn when the patient's wishes are clarified.

Step 6: Summarize and Establish Follow-Up

Finally, to provide a sense of closure and because information retention is usually poor in highly emotional conversations, the physician should summarize the

results of the discussion and should establish what will happen next, both with the medical therapy and in the next meeting.

SPECIFIC THERAPIES

Artificial Nutrition and Hydration

Patients who are unable to eat and drink because of illness can receive nutritional support through artificial nutrition and hydration. Nutritional therapy can sustain patients with reversible illness until they are able to eat and drink on their own again. Deciding whether to provide such therapy to patients with nonreversible illness requires consideration of ethical, legal, emotional, religious, and clinical issues.

The ethical and legal consensus in the United States is that artificial nutrition and hydration are medical therapies and should be treated as such when making treatment decisions. Ethicists and courts have both affirmed that death is caused by the disease that makes the patient unable to eat and drink, not by the act of withholding or withdrawing artificial nutrition and hydration.

The religious faith of patients and families may affect their views about artificial nutrition and hydration. The religious import of food and water stems from the view that life is sacred, a common belief in the major religious traditions (11, 12). However, the relative importance of providing food and water varies among traditions. Some patients and families feel, on the basis of their religious beliefs, that it is wrong to withhold or withdraw food or water.

Food and water have social and symbolic significance. They are a part of celebrations with family and friends, and sustenance is seen as a source of strength. Even those who logically understand that patients are unable to eat and drink as a result of their underlying illness may feel, on an emotional level, that it is wrong to deprive them of food and water and that not providing food and water is the same as not providing care. This distress is felt more strongly by families and providers than by patients because illness can cause anorexia in the patient. These issues often need to be negotiated with families.

As with other therapies, the decision to provide artificial nutrition or hydration must be made on an individual basis, by defining the goals of therapy and making therapeutic recommendations based on those goals. It is important to explore how patients and families feel about artificial nutrition and hydration, because the wish to provide food and water may have a primarily emotional or spiritual basis. It is important to educate families about the patient's overall prognosis and the benefits and burdens of therapy and to address the family's fear that the patient will suffer or be abandoned. It is also important to educate health care providers, who may be distressed by not providing food and water. For example, providers in long-term care facilities sometimes request feeding tube placement in patients with advanced dementia.

Artificial Nutrition

Artificial nutrition can be provided parenterally as total parenteral nutrition or enterally as tube feedings via nasogastric, gastrostomy, and jejunostomy tubes.

More than 160,000 percutaneous endoscopic gastrostomy tubes are placed annually in the US Medicare population alone. The question whether to provide long-term artificial nutrition frequently arises in patients who are unable to take oral nutrition or who have anorexia or weight loss. Inability to take food orally is commonly the result of advanced dementia or catastrophic neurological injury (stroke, ischemic encephalopathy, traumatic brain injury). Decreased appetite and weight loss are also associated with cancer and other chronic diseases.

Over the past decade, a clinical consensus has developed that artificial nutrition should not be routinely provided to patients with advanced dementia, because it is not of clinical benefit. Although the consensus is not as clear, the same is probably true for patients with metastatic cancer and other terminal illnesses in whom weight loss and decline in functional status are caused by the underlying disease, not by lack of nutrition. Enteral nutrition does prolong life in certain neurological illnesses such as persistent vegetative state. In these cases, the decision to withhold or withdraw therapy should be based on the patient's definition of quality of life.

Finucane and colleagues performed an evidence-based review of tube feeding in patients with advanced dementia and found that the expected life span of these patients is short (13). Median survival is less than 1 year, and mortality is 60% at 1 year and 80% at 3 years. Observational studies have shown that tube feeding does not prolong life in advanced dementia, nor has it been shown to decrease aspiration pneumonia, skin breakdown, or infections or to increase functional status. In fact, observational studies indicate that tube feeding may increase aspiration. Patient comfort is another consideration in deciding whether to provide enteral feeding. It is not possible to know with certainty whether patients with advanced dementia experience hunger, but their global decline in mental status would suggest that they do not. The tube itself may be a source of discomfort, and patients with feeding tubes require more chemical and physical restraints. Surveys of elderly adults reveal that most would not want a feeding tube placed if they were to develop advanced dementia.

Artificial Hydration

Although the potential benefits and burdens of artificial hydration at the end of life have been debated extensively (14), clinical outcome data to guide decision making are only beginning to emerge (15), and there is no clear clinical consensus about when artificial hydration should be provided. The potential benefits of artificial hydration at the end of life include decreasing thirst and dry mouth and decreasing terminal delirium. The reported incidence and severity of thirst in terminal patients vary among studies. It is not clear whether thirst is related to systemic dehydration, nor is it clear that parenteral fluids relieve it, although mouth swabs effectively do so (14). Parenteral fluids have been shown to decrease terminal sedation and myoclonus in dehydrated patients with cancer (15). The potential burdens of parenteral fluids at the end of life include increased respiratory secretions and resulting "death rattle," as well as volume overload with resulting pulmonary and peripheral edema. Evidence is insufficient to establish the frequency and severity of these burdens (14), although administration of large fluid volumes would seem likely to produce them.

Mechanical Ventilation

The inability to breathe is one of the most distressing symptoms encountered in medicine and also one of the most serious. Severe dyspnea is anxiety provoking for patients, families, and providers alike, thus making control of respiration and symptoms urgent. Untreated respiratory failure can lead quickly to death. Mortality of patients with acute respiratory failure is 30% at 1 month, and it increases to 50% in the presence of comorbid disease (16).

Although the withholding and withdrawing of interventions are considered equivalent from an ethical and legal perspective, the two may be very different emotionally, especially in the case of ventilator withdrawal. Because patients who are withdrawn from ventilators are expected to die shortly after withdrawal, removing the ventilator can be seen as actively causing the patient's death. Critical care physicians report that withdrawing mechanical ventilation is more likely to cause patient distress than is withdrawal of other life-sustaining treatments. However, mechanical ventilation can be withdrawn while maintaining patient comfort (17), and it should be withdrawn when the burdens of continuing therapy outweigh the benefits.

Methods of Ventilator Withdrawal

Patient comfort and family comfort are the primary considerations in withdrawing mechanical ventilation. The two methods of ventilator withdrawal are *terminal weaning* and *terminal extubation* (17). In terminal weaning, the artificial airway is maintained while ventilator support is gradually reduced. The patient may then be extubated. In terminal extubation, ventilator support is rapidly reduced, and the artificial airway is removed. There is little evidence to support a preference for one technique over the other, but terminal weaning is more commonly used (17). Terminal weaning can be performed over a period of minutes and has been shown to maintain patient comfort (17). The decision to extubate, either before or after reduction in ventilator support, should be made on the basis of the anticipated amount of airway secretions and the availability of staff to manage them (17). Protocols detailing the sequence of events during ventilator withdrawal (Table I–18–3) are useful to ICU staff.

Palliation of Respiratory Distress

Breathlessness associated with the withholding or withdrawing of mechanical ventilation can be treated with short-acting parenteral opiates and benzodiazepines dosed in boluses and infusions. Patients considered for ventilator withdrawal are usually already receiving these agents, and the doses can be adjusted as needed (see Table 1–18–3). Frequently, these patients are receiving neuromuscular blocking drugs, and these should be stopped a few hours before withdrawal is initiated. If paralysis has not resolved after a few hours, the decision to proceed should be made with the understanding that neuromuscular blockade will mask signs of distress. Opiates and benzodiazepines should be dosed accordingly.

When mechanical ventilation is withheld from patients with severe dyspnea, the use of opiates and benzodiazepines may be necessary (see Chapter I–13). Oxygen should be supplied by mask or nasal canula if the patient finds that it improves the symptoms. Efforts to diagnose and treat the underlying cause of the dyspnea should be made, as long as doing so does place too great a burden on the patient.

Table I–18–3 ■ Protocol for Terminal Ventilator Weaning

Preparation

Write do-not-resuscitate (DNR) order in chart.
Document the discussion with surrogate and rationale for withdrawing ventilator.
Discuss the procedure of withdrawal with loved ones and answer questions.
Discontinue monitoring, therapies, and devices not necessary for patient comfort.
Have support for loved ones available (pastoral care, social work, as appropriate).

Sedation and Analgesia

Infusions at current rates, or initiate with:
Opiate
  Fentanyl, 100 g/hr, or morphine, 10 mg/hr
Benzodiazepine:
  Midazolam, 10 mg/hr, or lorazepam, 5 mg/hr
For signs of discomfort, every 15 minutes:
  Bolus of opiate and benzodiazepine equivalent to hourly rate
  Increase infusion rates by 25%

Ventilator

Reduce ventilator alarms to minimum settings.
Reduce fractional inspired oxygen to room air and positive end-expiratory pressure to zero (over ~5 min)
Wean intermediate ventilation or pressure support incrementally.
Monitor for signs of discomfort, give boluses, and adjust opiate and benzodiazepine infusion rates.
Do not decrease support until the patient is comfortable at current settings (weaning is usually accomplished in ~15 min).
When intermediate ventilation is 4/min or pressure support 5 mm Hg, depending on anticipated airway secretions and ability to control,
  Extubate with suction immediately available
    or
  Disconnect ventilator, connecting artificial airway to T-piece with air.

After Withdrawal

Allow time for the family to remain with the patient; be available for support.
If the patient has not died, continue comfort measures and arrange a comfortable space for the patient and family.

Adapted from Treece PD, Engelberg RA, Crowley L, et al: Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit. Crit Care Med 2004;32:1141.

Depending on the severity of respiratory failure, patients may require doses of opiates and benzodiazepines that produce sedation. Medications should be given until the patient is no longer in distress. Ethically and legally, when medication is given with the intention of relieving suffering, any secondary effect the medication has that hastens death is seen as that, and the physician is not considered morally or legally culpable. Studies have shown no correlation between survival time after ventilator withdrawal and doses of opiates and benzodiazepines given during withdrawal (17).

Family Education and Support

Because most patients are unconscious when the withholding or withdrawing of mechanical ventilation is considered, the decision to withhold or withdraw this

treatment is usually made by surrogates. Families are comforted by being told how medications will be used to lessen respiratory distress. In the case of withdrawing, families should be invited to be present in the patient's room, although they should not be made to feel obligated. Before the ventilator is withdrawn, the process should be explained, and any questions should be answered. The possible outcomes should also be reviewed. When ventilator support is withdrawn in anticipation of death, most patients die within minutes of withdrawal. However, some live for hours or even days, and a few survive to be discharged from the hospital (2). As with any patient near death, support should be provided by staff, and social workers or pastoral care providers should be present as needed. Monitors can be distracting, and removing them as appropriate can restore a sense of humanness and closeness. After a patient's death, the family should be given ample time to remain at the bedside, and religious traditions should be accommodated.

Cardiopulmonary Resuscitation

CPR, initially consisting of closed chest compressions and artificial respiration, was developed in 1960 as a means of sustaining circulatory and respiratory function in patients who suffered from anesthetic-induced cardiac arrest in the operating theatre. The technique was soon extended to hospital policies recommending use of CPR for all cardiac arrests. Although generally healthy patients with reversible causes of cardiac arrest benefited from CPR, it soon became apparent that CPR could be a source of suffering and could simply prolong the dying process in patients with terminal illness. In the mid-1970s, hospitals began to use DNR orders to designate patients for whom CPR should be withheld. By 1988, the United States Joint Commission on Accreditation of Healthcare Organizations required hospitals to have DNR policies to be accredited. Although DNR orders are now common, debate still exists about who should receive CPR, who should decide who receives CPR, and how DNR orders should be discussed with patients and families.

Survival rates after CPR depend on the site of resuscitation, the cause of cardiac arrest, the time to resuscitation, and the patient's age, functional status, and comorbidities. In the general population, survival to hospital discharge for *out-of-hospital* cardiac arrests varies between 2% and 30% and depends significantly on the quality of local emergency services (10). On average, survival to hospital discharge for *in-hospital* arrests is approximately 15%, varying between less than 1% and 25% (18, 19). Witnessed cardiac arrests, younger age, and good general health are associated with higher survival rates (18, 19). The average survival rate for patients with chronic disease and decreased functional status is 5% (10, 19). Although CPR may lead to transient recovery of circulatory function in patients with metastatic cancer, sepsis, or acute stroke, the survival rate to hospital discharge for these patients is less than 1% (18, 19).

Because the provision of CPR is prescribed by hospital and emergency medical response policies, CPR is unique from an ethical and legal perspective. A physician must take a positive action (e.g., write a DNR order) for CPR to be withheld. This procedure is appropriate, given that CPR candidates are by definition dead, and any delay in initiation to consult with family members will lower survival rates. However, it leaves unresolved the issue of whether patient or surrogate consent is required for CPR to be withheld. From a legal perspective, the right of physicians

unilaterally to write DNR orders has not been established. Professional associations, including the American Medical Association and the American Heart Association, say that physicians are not obligated to provide CPR if they believe that it would be ineffective, but the recommendation should be based on an understanding of the patient's goals and code status discussions with the patient in anticipation of the possible need for CPR.

The objective of a code status discussion is to increase patient autonomy, to match a patient's care to his or her goals. Although patients base their decisions on whether to undergo CPR on their values and goals and their understanding of the likelihood of survival after CPR (10), these elements are not usually included in discussions of code status. A patient's perception of the likelihood of survival is frequently inflated, at least in part because of misinformation from television and the media (10). Education about the true likelihood of survival after CPR has been shown to decrease patient preference for its administration (10). Thus, any discussion of code status should begin with a review of the patient's overall condition, goals, and values. The physician can then make an appropriate recommendation about CPR and can explain the procedure and the likelihood of survival (see von Gunten).

Dialysis

Since the invention of dialysis and the end-stage renal disease amendment to the Social Security Act in 1972, use of this treatment has become more and more prevalent. In 2000, about 300,000 patients in the United States were undergoing maintenance dialysis, and 95,000 were starting dialysis (20). Patients with end-stage renal disease have a high rate of comorbid disease and a mortality rate comparable to that of patients with cancer (20). Over the past 20 years, it has become evident that dialysis is frequently discontinued. One of every five patients who undergoes dialysis in the United States discontinues dialysis before death (20). These high withdrawal rates have led to studies of the phenomenon and to the creation of guidelines to assist health care providers and patients in decision making. Most recently, in 2003, the Renal Physicians Association and the American Society of Nephrology convened a working group and published the *Clinical Practice Guideline on Shared Decision making in the Appropriate Initiation of and Withdrawing from Dialysis*, based on expert opinion and literature review (20). The guideline emphasizes shared decision making, considering the patient's overall prognosis and quality of life when recommending dialysis, and respecting the patient's right to refuse therapy.

More studies have focused on patients who withdraw from dialysis, rather than on those who choose not to initiate it. Those who discontinue dialysis are demographically similar to the general dialysis-treated population; that is, most of them are elderly and have a high rate of comorbid disease. Most have not been undergoing dialysis treatment for more than a few years. Death occurs within days to weeks after dialysis withdrawal. The most common reasons for withdrawal of dialysis are deterioration because of a chronic condition, acute deterioration as a result of a new diagnosis, or generalized failure to thrive. The quality of death in patients who withdraw from dialysis is usually good in that it is free from suffering, brief, and peaceful.

Symptoms while dying of renal failure are caused by uremia, volume overload, general debilitation, and comorbid disease. In one study, pain, agitation, and dyspnea were most prevalent during the last 24 hours of life; however, no frequently severe symptoms were observed. Although the dose and frequency may require adjustment, opiates should be used for moderate to severe pain and dyspnea. Because nausea is secondary to the effect of urea on the chemoreceptor trigger zone, centrally acting antiemetics such as phenothiazines (chlorpromazine) and butyrophenones (haloperidol) should be used. Antipsychotic agents are also useful in treating delirium. Finally, although they should be used cautiously, benzodiazepines can reduce dyspnea and agitation (see also Chapter II–4).

PEARLS

- The goal of the physician-patient relationship is to advance patient autonomy and health, as defined by the patient.
- Any recommendation to withhold or withdraw therapy should be preceded by a discussion of the overall goals of care.
- The clinician's role in decision making about withholding and withdrawing of therapies is to make recommendations based on the patient's values and beliefs, prognosis, and overall treatment goals.
- Surrogate-physician conflict surrounding withholding and withdrawing of therapies is more commonly caused by issues of communication rather than by the recommendation to limit therapy.
- Patients and their surrogates are less likely to prefer life-sustaining therapies if they understand the prognosis and the likelihood of success of the treatment being considered.
- Providers should be aware of and should respond to emotions.

PITFALLS

- Not knowing the ethical and legal consensus regarding withholding and withdrawing of therapies
- Asking patients to decide about treatments without educating them about the treatments and the accompanying risks and benefits
- Assumptions by clinicians that they know how a patient should define quality of life
- Expecting that decisions to withhold or withdraw therapies will be made after a single meeting
- Not being familiar with how to withhold or withdraw therapies while maintaining patient comfort

SUMMARY

Life-sustaining therapies are frequently withheld or withdrawn. Ethically and legally, the decision to withhold or withdraw therapies is guided by the principle of autonomy; patients or their surrogates have the right to refuse any therapy, even if it results in death. Decisions to withhold or withdraw therapies should be made

jointly between clinicians and patients or their surrogates, based on the patients' values and preferences for medical care. Each decision should be based on the patient's overall prognosis, the effectiveness of the therapy in question, its benefits and burdens to the patient, and the overall goals of care. Good communication is essential to increasing patient autonomy. Artificial nutrition and hydration, mechanical ventilation, CPR, and dialysis are commonly withheld and withdrawn. It is appropriate clinically, ethically, and legally to withhold or withdraw therapies when the burden to the patient outweighs the benefit. Distress of patients and their families can be minimized by symptom palliation and by providing information on the patient's condition, prognosis, and treatment alternatives.

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Last Hours of Living

19

Frank D. Ferris, Maria Danilychev and Arthur Siegel

CHAPTER OUTLINE

INTRODUCTION
PREPARE THE PATIENT AND FAMILY
Conduct a Family Meeting
Develop an Effective Care Team
Discuss Communication with the Dying Patient
Facilitate Life Closure
Rites and Rituals, Funerals, and Memorial Services
Provide Ongoing Support
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Loss of Ability to Close Eyes
Decreasing Fluid Intake and Dehydration
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BEREAVEMENT
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Attendance at Funerals and Memorial Services
PEARLS
PITFALLS
SUMMARY

INTRODUCTION

The end of life and death of someone close is never easy. No one can escape the experience. Everyone at the bedside will be seeing the potential for her or his own future end-of-life experience and death. If symptoms are not well managed, there may be unnecessary suffering. If the dying process is prolonged unnecessarily, those who watch may be left with memories that the death was not good and fears that their own death will be similar (1).

Because much of end-of-life care and dying takes place in hospitals and long-term care facilities, most people have never witnessed death or seen a dead body outside a funeral home. They have seen only media dramatizations on television or in the cinema. Based on their own experiences, many observers imagine what the patient must be feeling and do not realize that the patient's experience may be very different.

Along with end of life and death, the patient and family experience loss of functional capabilities, body image, sense of future, independence, control, and dignity. There are major transitions in roles, responsibilities, and family dynamics. Social support systems change under stress. Some people remain loyal to the patient and family, but others abandon them out of fear or for other reasons.

As the patient's physical capabilities diminish, there will likely be an increasing need for care, particularly as goals of care and treatment priorities start to shift frequently. Although individual family members may be willing to care for their loved one, they will benefit from considerable training and support from physicians and other health care professionals.

Ultimately, as the patient dies, the original family group adjourns. Those who survive will form a new family group with only the memory of the patient. Most families benefit from ongoing help from their physicians and health care providers to help them process the experience and return to normal all over again before they can begin to perform effectively (Fig. I–19–1) (2).

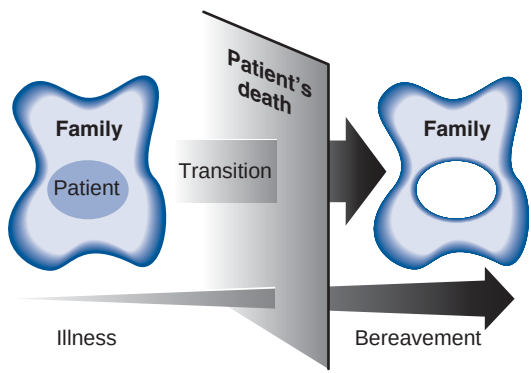

Figure I–19–1 ■ Family transitions. (From Ferris FD, Balfour HM, Bowe K, et al: A model to guide patient and family care: Based on nationally accepted principles and norms of practice. *J Pain Symptom Manage* 2002;24:106–123.)

PREPARE THE PATIENT AND FAMILY

Care during the last hours of life is a core competency of every physician and health care worker (3–5). People who know what to expect have a very different experience of dying and death than do those who are ignorant of the process. Time spent preparing patients, family members, and caregivers for the end of life has the following effects: it reduces their anxiety and fear; it increases their competence and confidence to provide care; it increases their sense of value and gifting during the process; it creates good memories of the experience; it prepares them for impending losses; it shifts their roles, responsibilities, and support systems; and it reduces their dependence on health care providers (i.e., the frequency of visits and urgent phone calls).

Conduct a Family Meeting

To help people prepare, conduct one or more family meetings to convey information, facilitate the development of an effective care team, facilitate life closure, help arrange for rites and rituals, and encourage planning for funeral or memorial services. The process of conducting a family meeting is another application of the six steps of effective communication. Be sensitive to personal and cultural differences related to information sharing and decision making.

1. Set the stage carefully to ensure that everyone who wants to attend is present.
2. Inquire: "What is known about the patient's illness and prognosis?"
3. Ask: "How would you like to receive information?"
4. Once family members are clear about that they would like to know, discuss the facts about the patient's illness and prognosis (i.e., that the patient is dying), and then stop talking.
5. Wait for emotional responses and provide support.
6. Once emotions have settled, check for understanding, questions, and preparedness for more information. If emotions have been intense and participants do not settle, it may be better to schedule a follow-up meeting.

If participants are prepared for further discussions, provide an overview of the changes and events that are likely to occur during the dying process (Table I–19–1).

Table I–19–1 ■ Changes during the Dying Process

Change During the Dying Process	Signs
Fatigue, weakness	Decreasing function, hygiene Inability to move around bed Inability to lift head off pillow Loss of muscle tone
Cutaneous ischemia	Erythema over bony prominences, cyanosis Skin breakdown Wounds
Pain	Facial grimacing Tension in forehead, between eyebrows

Table continued on following page

Table I–19–1 ■ Changes during the Dying Process (Continued)

Change During the Dying Process	Signs
Decreasing food intake, wasting	Anorexia Poor intake Weight loss (muscle and fat), notable in temples
Loss of ability to close eyes	Eyelids not closed Whites of eyes showing (with or without pupils visible)
Altered handling of fluids	Decreasing fluid intake Peripheral edema from hypoalbuminemia Dehydration, dry mucous membranes/conjunctiva
Cardiac dysfunction	Tachycardia and bradycardia Hypertension and hypotension Peripheral cooling Peripheral and central cyanosis (bluing of extremities) Mottling of the skin (livedo reticularis) Venous pooling along dependent skin surfaces
Renal failure	Dark concentrated urine Oliguria, anuria
Neurological Dysfunction	
Decreasing level of consciousness	Increasing drowsiness Decreased awareness of surroundings Difficulty awakening Lack of response to verbal or tactile stimuli
Decreasing ability to communicate	Decreased concentration, decreased attention Difficulty word finding Use of monosyllabic words, short sentences Delayed or inappropriate responses Lack of verbal responses
Terminal delirium	Early signs of cognitive failure (e.g., confusion, day-night reversal) Agitation, restlessness, hallucinations Purposeless, repetitious movements Moaning, groaning
Respiratory dysfunction	Dyspnea Change in ventilatory rate: increasing first, then slowing Decreasing tidal volume Abnormal breathing patterns: apnea, Cheyne-Stokes respirations, agonal breaths
Loss of ability to swallow	Dysphagia Coughing, choking Loss of gag reflex Buildup of oral and tracheal secretions Gurgling, noisy breathing
Loss of sphincter control, urinary retention	Incontinence of urine or bowels Maceration of skin Perineal infections (e.g., candidiasis)
Other Changes	
Fever Sweating Seizures Defibrillator shocks Bursts of energy just before death occurs (the “golden glow”) Aspiration, asphyxiation Hemorrhage, hemoptysis, exsanguination	

Determine who the caregivers may be and ask about their caregiving skills and experience. Facilitate decision-making discussions about the goals of care and treatment priorities. Develop a plan of care that includes personal activities that the patient may wish to complete before dying. Clarify who the surrogate decision maker will be in the event that the patient loses the capacity to make decisions. Review advance directives. Discuss the appropriateness and comfort of the family within the current setting of care (e.g., home) as the place for the patient's end-of-life care and death. If the family is not prepared for the patient to die at home, plan for a change in setting of care far enough in advance of the patient's death to ensure that it is safe for the patient, family, and all caregivers. Try to minimize the risk of sudden changes in the setting of care simply because the patient is dying. Transfers from a nursing home to a hospital or vice versa can be very disruptive and distressing to everyone.

Develop an Effective Care Team

Most family members are not skilled at caring for someone who is dying. Those who volunteer to provide care frequently need considerable training and support from the health care team.

As a care team forms, find out who would like to provide personal care, as opposed to help with other activities such as cleaning, shopping, and scheduling of visitors. Give everyone permission to be family first and bedside caregivers only if they are prepared for the role. To help minimize guilt, offer everyone an appropriate task so they feel helpful. Establish who will coordinate the care team (i.e., which clinician will lead the health care team) and who will coordinate family, friends, and caregivers.

Once the care team has been selected, educate family and caregivers about the following: changes and signs during the dying process (see Table I–19–1), including the unexpected; how to communicate during the dying process; signs that death has occurred (Box I–19–1); what to do when death occurs (Box I–19–2); specific caregiving skills (i.e., changing a bed with a patient in it; turning, massage, and passive movement of joints; management of urine and stool; mouth, nose, lip,

BOX I–19–1 *SIGNS THAT DEATH HAS OCCURRED*

Ensure that family, caregivers, and health care providers are familiar with the signs and potential events that may occur as the patient dies:

- The heart stops beating.
- Breathing stops.
- The pupils become fixed and dilated.
- Body color becomes pale and waxen as blood settles.
- Body temperature drops.
- Muscles and sphincters relax (muscles stiffen 4–6 hours after death as rigor mortis sets in).
- Urine and stool may be released.
- The eyes may remain open.
- The jaw can fall open.
- Observers may hear the trickling of fluids internally, even after the patient has died.

BOX I–19–2 *WHAT TO DO WHEN DEATH OCCURS*

Always be sensitive to and respect personal, cultural, and religious values, beliefs, and practices.

Ensure that family, caregivers, and health care providers know what to do when death occurs:

- There are no rules or regulations governing what happens after the patient dies.
- There is no need to call 911.
- There is no need to rush to call a physician or other health care providers. Invite the family and caregivers to call whenever they want support.

Encourage everyone:

- To spend the time they need to witness and realize what has happened and say their good-byes.
- To touch, hold, and even kiss the person's body, as they feel most comfortable.
- To complete the desired rites and rituals at the appropriate time.

Sufficient time spent at the bedside beginning to "realize" that their loved one has died will benefit everyone as they start to adapt to the changes in their lives.

When family members are ready for or need support, make sure they know who to call, such as the physician or the hospice.

and eye care; and how to deliver medications when the patient is unable to swallow). Ensure that everyone present knows how to practice universal body fluid precautions. Because numerous visitors can be very fatiguing for the patient and the family, have a care team member take on the task of scheduling visits so everyone has an appropriate length of time with the patient.

Use a logbook to facilitate communication among caregivers and to minimize repetitious questioning of patients and families about the following:

1. Goals of care
2. Active treatments
3. Patient preferences (e.g., food, conversation, turning)
4. Summaries of conversations, care provided, fluid and nutritional intake
5. Contact information for all professional and informal caregivers
6. What to do in an emergency
7. What to do when death occurs, whom to call

Discuss Communication with the Dying Patient

During the last hours of life, families frequently want "just a little more time" to communicate with their loved one and become very distressed when they are not able to do so. The degree of distress seems inversely related to the extent to which advance planning and preparation occurred.

Although we do not know what unconscious patients can hear, experience suggests that their awareness may be greater than their ability to respond. It is prudent to *presume that the unconscious patient hears everything*. Advise families and caregivers to talk as if the patient were conscious. Surround the patient with the people, children, pets, things, music, and sounds that she or he would like. Encourage family members to say the things they need to say. Share bad news away from

the bedside, in another room, behind closed doors. Encourage family to give the patient permission to "let go and die" using words that are comfortable to them. Suggest statements such as the following: "I know that you are dying, please do so when you are ready," "I love you. I will miss you. I will never forget you. Please do what you need to do when you are ready."

Encourage everyone to show affection in ways they are used to, including touching and lying beside the patient. Encourage as much intimacy as the family feels comfortable with. Maintain privacy.

Facilitate Life Closure

If they have the opportunity, many patients approaching the end of life want to finish business, organize financial and legal affairs, and reconcile both close and estranged relationships. Help them engage in activities to create memories, including reminiscence and life review through stories and photographs, family reunions and celebrations, letter writing and the creation of audio or video tapes, gift giving (i.e., thoughts, personal treasure or family heirlooms, money, organ donation such as corneas, autopsy), or a last "hurrah" and saying goodbye. Some patients even want to have a party before their death to give gifts and say goodbye to close family and friends.

Rites and Rituals, Funerals, and Memorial Services

Ensure that everyone is aware of personal, cultural, and religious traditions, rites, and rituals that may dictate how prayers are to be conducted, how a person's body is to be handled after death, whether health care providers can touch it, and when and how the body can be moved. Help the patients and family plan funeral or memorial services, burial, or cremation.

Provide Ongoing Support

Throughout the last hours of life, families benefit from repeated contact with their physicians and health care team. Review the status of the patient, family, and caregivers regularly. Repeat and clarify the goals of care, the futility of life-prolonging therapies, and the irreversibility of unfolding events. Modify the plan of care as needed to address the changing situation and goals of care. Assess the potential for an intense, acute grief reaction and determine who may be at high risk for a complicated grief reaction.

Because delays in communication only heighten anxiety, ensure that knowledgeable clinicians, including a physician, are available by telephone 24 hours per day, 7 days per week. Families and caregivers will have the best outcome if their questions and concerns are addressed promptly.

Dying in Institutions

Because many patients die in hospitals, nursing homes, prisons, and jails, a few remarks are warranted regarding the particular challenges of ensuring a comfortable death in institutions where the culture is not focused on end-of-life care.

Tradeoffs previously acceptable because the patient would get better (i.e., loss of privacy, no opportunity for intimacy) are no longer acceptable because this is the last chance for the patient and family to be together.

Provide a private environment where confidential conversations are possible and family can be present continuously, day or night (or move other patients out of a multibed room). Encourage the family to surround the patient with a few of her or his favorite personal belongings and photos.

This is the last chance for family members to be close, so intimacy should be encouraged. Teach them how to pillow side rails and curl up safely in a hospital bed beside their loved one. Provide privacy signs to hang on closed doors that staff will respect.

Ensure that the staff is knowledge and skilled in last-hours-of-life care and collaborates to provide a single plan of care across nursing shifts and changes in house staff. If the provision of environments conducive to end-of-life care proves to be difficult on the general medical/surgical units, establish a specialized palliative care unit where patients and families can be assured of the environment and the skilled care that they need.

MANAGE THE DYING PROCESS

As the last hours of life evolve, the many common, irreversible signs and symptoms can be alarming if they are not understood (Table I–19–1). Reassess the need for every therapeutic intervention. Stop all therapies that are inconsistent with the patient's goals of care. Continue only those medications that are needed to manage symptoms such as pain, breathlessness, or terminal delirium or to reduce secretions and prevent seizures (Table I–19–2).

Pharmacological and nonpharmacological management should be based on the etiology and underlying pathophysiology of each symptom. Always use the least invasive route of administration. This is usually the oral or buccal mucosa (buccal) routes, occasionally the subcutaneous or intravenous routes, but never the intramuscular route.

Weakness and Fatigue

Fatigue and weakness usually increase as patients approach death. Eventually, most patients are not able to move around the bed or raise their heads. Discontinue therapy to alleviate fatigue. Because joint position fatigue and significant achiness can develop if a patient remains in the same position without moving for prolonged periods of time, move joints passively every 1 to 2 hours to minimize any sense of achiness.

Skin Care

During the last hours of life, skin care focuses on hygiene, moisture, protection, pressure reduction, and massage. Bathe the patient routinely to maintain body hygiene, remove dead skin, clean up body fluids, (e.g., urine, stool), and minimize body odor. Use warm water and a gentle skin-cleansing agent. Dry thoroughly to

Table I–19–2 ■ Medications Used during the Last Hours of Life

Drug	Dosing	Notes
Lorazepam	1–2 mg buccal mucosal, PR, SL, SC, IV q1h to titrate, then q4h to maintain	If paradoxical agitation is observed, choose a nonbenzodiazepine for sedation.
Haloperidol	2–5 mg PR, SC, IV q1h to titrate, then q6h to maintain	Relatively nonsedating at low doses, it may require 10–30 mg/day to sedate.
Chlorpromazine	10–25 mg PR, SC, IV q4–6h	The parenteral route may require special exemptions from standard nursing policy in some settings.
Scopolamine (Hyoscine hydrobromide)	10–100 mcg/hr SC, IV continuous infusion or 0.1–0.4 mg SC q6h or 1–10 patches q72h	The transdermal preparation only delivers approximately 10 mcg/hr and takes many hours to reach therapeutic levels.
Glycopyrrolate	0.2–0.4 mg SC q2–4h and titrate	This agent does not cross the blood-brain barrier.

IV, intravenously; PR, rectally; SC, subcutaneously; SL, sublingually.

minimize the risk of maceration. Avoid soaps that are drying and perfumes that may be irritating or abrasive.

Moisturize the skin routinely to minimize the risk of dry, flaking skin and pruritus, to maintain elasticity, and to minimize the risk of tears. Avoid rubbing areas that are erythematous or have broken down.

Protect thin, fragile skin to minimize the risk of skin tears. This is particularly important in cachectic patients who have lost the elasticity and resilience effect previously provided by collagen and subcutaneous fat. Thin, transparent membranes reduce shearing forces. Hydrocolloid dressings add a cushioning effect.

Continuous pressure, particularly over bony prominences, increases the risk of ischemia, skin breakdown, and pain. To minimize sacral pressure, keep the head of the bed at less than 30 degrees. Raise it only for short periods of social interaction. Avoid resting one limb on another. Use a pillow or another cushioning support to keep the patient's legs apart. Protect bony prominences with hydrocolloid dressings.

Turning helps to maintain comfort, reduce pressure, and minimize the risk of ischaemia, skin breakdown, and joint position fatigue. When patients are unable to move themselves, turn the patient from side to side every 1 to 1.5 hours. Use a careful "log-roll" technique to distribute forces evenly across the patient's body and to minimize pain on movement. Use a draw sheet to reduce shearing forces that could lead to skin tears. If turning is painful, turn the patient less often, or place the patient on a pressure-reducing surface, such as an air mattress or air bed. As patients approach death, the need for turning lessens as the risk of skin breakdown becomes less important.

Massage intermittently to stimulate circulation, shift edema, spread out moisturizing lotions, and provide comfort. This is particularly helpful in dependent areas subject to increased pressure, before and after turning. Avoid massaging skin that is erythematous or has broken down.

Wound Care

During the last hours of life, wound care focuses exclusively on comfort, not healing. Minimize the frequency of dressing changes. Use nonstick, pain-reducing dressings (e.g., hydrogels and alginates). Control infections with topical antibacterials (e.g., iodine, metronidazole, or silver compounds) and antifungals (e.g., ketoconazole). Contain exudate flow with foam dressings. Absorb odors with kitty litter or activated charcoal placed in a pan under the bed, or have a candle burning in the room. Consider masking odors with alternative smells, such as vanilla or vinegar. Avoid scented deodorizers or perfumes.

Decreasing Nutritional Intake and Wasting

Most patients lose their appetite and reduce food intake long before they reach the last hours of life. Families and professional caregivers often interpret cessation of eating as "giving in" and worry that the patient will starve to death. In fact, most dying patients are not hungry; food is not appealing and may even be nauseating. Parenteral or enteral feeding at the end of life does not improve symptom control and it does not lengthen life (6).

Clinicians can help reframe the family's understanding of anorexia from "starving to death" to "metabolic abnormalities due to cancer that may be protective" (7). Ketones have been shown to improve the energy status of the working perfused heart markedly. In some patients with advanced astrocytomas, a ketogenic diet decreased tumor glucose uptake and increased patient performance. During fasting, ketosis appears to prevent the destruction of muscle mass by decreasing the gluconeogenic demands to provide glucose to the brain (8). Intellectual function remains intact for a longer period. Ketosis can also increase the patient's general sense of well-being.

Clinicians can help families and caregivers to realize that food pushed on an unwilling patient or one who is incapable of eating may inadvertently cause nausea, aspiration, or asphyxiation and may increase tensions and bad feelings (7). Clenched teeth may be the only way for the patient to exert control and should be respected. As an alternative, help family members and caregivers find different ways to provide appropriate physical care and emotional support to the patient.

Loss of Ability to Close Eyes

During the last hours of life, patients frequently leave their "eyes open," although the irises and pupils are not visible. This is *not* a sign of neurological dysfunction. Advanced wasting leads to loss of the retro-orbital fat pad. Muscles pull the orbit back into its socket. The patient's eyelids are not long enough to extend the additional distance backward and fully cover the conjunctiva. As a result, the eyelids no longer appose, and some conjunctiva remains exposed, even when the patient is sleeping. Educate the family and caregivers about the cause so they will understand what is happening and not find it distressing. When conjunctiva is exposed, maintain moisture by using ophthalmic lubricants, artificial tears, or physiologic saline (see the later discussion of oral, nasal, and conjunctival care).

Decreasing Fluid Intake and Dehydration

Most patients reduce their fluid intake or stop drinking before they die. This frequently causes distress to family and caregivers who worry that the patient will become dehydrated and thirsty and will suffer. Clinicians can help families and caregivers to understand that this is an expected event and can suggest alternate ways for them to give care.

When Fluid Intake Is Reduced

If the patient is still taking some fluid but not eating, salt-containing fluids, such as soups, soda water, sport drinks, and red vegetable juices (e.g., tomato juice) can facilitate rehydration, maintain electrolyte balance, and minimize the risk of nausea from hyponatremia. Fluids that are effectively "free water" and do not contain sodium bicarbonate are not rehydrating (e.g., water, fruit juices, sodas, soft drinks). Fluids that contain caffeine (e.g., coffee, tea, colas) are diuretics and worsen dehydration. Discontinue all diuretics and antihypertensives.

As patients develop cachexia and hypoalbuminemia, their oncotic pressure and intravascular volume decrease, and mild peripheral edema is expected. The absence of mild peripheral edema signals severe dehydration. Increased fluid intake increases the risk of peripheral and pulmonary edema. It does not replenish the intravascular volume.

An albumin infusion can temporarily restore intravascular oncotic pressure, produce a transitory diuresis, and reduce edema for a short period (hours to 1 or 2 days). Especially when combined with a loop diuretic, this approach may allow the patient to participate in a specific activity, such as a family reunion. Routine albumin infusions are not recommended in cachectic patients. The albumin is catabolized within hours as a fuel source for the patient (or tumor), and it does not reverse the underlying protein deficit. It is also an expensive procedure.

When the Patient Stops Taking Fluids

When a patient stops taking oral fluids, explain to the family that patients with peripheral edema or ascites have excess body water and salt and are not dehydrated. They will not become lightheaded or dizzy if they are not elevated in bed. Low blood pressure and a weak pulse are part of the dying process, not just an indication of dehydration. Most experts believe that dehydration in the last hours of life does not cause distress. It may stimulate endorphin release and add to the patient's sense of well-being.

The most frequent symptoms that dehydrated patients complain of are thirst, dry mouth, and fatigue. At the end of life, these symptoms are most likely to be caused by disease progression, mouth breathing, analgesics, anxiolytics, and anticholinergics used to control secretions. Several studies have shown that parenteral fluids do not affect the sensation of thirst and dry mouth that patients experience at the end of life. The best treatment for these symptoms is frequent and good oral care, ice chips, swabs with water, and nystatin if thrush is present. Parenteral fluids may help to reduce sedation and myoclonus, either from hydration or increased elimination of active opioid metabolites. However, parenteral fluids have not been shown to lengthen life and may even shorten life. They can worsen peripheral edema and ascites and can increase gastrointestinal and respiratory secretions,

which may result in breathlessness, pain, nausea and vomiting, and increased urination that requires catheter placement (9).

Oral, Nasal, and Conjunctival Care

During the last hours of life, meticulous oral, nasal, and conjunctival hygiene is essential to maintain comfort. To minimize bad odors and tastes and the sense of thirst and to reduce the risk of painful cracking and bleeding, moisten and clean the oral mucosa every 15 to 30 minutes with either a baking soda mouthwash (1 teaspoon salt [5 mL] plus 1 teaspoon baking soda [5 mL] mixed in 1 quart [$\sim$ 1 L] of tepid water), or an artificial saliva preparation. If oral candidiasis is present and the patient is able to swallow, treat with systemic fluconazole. Otherwise, dab white plaques with topical nystatin. Avoid swabs that contain lemon and glycerin because glycerin is desiccating and lemon is irritating, particularly on open sores.

To reduce evaporation, drying, and painful cracking of lips and nares, coat the patient's lips and anterior nasal mucosa with a thin layer of petroleum or other nonaqueous jelly every 4 hours. Be careful not to occlude nasal cannulae. Although not flammable, petroleum jelly could soften some plastics if exposure is prolonged. Avoid perfumed lip balms because these can be irritating.

To minimize the risk of painful, dry eyes, particularly when the eyes remain open, moisten conjunctiva with an ophthalmic lubricating gel every 3 to 4 hours or use artificial tears or physiologic saline solution every 15 to 30 minutes (these evaporate quickly).

Cardiac Dysfunction and Renal Failure

Cardiac output, intravascular volume, and urinary output normally decrease toward the end of life. As oliguria develops, the remaining urine typically becomes a very dark "tea" color. Ultimately, most dying patients become anuric. Rehydration with parenteral fluids is unlikely to reverse this circulatory shutdown or renal failure, particularly when the patient is hypoalbuminemic.

Neurologic Dysfunction: The Two Roads to Death

Neurologic changes typically manifest as one of two patterns that have been described as the "two roads to death" (Fig. I–19–2) (10). Seventy to 90% of patients follow the "usual road" and die quietly. Ten to 30% or more follow the "difficult road" and become terminally delirious (11).

The Usual Road

Patients following the usual road to death typically experience increasing drowsiness, decreasing ability to communicate, changes in their perception of pain, respiratory dysfunction, loss of ability to swallow, loss of sphincter control, coma, and, finally, a quiet death.

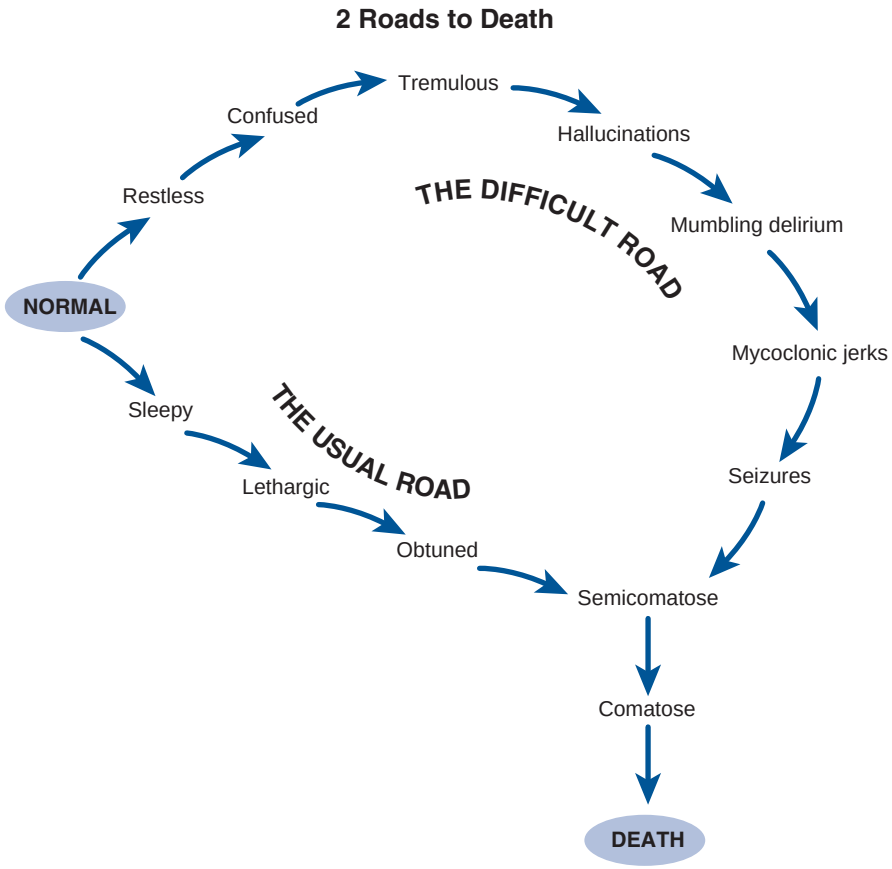

Figure I–19–2 ■ The two roads to death. (Adapted from Neuropsychiatric problems: Delirium. In Ferris FD, Flannery JS, McNeal HB, et al (eds): Module 4: Palliative Care. A Comprehensive Guide for the Care of Persons with HIV Disease. Toronto: Mount Sinai Hospital and Casey House Hospice, 1995.)

Eyelash Reflex

The eyelash reflex is a useful indicator to estimate the patient's level of awareness during the dying process. Previously used by anesthetists to guide the induction of anesthesia, the disappearance of the eyelash reflex suggests a profound level of coma equivalent to full anesthesia and a lack of any awareness of what is happening.

Pain

Many people fear that pain will suddenly increase during the last hours of life. In fact, the experience of pain during the dying process may decrease because of diminished neurological activity (i.e., nociception and transmission), lessened awareness and perception, and buildup of endorphins and other endogenous metabolites that have anesthetic properties (e.g., ketones).

Although difficult to assess in the semiconscious or obtunded patient, continuous pain may be associated with grimacing and continuous facial tension, particularly across the forehead and between the eyebrows. Physiologic signs (e.g., transitory tachycardia) may also signal acute changes (12).

Clinicians must be careful to not diagnose pain when fleeting forehead tension comes and goes, such as with movement, passage of gas, mental activity, dreams, or hallucinations. They must also be careful not to confuse pain with the restlessness, agitation, moaning, or groaning that accompanies terminal delirium. If the diagnosis is unclear, a time-limited therapeutic trial of opioids administered as needed may help to establish whether pain is driving the observed behaviors.

Knowledge of opioid pharmacology is critical to the management pain during the last hours of life. Codeine is metabolized into morphine. Morphine, oxycodone, and hydromorphone are conjugated into glucuronides by the liver, and then 90% to 95% of the metabolites are excreted renally. Some of these metabolites are potent analgesics, such as morphine 6-glucuronide (M6G); others may cause central nervous system excitation but no analgesia, such as morphine 3-glucuronide (M3G); and the effects of others, such as metabolites of hydromorphone and oxycodone, are less certain.

Because renal clearance decreases during the dying process (manifested by oliguria and anuria), decrease the routine administration of morphine (including continuous infusions) by 50% if urine output is less than 500 mL/24 hours, to avoid the accumulation of potentially toxic metabolites (e.g., M3G) and to minimize the risk of terminal delirium, and stop routine dosing once urine output is less than 200 mL/24 hours. Maintain analgesia by administering breakthrough doses of morphine to manage expressions suggestive of pain. Alternatively, consider the use of opioids with inactive metabolites, such as fentanyl or hydromorphone.

Respiratory Dysfunction

Before the last hours of life, correct reversible causes of respiratory dysfunction when appropriate. For example, treat pneumonia, perform therapeutic thoracentesis or paracentesis, use dexamethasone to reduce inflammation, or diurese edema related to heart failure.

During the last hours of life, altered breathing patterns may indicate significant neurological compromise. As the patient fatigues, breaths may become shallow and frequent, with a diminishing tidal volume. As the respiratory control center malfunctions, periods of apnea or Cheyne-Stokes pattern respirations frequently develop. Accessory respiratory muscle use may become prominent. A few, last reflex breaths may signal death. These *agonal breaths* can persist for minutes to hours, with significant gaps between each breath, and can be agonizing for everyone who watches.

Families and caregivers frequently find changes in breathing patterns to be one of the most distressing signs of impending death. Many fear that the comatose patient is suffocating. They are frequently comforted to know that the unresponsive patient may not be experiencing any sense of breathlessness or suffocation and that oxygen will not be of benefit and may actually prolong the dying process.

Because dyspnea is subjective, clinicians have to rely on patient self-report rather than objective measures such as respiratory rate or oxygen saturation (13). To avoid the risk of shortening the patient's life, administer low doses of opioids using standard dosing guidelines to manage any perception of breathlessness. Bronchodilators can be helpful for some patients. Nebulized opiates can be used, but the effect on shortness of breath is unclear, and they may provide better relief for cough.

Oxygen is generally helpful regardless of the degree of hypoxia or cause of dyspnea, and it can be delivered via nasal canula or an oxygen-conserving device (Oxymizer). Patients tend to tolerate these devices better than facial masks, which can be uncomfortable but not necessarily more helpful. Air flow may be as helpful as oxygen in treating breathlessness. A stream of air from a fan can also be very useful in managing dyspneic patients.

Chlorpromazine, 12.5 to 25 mg orally/rectally/subcutaneously every 4 hours as needed, may provide a beneficial effect and reduce dyspnea. Benzodiazepines such as lorazepam (1 to 2 mg orally/subcutaneously/intravenously/through buccal mucosa, elixir, or tablet predissolved in 0.5 to 1.0 mL water, or injectable, every 1 hour as needed) may also help to alleviate any associated anxiety. The use of these drugs will not shorten the patient's life (14).

Difficulty Swallowing

In the last hours of life as the patient dies, weakness and decreased neurologic function manifest as difficulty swallowing and coughing and loss of the gag reflex. Fluids build up in the tracheobronchial tree. Crackling and gurgling noises are caused by the movement of air through or over these pooled secretions. When these noises occur in the presence of other signs of the dying process, they are a strong predictor that death will occur within 96 hours (15). These noisy respirations, also known as the "death rattle," occur in 23% to 92% of patients. They are most common in patients with lung and brain tumors, either primary or secondary.

Family members are frequently disconcerted when their loved ones develop the death rattle because they are afraid that the patient is suffocating or drowning when they hear the noise. Other causes of noisy respirations in a dying patient are respiratory infections or pulmonary edema (1).

When a patient is unable to swallow, stop *all* oral intake. Warn families and caregivers of the risks of aspiration and asphyxiation. Before using medications, it is useful to try simpler nursing interventions, such as repositioning the patient, using postural drainage, educating the family, and suctioning:

- Reposition the patient onto his or her side. This may shift enough of the secretions that air flows over the fluid without making a sound.
- Secretions can also be cleared by postural drainage using the Trendelenburg position. In this position, gravity may draw fluids into the oropharynx where they can be removed with a sponge, gauze on a stick, or oropharyngeal suction. However, because of the risk of reflux and aspiration of gastric contents, do not maintain the Trendelenburg position for more than a few minutes.
- Educate families that the patient is not suffocating. This can reassure to families and assuage some of their angst.

- When secretions have reached the pharynx but are not clearing by repositioning, try oral suctioning. Suctioning is less effective when secretions remain beneath the pharynx and are difficult to reach with typical suctioning maneuvers. Avoid deep suctioning whenever possible. It can be highly stimulating and painful to an otherwise peaceful patient and may cause distress to family members who are watching.

Medications

Oropharyngeal and tracheobronchial secretions come from the production of saliva by the salivary glands and secretions from the bronchial mucosa. These glandular tissues contain muscarinic receptors (M3), and antimuscarinic medications (e.g., atropine, scopolamine hydrobromide, scopolamine butylbromide, and glycopyrrolate) are effective treatments for the death rattle. Although similar in action, there are significant differences among these medications. Scopolamine hydrobromide has a more rapid onset of action but a lower response rate than scopolamine butylbromide or glycopyrrolate (16). Scopolamine butylbromide has a significantly more powerful action compared with atropine. Although atropine may be equally effective in similar doses, it has an increased risk of producing undesired cardiac or central nervous system excitation. Glycopyrrolate and scopolamine butylbromide have the potential added benefit that they do not cross the blood-brain barrier. As a result, there is much less risk of short-term memory deficits. To minimize the accumulation of secretions, particularly in an unconscious patient, start one of these medications early and administer them routinely.

All these medications have the potential to worsen open-angle glaucoma. To prevent worsening of acute eye pain, continue glaucoma medications until the patient dies.

- Atropine is administered as 0.4 to 0.6 mg subcutaneously every 4 hours or one drop of atropine solution (containing 0.5 mg of atropine from a 1% weight/volume solution) sublingually every 4 hours.
- Scopolamine is given as 0.2 to 0.4 mg or more subcutaneously every 4 hours, one to three transdermal scopolamine patches every 72 hours or 0.1 to 1 mg/hour by continuous intravenous or subcutaneous infusion.
- Glycopyrrolate is given as 0.2 to 0.4 mg or more subcutaneously every 4 to 6 hours or 0.4 to 1.2 mg or more every 24 hours by intravenous or subcutaneous infusion.

Loss of Sphincter Control

In the last hours of life, fatigue and loss of sphincter control may lead to incontinence of urine and stool. Both can be very distressing to patients, family members, and caregivers, particularly if they are not warned in advance that this may happen. If incontinence occurs, clean the patient promptly and provide appropriate skin care. If urine flow is minimal, try to manage recurrent incontinence with absorbent pads placed under the patient. If urinary incontinence persists, a condom or indwelling urinary catheter may reduce the need for frequent changing and cleaning and may prevent skin breakdown. Although it may be convenient for caregivers, an indwelling urinary catheter may be uncomfortable for patients,

particularly male patients. Always instill lidocaine 2% gel into the urethra 10 to 15 minutes before catheterizing male patients. If diarrhea is considerable and relentless, a rectal tube may help to contain the liquid stool, minimize skin maceration, and maintain patient dignity.

The "Difficult Road"

Terminal Delirium

Terminal delirium is an irreversible, acute confusional state in the last hours or days of life that is associated with other signs of the dying process (see Table 1–19–2). It occurs in 10% to 88% of dying patients. It may be the first change to herald the difficult road to death. Failure to recognize terminal delirium may result in worsening of the patient's agitation. If left unmanaged, myoclonus and seizures can ensue, particularly when cerebral metastases are present.

Before the onset of terminal delirium, many patients have an altered sleep-wake cycle. Day-night reversal is common. Attention and ability to focus decrease. Patients lose touch with the surrounding environment and appear to be "in their own world."

In its initial stages, terminal delirium may be difficult to distinguish from reversible delirium. If signs of the dying process are not present, and if it is consistent with the goals of care, look for potentially reversible causes of delirium, including hypoxia, metabolic disturbances (e.g., electrolyte imbalance, acidosis), infections, toxin accumulation from liver and renal failure, adverse effects of medications, disease-related factors, and reduced cerebral perfusion. Always assess for urinary retention and fecal impaction because they are common and easily correctable causes of reversible delirium. Review medications for recent changes and potential adverse effects or medication interactions.

As with reversible delirium that occurs at other times in life, terminal delirium can be associated with significant patient distress as it evolves, including intermittent restlessness, agitation, and hallucinations. Symptoms typically wax and wane and are interspersed with periods of calm and even moments of lucidity. Slowly, or abruptly, it frequently evolves into a highly agitated state. Repetitious and purposeless movement (e.g., pulling blankets on and off, sitting up and lying down, or tossing and turning in bed) are very common. Unintelligible vocalization may be present.

Terminal delirium is often associated with moaning and groaning. When this occurs, it is frequently mistaken for pain. Escalating "pain" near the end of life in the setting of rapidly titrated opiates may be a manifestation of terminal agitation. To differentiate pain from the moaning and groaning of terminal delirium, look for tension across the forehead, furrowing of the eyebrows, or facial grimacing. When these are absent, the vocalization is more likely related to delirium than pain. Although a time-limited trial of opioids may be diagnostic, when renal clearance is compromised (e.g., when perfusion decreases as a patient is dying) extra opioid doses can lead to metabolite accumulation and more delirium.

Terminal delirium may also be difficult to differentiate from a psychological or spiritual crisis at the end of life, although the latter does not typically occur in the patient who has been previously calm and prepared for the end of her or his life.

There is a significant difference between the management of nonreversible terminal delirium in dying patients and the management of potentially reversible

delirium in patients who are not dying. In reversible delirium, neuroleptics are the mainstay of pharmacological treatment. Benzodiazepines are not appropriate because of their potential to worsen the symptoms of delirium and short-term memory deficits, particularly in elderly patients.

If discussed in advance, most patients will not want to experience or have any memory of the symptoms of terminal delirium. Patients and their families will want the process to be quiet and peaceful. In contrast to the management of reversible delirium, the management of irreversible terminal delirium focuses on settling the patient and the family and ensuring that the patient does not experience bad dreams, hallucinations, myoclonus, or seizures.

Utilize any nonpharmacological interventions that may be comforting, reduce agitation and improve the day-night cycle reversal (e.g., avoid restraints), provide a quiet and relaxed atmosphere (minimize external stimulation) preferably in a familiar environment, and use appropriate lighting (light during the day, dark at night).

If routine opioids are believed to be the cause and the patient is dehydrated, a trial of intravenous or subcutaneous fluids could help reduce the patient's symptoms. Alternatively, to minimize the accumulation of opioids and their metabolites as perfusion and renal clearance fail, as urine output drops to less than 500 mL/24 hours, reduce the routine dose of opioids by 50% or more. Once the urine output drops to less than 250 mL/24 hours, stop administering all routine opioids and offer opioids only on an as-needed basis for breakthrough pain.

In contrast to their contraindication in the management of reversible delirium, benzodiazepines are ideal for the management of terminal delirium for four reasons:

1. As anxiolytic/sedatives, they will settle the patient and will minimize her or his awareness.
2. As muscle relaxants, they will relax both skeletal muscles and contracted vocal cords (that lead to moaning and groaning).
3. As amnestics, they will ensure no short-term memory of the experience.
4. As antiepileptics, they will provide prophylaxis against possible seizures.

Benzodiazepines typically settle the patient quickly and, in turn, everyone who is watching. Lorazepam is a moderately long-acting benzodiazepine that is ideal for managing terminal delirium. Place lorazepam, 1 to 2 mg as elixir or tablet predissolved in 0.5 to 1.0 mL of water, against the buccal mucosa every 1 hour as needed and titrate until the patient is settled. Once the patient is settled, administer the dose used over 4 hours to settle the patient, every 4 hours to maintain the desired state. Typically, 2 to 10 mg of lorazepam every 4 hours will settle most patients. A few extremely agitated patients may require 20 to 50 mg or more of lorazepam in 24 hours.

As an alternative, midazolam is a fast-acting benzodiazepine that has been used in several studies. Start with 0.5 to 2.0 mg intravenously every 15 minutes and titrate to effect. Once the patient is settled, use midazolam 1 to 5 mg subcutaneously or intravenously every 1 hour to maintain sedation.

Although intravenous administration produces a quicker effect, if intravenous access is not available, benzodiazepines may be easily administered subcutaneously (as individual injections or an infusion), via buccal mucosa, or rectally.

If benzodiazepines are not available, chlorpromazine 10 to 25 mg or more orally, rectally, or intravenously every 4 hours, is preferred to haloperidol for the management of terminal delirium because it is more sedating. Use caution with neuroleptics because there is a small risk that they will lower a patient's seizure threshold and increase the risk of seizures.

Occasionally, a combination of a neuroleptic and a benzodiazepine is necessary for symptom control (17). If ineffective, barbiturates and propofol have been suggested as alternatives (18).

Seizures

If seizures occur during the dying process, manage them with high doses of benzodiazepines, such as lorazepam or midazolam subcutaneously or intravenously. Rectal diazepam gel administered in doses of 500 mg/kg rectally every 4 to 12 hours can be very effective. If seizures are resistant, other medications may be needed to establish control (e.g., phenytoin rectally or intravenously, fosphenytoin subcutaneously, or phenobarbital). Phenobarbital can be started with an initial dose of 100 to 200 mg rectally, intravenously, or subcutaneously, followed by additional doses up to a maximum of 600 to 1,000 mg at maximum rate of 100 mg/minute. Phenobarbital is usually effective in doses of 200 mg/24 hours.

OTHER SYMPTOMS AND END OF LIFE ISSUES

Hemorrhage

Bleeding may be present during the last hours of life. If extensive, it can be a frightening experience to everyone involved, from patient to family, caregivers, and staff. Bleeding is generally the result of superficial tumor friability, tumor eroding into a blood vessel, coagulopathy, low platelet count, or platelet dysfunction. It may also be secondary to a combination of the foregoing factors. Hemorrhage may be precipitated by minor trauma or pressure, but it may also happen spontaneously without warning.

If there is a possibility of bleeding, especially of extensive hemorrhage, advance planning is very helpful. Attempt to correct the coagulopathy or other potential causes if this is consistent with patient's goals of care. Provide interdisciplinary support. Keep dark towels easily accessible in the room in case there is acute bleeding. They will minimize the visibility of blood and will help to reduce patient and family distress. At the time of acute bleeding, midazolam 2 to 10 mg intravenously or subcutaneously can be given to minimize the anxiety and to produce amnesia. If the hemorrhage is severe, the patient may die within a few minutes, and it may not be possible to provide sedating medication quickly enough.

For superficial bleeding, apply pressure to the area. Topical hemostatic agents can be helpful unless the bleeding is extensive (Table I–19–3). In case of bleeding wounds, good wound care is essential. Radiotherapy, embolization, and endoscopic hemostasis may be helpful in the last weeks or months of life. These interventions are not appropriate during the last hours because the burden will outweigh the benefit. In case of variceal bleeding, medical management with octreotide or vasopressin may be helpful.

Table I–19–3 ■ Treatment Options for Bleeding

Type of Treatment	Examples	Notes
Temporary reversal of a bleeding disorder	Platelet transfusions Fresh frozen plasma Vitamin K Clotting factor replacement	If used, should be done before the last hours
Local therapy	Radiotherapy Embolization Cryotherapy Variceal banding	If used, should be done before the last hours
Systemic therapy	Tranexamic acid 1g PO q8h Aminocaproic acid 1g PO q6h Octreotide, vasopressin	
Topical therapy	Epinephrine 1:1,000 Thrombin 1,000–2,000 units/mL Calcium alginate Silver nitrate (sticks or liquid)	

PO, orally.

Fever

Fevers during the last hours of life are frequently multifactorial. They can be the result of infections, cancer, medications, or central in origin. Most often, their cause remains uncertain.

For the symptomatic management of fever, acetaminophen or other antipyretics may be effective. Nonsteroidal anti-inflammatory drugs are particularly helpful if the fever is tumor related. Often these medications will need to be given rectally once the patient stops swallowing. Topical cooling methods such as bathing with tepid water, alcohol sponging, or the use of cooling blankets can also be synergistic. Antibiotics do not provide any significant symptom relief for most patients. Discontinue them once the patient stops swallowing, if not beforehand.

If a neuroleptic malignant syndrome is present (a rare side effect of neuroleptics), discontinue all neuroleptics and use dopaminergic and anticholinergic drugs in conjunction with benzodiazepines to provide relief.

Turning off Defibrillators

As the prevalence of cardiovascular disease in our aging society increases, automatic implantable cardioverter-defibrillators (AICDs) are becoming more common. These devices can detect rapid life-threatening heart rhythms and can perform a cardioversion: delivery of an electrical shock to the heart that is intended to restore a normal heart beat. If a dying patient with an AICD has a rapid life-threatening rhythm, the device will attempt to deliver a shock as long as a "shockable" rhythm is present.

Although the patient is frequently unconscious when life-threatening arrhythmias are present, this is not always the case. Sequential shocks could be uncomfortable to the patient and distressing to family members who observe them, especially if it is clear that the patient is dying.

Unfortunately, when an AICD is implanted as a lifesaving device, some of the details of the potential end-of-life issues are frequently overlooked. When discussing goals of care with patients who have AICDs, inquire whether having an active defibrillator is consistent with the patient's overall goals. Obtain information about the manufacturer and the type of defibrillator. If the decision is made to keep the device active, offer pain relief and a sedative in case the device starts delivering a shock in the last days or hours of life because most patients report significant discomfort at the time of cardioversion. For those patients who choose to deactivate the AICD, ask the manufacturer or a cardiologist to turn the device off using special equipment (no procedures necessary). For patients who have a combination pacer and defibrillator, pacemaking function can be maintained even after the cardioverter-defibrillator function is switched off. If a cardiologist or a company representative is not available, a deactivating magnet can be held over the device to prevent continuous shocks in a dying patient.

WHEN DEATH OCCURS

When expected death occurs (see Table I–19–2), the focus of care shifts from the patient to the family and caregivers (see Table I–19–3). Everyone will have a different experience and a very personal sense of loss. Even though the death has been anticipated for some time, no one will know what the loss feels like until it actually occurs. Encourage family and caregivers to spend the time they need with the body to help them address their acute grief. It may take hours to days to weeks or even months for each person to realize the full impact of the changes.

It is rarely obligatory for physicians or health care providers to attend quickly to witness what has happened, unless the patient has requested organ donation or has made an anatomic gift to a medical school. However, the presence of a professional may be helpful if family members are distressed and need immediate support with their acute grief reactions or if they have questions.

Members of the health care team who have not been present for the death can assess how family members are handling the loss by listening to a recounting of how things went leading up to the death and afterward. Listen for signs of acute grief reactions that are beyond cultural norms. They may suggest a significant risk of complicated grief reactions. Watch for individuals who are showing little or no emotional reactions to the death or who may be catatonic. They will need significant acute support and interventions to push them to realize what has just happened. They are almost certainly at high risk for complicated grief reactions. Spiritual advisors or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the transition that those present are experiencing.

Rites and Rituals

After death occurs, ensure that all cultural and religious values, beliefs and practices, prayers, rites, and rituals are observed.

Pronouncing and Certifying Death

In teaching hospitals, medical students and residents are typically called to "pronounce" death. In nonteaching settings, the attending physician or nursing staff members may be the ones to do it. When a patient dies at home with hospice care, it is usually a nurse who confirms the absence of vital signs. Although local regulations differ, if an expected death occurs at home without hospice care and the patient has a physician willing to sign a death certificate, it may not be necessary to transport the body to a hospital for a physician to confirm death.

First, confirm that it is culturally acceptable for the physician to touch the patient to confirm that death has occurred. Then, verify the patient's identity. Ask those present for the patient's full name; verify it with the hospital identification tag if one is available. Observe the patient for several minutes. Note the general appearance of the body, particularly its color, presence of mottling (livedo reticularis), or venous pooling along dependent skin surfaces. Look and listen for the absence of spontaneous respirations. Listen for the absence of heart sounds. Feel for the absence of carotid pulse. Observe the size of the pupils. Test for the absence of pupillary light reflex. Test for response to verbal or tactile stimuli. Overtly painful stimuli (e.g., nipple or testicle twisting or deep nail bed or sternal pressure) are neither appropriate nor necessary.

If you have known the patient, stop. Spend a few moments taking in what has happened. This may your only personal opportunity to realize what has happened and to say goodbye. Once the pronouncement is complete, document all activities in the medical record.

All funeral directors require a completed death certificate to proceed with any body preparation and registration of the death. Some insist on having a death certificate before they pick up the body. Ensure that the physician has the information needed to complete the death certificate and ample warning of the time by which one will be required (19).

Notifying the Coroner

The medical coroner reviews cases in which the circumstances surrounding a death are unknown or when malice is suspected. In most jurisdictions, regulations also exist to trigger mandatory scrutiny of deaths that occur under specific circumstances (i.e., deaths that occur in acute care facilities within 48 or 72 hours of transfer of the patient from a long-term care facility). Because regulations vary, health care professionals must know the regulations in effect within the local jurisdiction. If there are any doubts about the circumstances surrounding a death, call the coroner's office, review the case, and ask for advice. If you are calling the coroner's office, do not move the patient, leave all lines and tubes in place, do not touch medications, and move nothing in the room until the coroner has reviewed and released the case. Make sure family and friends also know not to touch or move anything. If the coroner investigates a case, she or he will typically complete the death certificate before closing the case.

Notifying Family

Once the patient has been pronounced dead, let the family know what has happened, even if the coroner has not completed the investigation. Try to avoid breaking

unexpected news by telephone because communicating in person provides much better opportunity for assessment and support. When in the presence of family and caregivers, follow the six-step guideline for communicating bad news (8).

Preparing the Body for Viewing

Once the pronouncement is complete (and the coroner, if called, has released the body), you may wish to create a visually peaceful and accessible environment to make viewing of the body easier. Some cultures permit only designated people to touch the body after death. Before starting to prepare the body, ensure that your proposed preparation will be acceptable to the family.

Once you have permission to proceed, spend a few moments alone in the room to position the body, disconnect any lines and machinery, remove catheters, and clean up any mess. If the eyes remain open, hold the eyelids closed for a few minutes (they will usually remain closed once they dry). If they still remain open, a small amount of surgical tape or a short adhesive surgical strip will hold them closed without risk of pulling out eyelashes when the tape is removed. If the jaw falls open as muscles relax, place a rolled-up towel under the chin and elevate the head. This will usually hold the jaw closed until muscles stiffen. Remember that muscles will stiffen as rigor mortis sets in 4 to 6 hours after the death. To make transfers and funeral arrangements easier, make sure the patient's body is straight and flat, with the arms placed across the chest before this occurs.

Inviting Others to Bedside

When the body is ready for viewing, first invite family, then anyone who has been close to the patient, including friends, caregivers, and health care providers to come to the bedside to witness what has happened. Before taking visitors into the room, spend a few minutes to remind them of the changes in body color, temperature, and the scene they will see. This can reduce the surprise and can make the transition easier for everyone. Make sure everyone knows that there is no need to rush and that each person can take the time needed to witness what has happened and to say goodbye.

Moving the Body

Once the family and caregivers have had the time they need at the bedside to deal with their acute grief reactions and to observe their customs and traditions, preparations can begin for funeral or memorial service. Families who have not discussed funeral arrangements in advance may have many questions about embalming, burial, cremation, or different types of services. If the funeral director is not available, spend a little time answering questions. This will ease their anxiety about what happens next.

Invite family members or caregivers to help prepare the body for transfer to the funeral home or the hospital morgue. Some people find the touching, bathing, and preparation to be very therapeutic. It helps them to realize that the patient has, in fact, died. For many, such rituals are their final act of direct caring.

Occasionally, a family will want to keep the body at home (or in the room at the acute or long-term care facility) for 2 to 4 days until the funeral service, burial, or cremation. Although this is possible in most jurisdictions, some additional preparation of the body and good ventilation are essential. Ask the funeral home to help prepare the body before rigor mortis sets in (e.g., by positioning the body appropriately and by packing the throat and rectum so fluids do not escape unexpectedly).

Once the family is ready for the body to be moved, call the chosen funeral service provider and arrange for removal of the person's body. Most funeral services have transfer staff available 24 hours/day, 7 days/week. They usually arrive within a short time of the call. Once you know how long they will be, let the family know how much longer they have before the body will be moved. If the patient is in a health care institution, the transfer service will deal directly with the institution.

For many, the arrival of the funeral directors to remove the body is the next major confrontation with reality, particularly when the death has occurred at home. Some family members will wish to witness the removal. Others will find it very difficult. They may prefer to retire to another place and allow professional caregivers to handle things discreetly. For some, the thought that the person's body will be enclosed in a body bag is intolerable. Ensure that health care providers and funeral directors have the sensitivity to recognize when this is an issue and to negotiate a suitable alternative (e.g., not closing the bag until it has been removed from the vicinity of the home). Institutional staff should be aware that there may be similar reactions by family members when they prepare the body for transfer to the morgue.

After the Body Has Been Moved

Once the body has been removed and family members are settled, offer to assist with some of the immediate next steps. Notify other health care providers that the death has occurred (attending and consulting physicians, all involved health care service agencies, and all caregivers on the patient's care team).

Health care professionals will need to be clear about local regulations that govern ownership of medications and waste disposal after a death. Whenever possible, help family members to dispose of medications, particularly opioids, in the toilet. Document the type and quantity of medications discarded. Have the witness cosign the medical record. Also help family members dispose of biological wastes (typically double bagged and placed in trash) and sharps containers (health care providers typically take these with them for appropriate disposal), and secure any valuables.

When family members are ready, caregivers and health care providers can leave family and friends so they can have some privacy together. Before departing, let them know who to call, and how, if they have questions or need help or support, and establish the time of the first follow-up calls from the team.

BEREAVEMENT

Immediately after a death, those who are bereaved will need time to recover from the acute stress and fatigue and to restore their environments back to a normal

Table I–19–4 ■ Cognitive, Emotional, and Physical Responses to Loss and Grief

Cognitive	Emotional	Physical
Confusion	Abandonment	Appetite change
Disbelief	Ambivalence	Fatigue
Distrust	Anger	Gastrointestinal disturbances (e.g., diarrhea, heartburn, nausea/vomiting)
Dreams/nightmares of the deceased	Despair	Heart palpitations
Lack of concentration	Fear	Hiccups
Preoccupation with the deceased	Guilt	Hollowness in the stomach
	Loneliness	Insomnia
	Numbness	Skin reactions
	Relief	Tightness in the chest
	Sadness	Weakness
		Weight gain or loss

state. As they begin to realize the significance of the loss to their lives, they will likely experience an intense grief reaction with multiple cognitive, emotional, and physical responses (Table I–19–4) and will require considerable ongoing support to help them deal with all the changes to their lives. Some people who are bereaved will make a conscious effort to deal with the loss, emotions, and changes that follow the death of a loved one and will seek ongoing assistance from their physicians to help them address their feelings of loss and their emotions. Others will deny what is happening and will avoid dealing with any of these issues. They will be at high risk for a prolonged, complicated grieving process.

Follow-up

Most families expect the physician and other health care providers who have known the patient to provide initial follow-up support. A phone call followed by a bereavement card, with or without attendance at the patient's funeral, may be an appropriate way to provide initial followup. A phone call to key family members within 2 to 5 days of the death can be used to offer condolences, find out how everyone is doing, and plan further follow-up. A condolence note sent within 2 weeks of the death is an opportunity to offer tribute to the deceased as someone who was important. Use standard stationery and write it by hand. Mourners appreciate that time taken to sit and compose a personal message to them or to share a memory of the deceased.

Attendance at Funerals or Memorial Services

Health care providers may choose to attend some funeral or memorial services (20). In addition to supporting the family, many find that it helps them personally to close long-standing relationships that they have had with their patients and families. Let families know in advance so they will not be surprised, particularly if a family is

planning an intimate family gathering. Although most families do not expect health care providers to attend such services, most will be touched and appreciative.

PEARLS

- If managed well, the last hours can lead to significant personal and family growth.
- Advance preparation and education of professionals, family, and volunteer caregivers are crucial.
- Use only essential medications. Stop routine dosing and continue to offer opioids as needed. Accumulating serum concentrations of active drug and metabolites may lead to toxicity and terminal delirium.
- Know the signs of the dying process and understand the causes, underlying pathophysiology, and appropriate pharmacology to use in management
- Attend to acute grief reactions.

PITFALLS

- If managed poorly, life closure may be incomplete, unnecessary suffering may occur, family distress may continue long after the patient's death, and those who watch may worry that their own death will be similar.
- Maintaining parenteral fluids may have adverse effects that are not commonly considered.
- Oropharyngeal suctioning is not likely to be effective at clearing secretions, yet it is very effective at stimulating a gag, cough, or vomiting.
- Moaning, groaning, and grimacing that accompany agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring.
- Removal of the body insensitively or too soon can be more distressing for families than the moment of death.

SUMMARY

The last hours of living are some of the most important in the life of the patient and her or his family. Although the focus is on relieving the patient's suffering and ensuring a safe and comfortable death, the health care team is also caring for everyone at the bedside. Through an effective intervention by the physician and other health care providers, everyone will have a very different experience of end-of-life care and bereavement, and survivors will rebuild their lives sooner and more effectively.

Resources

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Legal and Ethical Issues in the United States

20

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CHAPTER OUTLINE

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INTRODUCTION

As the field of palliative care has grown and evolved, so also has an evolution occurred in the ethical and legal issues that are associated with care at the end of life. A consensus has developed concerning the ability of patients to refuse life-sustaining medical treatment, the importance of patient informed consent, and autonomous choice. Although other ethical and legal issues such as physician-assisted suicide and futility have a preponderance of opinion in professional guidelines, there is no such clear consensus. This chapter discusses current ethical and legal issues for palliative care in the United States and highlights some pearls and pitfalls.

ETHICS, LAW, AND END-OF-LIFE CARE

Palliative medicine in the United States, with its emphasis on end-of-life care, has long been inextricably intertwined with difficult ethical issues and consequent legal concerns (1). As technological advances have extended the ability to prolong life (and to prolong the dying process), ethical and legal questions have arisen about

the appropriate implementation or discontinuation of those technological interventions. Some US legal cases that deal with ethical issues at the end of life have had a major impact on the law of medical practice, although the legal precedents generally follow medical ethical principles.

Major ethical and legal issues for end-of-life care include the issues of informed consent and refusal, limitation of treatment including withholding and withdrawing life-sustaining medical treatment, the determination of a patient's decision-making capacity, and the way in which decisions should be made if the patient does not have decision-making capacity. Other ethical and legal issues include the use of advance directives, the proper use of opioids in end-of-life care, a patient's voluntary refusal of orally ingested nutrition and hydration, physician-assisted suicide, and palliative sedation.

INFORMED CONSENT

A basic tenet of Anglo-American law is the principle of *informed consent*. This doctrine is based on patient self-determination as well as the right of the patient to receive information that is material to making a decision to consent to a medical treatment or procedure. The principle of informed consent is based on a physician's duty to tell the truth about the patient's current medical condition and prognosis. In the past century, it was common to not tell patients who were diagnosed with a terminal condition about their diagnosis (2), but a sea change occurred when many inside and outside of the profession recognized that it was essential for the physician to disclose the diagnosis and prognosis to the patient (3).

The patient needed to be told the truth not only about the diagnosis and prognosis, but also about the proposed procedure or treatment, the risks associated with that treatment, the benefits of the treatment, and the alternatives to that treatment, including the alternative of no treatment (Salgo, Cal.App. 1957). Additionally, if patients refused treatment, they were also entitled to information about the consequences of that refusal (known as *informed refusal*) (Truman, Cal. 1980).

Often in end-of-life care, information that would normally be disclosed was forgone based on the assumption that it was lifesaving treatment, and, therefore, patients need not consent to that treatment. However, even life-sustaining medical treatment requires informed consent (Anderson, Ohio 1996), unless it is an emergency and the patient is no longer decisional and no legally authorized decision maker is available (4). Informed consent for end-of-life care should include not only the benefits of treatment, but also the burdens or risks of treatment that the patient will have to bear, as well as the prognosis of the disease (if known) both with and without treatment.

Before life-sustaining medical treatment is begun, the patient and family should understand that the burdens of treatment may become so great that they may outweigh the prospective benefits of treatment. Additionally, the patient should be told that physicians may limit or stop treatment if it is no longer effective. A timely discussion with the patient and family that leads to an understanding of treatment possibilities and limitations may preclude later, painful discussions of "futile" treatment. If treatment is not successful, then further discussion about stopping treatment may not surprise the patient or family. It also gives the patient

and family an opportunity to discuss with physicians, long before a crisis occurs, the fact that there may come a time when treatment may no longer be of benefit to the patient and thus will not be indicated.

LIMITATION OF TREATMENT

In the United States, a legal and ethical consensus for limitation of treatment developed (5) between the time the first state court considered the issue of withdrawing life-sustaining medical treatment (Quinlan, N.J. 1976) and the time of the U.S. Supreme Court's determination of the same issue 14 years later (Cruzan, U.S. 1990) (6).

The consensus holds that patients have the right to refuse any intervention, including life-sustaining medical interventions. A series of state Supreme Court decisions determined that patients have the right to refuse medical treatments that include ventilators (Bartling, Cal.App. 1984), administered nutrition and hydration (Bouvia, Cal.App. 1986), and blood transfusions (Wons, Fla.App. 1987). Another tenet of this consensus is that all patients—even incapacitated patients—have the right to refuse any medical intervention.

The U.S. Supreme Court confirmed this principle in the Cruzan case (U.S. 1990), holding that patients have a liberty interest under the Constitution's 14th Amendment due process guarantee to refuse life-sustaining medical treatment, although states may require clear and convincing evidence of the patient's wishes if the patient is incapacitated. Another important principle of the ethical and legal consensus is that withholding and withdrawing of life-sustaining medical treatment are essentially equivalent and are not homicide or suicide (Barber, Cal.App. 1983) and that orders to do so are valid (Dinnerstein, Mass.App. 1978). An additional important principle of this consensus is that courts need not be routinely involved in end-of-life care decisions.

DECISION MAKING FOR THE INCAPACITATED

Because many patients for whom life-sustaining medical treatment decisions must be made have lost decision-making capacity, ethically and legally there is a consensus as to decision making for those who are incapacitated and unable to make their own decisions. If the incapacitated patient left directions in advance regarding his or her wishes (through either a living will or a power of attorney for health care document), those wishes should be followed. If no written directives were made but the patient's wishes are known, a guardian, health care agent, or designated surrogate may make decisions on the basis of what the patient would have wanted, a process called *substituted judgment*. If the patient's wishes are unknown, the decision maker must use the *best interest standard,* that is, consider what is best for the patient.

In the Terri Schiavo case (Schiavo, Fla. 2004), the spouse and parents of an incapacitated patient in a persistent vegetative state battled over whether life-sustaining medical treatment in the form of artificial nutrition and hydration could

be withdrawn. This case encompassed many ethical and legal issues. As contentious as this case was, however, certain principles were reinforced: patients have the right to refuse life-sustaining medical treatment, even if incapacitated; and if a patient has expressed those wishes clearly, then a guardian may act according to those wishes. The Schiavo case also reinforced the principle that artificial nutrition and hydration are considered medical treatments and may be legally and ethically withdrawn under appropriate circumstances. Nonetheless, it is important to recognize that some disagreement exists among religious communities as to whether it is ethical to remove artificial nutrition and hydration from an incapacitated patient in a persistent vegetative state. The Schiavo case also demonstrated that family members may disagree about who should serve as guardian or surrogate for the patient.

DETERMINATION OF DECISION-MAKING CAPACITY

Patients who have decision-making capacity have the right to refuse life-sustaining medical treatment. Thus, when a patient refuses such treatment, the determination of decision-making capacity is crucial (7). *Decision-making capacity* has been defined as the ability to make decisions about medical care, and it can be contrasted with competence. The term *competence* is commonly used to indicate the ability to do something, but, in the medical milieu, it is more commonly used synonymously with legal competence, that is, the determination by a court as to the ability to make decisions about one's person or property. Not all patients who have lost the ability to make medical decisions will have been declared legally incompetent, nor will patients who have been declared legally incompetent necessarily be unable to make any decisions with respect to medical care.

Decision-making capacity is constituted by the ability to understand information, reason and deliberate about a choice, make a choice consistent with values and goals, communicate the choice, and maintain stability of that choice over time (8). Although it has been noted wryly that questions of patient decision-making capacity typically arise only when the patient chooses a course other than the one the health care professional finds most reasonable (9), this is, in fact, not so ironic. Health care professionals generally make a treatment recommendation that is in the best interest of patients, and when patients agree with this course of action, there is generally less concern about the patient's decision-making capacity. Thus, questions of decision-making ability arise when the patient chooses to refuse beneficial medical treatment.

Decision-making capacity is dependent on the individual abilities of the patient, the requirements of the task at hand, and the consequences of the decision. When the consequences of the decision are substantial, there is a greater need for certainty of the patient's decision-making capacity. Decision-making capacity is not necessarily established by simply expressing a preference, having the content of the patient's decision fit an "objectively correct" standard, or acting in accord with the physician's recommendation (10). Some patients (e.g., the comatose) are clearly incapacitated, whereas decision-making capacity may be more difficult to determine in others (e.g., those in the early stages of dementia) (11).

ADVANCE DIRECTIVES

Advance directives are written expressions of medical decisions that are made by the patient while he or she is still capable of making those decisions. A *living will* is a directive to a physician when the patient is nondecisional and has a terminal condition (or including, in some jurisdictions, persistent vegetative state) in which the patient refuses life-sustaining medical treatment. A *power of attorney for health care* is the appointment of an agent to represent the patient when the patient is no longer decisional. It applies during any incapacity and is often written with directions to the agent about the patient's treatment preferences, including preferences about nutrition and hydration.

Advance directives are appropriate planning tools for end-of-life decision making. However, only a minority patients actually complete an advance directive, although the proportion is higher for patients facing the end of life. Additionally, studies show that proxy decision makers are often poor predictors of the patient's wishes (12). There is also a current lack of evidence that completion of advance directives significantly guides the course of patient care (13). Nonetheless, failure to engage in advance care planning is probably worse, and advance directives may be more effective when they are part of a larger, advance care planning regimen in which the patient expresses wishes about end-of-life care to family members (14).

Advance directives are even more important in light of recent legal developments. In determining whether the guardian or surrogate may withdraw or withhold life-sustaining medical treatment of a patient who is no longer decisional, some state courts have required clear and convincing evidence of the incapacitated patient's wishes. This requirement results, in part, from legislative concerns about withdrawal of life-sustaining medical treatment without the patient's explicit consent, as well as the courts' concern that the consequences of decisions to withdraw life-sustaining medical treatment are, for the most part, ultimately irreversible.

Advance directives may satisfy legal requirements for clear and convincing evidence of the patient's wishes for withdrawal of life-sustaining treatment. The use of advance directives will allay legal concerns and may ensure that the patient's wishes are implemented.

GUARDIANSHIP AND SURROGATES

Patients who are not able to make decisions about their medical treatment may already have a guardianship in place. *Guardianship* (known in some jurisdictions as *conservatorship*) is a legal mechanism that allows the appointment of a person who will make decisions for the patient as they relate to the patient and his or her property. Although guardians have power to make decisions, including health care decisions, they generally do not have the information about patients' preferences that a person who has been specifically appointed power of attorney for health care would have. Guardians are charged with acting in the best interest of the patient or, when possible, acting in the adult patient's substituted judgment when the patient's wishes are known. Additionally, parents are generally guardians of their child's best interest until the child reaches the age of majority or maturity. When the incapacitated patient does not have an advance directive, some states

have an automatic hierarchy of surrogates or decision makers for incapacitated patients, including spouses, adult children, parents, and other relationships of significance (e.g., Ill. 1991).

REFUSAL OF ORALLY INGESTED NUTRITION AND HYDRATION

Patients have the right to refuse life-sustaining medical treatment, and, at the end of life, that ability to refuse treatment encompasses the patient's refusal of orally ingested nutrition and hydration. In the dying process, ketonemia causes the patient to have a lack of appetite. Oral discomfort (e.g., dryness of the mouth) can be alleviated with ice chips. To decline orally ingested nutrition and hydration, patients must have the decision-making capacity to make this choice and should also complete an advance directive that indicates their continued wish to refuse artificial nutrition and hydration so their wishes will still be honored after their decision-making capacity is lost (15).

OPIOIDS IN END-OF-LIFE CARE

In the past, physicians reported that, although they used opioids appropriately in end-of-life care by their own evaluation, nonetheless, medical examining boards could reprimand them for repeatedly prescribing narcotics to an individual patient, even if that patient was facing the end of life. There have, however, been significant changes in medical examining board policies. The Federation of State Medical Board's model guidelines on the appropriate use of narcotics at the end of life (16) recognize that neither the amount nor the chronicity of opioid prescription for patients at end of life should automatically serve as an indication of inappropriate use of narcotics. In general, physicians have enjoyed a wide berth from medical examining boards that realize that patients at the end of life need appropriate opioid treatment (17).

The current trend involves cases in which physicians who did not provide appropriate pain medication were found to be in violation of medical examining board regulations (18) or were found liable for malpractice (Bergman, Cal.Sup. Ct. 2001). The Federal Drug Enforcement Administration stated: "It is crucial that physicians who are engaged in legitimate pain treatment not be discouraged from providing proper medication to patients as medically justified" (19). Most cases dealing with inappropriate narcotic prescriptions have involved treatment of patients with chronic pain rather than treatment of patients who were facing the end of life. Despite physicians' fears about the possibility of criminal liability for appropriate end-of-life treatment, millions of patients are treated at the end-of-life each year, but in very few cases have physicians been charged and prosecuted for intentional homicide during treatment at the end of life. In one extremely rare case, a physician was convicted, and that conviction was upheld on appeal. Those rare cases often involve troubling aspects of care in which the claimed appropriate medical treatment was difficult to defend (20). The U.S. Supreme Court recognized the principle of double effect: if the physician does not intend the patient's death

but the patient's death comes as an unintended side effect of appropriate treatment, the physician should not be liable for intentionally causing the death of the patient (21). Thus, physicians should continue to treat patients at the end of life with appropriate amounts of medications despite the possibility of an unintended side effect of hastened death.

PHYSICIAN-ASSISTED SUICIDE

Although there was a movement to recognize legally that patients facing a terminal condition should be able to end their lives of their own voluntary accord, the U.S. Supreme Court found no constitutional right to physician-assisted suicide in the United States under either the due process or the equal protection provision of the 14th Amendment (Glucksberg, U.S. 1997, Vacco, U.S. 1997). However, the Court did recognize that the states were free to develop laws on physician-assisted suicide, and Oregon is the prime and sole example of the state in the United States that allows physician-assisted suicide under certain conditions.

The Oregon statute that was passed by referendum in 1994 and reaffirmed in 1997 allows a patient who is facing a terminal illness to ask a physician to write a prescription for a lethal dose of medication if that patient is both decisional and a resident of Oregon. The patient needs to make two separate requests 15 days apart, and the prescription may not be filled until 48 hours after being presented to a pharmacist (Ore. 1995). Legal challenges to the Oregon law have failed (Gonzalez. U.S. 2006). The Oregon experience shows that small numbers of end-of-life patients avail themselves of this option each year. The patients who choose this option tend to be those who are concerned about self-determination, self-control, and being a burden on others. Only a few of these patients are primarily concerned with unrelieved pain (22). In all other states in the United States, physician-assisted suicide is prohibited by either statute or common law.

FUTILITY

One of the more contentious issues in medical ethics at the end of life is whether and under what circumstances physicians may determine that, despite the demand from patients and families that physicians "do everything," further treatment would lack benefit and would prolong the dying process. The American Medical Association's Code of Ethics states that providers are under no obligation to provide futile treatment (23). Some hospitals and health systems have established policies to define and resolve these situations. Methods to resolve these difficult problems include identifying the goals of treatment and determining whether there is an objective benefit to the patient if medical treatment continues, obtaining a second opinion, considering ethics consultation, and offering transfer of care to another provider. Ultimately, if no willing provider is found, there is no obligation to provide nonbeneficial treatment.

Texas has codified its approach to resolution of this vexing issue through a process that includes determination by an ethics committee, review by a court,

and an opportunity for a patient and family to find other willing practitioners (Tex. 2002). The Texas experience has shown that physicians may appropriately determine futility within a legal and ethical framework (24). The case law concerning the issues of futility varies depending on the facts of case and jurisdiction. Unilateral determinations of futility by physicians should be rare.

PALLIATIVE SEDATION

A trial of palliative sedation is an option for end-of-life patients who have intractable pain or suffering if all other methods to relieve the suffering have been unsuccessful. In palliative sedation, the patient is sedated to the point of unconsciousness for palliative relief. An intermediate step is a trial of palliative sedation in which the patient is sedated to unconsciousness and, after a certain period of time, is reawakened to determine whether the pain or suffering has been alleviated. If not, the patient is sedated again.

Because the patient is not eating or drinking during this period, death would be caused by either the underlying disease or a known but unintended side effect of the treatment regimen (25). Critics of the practice are concerned that the use of palliative sedation for so-called "existential" suffering would allow this practice to move toward euthanasia. Some health care systems have developed guidelines to ensure that palliative sedation is used for intractable and measurable pain. An appellate level court in the United States has not yet made a full legal consideration of the issues of palliative sedation. Many ethical and legal commentators find this practice an acceptable alternative to physician-assisted suicide and argue that without this treatment there would be more pressure to allow physician-assisted suicide.

PEARLS AND PITFALLS

- All patients should be informed of the benefits and risks (burdens) of life-sustaining medical treatment. They should also be informed that treatment will be discontinued if it is no longer effective.
- Patients have the right to refuse life-sustaining medical treatment. The patient's right to refuse life-sustaining medical treatment may be asserted by a guardian, an agent of a power of attorney for health care, or a surrogate.
- Advance directives, used in a context of advance care planning, are legally valid documents in which patient preferences concerning end-of-life care may be described.
- Opioids should be administered appropriately to patients at the end of life.
- Physician-assisted suicide is prohibited in all U.S. states except Oregon.
- Issues of futility may be resolved through a due process approach.
- The ethical and legal issues of palliative sedation should be carefully considered.

SUMMARY

Patients who are facing the end of life should have full, informed consent regarding life-sustaining medical treatments. Patients may refuse all medical treatments

including artificial nutrition and hydration. Because many patients are unable to speak for themselves at the time that end-of-life choices must be made, advance directives (legal documentation of directions in advance of incapacity) have been created. For those patients without advance directives, physicians and surrogates should make choices on the basis of the patient's substituted judgment or best interest. Opioids should be administered appropriately to relieve suffering at the end of life. Other difficult ethical and legal issues include situations in which medical treatments are not indicated despite patient or surrogate demand and the practices of physician-assisted suicide and palliative sedation. These situations can, nonetheless, be guided by professional standards and legal precedent.

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SECTION II

Specific Types of Illness and Sites of Care

Hematology/ Oncology

1

Toby C. Campbell and Jamie H. Von Roenn

CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

Cancer survivors face a myriad of challenges and physical symptoms related to the disease and its treatment. The emotional and physical concerns associated with *cancer* begin with the diagnosis. Palliative care of the oncology patient focuses on the assessment and treatment of the multidimensional experience of cancer: the physical, emotional, and spiritual concerns. Although each of these elements is important in the total care of patients, this chapter focuses on the physical manifestations of disease and specific approaches to supportive care of the oncology patient.

Patients with advanced cancer are living longer and continue to experience symptoms attributable to cancer and its treatment. This is true even for the 50% of patients with cancer who are ultimately cured of the disease. This chapter presents a practical approach to the presentation, evaluation, and supportive

management of several common oncologic problems, including brain, liver, and bone metastases, bowel obstruction, and malignant effusions.

APPROACH TO BRAIN METASTASES

Incidence

Brain metastasis, a common complication of systemic cancer, is present in 98,000 to 170,000 new patients each year, approximately 30% of all patients with malignancy (1). The incidence is rising because of the use of more sensitive detection techniques and the prolonged survival of patients with metastatic disease from common malignant tumors. The primary sites most frequently associated with brain metastases are lung (50%), breast (20%), unknown primary (10%), melanoma (10%), and colorectal (5%) (1). The prognosis is dependent on several factors, including performance status, number of lesions (single or multiple), site of the primary cancer (e.g., lung), and extent and responsiveness of systemic disease.

Presentation

Brain metastases may manifest with the rapid onset of symptoms or with slowly progressive neurologic dysfunction. Frequent presenting symptoms include headache (49%), a focal neurologic deficit (30%), cognitive disturbance (32%), ataxia (21%), seizures (18%), dysarthria (12%), visual disturbances (6%), sensory disturbance (6%), and limb ataxia (6%) (1).

Evaluation

Imaging studies are recommended for any patient with a history of cancer and new neurologic symptoms. Contrast-enhanced computed tomography (CT) and magnetic resonance imaging are both appropriate, although gadolinium-enhanced magnetic resonance imaging is more sensitive and specific for the detection of central nervous system metastases. Of enhancing metastatic lesions, 30% are solitary, well circumscribed, and associated with vasogenic edema. If there is clinical uncertainly about the origin of brain lesions, a stereotactic biopsy can differentiate metastatic disease from a primary brain tumor or a nonmalignant cause, such as infection. In fact, a single brain metastasis in a patient otherwise free of disease should generally be resected. A biopsy is generally not indicated in patients with multiple metastatic lesions and known malignant disease, particularly a tumor that commonly metastasizes to the brain. A biopsy should be considered in patients with acquired immunodeficiency syndrome, even when patients have multiple lesions, if *Toxoplasma* titers are negative, to differentiate cancer, particularly lymphoma, from infectious causes.

Management

Medical

The goal of medical therapy for newly diagnosed symptomatic brain lesions is to control edema and to minimize symptoms while evaluating for more definitive

therapeutic options. Treatment options include surgical resection, radiosurgery, whole-brain radiation therapy (WBRT), and medical therapy. Untreated, patients with multiple brain metastases have a median survival of approximately 1 month (2). Corticosteroid therapy reduces edema and doubles the median survival to 2 months (1). Corticosteroids reduce vasogenic edema. These agents are the first step in the management of all patients with brain metastases as nearly 70% of patients will experience significant relief of symptoms in the first 48 hours with corticosteroids (3). Patients who do not improve in the first 2 days generally have a very limited life expectancy of days to weeks and face significant progressive neurologic disability. Although there is no evidence-based consensus on the optimal corticosteroid dose, dexamethasone, at 16 to 24 mg/day, in divided doses every 4 to 12 hours, is a reasonable recommendation. Dexamethasone is the preferred corticosteroid because of its reduced mineralocorticoid effects and relatively long half-life. In patients with symptomatic brain lesions who are near the end of life, corticosteroids are continued for the remainder of the patient's life.

Patients receiving high doses of corticosteroids experience several predictable side effects, including oral candidiasis, gastritis, central adiposity, proximal myopathy, leukocytosis, and hyperglycemia. When steroid therapy is initiated, patients should simultaneously start prophylactic antifungal therapy, antacids, and regular blood glucose monitoring.

Interventional

Surgical resection of metastatic brain lesions is indicated for patients with a good performance status, a single lesion in a surgically accessible field, good neurologic function, and well-controlled systemic cancer (4). Surgery should be followed by WBRT to reduce the risk of central nervous system recurrence. In a recent meta-analysis comparing surgery with surgery plus WBRT, survival was equivalent, but patients treated with combined-modality therapy tended to have greater improvement in function and a reduction in death from neurologic causes (5).

For patients who are not surgical candidates or for those who present with multiple brain metastases, palliative WBRT is the standard of care. WBRT improves median survival over dexamethasone alone to 3 to 6 months. WBRT may be administered as 10 to 15 fractions and is generally well tolerated. The most frequent side effects include fatigue, alopecia, and cognitive deficits, particularly problems with short-term memory.

Radiosurgery uses either γ-radiation or a linear accelerator to deliver a high dose of radiation to a defined target. It is an appealing alternative to surgery because it is noninvasive, can be administered quickly, and can access regions of the brain not amenable to surgical resection. The median survival after radiosurgery appears to be equivalent to that after surgery, ranging from 7.4 to 12.9 months. Selection criteria for radiosurgery are similar to those for surgery: limited systemic disease, good performance status (Karnofsky Performance Scale [KPS] >70), and the presence of fewer than three metastatic lesions. Lesions amenable to radiosurgery should be well circumscribed, spheric, <4 cm, and without invasion deep into the brain tissue. Although single-institution studies are subject to significant selection bias, researchers have reported local control rates of 88% for patients treated with radiosurgery. Compared with WBRT alone, radiosurgery in combination with WBRT offers a survival advantage for patients with a single brain

metastasis. In addition, patients treated with combined therapy are more likely to achieve a stable or improved KPS score than are patients receiving WBRT alone. These advantages were observed only in patients with a single brain metastasis (6).

APPROACH TO LIVER METASTASES

Presentation

Patients with liver metastases may be asymptomatic, or they may have a range of abdominal or constitutional symptoms depending on the volume and location of disease in the liver. For many patients, liver metastases manifest with vague abdominal symptoms followed by increasing gastrointestinal and constitutional symptoms if left untreated. Liver metastases are not infrequently uncovered during routine surveillance imaging studies in patients with a history of cancer even before symptoms develop (e.g., colon cancer). Patients with extensive liver metastases may present with signs (ascites, jaundice, coagulopathy, encephalopathy) or symptoms (pain, fever, night sweats, anorexia) of advanced liver disease. Liver metastases historically confer a poor prognosis, often less than a year. However, there is significant variability based on tumor type (e.g., colon versus lung), treatment options, and comorbid disease.

Evaluation

After a careful history and physical examination, evaluation includes imaging studies, typically a contrast-enhanced abdominal CT scan, to assess for the presence and extent of liver disease, biliary or hepatic obstruction, portal vein thrombosis, ascites, and peritoneal disease. Ultrasound can identify liver lesions or biliary obstruction, but although it is helpful for patients who cannot tolerate a CT scan, it does not provide the same degree of diagnostic information. Laboratory studies should include liver function tests, albumin, coagulation studies, chemistry profile, and complete blood count. If ascites is present, diagnostic paracentesis with ascitic fluid analysis for cell count, differential, albumen, and cytology is indicated.

Management

Medical

After a clear discussion of the goals of care, treatment may be directed at the tumor in concert with treatment of the patient's primary symptoms, or it may be focused on symptom management alone. Early satiety, pain, fever and sweats, anorexia and weight loss, pruritus, nausea, abdominal fullness, and confusion are all common symptoms attributable to bulky liver metastases.

Right upper quadrant pain or discomfort secondary to liver capsular stretch, distention, or bulky disease is common. Opioids are the mainstay of management for malignant pain. Even in patients with liver failure and impaired metabolism, opioids can be used safely and effectively when titrated to effect (see Chapter 1–7). Capsular distention is thought to produce pain, in part from a local inflammatory reaction, and corticosteroids are commonly used as adjuvant pain relievers.

In addition, for patients with very advanced disease and multiple symptoms, corticosteroids may transiently ameliorate fatigue and nausea, stimulate appetite, reduce fever and sweats, and improve a patient's general sense of well-being. Evidence-based dosing recommendations are not available, although clinical experience suggests that modest doses of dexamethasone (6 to 10 mg/day) given orally or intravenously in the morning are often effective.

Fever and sweats associated with malignant liver disease are difficult to control. The treatment of choice is control of the cancer if possible. Palliative treatment options include antipyretics (nonsteroidal anti-inflammatory drugs, corticosteroids, and acetaminophen), sponging with cool water or an isopropyl alcohol solution, and hypothermic agents (chlorpromazine) that act by directly lowering the core body temperature. Therapies for malignancy-associated sweats are not well studied, and reports of successful agents are anecdotal: low-dose thioridazine, the H_2 receptor blocker cimetidine, and thalidomide have been reported to improve sweats in patients with advanced cancer (7, 8).

Pruritus is a disruptive and troublesome symptom for patients. Pruritus secondary to liver disease is most often observed in the setting of obstructive jaundice; the severity of the pruritus, however, does not directly correlate with the degree of bilirubin elevation. Decompression, or even partial decompression, of the biliary tree, either through percutaneous or endoscopic approach, can provide significant relief of the itching.

Interventional

Liver-directed treatment strategies now provide additional options for the treatment of liver metastases. Currently available liver-directed approaches include surgical resection, radiofrequency ablation (RFA), chemoembolization, cryotherapy, and brachytherapy with radiation-impregnated glass beads. The risks, benefits, and patient characteristics leading to a recommendation for one technique or another are highlighted in Table II–1–1. In particular, patients with colorectal cancer and hepatic metastases, without evidence of other metastatic disease, have dramatically improved survival if their lesions are surgically resected (55% to 80% survival at 1 year and 25% to 50% at 5 years) compared with best supportive care (survival <1 year) (9). Liver-directed therapies minimize systemic toxicity and spare most normal liver tissue. Patients with a good performance status (KPS >70), fewer than four metastatic liver lesions, lesions 5 cm or smaller, and minimal systemic metastases are candidates for liver-directed therapy.

APPROACH TO BONE METASTASES

Presentation

Patients with bone metastases may present with pain, usually localized to the site of the metastasis. The growth of malignant tumors creates pressure inside the bone and stimulates nociceptors sensitive to pressure. Locally active substances, such as prostaglandin E_2 and osteoclast-activating factor, are secreted, leading to necrosis. Malignant bone pain is classically insidious, with progressive severity

Table II–1–1 ■ Liver-Directed Therapy

Modality	Technique	Patient Factors	Risks	Benefits
Surgical resection	Open or laparoscopic approach	Good performance status, ability to tolerate major surgery, no other distant disease	Operative morbidity and mortality; postprocedure pain, prolonged recovery	Possibility for cure, best survival outcomes, complete resection
Radiofrequency ablation	Percutaneous friction heat ablation	Unresectable, fewer than five lesions, <4 cm in size, surrounded by liver parenchyma, >1 cm from vessels	Postprocedure pain, tract seeding of tumor	Outpatient procedure, no general anesthesia, improved 5-year survival rates for metastatic colon cancer
Cryotherapy	Cold temperature ablation, −190°C	Unresectable, fewer than five lesions, <4 cm in size, surrounded by liver parenchyma, >1 cm from vessels	Postprocedure pain, less effective than radiofrequency ablation	Modest survival benefit when combined with systemic therapy
Chemoembolization	Chemotherapy directed into the tumor blood supply	Unresectable primary liver tumors, better outcome with normal hepatic function pretreatment	Postprocedure pain, fever, nausea, fatigue, acute hepatitis	Minimal systemic toxicity, prolonged survival
Therasphere	Radioactive glass beads	May have multiple liver lesions, fair hepatic reserve, no hepatopulmonary or gastroduodenal shunting	Acute liver toxicity or failure, gastritis or ulcers, pulmonary toxicity if hepatopulmonary shunting exists	Ease of administration, minimal discomfort, effective, sparing of normal liver, survival similar to chemo-embolization

over weeks to months. The pain is often described as a focal, constant, deep ache or boring pain without significant radiation. Patients occasionally present with the acute onset of moderate to severe pain after a pathologic fracture. Bone metastases can occur secondary to any solid tumor but are most common in patients with prostate, breast, and lung cancers. In autopsy series, 85% of patients with these three malignant diseases have bone metastases at the time of death (10).

Evaluation

The initial evaluation of bone pain begins with a good pain history and physical examination focused on the sites of pain: percussion over the bones frequently identifies areas of point tenderness, a red flag for the diagnosis of a metastatic bone lesion. Particular attention should be paid to patients with pain over a vertebral body because it could be a potential sign of vertebral involvement. Localized back pain is the most common presenting symptom of spinal cord compression and should be evaluated in an expedited fashion. Patients with extensive bone metastases may have myelophthisic anemia secondary to tumor infiltration of the bone marrow, characterized by a leukoerythroblastic peripheral blood smear, or elevated markers of bone turnover such as a high serum alkaline phosphatase.

The initial laboratory evaluation should include a chemistry profile with calcium level, complete blood count, and alkaline phosphatase. A clinical suspicion of bone metastases dictates an initial evaluation of the affected area by a plain film. Radiographs often identify a patient at risk for pathologic fracture. Lesions with an axial cortical involvement greater than 30 mm indicate an increased risk for fracture, and prophylactic surgical stabilization followed by local radiation therapy should be considered for weight-bearing bones (11). The most sensitive test to determine the extent of metastatic disease and to characterize (osteolytic or osteoblastic) the lesions is a radionuclide bone scan, although it does not visualize the lesions of multiple myeloma clearly. If a plain film is nondiagnostic, then a bone scan should be performed in most patients at high risk for bone metastases who are experiencing bone pain.

Management

Medical

The treatment of metastatic bone lesions is palliative, directed at the patient's presenting symptoms and the prevention of skeletal complications. Pain secondary to bone metastases is initially treated with medical therapy. First-line analgesic agents for mild skeletal pain include nonsteroidal anti-inflammatory drugs and acetaminophen. If pain control is inadequate, opioids are added to achieve optimal pain control. Antitumor therapy, directed either at the site of metastasis or systemically, may reduce pain and allow dose reductions or discontinuation of analgesics.

The medical management of malignant bone lesions has changed in the era of oral and intravenous bisphosphonates, a class of agents with a variety of actions, most importantly a multifaceted inhibition of osteoclast activity. These agents may improve pain control and delay skeletal complications of metastatic disease,

but they do not affect survival. Zoledronic acid is often used because of its potency and ease of infusion (4 mg over 15 minutes). The main toxicities associated with bisphosphonates are renal impairment, flulike symptoms, and bone pain, as well as the rare but significant complication of osteonecrosis of the jaw.

Additional interventions for the treatment of bone metastases include systemic antineoplastic therapy, radiation therapy, RFA, and surgical fixation. Systemic chemotherapeutic options may exist for some patients with highly responsive cancers, for example breast and testicular cancer. Pathologic fractures of weight-bearing bones require surgical stabilization, whereas vertebral fractures may be treated with vertebroplasty or kyphoplasty.

Radiation

External-beam radiation therapy relieves pain, minimizes further tumor destruction, and prevents or delays pathologic fractures. Although most commonly delivered as multiple fractions, a single, higher-dose fraction (generally 800 Gy) reduces the treatment time necessary and minimizes the overall treatment burden for the patient. A meta-analysis (12 trials, 3508 patients) comparing single-fraction with multifraction radiation treatment of bone metastases demonstrated equivalent reduction in pain (60%), complete pain relief (34%), and toxicity. The necessity for repeated treatment, however, was higher for patients treated with a single-fraction versus multiple fractions, 21.5% versus 7.4%, respectively (12). The choice of therapy depends on the goals of care and life expectancy.

RFA, an emerging technique for the treatment of bone metastases, introduces a high-frequency current into the tumor bed that induces frictional heating and necrosis. There is significant experience using this technique for the treatment of liver metastases, but data evaluating the effectiveness of RFA for reducing pain from bone metastases are limited. Goetz and colleagues, in a multicenter trial, treated 43 patients with painful osteolytic bone metastases with RFA. Eligible patients were without risk for pathologic fracture, and their lesions were not adjacent to large vessels or the spinal cord. Sustained pain relief was achieved in 95% of patients, with mean pain scores falling from 7.9 to 1.4 ($P < .0005$) over the 24 weeks following treatment (13). Prospective, randomized data comparing radiation therapy and RFA for pain relief, mobility, and post-treatment pathologic fractures are not yet available.

Surgery

Surgical stabilization can relieve pain and preserve function in patients with unstable vertebral fractures and spinal cord compression and in those with or at risk for pathologic fracture of a weight-bearing or other long bone. Although there are no established criteria, surgical stabilization is generally considered in patients with good functional status (KPS >70), life expectancy longer than 3 to 6 months, and the ability to tolerate major surgery. Surgical risk depends on a variety of patient-related factors, including comorbid cardiopulmonary disease and relative difficulty of the surgical fixation. Prophylactic stabilization procedures are generally less invasive and better tolerated than fixation procedures after a fracture has already occurred. Surgery provides an opportunity to prevent fracture and to preserve ambulation, but it comes with significant potential morbidity and mortality (14).

Table II–1–2 ■ Bone-Seeking Radiopharmaceuticals

Drug	Mechanism of Action	Indication	Contraindication
Strontium-89	Calcium homologue tracks to deposition of calcium		
Phosphorus-32 (rarely used)	Tracks inorganic phosphorus in the body	Similar for all agents: Positive bone scan Bone pain related to cancer Multifocal disease	Similar for all agents: Mainly soft tissue disease Unifocal bone lesion Negative bone scan Significant myelosuppression
Samarium-153 EDTMP	Phosphonic acid group on carrier molecule, EDTMP, carries agent to areas of newly deposited bone		

EDTMP, ethylene diamine tetramethylene phosphonate.

Vertebroplasty offers a nonsurgical approach to stabilize a vertebral fracture. The procedure is performed with the patient under conscious sedation with radiographic guidance. Cement is injected into the fractured vertebra to stabilize it, maintain column height, and prevent future nerve impingement. Although data are limited, case reports and a small case series suggest that vertebroplasty can reduce pain rapidly and is safe in conjunction with radiation therapy (15). Vertebroplasty is contraindicated in patients with spinal cord compression or with a compression fracture with retropulsed fragments.

Radiopharmaceuticals are indicated for the treatment of multiple painful bone metastases in patients with predominantly osteoblastic metastases. These agents work by tracking to binding sites in the bone matrix at the tumor-bone interface and then delivering a therapeutic radiation dose to the local area (Table II–1–2). Because these agents are administered systemically, they are appropriate only for patients with multiple painful lesions who are without other options for systemic antineoplastic agents. A Cochrane meta-analysis to evaluate the efficacy of radiopharmaceuticals for metastatic bone pain identified four trials (325 patients with prostate or breast cancer) and demonstrated a small benefit from radioisotopes for the control of bone pain for 1 to 6 months after treatment, without improvement in survival or reduction in the incidence of spinal cord compression. These agents are associated with significant myelosuppression and cost (16).

APPROACH TO BOWEL OBSTRUCTION

Presentation

In the majority of patients, the diagnosis of malignant bowel obstruction can be made by history and physical examination. Abdominal distention, nausea, vomiting, crampy abdominal pain, and an absence of flatus and bowel movements are typical presenting symptoms. The colon may take as long as 12 to 24 hours to

empty completely; thus, patients with small bowel obstruction may continue to pass flatus and stool even after the obstruction occurs. The classic complaint is of periumbilical, paroxysmal, crampy abdominal pain. Obstruction should be differentiated from perforation: peritonitis is suggested by symptoms of focal or diffuse abdominal pain, fever, hemodynamic instability, or peritoneal signs (severe pain with movement, firm abdomen, rebound tenderness, involuntary guarding).

The most common tumors causing malignant bowel obstruction are metastatic ovarian and colon cancers, although any patient with advanced cancer can develop an obstruction, particularly a patient with a history of multiple prior abdominal surgeries or abdominal radiation therapy. In as many as one third of patients, the cause of the obstruction is nonmalignant, that is, secondary to adhesions or other causes. Patients with advanced cancer and malignant bowel obstruction have a short life expectancy, generally measured in weeks.

Evaluation

The physical examination in patients with obstruction is highly variable: fever and tachycardia may be signs of a strangulating obstruction or perforation; auscultation may reveal high-pitched, tinkling or hypoactive bowel sounds and is not generally diagnostic; oliguria and dry mucous membranes are signs of dehydration; tympany on abdominal percussion suggests dilated loops of bowel; rebound tenderness, guarding, pain with light percussion, and abdominal rigidity suggest peritonitis. A rectal examination often detects an empty vault but may demonstrate an obstructing rectal mass or blood.

Plain radiographs of the abdomen and an upright chest radiograph will detect free peritoneal air if perforation is present and the classic dilated loops of bowel with air-fluid levels when obstruction is the cause of the patient's symptoms. The presence of air in the colon or rectum makes a complete obstruction unlikely. In patients with malignant disease, an abdominal CT scan helps to define the extent of the underlying disease and may identify the site of the obstruction. An isolated point of obstruction is potentially reversible with surgical resection. Laboratory evaluation, including chemistry panel and complete blood count, will illuminate electrolyte imbalances, dehydration, anemia, acid-base disorders, or signs of secondary infection.

Management

Medical

The management goals of bowel obstruction in the setting of advanced cancer are to minimize bowel wall edema, to treat and prevent nausea and vomiting, to control pain, to decrease intestinal secretions, and to address end-of-life issues. The initial intervention for patients with a bowel obstruction is nasogastric tube drainage to prevent emesis and to relieve the nausea caused by gastric distention. Occasionally, obstructions remit spontaneously with conservative management: nothing-by-mouth, nasogastric suction, intravenous fluids, and analgesics. Intravenous corticosteroids may minimize bowel wall edema and may partially reverse an obstruction. A Cochrane meta-analysis evaluating dexamethasone, 6 to 16 mg/day, for the treatment of malignant bowel obstruction revealed

a trend toward resolution of the obstruction with steroids, but no survival advantage (17).

Pain management is vital for patients with a malignant bowel obstruction. Opioid analgesics are recommended. Patients with a nonfunctioning intestinal tract rely on alternate routes of analgesic administration. Fentanyl transdermal patches, rectal administration of long-acting opioids, and subcutaneous or intravenous opioid administration provide predictable analgesic delivery in the absence of a functioning upper gastrointestinal tract.

Somatostatin analogues, such as octreotide, may provide significant relief of symptoms associated with small bowel obstruction and may be used as first-line therapy in patients who are not surgical candidates. Octreotide reduces gastric acid secretion, inhibits the release of gastrointestinal hormones and therefore decreases intestinal fluid secretion, slows intestinal motility, decreases bile flow, decreases mucous production, and reduces splanchnic blood flow. Furthermore, it inhibits acetylcholine release, resulting in muscle relaxation and reduction in the colicky pain associated with spastic gut activity. These inhibitory effects on peristalsis and gastrointestinal secretions reduce bowel distention, pain, and vomiting. Octreotide is administered by either subcutaneous bolus or continuous infusion. The recommended starting dose is 0.3 mg/day subcutaneously and may be titrated upward until symptoms are controlled; most patients require 0.6 to 0.9 mg/day. Octreotide is expensive, and the cost-to-benefit ratio must be considered, especially for patients who may require prolonged treatment. The main side effects of octreotide are gastrointestinal (nausea, vomiting, abdominal pain), injection site reactions, and hyperglycemia.

Despite aggressive supportive care, a malignant bowel obstruction does not resolve with medical management in most patients with advanced cancer. Without aggressive symptom management, patients with persistent malignant bowel obstructions can develop feculent emesis, intractable pain, and distress.

Interventional

Surgical exploration is the initial treatment of choice for patients with a single site of obstruction, a reasonable quality of life, good performance status, and well-controlled systemic disease. Additionally, for patients who present with a malignant bowel obstruction leading to the diagnosis of cancer, surgery, with or without a diverting ostomy, is standard care. With successful resection of an obstruction point, bowel function may return for an extended period of time, thus reducing requirements for supportive medications.

A less invasive alternative to surgery is an endoscopically placed colonic stent. Because urgent surgical intervention is associated with a modest risk of morbidity and mortality, 16% to 23% and 5% to 20%, respectively, colonic stents are used in patients who are not operative candidates. In surgical candidates, temporary stents may be used for symptom relief before subsequent surgical intervention. Colonic stents provide immediate relief of the obstruction and rapid symptom improvement. Left-sided colon lesions are technically more amenable to stenting. Complications occur in 10% to 20% of cases and include stent migration, pain, bleeding, occlusion, and bowel perforation (18).

Venting gastrostomy tubes (percutaneous gastric tubes placed into the stomach) relieve intractable nausea, vomiting, and pain by decompressing the

stomach and proximal small bowel. They also enable a patient to eat and drink small amounts without symptoms, thus allowing social interactions at mealtime. Oral medications can be administered by clamping the gastric tube for 30 to 90 minutes, thereby allowing some absorption in the stomach and proximal small intestine, although bioavailability of medications in this setting is unpredictable. All patients with advanced cancer and a malignant bowel obstruction, with or without surgical intervention, have a poor prognosis and a high rate of in-hospital mortality.

APPROACH TO MALIGNANT EFFUSIONS

Pleural Effusions

Presentation

Malignant effusions are common in patients with cancer. Pleural effusions may manifest insidiously or with severe shortness of breath, depending on the size and speed of accumulation. Pleural effusions produce dyspnea, cough, and pleuritic-type chest pain. Patients often detail progressively worsening shortness of breath, escalating from mild dyspnea on exertion to shortness of breath at rest and orth opnea. Patients may complain of heaviness in the chest and, less frequently, pleuritic chest pain. Physical examination is remarkable for absent or decreased breath sounds and dullness on percussion, typically in the dependent regions of the chest cavity. Although any disease metastatic to the lungs can cause an effusion, 75% of malignant pleural effusions are associated with primary lung, breast, lymphoma, and ovarian cancer. The median survival of patients with a malignant pleural effusion is 3 months unless effective antineoplastic options are available (19).

Evaluation

Pleural effusions are easily visualized with standard upright and lateral chest radiographs. Decubitus films identify the fluid as free flowing or not. A CT scan of the chest is useful to evaluate the degree of loculation of the fluid and the status of the underlying malignant disease. A clinically significant pleural effusion of unknown origin is an indication for thoracentesis. Pleural fluid should be analyzed for cytology, culture, cell count and differential, lactate dehydrogenase, protein, and pH. Malignant effusions are exudates characterized by a high lactate dehydrogenase and protein and low pH (Table II–1–3). The sensitivity of pleural fluid cytology for the diagnosis of adenocarcinomas rises with three serial thoracenteses to almost 70%, although it is less sensitive for other malignant cell types (e.g., squamous cell carcinoma).

Management

The management of malignant pleural effusions focuses on control of dyspnea, cough, and pain while establishing the overall goals of care and considering therapeutic options.

Table II–1–3 ■ Light's Criteria for Transudative versus Exudative Effusions

Test	Exudate	Transudate
Cytology	Positive	Negative
Cell count	High	Low
Total protein	Pleural:serum ratio <0.5	Pleural:serum ratio >0.5
Lactate dehydrogenase	Pleural:serum ratio <0.6	Pleural:serum ratio >0.6
pH	Acidic, <7.3	Basic, >7.3

Data from Light, RW, Macgregor, MI, Luchsinger, PC, Ball, WC Jr. Pleural effusions: the diagnostic separation of transudates and exudates. *Ann Intern Med* 1972; 77:507.

Medical. Shortness of breath, the sensation of suffocation described by patients, is often relieved with low-dose opioids. In opioid-naive patients, 2.5 to 5 mg of immediate-release morphine will ease the sensation of dyspnea. Furthermore, when given in anticipation of activity likely to cause dyspnea, opioids are effective for prevention. For patients with persistent anxiety even after relief of acute dyspnea, anxiolytics (e.g., benzodiazepines) are added adjunctively. Supplemental oxygen may ease dyspnea, although there is no correlation between the respiratory rate or the oxygen saturation and the sensation of dyspnea. Increasing the airflow by using a fan directed toward the patient's face may be beneficial. Some evidence suggests that air movement stimulates the trigeminal nerve, which, in turn, has a central inhibitory effect on dyspnea. This may also explain why oxygen, even in the absence of hypoxia, eases dyspnea. Finally, behavioral strategies, including placing the patient in a recumbent position, encouraging slow movements, and preparing for activity with oxygen and opioids, help to reduce symptoms and increase the patient's sense of control.

In addition to relieving dyspnea, the clinician should consider available options for systemic antitumor therapy, especially for chemotherapy-responsive cancers such as breast, testicular, or lung cancer. Symptom control and, in some cases, survival may be improved with chemotherapy. In patients with lung cancer particularly, chemotherapy has been shown to reduce symptoms and improve quality of life even when it does not prolong life.

Drainage. The majority of patients with malignant pleural effusions will require some type of mechanical drainage. Drainage of a pleural effusion may relieve dyspnea, improve function, and reduce medication requirements. Serial thoracentesis is generally not recommended for long-term management because of the increasing incidence of such complications as pneumothorax and loculated fluid collections. In patients whose pleural fluid reaccumulates after therapeutic thoracentesis, more definitive intervention should be considered. Reexpansion pulmonary edema is a rare and potentially fatal complication of thoracentesis, but it does not appear to correlate with the volume of fluid removed (20).

Interventional. A tunneled pleural catheter (e.g., PleuRx® catheter) permits long-term drainage on an outpatient basis and controls the effusion and related symptoms for more than 80% of patients. Patients and families can readily be taught to access the catheter at home and to drain up to 1000 mL of fluid every

other day. Patients with a good performance status, limited systemic antitumor options, and symptom improvement after therapeutic thoracentesis should be considered for a tunneled catheter for long-term drainage. The catheter provides the patient with control over the effusion and has been proven safe and effective in the outpatient setting.

Autopleurodesis occurs in approximately 40% of patients by 30 days. Complications from catheters tend to be minor (e.g., local skin infection, catheter occlusion, and skin breakdown) but can be severe (e.g., pleural fluid infection) and occur in 16% to 20% of patients (21). Traditional pigtail-type catheters are another option for chronic drainage of pleural effusions. Pigtail catheters are placed percutaneously and curl inside the body cavity, thus holding them in place. These catheters are of a smaller caliber than PleuRx®, and autorepositioning in the chest is facilitated as the effusion resolves. When compared with tunneled catheters, however, they have an increased risk of pleural and skin infection as well as occlusion.

For patients with recurrent effusions, pleurodesis, either at the bedside via chest tube or with a thorascopic approach with video assistance (VATS), offers long-term control. Chemical pleurodesis acts by inducing an acute pleural injury, resulting in pleural inflammation that, if successful, leads to fibrosis and pleurodesis. Although multiple sclerosing agents are available, sterile talc has become the sclerosant of choice (when compared with bleomycin, tetracycline, mustine, and tube drainage alone) because of cost, availability, and high reported success rates. VATS with talc pleurodesis provides the greatest likelihood of success, although trial results are mixed when comparing VATS with a bedside approach.

A Cochrane systematic review found that VATS-treated patients had a lower effusion recurrence rate (relative risk 1.19; 95% confidence interval, 1.04 to 1.36) compared with beside pleurodesis (relative risk, 1.68, 95% confidence interval, 1.35 to 2.10), but the review was unable to determine differences in toxicity. A recent phase III trial comparing bedside pleurodesis with VATS showed equivalence with regard to control of the effusion at 30 days (71% versus 78%, respectively) with similar treatment-related mortality. There were more respiratory complications (14% versus 6%), including respiratory failure (8% versus 4%), with VATS versus bedside pleurodesis, although VATS-treated patients experienced less fatigue and chest pain (22, 23).

Ascites

Presentation

Ascites is common in patients with abdominopelvic malignant tumors or metastatic disease to the liver. Enlarging abdominal girth, generalized edema, tight-fitting pants, and complaints of early satiety, vomiting, dyspnea when lying flat, weakness, and weight gain suggest the presence of ascites. As the tension in the abdominal cavity rises, pain and shortness of breath increase.

Evaluation

Mild to moderate ascites is frequently difficult to detect on physical examination, and imaging studies may be necessary. Symptomatic ascites is often readily apparent, and imaging, such as an abdominal CT scan, can provide information about tumor bulk, vascular occlusion (e.g., portal vein thrombosis), associated peritoneal

Table II–1–4 ■ Ascites Analysis

Cause of Ascites	Cytology	SAAG	Polymorphonuclear Cell Count (Leukocytes)
Malignant effusion	Positive	<1.1	<250
Cirrhosis	Negative	>1.1	<250
Spontaneous bacterial peritonitis	Negative	<1.1	>250
Right heart failure	Negative	<1.1	<250

$$\text{SAAG, serum} - \text{ascites albumin gradient} = \frac{\text{serum albumin (g/mL)}}{\text{ascitic albumin (g/mL)}}$$

or hepatic disease, and the volume of ascites. Diagnostic paracentesis may be helpful to differentiate malignant ascites from other types. Routine fluid analysis includes a cell count and differential, albumin, cytology, and culture (Table II–1–4). Peritoneal carcinomatosis accounts for roughly two thirds of patients with malignant ascites. Cytology is positive in nearly 100% of these patients as a result of exfoliation of malignant cells into the ascites. Other causes of malignant ascites include bulky liver metastases and hepatocellular carcinoma with cirrhosis. Chylous ascites from lymphoma is an infrequent cause of ascites and is rarely associated with positive cytology. A neutrophil count greater than 250/mm^3 in the ascitic fluid is suggestive of infection. A serum-ascites albumin gradient (SAAG) of <1.1 g/mL eliminates portal hypertension (e.g., cirrhosis) as an explanation for the ascites.

Management

The treatment of malignant ascites is aimed at palliation of symptoms and may involve medical therapy, intermittent paracentesis, a semipermanent drainage catheter, or shunt placement.

Medical. The origin of the fluid and the overall goals of care are paramount when considering treatment options. For patients nearing the end of life, relief of pain and shortness of breath may be accomplished with titrated doses of opioids. Nausea is treated with dietary changes (small, frequent meals) and antiemetics, primarily a prokinetic agent (e.g., metoclopramide). Metoclopramide, a dopaminergic antagonist centrally and cholinergic in the gut, is the first-line agent in patients with ascites. It stimulates smooth muscle activity, speeding gastric emptying, and inhibits D_2 receptors in the chemoreceptor trigger zone, thus inhibiting nausea centrally. Other antiemetics such as serotonin antagonists (e.g., ondansetron) and other dopamine antagonists (e.g., prochlorperazine) may be added if needed.

Although malignant ascites is typically resistant to diuretic therapy, an attempt to control the accumulation of ascites with diuretics may be appropriate in patients with signs suggestive of portal hypertension (e.g., a SAAG >1.1 g/dL). Patients with portal hypertension may respond to escalating doses of diuretics in combination with a low-sodium, fluid-restricted diet. Finally, therapies aimed at controlling the underlying malignant disease should be considered in certain patient populations with preserved performance status (KPS >70) and effective antitumor options.

Drainage. Therapeutic paracentesis improves symptoms immediately, is easily performed in an outpatient or home setting, and carries minimal risks. In patients with a low SAAG (<1.1 g/dL), the risk of hemodynamic compromise with large-volume paracentesis (>5 L) is low. Frequently, fluid reaccumulates rapidly, necessitating repeated large-volume paracenteses for chronic management of the ascites. With repeated large-volume paracenteses, the risk of complications increases, particularly in patients with prior abdominal surgical procedures or peritoneal carcinomatosis, because both conditions predispose to loculated effusions and adherent loops of bowel. Intermittent large-volume paracentesis is appropriate in many patients who require relatively infrequent paracenteses or in those nearing the end of life.

For patients with preserved performance status, an indwelling peritoneal catheter can be considered. Indwelling catheters allow a patient the freedom to drain ascites "as needed" to maintain symptom control. Indwelling catheters are, however, more expensive to place, maintain, and use. The most readily available catheters are pigtail catheters, which use a programmed internal coil to hold them in place. They can be easily inserted in the outpatient setting with minimal risk. Pigtail catheters relieve distention immediately but they are occasionally complicated by catheter-related sepsis, hypotension, and occlusion (24, 25). Tunneled catheters (e.g., PleuRx®) are associated with fewer infectious complications than nontunneled catheters and are currently under evaluation for ascites management. Early reports from these data suggest good symptom control with few catheter-related infections (26).

Pericardial Effusions

Presentation

Pericardial effusions occur in a significant percentage of patients with metastatic cancer. The most frequent causes are leukemia (69%), melanoma (64%), and lymphoma (24%). Autopsy series report an incidence up to 20% (27). The effusion is most commonly caused by pericardial metastases, but it may result from direct pericardial tumor invasion or disruption of normal lymphatic drainage (28). Direct tumor extension to the pericardium occurs from breast, lung, and esophageal cancers. Pericardial effusions may manifest with nonspecific symptoms such as weight loss, fatigue, and nausea. Patients may also present with more severe symptoms of dyspnea on exertion, paroxysmal nocturnal dyspnea, and orthopnea, or with life-threatening cardiovascular shock. As the effusion progresses, patients may develop chest pain, dizziness, and syncope. Pericardial tamponade or constrictive pericarditis manifests with chest pain and dyspnea, and unstable vital signs or shock may also be present.

Pericardial effusions confer a poor prognosis on patients with lung or breast cancer: median survival of 3.2 and 8.8 months, respectively. Patients with hematologic diseases and a malignant pericardial effusion fare better, with a median survival of 17 months (28).

Evaluation

Pericardial effusions may be suspected on physical examination if the percussed heart border is enlarged, pulsus paradoxus is present, or if a flat percussive sound

is heard over the lower two thirds of the sternum (Dressler's sign). The effusion is best evaluated with a transthoracic echocardiogram to determine its size, quality, and physiologic significance.

Management

Medical. Many patients with malignant pericardial effusions have vague symptoms related to the slow accumulation of fluid and can be managed with medications directed toward specific symptoms. Supportive medications for dyspnea, nausea, and fatigue are appropriate, such as low-dose opioids, antiemetics, or psychostimulants (e.g., methylphenidate), respectively. Antitumor therapy, if available, may reduce or eliminate the effusion and is particularly effective in patients with hematologic malignant diseases.

Drainage. Pericardiocentesis, in the setting of a hemodynamically significant effusion, relieves tamponade and immediately improves signs and symptoms. However, if left untreated, 90% of malignant pericardial effusions will reaccumulate within 3 months (29). Pericardial effusions are definitively treated by placement of a pericardial window that allows the fluid to drain continuously. This procedure may be performed through a thorascopic or open approach. There are multiple case reports in the literature of successful management of pericardial effusions by infusing various chemotherapeutic agents into the pericardial sac. None of these agents has been studied in a controlled clinical trial, and the best recommendation for management remains the placement of a window or intermittent pericardiocentesis.

PEARLS AND PITFALLS

- Neurologic symptoms in patients' with a history of malignancy should be evaluated quickly and thoroughly.
- Corticosteroids are an important adjunctive symptom reliever for cancer patients with a variety of symptoms including pain, anorexia, and constitutional symptoms.
- Strong opioids are frequently required to manage pain in cancer patients and may be used in conjunction with various adjuvant pain relievers.
- Malignant bowel obstruction is a particularly lethal complication of cancer but consideration should be given to the extent of the illness and the precise cause of the obstruction before ruling out the possibility of surgical intervention.
- The most effective symptom relieving intervention for cancer patients may be anti-tumor therapies used in conjunction with palliative medications.

SUMMARY

Patients with cancer face many symptoms and complications from the underlying cancer and its treatment. Aggressive symptom control is vital to maximize quality of life. Only by careful attention to the prevention, evaluation, and treatment of symptoms will patients with cancer receive optimal cancer care.

Patients with malignant disease experience a myriad of physical symptoms related to the disease and its treatment. Symptoms related to the malignant process should be evaluated completely, and treatment should be directed at the primary cause, if possible. The prognosis varies according to many individual factors and must be carefully considered when making management decisions.

Resources

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HIV/AIDS

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2

CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

The human immunodeficiency virus (HIV) is a retrovirus that causes the acquired immune deficiency syndrome (AIDS). Previously a disease with no treatment, it uniformly resulted in death within a few years. With the advent of antiretroviral treatment, HIV/AIDS has become a chronic progressive illness that is still incurable and causes significant morbidity (1). Chronic illness is characterized by a waxing and waning course, but the long prodrome predictive of decline in the early stages of the epidemic may be missing in the era of highly active antiretroviral therapy (HAART).

Although many definitions of palliative care are recorded in the literature, one was developed specifically by the HIV/AIDS Bureau of the Health Services and Resources Administration in the US Department of Health and Human Services before the call for demonstration projects of palliative care in HIV disease. These projects were authorized under Title VI of the Ryan White CARE Act (Special

Projects of National Significance) from 2000 through 2004. The definition was crafted by a multidisciplinary group of practicing HIV clinicians.

Palliative care is patient- and family-centered care. It optimizes quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness and places critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs. It facilitates patient autonomy, access to information, and choice (2).

With this definition, it is clear that palliative care relates to concurrent care with optimal treatment throughout the trajectory of illness and that palliative aspects of management cannot be neglected (3). Symptom recognition and control are paramount, regardless of disease stage. In the United States, many patients have a treatment history of sequential single-drug therapy, and although survival may be prolonged, these patients are often plagued by long-term toxicities as well as by the fear that they may develop resistance to available therapies. Palliative care can help patients with these issues. It is clear that patients with late-stage disease have improved control of physical symptoms, anxiety, insight, and spiritual well-being when care is provided by home palliative care or inpatient hospice workers (4). More study is needed to evaluate the effectiveness of this type of care across the continuum.

SURVIVAL IN THE POST–HIGHLY ACTIVE ANTIRETROVIRAL THERAPY ERA

Since HAART became uniformly available after 1996, the course of illness has changed dramatically. Before that time, pretreatment HIV-1 RNA level (referred to as *viral load*) and T-helper ($CD4^+$) cell count were predictive of life expectancy. Now, however, the ability to suppress viral replication fully and to maintain this suppression predicts clinical outcomes. Even advanced immunosuppression can be overcome if the post-treatment $CD4^+$ cell counts can be raised to more than 0.200×10^9 cells/L (5). The incidence of AIDS-defining events declined significantly ($P < .001$) after the initiation of HAART, especially events with a viral origin (6).

Despite these advances, the Centers for Disease Control and Prevention consistently reports 15,000 to 16,000 deaths from AIDS on a yearly basis in the United States. Statistics show a slight increase in this trend (7), an increase that may reflect either increasing infection rates in young people who believe that HIV is no longer a problem or the growing resistance to antiretroviral therapy that plagues cities with the highest infection rates.

DEVELOPMENT OF VIRAL RESISTANCE TO THERAPY

The HIV virus mutates rapidly, hence the need for combination chemotherapy. Resistance has become a major problem in the United States. Some cities have a very low treatment success rate even after 1 year of use. This problem likely has multiple causes, but lack of adherence to the regimen is probably the most

common. Lack of understanding of resistance also appears to play a role; a patient may feel protected by taking fewer pills than prescribed, or families may decide to share their medications.

IMPORTANCE OF SYMPTOMS

Specific aspects of symptom management are dealt with in Section I. Good HIV care includes attention to the management of side effects and long-term toxicities, and palliative care extends this management to include the whole person and the family unit. Although a symptom may be expressed as a physical sign, it frequently reflects, or is modified by, emotional, social, and spiritual issues. For example, many pain problems take on meanings of their own to the patient: fear of being punished for a lifestyle, memories of a friend who died with unrelieved pain or angst that there is no appropriate guardian for children can all amplify the experience of pain. Without recognizing these components, the symptom in question may be relieved acutely, but it may become a recurrent problem or may seem "out of proportion" to the identified stimulus.

Studies conducted by the AIDS Clinical Trials Group have identified multiple symptoms that plague patients taking HAART therapy. Symptom prevalence has been documented throughout the epidemic (Table II–2–1). An individual patient may have as many as 16 active signs or symptoms at any given time (8). The AIDS Clinical Trials Group has developed a symptom index that can be used clinically to document problems that patients face on a daily basis, and the index can be used in the waiting area to provide a more objective picture of each patient (9).

Providers underestimate the number of symptoms by threefold and do not appreciate the degree of severity (10). The HIV Cost and Service Utilization Study has even shown that information about the *number* of symptoms may have greater impact on the health-related quality of life than the $CD4^+$ cell count and the measured viral burden (11). Because all problems cannot be addressed in one visit, clinicians should make use of other professionals who may have more time to investigate these issues. A follow-up appointment may be needed to address specific symptoms. It is not unusual for other problems to become apparent after the most severe problem has been addressed. Opportunistic infections, wasting syndrome, and characteristic malignant diseases are the hallmarks of HIV infection and deterioration of the immune system. It is useful to associate the level of T-helper cell destruction with specific symptomatic problems (Table II–2–2).

Constitutional symptoms such as cachexia, anorexia, night sweats, and fevers occur in persons with unrecognized HIV infection and may be the presenting symptoms. These problems are associated with advanced disease and should generally be treated initially with antiretroviral therapy to determine whether the patient will be responsive. These symptoms may also occur in patients who are no longer responsive to treatment, either because of viral resistance or as a result of the patient's decision to stop therapy. When these symptoms are present in patients who were previously taking antiretroviral agents, "salvage therapy" may be possible, but it should be offered in consultation with an HIV specialist. Regardless of the cause of these symptoms, they should be addressed symptomatically while the management strategy is being considered.

Table II–2–1 ■ Symptom Prevalence

Sign/Symptom	Fontaine et al (N = 290) (%)	Whalen et al (N = 114) (%)	Vogl et al (N = 504) (%)	Matthews et al (N = 3,072) (%)	Fantoni et al (N = 1,128) (%)
Fatigue	77	53	85	68	55
Fevers	59	41	—	51.1	29
Hand/foot pain	—	37	—	48.9	—
Nausea	48	25	—	49.8	22
Diarrhea	45	31	—	51	11
Sadness/ depression	63	62	82	—	—
Sleep droblems	62	61	73.8	—	—
Skin problems	37	46	—	24.3	17
Cough	57	50	60.3	30.4	32
Headache (type of pain)	—	55	—	39.3	—
Appetite loss (Anorexia)	55	32	—	49.8	34
Weight loss	60	16	—	37.1	—
Pain	—	—	76	—	29
Dyspnea	41	32	62.4	30.4	19

Data from Fontaine A, Larue F, Lassauniere JM: Physicians' recognition of the symptoms experienced by HIV patients: How reliable? J Pain Symptom Manage 1999;18:263–270; Whalen CC, Antani M, Carey J, Landefeld CS: An index of symptoms for infection with human immunodeficiency virus: Reliability and validity. *J Clin Epidemiol* 1994;47:537–546; Vogl D, Rosenfeld B, Breitbart W, et al: Symptom prevalence, characteristics, and distress in AIDS outpatients. *J Pain Symptom Manage* 1999;18:253–262; Mathews WC, McCutchan JA, Asch S, et al: National estimates of HIV-related symptom prevalence from the HIV Cost and Services Utilization Study. *Med Care* 2000;38:750–762; Fantoni M, Ricci F, Del Borgo C, et al: Multicentre study on the prevalence of symptoms and symptomatic treatment in HIV infection: Central Italy PRESINT Group. *J Palliat Care* 1997;13:9–13.

Table II–2–2 ■ Infections Correlated with $CD4^+$ Cell Count

$CD4^+$ Cell Count	Infection
>500	Candidal vaginitis
200–500	Pneumococcal disease, herpes zoster, pulmonary tuberculosis, Kaposi's sarcoma, oral thrush, cervical cancer, idiopathic thrombocytic purpura
<200	*Pneumocystis* pneumonia, miliary and extrapulmonary tuberculosis, wasting, peripheral neuropathy, non-Hodgkin's lymphoma, disseminated histoplasmosis, recurrent bacterial disease (e.g., pyomyositis)
<100	Toxoplasmosis, cryptococcosis, chronic cryptosporidiosis, microsporidiosis, candidal esophagitis
<50	Cytomegalovirus, atypical *Mycobacterium,* central nervous system lymphoma, progressive multifocal leukoencephalitis

From Khambaty M, Personal Communication. Baltimore: Institute of Human Virology.

Table II–2–3 ■ Pain as an Important Symptom

Types of Pain in HIV/AIDS
Headaches
Oral cavity/throat/esophagus
Chest
Abdomen
Genital/rectal
Extremities
Related to diagnostic procedures

A survey of New York City inpatients documented that pain (40%), psychosocial issues (31%), depression/anxiety (23%/19%), and insomnia (13%) continue to be problematic (12). A multisite study documented that 13% to 30% of patients with HIV disease have major depression that had not been diagnosed previously (13).

Pain continues to be an important symptom in HIV disease despite improvement secondary to HAART (Table II–2–3). Management of pain is made more difficult by the overlay of substance abuse. It is useful to obtain a baseline pain consultation on any patient. If substance abuse is a part of the history, tolerance to opioids will exist, and patients may require higher doses for routine management. Clinical experience suggests that patients with pain are grateful for attention paid to this symptom and will not exhibit "drug seeking" behavior if acceptable symptom control is achieved. The optimal management of pain requires a multidisciplinary team.

Peripheral neuropathy, the most common pain experienced, can be present during any stage of the illness. The cause might be immune modulated, infectious, or drug related. Treatment should be based on the origin and location of pain and often requires an adjuvant medication along with opioids. Adjuvants for neuropathic pain are usually an anticonvulsant (e.g., carbamazepine or gabapentin), an antidepressant (e.g., nortriptyline), or a nonsteroidal anti-inflammatory drug. When initiated at the same time as opioid therapy, adjuvant medication can lower the total dose of the opioid. In the past, it was believed that opioids were ineffective for neuropathic pain, but it is now known that this type of pain simply requires higher doses of opioids (Table II–2–4).

Pseudoaddiction, in which a patient reports inadequate control of symptom (e.g., pain), can appear to clinicians to be drug-seeking behavior. End-of-dose failure, because of a short drug half-life, results in loss of symptom control before the next scheduled dose and accounts for this phenomenon (14).

SIDE EFFECTS OF ANTIRETROVIRAL THERAPY

Some signs and symptoms are related to HIV disease itself and can occur despite optimal disease control. A recent survey of outpatients who are taking HAART in the United Kingdom showed that patients receiving therapy experience more

Table II–2–4 ■ Principles for Managing Signs and Symptoms

Believe the patient.
Take a detailed history.
Complete a targeted examination (try to reproduce the symptom).
Obtain any necessary studies for evaluation.
Educate the patient regarding the use of a 0–10 severity scale (0 = none, and 10 = worst possible).
Begin therapy at the time of evaluation to achieve initial control of symptoms.
Use around-the-clock dosing to avoid peaks and troughs, NOT as-needed orders.
Give directions for what to do if the symptom recurs before the next dose of medication is due (i.e., prescribe a breakthrough dose: one sixth of the total daily dose q2h between scheduled doses).
Establish a mechanism to reassess response to therapy within the first hour after treatment if medication is given by mouth and sooner if using the intravenous route.
Repeat the use of the severity scale to assess relief.
Adjust treatment as necessary.

Adapted from Ingham JM, Portenoy RK: The management of pain and other symptoms. In Doyle D, Hanks GWC, McDonald N (eds): Oxford Textbook of Palliative Medicine, 2nd ed. Oxford: Oxford University Press, 1998.

symptoms than do those who are not being treated (15). An experienced HIV clinician knows that most side effects resolve after 2 to 4 weeks of treatment with a particular medication and can offer advice and even medication to prevent side effects at the time therapy is initiated. These weeks, although brief from the point of view of the provider, may be quite difficult for the patient to tolerate and can be a reason for poor adherence to the regimen.

As the approach to viral control has improved, so has the "cocktail" used for treatment. It has reduced side effects, is less expensive, requires fewer pills, and has less demanding dosing intervals. Nevertheless, these agents are still a form of chemotherapy and are not easy for patients to tolerate (Table II–2–5).

Some symptoms can be caused both by the disease itself and by the medication. Xerostomia can be caused by direct invasion of the salivary glands by HIV, or it may be related to the use of medications such as didanosine. Likewise, peripheral neuropathy may result from the damaging effects of HIV, or it may be an effect of a medication such as stavudine or isoniazid. Problems such as xerostomia and peripheral neuropathy are frequently overlooked in a routine review of systems, and they can result in great distress. If identified early enough, the problem can be overcome by modifying the HAART regimen to replace the offending agent. Neither of these symptoms is reversible if the drug is continued, and both can be quite debilitating.

COMORBIDITIES AND LONG-TERM TOXICITIES

In the growing population of those who acquired the virus through intravenous drug use, there are comorbidities that impact overall progress. Hepatitis C is probably the most serious and is found in 52% to 90% of drug users. Because all antiretroviral therapy (and many medications used to treat side effects) is metabolized through the liver, this disease becomes a limiting factor in the attempt to manage

Table II–2–5 ■ Side Effects of Frequently Used Antiretroviral Therapy

Drugs	Side Effects
Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	
Abacavir	Hypersensitivity reaction, nausea, malaise
Didanosine (ddI)	Pancreatitis, xerostomia, peripheral neuropathy
Lamivudine (3TC)/ emtricitabine (FTC)	Negligible, occasional hyperpigmentation of palms and soles
Stavudine (D4T)	Peripheral neuropathy, lipoatrophy, lactic acidosis, steatosis
Tenofovir	Bloating, Fanconi's syndrome
Zidovudine (AZT)	Headache, anemia, nausea, pigmented nail beds, darkened skin, insomnia, myopathy
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	
Efavirenz	Vivid dreams, mental status changes, lowers methadone levels, rash
Nevirapine	Rash (15%–30%), hepatotoxicity (fatal)
Protease Inhibitors (PIs)	
Lopinavir/ritonavir	Nausea, bloating, diarrhea (15%–25%)
Indinavir	Renal stones, diarrhea, GI distress
Nelfinavir	Diarrhea
Atazanavir	Hyperbilirubinemia, GI distress
Saquinavir	GI intolerance, headache
Amprenavir	Diarrhea, oral paresthesias, rash
Fusion Inhibitors	
Enfuviride (T20)	Local induration at injection site

GI, gastrointestinal.

symptoms and prolong survival. Another is mental illness (including the use of injection drugs despite harm to the individual) that results in patients' having inadequate support systems, disenfranchisement from society, and diminished ability to make decisions.

Regardless of risk factors for acquiring HIV, as life expectancy is extended, infected individuals are developing more malignant diseases and end-organ failure related to long-term toxicity from the antiretroviral therapy itself. The spread of disease through the illicit use of intravenous drugs is also associated with local and systemic infections related to blood-borne pathogens.

Toxicity from thymidine analogues (nucleoside reverse transcriptase inhibitors) is insidious and progressive and is related to mitochondrial damage. It may first manifest with loss of facial fat and muscular wasting, followed by nonspecific anorexia, myalgias, and nausea, and finally becoming fatal with a presentation of unresponsiveness and sepsis. Clinicians must be aware of this syndrome to remove the offending agents and attempt to reverse the process soon enough to avert rapid demise, which often happens in an intensive care setting (Table II–2–6).

Attention to symptoms helps to build a trusting patient-provider relationship. It may be necessary to involve specialists from other areas in the care of patients with HIV/AIDS who experience these long-term problems. When this happens, it is imperative that the managing provider keep patient and family goals of care in sight. Dealing with multiple specialists may distract both patients and providers

Table II–2–6 ■ Toxicities Associated with Highly Active Antiretroviral Therapy and Prolonged Survival

Intravenous Drug Use
Injection site abscess
Sepsis
Endocarditis
Hepatitis B and C
Highly Active Antiretroviral Therapy Toxicity
Anemia (zidovudine)
Peripheral neuropathy (stavudine, didanosine, zalcitabine)
Xerostomia (didanosine)
Rash (nevirapine)
Lipodystrophies (protease inhibitors)
Osteoporosis (?)
Lactic acidosis (thymidine analogues)
Cardiomyopathy (protease inhibitors)
Hepatotoxicity (non-nucleoside reverse transcriptase inhibitors)
Hypersensitivity reaction (abacavir)
Infectious Complications (Nonopportunistic)
Recurrent bacterial pneumonias
Liver failure (hepatitis C)
Vaginitis
Malignant Diseases
Kaposi's sarcoma
Rectal cancer (human papillomavirus)
Non-Hodgkin's lymphoma
Lung cancer (16) (smoking)
Cervical cancer (human papillomavirus)

from other substantive issues, such as identification of a health proxy or psychospiritual components of care. The primary provider must routinely and specifically ask the patient about goals of care and must avoid falling into the trap of just trying to prolong life without balancing the burden of illness.

SENTINEL EVENTS IN MANAGEMENT

Similar to patients with cancer who become conditioned to respond to their blood count results, those with HIV are very sensitive to changes in their $CD4^+$ cell count and the viral load. The practitioner must be sensitive to the emotional impact of these changes and must be proactive in framing the importance of these numbers. Some reports of changes may even precipitate depression or lack of adherence to medications.

IMPORTANCE OF TEAMWORK

HIV/AIDS is a complex illness because physically it can involve any system in the body and is often complicated by overlying psychological and social issues. It can

cause anxiety and depression, and AIDS-related dementia can exist in the advanced stages. After 25 years and effective therapy, stigma remains an issue even in the United States. For these reasons, it is simply not realistic for one physician or provider to attempt to manage this illness without involving other members of an interdisciplinary team, regardless of the stage of disease. Team members can provide invaluable assistance and insight, and their level of participation may be related to how the disease was acquired.

ADVANCE CARE PLANNING

Discussing any topic pertaining to serious illness and the end of life is difficult for both clinicians and families. Having a conversation well ahead of time can remove some of the emotionality and can help to ensure that patients will receive the best care and support when decision-making capacity is diminished or lost. The availability of palliative care ensures that clinicians will not need to say, "There is nothing else we can do." (See also Chapter I–16.)

Because it may not be possible to anticipate every possible situation and outcome, it is vitally important for patients to appoint a proxy with health care power of attorney. Making a living will is useful but may not be relevant at the time it is needed. Identifying and documenting the name and contact information of the proxy in the medical chart are essential. If the chosen surrogate is not related by blood or marriage, a well-documented legal designation is the only effective method of ensuring that this person will be respected as a decision maker. Clinicians should also realize that determining the person who is best suited to make decisions for the patient—if and when the patient is no longer competent to make decisions for himself or herself—may take time and may not be accomplished in one visit. Patients usually respond better if they have time to consider these issues.

UNIQUE FAMILY UNIT

Clarifying significant relationships (be they family of origin or other) is critical because patients may become acutely ill, require support in an intensive care unit, and be unable to make their wishes known. Stigma still plays a significant role in the ability of some families to deal openly with HIV/AIDS. When substance abuse plays a role in the cause, there are myriad problems ranging from antisocial behavior, such as stealing, to complete breakdown of family-of-origin relationships. Mental illness is a frequent comorbidity in these patients, and finding a health care proxy can be quite challenging. Having a strong working relationship with the provider is one mechanism for promoting open and honest conversations about end-of-life preferences.

ADJUSTED MANAGEMENT NEAR THE END OF LIFE

As a patient moves closer to the time of death, management options change. This is a time to consolidate treatment and to eliminate unnecessary drugs. For example,

medications geared to long-term effects, such as those used to control lipid levels, can be discontinued. However, medications that protect against opportunistic infections may be maintained until the last weeks of life. The managing provider must be aware of the emotional and psychological trauma of being told that medications required so diligently for years are no longer necessary. It may be helpful to use wording that implies the need to reduce further toxicity by eliminating certain medications.

The Medicare hospice benefit provides care when life expectancy is less than 6 months. This is often not a realistic guideline for patients with HIV disease. Prognostication is uncertain for someone still taking antiretroviral therapy. It is extremely difficult for most patients with HIV disease to stop therapy, and, as a result, few are referred for hospice management. This situation presents a dilemma because patients and family members need and appreciate the services and support, but the hospice capitation system cannot afford to pay for antiretroviral treatment unless the hospice has a large average daily census and can diffuse the cost. Palliative care programs, including hospice, are beginning to provide supportive care without demanding cessation of antiretroviral therapy. The program may consider it part of their mandate to help the patient gradually let go of these therapies if impending death seems likely.

Predicting prognosis is the foundation of good end-of-life care, but it is very difficult in patients with HIV/AIDS. In the past, many of these patients experienced a gradual deterioration that alerted clinicians to their poor prognosis. With improved medical management, comorbidities or complications of intravenous substance use are often the cause of death. Long-term toxicities such as lactic acidosis can result in very rapid death. Table II–2–7 lists indicators of a poor prognosis.

End-stage events associated with these conditions can arrive with little warning; it is not unusual to see patients with HIV/AIDS admitted, intubated, and dead within hours to days. For this reason, it is even more important to hold conversations regarding end-of-life care well ahead of time. Sudden critical illness is a time when the input of the primary care provider is most useful in determining a patient's wishes.

Table II–2–7 ■ Predictors of Poor Prognosis

Laboratory Data
Persistent $CD4^+$ cell count <25 cells/mm^3
Persistent HIV RNA >100,000 copies/mL
Serum albumin <2.5 g/dL
Central nervous system disease (e.g., lymphoma, unresponsive toxoplasmosis, progressive multifocal leukoencephalopathy)
Unresponsive lymphoma, visceral Kaposi's sarcoma, other progressive malignant disease
Persistent cryptosporidiosis-related diarrhea (>1 mo) (17)
Advanced end-organ failure (e.g., liver failure secondary to hepatitis C; cardiomyopathy)
Disseminated and resistant atypical *Mycobacterium avium* complex (MAC)
Resistant wasting (>10% body weight loss)

Adapted from National Hospice Organization: Medical Guidelines for Determining Prognosis in Selected Noncancer Diseases, Arlington, VA: National Hospice Organization, 1996; based on literature before the use of highly active antiretroviral therapy.

CLOSURE NEAR THE END OF LIFE

For most, families and professionals alike, approaching the bedside of someone who is dying can be uncomfortable and disconcerting. It is helpful to remember that most people want to know that they are loved and will be remembered after death. Talking about happy, funny, and even sad events by sharing stories and memories is an ideal method for reinforcing this to the patient. In many cultures and religions, forgiveness is of paramount importance, and providing an opportunity to discuss this issue is usually welcomed. It is a difficult time to talk, and conversation may seem uncomfortable at first, but those who are approaching the end of life have little time for superficial discussion and will appreciate meaningful time spent with close family and friends. An experienced provider recognizes that these conversations take time and will initiate the topic when signs begin to suggest deterioration of the patient's condition (Table II–2–8).

CULTURAL ASPECTS OF END-OF-LIFE CARE

For those who experience the loss of someone they care for either personally or professionally, the *feelings* or emotions that accompany the end of life tend to be similar across race, culture, religion, and country of origin, but the responses and methods for recognizing and coping with that loss vary remarkably. Clinicians should try to understand the approach desired by the family to support their grieving. Anger frequently accompanies the dying process in any culture, and staff must be clear that this is not directed at them personally. A listening response tends to be helpful for the patient and family.

A secondary cultural overlay reflects health care providers themselves. Much has been written about the difficulty for workers who need to cope with dying patients, particularly patients who are young. Karasz and colleagues conducted interviews with 16 physicians in the post-HAART era and identified two core myths: "The Good Doctor" and "The Good Death." The realities of care are that each of these is often thwarted. The physician is challenged with finding cognitive and behavioral strategies, and this has psychological consequences to the providers and may affect care (19). Providers should be aware of how care delivery affects them on a daily basis. A premise of palliative care is that the care provider requires support, too. Studies such as this one illustrate the importance of insight and the judicial use of professional support mechanisms.

Table II–2–8 ■ Topics for Families to Discuss with Patients Near the End of Life

Thank you for all that you have given me or done for me.
I love you, and your memory will stay alive with me.
Please forgive me if I have done anything to offend or hurt you.
I forgive you for any incidents that still concern you.
Goodbye—you have my permission to die; I will be okay, but I will remember you.

Adapted with permission of the Free Press, a division of Simon & Schuster Adult Publishing Group, from The Four Things that Matter Most: A Book About Living by Ira Byock, M.D. Copyright 2004 by Ira Byock, M.D. All Rights Reserved.

SYNDROME OF MULTIPLE LOSS

For various reasons, a good support system is not always available, and mental health issues are frequent in HIV/AIDS. Families, clinicians, and patients living with the disease have suffered multiple losses, and this situation can further complicate the grieving process. Grieving the loss of persons with HIV/AIDS can lead to complicated or unresolved grieving (20). Confronting more than one death in a brief time span is not the same as experiencing a single loss. Inner city mothers, for example, may have had children who died of overdose or were randomly murdered in addition to having a son who contracted HIV through homosexuality. Such persons should be referred to counselors who are accustomed to dealing with survivors of multiple losses because the usual approach to support is probably not as helpful to these survivors.

IMPORTANCE OF RITUAL

The AIDS Quilt that memorializes more than 83,000 individuals who have died of AIDS would now be more than 51 miles long if individual panels were laid end to end (www.aidsquilt.org). It is a visual reminder and represents the mourning of a society for those who have died as children and young people, thus robbing the survivors of a future with their loved ones. However, this mourning is often carried on silently by health care providers and workers and can become a source of chronic stress that leads to burnout and decreased effectiveness. The use of ritual is one mechanism to avert this syndrome.

Placing a silk flower on the vacated hospital bed after death, keeping a bulletin board in the staff area with pictures of patients, or creating a routine opportunity for staff members to remember those who have died can help individual workers achieve emotional closure after the death of a patient. Staff members frequently become surrogate family for patients who have outlived their own support systems. Avoiding self-care activities may result in staff members who are dysfunctional, short-tempered, or prone to skipping work.

PEARLS

- The number of symptoms present has more impact on quality of life than viral load and CD4 cell count.
- Use a checklist of common symptoms; health professionals minimize these.
- A short course of steroids stimulates appetite, activity, and well-being in patients with advanced disease.
- Control of one pain usually unmasks others.
- Loss of the facial fat pad forewarns of mitochondrial toxicity.

PITFALLS

- Avoiding having routine discussions, by the calendar, about a patient's desired goals of care.

- Not having the opinion of an HIV specialist when trying to predict prognosis.
- Not taking into account the performance status and wishes of the patient when determining prognosis.
- Focusing on making a living will when what is needed is a health power of attorney.
- Assuming that current staff members can handle a patient's death without debriefing.

SUMMARY

AIDS, or acquired immune deficiency syndrome, has been transformed by high active antiretroviral therapy (HAART) into a chronic disease. Palliative care that focuses on quality of life is relevant throughout the trajectory of the illness. Prognosis is predicted by response to therapy, which can be dramatic. Nonetheless, AIDS continues to claim large numbers of lives, and increased infection rates are seen in some groups. Resistance to therapy is a major problem since human immunodeficiency virus (HIV), the virus that causes AIDS, mutates rapidly. Incorrect use of therapy, for instance by reducing frequency of doses in an effort to prolong the duration of therapy or share it with family members, may account for much of the problem.

Symptom prevalence is high among AIDS patients—many have as many as 16 symptoms at any given time; providers consistently underestimate this. Peripheral neuropathy is the most common pain experienced; both HIV and the antiretroviral therapies may contribute to this. Co-morbidities exist among many AIDS patients, such as hepatitis C among those who acquired HIV through intravenous drug use, and including end-organ failure and malignancies that are related to either HIV or therapy. Patients with AIDS face many losses and they face stigma; team work and support for the patient's unique family unit is important.

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Heart Failure

3

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CHAPTER OUTLINE

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Case Study II–3–1 ■

An 82-year-old woman who had not been to a physician in more than 30 years was admitted to the hospital with fatigue and dyspnea. She had been bedbound at home for the past 2 months, getting up only to use the bathroom, which caused her dyspnea and a sense of panic. She had also lost 20 to 30 pounds during this time. On physical examination, she had rales half-way up both lung fields and a prominent systolic ejection murmur. An echocardiogram revealed severe systolic dysfunction.

After a discussion with her son, she informed her physician that she did not want further intervention or investigation of either her cardiac status or her weight loss. Nevertheless, her physician called a palliative care consultation and told the palliative care physician, "I'm not sure why, but I think it will help—she's not really in pain or anything." At the end of the conversation, he added, "And I don't want her to give up."

QUESTIONS RAISED BY THE CASE

In what way is this palliative care?
Is the patient giving up? Is her doctor giving up?

What are the appropriate treatments for her dyspnea?
What other symptoms could she be expected to have?

INTRODUCTION

This case is not unusual, and it highlights the currently uncertain role of palliative care for patients with heart failure. Even though heart disease is the leading cause of death in the United States, only a few patients in palliative care and hospice programs present because of heart disease. In 2003, the last year for which full figures are available, heart disease accounted for more than 685,000 deaths in the United States, or more than 28.0% of all deaths (1). Two other diseases that are closely linked to heart disease, cerebrovascular disease and diabetes, contribute to another 241,000 deaths annually. In the same year, cancer accounted for more than 556,000 deaths, or 22.7% of all deaths. By contrast, in 2003, 11.0% of patients enrolled in hospice had a primary diagnosis of heart disease, and 49.0% had a primary diagnosis of cancer (2). Given this dramatic incongruence, it is likely that many patients who could benefit from hospice are not receiving it. It is hoped that some patients with heart disease receive palliative care through services other than hospice; nonetheless, these numbers serve as some objective data concerning the volume of patients formally enrolled in one type of palliative care program.

This chapter discusses the epidemiology of heart failure and the prevalence and treatment of common symptoms in patients with heart failure. The chapter ends with a consideration of some of the issues unique to heart failure and palliative care.

HOW IS HEART FAILURE DIFFERENT FROM CANCER?

Both cancer and heart failure are increasingly viewed as chronic and manageable illnesses, and both should be treated with goals of care that emphasize survivorship, rehabilitation, and quality of life. The developing view of heart failure as a chronic condition emphasizes that there may not be a discrete point at which heart failure is considered a "terminal illness." Rather, heart failure has multiple stages during which a combination of disease-modifying and symptom-directed (or palliative) therapies are appropriate. Recent data from Lunney and colleagues have lent empirical evidence to the chronic and stuttering trajectory of symptoms and care that patients with heart failure experience in the last year of life (3). It is a trajectory that frequently involves multiple exacerbations of symptoms, multiple changes in medications and management strategies, and multiple emergency department visits and hospitalizations. Paradoxically, this view of heart failure as a chronic illness may make the transition to palliative care more challenging: cardiologists and their patients often perceive that continuing advances in drug therapy and cardiac devices will prolong life and will enhance the quality of life, and thus they may be less inclined to consider the possibility of treatment failure than oncologists and their patients. As an example, Schoevaerdts and colleagues identified certain differences between cancer and heart failure that could influence decisions about palliative care (4): the illness course is often perceived as fluctuating, rather than progressive; prognosis is perceived as unpredictable, as opposed to pre-

dictable; the terminal phase of the illness is less clearly delineated; and sudden death is more frequent in heart failure than in cancer.

Indeed, data suggest that physicians may view palliative care and heart failure as an unusual combination. In a qualitative study of British physicians that included cardiologists, general practitioners, and palliative medicine specialists, Hanratty and colleagues (5) found that barriers to integrating palliative care with heart failure fell into three main groups: the organization of health care, the unpredictable course of heart failure, and the physician's understanding of the roles of different specialists and disciplines in caring for patients. It is likely that each of these may be a barrier for the optimal delivery of palliative care to patients with heart failure.

These differences in perception have implications for how physicians care for patients with heart failure. A study by McKinley and colleagues compared care delivered by general practitioners in the last year of life to people who died with cancer and with cardiovascular and respiratory disease (6). These investigators found that patients who died of cancer were more likely to have had a terminal phase of the illness identified by their health care providers and to have been prescribed more palliative medications. At the same time, there were some encouraging similarities in the care of both groups: they had a similar number of specialist consultations, experienced similar continuity of care, had similar levels of comorbid conditions, and were equally likely to die at home.

EPIDEMIOLOGY

Currently, 5 million US residents live with heart failure, and 550,000 new (or incident) cases are reported each year (7, 8). The number of patients discharged from hospitals with a diagnosis of heart failure increased from 399,000 in 1979 to 1,093,000 in 2003 (8). This prevalence can be expected to continue to increase with the aging of the population. It is estimated that more than 5% of the US population older than 65 years and 10% of those older than 75 years have heart failure (8). From an economic standpoint, the direct cost of care for these patients may be as high as $58 billion a year (9). The indirect costs in terms of lost wages and family caregiving are likely to be significantly higher.

In terms of mortality, newly diagnosed heart failure in the community carries a mortality of 24%, 37%, and 75% at 1, 2, and 6 years, respectively. For patients with advanced heart failure (New York Heart Association class IV), the rate of rehospitalization or death is 81% at 1 year. In patients with a left ventricular ejection fraction of less than 25%, New York Heart Association class IV symptoms (e.g., dyspnea and angina at rest) for more than 90 days, oxygen consumption of 12 mL/kg or inotropic dependence, mortality is 50% at 6 months. For patients receiving continuous inotropic support, mortality is 75% at 6 months. Unlike cancer, in which death may be perceived as following a predictable course, up to one-half of all deaths from heart failure are sudden (10).

GUIDELINES

Because of the high disease burden that heart failure confers on the population, the consideration of palliative care for these patients has taken on some urgency.

In general, the integration of palliative care principles into disease-specific guidelines has been an important step in increasing the presence of palliative care in mainstream medicine for both cancer and noncancer. The American Hospice Foundation, for example, has developed such guidelines for cancer and noncancer illnesses, and the National Comprehensive Cancer Network has done so for a range of cancer diagnoses (11, 12). More recently, in cardiology and pulmonary medicine, guidelines issued by both the American College of Chest Physicians (13) and the American College of Cardiology/American Heart Association (ACC/AHA) (14) have addressed palliative strategies within their overall management guidelines.

The newest ACC/AHA guidelines endorse clear assessment and management strategies for every stage of heart failure. Importantly, these guidelines include a section on "end of life considerations in the setting of heart failure." Among the recommendations for patients with end-stage heart failure are areas such as ongoing education for patients and their families concerning prognosis, functional capacity, the role of palliative care, implantable cardiac defibrillator (ICD) deactivation, coordination of care, and the use of opioids for symptomatic relief.

These recommendations parallel an overall palliative approach to any illness in that they address symptoms, comprehensive assessment, whole-person care, goals of care, and coordination of care. In addition to these general principles, the ACC/AHA guidelines advise that "aggressive procedures (including intubation and [automatic implantable cardiac defibrillators] AICDs) within the final days are not appropriate." Although this presents a challenge to our recognized inaccuracies of prognostication (15), palliative care physicians routinely use generally agreed on criteria (including decreased responsiveness, severely compromised functional status, and decreased urine output) to assess the last days of life. However, these criteria have not been subjected to empirical scrutiny in the setting of heart failure or other illnesses. The ACC/AHA guidelines take a broad view of the question of determining when the "end of life is nearing" to include multiple subjective and objective factors, including functional status, oxygen dependence, and echocardiographic evidence of heart failure. In the end, however, the guidelines recommend an individualized approach to care: "Ultimately the decisions regarding when the end of life is nearing reflect a complex interaction between objective and subjective information, emotions and patient and family readiness."

The ACC/AHA guidelines are a comprehensive attempt to gather the best current evidence for recommendations to clinicians. For many of the recommendations concerning disease-specific treatments, such as the use of angiotensin-converting enzyme (ACE) inhibitors and β-blockers, evidence reaches the level of class A (data derived from multiple, randomized clinical trials or meta-analyses). For all the recommendations concerning palliative care, however, it is revealing that the level of evidence is class C (consensus, case studies, and standard of care, as opposed to data from clinical trials). This means that the field is young, and future research in palliative care will adjust and solidify the guidelines. However, the trials needed to support improved quality of life from the palliative interventions differ from traditional clinical trials in heart failure related to disease-modifying medications and devices.

Another set of guidelines specific to palliative care and heart failure was recently issued by a group of cardiologists and palliative care physicians (16). These guidelines were generated by a consensus conference that was "convened to define the current state and important gaps in knowledge and needed research on

'Palliative and Supportive Care in Advanced Heart Failure.'" Although the participants did not formally grade their evidence in the same manner as the ACC/AHA guidelines, they derived their guidelines from expert opinion and from extensive review of the medical literature and other guidelines. They identified the need for research on symptom clusters, prognostication, and coordination of care approaches to heart failure as priorities in the fields of palliative care and heart failure.

SYMPTOMS

Despite this need for research, some data exist concerning symptoms in patients with heart failure. Two of the largest trials that examined symptoms in patients near the end of life include the SUPPORT trial (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (17) and the United Kingdom Regional Study of Care of the Dying (RSCD) (18). Each of these studies had a component that assessed symptoms of patients facing the end of life, and each included patients with heart failure.

One analysis of the SUPPORT trial examined elderly patients with heart failure. Levenson and colleagues reported that 60% of these patients had dyspnea, and 78% had pain. Among those in the hospital, the number in pain was 41%. Notably, these symptoms persisted through the final days of life. Patient surrogates reported that 41% of patients were in severe pain, and 63% were severely short of breath at some point during the final 3 days before death (19). Psychological symptoms (including depression, anxiety, and confusion) were found among 10% to 20% of this sample from SUPPORT. In the subsample of patients with heart failure in the RSCD, pain was experienced by 50%, dyspnea by 43%, and low mood and anxiety in 59% and 45% of patients, respectively.

Smaller studies of the prevalence of symptoms in patients with heart failure reported similar results. In a study of patients in one hospital, Jiang and colleagues found that 35% of patients screened positively on the Beck Depression Inventory, and 13.9% of patients had a diagnosable major depressive disorder. These numbers have prognostic implications for patients. The study by Jiang and associates found that untreated depression in the setting of heart failure is a risk factor for increased mortality (20). The high symptom burden on patients with heart failure is not just for those who are hospitalized. A study of patients with heart failure in a community-based hospice found a prevalence of pain in 25%, dyspnea in 60%, and confusion in 48% (21). These numbers probably underrepresent the prevalence in a general population of homebound patients with heart failure because hospice patients were presumably receiving symptomatic care.

TREATMENT

Standard Treatment

Heart failure is unlike some illnesses in palliative care because some treatments for heart failure have both quality of life benefits and disease-modifying effects. This finding contrasts with many types of disease-modifying cancer treatments that

may have deleterious effects on quality of life. For example, two of the cornerstones of treatment for heart failure, described in the most recent ACC/AHA guidelines (22), as well as in recent review articles (23, 24), are the use of ACE inhibitors or angiotensin receptor blockers and β-blockers. Both types of medications have been shown to improve survival and to decrease repeated hospitalizations. Because they have documented effects on quality of life, these medications should be continued in palliative care.

Two other medications for heart failure, diuretics and digoxin, also have clear effects on quality of life. Furosemide is the main diuretic for use in patients with heart failure who have fluid overload. Its effects can be potentiated by spironolactone, which, when added to a loop diuretic such as furosemide, has been shown to lessen both mortality and symptoms and also to reduce hospitalizations in the setting of heart failure (25). Although digoxin has no documented effect on mortality (26), it has been shown to have symptomatic benefits in terms of decreased dyspnea and decreased hospitalizations. Therefore, these medications should be continued as well.

Intravenous inotropic medications (e.g., dobutamine) represent a dilemma for many patients, families, and health care providers. Although these medications have been shown to result in excess mortality in randomized trials, they have also been shown to decrease hospitalizations and symptoms among patients with end-stage heart failure (27). In advanced heart failure management, these medications are generally recommended for use as a "bridge" to cardiac transplantation and as a palliative measure in patients with end-stage heart failure whose symptoms are refractory to other treatments (27). In the setting of hospice and palliative care, the use of intravenous inotropes can be confusing. In terms of philosophy of care, is this "aggressive" or "palliative"? In terms of resources, do we have the resources among our nurses or physicians to administer these safely in the home or nursing home setting? In view of capitated reimbursement, are we able to afford this medication? Although there are no clear guidelines at this time for the use of these medications in the palliative care or hospice context, case studies of patients who have benefited from using them have been published (28). More and more individual programs and physicians will face this dilemma as increasing numbers of patients with heart failure elect hospice care.

Symptom Management

The treatments described earlier, which are directed at the underlying pathophysiology of heart failure itself, frequently have symptomatic benefits. However, in addition to such disease-modifying treatments, additional symptom Management is essential for every patient with heart failure.

Dyspnea

The key medications for the treatment of dyspnea in patients with heart failure include diuretics and opioids. Whenever possible, treatment directed at the underlying cause of the dyspnea will help to avoid the potential side effects of opioids. For example, if dyspnea is the result of a pleural effusion, drainage by thoracentesis may be effective temporarily, but these effusions frequently recur. If dyspnea is the result of pulmonary edema, furosemide or another loop diuretic will often be effective.

Patients with heart failure may have other causes of dyspnea: when it is the result of cardiac ischemia (angina), a nitrate should be used. This can include immediate-release sublingual nitroglycerin and extended oral or transdermal nitrates when the angina is recurrent and predictable. Patients who experience anginal symptoms and dyspnea with a predictable amount of exertion can be counseled to take a nitrate before activity. When dyspnea is the result of rapid atrial fibrillation, rate control with digoxin, a β-blocker, or another agent to decrease cardiac workload is appropriate.

Before ascribing all symptoms to their primary diagnosis, clinicians also need to be alert to comorbid, noncardiac conditions in patients with heart failure. When dyspnea is caused by coexisting asthma or chronic obstructive pulmonary disease (COPD), an appropriate symptomatic approach includes inhaled β-agonists (e.g., albuterol), inhaled steroids (e.g., beclomethasone), or inhaled anticholinergic medications (e.g., ipratropium bromide), as well as oral steroids (e.g., prednisone). If it is difficult to differentiate between heart failure and COPD as the cause of dyspnea, the measurement of brain natriuretic peptide can help to distinguish between the two conditions and can help to direct therapy. Pneumonia is also common in patients who are debilitated by heart failure, and treatment in such cases depends on the patient's overall prognosis and goals of care. Consider, for example, a patient with a life expectancy of weeks to months whose family and clinical team decide that pneumonia should be treated with either oral or intravenous antibiotics. In another situation, a patient with heart failure is bedbound, minimally responsive, and has a likely life expectancy of days. In this case, a candid and sensitive discussion with the patient and his or her family may result in a decision not to use antibiotics, but rather to emphasize treatments for the symptom of dyspnea alone.

Finally, sleep apnea has been associated with heart failure, and treatment of the sleep apnea may help to improve symptoms of fatigue and dyspnea (29). The formal diagnosis of sleep apnea requires an overnight sleep study in a sleep laboratory. In homebound patients, overnight pulse oximetry in the home can sometimes be an alternative. The standard treatment for sleep apnea is the use of continuous positive airway pressure (CPAP) at night. More recently, a randomized trial has shown some efficacy using acetazolamide as treatment for sleep apnea (30). Although the use of CPAP is initially difficult for many patients, they can frequently adapt to and tolerate it after continued use. Medical centers with experienced respiratory care programs have expertise in the adjustment of specific ventilatory settings, as well as tips to increase patient comfort and tolerance of CPAP.

Although oxygen is commonly used in hospice and hospital contexts, a recent review found few data to support its use in relieving dyspnea secondary to heart failure (31), especially when oxygen is used as the sole treatment for dyspnea. As an adjunct to other symptomatic treatments described earlier, the efficacy of oxygen is also equivocal. It may hold symbolic value in that the patient and family view the use of oxygen as an example of continued care and attention for the patient. The clinician should therefore have an open discussion with the patient and the family about the use of oxygen and should note the absence of evidence that it prolongs life. Patients and families may feel that oxygen is a requirement for a hospitalized patient and may not be aware that, like any other intervention, its use should be considered in terms of overall goals of care for a given patient.

Conversely, patients and families may perceive discontinuing oxygen as a sign that the physicians are giving up on a patient. Patients may be accustomed to having their pulse oximetry measured at regular intervals and oxygen titrated accordingly. If oxygen is not an adjunct to a curative intervention, both the administration and monitoring of oxygen should be readdressed with patients and their families.

Pain

As noted earlier, pain is common in patients with heart failure. Most of this pain is actually noncardiac in origin and stems from coexisting arthritic or musculoskeletal disease (21). Anginal pain can be treated with nitrates to increase myocardial perfusion. Other pain in patients with heart failure can be treated with standard doses of opioids, according to World Health Organization criteria (32). Renal insufficiency is common in patients with advanced heart failure. One should be cautious in prescribing medications for such patients because nonsteroidal anti-inflammatory (NSAIDs) medications can worsen renal insufficiency and both morphine and hydromorphone (Dilaudid) have metabolites that can accumulate and lead to adverse neuroexcitatory effects such as tremors, myoclonus, and more rarely, seizures. Generally, doses should start low and should be increased slowly, especially in elderly patients. When neuroexcitatory side effects do occur, one can reduce the opioid dose, rotate opioids, or add a low dose of a benzodiazepine such as clonazepam. Because patients with heart failure are frequently receiving multiple medications and thus are at risk for polypharmacy, this last approach should be reserved for when opioid dose reduction or opioid rotation has been unsuccessful. When the pain has a neuropathic component, treatment with an adjuvant medication such as a tricyclic antidepressant (e.g., nortriptyline, which has fewer anticholinergic side effects than amitriptyline) or an anticonvulsant (e.g., gabapentin or pregabalin) is effective.

NSAIDs should generally be avoided because of the risks of renal dysfunction and increased sodium and fluid retention. Clinicians need to balance the risks and the benefits of NSAID therapy in patients with coexisting arthritis whose pain has been amenable to NSAIDs. A recent review in this area strongly recommended the use of acetaminophen instead of NSAIDs for these reasons (33). However, the use of NSAIDs needs to be considered in patients for whom acetaminophen is insufficient, for those whose prognosis may be weeks or less, and for those who experience unacceptable side effects of opioids or steroids.

Depression

In populations of patients with heart failure, the prevalence of depression ranges from 24% to 42% (34). Predictors of depression in patients with heart failure include living alone, alcohol abuse, perception of medical care as a substantial economic burden, and poor health status (35). The presence of depression is associated with increased mortality in patients with heart failure (36), but this symptom is often overlooked in the course of treatment. According to one study, health care workers failed to diagnose depression in up to 50% of depressed patients (37).

The treatment approach should include counseling interventions and the use of selective serotonin reuptake inhibitors (SSRIs). Tricyclic antidepressants are often avoided because of their potential cardiotoxic effects. The data concerning

counseling and psychological interventions are mixed. A recent review from the Cochrane collaboration concerning depression in the setting of heart failure found that although there is randomized, clinical trial evidence for the effectiveness of counseling for depression following myocardial infarction, there is no such evidence for patients with heart failure. These investigators did, however, identify three observational trials that suggest some benefit to counseling (38). The overall message of these studies is that depression is common, it should be screened for, and treatment requires both medication and counseling.

We now turn to three topics that distinguish heart failure from other illnesses in the palliative care context: resuscitation and AICDs, prognosis, and disease management programs.

RESUSCITATION AND AUTOMATED IMPLANTABLE CARDIAC DEFIBRILLATORS

Resuscitation

More than 15 years ago, Wachter and colleagues found that do not resuscitate (DNR) orders were instituted for 5% of patients with heart failure, 47% of patients with unresectable malignant disease, and 52% of patients with acquired immunodeficiency syndrome (39), even though all three diseases carry similar prognoses. In a more recent trial that analyzed data from the SUPPORT study, Krumholz and colleagues found a low level of preferences for a DNR order and a low level of discussions of resuscitation among patients with heart failure, 23% and 25%, respectively. This study also found a moderate level of instability among preferences. For example, when answering the same question about resuscitation 2 months later, 14% of patients who initially wanted resuscitation had changed their preferences, and 40% of those who had not wanted resuscitation changed their preferences (40). In a study of homebound elderly patients with heart failure and dementia, investigators found that patients with heart failure were less likely to have a DNR order (62% versus 91%), less likely to use hospice (24% versus 61%), and more likely to die in a hospital (45% versus 18%) compared with patients with dementia (41).

In summary, patients with heart failure appear to exhibit a lower prevalence of having DNR orders. Although these studies cannot specify the "correct" number of patients who "should" have a DNR order, the lack of DNR orders is probably indicative of a lack of discussion about goals of care and prognosis with these patients and their families.

Automated Implantable Cardiac Defibrillators

The use of AICDs for a specific type of resuscitation is often indicated in patients with heart failure. The numbers of patients who receive AICDs will undoubtedly expand significantly as indications for these devices grow (42). Both conceptual and empirical literature concerning ethical issues in the use AICDs (43) is beginning to develop and includes issues about when these devices should be deactivated and how clinicians should discuss the decision with patients. There are parallels with overall advance care planning discussions and discussions about general DNR orders.

As with many new technologies, however, the clinician's comfort level in utilizing the technology may be outpacing the comfort level in communicating with patients and families about the technology, both its benefits and its burdens. In one empirical study in this area, Goldstein and colleagues examined family members' views of the management of AICDs in end-of-life care (44). In a retrospective survey of 100 family members of patients who died with AICDs in place, these investigators found that only 8 family members recalled patients receiving a shock from their AICDs in the minutes before death. They also found that these family members reported discussions of possible deactivation in only 27 of 100 cases, and these discussions often happened in the last few days of life. Although this study did not attempt to characterize the optimum time or the optimum structure for such discussions, it suggests that both AICD-delivered shocks for resuscitation and prospective discussions of AICD deactivation may be uncommon in this group of patients.

PROGNOSIS

One of the recurring challenges in applying palliative care principles to heart failure is the issue of prognosis. Although there is evidence for short hospice survival among patients with heart failure, the most comprehensive trial in this regard showed the hospice length of stay among patients with heart failure to be slightly greater than among all hospice patients, regardless of diagnosis: 43.5 versus 36.0 days (45). In a more recent, smaller survey of hospice providers, Goodlin and colleagues found a mean length of stay of 60 days for patients with heart failure in 70 US hospices (46).

In recent years, investigators have developed more sensitive and better-validated models to estimate prognosis for inpatients with heart failure. Fonarow and colleagues used admission blood urea nitrogen (43 mg/dL), creatinine (2.75 mg/dL) (47), and systolic blood pressure (115 mm Hg) to identify in-hospital mortality of 20% when all three criteria were met. Lee and colleagues identified clinical criteria to predict 1-year mortality of 1% to 10% for the lowest-risk patients with heart failure and mortality of 50% to 75% for the highest-risk patients (48). Clinicians must use the information to guide care and discussions with patients.

Hospice Criteria for Heart Failure

The National Hospice and Palliative Care Organization (NHPCO) published criteria for the determination of prognosis in the setting of heart failure and other noncancer diseases. Because these criteria were issued before some of the studies cited earlier, they lack some of the more specific prognostic markers that those investigators found. Nonetheless, they do provide a framework for prognostication for patients with heart failure. The criteria include "symptoms of recurrent heart failure at rest (including an ejection fraction of 20%)," "optimal treatment" with medications directed at heart failure, and certain comorbidities including documented arrhythmias, syncope, previous cardiac arrest, and coexisting cerebrovascular disease (49).

A study by Fox and colleagues, using data from the SUPPORT trial, underscored the need for better prognostic information and guidelines (50).

These authors tested the ability of three levels of criteria (broad, intermediate, and narrow) aimed at providing low, medium, and high thresholds for hospice eligibility based on NHPCO guidelines. Broad inclusion criteria identified the most patients eligible for hospice care, 70% of whom survived longer than 6 months. Intermediate inclusion criteria identified only one third as many patients, 65% of whom survived longer than 6 months. Narrow inclusion criteria identified only 19 patients for inclusion, 53% of whom survived longer than 6 months. These investigators concluded that recommended clinical prediction criteria from NHPCO are not effective in identifying a population with a survival prognosis of 6 months or less in seriously ill hospitalized patients with advanced COPD, heart failure, or end-stage liver disease. An analysis of SUPPORT data cited by Albert and colleagues demonstrated similar difficulties in our ability to prognosticate: among those with a predicted survival of 10% at 6 months, 38% were alive 6 months later (51).

DISEASE MANAGEMENT PROGRAMS

One investigator who studied physicians' views of palliative care and heart failure identified a disturbing, but perhaps not surprising, trend:

Care for patients dying with heart failure was described as uncoordinated, with patients going from hospital to community and back again. Repeated admissions to different consultant teams were common, and patients' medical notes were sometimes said to arrive on the wards after the patient had been discharged or died. A picture emerged of poor quality care for the patients and frustration for the doctors (5).

The further promotion of disease management programs for patients with heart failure and the integration of these programs with palliative care programs could possibly provide a solution. Although these programs have generally been distinct from hospice programs, they share certain care processes and goals of care with traditional hospice: they usually consist of an interdisciplinary team that proactively manages patients at home with the goals of improved coordination and continuity of care and prevention of inappropriate hospitalization or emergency department use. These programs generally consist of phone calls or electronic contact with patients on at least a weekly basis to inquire about symptoms such as dyspnea or chest pain and signs such as weight gain or edema and to adjust medications (principally diuretics) and physicians' visits accordingly. Some of these programs have shown mortality benefits as well as reductions in hospitalizations and costs for patients (52–55). As palliative care and hospice continue to integrate the care of patients with heart failure, it will be crucial to take advantage of the both the infrastructure and the management techniques of these programs.

PEARLS

- Optimal treatment for patients with heart failure who are receiving palliative care includes standard medications for heart failure directed at the

underlying disease (e.g., ACE inhibitors and β-blockers) as well as medications primarily for symptoms (e.g., opioids or sedatives)
- Patients and families need frank and direct discussions of likely symptoms and prognosis at multiple points in time along the trajectory of heart failure.
- Patients' weight can be a sensitive marker of worsening heart failure and the need for adjustment of diuretic medications and can be followed by a home care or hospice service.
- Measurement of brain natriuretic peptide can help to distinguish between dyspnea caused by heart failure and that related to other conditions, such as pneumonia and COPD.

PITFALLS

- Assuming that, unlike cancer, heart failure is not a life-threatening illness
- Neglecting to discuss deactivation of AICDs in patients with these devices
- Ignoring basic heart failure care, such as ACE inhibitors and β-blockers, while providing medications directed at symptoms
- Assuming that all symptoms that patients experience are referable to their heart failure. Patients with heart failure frequently have multiple comorbid illnesses, and attention should be paid to other potential causes of symptoms such as pain and shortness of breath, especially when this knowledge may change treatment approaches.

SUMMARY

Part of the difficulty in transitioning patients with heart failure to palliative care or hospice is that the move is often considered only after the most aggressive treatments have been tried or proposed. This makes it a sudden shift in care and goals rather than a smooth transition for many patients and their families. It is likely that palliative care principles (symptom management, attention to goals for care, and support for patients and their families) will have the greatest impact on quality of life when they are introduced as early as possible in a patient's management. This will not mean abandoning traditional care and management of heart failure, but rather augmenting them.

In Jessup and Brozena's review of heart failure in the *New England Journal of Medicine*, the stepwise management model includes treatments such as inotropes, ventricular assist devices, and cardiac transplantation for patients with refractory symptoms. This is a helpful algorithm for physicians. Yet when these measures fail, the last step is hospice. By definition, this last step clearly includes aggressive means of symptom control and support for patients and their families. In this sequence of heart failure management, however, the most symptom-focused approach comes only after the most invasive, disease-modifying approaches. As an alternative, increasing numbers of practitioners in the cardiology community are now advocating for early integration of symptomatic care in the management of patients with heart failure, just as many in the palliative care community have advocated for the early integration of palliative principles from the time of diagnosis onward. Because many symptomatic therapies have disease-modifying aspects, this integration is all the more crucial.

This sentiment that palliative care is a dramatic, and perhaps unwelcome, alternative to cure, is not isolated to heart failure. Clinicians should not necessarily idealize palliative care as equivalent to a curative approach because, for most patients and families, it is not. Nor should clinicians underestimate its importance. Morgan and Murphy wrote of this sentiment in an editorial concerning the treatment of children with cancer: "In the United States, the need to fight the good fight is idealized and resistance to giving up is continued even in the face of overwhelming odds. The shift in the goal from achieving a cure to making the patient comfortable usually occurs only when all other options have been exhausted, perpetuating the myth that palliative care is second best" (56). For patients with heart failure, their families, and the health care team, it may be important to engage in this "fight," especially in the presence of expanding technologies and treatments with clear mortality benefits for heart failure. However, two clinical instincts need to accompany this fight: the integration of palliative care principles from the time of diagnosis onward and the recognition that a patient may be better served by refocusing the goals of such a battle from victory in the form of a "cure" to victory in the form of the best possible quality of life and support that medicine can offer.

Resources

The Heart Improvement Program: Supporative and palliative Care (UK). http://www.heart.nhs.uk/endoflifecare/

Palliative Care Heart Failure Education and Research Trails. http://www.pc-heart.org

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Kidney Failure

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CHAPTER OUTLINE

INTRODUCTION
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Pain Management
Other Symptom Management
CARE PLANNING
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INTRODUCTION

A textbook on palliative care would not be complete without a chapter on kidney disease. Palliative care is especially appropriate for patients with kidney disease who are undergoing dialysis because of their significantly shortened life expectancy, high symptom burden, and multiple comorbid illnesses. In addition, there is an increased need for advance care planning for these patients because of their dependence on life-sustaining treatment for their continued existence and because, for approximately 25% of these patients, death is preceded by a decision to stop dialysis. As in other populations, pain is undertreated in patients undergoing dialysis. Research suggests that 75% of patients undergoing dialysis have either untreated or undertreated pain. Treatment of pain in patients with kidney disease is more challenging because of the renal excretion of some opioid metabolites and the development of opioid neurotoxicity. For this reason, morphine is not recommended for the treatment of severe pain in patients with kidney disease. The nephrology community has developed a clinical practice guideline on dialysis decision making. The guideline endorses the process of shared decision making in reaching decisions about who should undergo dialysis. It recognizes that the burdens of dialysis may substantially outweigh the benefits in some patients. Almost all patients with end-stage renal disease (ESRD) who stop dialysis die within a month. Research

shows that only about half these patients are referred to hospice. This chapter describes the growing interest in the nephrology community of incorporating palliative care into the routine treatment of patients with chronic kidney disease who receive in dialysis units.

RELEVANCE OF PALLIATIVE CARE

There is an increasing recognition that skills in palliative and end-of-life care are required for physicians, nurses, and others who treat patients who have ESRD and who are undergoing dialysis. The principal reasons are as follows: First, patients with ESRD who are undergoing dialysis have a significantly shortened life expectancy; they live approximately one fourth as long as age-matched patients without kidney disease. For example, a 70-year-old white man starting dialysis has a life expectancy of 2.8 years, compared with 13.2 years for an age-matched white man in the general US population. The 5-year survival for incident patients undergoing dialysis is only 31%, and the 10-year survival is only 10% (1). Patients for whom palliative care is unquestionably considered appropriate (e.g., those with cancer and acquired immunodeficiency syndrome) have more than twice the survival rate of patients with ESRD. Approximately 23% of patients undergoing dialysis in the United States die each year. In the United States in 2002, more than 79,000 patients undergoing dialysis died. Approximately 20% of those patients died after the decision was made by the patient or family to stop dialysis. There is an average of 17 deaths per dialysis unit per year. Hence, the death of patients undergoing dialysis is not an uncommon occurrence for health care professionals who treat these patients.

Second, patients with ESRD have multiple comorbidities and consequently many symptoms. Forty-five percent of all new patients undergoing dialysis have diabetes mellitus. The prevalence of congestive heart failure and coronary artery diseases is also quite high. Cardiac disease accounts for 45% of all-cause mortality in patients undergoing dialysis. More than 80% of new patients undergoing dialysis have anemia at the start of dialysis. Peripheral vascular disease is also prevalent in 10% to 20% of new patients. With better care of cardiac disease, diabetes, hypertension, and cancer, patients are living long enough to develop kidney disease, and older patients with considerable comorbidities who previously would not have survived as long are now starting dialysis. Patients undergoing dialysis have been found to have a mean number of nine symptoms per patient; pain, fatigue, and itching are ranked as most severe by the highest number of patients.

Third, the dialysis population has been growing progressively older. In 2002, the median age for new patients starting dialysis in the United States was 65.1 years. The incidence rates of ESRD are highest in patients 75 years old and older, and they continue to rise in this group. Older patients survive the shortest period of time on dialysis, and they withdraw from dialysis significantly more often than younger patients.

In consideration of the high symptom burden and the low survival rate for patients undergoing dialysis, leading nephrology organizations such as the American Society of Nephrology (ASN) and the Renal Physicians Association (RPA) have recommended that dialysis units incorporate palliative care into their

treatment of patients (2). Nephrologists have been encouraged to obtain education and skills in palliative care so that they are comfortable addressing end-of-life issues with their patients, and dialysis facilities have been urged to developed protocols, policies, and programs to ensure that palliative care is provided to their patients (3). Since 2004, the US Centers for Medicare and Medicaid Services (CMS) have been providing funding to ESRD networks to improve palliative care for patients undergoing dialysis. As part of this effort, dialysis units have been encouraged to develop a working relationship with local palliative care programs so patients with ESRD who stop dialysis or patients undergoing dialysis with a nonrenal terminal diagnosis may be referred for palliative care.

SYMPTOM MANAGEMENT

Pain Management

As in other patient populations, the burden of symptoms for patients undergoing dialysis is inversely associated with their reported quality of life (4). Pain is the most common symptom reported by patients undergoing dialysis, and several studies have found that approximately 50% of these patients report pain. For most patients undergoing dialysis, the pain is musculoskeletal in origin. Smaller numbers of patients have pain related to the dialysis procedure, peripheral neuropathy, peripheral vascular disease, or carpal tunnel syndrome. Less frequent causes of pain include that from polycystic kidney disease, malignant disease, or calciphylaxis (calcification of cutaneous blood vessels associated with skin necrosis). Two studies have found that pain is undertreated in 75% of patients undergoing dialysis (5, 6).

There has been one study of the outcomes of pain management in patients undergoing dialysis, using the World Health Organization (WHO) three-step analgesic ladder, which is evidence based and convenient to apply to the treatment of patients with chronic kidney disease and patients undergoing dialysis (6). This study and other clinical experience suggest that application of the WHO analgesic ladder results in effective pain relief for patients undergoing dialysis, and its use has been recommended to nephrologists treating patients with ESRD (7). Not all drugs in the WHO ladder are recommended for use in chronic kidney disease, however (Table II–4–1). Morphine should be used with caution, if at all, in patients with kidney disease because its metabolites are excreted renally, and its use has been associated with major opioid toxicity. Morphine is the best studied of these drugs, and its most common metabolites (including morphine-3-glucuronide, morphine-6-glucuronide, and normorphine) are excreted renally. The clearance of these metabolites therefore decreases in renal failure. Morphine-6-glucuronide is an active metabolite with analgesic properties and the potential to depress respiration. Morphine-6-glucuronide crosses the blood-brain barrier and may have prolonged central nervous system effects because, even though it may be removed by dialysis, it diffuses out of the central nervous system slowly. Morphine-3-glucuronide does not have analgesic activity, but it may cause neurotoxicity manifested by agitation, myoclonus, or confusion. Morphine is 35% protein bound, and it has intermediate water solubility. Studies suggest that morphine is dialyzable to a limited degree. Some clinicians recommend the use of morphine for patients undergoing dialysis but with a decreased dose or an increased dosing interval. A comprehensive review

Table II–4–1 ■ Recommendations for Opioid Use in Kidney Failure

Safe and Effective	Use with Caution	Do Not Use
Fentanyl Methadone	Hydromorphone Oxycodone	Codeine Meperidine Morphine Propoxyphene

Adapted from Dean M: Opioids in renal failure and dialysis patients. *J Pain Symptom Manage* 2004;28:497–504, with permission from the U.S. Cancer Pain Committee.

of the use of opioids in renal failure recommended that morphine not be used in patients with kidney disease because it is so difficult to manage the complicated adverse effects of the morphine metabolites (8).

Codeine is metabolized to codeine-6-glucuronide, norcodeine, morphine, morphine-3-glucuronide, morphine-6-glucuronide, and normorphine. Studies of codeine pharmacokinetics suggest that codeine metabolites would accumulate to toxic levels in a majority of patients undergoing hemodialysis. It is recommended that codeine not be used in patients with kidney failure because of the accumulation of active metabolites and because serious adverse effects have been reported from codeine use in patients with chronic kidney disease.

Hydromorphone is metabolized in the liver to hydromorphone-3-glucuronide as well as to dihydromorphine and dihydroisomorphine. Small quantities of additional metabolites are also formed. All metabolites are excreted renally. The hydromorphone-3-glucuronide metabolite does not have analgesic activity, but it is neuroexcitatory in rats. This metabolite also accumulates in patients with kidney disease. Some studies suggest that hydromorphone is removed with dialysis. It is recommended that hydromorphone be used cautiously in patients undergoing dialysis. The parent drug is probably removed by dialysis, but no data exist concerning the removal of the metabolites by dialysis.

On the WHO analgesic ladder, oxycodone is recommended for treatment of both moderate and severe pain. Use of oxycodone in patients with kidney disease has not been well studied. The elimination half-life of oxycodone is lengthened in patients undergoing dialysis, and excretion of metabolites is impaired. Almost all the oxycodone metabolites are inactive. There are anecdotal reports of opioid neurotoxicity when oxycodone was used in patients with kidney disease. Oxycodone has limited water solubility and 45% plasma protein binding, both of which suggest limited dialyzability. Oxycodone can be used with caution and careful monitoring in patients with chronic kidney disease who are undergoing dialysis.

The WHO analgesic ladder recommends the use of fentanyl for severe pain. Fentanyl is metabolized in the liver primarily to norfentanyl. There is no evidence that any fentanyl metabolites are active. Several studies have found that fentanyl can be used safely in patients with chronic kidney disease. Because 85% of fentanyl is protein bound and fentanyl has very low water solubility, it has negligible dialyzability. Fentanyl use is probably safe in patients with chronic kidney disease, at least in the short term.

The WHO analgesic ladder recommends methadone for severe pain. Twenty to 50% of methadone is excreted in the urine as methadone or as its metabolites, and

10% to 45% is excreted in the feces as a pyrrolidine metabolite. Studies in anuric patients have found that nearly all of methadone and its metabolites doses are excreted in the feces, mainly as metabolites. Methadone metabolites are inactive. Methadone is 89% bound to plasma proteins and has moderate water solubility. These two factors suggest that it is poorly removed by dialysis. No dose adjustments are recommended for patients undergoing dialysis. The use of methadone appears safe in patients with chronic kidney disease and those undergoing dialysis.

Opioids are often used to treat pain or dyspnea at the end of life in patients with chronic kidney disease or undergoing dialysis. In the setting of worsening renal function or withdrawal of dialysis, the clinician may be challenged to distinguish uremic encephalopathy from opioid neurotoxicity. Both can cause sedation, hallucinations, and myoclonus. If respiratory depression is also present, it is advisable to stop the opioid until the respiratory depression subsides. If the patient's respiratory rate is not compromised, the opioid can usually be continued, and a benzodiazepine such as lorazepam is added to control the myoclonus. Occasionally, a lorazepam continuous intravenous infusion at 1 or 2 mg/hour is necessary to control the myoclonus.

Nonsteroidal anti-inflammatory drugs are recommended for use in step 1 on the WHO analgesic ladder. They may also be used as adjuvant medications for patients with moderate to severe pain. The use of these drugs in patients with chronic kidney disease is contraindicated because of their nephrotoxicity, and their use in patients undergoing dialysis is risky because of the higher frequency of upper gastrointestinal bleeding in these patients. The use of these drugs may also cause loss of residual renal function.

Other Symptom Management

Because of their comorbid illnesses, patients undergoing dialysis are among the most symptomatic of any population with chronic disease. In one study (9) of 162 patients undergoing dialysis from three different dialysis units, the median number of symptoms reported by patients was 9.0. Pain, dyspnea, dry skin, and fatigue were each reported by more than 50% of the patients. Of the 30 different symptoms reported by the patients, the 6 most bothersome (starting with the worst first) were as follows: chest pain, bone or joint pain, difficulty becoming sexually aroused, trouble falling asleep, muscle cramps, and itching.

The greater the number of troublesome symptoms reported by patients undergoing dialysis, the lower they rate their quality of life. For this reason, it is very important for clinicians who treat these patients to assess and manage symptoms. Treatment of anemia with erythropoietin therapy in patients undergoing dialysis has led to a correction of the anemia with improved quality of life, decreased fatigue, increased exercise tolerance, and improved overall general well-being. It also has been shown to improve sexual desire and performance in some, but not all, patients undergoing dialysis. Pain from muscle cramps is a common symptom among these patients, especially if they undergo significant fluid removal during dialysis. Decreasing the volume of fluid removed during any given dialysis treatment may lessen cramps. For patients with chronic kidney disease who are not yet undergoing dialysis, decreasing the dose of diuretic often works to eliminate

cramps. Patients need to limit their intake of fluids and salt-containing fluids to avoid worsening of edema and fluid overload if diuretic doses are decreased. Benzodiazepines may be helpful.

Pruritus or itching is one of the most common and frustrating symptoms experienced by patients undergoing dialysis. Secondary hyperparathyroidism, increased calcium-phosphate deposition in the skin, dry skin, inadequate dialysis, anemia, iron deficiency, and low-grade hypersensitivity to products used in the dialysis procedure have all been identified as possible contributory factors. In addition to careful management of all these factors, the following interventions have been tried for pruritus with some success: emollient skin creams, phototherapy with ultraviolet B light three times weekly, intravenous lidocaine (100 mg) during dialysis for severe, refractory itching, and thalidomide (100 mg at bedtime; must not be used in pregnant women).

Insomnia is also reported by the majority of patients undergoing dialysis. In obese patients, sleep apnea should be excluded. The patient should also be evaluated for adequacy of dialysis. Avoidance of caffeinated beverages, alcoholic drinks, and naps have all been recommended. If these measures are not effective in improving insomnia, anxiolytic/hypnotics (e.g., zolpidem) or benzodiazepines (e.g., triazolam) are generally safe in patients undergoing dialysis (10).

CARE PLANNING

Advance Care Planning

Advance care planning is a process of communication among patients, families, health care providers, and other important individuals about the patient's preferred decision maker and appropriate future medical care if and when a patient is unable to make his or her own decisions. Advance care planning has been recognized as particularly important for patients undergoing dialysis for three reasons. First, more than half of all new patients undergoing dialysis are more than 65 years old, and elderly patients are the most likely to withdraw or be withdrawn from dialysis. Second, prior discussions of patients' wishes and completion of advance directives have been shown to help patients undergoing dialysis and their families approach death in a reconciled fashion. Third, unless a specific directive to withhold cardiopulmonary resuscitation (CPR) is obtained (which can be done within the framework of advance care planning), this treatment will automatically be provided, although it rarely leads to extended survival in these patients. For these reasons, clinicians have been encouraged to discuss with their patients the circumstances under which patients would want to discontinue dialysis and forgo CPR and to urge patients to communicate their wishes to their family verbally and through written advance directives.

The benefits of advance directives for patients and families and clinicians are twofold. First, families report that it is easier for them to make a decision to stop dialysis of a loved one if their loved one told them the health states under which he or she would not want to continue treatment. Second, patients undergoing dialysis who discuss and complete written advance directives are significantly more likely to have their wish to die at home respected.

Despite these benefits, the practice of advance care planning, including the completion of advance directives, has not been optimized for patients undergoing dialysis. First, most of these patients do not discuss or complete an advance directive, even though advance directives are particularly important for chronically ill patients with shortened life expectancy who are dependent on life-sustaining treatment for their daily existence. Dialysis units were not included in the US Patient Self-Determination Act list of health care providers who were required to ask patients about completion of advance directives and also provide them with an opportunity to execute an advance directive. Second, even when patients undergoing dialysis complete written advance directives, only one third have indicated to their family the circumstances under which they may want to stop dialysis (11). This failure to indicate their preferences is disappointing because patients undergoing dialysis do have strong preferences about stopping dialysis and other life-sustaining treatments under certain health states. For example, fewer than 20% of patients undergoing dialysis would want to continue dialysis, have CPR, or be maintained with tube feedings or a ventilator if they had severe dementia or were in a permanent coma (12). Recognizing these deficiencies, the ASN, the National Kidney Foundation, the RPA, and the Robert Wood Johnson Foundation's ESRD Workgroup on End-of-Life Care have all strongly encouraged dialysis units to provide advance care planning to patients undergoing dialysis and their families and in the process to include a discussion of health states under which patients would want to stop dialysis and other life-sustaining treatments.

Patients undergoing dialysis and their families should view advance care planning as a way to prepare for death, relieve burdens on loved ones, strengthen interpersonal relationships, and maintain control over present and future health care. Research with patients undergoing dialysis and families shows that patients prefer to center the advance care planning process within the patient-family relationship rather than the patient-physician relationship. Clinicians who treat patients undergoing dialysis should urge them to participate in an advance care planning discussion with their families and should instruct them to tell their families and put in writing health states in which they would not want life-sustaining treatment, including dialysis.

Cardiopulmonary Resuscitation

There is a low likelihood of benefit from CPR for most patients undergoing dialysis. One 8-year study of the outcomes of CPR in a dialysis population documented an 8% survival to discharge rate after CPR (13). Other studies have documented similarly poor results. Despite these findings, almost 9 out of 10 patients undergoing dialysis would want to undergo CPR if cardiac arrest were to occur during dialysis or at other times. Patients who have seen CPR on television are more likely to report that they know what it is and that they want it. Because patients undergoing dialysis have an overly optimistic assessment of the outcomes of CPR, clinicians need to educate patients and their families about the risks and benefits of CPR, based on the patient's condition, before asking patients about their preferences. Patients undergoing dialysis frequently have other comorbid conditions that would also indicate a poor outcome from CPR, even without factoring in the patient's ESRD. Patients undergoing dialysis who do not want CPR are significantly older, have more comorbid conditions, and are more likely to have a living will, be

widowed, and live in a nursing home. Black patients undergoing dialysis are six times more likely to want CPR than white patients receiving the same treatment (14). Ninety-two percent of patients undergoing dialysis who want CPR agree that patients who do not want CPR should have their wishes respected by the dialysis unit. Most important, health care professionals in dialysis units and others who care for patients undergoing dialysis need to educate them about the poor outcomes of CPR so these patients can make an informed decision about CPR.

DIALYSIS DECISION MAKING

For more than a decade, nephrologists have reported being increasingly asked to dialyze patients for whom they perceive dialysis to be of marginal benefit. At the end of the 1990s, the leadership of the RPA and the ASN assigned the highest priority for clinical practice guideline development to the topic of appropriateness of dialysis for patients. The subsequent guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, was published in 2000 and provides nine recommendations for the dialysis of patients with acute renal failure and ESRD (Table II–4–2). In the context of an expanding dialysis program with an increasing number of patients who have substantial comorbid conditions, the nephrology leadership believed that an evidence-based clinical practice guideline that could assist patients, families, and the nephrology team in making decisions about initiating, continuing, and stopping dialysis would be timely and quite beneficial. The guideline recommendations have been widely accepted and endorsed by 10 professional organizations. In addition, the guideline has been cited in numerous publications. It helps physicians and nurses answer the question, "Who should be dialyzed?" The guideline recommends that *shared decision making*—the process by which physicians and patients agree on a specific course of action based on a common understanding of the treatment goals and risks and benefits of the chosen course, compared with reasonable alternatives—should be used in making decisions about dialysis. In most cases, the shared decision-making process results in decisions that are individualized to the patient's particular circumstances and preferences. The guideline recognized, however, that limits to the shared decision-making process protect the rights of patients and the professional integrity of health care professionals. The patient has the right to refuse dialysis even if the renal care team disagrees with the decision and wants the patient to undergo dialysis. Similarly, the renal care team has the right to not offer dialysis when the expected benefits do not justify the risks. The guideline also recognizes that there are circumstances in which patients and renal care teams may disagree about decisions to start, continue, or stop dialysis; the guideline recommends process-based conflict resolution in these cases.

The process of shared decision making results in the physician's obtaining informed consent or refusal for dialysis. The treating physician first needs to assess whether the patient has decision-making capacity and is capable of giving informed consent or refusal. For patients with acute renal failure or ESRD, decision-making capacity may be diminished by uremic encephalopathy, infection, hypoxia, major depression, drug adverse effect, or some other disorder. If the patient lacks decision-making capacity, the physician must have discussions and

Table II–4–2 ■ Recommendations in the Clinical Practice Guideline: Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis

Recommendation No. 1: Shared Decision Making

A patient-physician relationship that promotes shared decision making is recommended for all patients with either ARF or ESRD. Participants in shared decision making should involve at a minimum the patient and the physician. If a patient lacks decision-making capacity, decisions should involve the legal agent. With the patient's consent, shared decision making may include family members or friends and other members of the renal care team.

Recommendation No. 2: Informed Consent or Refusal

Physicians should fully inform patients about their diagnosis, prognosis, and all treatment options, including: available dialysis modalities; not starting dialysis and continuing conservative management, which should include end-of-life care; a time-limited trial of dialysis; and stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary. The renal care team, in conjunction with the primary care physician, should ensure that the patient or legal agent understands the consequences of the decision.

Recommendation No. 3: Estimating Prognosis

To facilitate informed decisions about starting dialysis for either ARF or ESRD, discussions should occur with the patient or legal agent about life expectancy and quality of life. Depending on the circumstances (e.g., availability of nephrologists), a primary care physician or nephrologist who is familiar with prognostic data should conduct these discussions. These discussions should be documented and dated. All patients requiring dialysis should have their chances for survival estimated, with the realization that the ability to predict survival in the individual patient is difficult and imprecise. The estimates should be discussed with the patient or legal agent, patient's family, and among the medical team. For patients with ESRD, these discussions should occur as early as possible in the course of the patient's renal disease and continue as the renal disease progresses. For patients who experience major complications that may substantially reduce survival or quality of life, it is appropriate to discuss and/or reassess treatment goals, including consideration of withdrawing dialysis.

Recommendation No. 4: Conflict Resolution

A systematic approach for conflict resolution is recommended if there is disagreement regarding the benefits of dialysis between the patient or legal agent (and those supporting the patient's position) and a member of the renal care team. Conflicts may also occur within the renal care team or between the renal care team and other health care providers. This approach should review the shared decision-making process for the following potential sources of conflict: miscommunication or misunderstanding about prognosis, intrapersonal or interpersonal issues, or values. If dialysis is indicated on an emergency basis, it should be administered while pursuing conflict resolution, provided the patient or legal agent requests it.

Recommendation No. 5: Advance Directives

The renal care team should attempt to obtain written advance directives from all dialysis patients. These advance directives should be honored.

Recommendation No. 6: Withholding or Withdrawing Dialysis

It is appropriate to withhold or withdraw dialysis for patients with either ARF or ESRD in the following situations:

Patients with decision-making capacity who, being fully informed and making voluntary choices, refuse dialysis or request dialysis be discontinued

Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive

Patients who no longer possess decision-making capacity and whose properly appointed legal agents refuse dialysis or request that it be discontinued

Table continued on following page

Table II–4–2 ■ Recommendations in the Clinical Practice Guideline: Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis (Continued)

Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment

Recommendation No. 7: Special Patient Groups

It is reasonable to consider not initiating or withdrawing dialysis for patients with ARF or ESRD who have a terminal illness from a nonrenal cause or whose medical condition precludes the technical process of dialysis.

Recommendation No. 8: Time-Limited Trials

For patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis, nephrologists should consider offering a time-limited trial of dialysis.

Recommendation No. 9: Palliative Care

All patients who decide to forgo dialysis or for whom such a decision is made should be treated with continued palliative care. With the patient's consent, persons with expertise in such care, such as hospice health care professionals, should be involved in managing the medical, psychosocial, and spiritual aspects of end-of-life care for these patients. Patients should be offered the option of dying where they prefer, including at home with hospice care. Bereavement support should be offered to patients' families.

ARF, acute renal failure; ESRD, end-stage renal disease.

Adapted from Renal Physicians Association and American Society of Nephrology: Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Washington, DC: Renal Physicians Association, 2000.

obtain consent or refusal from the patient's legal agent (e.g., durable power of attorney for health care or health care surrogate, depending on state statutes).

The RPA/ASN guideline recommends that a discussion about starting or stopping dialysis should contain an estimate of prognosis, life expectancy, and likely quality of life. Although there is not yet a single mathematical formula to combine all risk factors to provide a numerical estimate of life expectancy, certain factors identified by multivariate analyses are significant predictors of mortality for patients with ESRD: older age, low serum albumin level, limited functional status, and number and severity of comorbid illnesses (usually measured by the Charlson Comorbidity Index or Index of Coexistence Diseases). The RPA/ASN guideline has a concise review of these most significant predictors.

Most nephrologists have encountered patients undergoing dialysis with poor predicted survival who have outlived life expectancy estimates. Thus, a complicating factor is clinical uncertainty. In fact, it is in situations of clinical uncertainty that patients introduce their own extramedical values (e.g., importance of living for an upcoming wedding of family member or a desire to not be a burden on family) to assist in the decision-making process; hence candor about the uncertainty of the prognosis may encourage shared decision-making (15).

Nephrologists have been urged to consider providing a time-limited trial of dialysis when the treating team and consultants cannot reach a consensus and also when dialysis is indicated but the prognosis is uncertain. The patient's clinical course during the time-limited trial may provide patients and families with a better understanding of dialysis and its benefits and burdens. The trial will also provide the treating team with a more informed assessment of the likelihood that the

benefits of dialysis will outweigh the burdens. Surveys of nephrologists have indicated that more than three fourths utilize time-limited trials of dialysis for this purpose and that dialysis is stopped after a trial in only 20% of cases.

Recommendation number 6 of the RPA/ASN guideline identifies patients for whom the consensus is that dialysis should be withheld or withdrawn. In addition to patients who previously indicated that they would not want dialysis or for whom such a decision is made by their appropriate legal agent, dialysis is also not appropriate for patients with irreversible neurological impairment so profound that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment. Patients who are permanently unconscious (e.g., those in a persistent vegetative state) or those who are comatose from a cerebral vascular accident fall into this category. In addition, recommendation number 7 identifies two additional groups of patients for whom it is reasonable to consider not providing dialysis. These are patients who have a terminal illness from a nonrenal cause such as cancer and those whose medical condition precludes the technical process of dialysis, such as patients with severe mental retardation or advanced dementia.

For patients for whom dialysis is being withheld or withdrawn, the RPA/ASN guideline recommends a palliative care approach in collaboration with health care professionals who have expertise in managing the medical, psychosocial, and spiritual aspects of end-of-life care. The RPA/ASN guideline recognizes the role of palliative care professionals.

For patients other than those identified in recommendations 6 and 7, there may be conflict about the appropriateness of dialysis. Some may use the argument of medical futility. Strictly speaking, in patients for whom it is possible to conduct dialysis (i.e., they have adequate blood pressure and access to the circulation to enable dialysis), dialysis is not futile because it improves blood chemistry and volume status. Recommendation number 4 of the RPA/ASN guideline recommends a systematic approach for conflict resolution when disagreement about the benefits of dialysis exists between the patient (or his or her legal agent) and members of the treating team. The fair process-based approach for conflict resolution recommended in the guideline was adapted from that proposed by the Council on Ethical and Judicial Affairs of the American Medical Association (16).

Nephrologists and others who treat patients undergoing dialysis may also be challenged by a patient's request to stop dialysis. To ensure that potentially reversible factors such as depression or family conflict are not responsible for the patient's request, the treating physician needs to consider certain questions before honoring the patient's request (Table II–4–3). After a systematic evaluation, if it is determined that the patient has capacity and is making an informed decision to stop dialysis, the patient's decision should be honored. Patients at high risk for withdrawing from dialysis have been identified from research studies; they are more likely to be older, diabetic, and divorced or widowed, to live in a nursing home, and to have a higher comorbidity index.

Once the decision has been made to stop dialysis, patients and families should be informed that death will probably occur in 8 to 12 days and will be caused by uremia resulting from a buildup of toxins and electrolyte disturbances. In 10% of cases, death may take up to 1 month to occur. The likelihood of a more prolonged dying course depends on the extent of the patient's residual renal function as reflected by daily urine output. Patients and families should be informed that death from uremia is usually a comfortable and peaceful one in which the patient

Table II–4–3 ■ Questions to Answer in Responding to a Patient's Request to Stop Dialysis

1. Does the patient have decision-making capacity, or is the patient's cognitive capacity diminished by major depression, encephalopathy, or other disorder?
2. Why does the patient want to stop dialysis?
3. Are the patient's perceptions about the technical or quality of life aspects of dialysis accurate?
4. Does the patient really mean what he or she says, or is the decision to stop dialysis made to get attention, help, or control?
5. Can any changes be made that could improve life on dialysis for the patient?
6. Would the patient be willing to continue dialysis while the factors responsible for the patient's request are being addressed?
7. Has the patient discussed his or her desire to stop dialysis with significant others such as family, close friends, or spiritual advisors? What do they think about the patient's request?

Table II–4–4 ■ Management of Patients Who Withdraw from Dialysis

Fluid overload	Salt and fluids restriction and/or use of ultrafiltration without diffusion to remove fluid
Pain	Methadone or fentanyl*
Nausea	Haloperidol, metoclopramide, or prochlorperazine
Dyspnea	Methadone or fentanyl*
Hiccups	Chlorpromazine or baclofen
Myoclonus	Clonazepam or lorazepam
Agitation/restlessness	Haloperidol or lorazepam
Excessive secretions ("death rattle")	Glycopyrrolate or scopolamine
Seizures (occur in only 10% of cases)	Diazepam or phenytoin

*Half-life is short, so use as a continuous infusion.

becomes increasingly somnolent and then dies. Patients who have decided to stop dialysis should be referred to a palliative care program, and the dialysis team should adopt a palliative care approach to patient care. It is important to determine where the patient would like to die and whom the patient would like to be with during the dying process. Medications and measures useful to treat the common symptoms and signs that result from dialysis withdrawal are listed in Table II–4–4.

Despite the recommendations of the ASN, the RPA, and the Robert Wood Johnson Foundation's ESRD Peer Workgroup on End-of-Life Care, hospice utilization by patients undergoing dialysis in the United States is very low. In a 2001 to 2002 cohort study of these patients, the United States Renal Data System reported that only 13.5% of patients undergoing dialysis died with hospice, about half the national average for the percentage of patients dying with hospice, and fewer than half (42%) of the patients who withdrew from dialysis and for whom death was expected within 1 month received hospice care. The low referral rate to hospice appears to result from at least two factors: physician practice patterns and a lack

Table II–4–5 ■ Components of a Dialysis Unit Palliative Care Program

1. Palliative care focus
   a. Educational activities including dialysis unit in-services
   b. Quality improvement activities, including morbidity and mortality conferences
   c. Use of the "Would you be surprised if this patient died within the next year?" question to identify patients appropriate for palliative care
   d. Collaboration with local palliative care programs to coordinate a smooth transition to end-of-life care
2. Pain and symptom assessment and management protocols
3. Systematized advance care planning
4. Psychosocial and spiritual support to patients and families, including the use of peer counselors
5. Terminal care protocols that include hospice referral
6. Bereavement programs for families that include memorial services

of knowledge about hospice on the part of patients undergoing dialysis and families. The latter may be the result of a widespread lack of understanding of the life-limited nature of ESRD and the failure of the multidisciplinary team members to talk to patients undergoing dialysis and their families about end-of-life issues. It also appears that many hospices may not want to accept such patients unless they discontinue dialysis. Medicare regulations allow patients undergoing dialysis to continue dialysis and receive the Medicare hospice benefit, provided the patient's terminal diagnosis for hospice is not related to kidney disease. The National Hospice and Palliative Care Organization in the United States is conducting programs to educate hospices that continuation of dialysis for patients in this situation is not a violation of the hospice philosophy, but instead affords terminally ill patients undergoing dialysis the opportunity to receive pain and symptom management, advance care planning, and support for themselves and their families during the final stages of their lives. The CMS are also committed to improving end-of-life care for patients undergoing dialysis. In October 2004, the CMS added a question about hospice utilization to the CMS-2746 ESRD Death Notification Form.

The Robert Wood Johnson Foundation's ESRD Peer Workgroup on End-of-Life Care recommended that dialysis units and large dialysis provider organizations establish palliative care programs in individual dialysis units. A comprehensive dialysis unit palliative care program has multiple components (Table II–4–5); it is easiest to introduce them incrementally. Palliative care consultants and hospice personnel can help dialysis units implement palliative care programs. Dialysis units and hospices working collaboratively can help to ensure quality end-of-life care for patients undergoing dialysis.

PEARLS

- The 5-year survival rate for patients undergoing dialysis is 33%, half that of patients with cancer (65%).
- Hospices are underutilized by patients undergoing dialysis. Only one in seven of these patients die with hospice compared with the national average of one in four.

- Even though patients who stop dialysis have 1 month or less to live, only 42% receive hospice services at the end of life.
- When a patient stops dialysis, it is highly likely that the patient will die within 8 to 12 days. Almost all patients undergoing dialysis who stop dialysis die within 1 month.
- Because they do not have active renally excreted metabolites, fentanyl and methadone are the safest drugs to use in patients with kidney disease.
- Collaboration with hospices can help dialysis units implement a palliative care program and appropriately refer patients for hospice care at the end of life.

PITFALLS

- Only one third of patients undergoing dialysis who complete a living will and a medical power of attorney indicate the circumstances under which they would want to stop dialysis. Studies show that patients undergoing dialysis are most comfortable indicating the health states (e.g., severe dementia or permanent coma) under which they would want to forgo dialysis, mechanical ventilation, CPR, and tube feeding.
- Advance directives are completed by fewer than 50% of patients undergoing dialysis. Dialysis units were not included on the list of health care providers in the Patient Self-Determination Act that were required to ask patients about advance directives.
- Almost 9 out of 10 patients undergoing dialysis indicate that they would want CPR even though CPR results in survival to discharge in fewer than 10% of patients undergoing dialysis. Patients who have seen CPR on television are significantly more likely to report that they know what it is and to indicate that they want it. Education of patients and families on the topic is needed.
- Dialysis is often requested by families of patients with a very poor prognosis. Significant predictors of early mortality for ESRD patients are age, serum albumin level, functional status, and comorbidity illnesses. A fair process-based approach for resolving conflicts with families over the provision of dialysis is described in the RPA/ASN Clinical Practice Guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis.*

SUMMARY

There is a growing commitment among nephrology leadership and the CMS to improve end-of-life care for patients undergoing dialysis. It is highly likely that palliative care for patients undergoing dialysis will be significantly improved over the next decade as nephrologists and palliative care consultants apply the knowledge and skills discussed in this chapter.

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Gastrointestinal Malignancies

5

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CHAPTER OUTLINE

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PANCREATIC CANCER
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INTRODUCTION

Gastrointestinal malignancies are among the most commonly diagnosed cancers in the world. They have significant geographic, ethnic, and socioeconomic differences in distribution, as well as diverse presentations. Symptoms vary widely and are often exacerbated by disease progression and tumor-directed therapy. Those caring for patients with gastrointestinal malignancies must be cognizant of the prevalence of debilitating symptoms and the effect on quality of life. This chapter provides an approach to palliative management of patients with various gastrointestinal cancers.

GASTRIC CANCER

Gastric cancer remains one of the most common forms of cancer worldwide, with approximately 870,000 new cases diagnosed and 650,000 deaths reported per year (1). In the United States, the incidence is approximately 9 cases/100,000 people. Higher incidences are seen in Eastern Europe, Asia, and portions of South America. Worldwide, the incidence of gastric cancer has decreased steadily. This is because of the recognition of causative agents including *Helicobacter pylori* infection and dietary risks. The incidence of distal esophagus, gastroesophageal junction, and gastric cardia adenocarcinomas is increasing. Because advanced disease

is often present in 50% of patients at the time of diagnosis, supportive symptom control is essential. Weight loss and abdominal pain are common presenting symptoms. Patients may present with symptoms such as nausea, abdominal pain, gastric outlet obstruction, perforation, early satiety, dysphagia, hiccups, or gastrointestinal bleeding. Palliative cancer treatments can be local or systemic, depending on the symptoms. Given the large numbers of patients who have unresectable disease at the time of diagnosis and the high risk of recurrence after surgery with curative intent, several treatment strategies are aimed at improving symptoms. These palliative treatments include surgical resection, surgical bypass, radiation therapy, chemotherapy, and endoscopic procedures. When determining treatment plans for advanced gastric cancer, it is important to remember that total or radical gastrectomy provides no survival benefit. Palliative subtotal gastrectomy, when feasible, can lead to significant symptomatic relief and prolongation of life. External-beam radiation therapy can be useful to manage pain, bleeding, or obstruction. Radiation doses of 40 Gy or more are often required for palliation of obstruction, with lower doses to control bleeding. Endoscopic laser treatment can effectively palliate dysphagia resulting from an obstructing tumor in 75% to 93% of patients (2). Endoscopic stent placements have become common procedures for the relief of gastric outlet and proximal small bowel obstructions. A series that analyzed 36 patients who underwent 52 endoscopic stent procedures demonstrated successful placement in 92% of patients and improvement in symptoms in 75%. Stent dysfunction, including stent migration, perforation, and biliary obstruction, occurred in 36% of patients and required subsequent endoscopic interventions (3). Endoscopic stent placement should be done at institutions with experienced personnel. The benefits versus the risks of the procedure should be considered.

Chemotherapy has been shown to improve symptoms and prolong survival somewhat. Typical regimens include combinations of 5-fluorouracil or consist of regimens which are platinum, taxane, or irinotecan based.

NEUROENDOCRINE TUMORS

Carcinoid tumors are the most common neuroendocrine tumors of the gastrointestinal tract. They are rare, however, and the incidence is calculated to be 1 per 100,000 people. The disease typically manifests in the fifth or sixth decade of life. Carcinoid tumors arise from enterochromaffin cells of the gastrointestinal tract and are comparatively less aggressive than the frequently encountered adenocarcinoma. The clinical characteristics of carcinoid tumors vary with the location of the tumor and the stage of disease. Approximately 50% to 95% of patients with neuroendocrine tumors will develop advanced disease with liver metastases. A 2003 study of 13,715 patients with carcinoid tumors reported that the highest percentage of metastatic disease found at diagnosis was with small intestine and colon carcinoid tumors (4). Carcinoid tumors of rectal, bronchopulmonary, or gastric origin were more likely to be localized. Symptoms of carcinoid tumors vary from asymptomatic to debilitating. Carcinoid syndrome is a collection of symptoms that results from secretion of excessive serotonin and other biologically active amines. The syndrome is often associated with flushing, diarrhea, abdominal cramping,

wheezing, pellagra, and heart disease as a result of carcinoid infiltration. Carcinoid syndrome is often present in the setting of advanced liver disease or bulky localized tumor. Carcinoid crisis results from a sudden, immense release of serotonin and other active amines. This often manifests as flushing, hypotension or hypertension, and bronchospasm.

The liver is the predominant site of metastatic disease. Resection of hepatic metastases can effectively palliate symptoms of amine excess and may result in long-term survival. Other approaches include the use of radiofrequency ablation and cryoablation, as well as chemoembolization either alone or in conjunction with surgical debulking.

Supportive management of patients with carcinoid tumors is essential in improving quality of life and in delaying the need for other toxic treatments. The use of somatostatin analogues (which have a low side effect profile) can decrease the secretion of excess hormone levels. Symptoms of flushing and diarrhea are relieved in 75% to 80% of patients treated with the initiation dose of 50 to 150 μg of octreotide subcutaneously three times a day. Side effects of octreotide are reported in one third of patients, often at the start of therapy, and include nausea, abdominal pain, bloating, and fat malabsorption. Long-term complications include development of cholesterol gallstones or gallbladder sludge, for which prophylactic treatment with ursodeoxycholic acid should be considered. Long-acting preparations of octreotide can be given once a month or every 10 days. A randomized, crossover study of lanreotide (20 mg intramuscularly every 10 days) versus octreotide (200 μg subcutaneously two or three times daily) in 33 patients demonstrated equal efficacy for symptom control (6). Patients with diarrhea who cannot tolerate octreotide can be treated with cyproheptadine, a serotonin antagonist. Antimotility agents such as loperamide and diphenoxylate can be used to treat diarrhea, in addition to opioid derivatives. Bronchospasm should be treated with β-adrenergic bronchodilators. Side effects such as flushing and palpitations are less common with the selective β_2-agonists terbutaline and albuterol. Pellagra (vitamin B deficiency) is rare complication that typically manifests late in the course of the disease and should be treated with low doses of niacin supplements.

Interferon-α can be used as tumor-directed therapy and has a response rate of stabilization in 20% to 40% of patients. In one series of 130 patients with metastatic carcinoid tumors, interferon therapy resulted in decreased urinary 5-hydroxyindolactic acid excretion in 42% and tumor regression in 15% (6). Dosing is limited by side effects, which may include flulike symptoms, fatigue, and depression. Chemotherapeutic agents such as fluorouracil, dacarbazine, streptozocin, cyclophosphamide, and doxorubicin have been used in different combinations but have limited response rates. Complications of toxicity far outweigh the benefits.

HEPATOCELLULAR CARCINOMA

Hepatocellular carcinoma ranks as the fifth most common solid tumor worldwide and is the fourth leading cause of cancer-related mortality. Most cases occur in developing countries, but over the last decade the incidence has increased in developed nations, including the United States. The main risk factor for the

development of hepatocellular carcinoma remains hepatocellular injury resulting from chronic liver disease or cirrhosis. Hepatocellular carcinoma is often diagnosed late in its course, thus making the tumor rarely operable. The median survival following diagnosis is approximately 6 to 20 months. Initial treatment is often limited by the extent of hepatic dysfunction. The current mainstay of therapy is surgical resection, but approximately 70% to 85% of patients are not surgical candidates at the time of presentation.

Several other treatment modalities are available. These include transplantation, radiofrequency ablation, percutaneous ethanol or acetic acid ablation, transarterial chemoembolization, cryoablation, radiation therapy, and systemic chemotherapy. Each one of these therapies has its own associated toxicity and complications. Patients with end-stage disease and heavily impaired liver function (Child-Pugh class C) or severe physical impairment (Eastern Cooperative Oncology Group performance status 3 to 4) at diagnosis should receive treatment aimed only at relieving symptoms. Systemic chemotherapy, octreotide, internal radiation with iodine-131, proton beam radiation, antiandrogens, interferon, and immunotherapy may have shown some antitumor activity, but they have not been shown to improve survival when compared with no treatment (7). Two therapies that have been extensively evaluated through prospective, randomized trials include transarterial embolization, with or without associated chemotherapy, and tamoxifen administration. A prospective study of 56 patients demonstrated a 74% survival rate at 12 months in patients who received embolism therapy versus 39.4% in control patients (8).

A retrospective study of 991 patients in a hospital-based hospice ward in Taiwan demonstrated that the most common symptoms at admission were pain, fatigue, weakness, anorexia or vomiting, peripheral edema, cachexia, and ascites (9). Additional symptoms often complicate the progression of disease. Obstructive jaundice can result from biliary tree invasion or intrahepatic duct compression. Endoscopically placed, expandable metal stents can provide minimally invasive, effective palliation of jaundice and obstructive symptoms. Bone pain and dyspnea are often seen secondary to metastases. Opioids, anti-inflammatory drugs, and corticosteroids can provide relief of pain associated with bone metastases. Oxygen, opiates, and anxiolytics can be beneficial for symptom control related to pulmonary metastases. A serious but infrequent complication associated with hepatocellular carcinoma is tumor rupture that can result in intraperitoneal bleeding and sudden death. Fever can develop as a result of central tumor necrosis and is treated with a combination of antipyretics and corticosteroids.

Pain often results from inflammation and stretching of the liver capsule. Opioids and adjuvant medication such as corticosteroids should be used to treat pain associated with hepatocellular carcinoma. Caution should be used with morphine administration. A study of 15 patients demonstrated a three- to fourfold increase in the peak concentration of morphine as a result of hepatic dysfunction and the reduction in first-pass metabolism within the liver (10). Management of ascites includes therapeutic paracentesis and placement of externally draining, implanted abdominal catheters in select patients. A study comparing ascites drainage by serial paracentesis or an implanted abdominal catheter was conducted with 107 patients (11). Results concluded that the catheter provided effective palliation with a complication rate similar to that for large-volume paracentesis and

also a diminished the need for frequent hospital visits for repeated percutaneous drainage.

PANCREATIC CANCER

Currently, pancreatic cancer is the 10th most common malignancy in the United States, but it is the fourth most common cause of all cancer deaths. Patients typically present with unresectable disease at the time of diagnosis. Patients with advanced pancreatic adenocarcinoma have a poor response, progression-free survival, and poor overall survival with standard treatment. The overall 5-year survival rate is 5%, thus making this disease a model example of the need for attentive palliative care discussion and treatment in oncology.

Because 70% to 85% of patients have tumors involving the pancreatic head, jaundice is a common presentation at the time of diagnosis. Biliary obstruction may occur later in the illness as a result of the growth of an unresected primary tumor. Ninety percent of patients have jaundice at some time during their illness. This is typically associated with malaise, pruritus, anorexia, and pain. A recent study looked at 243 patients with malignant biliary obstruction who underwent transhepatic placement of metallic stents or plastic tubes. It was determined to be a well-tolerated palliative procedure that is well tolerated by patients. After stenting, treatment for local tumor may prolong the duration of stent patency and the survival of patients (12). Pain is present in up to 85% of patients with locally advanced or metastatic pancreatic cancer. The typical pain is a dull ache located in the epigastric region that often radiates through to the back. It may be intermittent and may worsen with eating. Opioid therapy should be initiated and titrated to achieve adequate pain control. Percutaneous celiac plexus blockade, sometimes done intraoperatively, can be a beneficial adjunctive interventional technique in individuals whose pain is poorly controlled with standard analgesic medications. No controlled trials have been conducted in which conventional pain management is compared with neurolytic intervention. Complications are usually mild, but they rarely can result in a debilitating complication, including pneumothorax, paraplegia, and ischemic gangrene of the bowel.

Depression is a common symptom in patients with pancreatic cancer, and it can amplify pain and other symptoms, thus resulting in a poorer quality of life. A study of 139 patients admitted to the hospital with symptoms suggestive of either colon or pancreatic cancer determined that 76% of patients with pancreatic cancer had depressive symptoms before surgery, compared with 17% of patients with colon cancer (13). Weight loss and fatigue can be profound and may be associated with anorexia, early satiety, diarrhea, or steatorrhea.

Palliative chemotherapy for metastatic pancreatic cancer usually incorporates gemcitabine. The response rate of gemcitabine chemotherapy in phase II studies was 11% and 6.3%, with a median survival of 5.6 and 6.3 months, respectively (14). Phase III trials demonstrated that the combination of gemcitabine with erlotinib was associated with a further survival prolongation (15). Additional improvements in quality of life were observed beyond that suggested by the objective response rates in most studies of gemcitabine therapy in pancreatic cancer.

BOWEL OBSTRUCTION/GASTRIC OUTLET OBSTRUCTION

Intestinal obstruction involves a partial or complete blockage of the bowel. Abdominal symptoms such as distention, pain, cramping, vomiting, and constipation are common. These symptoms are often related to the tumor itself or to side effects of other therapeutic maneuvers, including adhesions and strictures after surgery, analgesic therapy, and chemotherapy. The obstruction can also be caused by ileus or pseudo-obstruction, in which no identifiable, mechanical origin is identified. The causes of paralytic ileus may include medications, intraperitoneal infection, mesenteric ischemia, or uremia. Bowel obstruction can be a primary or secondary complication of malignancy and may occur in the upper small bowel or large colon. It is essential to distinguish the location of the obstruction to determine a treatment strategy.

Gastroduodenal obstruction is primarily the result of gastric or pancreatic carcinoma. Approximately 20% of patients with newly diagnosed gastric cancer present with gastric outlet obstruction. Similarly, up to 20% of patients with pancreatic cancer develop gastric outlet obstruction. Traditionally, these patients have been managed with an open gastrojejunostomy. A novel and experimental alternative approach of performing laparoscopic gastrojejunostomy with the goal of palliation showed that the procedure was both safe and effective.

Patients who present with obstructive symptoms should undergo a careful history and physical examination. Common symptoms in patients with bowel obstruction include the following (16):

- Nausea and vomiting, present in 68% to 100% of patients, may be intermittent or continuous. Depending on the level of obstruction, the vomitus may be anything from undigested stomach contents to feculent material.
- Continuous pain, present in 92% of patients, may result from bowel distention, tumor mass, or hepatomegaly.
- Colicky pain, present in 72% to 76% of patients, is of variable intensity and localization and occurs only in mechanical obstruction.
- Abdominal distention is variable.
- Constipation may be intermittent or complete, with absence of flatus.
- Diarrhea, the result of bacterial liquefaction of fecal material blocked in the sigmoid or rectum, may occur initially.
- Other symptoms include dry mouth, acid reflux, bloating, hunger, anorexia, thirst, drowsiness, and dyspnea.

Common signs of malignant bowel obstruction include the following:

- On inspection, the patient may have abdominal distention, visible loops of distended bowel, or visible peristalsis.
- On palpation, there may be masses, organomegaly, ascites, or tenderness, including rebound tenderness.
- Abdominal distention varies. With extensive peritoneal spread, there may be little or no abdominal distention.
- Auscultation of the abdomen gives information about bowel sounds. Bowel sounds may be increased or decreased. Bowel sounds are absent in late obstruction, peritonitis, and functional bowel obstruction. There may be a succussion

splash when the stomach is filled with a large amount of fluid, as in gastric outlet obstruction.
- Rectal examination is an essential part of an assessment of a patient with suspected malignant bowel obstruction. There may be palpable masses, a rectal shelf, and impacted, rock-hard stool that indicates significant constipation or an empty rectal ampulla that may indicate colonic obstruction higher up or high-level constipation.
- Signs of dehydration such as dry membranes, decreased skin turgor, and a postural drop in blood pressure may be present.

Radiographic films should be conducted to evaluate the extent of the obstruction. The initial imaging study should be comprised of plain films of the abdomen and chest. A computed tomography (CT) scan should be done for patients with inconclusive plain films or a worsening abdominal examination, as well as also for preoperative candidates. CT scanning is reported to have good sensitivity for detection of a small bowel obstruction of more than 90% for complete or high-grade obstruction, and it discloses the causes of obstruction in 70% to 95% of cases. CT may also provide characteristic findings that indicate the presence of closed-loop obstruction and intestinal ischemia, which can lead to appropriate and timely management of these emergency cases.

Palliative management of bowel obstruction includes both surgical and less invasive options. Therapeutic selection is often decided based on patient and physician preference and anticipated life expectancy. Bowel obstruction remains one of the most common reasons for emergency abdominal surgery in patients with a history of malignancy. Available therapies include laparotomy, enteral intubation, bowel resection, ostomies, intravenous and subcutaneous hydration, parenteral nutrition, and pharmacologic agents.

Obstructed patients often present with anorexia, nausea, and vomiting, and, depending on the illness trajectory, they may require aggressive hydration. The optimal procedure for patients with gastroduodenal obstruction is surgical resection or a bypass procedure. This pertains to patients who are stabilized and who qualify as surgical candidates. Pharmacologic and other less invasive procedures are used for patients who are unable to undergo an invasive procedure. Most small bowel obstructions resolve within 3 to 5 days of presentation with supportive care measures such as intravenous hydration, medications, and nasogastric decompression. Bowel strangulation, perforation, and gangrene are rare complications. Patients with persistent symptoms should be considered for surgical therapy if the patient is a candidate for bowel resection. Patients with anatomic obstructions of the large intestine should be evaluated for surgical intervention (e.g., colostomies) and resection because conservative therapy is associated with a poorer outcome.

In a recent retrospective review, 114 patients with metastatic colorectal and gynecologic malignancies and bowel obstruction (17) were treated with either conservative or invasive methods. Mean survival was 3 months. There was no significant difference in overall or obstruction-free survival in the two groups of patients, and the only significant risk factor predicting poor outcome was the interval to obstruction. This trial emphasizes the need for patient-specific management. Patients who are hemodynamically stable and who are undergoing conservative

management of the diagnosed bowel obstruction should be monitored routinely with serial physical examinations and radiographic imaging as necessary.

The hallmark of medical management is a focus on symptom control in an effort to decrease abdominal pain, to diminish nausea and vomiting, and to attempt to restore bowel function. The combination of propulsive and antisecretory agents can act synergistically to allow fast recovery of bowel transit without inducing unpleasant colic. Opioids and antisecretory drugs such as octreotide and anticholinergic agents are used to manage abdominal cramping and may be administered intravenously, rectally, or subcutaneously. Nausea and vomiting can be controlled with the usual antiemetic drugs. Reduction of gastrointestinal secretions enhances treatment of bowel obstruction. Hyoscine butylbromide, scopolamine, glycopyrrolate, and octreotide have been used successfully to decrease secretions. In one study, treatment with scopolamine or octreotide led to the successful removal of nasogastric tubes in all 13 patients with terminal cancer (18). Although corticosteroids, particularly dexamethasone, are commonly used to reduce edema and inflammation in the area surrounding the obstructing tumor, there is no clear evidence of efficacy (19). Although oral hydration is contraindicated in bowel obstruction, intravenous and subcutaneous hydration can be used when indicated for symptom control and to alleviate thirst if the patient is not at the very end of life. A total of 1 L/day can be administered subcutaneously.

Patients who are not surgical candidates have options for less invasive procedures if pharmacologic measures do not alleviate the bowel obstruction. These include venting enterostomy or gastrostomy tube placement, laser therapy, and stenting. Placement of a venting gastrostomy tube in the presence of irremediable obstruction offers an alternative for long-term nasogastric suctioning and often provides relief of obstructive symptoms, thus allowing the patient to restart some oral intake. Laser therapy has been an effective palliative option for patients with left-sided colonic obstruction. Enteral stent placement has been reported to be an effective alternative for palliation of high-risk surgical patients with malignant gastric outlet and small bowel obstruction. Placement of metallic stenting is an option for both upper and lower left-sided colon obstructions.

COLON CANCER

Currently, colorectal cancer is the fourth leading cause of cancer and the second leading cause of cancer-related mortality in the United States. *The American Cancer Society estimated that approximately 148,600 people in the United States would be diagnosed with colon cancer in 2006. Worldwide, there is an estimated incidence of more than 850,000 cases and 500,000 deaths* (20). Five-year survival depends on the stage of disease at presentation; patients with stage I, stage IIIA, and stage IV disease have a survival rate of 93%, 83%, and 8%, respectively (21). Most patients with colorectal have hematochezia or melena, abdominal pain, weight loss, tenesmus, and a change in bowel habits. Abdominal pain can be the result of a partial obstruction, peritoneal dissemination, or intestinal perforation that leads to generalized peritonitis. Tenesmus may be the result of a locally advanced lesion encroaching on the sciatic or obturator nerve, leading to a neuropathic pain syndrome.

Approximately 15% to 20% of patients have distant metastatic disease at the time of presentation. Symptoms that often herald advanced disease include abdominal pain, distention, early satiety, weight loss, and the presence of supraclavicular adenopathy.

Resection of the primary tumor, if possible, must be considered in all patients to prevent obstruction and other problems such as anemia, hemorrhage, and perforation. For patients in whom surgery is not an option or if the tumor is unresectable, metallic stents can be placed in the large colon. Late complications can occur, including stent migration, bleeding, and obstruction of the stent. Another alternative for patients is laser endoscopy.

Systemic chemotherapy has demonstrated an improvement in median, overall survival and progression-free survival compared with the best supportive care. Without intervention, patients with metastatic colon cancer have a life expectancy of 5 to 6 months. Median overall survival can exceed 20 months with a combination of agents over time including 5-flurouracil and leucovorin, oxaliplatin, irinotecan, bevacizumab, and cetuximab (22). In patients who undergo chemotherapy, attention must be aimed at controlling the potential toxicity related to chemotherapy. Results from a 2004 study comparing FOLFOX (5-fluorouracil, leucovorin, and oxaliplatin), IFL (irinotecan, 5-flurouracil, leucovorin), and IROX (irinotecan and oxaliplatin) demonstrated that the FOLFOX regimen was superior with regard to median time to progression response rate and median survival time. The regimen was also associated with a lower rate of toxicity, including severe nausea, diarrhea, and dehydration (23). Patients in whom fluorouracil therapy has failed may have improved outcomes with single-agent irinotecan (24). Despite the side effects of treatment, patients who have metastatic colorectal cancer, and in whom fluorouracil has failed, have a longer survival, fewer tumor-related symptoms, and a better quality of life when they are treated with irinotecan than with supportive care alone.

ESOPHAGEAL CANCER

Esophageal cancer remains the third most common gastrointestinal malignancy worldwide. The incidence is highest in areas of Asia, where new cases comprise more than 100 per 100,000 individuals. In comparison, esophageal cancer is uncommon in the United States, with an incidence of approximately 5 per 100,000 individuals. The mortality rate is increasing, however, among both male and female patients. Tobacco, ethanol consumption, and dietary patterns are risk factors in the development of esophageal cancer. Squamous cell carcinomas comprise the majority of esophageal cancers in the United States, followed by adenocarcinomas. This excludes distal esophagus and gastroesophageal junction malignancies, which have a rising incidence.

At diagnosis, nearly 50% of patients have advanced disease that extends beyond the primary tumor. Fewer than 60% of patients with locoregional cancer can undergo curative resection. Five-year survival following resection of primary esophageal tumor remains at 15% to 20%, and clinicians often tailor treatment goals to symptom management. Early stages of esophageal cancer are often asymptomatic. Tumor progression is often associated with the following symptoms:

dysphagia, odynophagia, hemoptysis, chronic cough, hoarseness, pain in the throat and chest, weight loss, and vomiting.

Dysphagia is the most frequent presenting symptom and remains difficult to treat throughout the patient's course. Treatment must be determined by individual's presentation and presenting symptoms. The goal of most treatments is to maintain oral food intake and to improve quality of life. Stent placement is the most widely used intervention for palliation of dysphagia from esophageal cancer (25). Laser therapy and brachytherapy offer alternative palliation options. Manual dilation may be used as temporary therapy or before laser therapy and brachytherapy. Stent placement often provides relief of dysphagia within days; however, the rate of complications, including retrosternal pain, hemorrhage, and recurrent dysphagia from stent migration and tumor overgrowth, remains high. Stent migration can occur in up to 20% of patients. Recent trials have looked into the use of covered, rather than uncovered, metal stents to reduce the occurrence of migration and tumor overgrowth. Stent migration and tumor overgrowth are treated with placement of a second stent. If stent placement is unsuccessful, the option of a percutaneous endoscopic gastrostomy tube to maintain caloric intake is available.

Laser therapy is best reserved for tumors that are relatively short (<6 cm), exophytic, and located in the midesophagus (26). Approximately 35% to 80% of patients report a significant improvement in dysphagia within days after the procedure. Multiple treatment sessions are common, to control symptoms. A randomized trial of 60 patients compared laser therapy, uncovered stent placement, and covered stent placement. The conclusions showed that stent placement was more effective for the palliation of malignant dysphagia when compared with laser therapy.

Use of single-treatment brachytherapy has emerged as palliative therapy for advanced esophageal cancer. Local control rates range from 25% to 35%, and median survival is approximately 5 months following the procedure (27). Complications include fistula formation, mild retrosternal pain, and radiation-induced esophagitis. A randomized trial of 209 patients with advanced esophageal cancer and dysphagia compared the use of brachytherapy and stent placement. Results showed that dysphagia improved more rapidly in patients who received stent placement. However, long-term control was better achieved in the group that received brachytherapy. Stent placement was also associated with higher complication rates and lower quality of life scores (28).

Patients with distant metastases and a good performance status are candidates for palliative chemotherapy. Squamous cell carcinoma and adenocarcinoma are relatively chemosensitive tumors (29). Common chemotherapeutic regimens are often cisplatin based and have response rates that range from 35% to 50%. There is no evidence of survival benefit from palliative chemotherapy, although some symptom benefit may occur.

The presence of an esophageal tumor and the designated treatment can often lead to the development of pain. Pain control may be achieved with the use of radiotherapy in combination with opioids. Patients need to be warned of the risk of hemorrhage. Surgery or radiotherapy and endoscopic therapy may be indicated in patients with brisk bleeding from the carcinoma. Feeding gastrostomy tubes are used with increasing frequency in patients with esophageal cancer. The benefits of such tubes relate to the provision of nutrition and fluids in patients who have continuing significant esophageal obstruction. However, as patients live longer,

the use of gastrostomy tubes may lead to the development of major problems with the tumor. Patients should be given the option of not having a gastrostomy tube. These patients can then be managed with the best supportive care. Supportive care, including palliative sedation, is also indicated for patients with uncontrollable hemorrhage. Parenteral, transmucosal, and transdermal opioids and benzodiazepines should be used to provide comfort.

PEARLS

- Gastrointestinal cancers are common and present considerable challenges in palliating the disease and the resulting symptoms.
- Hepatocellular carcinoma is often not resectable at the time of diagnosis and presents considerable symptom control problems.
- Small bowel obstruction may be treated successfully with medical management using analgesics and antisecretory drugs.
- Patients with unresectable esophageal cancer who are completely or almost completely obstructed should be given the option of not having a gastrostomy tube for feeding.

PITFALLS

- The failure to advance care plan with patients with advanced diseasse.

SUMMARY

Gastrointestinal malignancies are common in cancer care and in palliative care. Patients often present with symptoms such as pain and nausea and early symptom control efforts are called for. If surgical cure is not possible, these patients should be considered "palliative" from the beginning of their anticancer treatment so that holistic and comprehensive care to manage physical, psychological, social and spiritual needs can reduce unnecessary suffering.

Resources

National Cancer Institute: Available at http://www.cancer.gov
American Cancer Society: Available at http://www.cancer.org
Canadian Cancer Society: Available at http://www.cancer.ca
Colon Cancer Alliance: Available at http://www.ccalliance.org
CANCER*care*: Available at http://www.cancercare.org
World Health Organization: Available at http://www.who.int

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Neurodegenerative Diseases

6

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CHAPTER OUTLINE

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INTRODUCTION

Patients with neurodegenerative disorders deserve the best of palliative medicine: knowledge, communication skills, and interdisciplinary teamwork that are grounded in a sound ethical base and include timely discussions and decisions.

Amyotrophic lateral sclerosis (ALS) is the most common cause of neurologic death in adults and is also the most common degenerative motor neuron disorder in that age group. Although there are multiple neurodegenerative diseases with many subcategories, ALS is used as the prototype for this chapter. The prevalence of ALS is 6 to 8 per 100,000 people and there appears to be a slowly increasing incidence of 1.5 to 2 more per 100,000 each year (1). The peak age of incidence is 74 years, and the prevalence in male and female patients is about equal. The average life expectancy from the time of diagnosis is 3 years. Twenty percent of those affected may live 5 years, and an additional 10% may survive 10 years.

The care of someone with ALS may be a prototype for palliative medicine; it requires interdisciplinary care, excellent timely communications, and advance planning, and it is palliative from the time of diagnosis because there is no known cure. The need for an interdisciplinary team becomes evident as issues in multiple

domains of best practice care are addressed (2): disease management, physical symptoms, psychological symptoms, social issues, spiritual questions, practical needs, end of life and death management, and the grief process for both patient and surviving family. Excellent communication among team members is paramount as the process of care delivery evolves, including assessments, the sharing of information, decision making, and the planning and delivery of care.

AMYOTROPHIC LATERAL SCLEROSIS

ALS has been viewed as a disease of the motor neurons (3). ALS can manifest with different patterns and is categorized depending on the grouping of neurons involved. The motor neurons in the lower spinal cord control the muscles in the legs and feet. Motor neurons in the upper spinal cord control muscles in the arms and hands. Finally, motor neurons in the brainstem (bulbar) control speaking, chewing, and swallowing. With the death of motor neurons, muscles atrophy, and sclerosis is seen in the lateral tracts in the spinal column where the motor neurons reside.

Symptoms are vague at first, and, with hindsight, patients can often pinpoint the early evidence that was misinterpreted for months or years before a definitive diagnosis. Often, weakness of a leg or foot and tripping, muscle fasciculations, or spasms are the first indicators. Although the diagnosis may be suspected by a family physician, the definitive diagnosis is usually made by a neurologist. Electromyographic studies are used to define the loss of nerve-to-muscle communication. As the disease progresses, the main symptom is muscle weakness. The illness does not affect the senses, eye muscles, heart muscles, or the bladder or bowel, and, until recently, it was not believed to affect the mind. Some more recent evidence may indicate that the disease is not so simple. ALS has long been viewed as a pure motor neuron disease. It is now becoming evident that ALS is part of a central nervous system disorder (4). Some patients develop frontotemporal dementia (FTD) that features changes in personality and word-finding difficulty, as well as problems with executive function (the ability of a person to organize the world around them, prioritize, and build strategies), yet this condition is different from dementia because the memory is mostly unaffected in FTD (5).

GIVING THE NEWS

It is difficult for both patient and family to receive news of this diagnosis, and the patient often hears only the first part of the discussion. It is important to use good communication skills. In his six steps for giving bad news (6), Buckman outlines how to prepare for the meeting:

1. Provide a quiet and private environment, appear to be unhurried (sit down), have a support person present for the patient, and acknowledge that time will be required to process the information.
2. Determine what the patient knows (or suspects).
3. Define what the patient wants to know.

4. Share information using simple language, pause often, and avoid euphemisms, to promote a dialogue rather than delivering a monologue.
5. Respond to feelings.
6. Plan for follow-up.

If the patient and family have traveled some distance to see the specialist, a strategy should be put into place for future discussions to occur when the patient is ready and able to handle the information. The patient and family should be provided with information on knowledgeable providers near the patient's home (the patient's family physician should be alerted) and should be given information about the local ALS Society. Everyone will need support: the patient, the family, and friends. People have different needs for information and have different styles of learning. Some need a written word, some want Internet sites, and some want to have further discussions with professionals. The patient has the right to know *and* the right not to know any information at any time.

At present, there is no cure for this illness, but ongoing research may lead to new treatments, and opportunities to participate in research projects may arise. Some treatments are available that may slow the progression of the disease (7). The ALS Societies of Canada and the United States can provide helpful information to patients and family caregivers (3), and these organizations issue regular bulletins about clinical trials.

Because ALS is an illness that always results in death, the question arises when to have the end-of-life discussion. One program (8) suggests the following triggers for this discussion:

- The patient or family asks and wants to hear.
- There is evidence of severe psychological or spiritual distress.
- The patient has pain that requires the use of opioids.
- The patient has dysphagia (difficulty swallowing or eating).
- The patient has dyspnea (feeling of being short of breath) or symptoms of hypoventilation, or the vital capacity has dropped to less than 50%.
- The patient has lost function in two body regions (legs/arms/cranial nerves).

Many patients with ALS worry about choking to death or suffocating, and clear discussions focused on goals and options for care can often be very reassuring. Death is usually peaceful. A few patients may develop air hunger, but this can be managed with the use of medications. Discussions need to occur when certain critical decision points are approached, that is, when the patient is having difficulty speaking, having difficulty swallowing or eating, or feeling short of breath. There is no predictable order to the progression of the illness, and each patient may have a different pattern.

SYMPTOMS

Symptoms of ALS may be divided into those that are direct (a direct consequence of the muscle weakness) and those that are indirect. Direct symptoms include weakness, fasciculations, cramps, spasticity, dysarthria, dysphagia, sialorrhea (drooling), and dyspnea (awareness of shortness of breath). Indirect symptoms can include pain, constipation, nausea, sleep disturbances, and depression. If one

includes FTD, then irritability, personality change, and social withdrawal may also become symptoms. In addition, a syndrome of pathologic laughter or tears can occur.

Progressive Muscle Weakness

Progressive muscles weakness is the hallmark of the disease. Patients may first notice greater than normal fluctuations in their day-to-day stamina. Physical therapists and occupational therapists should be involved to assess safety issues and to employ active and passive exercises to prevent contractures and joint stiffness. Although patients may resist equipment (e.g., walkers, wheelchairs, mechanical lifts) because it is seen as a concrete symbol of the disease and its progression, they should be advised that "it is better to have it and not need it than to need it and not have it."

Early in the disease process, acetylcholinesterase inhibitors (pyridostigmine) may be helpful for short-term improvement in muscle strength (1). Although there is no indication for the long-term use of these drugs, these agents are sometimes prescribed on a short-term basis for special occasions such as graduations and special holidays.

Muscle Fasciculations and Cramping

Muscle fasciculations and cramping can be an early sign of the disease. Moderate spasticity can be useful when leg muscles are weak because a patient can stand on stiff legs better than on completely flaccid legs. Medications that may be useful for fasciculations, cramping, and muscle spasms are shown in Table II–6–1 (9).

Dysarthria

Dysarthria may occur if the cranial muscles to the tongue and mouth are involved. This difficulty forming words and being understood is extremely frustrating and may be a cause of social isolation for the patient. This symptom may necessitate spending extra time during visits and discussions with caregivers and health care professionals. Multiple tools are available to assist in communication (e.g., compu-

Table II–6–1 ■ Medications Used for Muscle Fasciculations and Cramping

Medication	Dose
Quinine sulfate	200 mg bid
Carbamazepine	200 mg bid; may be titrated upward
Vitamin E	400 IU daily
Phenytoin	100–300mg/day
Magnesium	5 mmol od–tid
Verapamil	120 mg od

From Oliver D, Borasio GD, Walsh D (eds): Palliative Care in Amyotrophic Lateral Sclerosis (Motor Neuron Disease). New York: Oxford University Press, 2000.

ters, electronic voice writers, picture pointers). The use of these tools requires knowledge about what aids are available, which ones are appropriate, and how and where to access them. Because it takes times to assess and access these aids, planning in advance is very important.

Dysphagia

Dysphagia that involves the tongue, cheek, or mouth may hinder nutrition, so an early change in the consistency of the patient's diet may be helpful. A speech therapist and dietitian should be involved to assess swallowing ability and diet. Recipe books written especially for persons with muscular weakness are available, and helpful material is available from the Muscular Dystrophy Association's Web site (10) and the ALS Society.

Swallowing becomes more difficult as the weakness progresses. A discussion about goals of care (including whether the patient may want a feeding tube) should occur if there is frequent choking, if eating a meal requires more than an hour, if there has been a 10% to 20% weight loss, or if the patient's vital capacity has slipped to 50%. It is important that these discussions take place at the patient's best time of day and in surroundings that encourage discussion. It is also important that the right people be present (team members, family members) and that ample time be allotted to review the situation and options. These decisions are best thought of as a process. A decision cannot always be reached during the initial discussion.

Feeding tubes are one option. Most often, a percutaneous tube is placed into the stomach (percutaneous endoscopic gastrostomy) or into the jejunum (percutaneous endoscopic jejunostomy). Nasogastric and nasojejunal tubes are less common because they pass through the nose and cause discomfort to the patient. It is important to insert the endoscopic feeding tube when the patient is still feeling "well" and not having difficulty with breathing. Dangerous complications can occur with this relatively simple procedure if the patient's vital capacity is less than 50%.

If the patient requests placement of a feeding tube, it is important to monitor respiratory function even if he or she continues to swallow safely. Consideration should be given to placing the feeding tube at a time when the patient's vital capacity remains at or higher than 50%. If the patient continues to swallow safely, the feeding tube may remain in situ and capped with maintenance flushing until it is needed for nutritional support.

The discussion about feeding tubes should include the medical indications, whether or not it would support the patient's goals of care, possible complications, and financial costs. Feeding will not change the progression of the ALS, it may or may not extend life, it may improve or maintain quality of life, and the feeding tube will not prevent aspiration. Aspiration may be common with overfeeding or feeding at night when the patient's head is down. It is ethically, morally, and legally acceptable for the patient to make an informed decision not to have a feeding tube if he or she is capable of making such a decision. If the feeding tube is chosen, gastroesophageal reflux is quite common because of weakness in the diaphragm and lower esophageal sphincter. Proton pump inhibitor and prokinetic medications may be indicated. If the patient who has chosen a feeding tube retains decision-making capacity, he or she can also choose to stop feedings at any time,

but it is emotionally much more difficult to stop treatments and feedings once they have been initiated.

Whether or not the feeding tube is used for nutrition, it may be used for medications as necessary. Some medications come in commercial oral solution or dispersible tablets. The health care provider should be aware of the amount of sorbitol present in oral solutions because too much sorbitol is a cause of diarrhea. If tablets are crushed, they should be fully dispersed and well flushed. Some medications may be prepared as suspensions by the pharmacy. Some injectable formulations can be used via the feeding tube. Some medications bind to the tubing, and other medications have different bioavailability between a tablet by mouth and a liquid. Medications should be given one at a time and flushed well, and they should never be mixed in with the feeding. A referenced guideline is available as an appendix on one palliative medicine Web site (11).

Control of Secretions

Control of secretions is a common problem as the disease involving the upper muscles progresses. Patients can suffer from drooling (sialorrhea) or secretions that are very thick, dry, and difficult to clear. Medications that may help to dry secretions are shown in Table II–6–2 (12).

If the anticholinergic effect is helpful but causes confusion, the dose can be lowered, or a switch can be made to hyoscine butylbromide (which does not cross the blood-brain barrier). Some centers may use botulinum toxin injections to decrease salivary function, and radiotherapy is occasionally administered. When secretions are very thick, some relief may be obtained by using physical therapy, hydration, drinking dark grape juice or papaya juice, saline inhalations (alone with a compressor or with the addition of *N*-acetylcysteine 20%, 3 to 5 mL every 4 hours or as needed).

Sense of Breathlessness (Dyspnea)

A sense of breathlessness (dyspnea) is often the final turning point of the illness. The decrease in vital capacity is often underestimated because of the decrease in

Table II–6–2 ■ Medications Used to Control Secretions

Amitriptyline	10–150 mg od po
Trihexyphenidyl	1–2 mg tid po slowly increasing to 5 mg tid
Clonidine	0.1 mg 0d–tid po
Hyoscine butylbromide	10–20 mg qid po/sq
Scopolamine transdermal	1 patch each 3 days
Atropine 1% eyedrops	1–3 drops po q4h prn
Benzotropine	0.5–2.0 mg po od-bid
Glycopyrrolate	0.1–0.2 mg po/sq tid

bid, twice daily; po, orally; prn, as needed; Sc, subcutaneously; tid, three times daily.

Modified from Oliver D, Borasio GD, Walsh D (eds): Palliative Care in Amyotrophic Lateral Sclerosis (Motor Neuron Disease). New York: Oxford University Press, 2000.

the patient's mobility. The vital capacity may be less than 60% of predicted value when the patient becomes aware of breathlessness at rest. One way to monitor respiratory function is to have the patient take a deep breath and to count slowly out loud while exhaling. Over time, the clinician, the patient, and the family can follow the decline in vital capacity as evidenced by the number reached when counting during the exhalation of one breath. As the number becomes lower, it may help to trigger important conversations.

Patients fear choking to death. Death caused by respiratory failure is common in ALS and can be peaceful. Advance planning is paramount because the patient with ALS may decompensate so quickly that there is little time to make choices. At this point of increasing dyspnea or increasing symptoms of hypercapnia, 40% of patients will deteriorate and die within 12 hours, although 18% may survive for 24 hours.

The warning signs of chronic respiratory insufficiency include the following:

- A sense of breathlessness (dyspnea)
- Signs of hypercapnia (retained carbon dioxide): morning headache, excessive drowsiness during the morning, and mood changes
- Change in sleep with apnea and nightmares
- Nervousness, tremors, anxiety, and increased sweating

When vital capacity is waning, critical decisions need to be made by the patient along with the caregivers, professionals, and family. It is useful to review the options available (e.g., noninvasive positive pressure ventilation and full ventilator support) and equally useful to evaluate the probable outcome without these options. Death by respiratory failure can be peaceful because the gradual hypercapnia can lead to somnolence. The death may seem "sudden" to caregivers and it may happen at night, when there is less respiratory drive and stimulation. On average, death from respiratory failure occurs 3 years from the time of diagnosis if life-prolonging interventions are not chosen.

If noninvasive positive pressure ventilation is chosen, the device is often worn at night and can help with the symptoms of hypercapnia. This option is intended to improve the quality of remaining life rather than to extend life. Ventilator support availability varies from region to region, even within the same country. The discussion should include whether such support is offered, whether it is available within hospital settings only, or whether a community-based program is available. It should be made clear during the discussion that a tracheostomy will be required for ventilator support. The discussion may also be an opportunity to determine whether the patient wants to continue ventilator support as the disease progresses. Guidelines exist to ensure that the patient does not suffer anxiety or shortness of breath (13) if ventilator support is discontinued. Prerequisites include secure venous access, appropriate medications, and the physical presence of the physician.

Certain interventions can help to modify the sense of breathlessness. Education and a calm environment are important to break the dyspnea-anxiety cycle. Cool air moving across the face has been shown to decrease the sense of breathlessness.

Systemic opioids are the most effective pharmacologic agents to ease the symptom of dyspnea (14–16). The choice of opioid should follow the same principles as for the selection of analgesia and includes the addition of a bowel routine to avoid constipation. Consideration may also be given to a prophylactic antiemetic.

The use of oxygen is generally not recommended because these patients are often hypercapnic and rely on their low oxygen as a breathing stimulation. If oxygen is chosen, the recommendation is that it be used on low flow (<2 L/minute) and only during the daytime.

Pain

Pain is also a symptom suffered in ALS. The pain is related to unphysiologic stress on joints and bones. The human body has a loss of protective musculature. Immobility leads to painful joints and possibly contractures. The involvement of physical therapists and occupational therapists to plan passive and active exercises, stretching, range-of-motion exercises, and seating and bed assessments is very important. Seating assessments will need to be repeated as the disease progresses and the patient's body changes.

General principles for assessment and treatment of pain must be followed and should begin with the question: "Why does this patient have this pain now?" Validated tools should be used to assess and monitor the pain. Pain is subjective; only the patient can tell us how much pain he or she is suffering. Depending on the assessment of the likely cause of the pain, treatment options can be chosen and may include exercise, massage, a change in mattress, and a seating assessment, as well as pharmacologic interventions. The use of medications (including opioids) for control of pain is not contraindicated, and, used properly, these agents will not cause respiratory depression. The need for opioids to control pain is a recognized trigger for the initiation of the end-of-life discussion. The selection of opioids follows the same guidelines as for malignant pain: short-acting agents, regular administration with breakthrough pain dosing, a bowel protocol to prevent constipation, and consideration of prophylactic antiemetics.

The emerging evidence of FTD that is recognized in some ALS syndromes may suggest the need for an early discussion about options of care and early delineation of a substitute decision maker. FTD is a disorder of personality change that manifests as loss of insight, decline in social conduct, emotional blunting, and indifference to others. There is evidence of changes in executive function and language, although memory seems to be unaffected. Confusion between true FTD and other consequences of ALS that could alter cognitive functioning (e.g., clinical depression, unresolved pain, hypoxemia, and hypercapnia) must be resolved. The actual prevalence of FTD is unknown, but some studies suggest that a mild dysexecutive syndrome (loss of the executive function such as the ability to organize, prioritize, and build strategies) is present in up to 35% of patients with ALS.

Recognition that FTD may be a part of ALS is important for three reasons:

1. The timing of difficult treatment decisions
2. The recognition that some behaviors demonstrated by the patient are part of this process can be helpful to the caregivers who may be struggling to cope with the patient's irritability, aggression, suspiciousness, or lack of compliance
3. Management and care implications

Patients with ALS and FTD may have more difficulty following medical advice and may need special safety precautions when eating (limiting solid foods, placing too much food in the mouth) and when walking (loss of judgment, poor decisions about when to walk, where to walk, whether and how to use the walker).

Table II–6–3 ■ Medications Used to Control Pathologic Laughing or Crying

Amitriptyline	10–150 mg od
Lithium carbonate	400–800 mg/day
L-Dopa	600–1000 mg/day

Modified from Oliver D, Borasio GD, Walsh D (eds): Palliative Care in Amyotrophic Lateral Sclerosis (Motor Neuron Disease). New York: Oxford University Press, 2000.

Some treatment options may include the following (5):

- Selective serotonin reuptake inhibitors to increase the serotonin neurotransmitter in the frontal lobes (and also help with clinical depression)
- Atypical antipsychotics to control behavior
- Discontinuing medications with anticholinergic side effects. If anticholinergic side effects are required to control secretions, consider using an agent such as hyoscine butylbromide that does not cross the blood-brain barrier. Anticholinergics have been shown to decrease blood flow to the frontal lobes.

Pathologic Laughing or Crying

Pathologic laughing or crying is also known as *pseudobulbar affect* or *emotional incontinence*. Patients have episodes of laughing or crying that are out of proportion to or incongruous with actual feelings of sadness or happiness. Patients can recognize these outbursts as inappropriate to their mood, yet they appear helpless to control them. Medications suggested for this problem are shown in Table II–6–3 (17).

Laryngospasm

This sudden closure of the vocal cords understandably can cause panic. However, laryngospasm resolves in a few seconds. The health care provider should try to recognize and remove the stimulus, which may be emotional, a strong smell, or hot or cold liquids.

Jaw Quivering

Jaw quivering or clenching of the teeth may occur in patients with bulbar involvement. This may be associated with a recognizable stimulus that can be eliminated. Some practitioners use benzodiazepines to calm this symptom (18).

PRACTICE WISDOMS

How do we create space for healing in "places that reek of impossibility" (19)? Every tragedy comes with a gift in hand, a possibility for healing. It is worth remembering that healing takes place one person at a time, that the sacred is

between people. Rainer Maria Rilke stated: "Love and death are the great gifts that are given to us. Mostly they are passed on unopened" (20). With courage and with gentle openness, we can be healers in places that reek of impossibility.

"We have hands to touch and to hold, eyes to absorb distress and convey our concern. We have a voice to acknowledge fear and sorrow. We have hearts committed to provide a holding environment that is safe and secure. We have silence to convey respect and awe for the predicament faced by the patient. We do it when we support an unsteady patient to their seat or the examination table. It takes seconds" (21).

There may be a need to explore the meaning of this life, this disease, this death. Health care providers will not have the answers; the answers must come from within the individual. Rather, the health care providers must be comfortable with the questions; we must wrestle with these questions ourselves.

It is of utmost importance to keep the team current; this is not a static condition. As the patient's disease progresses, the team must be prepared, and care plans need to evolve. The interdisciplinary team may need to change; persons on the team and their degree of involvement will change over time. In this way, the treatment team remains vital, by growing and changing in response to the needs of the patient and the family. Assessments will need to be repeated and updated. Agencies that provide care must be aware that repeated assessments will be required, and more time will be necessary as communication becomes more difficult. A dyspneic patient needs more time to speak, and a patient with dysarthria must repeat words to be understood. The use of picture boards or electronic voice writers to communicate also takes longer. However tempting, the health care provider should not finish sentences for the patient because this tends to impose our needs and beliefs and does not give the patient his or her due. The health care provider's body language may betray impatience. Clinical visits should be planned to coincide with the patient's best time of day and also at a time when the health care provider is the least rushed.

Special attention must be given to family and informal caregivers. Family relationships can be lost in the caregiving process. The steadily increasing burden of care on the informal caregivers requires adjustment by the formal caregiving team. This disease happens to an individual, yet the whole family is affected. Psychosocial supports (respite, financial help, support for children) are all very necessary.

Timely and tactful discussions with the appropriate participants are important to enable the patient and family to make decisions that are most appropriate for them. Although it may be difficult to bring up the end-of-life discussion, the health care provider should take note of the triggers for that discussion and should take the lead. This discussion is often a relief to the patient and family who have been aware of the "elephant in the room" but have been hesitant to raise the topic.

The health care provider should try to stay one step ahead by anticipating what issues will arise. Making these decisions is a process that requires time. To ensure that accidental interventions are not made in emergency situations, the health care provider should anticipate what decisions need to be made and should allow enough time during meetings for the patient and family to discuss options and goals of care.

Every decision is embedded in rich context. There are times when the right course of action may be difficult to discern, when there is more than one right choice, or when there is disagreement. Legal requirements and ethical princi-

ples must be considered. It is within this framework that discussions that lead to care decisions occur.

The right persons: Consider which persons the patient wants to include and which members of the multidisciplinary team should be present. Is a special mediator needed? Does the family wish to involve their spiritual leader?

The right place: The discussion room should encourage open conversation, should be subject to minimal interruptions, and should have sufficient seating.

The right time: The discussion must be timely with respect to the medical condition, and enough time must be allotted for the conversation. When planning this meeting, remember that communication with any of the often-used aids often takes longer. If the patient is hypercapnic on awakening, it may be necessary to schedule the discussion later in the day. The patient's capacity may fluctuate during 24 hours. Coming to decisions is a process, not an event, and the patient and family may not reach a decision at the first meeting. It is better to start these discussions early in the disease process so the patient, family, and caregivers have time to work through to a conclusion.

The right process: Outlined in the following subsections is a four-piece framework that may be useful in building ethical discussions with patients and families (22). Discussing the decision in question in each of the four areas helps to build a robust dialogue.

Medical Indication

Review the diagnosis, prognosis, current situation, and treatment options. Review the goals of care. What will the proposed treatment do? What will it not do? What are the probabilities? What are the risks, burdens, and potential benefits? For example, if the goal of care has been comfort care in the home at end of life, will a particular treatment help to meet this goal?

Patient Preference

Patient preference is the ethical principle of autonomy that is embedded in our legal framework. Informed consent, capability, competency, and the substitute decision maker are all elements of our legal system. The role of the substitute decision maker is to use all available information and to consider the patient's goals and values, to come to a decision that the patient would have wanted.

We need to be sensitive to cultures in which interdependence rather than independence is the social norm. Independence is the North American norm. Some family systems may rely on elders, priests, and heads of household in decision making.

Quality of Life

Only the patient can make a judgment about his or her quality of life; physicians notably judge a patient's quality of life to be lower than the patient does. Quality of life is subjective, and we need to be aware of our prejudices (-isms: ageism, classism, sexism). Some patients view intravenous access and subcutaneous

injections as a detriment to the quality of life and feel that the burden of such interventions outweighs the benefits; others readily accept such interventions.

Contextual Features

Every decision is made in a context: social, psychological, physical, ethical, religious, financial. While discussing treatment options, the health care provider should explain what each option entails, such as the necessity of transfer to hospital for the first dose of antibiotic intravenously, hospital admission for ventilation, or a lack of resources that makes the goal of staying at home impossible.

If clear decisions have been made, the care plan should reflect this, and appropriate documentation should be readily available in case the patient is in crisis and is transferred by the ambulance to an emergency room. The health care provider should be aware of jurisdictional requirements for a "no resuscitation" decision to be honored if that is what the patient and family have chosen and have documentation ready. A competent patient can change his or her mind at any time. Furthermore, competent medical care can be directed to ameliorate symptoms to meet the goals of care even when a cure is not possible and or when resuscitation is not requested. Providing the patient and family with options and giving them time to come to a decision are ways to include them in the process and may give them some element of control as the disease progresses.

The health care provider should be familiar with the local resources and support groups, such as ALS chapters. The materials being developed are excellent resources for both informal and formal caregivers. Advice and support from those living with or who have lived with ALS are priceless.

PEARLS

- Contact the ALS society as soon as your patient receives the diagnosis. The ALS society has information, educational materials, practical help, and support for the patient and family and for professional caregivers.
- Contact the home care service early. Community support services such as home care, nursing, therapy services, and counselors will become involved, and early involvement helps to build the team.
- With your patient's permission, plan a family meeting with the patient, family, and identified support persons to review what they understand, what they want to know, what their hopes are, and what current needs are and to plan for regular assessments.
- With your patient's permission, plan a care conference with the care team, including (if possible) the community care case manager and possibly an educator or support person from the ALS society. This is the opportunity to start building the team and setting the care plan by using the domains of care identified by the Canadian Hospice and Palliative Care Association: disease management; physical symptoms; psychological, spiritual, practical, loss, and grief-related issues; and, if time, death management.
- Book regular assessments.
- Identify the team leader. When many professionals are involved, and sometimes many consulting physicians, it is important for the patient and family

to know who the team leader is. This is the person who can call a case review and a family meeting and who can add additional consultants.
- Talk about the critical decisions including end-of-life care sooner rather than later. Remember that these decisions are a process and may require time and more than one visit or discussion.
- Involve the right people in these discussions.
- Remember that when the patient is suffering from shortness of breath at rest, respiratory capacity is severely compromised.
- Plan ahead. When the patient is having difficulty swallowing, review the medications and plan alternate routes of medications that are necessary for continued comfort.
- Support the informal caregivers, family, and friends. Always inquire about their needs. Without them, the patient would not be able to remain at home.

PITFALLS

- Not using resources available to you. One person alone cannot provide the necessary care and support for the patient and family.
- Not ensuring that everyone is in agreement and that the care plan is clear.
- Not identifying a team leader. This can lead to confusion and increased anxiety for the patient, family, and team members.
- Not booking regular reassessments in an ever-changing illness. This can lead to crises and difficult decisions made in an emergency room by persons not familiar with the patient or family and the goals of care. It is more difficult to withdraw or to stop a treatment than not to start it.
- Not booking long enough time for the assessments. Communication will become more difficult and require more time. Do not feel rushed.
- Not recognizing the important triggers to the end-of-life discussions.
- Not reviewing what a treatment option can do, what it cannot do and, if it proceeds, when to stop it.
- Not taking the lead on initiating these difficult discussions. The patient and family will assume that the physician or nurse knows best. It is important to take the lead.
- Not recognizing the severity of the respiratory compromise when the patient develops dyspnea at rest.
- Not being prepared for sudden declines and changes. This can lead to emergency room visits.
- Not caring for the family as well as the patient. This can rapidly lead to burnout by family members.

SUMMARY

In summary, a patient with ALS deserves the very best of palliative medicine. The interdisciplinary team must stay vital and current and must communicate with each other as well as with the patient and family. With excellent communication, ethical decision making, and attention to details, the death may bring sadness, but it need not cause panic and regret.

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Principles of Palliative Surgery

7

Peter Angelos

CHAPTER OUTLINE

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INTRODUCTION

The old adage, "a chance to cut is a chance to cure" is often used to describe an important motivation for many surgeons. Such a statement clearly ties surgery to the possibility of cure. Yet much of surgical care is aimed not at cure but at palliation. In the following pages, I explore the concept of palliative surgery. I first consider how the curative model affects the goals of surgical intervention and how these goals are changed by a shift to a palliative model. Next, I explore the long tradition of palliative surgery in surgical history. Subsequent attention focuses on various definitions of palliative surgery. I consider the goals of palliative surgery in different disease settings. The important ethical issues surrounding operating on patients who have a "do not resuscitate" (DNR) order are considered, along with the importance of communicating well with patients and families in palliative surgical situations. Finally, I consider the challenges to conducting palliative surgical research.

PHILOSOPHY

Much of medical care is derived from the widely accepted curative model of disease. According to this model, the goal of medicine is to cure disease where "cure" is understood as, "the eradication of the cause of an illness or disease [or] the ... interruption and reversal of the natural history of the disorder" (1). This model is commonly assumed by many patients when they seek the assistance of a physician. Many physicians, in fact, believe that cure should be the primary goal of all medical or surgical interventions. As appealing as such an approach may seem initially, the curative model pushes physicians to focus on the disease rather than on the patient. The disease focus emphasizes analytic and rationalistic thinking that favors objective facts and empirical knowledge over subjective issues (2). Such an approach to medical care suggests that physicians have little to offer when cure is not possible. As such, the curative model provides an unacceptably narrow conception of medical and surgical care.

In contrast to the curative model, the palliative model focuses far more on the patient than on the disease or illness itself. The palliative model aims to control symptoms, relieve suffering, and reestablish functional capacity (3, 4). All these goals are directly related to how the patient experiences the illness. As such, the patient and his or her circle of family and immediate community become central to the palliative model of medicine, and subjective assessments by patients are of critical importance. Although the strict dichotomy between the curative model and the palliative model is somewhat artificial, these opposing approaches emphasize different aspects of the interaction between physician and patient.

Because it stresses the patient's experience of illness and disease, the palliative model provides a better conceptualization of the central tenets of the surgeon-patient relationship. Every surgical intervention is grounded in an analysis of the risks and benefits of the operation for the particular patient. There can be no meaningful general discussion of the risks and benefits of an operation with a patient. For such a discussion to be meaningful, the surgeon must help the patient to consider the individual risks and benefits of the particular operation for himself or herself. The analysis of risks and benefits of an operation are necessarily specific to a particular patient. In fact, one cannot really understand benefits without a particular patient to define what will be of benefit to him or to her. For these reasons, the palliative model is more closely associated with the relationship between surgeons and patients even though much of surgical thinking about intervention is still currently focused on cure.

HISTORY

Although many surgeons consider cure the logical goal of most operations, this development is recent. Before the last century and a half, illness and disease existed primarily as symptoms. There was no basis for conceptualizing a disease apart from the symptoms that it caused a patient. As such, surgery was firmly grounded on procedures that were thought to alleviate symptoms. Blood letting, cauterization, amputations, and extractions of bladder stones are all examples of common surgical

procedures from ages past (5, 6). None of these procedures are curative, yet at one time they were thought to help in the alleviation of symptoms.

Surgery frequently continues to be directed at palliation rather than at cure. In recent decades, the explosion of cardiac surgery to treat coronary artery disease is certainly palliative surgery (7). Patients with angina are operated on to diminish or eliminate the symptoms of coronary artery disease. Coronary artery bypass grafts are not justified as curative operations. This procedure does nothing to alter the disease process of atherosclerotic narrowing of the coronary vessels, and there is little or no effect on longevity, but quality of life is much improved. The status of peripheral vascular surgery is similar in that the operations seek to find alternate routes around blocked or narrowed arteries. These surgical procedures are designed to be palliative, but they are never curative.

In transplant surgery, for example, the replacement of a failed kidney with a new donor kidney does not cure the underlying cause of the renal failure. The new kidney may be seen as a cure for end-stage renal disease; however, the operation does nothing to alter the disease process that led to the renal failure. Other common examples of palliative surgical procedures are the increasingly frequently performed laparoscopic fundoplication procedures to treat gastroesophageal reflux disease and the common bariatric surgical procedures for morbidly obese patients. Both operations aim to improve problematic symptoms and quality of life, and perhaps to palliate, but not to cure the underlying cause of illness.

All these examples should emphasize the fact that although surgeons may tend to think of their procedures as leading to cure, most surgical procedures over the last several hundred years were, at best, palliative. The focus on curative surgery is a phenomenon of the last few decades, even though many procedures still have a strong element or sole goal of palliation. In fact, cancer surgery provides one of the few examples in which an operation may help lead to a cure of a disease.

DEFINITIONS

Palliative surgery is directed at alleviating symptoms rather than curing disease. However, the term *palliative surgery* is defined in various ways in the surgical literature. As Easson and colleagues suggested, palliative surgery in oncology has been defined in three distinct ways relative to the extent of resection possible:

1. Surgery to relieve symptoms, with knowledge in advance that all the tumor cannot be removed
2. Resection with microscopic or gross residual tumor left in situ at the end of the procedure
3. Resection for recurrent or persistent disease after primary treatment failure (8)

Despite this varied usage of the term palliative surgery, in what follows, I specifically define palliative surgery as focused on relief of suffering rather than on cure of disease.

An important feature of defining palliative surgery as aiming to relieve symptoms is that it has implications for how success and failure are defined. Based on this description, a failed curative operation will not necessarily become a palliative operation. Especially in the realm of cancer surgery, one must be careful to distinguish

an operation that has been designed and performed as a method of relieving the patient's symptoms from a noncurative resection. Some procedures are both curative and palliative, others are neither curative nor palliative, and yet others are palliative but not curative. For example, if a patient has obstructing colon cancer and carcinomatosis, resection could certainly be palliative even though it is not curative. However, if a patient has a localized low rectal carcinoma that is resected, but the margins are found to be positive, this procedure becomes part of a diagnostic process and possibly part of a treatment plan, but it is neither curative nor strictly palliative.

When considering whether to proceed with a palliative operation, the surgeon must carefully assess what symptoms the operation may be able to palliate. As with any surgical intervention, a careful assessment of risks and benefits to the patient must be undertaken. This consideration requires the surgeon to assess the patient's symptoms and then, with the patient's input, consider whether the symptoms can be alleviated by an operation. Patients are frequently more willing to accept higher risks of morbidity and mortality if the potential benefit is cure, but each individual case is different and requires that the surgeon and patient communicate about the risks and potential benefits of the procedure.

Patients must fully understand the goals of an operation before they consent to the procedure. If the goal is palliative resection of bleeding gastric carcinoma, the patient should not expect that curative resection will be the outcome. Sometimes if curative resection is not possible, a palliative operation will be performed. For example, in patients with obstructing jaundice from cancer of the head of the pancreas, most surgeons plan a palliative choledochojejunostomy if a potentially curative pancreaticoduodenectomy is not possible. In such a situation, it is important for the patient to understand the likelihood of a curative resection relative to the possible nonoperative means of alleviating symptoms.

It is also important for patients to understand the potential time frame for palliation. For example, it may be very significant for a patient to know that the alleviation of symptoms from an operation would be expected to last for a few weeks rather than for a few months. If a patient has a short life expectancy, then the benefits of a palliative procedure may be offset by the longer hospital stay. Similarly, the appeal to a patient of a palliative procedure may diminish if there is a high risk that the patient will not survive until discharge from the hospital.

These considerations should suggest that it is essential for surgeons to understand the patient's goals when any intervention is considered. To give recommendations about what procedure is best for a patient with a potentially incurable disease, the surgeon must first fully understand the patient's goals so the benefits of the procedure can be truly assessed. The success of a curative procedure may be defined by the pathologists relative to the extent of the disease, but a palliative procedure can be deemed a success only relative to the patient's goal for alleviation of symptoms.

GOALS OF PALLIATIVE SURGERY

In determining whether a palliative operation should be performed, the surgeon and patient should consider how the procedure will benefit the patient. Many

different procedures may be performed related to multiple different organ systems, yet the procedures can be broadly categorized as directed toward four general symptom-related goals: local control of disease, control of pain, control of other disturbing symptoms, and other goals related to the relief of suffering.

A mastectomy to remove a fungating breast carcinoma that is performed on a patient with distant metastases is an example of a palliative procedure directed solely at control of local disease symptoms. Although the operation will not cure the disease, it may alleviate major problems associated with the local extension of the tumor through the skin.

The well-proven benefits of celiac plexus block for unresectable pancreatic carcinoma illustrate how a palliative procedure can be directed specifically at alleviation of pain (9).

The broadest categories of palliative procedures are those directed at control or alleviation of disturbing symptoms other than pain. Procedures such as bypasses to relieve intestinal or vascular obstructions, tumor resections to control bleeding, and drainage of pleural effusions to alleviate dyspnea are all important palliative procedures that are specifically directed at alleviating diverse, specific symptoms (10).

Sometimes other goals are met by palliative procedures. For example, the placement of a feeding jejunostomy tube may allow parenteral nutrition that could facilitate a patient's discharge from the hospital.

PALLIATIVE SURGERY BY ALL SURGEONS

The most recent American College of Surgeons (ACS) Statement of Principles of Palliative Care (Box II–7–1) is an important document that seeks to define the manner in which palliative care is integral to the comprehensive care of all surgical patients (11).

All surgical textbooks contain descriptions of the techniques utilized for these numerous palliative procedures. However, it is critical for the surgeon to apply those techniques in a manner that best benefits individual patients. To do so, the surgeon must think broadly of the impact that the procedure will have on the patient's symptoms.

Because virtually any surgical intervention may be palliative for some patient, every surgeon must be fully competent in how to make decisions about palliative surgery. Unlike internal medicine, which has defined palliative care as a specialty, all surgeons must be able to apply the techniques of their particular anatomic area of expertise to the goal of palliation of patient's symptoms. Although surgeons should consult appropriate palliative care specialists to aid in the treatment of their patients, every surgeon should be prepared to apply surgical techniques to palliate symptoms. Indeed, part of the skill of surgery is to make intraoperative decisions to allow the greatest relief of patients' symptoms.

Cancer and Palliative Surgery

As noted earlier, palliative procedures are found in virtually every aspect of surgery. Much attention in surgical palliation is appropriately directed toward treating the terminally ill patient with cancer. This group of patients is particularly challenging to treat because of the inherent stresses suffered by patients, caregivers, and families

BOX II–7–1 *AMERICAN COLLEGE OF SURGEONS STATEMENT OF PRINCIPLES OF PALLIATIVE CARE*

Respect the dignity and autonomy of patients, patients' surrogates, and caregivers.
Honor the right of the competent patient or surrogate to choose among treatments, including those that may or may not prolong life.
Communicate effectively and empathetically with patients, their families, and caregivers.
Identify the primary goals of care from the patient's perspective, and address how the surgeon's care can achieve the patient's objectives.
Strive to alleviate pain and other burdensome physical and nonphysical symptoms.
Recognize, assess, discuss, and offer access to services for psychological, social, and spiritual issues.
Provide access to therapeutic support, encompassing the spectrum from life-prolonging treatments through hospice care, when they can realistically be expected to improve the quality of life as perceived by the patient.
Recognize the physician's responsibility to discourage treatments that are unlikely to achieve the patient's goals, and encourage patients and families to consider hospice care when the prognosis for survival is likely to be less than a half-year.
Arrange for continuity of care by the patient's primary or specialist physician, thus alleviating the sense of abandonment patients may feel when "curative" therapies are no longer useful.
Maintain a collegial and supportive attitude toward others entrusted with care of the patient.

Adapted from American College of Surgeons: Statement of principles of palliative care. Bull Am Coll Surg 2005;20:34–35.

when a patient is nearing the end of life. Although these stresses have always been present, the issues have become more problematic in recent decades for several reasons (12). First, physicians have more life-prolonging options to offer patients, although many of these options do not alleviate symptoms. Second, because social changes have increased the importance of shared decision making, physicians are required to become better at communicating with patients about the patient's values and interests, to determine what will benefit the patient. Finally, with the increasing mobility of modern society, few patients have long-standing relationships with their primary care physicians, let alone with their surgeons. As a result, surgeons must seek to understand the values and interests of their patients rapidly, to help them decide how best to palliate the disease processes.

In caring for patients with cancer near the end of their lives, physicians must be sure that patients and families are fully cognizant of the goals of specific interventions. Because so much care in the early phases of cancer is directed toward eradicating the disease, patients and families are sometimes hesitant to focus on interventions that can diminish symptoms. When a decision is made to pursue a palliative operation in a terminally ill patient with cancer, the patient and family may harbor unreasonable expectations that the intervention will not only alleviate symptoms but also extend life. Care must be taken to ensure that the patient, family members, and physicians all understand that the intervention is designed to improve symptoms. In such situations, informed consent requires a discussion of the various possibilities related to both curative and palliative goals.

Patient Selection for Surgical Palliation

In any situation in which the decision is made to proceed with a palliative operation, a careful assessment of the risks and benefits of the procedure must be undertaken. When the benefits of an operation are potential cure, the risks a patient is willing to take may be quite large. However, when the benefit is alleviation of some of the patient's symptoms, the risks must be careful compared with the proposed benefit. An assessment of whether there are any nonsurgical means to achieve palliation is necessary. When there are both surgical and nonsurgical means of alleviating symptoms, the nonsurgical approach should often be favored unless the nonsurgical option has further side effects. In some situations, the possible benefits of the palliative operation to the patient may be so very low that the surgeon will decide that the procedure should not be performed. One may come to such a conclusion when there is a small chance that the procedure will alleviate the patient's symptoms or when the patient is so critically ill that the operation itself would likely cause death. This situation is captured in the assessment that a patient is "too sick for surgery" (11). There is no sound ethical argument to operate on a patient who will certainly not survive the operation, and surgeons should not feel obligated to undertake such procedures.

SPECIAL TOPICS

Do Not Resuscitate Orders in the Operating Room

Because palliative surgery is frequently contemplated for patients with incurable diseases who are near the end of life, many of these patients have DNR orders. It is therefore important to consider what a DNR order really means and the impact it has on operative interventions.

DNR refers to a decision to withhold cardiopulmonary resuscitation (CPR) from a patient. When a patient has been suitably included in the decision to write a DNR order, it is a means of extending a patient's autonomous decision making so the patient can specifically opt out of the presumed consent for CPR in the hospital. Thus, DNR orders can be seen as grounded in the principle of respect for patient autonomy (13).

Although the writing of DNR orders seems to be increasing and they are widely accepted in hospitals (14), problems remain when a patient with a DNR order has surgery. DNR orders in the operating room and during the perioperative period are problematic for several reasons. First, there is a clear precedent for a patient's previous hospital orders to be seen as irrelevant in the specialized environment of the operating room. This assumption is seen in the common practice of writing a new complete set of orders after a patient leaves the operating room. Second, the relationship between "resuscitation" and providing general anesthesia is complex. Because general anesthesia frequently involves intubation, positive-pressure ventilation, paralysis, and fluid resuscitation, it often becomes difficult to determine where the administration of anesthesia ends and resuscitation begins (15). Third, pulmonary or vascular compromise in the operating room and during the perioperative period is more readily reversible than at any other place in the

hospital. As a result, it is very difficult for surgeons and anesthesiologists to start an operation that could precipitate a patient's death if they are forbidden to try to resuscitate the patient.

For the reasons noted, many hospitals have adopted policies that do not allow a patient to enter the operating room unless all DNR orders are rescinded. However, such an approach seems inappropriately to limit the autonomy of patients who may have very thoughtful and clear reasons for retaining their DNR order even in the operating room. Some have argued that patients should not be deprived of having their autonomous choices respected just because they need an operation. Furthermore, even if surgery with a DNR order is riskier than surgery without one, patients are allowed to choose riskier procedures or to reject beneficial ones (11).

How can this dilemma be settled? In 1991, Cohen and Cohen suggested an approach called "required reconsideration" that has subsequently been endorsed by the ACS and the American Society of Anesthesiologists (16). *Required reconsideration* is described as "an individualized policy of required reconsideration by which patients and their responsible caregivers would reexamine DNR orders before surgery whenever possible" (15). According to this approach, the involved physicians and the patient must agree on a definition of "resuscitation." Once this is agreement is reached, the parties must consider whether withholding resuscitation will compromise the patient's basic objectives. Finally, the positions taken must be clearly communicated so caregivers, patient, and family fully understand the plan for resuscitation in the operating room. This agreement should also be documented in the medical record.

Two hypothetical cases help to illustrate how required reconsideration can be valuable in considering requests for DNR orders in the operating room. Consider the case of a patient with advanced gastric lymphoma who is admitted with pneumonia. The patient requested a DNR order at the time of admission because she has no desire to receive further chemotherapy, and if her heart stops, she does not want CPR. Although she does not want CPR if cardiac arrest occurs in the operating room, she would possibly seek operative intervention if she were to develop a life-threatening gastrointestinal hemorrhage. Such a request is consistent with the patient's basic goals of care. If the parties agree, for example, that the DNR order should be restricted to actual cardiac arrest in the perioperative period, this could be documented in the chart, and the operation should proceed (11).

In contrast, consider a case in which an 80-year-old man with rectal carcinoma and extensive local disease is scheduled for a pelvic exenteration. This patient requests a DNR order be in effect before and during surgery and states that he hopes to die in his sleep while in the operating room. If the patient confides that he agrees to the operation and hopes that the surgery and anesthetic will kill him, then this is clearly a very different type of situation. Surgery should not be used as a pretext for desired passive euthanasia. When considering the issues of required reconsideration, a clear discrepancy can be detected between the goals of the operation as understood by the patient in contrast to the goals as understood by the anesthesiologist and surgeon. In this case, the surgeon and anesthesiologist would be justified in denying the patient's request for the DNR order in the perioperative period (11).

Advance Care Planning

When a patient has a palliative operation, it is important that the patient, family, and caregivers fully understand the goals of the intervention. In addition, when the discussion about the palliative operation occurs, the physician should also explore the patient's wishes regarding future decision making. In other words, if the patient is able to participate in the decision to have a palliative operation, the surgeon should take this opportunity to explore the patient's choices about what decisions he or she would prefer if he or she became unable to make autonomous choices. This attempt to identify advance directives may help to alleviate problems in the future. If these discussions are pursued while the patient is able to participate, the family may benefit greatly in the future should the patient be unable to participate in the decision-making process. Although it is sometimes difficult to discuss with a patient what he or she would want done if the palliative operation does not go well, it is certainly preferable to have those discussions with the patient rather than with surrogates who may not fully understand the patient's wishes.

Futility

Sometimes discussions about palliative surgery involve the question whether there is even a role for surgery when the likelihood for success is very low. In some circumstances, these discussions revolve around the concept of futility. The argument often proceeds as follows: "Physicians need not provide futile care. Any intervention that is an exercise in futility should not be provided even if the patient wants it" (11). The flaw in this line of thinking is the assumption that futility is an objective determination.

The attempt to make futility an objective concept was proposed by Schneiderman and colleagues. These authors defined a treatment as futile if empirical data showed the treatment to have a less than 1 in 100 chance of success (17, 18). According to this definition, if an operation has a less than 1 in 100 chance of providing palliation, a surgeon would not be obligated to perform such a palliative operation. As appealing as it may initially be to make such decisions into empirical facts, there are problems with the attempt to make such decision making dependent on empirical data. First, do we really need to see that something does not work 100 times in a row to conclude that it will not work the next time? Such an assumption seems to ignore how physicians use clinical judgment to make decisions. Second, and more important, to determine whether an operation will benefit a patient, the physician must consider the patient's values. Benefit cannot be defined theoretically, but rather relative to a particular patient with specific goals. As Truog and colleagues suggested: "It is meaningless to say that an intervention is futile; one must always ask, 'Futile in relation to what?'" (19). Thus, rather than trying to define an operation as futile, one should attempt to determine whether it will lead to realistically possible benefits that are sought by the patient. In other words, surgeons must use the concept of a risk-to-benefit analysis for a specific patient in which the patient's values define what will be of benefit to him or her.

MANAGING THE SUFFERING OF SURGERY

Surgeons should be cognizant of the significant suffering associated with any surgical intervention, whether curative or palliative. However, for the reasons noted in this section, many patients are at greater risk for potential suffering when they face a palliative, rather than a curative, operation. The suffering that patients endure with surgery can be broadly categorized as mental, physical, social, and existential. Mental suffering may be preoperative (e.g., anxiety about the procedure and what to expect) or postoperative (e.g., postoperative confusion or delirium from narcotic pain medication). Mental suffering is perhaps best addressed preoperatively by the surgeon's careful descriptions of what to expect from the procedure. Postoperative mental suffering can best be addressed by a high degree of sensitivity to the anguish that such confusion can cause patients.

Care of physical suffering has seen the most dramatic improvements in recent decades. Surgeons should strive to reduce physical suffering through intraoperative choices, such as avoiding a nasogastric tube if it is not necessary or considering a gastrostomy tube if the nasogastric tube is likely to be needed for a long period. Whenever possible, postoperative pain medication should be given intravenously rather than intramuscularly. Allowing patients to administer their own analgesia with a patient-controlled analgesia device can also decrease physical suffering and the dependence on nurses to administer the medication.

Social suffering may be related to the disability of the postoperative period and the resulting role changes or financial hardships. Surgeons can help to alleviate these issues by preoperative discussions and preparation of patients regarding what to expect after surgery. In the postoperative period, a sensitivity to social suffering should lead surgeons to inquire about these issues with their patients and to consult appropriate support personnel as needed.

Existential suffering relates to the big questions patients may have regarding an operation, such as, "Will I die on the table?" Although the likelihood that a patient will have existential suffering is clearly dependent on the patient's overall medical condition and the operation being undertaken, most patients have some similar concerns even if they do not fully express them to their physicians. Surgeons can best alleviate such existential suffering by encouraging patients to be open about their concerns and to ask questions.

All the parameters noted here are often more serious in patients who undergo palliative surgical procedures. When facing a palliative operation, the patient may have heightened anxiety about the surgical procedure and may be more susceptible to postoperative confusion or delirium. Furthermore, with fewer reserves for physical recovery, many patients have the potential for greater physical suffering. Finally, if patients are near the end of life, social and existential concerns may be further heightened. Surgeons must be prepared to address these issues when palliative surgery is being considered.

THE ROLE OF RESEARCH

Palliative surgery is quite different from a failed curative operation. Because the goals of a curative operation are so very different from the goals of most palliative procedures, the effectiveness of palliation must be studied specifically and sepa-

rately from studies of the optimal curative procedures. Thus, a clinical trial designed to determine which intervention leads to the highest cure rate would rarely shed light on the question of which intervention would be most likely to lead to optimal palliation of symptoms.

To determine which approaches provide the best palliation, surgeons must explore these questions with the same rigor that has been used to explore optimal curative resection strategies. Because the success of palliative surgery is relative to the patient's symptoms, data are much more subjective than those considered for curative trials. This situation leads to more complex end points that are frequently more difficult to assess. In addition, it is difficult to obtain funding for palliative clinical trials because the end points are not the usual ones of disease-free survival or longevity. Furthermore, because palliative surgery is commonly done near the end of life, a subject who has consented to participate in a research protocol may soon lose the capacity to give consent. These issues suggest the importance of developing and completing carefully designed palliative surgical trials. Surgeons will be able to determine the optimal palliative procedures for many diseases only after such trials have been completed.

PEARLS

- Much surgery is palliative; it is suitable for people near the end of life and for the chronically ill.
- Palliative surgery is a core part of the profession.
- Measure the quality of palliative surgery by the reduction in suffering.
- Impeccable perioperative symptom management is essential and should include all domains of suffering: physical, mental, social, and spiritual.

PITFALLS

- Measuring the quality of palliative surgery by technical aspects alone is too limited. Technical quality is necessary but not sufficient.
- Omitting discussions with the patient and family about goals of care is risky. They may accept interventions they do not really want or need.
- Barring all patients with a DNR order from surgery is problematic. Use the required reconsideration approach so the DNR order applies to, for example, cardiac arrest but not palliative surgery.
- Research that uses designs and outcome measures that fail to reflect palliative surgery goals will misguide practices. Select designs and outcome measures that take palliative care approaches into account.

SUMMARY

In the previous pages, I have explored many of the central issues of palliative surgery. I have sought to show the tradition of surgical palliation in the history of surgery and how surgical palliation can be so very important to a patient's well-being. Although surgeons have not always been at the forefront of the development of palliative care as an important component of comprehensive care, the

ACS has taken a leadership role in teaching surgeons the importance of palliative care in surgery. The most recent ACS Statement of Principles of Palliative Care (see Box II-7-1) is an important document that seeks to define the manner in which palliative care is integral to the comprehensive care of all surgical patients (11). Although much of the foregoing discussion has focused on the patient with cancer at the end of life, a review of the ACS Principles of Palliative Care will readily show that palliative care is essential throughout the course of a patient's illness. Surgeons need to be prepared to intervene to improve a patient's symptoms and to alleviate the suffering of patients in all stages of illness and disease. Surgeons must understand that appropriate preoperative discussions with patients and families, intraoperative decision making, and postoperative attention to patient needs can optimize the alleviation of suffering.

Resources

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Chronic Disease and Geriatrics

8

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CHAPTER OUTLINE

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DEMENTIA
Prognosis
Pharmacologic Management
Pain Assessment
Decision Making
Caregiving
URINARY INCONTINENCE
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SUMMARY

INTRODUCTION

This chapter focuses on the specialized knowledge needed to care for older patients with dementia. It also provides a discussion of the two common geriatric syndromes relevant to the palliative care of older patients: urinary incontinence (UI) and falls.

Adverse physical and psychological outcomes are associated with UI, including falls, urinary tract infection, pressure ulcers, social withdrawal, body image distortion, and depression. UI has also been noted to increase caregiver burden substantially, and it is an independent predictor of nursing home placement. A growing body of evidence shows that the burdens of serious illness clearly extend to families and friends.

Falls have a significant impact on quality of life. Not only do they cause injury and pain, but also they can cause significant fear, anxiety, and decreased function that can lead to decreased socialization. Identification of reversible causes of falls contributes to the key goal of preventing future falls and diminishes the associated fear and anxiety.

Restraints are a known risk factor not only for falls, but also for falls that cause serious injury in nursing homes and hospitals. Restraints are known to be a risk factor for UI, delirium, and psychological distress. The use of restraints in the palliative care population should be avoided, and alternative strategies, such as the employment of sitters and bed alarms, should be considered.

DEMENTIA

Dementia is a progressive, chronic, and incurable neurodegenerative disorder that results in much suffering and loss as patients develop impairments in memory, judgment, language, behavior, and function. Multiple types of dementia have been defined, but Alzheimer's is the most common type, followed by vascular dementia. The prevalence of dementia increases with age from roughly 1% in persons aged 60 to 65 years old to approximately 40% of those more than 85 years old. The current US population of patients with dementia is roughly 4 million and is projected to increase 10-fold, to approximately 40 million, in the next 40 years. Worldwide, the demented elderly population is projected to increase from 25 million in the year 2000 to 114 million in 2050. Patients with dementia are increasingly receiving hospice and palliative care for other life-limiting diagnoses. The palliative care specialist therefore needs to be proficient in providing care to patients with early stages of dementia, as well as to patients with advanced dementia who enroll in hospice care with a primary diagnosis of dementia.

Prognosis

The failure to recognize dementia as an incurable and progressive disease may result in inadequate end-of-life care, including delayed referral to hospice (1). However, it is challenging to determine prognosis in dementia. Prognosis guidelines focus on functional indicators for people with Alzheimer's disease. For example, the Functional Assessment Staging Scale (FAST) describes the progression of functional decline in demented patients in a series of seven stages. In a validation study of the FAST staging system, patients who reach stage 7 (language limited to several words and dependence in all activities of daily living [ADLs]) have a prognosis of less than 1 year. Based on the results of this study, the loss of the ability to ambulate (stage 7c) is particularly indicative of a prognosis of less than 1 year, and it is included as a criterion for hospice enrollment in guidelines for noncancer diagnoses from the National Hospice and Palliative Care Organization (2). A recent study describes additional criteria that may more accurately identify patients with dementia who have a prognosis of 6 months or less (3). These authors analyzed data from the Minimal Data Set, a federally mandated, standardized assessment that was collected on admission and quarterly for every nursing home resident. The research shows the following significant mortality risk factors for nursing home residents diagnosed with dementia: a decline in ADLs, a secondary diagnosis of cancer, congestive heart failure, dyspnea and oxygen requirement, aspiration, weight loss, and age greater than 83 years. A mortality risk index score based on these data was derived that stratifies patients into degrees of risk of 6-month mortality. This study also suggests that hypoactive delirium is a marker of poor prognosis in dementia. This was a study of patients who were recently admitted to a nursing home, so the results may not be applicable to a wider population. Similarly, in a review of the medical records of hospice-dwelling patients with dementia, chonwetter and colleagues found that age, anorexia, and the combination of nutritional and functional impairment were associated with shorter survival times (4).

As discussed earlier, it may be possible to identify characteristics that predict poorer prognosis in people with dementia. In addition, acute illness that requires

hospitalization may also be associated with poor prognosis. A study of demented patients who were admitted to the hospital with a diagnosis of hip fracture or pneumonia found that more than half the patients died within the 6-month post-discharge period.

Pharmacologic Management

In addition to providing information about diagnosis and prognosis, palliative care physicians may need to provide information about treatment options. In the early stages, families and patients often seek guidance regarding potential pharmacologic treatments for dementia. All acetylcholinesterase inhibitors are thought to have similar efficacy (5). Although a modest benefit was seen in about 30% to 40% of study subjects, the benefit to an individual patient may be difficult to recognize clinically. Therefore, families need to be counseled that, although these medications may slow the progression of the dementia and may result in minimal improvement in functional status, behavior, and memory, it is unlikely that they will significantly improve the patient's cognition. The side effect profile of the acetylcholinesterase inhibitors, including anorexia, nausea, and weight loss, may be particularly burdensome for older patients, who often have decreasing oral intake. There are very few data to describe efficacy in end-stage dementia. Memantine, an *N*-methyl-D-aspartate receptor antagonist, was approved by the US Food and Drug Administration in 2004 for the treatment of moderate to severe dementia. It was shown to decrease the rate of cognitive decline modestly in patients with moderate to severe dementia (by Mini Mental Status Exam) (3, 5). Some clinicians believe that combining memantine with an acetylcholinesterase inhibitor may benefit some patients. However, further research is required before this regimen is made standard practice. Vitamin E, at high doses of 1000 IU twice daily, was shown to delay the time to nursing home placement as well as the time to impairment in ADLs in patients diagnosed with Alzheimer's disease. However, more recent data suggest a possible trend toward an increase in overall mortality in patients who take high doses of vitamin E, and therefore the risks and benefits of this treatment need to be carefully weighed.

Determining the appropriate time to discontinue dementia-specific medications is a complicated decision. Medication cessation may result in a full spectrum of family response, from significant psychological distress to great relief. The data on efficacy of these medications in severe end-stage dementia are limited. There may be some benefit of these medications for behavior apart from cognition (5), so discontinuation may raise concerns of worsening behavioral problems. Moreover, one study suggests that stopping acetylcholinesterase inhibitors and then resuming usage at a future date may result in decreased responsiveness to the medication. Regardless, concerns about side effects, the considerable cost, and perceived prolongation of poor quality of life may lead clinicians to advise and families to decide to discontinue the therapy, particularly for patients near the end of life and for whom Alzheimer's dementia is the terminal diagnosis.

Psychiatric and behavioral problems are frequent in dementia. Palliative care providers who care for patients with dementia can play an important role by offering guidance about these problems to families and caregivers. Depression is common throughout the course of dementia, but it may be easier to recognize in the early stages when patients are better able to communicate and express some insight

into their experience. In later stages, behavioral problems such as visual and aural hallucinations, paranoia, agitation, and restlessness are common and occur in up to 80% of patients. Patients may also exhibit physical or verbal aggression and sexually inappropriate behaviors.

For acute changes in behavior, the first step should be to assess for potential delirium with a focused assessment to rule out a reversible medical condition such as fecal impaction or medication effect. After ruling out a reversible cause, the initial management should focus on nonpharmacologic modifications, especially decreasing external stimuli and encouraging family visits or the use of a sitter. Strategies to control behaviors include the creation of a safe, physical home environment, distraction and re-direction from sources of anxiety, the identification of non-stressful activities (i.e., day care, groups), and the use of calming, sensory experiences such as aromatherapy, soothing sounds, or touch (6). There are several well-referenced reviews on treatments for behavioral problems in dementia. However, few randomized, controlled trials have been conducted that substantiate efficacy (6).

Antipsychotic medications are the main agents used to treat dementia-associated agitation and behavioral problems. These antipsychotic drugs are generally divided into two groups based on side effect profile: typical (e.g., haloperidol) and atypical (e.g., risperidone).

The atypical antipsychotics also have a role in controlling agitated behavior. Several placebo-controlled studies have shown efficacy of the atypical antipsychotic medications risperidone and olanzapine in controlling aggressive behaviors and psychosis in patients with moderate to severe dementia, with virtually no extrapyramidal side effects or tardive dyskinesia. Head-to-head comparisons of haloperidol and risperidone show no difference in efficacy or side effects in the treatment of delirium. Sedation is a notable side effect for all antipsychotic medications, and the development of parkinsonism may limit their use. In addition, the Food and Drug Administration has issued a warning of a possible increased risk of stroke in older people who take any antipsychotic. Recent data also suggest that haloperidol and the atypical antipsychotics are both associated with increased mortality (7). The atypical antipsychotics (olanzapine in particular) may also predispose diabetic patients to hyperglycemia. Although important considerations, concern for these side effects may not be as relevant for patients close to the end of life or for those cases in which the primary goals are to decrease the severity of behavioral problems and caregiver burden. Given these potential adverse effects, however, it is important to review a patient's need for antipsychotics periodically and to consider discontinuing or decreasing the medications, if possible (6). This is of particular importance when caring for patients in nursing homes. Since the passage of the Omnibus Budget Reconciliation Act in 1987, physicians must document the indication for the use of all such psychotropic medications in the nursing home setting, as well as intermittent attempts to wean the dose. A systematic review of the pharmacologic treatment of neuropsychiatric symptoms of dementia suggests guidelines for the best therapeutic strategy (8). Second-line and third-line classes of drugs, including benzodiazepines and anticonvulsants, are discussed in this review.

Pain Assessment

Assessing symptoms can be challenging in patients who have difficulty verbalizing their needs. Clinicians must therefore pay close attention to nonverbal signs.

Several scales can be used to assess the nonverbal, behavioral signs of pain. One useful scale is the Checklist of Non-verbal Pain Behaviors, which includes six pain-related behaviors: vocalizations, grimacing, bracing, verbal complaints, restlessness, and rubbing (9). This scale was tested on 88 cognitively impaired and cognitively intact older adults who were hospitalized with hip fractures. No differences were identified in the pain-related behaviors of the cognitively impaired and intact patients and the pain-related behaviors correlated with verbal reports of pain. Another pain scale is the Hurley Hospice Approach Discomfort Scale, which evaluates nine behaviors such as tense body language and frightened expressions. This scale was originally tested longitudinally in 82 nursing home residents with advanced Alzheimer's disease. The traditional signs of facial grimacing were accurate for the presence of pain but not pain intensity. Physician assessment of pain has been found to be accurate in mildly to moderately demented patients, but less accurate in severely demented people. Data also suggest that caregivers tended to underestimate the severity of pain.

Many patients with dementia can express that they are experiencing pain, and most are able to complete a pain assessment instrument. Such instruments can be helpful in the initial evaluation of pain as well as in follow-up assessment. In addition to their own assessment, clinicians may need to use multiple assessment tools and caregiver input to assess pain.

Documented changes in behavior and delirium, whether more disruptive or withdrawn, should prompt a thorough pain assessment as part of the routine assessment for an acute medical illness or unmet needs (e.g., need for toileting or feeding). In these cases, analgesics should be used on a trial basis when history and physical findings suggest a cause of pain. The American Geriatric Society guidelines for the management of chronic pain in older persons endorse this strategy (10). Depending on the likely source of pain, a trial of opioids or nonsteroidal anti-inflammatory drugs may be beneficial. Such use of analgesics should be reassessed frequently to ensure that medications are not being used for sedative side effects in the absence of pain (9).

Decision Making

Palliative care physicians play an important role by addressing advance care planning and discussing goals of care with patients and families early in the disease course. For example, a randomized, controlled trial that involved palliative care consultations for patients with advanced dementia showed that the intervention group was significantly more likely to have a palliative care plan on discharge (23% versus 4%) and more likely to decide to forgo medical interventions (e.g., intravenous fluids) (11). In another study, proactive involvement of an inpatient palliative care service decreased intensive care unit length of stay for patients with dementia, reduced nonbeneficial interventions, and increased the identification of poor prognosis and "do not resuscitate" goals. Because the patient's cognitive status will eventually decline, it is of prime importance to assist with the timely discussion of advance directives and to facilitate completion of appropriate paperwork as early as possible. It is also consistent with the overall goal of honoring the patient's wishes.

Patient-centered care is a major goal of palliative medicine. The determination of a patient's ability to make decisions is fundamental to respecting his or her wishes. Certainly, at some point in the progression of dementia, a patient will no longer be able to make decisions. However, physicians should recognize that a person with dementia may still be able to make some decisions. Demented patients often still want to participate in their care. In one study, 92% of patients with mild to moderate dementia indicated that they wanted to be involved in treatment options, and most of their caregivers supported this decision. Much of the focus of research and effort in this area is on the capacity to consent to treatment. *Decision-making capacity* is defined as the clinical determination that a patient is able to understand the risks and benefits of a specific medical decision, to appreciate that these risks and benefits apply to their personal care, to reason the choice to be made, and to communicate that choice. Determining capacity is essential to determining who should make a treatment decision for the patient, and it affects the relation of the physician to family members.

People with dementia may still participate in decision making, even if they need assistance in that process. Using three assessment instruments, one study showed that most mildly to moderately demented patients had acceptable decision-making capacity based on the domains of understanding, appreciation, reasoning, and choice. Although mean performance for subjects was lower than that of controls on all the instruments, most subjects were still in the normal range for each domain. Capacity is specific to the level of decision making, and a patient may still retain the ability to make decisions at a simpler level (e.g., refusing a urinary catheter), even when he or she is not able to decide a more complex matter (e.g., neurosurgery).

The distinction between competency and decision-making capacity is important. Whereas *competency* is a legal term in which an individual retains their legal rights, *decision-making capacity* reflects a person's ability to demonstrate understanding of a central issue, the options, to appreciate the consequences, reasons, and to voice a decision about a specific situation at a specific point in time. Thus, a person may be competent (in that a judge has not appointed a conservator or guardian) but may not have reasonable decision-making capacity as determined by a licensed physician, psychiatrist, or psychologist. Impairment of capacity may be temporary, such as resulting from delirium or depression. In these situations, the stability of the decisions and their consistency with prior expressed wishes become key pieces of information. Loss of competency is relatively permanent, until a court gives the individual his or her rights back.

Caregiving

Those who care for demented patients at the end of life face considerable challenges. These challenges include management of the disturbing behavioral problems described earlier and the inability to stop the relentless and severe functional and cognitive impairments that worsen over time. Many caregivers provide care for their loved one for years and incur both personal and financial costs. A recently published study characterizes family caregiving for demented patients at the end of life. In this study, more than half of the caregivers spent 46 hours or more weekly assisting with ADLs and independent ADLs, and more than half reported that they provided care 24 hours a day. Another study reports that 75% of hours

spent caring for patients with dementia are provided by family caregivers. It is not surprising that caregivers of demented patients are at increased risk for medical and psychiatric disease, and possibly even death. In addition, many families of patients with dementia suffer significant financial losses, including the value of caregiving time, the caregiver's lost income, out-of-pocket expenditures for formal caregiving services, and caregivers' excess health costs (12).

A growing body of evidence describes the morbidity and mortality of caring for chronically ill, functionally impaired persons, including those who are not demented. The burdens of serious illness clearly extend to families and friends. A study that analyzed the effects of caregiving reported that 34% of patients who needed 24-hour care were cared for by the family, 20% of families experienced a major life change (e.g., a child did not go to college), and 12% reported a family illness that was attributable to the stress of caring for family member (13). Studies have found that caregivers have an increased risk of clinical depression and anxiety and decreased use of preventive health measures. Finally, troubling data suggest that caregivers with unmet needs are more likely to consider euthanasia and physician-assisted suicide.

URINARY INCONTINENCE

UI, the involuntary loss of urine, is a troubling and common concern for palliative care patients. Some aspects of UI are particularly relevant for elders. For other aspects and a fuller treatment of the subject, the reader is referred to Chapter I–11. Potential adverse, physical outcomes are associated with UI, such as falls, urinary tract infection, and pressure ulcers, as well as psychological consequences that can undermine a patient's quality of life and quality of dying. UI has also been noted to increase caregiver burden substantially, and it is an independent predictor of nursing home placement (14).

Acute onset of UI may be secondary to an easily reversible cause, and, although less likely, chronic UI may have a reversible component. Thus, a thorough medical and environmental evaluation of the patient is often warranted. If no clearly reversible cause is found, the decision whether to address UI further can be made based on the goals of care and the invasiveness of the proposed evaluation and treatment. In many cases, limited evaluation and no intervention will be desired. However, in some cases, even small interventions aimed at the specific type of UI may go far in improving an individual's quality of life.

Functional Incontinence

Functional UI is the loss of urine resulting from the inability of a patient to reach the toilet or coordinate the movements necessary to use the toilet. Given the frequency of functional decline in palliative care patients, particularly the loss of mobility, functional UI is likely the most common form of UI in this setting and should be high in the differential diagnosis. Patients with dementia also develop functional UI when they forget how to use the toilet or lose the ability to ambulate. Functional UI can often be ameliorated simply by providing appropriate assistive devices for impaired mobility or rearranging furniture. The provision of a bedside

commode or assistance with transfers may be all that is needed. Eliminating the use of restraints (chemical and physical), treating depression, and scheduling voids may also be effective strategies. Finally, patients can be advised to decrease the amount of fluid they consume in the evening, and diuretics can be stopped or administered early in the day to prevent nocturnal UI. Family members and caregivers should be advised that all patients with life-limiting disease, particularly those with dementia, will eventually develop functional UI as they decline. These patients are also at risk for fecal incontinence, and a similar management approach is recommended.

Other Forms of Incontinence

In addition to functional UI, geriatric palliative care patients may also experience urge, stress, or overflow UI. *Urge UI* is caused by irritability of the detrusor muscle or uninhibited bladder contractions. This may be associated with local irritation (e.g., atrophic vaginitis, tumor, or infection) or neurologic disorders such as dementia, stroke, and Parkinson's disease. Patients with urge UI report having an uncontrollable sensation or urge to urinate accompanied by the leakage of large volumes of urine. Classically, patients say they cannot get to the toilet quickly enough. Treatment of urge UI with behavioral modifications (e.g., bladder retraining) (15) may be challenging for many palliative care patients. Medications with anticholinergic (e.g., oxybutynin and tricyclic antidepressants) and smooth muscle relaxation (e.g., calcium channel blockers) effects can be utilized. However, elders may be particularly susceptible to the side effects of anticholinergic medications (delirium, dry mouth, and constipation), and the side effects may be particularly burdensome for palliative care patients. Thus, medication effects should be appropriately balanced to support the goals of care.

Stress UI results from a weakening of the pelvic floor muscles. Patients complain of leaking small amounts of urine in the setting of increased intra-abdominal pressure such as coughing or laughing. This is rarely a significant concern for the palliative care population. Some patients also benefit from treatment with local estrogen cream or an oral α-agonist (e.g., phenylpropanolamine), which although rarely used in general geriatric patients, has added benefits in palliative care, such as improving hypotension and increasing energy and alertness.

Overflow UI occurs when urine escapes from a full, distended bladder as a result of mechanical obstruction (e.g., prostate enlargement or stricture), atonia secondary to neurologic causes (e.g., spinal cord injury or autonomic neuropathies), or medications. Patients often report small amounts of continuous or frequent urine leakage, or they may be unaware of the episodes. In addition, patients may experience exceptional pain from the accompanying bladder distention and because this can be a stimulus for behavioral changes and delirium, it should always be considered in the category of reversible causes of agitation. Notably, urinary retention may be associated with opioid use.

Treatment focuses on relief of the obstruction. Options include medications that decrease bladder sphincter tone (e.g., α-blockers), surgery, intraurethral stent placement, and bladder catheterization. Intermittent catheterization may be a reasonable choice to avoid the risks of discomfort from urinary retention and infection from an indwelling urinary catheter for patients who are not at the end of life. Patients with dementia may have a difficult time understanding why they must

endure the burden of such a frequent, uncomfortable procedure. For many, an indwelling catheter may be the best option for ease of care and protecting skin from repeated moisture exposure (16).

FALLS

Falls have a significant impact on quality of life. Not only do they cause injury and pain, but also they can cause significant fear, anxiety, and decreased function, which can lead to decreased socialization. In the geriatric palliative care population, falls are generally a marker of overall decline. However, identification of reversible causes will contribute to the key goal of preventing future falls and diminishing the associated fear and anxiety.

Prevention

Although very limited information has been published about falls in palliative care settings, several well referenced, published guidelines may help to guide the evaluation and prevention of falls in seriously ill and dying patients (17, 18). Falls are likely common in palliative care patients because they frequently possess many identified risk factors for repeated falls, including polypharmacy (four or more medications prescribed), advanced age, a history of orthostatic hypotension, cognitive impairment, arthritis, balance and gait disturbance, and muscle weakness.

In general, geriatricians advocate a complete assessment of falls after a patient has had two or more falls or experiences persistent gait and balance difficulties. In a palliative care setting, however, this assessment should be weighed with the goals of care and the advanced state of the patient's illness.

If a patient is ambulatory and wishes to undergo evaluation for fall prevention, findings from a focused history and physical examination may reveal opportunities for simple, targeted interventions. First, a focused history can be completed to address the circumstances and frequency of falls, as well as to rule out falls associated with loss of consciousness. The physical examination should focus on abnormalities that can be ameliorated to aid in fall prevention. The examination includes measurements of orthostatic blood pressure and a musculoskeletal examination to document arthritic changes and joint motion limitations. The head and neck examination should include tests to uncover visual, balance, and hearing impairment that may be easily corrected with appropriate assistive devices. A focused neurologic examination may reveal reflex, mental status, gait, and proprioception abnormalities that require an assistive device or further workup with imaging and laboratory studies. One well-studied test for functional gait disturbance is the "Get Up and Go Test." To administer this test, the clinician asks the patient to rise from a chair, walk 3 m, turn around, and return back to a seated position while the clinician keeps time. A score of greater than 30 seconds indicates that the patient has impaired mobility and is at risk for falls. The extent of investigation should be consistent with the patient's goals of care.

A complete falls assessment should address specific risk factors. The patient's living environment should be examined for known hazards that contribute to falls, including throw rugs, poor lighting, unstable furniture and railings, and clutter. The bathroom is a particularly dangerous place for falls and therefore should be examined carefully for the need of a nonslip bath mat, shower seat, and rails. Studies

have shown that the modification of environmental hazards may significantly decrease the risk of falls, particularly after hospitalization. A referral to an occupational therapist for a home safety evaluation is often the best way to achieve this goal.

Deconditioning is another risk factor to consider. A referral to physical therapy may benefit some patients, although it may be inappropriate for patients near the end of life. Physical therapists may be able to focus on general conditioning and specific interventions to address gait and balance disturbances. For example, one study on the use of physical therapy in a hospice facility showed a 27% overall improvement in mobility. Forty-nine of the 301 patients improved their function to such an extent that they were able to go home. The Medicare Hospice Benefit includes physical therapy and occupational therapy treatment when it consistent with the patient's care plan. These suggestions have been well described elsewhere, but they are based on limited data, as well as expert opinion.

As patients progress in their illness, some may become agitated, and some caregivers may use restraints in an attempt to protect patients from hurting themselves. However, restraints are a known risk factor not only for falls, but also for falls that cause serious injury in the nursing home and in the hospital (19, 20). In addition, restraints are known to be a risk factor for UI, delirium, and psychological distress. Therefore, the use of restraints in the palliative care population should be avoided, and alternatives strategies, such as the employment of sitters and bed alarms, should be considered.

Polypharmacy is another well-documented risk factor for recurrent falls. Specific categories of medications have been shown to be associated with the highest risk of recurrent falls, including tricyclic antidepressants, neuroleptic agents, benzodiazepines, anticonvulsants, selective serotonin reuptake inhibitors, and class 1A antiarrhythmics. Thus, the patient's medication list should be reviewed, and all unnecessary medications should be tapered or stopped, particularly if they are likely contributing to the risk of falls.

PEARLS

- Antipsychotic medications are the main agents used to treat dementia-associated agitation and behavioral problems.
- Assessing pain and other symptoms can be challenging in patients with advanced dementia who have difficulty verbalizing their needs. Clinicians must therefore pay close attention to nonverbal behavioral signs.

PITFALLS

- The failure to recognize dementia as an incurable and progressive disease may result in inadequate end-of-life care, including delayed referral to hospice.

SUMMARY

A comprehensive assessment of older patients for known geriatric syndromes such as dementia, UI, and falls may allow palliative care physicians to discover

simple, noninvasive treatment strategies that have the potential to improve a patient's quality of life greatly. As with all health care decisions, the risks and benefits of these assessments and therapeutic interventions must be carefully weighed against the patient's stage of illness and goals of treatment.

Resources

Alzbeimer's Association: www.alz.org
American Academy of Hospice and Palliative Medicine: www.aahpm.org
National Hospice and Palliative Care Organization: www.nhpco.com
National Family Caregiver's Association: www.thefamilycaregiver.org

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Pulmonary Palliative Medicine

9

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CHAPTER OUTLINE

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PATHOPHYSIOLOGY OF DYSPNEA
PRIMARY DISEASE MANAGEMENT
Bronchodilators
Corticosteroids
Oxygen
Other Modes of Primary Disease Management
SYMPTOM MANAGEMENT
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PEARLS
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SUMMARY

INTRODUCTION

The symptoms that derive from pulmonary disease processes account for a large percentage of referrals to palliative care practices. Although most of these cases involve malignant lung disease, more than 7% of palliative care referrals are for primary pulmonary diseases such as chronic obstructive pulmonary disease (COPD), interstitial lung diseases, and acute respiratory distress syndrome (1). These diseases are uniformly chronic, progressive, and debilitating, thus mandating that comprehensive care of these patients includes a solid understanding of palliative methods.

This chapter outlines how palliative care can be applied to patients who suffer from a primary pulmonary disease. COPD receives the most attention because of its relatively high prevalence.

PATHOPHYSIOLOGY OF DYSPNEA

The symptoms of dyspnea are comprehensively addressed elsewhere in this text. However, for the purposes of discussing COPD disease and other primary pulmonary disease processes here, a brief description is given of the pathophysiology of

dyspnea as encountered in the palliative care of the patient with pulmonary disease. A common definition of *dyspnea* is an unpleasant or uncomfortable sensation of breathing or a sensation of breathlessness.

As a qualitative symptom, characterizations of dyspnea may vary widely among patients with different disease processes or even among individuals with similar, underlying cardiopulmonary diseases. In a manner similar to generating a differential diagnosis for chest pain, the clinician may find that different adjectives help to uncover the origin of the patient's dyspnea. Several studies that examined patients' descriptors of dyspnea have demonstrated that feelings of "chest tightness" and "increased work of breathing" may be more strongly associated with asthma, whereas "suffocation" and "air hunger" are more consistent with COPD or congestive heart failure (2).

The origins of dyspnea are complex at best. Many details of the underlying pathophysiology have yet to be described, particularly the neural pathways that contribute to generating a sensation of breathlessness. Additionally, correlating the symptom onset with a specific underlying stimulus can be quite difficult for both clinician and researcher. For example, in a given patient with metastatic lung cancer, is the dyspnea the result of tumor compression of the bronchi, the malignant pleural effusion, the pulmonary embolism, existential anxiety, or a combination thereof? Chapter I–13 provides a more detailed discussion of the pathophysiology of dyspnea. Here, we consider three major mechanisms through which dyspnea manifests itself in COPD: chemoreceptors, mechanoreceptors, and the sensation of respiratory effort (2).

Both peripheral and central chemoreceptors are thought to play a role in evoking dyspnea, although it is not always clear exactly how this occurs. Normal subjects and patients suffering from pulmonary diseases complain of dyspnea while breathing carbon dioxide (CO_2). Conversely, many patients, especially those suffering from COPD, have baseline elevations of the partial arterial pressure of CO_2 ($PaCO_2$) at rest without experiencing breathlessness (3). Similarly, although hypoxia is commonly thought to contribute to dyspnea (it is known to stimulate respiration via chemoreceptors), many dyspneic patients are not hypoxic. Furthermore, in those who are hypoxic, correction often only partially alleviates the symptom (3).

Mechanoreceptors in the upper airways may explain the benefit that many pulmonary patients receive when they sit next to an open window or a fan. Several studies have suggested that vibration of mechanoreceptors in the chest wall may improve dyspnea in normal subjects and in patients with COPD (3). In the lung, epithelial irritant receptors contribute to bronchospasm, whereas unmyelinated C-fibers in the alveolar walls respond to pulmonary congestion (2). Interestingly, many patients with COPD exhibit dynamic airway compression, as evidenced by an improvement in breathlessness from pursed-lip breathing. One study described such an improvement when patients with COPD who did not normally breathe in such a manner were taught how to do so. However, the degree to which each of these mechanisms contributes to dyspnea is unclear and is likely relatively specific to the individual patient.

Finally, one's sense of respiratory effort—the conscious awareness of the activity of the skeletal muscles—seems to play a part as well. This effort is related to the ratio of pressure generated by the respiratory muscles to the maximum pressure generated by the muscles. Evidence indicates that most of this sense derives from simultaneous activation of the sensory cortex at the initiation of the motor cortex

to breathe (2). A stimulus that increases the neural drive to breathe (either when the respiratory muscle load is increased or when the muscles become fatigued) will increase this ratio and therefore the sense of effort, as seen in patients with neuromuscular disorders such as amyotrophic lateral sclerosis or myasthenia gravis (2).

Unfortunately, although we understand many of the mechanisms that contribute to dyspnea, no one mechanism has been linked to a single disease process. It is more likely that dyspnea in a patient with pulmonary disease is multifactorial. For example, a patient with COPD may experience breathlessness from airway hyperinflation leading to weakened diaphragmatic muscle curvature and inspiratory muscle fibers, acute or chronic hypoxia, hypercarbia, mechanical compression of the airway, or increased dead space requiring increased minute ventilation (4). The clinician must bear in mind such pathophysiologic complexity when caring for the patient with advanced pulmonary disease processes because effective palliative management usually requires multiple approaches, both pharmacologic and nonpharmacologic. The next section introduces possible interventions for symptom palliation in the patient with COPD. As yet, no published data describe when to begin palliation of COPD with opioids or benzodiazepines. Traditional primary care and pulmonary specialty practice tend to begin these agents when the disease is far advanced and more "conservative" therapies have proven to be of only marginal benefit. Concern about opioid and benzodiazepine side effects is often cited as the primary reason for the delay in initiation of these therapies (5).

PRIMARY DISEASE MANAGEMENT

Representing the majority of pulmonary diseases for which many data are available regarding palliative management and referrals to hospice and palliative care, the major focus of this chapter is palliative management of COPD. In 1997, COPD affected 10.2 million US residents; in 1998, it accounted for between 15% and 19% of hospitalizations in the United States (6). It is the fourth leading cause of death in the world (7). This section reviews approaches to primary disease treatment, as well as emerging pharmacologic and nonpharmacologic palliative techniques for managing the symptoms of COPD (primarily dyspnea).

It is important to underscore the distinction between the goals of treating the primary disease ("curative" or "disease modifying") and relieving symptoms associated with a given disease, so-called palliative therapy. The *Merriam-Webster Dictionary* suggests that *palliation* is "treatment aimed at lessening the violence of a disease when cure is no longer possible" (8).

Primary disease management of COPD includes prescribed combinations of short- and long-acting bronchodilators, corticosteroids, and oxygen, as well as nonpharmacologic interventions such as pulmonary rehabilitation and preventive measures such as influenza and pneumococcal vaccinations. Treatment regimens must be designed specifically for each patient based on responses to medications. No drug or drug combination has been shown to modify the progressive decline of the disease process itself. Therefore, although the foregoing framework is often useful, in the management of COPD the distinctions between disease modifying and palliative are particularly blurred or overlapping. Generally, the success of pharmacologic and nonpharmacologic management strategies has been evaluated

Table II–9–1 ■ Pharmacologic and Nonpharmacologic Interventions Applicable to Managing Symptoms in Chronic Obstructive Pulmonary Disease

Drug/Intervention	Curative	Disease-Modifying	Longevity Modifying	Palliative
Lung transplant	X			
β_2-Agonists		X		X
Anticholinergics		X		X
Methylxanthines		X		
Corticosteroids				X
Oxygen			X	X
Opiates (systemic)				X
Opiates (nebulized)				(Unclear if any benefit)
Benzodiazepines				X

in terms of improvement in pulmonary function tests, exercise capacity, and symptoms. Established guidelines are readily available (7). A summary of interventions is provided in Table II–9–1. The primary focus here is on symptom control and a review of the evidence surrounding various traditional pharmacologic and nonpharmacologic interventions.

Bronchodilators

Bronchodilators (β_2-agonists, anticholinergics, methylxanthines) tend to be the first-line interventions in attempts to improve dyspnea in the patient with COPD. The β_2-agonists and anticholinergics may be delivered in short- or long-acting compounds and in inhaled forms (β_2-agonists are also manufactured in oral formulations, but these are not frequently used in adults). Short-acting bronchodilators can improve symptoms rapidly and can be administered on a scheduled basis for consistent control. For stable disease (i.e., not acute symptom management), the regular use of long-acting formulations has been reported to be more effective than short-acting bronchodilators, and once- or twice-daily dosing promotes improved compliance. These drugs are, however, more expensive (see Table II–9–2) (7). Inhaled forms (via metered-dose inhaler or nebulizer) are typically better tolerated and have fewer side effects, but they require additional patient and caregiver education for correct administration. The results of this education have demonstrated important benefit, however (9).

For the stable patient with COPD, short-acting β_2-agonists or short-acting anticholinergics should be administered at intervals of 4 to 6 hours for symptom improvement beginning at mild stages of disease (forced expiratory volume in 1 second [FEV_1]/forced vital capacity [FVC] <70, $FEV_1 \geq 80\%$ predicted, with or without symptoms at baseline) (7). A Cochrane meta-analysis examining patients with a predicted FEV_1 of 60% to 70% studied the scheduled administration of inhaled short-acting β_2-agonists for 7 days to 8 weeks and demonstrated that regular use of inhaled short-acting β_2-agonists for at least 7 days improved breathlessness scores (10). Long-acting bronchodilators should be reserved for those

Table II–9–2 ■ Common Pulmonary Medications: Mechanism, Dosing, Costs, Route of Administration

Drug Class	Drug Name	Mechanism and Dosing Interval	Cost
B-agonists	Albuterol (generic)	Short acting (q4–6h)	$30 (inhaler)
	Metaproterenol (Alupent)	Short acting (q4–6h)	$56 (inhaler)
	Pirbuterol (Maxair)	Short acting (q4–6h)	$95 (autoinhaler)
	Albuterol (Ventolin)	Short acting (q4–6h)	$36 (inhaler)
	Terbutaline (generic, Brethine)	Intermediate (q6–8h)	$31 (oral, subcutaneous, intravenous)
	Albuterol (Proventil)	Intermediate (q6–8h)	
	Levalbuterol (Xopenex)	Intermediate (q6–8h)	
	Formoterol (Foradil)	Long acting (q12h)	$38 (inhaler)
	Salmeterol (Serevent)	Long acting (q12h)	$65 (inhaler)
			$97 (inhaler)
			$98 (inhaler)
Anticholinergics	Ipratropium (generic)	Short acting (q4–6h)	$34 (inhaler)
	Ipratropium (Atrovent)	Intermediate (q6–8h)	$77 (nebulized)
	Tiotropium (Spiriva)	Long acting (q24h)	$120 (inhaler)
Inhaled steroids	Triamcinolone (Azmacort)	Intermediate (q6–8h)	$90 (inhaler)
	Flunisolide (AeroBid)	Long acting (q12h)	$75 (inhaler)
	Fluticasone (Flovent)	Long acting (q12h)	$92 (inhaler)
	Beclomethasone (QVAR)	Long acting (q12h)	$74 (inhaler)
	Budesonide (Pulmicort)	Long acting (q12–24h)	$148 (inhaler)
Combination	Combivent, DuoNeb (Albuterol/Ipratropium)	Short acting (q4–6h)	$74 (inhaler)
	Advair (Fluticasone/ Salmeterol)	Long acting (q12h)	$148 (inhaler)

with moderate to severe COPD (i.e., $FEV_1/FVC < 70$, $FEV_1 \geq 80\%$ predicted, with or without symptoms) (7). Long-acting β_2-agonists have also been associated with slight decreases in breathlessness (11). In one study, the administration of salmeterol, 50 μg twice daily, resulted in significant improvement in health-related quality of life scores versus placebo. Interestingly enough, 100 μg twice daily did not have the same effect (12). Administration of the long-acting anticholinergic tiotropium bromide also demonstrated statistically significant improvement in dyspnea as compared with placebo, as well as better dyspnea relief as compared with salmeterol (13).

Methylxanthines (most commonly theophylline) remain third-line agents, given their relatively wide side effect profile and narrow therapeutic window. Patients with COPD who were more than 60 years old who took a long-acting formulation of theophylline exhibited wider interpatient variability and fluctuation in serum drug concentration (14). Therefore, careful and frequent drug level monitoring is essential.

Corticosteroids

Inhaled corticosteroids do not modify progressive decline in FEV_1. Thus, they are not disease-modifying agents but rather purely palliative in symptom relief (dyspnea and congestion). Steroids may be appropriate for symptom management in patients with severe ($FEV_1 < 30\%$ predicted) to very severe ($FEV_1 < 50\%$ predicted) COPD (7). This treatment may decrease the frequency of exacerbations, and it does

improve respiratory symptoms and decrease utilization of hospital resources for respiratory management (15). Withdrawal of inhaled corticosteroids has been shown to increase the frequency of exacerbations (16). The combination of inhaled corticosteroids and a long-acting β_2-agonist demonstrated greater efficacy in controlling respiratory symptoms than did the combination of a short-acting anticholinergic and β_2-agonist (17).

Courses of intravenous or oral corticosteroids are commonly employed during COPD exacerbations and work best in those patients with a strong inflammatory component to the disease; these systemic formulations have been repeatedly demonstrated to shorten recovery time from a COPD exacerbation. One randomized, controlled trial found inhaled budesonide to be as efficacious as oral prednisolone in patients hospitalized for COPD exacerbations (18). However, long-term courses of oral corticosteroids have not been shown to be of benefit in symptom management, and there is an increased risk of proximal myopathy that adversely affects respiratory mechanics and management of oral secretions. Other deleterious effects of long-term corticosteroid use are osteopenia, fat redistribution, diabetes, decreased immune function, and increased infection. Systemic corticosteroids are not recommended for long-term use in COPD (7).

Oxygen

Oxygen remains a mainstay in the management of COPD and other chronic lung diseases. Benefits of long-term oxygen use in patients with COPD include improvements in hemodynamics, hematologic characteristics, exercise capacity, lung mechanics, and mental state. More importantly, oxygen increases survival, a truly disease-modifying increase in survival (7). In general, therapy should be initiated in patients with very severe COPD, that is, patients with either (a) arterial partial pressure of oxygen (PaO_2) lower than 55 mm Hg or oxygen saturation (SaO_2) less than 88% or (b) PaO_2 lower than 60 mm Hg or SaO_2 less than 89% *and* pulmonary hypertension, evidence of congestive heart failure, or secondary polycythemia.

With regard to symptomatic management, however, strong evidence that supports the long-term use of oxygen remains somewhat elusive; it is not clearly "palliative." Although investigators do record changes in physiologic variables with oxygen use, many studies have not employed dyspnea assessments. Confounding this is the issue that few studies are randomized, controlled trials, and most studies involve small patient numbers. A summary from the Association of Palliative Medicine Science Committee regarding patients with COPD advises the following:

1. There is currently equivocal evidence for the use of long-term oxygen at rest for palliation of dyspnea.
2. Oxygen may be appropriate for decreasing breathlessness associated with exercise.
3. The effect of oxygen on quality of life during ambulation cannot be predicted a priori by patient characteristics (19).
4. Short-term therapy during exacerbations of dyspnea or during ambulation and exercise may be useful in patients with COPD (19).

Other modes of primary disease management

Other pharmacologic modifiers used in the management of the patient with COPD include leukotriene inhibitors, chemokines, inhibitors of tumor necrosis factor-α, and phosphodiesterase inhibitors. Each of these drug classes may subsequently be shown to contribute to disease improvement in COPD and to palliative relief of breathlessness. At this time, however, no clear evidence exists to support the routine use of these medications for the palliation of COPD symptoms.

SYMPTOM MANAGEMENT

Opiates

Opiates are the mainstay of palliative management of dyspnea in COPD. Opiates decrease the ventilatory response to exercise, hypoxia, and hypercarbia. It is possible that they decrease the sensation of breathlessness by decreasing respiratory effort.

Intermittent dosing of opioids has been studied in patients with COPD. Most of these studies enrolled relatively small numbers of patients, administered study drug and placebo orally, and utilized exercise testing as a means of measuring improvement in dyspnea. Although one meta-analysis of nine studies demonstrated significant heterogeneity in study results, it nevertheless appears evident that systemic opiate administration improves breathlessness in patients with COPD (20). Notably, four of the nine studies measured arterial blood gas tensions before and after treatment; three of these studies found no significant difference. In the one study that did find a difference, using dihydrocodeine in multiple-dose exercise testing, $PaCO_2$ never rose more than 40 mm Hg, and PaO_2 did not change significantly (21).

The benefits of scheduled or sustained-release opiates are less clear in patients with COPD who require more than intermittent dosing of opiates for relief. There have been even fewer trials investigating these methods and dosing of drug administration, and these trials have tended to demonstrate mixed results. For example, one study employed 30 or 60 mg of dihydrocodeine or placebo administered three times daily; compared with placebo, a benefit was found in the 30-mg group but not in the 60-mg group (21). The same confounding results ring true for sustained-release opiates. In a randomized, double-blind, crossover trial, sustained-release morphine was shown to have no benefit over placebo in breathlessness scores and was actually associated with decreased exercise tolerance (5). However, in a similarly designed study, 4 days of sustained-release morphine provided improved dyspnea scores and improved sleep as compared with placebo (22). Therefore, whereas sustained-release opiates are a mainstay of clinical palliative care practice, with seemingly positive benefit, the data are still unclear regarding whether scheduled or sustained-release opiates will prove beneficial for management of dyspnea in patients with COPD.

Clinicians continue to examine alternative routes of administering opiates. Nebulization of morphine or fentanyl is of interest to many investigators because of possible benefits localized to lung parenchyma and neuromusculature and less risk of the side effects that are associated with systemic administration (most commonly constipation and nausea). In spite of numerous trials, meta-analyses still suggest that nebulization of morphine has no role in relief of dyspnea (20),

and although several researchers are now turning their attention to nebulized fentanyl, no study has yet investigated the role of this agent in COPD. Finally, epidural opiate administration may eventually prove an additional route for symptom relief in COPD, as shown by one uncontrolled trial of nine patients who gained relief of breathlessness with epidural methadone (23).

Benzodiazepines

Benzodiazepines can be useful in palliating dyspnea. Typically, they are initially administered on an as needed dosing schedule and then scheduled when necessary. For more information on the general role of benzodiazepines, see Chapter II–13. Although benzodiazepines are often used for symptom management in palliative care patients (anecdotally, with significant success in patients with dyspnea), few studies have examined the role of benzodiazepines in patients with COPD. One study examined the effect of alprazolam on exercise capacity and dyspnea and found no significant difference between intervention and placebo (24). Further research is needed to understand better the role of benzodiazepines in this setting.

As a corollary, the prevalence of anxiety is quite high among patients with COPD, and as many as 34% of patients meet the criteria for either generalized anxiety disorder or panic disorder, a rate at least three times that of the general population (25). Certainly, anxiety negatively affects the lives of these patients, especially in terms of functional status, mental health function, and bodily pain perception (25). However, benzodiazepines are not recommended for routine treatment of anxiety in patients with COPD, given the concern for decreased respiratory drive and worsened exercise tolerance. Several small studies have suggested that buspirone (26), sertraline (27, 28), or nortriptyline (29) should be used for the pharmacologic management of anxiety. Nonpharmacologic management strategies include cognitive-behavioral therapy and pulmonary rehabilitation (25).

END-OF-LIFE CARE

Despite aggressive research and advances in therapy during the second half of the 20th century, the fact remains that COPD is still a disease marked by inexorable decline and increasingly frequent hospital admissions to treat exacerbations, often requiring extensive periods of ventilator support. Nevertheless, relatively few data have been gathered and incorporated into management guidelines for end-of-life treatment of these patients (30). One study demonstrated that patients with terminal COPD experience a poorer quality of life, more unaddressed psychological and emotional distress, and less social support compared with patients with inoperable non–small cell lung cancer (31). Another study found that patients with COPD desire more education than those with cancer or AIDS about the disease process, including what they may experience in the dying process, and information on advance care planning (32).

Such findings underline the need for overall improved communication with, and multidisciplinary support for, patients who are terminally ill with COPD. In a recent retrospective survey of 399 British patients who died of COPD, the investigators found that, during the last year of life for these patients, 41% either

left the house less than once a month or never left, 47% were hospitalized at least twice, 67% died in the hospital, and only 63% knew that they could die (33). Clearly, these findings exemplify the need for more extensive palliative care services.

In the last days of life, it is common for patients with COPD to experience progressive dyspnea that proves refractory to bronchodilators, corticosteroids, and oxygen. As hypoxia and hypercarbia worsen, patients may become delirious and more anxious. In an attempt to manage these symptoms, hospice and palliative care physicians typically titrate opioids and benzodiazepines for comfort, sometimes at the expense of responsiveness. In these situations, the goal of therapy should remain the alleviation of symptoms rather than sedation. As indicated by the studies cited earlier, it is essential to provide education as well as comprehensive support to the patient and family throughout the dying process.

PEARLS

- Pulmonary disease processes (excluding malignant diseases) constitute more than 7% of palliative care referrals. Most of these referrals are for management of symptoms associated with COPD.
- For patients with COPD, the mainstay of symptom palliation remains similar to treatment during disease exacerbations: bronchodilators (especially anticholinergics and β_2-agonists), oxygen, and short courses of corticosteroids.
- Additional palliation of dyspnea can be achieved with the use of opiates. Current data recommend administration of short-acting rather than long-acting preparations. However, normative palliative practice tends to favor long-acting preparations to improve adherence and compliance when a stable dose of short-acting opiate has been determined.
- As yet, there is no consensus about precisely when in the disease course patients with chronic, degenerative pulmonary disease processes should be referred for palliative care. Where palliative care consultants exist, most pulmonary and critical care physicians have found that early consultation and collaboration with palliative care support are beneficial.

PITFALLS

- There is no proven benefit to the extended use of corticosteroids for COPD palliation.
- Currently, there is only anecdotal evidence to support use of benzodiazepines for palliation of dyspnea.
- Data are insufficient to support the development of palliative care algorithms for COPD. There is, however, a tremendous opportunity for collaboration between pulmonary and palliative care specialists to build this literature.

SUMMARY

This chapter has introduced strategies for managing symptoms in patients who suffering from pulmonary disease and has focused primarily on COPD. No data are available at this time to indicate definitely when patients with chronic, progressive lung disease should be referred to palliative care specialists. However, in

the natural course of such diseases, most available therapies are, indeed, palliative (Table II–9–2). Within the category of primary disease management or disease-modifying therapy, inhaled β-agonists, oxygen, and anticholinergics are beneficial. For primary symptom relief (pure palliation), β-agonists, anticholinergics, oxygen, systemic opiates, and benzodiazepines have been shown to provide some benefit, although data are limited. Thus, both the general practitioner and the pulmonary specialist should be acquainted with various approaches to addressing chronic and recurring symptoms of dyspnea and anxiety. Given the prevalence of the symptom of dyspnea and the paucity of data regarding its palliative management, clearly more research is needed to improve care for patients with pulmonary manifestations of a variety of diseases.

Resources

End of Line/Palliative Care Research Center: Fast Fact and Concept 027: Dyspnea at End-of-Life. Available at http://www.eperc.mcw.edu/fastFact/ff_027.htm.

World Health Organization: Management Plan for COPD. Available at http://www.who.int/respiratory/copd/management/en/.

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Pediatric Palliative Care

10

Stephen Liben

CHAPTER OUTLINE

INTRODUCTION
THE WHO, HOW, WHAT, WHEN, AND WHERE OF PEDIATRIC PALLIATIVE CARE
COMMUNICATION WITH CHILDREN AND FAMILIES
SYMPTOM MANAGEMENT
PEARLS AND PITFALLS
SUMMARY

INTRODUCTION

Many of the skills required of general medicine physicians in the day-to-day care of patients are the same as those needed for specialist palliative care. Knowing how to communicate, appreciating the meaning of illness and suffering, and assessing and treating pain and other symptoms are but a few examples of the clinical competencies required by physicians in both general and specialist practice. Just as the spectrum of clinical competencies that make up general medical practice overlaps with competencies required in palliative care for adults, the core skills required in adult palliative care overlap with those required for the palliative care of children. Although the general foundations of palliative care apply to both adults and children (e.g., appreciating the importance of care of the "whole person" in body, mind, and spirit) and many medical treatments in pediatric palliative care are based on their success in adults (e.g., pharmacological management of many symptoms), there are important differences in palliative care for children. Many chapters in this textbook cover areas of care that apply equally to children and adults, but this chapter outlines how pediatric palliative care is different from adult palliative care.

THE WHO, HOW, WHAT, WHEN, AND WHERE OF PEDIATRIC PALLIATIVE CARE

Smaller numbers of children die compared with adults. In the United States, approximately 55,000 children 19 years of age or younger die per year as compared

to 2.3 million adults (1). Although precise statistics are not known, many children in developed (or richer) countries die in hospitals. For a medium-sized pediatric hospital of 150 to 200 beds, about 100 to 150 children may be expected to die per year. This means that health care workers in a pediatric hospital can expect two deaths per week, yet it has only recently been recognized that the needs of these dying children and their families require specialized knowledge and increased attention (2). Medical advances have resulted in the current high cure rate of approximately 85% for pediatric cancers, but the fact remains that 15% of such children still die of the disease. The relative paucity of pediatric deaths compared with adult deaths, coupled with the cultural taboos surrounding death in general, combine to make the experience of a child's death a rarity for most people, including health care professionals. A hundred years ago, most families would have had the unfortunate experience of having at least one child die, and most physicians would have seen children die as part of their regular practice. Because most pediatric deaths in richer nations now occur in tertiary care hospitals, there are few professionals with experience and training in meeting the needs of the children who do die. Pediatric palliative care has grown out of the adult palliative care movement in an attempt to meet the needs of these children and their families.

Children die of a larger number of causes than do adults. Adult palliative care services have historically been oncology based, although it is recognized that other illnesses that lead to death in adults would also benefit from the principles of palliative care. The most frequent causes of death in children are age dependent (3):

- Infants age 0 to 1 year: Congenital anomalies, prematurity, and sudden infant death syndrome
- Children age 1 to 14 years: Accidental and nonaccidental trauma, cancer, congenital abnormalities, and "other"
- Older children and adolescents age 15 to 19 years: Trauma (including suicide), cancer, and congenital abnormalities such as cardiac disease

Unlike the adult population in which cancer and cardiovascular disease make up a large percentage of the major causes of death, wide ranges of diseases (some very rare) lead to death in children. Although cancer is a common cause of death for adults, it is responsible for only 4% of deaths in childhood (1).

Large numbers of "miscellaneous" disorders result in death in children, including rare inborn errors of metabolism and genetic syndromes that are not all well described. For many of these causes of death, little is known about the natural history of the disease and its optimal management, including how to best provide symptom control. For these children, the best way to manage the illness is to apply general principles of pediatric care together with the general principles of palliative care. Another way of answering the question "What is pediatric palliative care?" is to answer that it takes the best practice from general pediatric medicine and combines it with the specialized knowledge of adult palliative care.

Case Study II–10–1 ■

A 4-month-old boy was found to have profound weakness and resulting respiratory failure resulting from a rare, inherited form of congenital myopathy about which there was a lack of information in the medical literature. After much discussion about quality of life and possible outcomes, his parents agreed to placement of a tracheostomy, initiation of mechanical ventilation, and placement of a percutaneous gastrostomy. The child then lived in the hospital for 2 years, during which time his quality of life was maximized with

in-hospital music therapy, regular volunteers assigned to his care, massage therapy, a regularized daily schedule, and personalization of his room. He then developed severe weakness with resulting skin breakdown and many pulmonary infections. His parents, together and in discussion with medical staff, came to accept that his quality of life had deteriorated to the point that he was suffering daily because of his worsening, irreversible illness. After discussions with their religious leaders and the hospital staff, his parents decided to allow him to die at home by removing the ventilator.

The hospital-based pediatric palliative care program had been introduced to the child and family at an early stage for help with symptom control and for anticipatory guidance. The roles and involvement of the pediatric palliative care team evolved as needed at different points in the child's illness trajectory. The initial role of the team was to establish a therapeutic relationship with his parents and to support the health care staff (e.g., intensive care unit staff and surgeons) in the many discussions that occurred at different decision-making points. As his care evolved more toward the end of life, the pediatric palliative care team became more directly involved in planning for how end-of-life care would be transferred to the home, including how the child would be taken off the ventilator.

Many children who could benefit from palliative care live with illnesses that have an unpredictable time course that varies from a short-term illness that quickly leads to death to complex chronic diseases that may evolve over years. For complex chronic diseases, the time course may not only be long, spanning years, but may also be unpredictably intermittent in the need for acute and palliative care. For example, a child with severe cerebral palsy and a seizure disorder may be stable for years and may then present suddenly with life-threatening aspiration pneumonia that may or may not become a fatal episode. At such times of intermittent crises, it is helpful if a management plan was prepared in advance that includes thinking through the kinds of interventions that may or may not be desired for that particular child (e.g., decisions about whether to provide mechanical ventilation). The life-threatening crisis may evolve into an end-of-life situation, or, alternatively, the crisis may resolve and the child may once again require high levels of supportive and rehabilitative care, including access to supportive services for the handicapped (e.g., seating programs, antispasticity programs, multispecialist care). In this way, pediatric palliative care is often not a smooth transition from health to ill health, but is rather an intermittently required service that may need to move in and out of a child's care plan as needs change and evolve. It is always helpful to plan ahead by initiating early discussions about how palliative care may be helpful if and when a life-threatening crisis occurs rather than waiting for the crisis to manifest. Evaluations of the child and family that occur between crises have the advantage of assessing the child when he or she is at the best level of function and offer the opportunity for families to reflect on discussions and take the time needed to come to important decisions about care planning.

Even in places where pediatric home palliative care is available, many children who die do so in hospitals. Most children who are able to make a choice prefer to die at home, if possible. There are several possible explanations for why many children still die in hospitals despite their preference to be at home. These include the unpredictability of when a critical illness is actually a fatal event, as opposed to one from which the child may recover, the lack of availability of home pediatric palliative care services, and the need of many parents to feel that everything possible was done to help avoid the death of their child, including the use of medical technologies that are possible only in a hospital. Pediatric and neonatal intensive care units are common locations of pediatric deaths, and because these deaths are a frequent

occurrence, many units have their own individualized palliative care and bereavement programs. In some centers, hospitals have set up palliative care rooms that allow families to remain together in a more homelike environment than is typically found in a hospital setting. Unlike adult palliative care, there are rarely entire wards in pediatric hospitals dedicated to palliative care. For the most part, pediatric palliative care programs have developed as consultant services (as opposed to primary care services) to help support the primary caregivers in other pediatric specialties. For example, in-hospital palliative care programs may follow children on different speciality wards as care is concurrently delivered with another pediatric subspecialty, such as respirology for patients with cystic fibrosis and neurology for children with severe cerebral palsy. Not surprisingly, some evidence indicates that instituting the supports necessary to provide services in the home results in larger numbers of children who are then able to die at home instead of at the hospital (4). In contrast to the United Kingdom, where large numbers of specialized pediatric hospice centers are already in operation, few adult hospices in North America will admit a child for terminal care. For a dying child and his or her family, the ideal situation is to be able to offer them as many options as possible, including the opportunity for care to alternate among hospital, home, and hospice as needs and situations change.

COMMUNICATION WITH CHILDREN AND FAMILIES

Maintaining hope is a cornerstone of pediatric palliative care and is a common and challenging task for children, parents, and professionals. The difficult question is sometimes asked directly—"How can we maintain hope in the face of our child's death?"—or indirectly in other ways: "What do we do now?," "How can we go on?," "What is the point of anything?" These questions speak to the need to maintain hope and the struggle to find meaning in the tragic loss that is the death of a child. In the face of such questions (which may be unspoken for some), the role and challenge for the pediatric palliative care professional are to assist in reframing what hope can be when a cure is no longer possible. For example, it can be comforting to know that other families have found a way to maintain hope by shifting from hope for cure to hope for a meaningful life or hope for a peaceful death. A starting point for the health care professional is to recognize his or her own need to maintain hope and to find meaning in the work that he or she does. "Hoping" is understood to be distinct from "wishing." Hope is the understanding that things will somehow be all right, no matter what the outcome. Wishing may be another way to deny reality and is the insistence that, despite the facts, the outcome will somehow "magically" be different. A practical approach to maintaining hope is as follows:

1. Accept that, at times, loss of hope may be part of the process.
2. Be an active listener as families may find their own way to meaning.
3. Facilitate the process that leads to a shift from hoping for cure, to hoping for quality of life, to hoping that death will be as comfortable as possible.
4. Create the conditions that allow for the possibility of maintaining hope and finding meaning by optimizing physical comfort and providing care in the best possible setting (e.g., in the home when it is desired and possible).

Understanding children's developmental concepts of death is important in helping guide the content and timing of communication with ill children and

their siblings. It is now understood that even very young terminally ill children are often aware that they are dying, despite efforts their parents may have made to keep that information from them (5, 6). The following is an approximate guide of how children understand death at different ages:

- Very young children, less than 3 years old: These children are mostly preverbal, with their needs focused on immediate physical gratification. Their major concerns are often physical comfort and not to be separated from their parents.
- Early childhood, age 3 to 6 years: These children lack appreciation of core concepts of death. At this stage, many fears result from misunderstanding the core concepts of death and may be alleviated by explanation and discussion. These concepts include the following:
  - Irreversibility: Death is permanent, and the dead cannot be made alive again.
  - Universality: Death happens to everyone, not just old people or those who become sick.
  - Nonfunctionality: Being dead means that you do not have to breathe, or eat, or maintain other bodily functions.
  - Causation: "Bad" people are not the only ones who die, and wishing death on someone cannot magically cause his or her death. It is important for siblings to understand this because they may have wished their ill brother or sister "dead" at some time in the past and now wonder whether that wish is coming true.
- Middle childhood, age 6 to 12 years: These children begin to understand concepts of irreversibility, universality, nonfunctionality, and causation. They may believe that death is caused mostly by external forces such as accidents, although they are beginning to understand that it also occurs via internal (illness) causes.
- Adolescence, more than 12 years of age: Adolescents may have a disconnect between their factual understanding of the core concepts of death and simultaneous magical thinking that it still cannot happen to them (risk taking is common at this stage).

Many of the children who require palliative care are either preverbal because of their young age or nonverbal because of their underlying illness. Although communication does occur through nonverbal means, there are many instances in which a lack of cognitive ability limits the child's ability to comprehend and be an active partner in decisions about treatment. In adult palliative care, even if an adult becomes nonverbal, there is still a previous lived experience of the person to help. In contrast, young children are frequently without such a prior history proxy decision makers. It is often the parents, as proxy decision makers, who make major decisions for and about their children. One challenge in pediatric palliative care is to help parents make decisions that respect what is in the best interests of their child versus those decisions that may help to alleviate their own legitimate suffering. When it is difficult to separate the nonverbal child's suffering from that of the parents, it can be helpful to reframe the situation by asking parents to try to interpret what their child may be "telling" them in actions as opposed to in words. Some parents come to interpret repeated life-threatening episodes as meaning that their child is "ready to go" and may find some solace in knowing that they have found a way to "listen" to the nonverbal messages their child is sending.

Communication with verbal children includes, but is not limited to involving children in their own treatment decisions, listening for their preferences about the way they wish to live, and offering them the opportunity to create lasting memories for the bereaved (e.g., memory books, pictures, bequeathing cherished toys, making personalized music recordings, and paintings). The opportunity to express themselves creatively and nonverbally need not be limited to specialists in expressive therapies; simply offering crayons and paper with the instruction to "make any picture you like" and then asking the child to explain what he or she drew can be very helpful in better understanding what the child is thinking.

It is an axiom in pediatric palliative care that the unit of care is both the child and family, with the definition of family meant to include any loved one who is significant to that child. Communicating with parents, siblings, and extended family can be a challenge and will depend on the particulars of each family. Encouraging parents to include siblings in appropriate discussions and involving siblings in care may serve to improve the long-term function of the bereaved sibling (7).

Offering ideas about how to share meaning even in uncertain times can be helpful. For example, when a child is near the end of life, families may feel stressed by trying to time important celebrations in this unpredictable situation. It can be suggested that other families in similar situations have chosen to have the event (e.g., a birthday or holiday celebration) as soon as possible and then to repeat it on the actual calendar date if the child continues to do well.

SYMPTOM MANAGEMENT

Most children's pain and many other physical symptoms can be managed with the application of current accepted therapeutic interventions (8). It remains a distressing fact that many children still have unrelieved pain and symptoms because proven, effective, symptom management techniques are not applied (9). Fears and misunderstandings that have kept pain relief withheld from children include not recognizing the following:

1. Children and neonates feel pain and respond to both pharmacological and nonpharmacological management.
2. The use of opioids to manage pain in children is safe and effective when given in age- and weight-appropriate doses by the least invasive route.
3. There are behavioral, cognitive, and other nonpharmacological techniques to reduce pain that are both safe and effective.

Good pain management begins with a pain assessment. Whenever possible, pain assessment should be based on the child's self-report. For the infant and very young child, various pain scales may be useful in particular situations (e.g., the COMFORT scale used in an intensive care setting). In clinical practice, pain in infants and young children is most often assessed by a combination of physiological parameters (e.g., heart rate), behavioral observation (e.g., observation of facial grimacing), and parental report. Children around the ages of 4 to 7 years can use self-report scales. One such scale, the Bieri faces scale, has a pictorial scale of six faces, and the child is instructed to point to the face that shows how much pain (or "oowie" or "boo-boo") the child is having. For children older than about age 7 years, a standard 0 to 10 (or 0 to 5) numeric scale can be used. For older

nonverbal or cognitively impaired children, practical pain assessment is usually dependent on a combination of physiological, behavioral, and parental report parameters similar to that used in preverbal infants. With this population of handicapped children, it is often the parents who are aware of even subtle changes in the physical and psychological states of their children. One potential pitfall is the mistaken extrapolation of the use of physiological parameters (e.g., heart rate) to assess chronic pain. Chronic pain is often not associated with the kinds of physiological and behavioral changes that are typically seen with acute pain. One practical approach to pain management in nonverbal children is the following: when in doubt about whether pain is present, a trial of an analgesic medication can be given, and its effects on the child's behavior can be observed.

Procedure-related pain is a common cause of significant suffering in children (when treatment may be more painful than the disease). Pharmacological pain management (e.g., the use of topical analgesics such as topical anesthetic gels coupled with systemic short-acting sedatives and analgesics) and concomitant nonpharmacological techniques are very effective in reducing procedure-related pain in children. Some examples of easily applied nonpharmacological techniques include the following:

- Discuss the child's preferences about who should be present during the procedure; a trusted adult or a parent may be very helpful. Be sure to prepare the adult for exactly what to expect.
- Distraction: Pop-up books, blowing bubbles, movies, and small portables toys with motion can be used.
- Offering choices: Offer the choice of right or left hand for placement of intravenous lines.
- Physical measures: These include light touches and the application of cold.
- Reading a story or having a parent sing a favorite song is another technique.
- Guided imagery and guided relaxation are powerful techniques to help alleviate procedure-related pain. To be effective, these techniques require specialized training and expertise.

Most pain in children can be successfully managed with a stepwise approach as advocated by the World Health Organization (WHO) analgesic ladder, which has been adapted for pediatrics (see Chapter I–7). In rare instances, pain may be refractory, and the use of invasive techniques (e.g., epidural blocks) or high doses of sedating medications may be required. Special considerations in the use of opioids and coanalgesics in children include the following:

1. Regular pain should be treated with regularly (not "as needed") scheduled medications (by the clock). As needed rescue doses should be added in case of breakthrough or intermittent pain.
2. The oral route (by the mouth) is always the first choice. Intramuscular injections are painful and should be avoided. Alternate routes to oral administration include subcutaneous and rectal routes, as for adults. Because children have smaller dose requirements, many standard rectal doses are too large, and specially prepared suppositories can sometimes be used. Many children with cancer already have a permanent intravenous port that may be accessed in emergencies, but for care at home, continuous intravenous infusions are technically difficult, and the subcutaneous route is often used instead. For older children, a patient-controlled

analgesia pump may be used, although caution should be used if the parents were taught to use the pump on demand. Transdermal fentanyl patches must be used with caution by experienced personnel and are appropriate only in children who are not opioid naive.

3. An approach to mild moderate and severe pain should begin with the WHO analgesic ladder (see Chapter I–7).
4. In the first 6 months of life, opioids are more likely to cause respiratory depression, and this risk mandates more careful monitoring and lower initial doses (start with ~25% of the usual pediatric per kilogram opioid dose).
5. The initial dose of opioid medication is only a guide, and some children may need lower or higher doses to achieve pain control.
6. Adjuvant medications include coanalgesics that allow for lower opioid doses and therefore fewer opioid side effects. Adjuvants are often used for their desirable side effects (e.g., sedation). A list of the some of more common adjuvants includes the following:
   - Corticosteroids such as dexamethasone used as an appetite stimulant, coanalgesic, particularly in bone pain and in headaches caused by increased intracranial pressure
   - Stimulants such as methylphenidate in opioid-induced somnolence or for short-term treatment of depression
   - Tricyclic antidepressants such as amitriptyline for neuropathic pain
   - Anticonvulsants such as phenytoin and gabapentin for neuropathic pain
   - Benzodiazepines such as lorazepam for muscle spasticity and as hypnotics
   - Neuroleptics such as chlorpromazine for delirium or nausea
   - Antispasmodics such as baclofen for muscle spasticity

Management of symptoms other than pain in pediatric palliative care is based on the same principles as in adult palliative care. In other words, the benefits of interventions are weighed against the risks of side effects for each symptom and each person. Dyspnea is often responsive to blowing air by the face, positioning to prevent aspiration of secretions, and use of systemic opioids to relieve the sensation of breathlessness. The usefulness of oxygen in treating dyspnea is uncertain in children. A practical approach is to use a brief trial of oxygen (if available) to see whether it reduces breathlessness. One caveat is to avoid gauging the success or failure of oxygen by its impact on oxygen saturation alone because oxygen saturation is not necessarily correlated with the sensation of dyspnea. In the event of a sudden episode of anxiety related to the rapid onset of dyspnea, rectal diazepam may provide a good first-line, at-home treatment that can easily be taught to parents. Airway secretions are often problematic in children who have neurological disorders, and suctioning and the use of oral drying agents such as glycopyrrolate have been used with some effectiveness. The recent use of botulism toxin injection into the salivary glands holds promise as a possible new treatment for excessive saliva.

Feeding and hydration issues commonly manifest as ethical issues in pediatric palliative care. The decision to provide nasogastric feedings that are commonly used in the care of ill neonates requires an individualized approach and a careful consideration of the possible benefits versus burdens of treatment. In many circumstances, it is appropriate to initiate a trial of nasogastric feedings for a short period. As in adult palliative care, there is little evidence to suggest that hydration

makes the patient feel more comfortable, and equating hydration with comfort may lead to the ineffective and deleterious use of intravenous hydration in a dying child. There may be advantages to less fluid intake for a child in the terminal stages of illness, including decreased airway secretions and decreased urination, both of which may serve to increase comfort.

Constipation is a common symptom that requires proactive treatment with stool softeners and stimulants and, at times, suppositories or enemas. It is important to recognize the phenomenon of paradoxical diarrhea that may result from overflow constipation. Nausea may be more disturbing to the patient than vomiting and can be treated with both centrally acting medications (e.g., ondansetron) and motility agents (e.g., metoclopramide).

Seizures are common in pediatric palliative care, given the significant numbers of children who have underlying neurological disease. A practical approach for any child at risk for a seizure (e.g., in the case of a brain tumor) is to ensure that a dose of rectal diazepam is available in the home and that parents are comfortable administering it in case of need.

Bleeding is often a concern because of chemotherapy-related thrombocytopenia, but it is rarely life-threatening. The use of intermittent blood and platelet transfusions to maintain energy levels and to decrease the risks of bleeding episodes requires individualized judgments based on the availability of transfusions and the effects of coming in to the hospital for children who are otherwise at home and have a short life expectancy.

Skin care issues are important and should be addressed to avoid bedsores and ulcers, which are difficult to treat once they become severe. The use of specialized weight-distribution mattresses, air beds, and careful positioning is important in preventing bedsores, especially for children who are cared for at home.

Most parents look outside traditional medicine for possible alternatives to treat their ill child. It is important for health care professionals to be open to parental use of complementary or alternative treatments and to ask about the use of such therapies because some treatments may be dangerous (e.g., high potassium supplements in a child with renal failure).

PEARLS AND PITFALLS

- Caring for children means being able to appreciate and understand the spectrum of differing needs (of mind, body, and spirit) from the time from birth through adolescence.
- Pediatric palliative care should be partnered with curative therapies long before all attempts at cure have been exhausted.
- The goal of pediatric palliative care is to make the most of whatever time the child has left, and, as such, the focus is mostly on how to live well rather than on dying.
- In the face of uncertainty about the presence of pain in a nonverbal child, give a trial of an analgesic and observe for changes in behavior that may signal the need for regular analgesics.
- As with pain, a limited trial of therapy is often the only way to assess the effectiveness of a therapy for any given patient and may include such interventions as nasogastric feedings for questions about hunger and oxygen for dyspnea.

- The death of a child is one of the most stressful life experiences, and the void it leaves for the bereaved remains inadequately understood.

SUMMARY

Pediatric palliative care comprises a diverse population with a wide variety of often rare diseases for long and unpredictable periods of time. Communication is a core skill needed to help children with life-limiting illness and their families, and it requires competencies that include nonverbal assessments and proxy decision making. Pediatric palliative care clinicians must attempt to ensure that these children and their families have the best quality of life possible under very difficult circumstances by managing painful and unpleasant symptoms as much as possible, offering choices about where and how care is to be delivered, and, perhaps most importantly, recognizing that being with children and families as they live through the end of a child's life is both a duty and a privilege that can make a difference.

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Palliative Care in the Intensive Care Unit

11

Laura Hawryluck

CHAPTER OUTLINE

INTRODUCTION
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INTRODUCTION

The primary goal of intensive care medicine is to attempt to save lives by supporting and normalizing physiology as much as possible during an acute life-threatening illness. Since the inception of critical care medicine in the 1960s, technological advances, innovations in therapeutics, and a greater understanding of life-threatening illnesses have, in fact, resulted in significant improvements in morbidity and mortality. As a result, the practice of critical care medicine has also evolved. Although most people are still admitted with acute illnesses or an acute deterioration of a chronic illness, the improvement in the ability to sustain life has resulted in more prolonged stays in the intensive care unit (ICU) for many patients, as well as a greater incidence of secondary complications that may be life-threatening in and of themselves. Those who do survive often have significant short- and long-term changes in quality of life. For these reasons, many people fear needing ICU care under any circumstances. Others fear being kept in a state of bare existence, and some fear surviving a life-threatening illness only to be restored to an unacceptable quality of life. Such fears have been the driving force behind advance care planning initiatives and legislation to mandate that patients have a voice in their

own health care. Unfortunately, only 10% to 20% of people complete an advance care plan (1). Moreover, the impact of advance care planning efforts has been limited because it is estimated that only one third of patients receive care according to their preferences, at least in circumstances in which such preferences were more consistent with a palliative care plan (2).

The current reality is that one in five US residents will die in an ICU (3). Research reveals that 11% of Medicare recipients spend more than 7 days in intensive care during the last 6 months of life (4). Such care may not be inappropriate if it has the ability to restore a person to some acceptable quality of life, even if only for a short time. However the point is that the numbers are large and they are expected to increase as our population ages. Life in the ICU is continuously and precariously in balance with death on a day-to-day basis and, for the sickest patients, even on a moment-to-moment basis. Caring for dying patients and their families is very much integral to the practice of intensive care medicine, yet palliative care in the ICU poses its own set of unique challenges.

NEGOTIATING GOALS OF CARE

The need for admission to the ICU usually occurs with little warning of the drastic illness and resultant changes in a person's life. Initial goals of ICU care are always to resuscitate, stabilize, and try to save the life of the critically ill patient. The course of critical illness, in spite of all of the extensive monitoring and available diagnostic testing, often remains unpredictable. Although the ICU team hopes for steady improvements after the initial resuscitation efforts, deteriorations can be unexpected and profound. Subsequent recovery, if it occurs, is never fast.

Many severity of illness scores (e.g., Acute Physiology and Chronic Health Evaluation [APACHE], Sepsis-Related Organ Failure [SOFA]) have been developed to help improve prognostication. Such scores enable the characterization of patient populations, the ability to audit and compare outcomes, and the ability to stratify for research studies and to quantify resource needs. These scores have limitations, however. The patient population from which they were derived may not apply in all situations of critical illness, the data needed to calculate the score may be unwieldy, collection errors may occur, and the model may not reflect advances in critical care medicine. These scoring systems were developed to predict outcomes for *populations*, not individual patients. Their accuracy in predicting survival for an individual patient is not as reliable or precise (5). These scoring systems do have value, however, because most intensive care specialists tend to overestimate mortality, and these estimates ultimately influence decisions to withdraw treatment (6). It has been shown that intensive care specialists are more accurate in their predictions than primary team physicians, who tended to overestimate the probability of favorable outcomes (7).

Another goal of life-sustaining interventions, be they mechanical ventilation or inotropes or vasopressors, is to alleviate symptoms such as dyspnea and pain. However, the interventions themselves may be a source of significant discomfort and have the potential to cause secondary acute life-threatening complications. These complications, usually infectious or ischemic, may arise after the original illness is cured and can ultimately be fatal.

The double-edged sword nature of life-sustaining interventions must not be forgotten, nor should the discomforts that patients are "asked" to endure while in the ICU as the team attempts to save their life and restore them to health. Critically ill patients experience distressing symptoms, including anxiety (68%), depression (40% to 70%), fear (54%), pain (52% to 75%), discomfort from the endotracheal tube (60%), discomfort from the nasogastric tube (48%), nightmares and hallucinations (31% to 74%), dyspnea (33%) insomnia (13%), and thirst (10%). Most patients rate these symptoms as moderate to severe in intensity (8, 9).

Although advance care planning is an important tool designed to give voice to an otherwise silent patient, one of the most fundamental flaws in the process is the public's fear and general lack of understanding of what life-sustaining interventions really entail. The question in an ICU is often: "Just because I can, should I?" Concepts of suffering, of burdens versus benefits, of likelihood of survival, and, finally, of quality of life are different for each person. Regular discussions and negotiations and revisions of the goals of care are an absolute necessity to ensure that the wishes, values, beliefs, and goals of individual patients are respected.

Each member of the ICU team can play an invaluable role in improving communication, providing support, and facilitating such decision making, whether with the patient or with a surrogate. The ICU team has an obligation to ensure that any information it communicates is consistent. To this end, any intrateam conflict should be resolved without ensnaring the patient or family. Furthermore, it is not uncommon for people to choose different words to communicate the same thing, and at times it may seem that different messages are being conveyed. Warning patients and families of these common communication difficulties may encourage them to seek clarification and so help prevent confusion and conflict.

It is often difficult to determine the optimal timing of the switch from a predominantly curative approach (when pain and symptoms are treated, just not as the main goal of therapy) to a predominantly palliative approach (when survival is no longer possible or even desired). A gradually shifting blend of goals, with each decision tailored to the likelihood of success for an individual intervention, is often the best. The knowledge of the invariably rocky nature of any critical illness, the problems in prognosticating, conflict within and among health care team members regarding prognosis and treatment plans, religious and cultural beliefs, patient and surrogate decision makers' wishes to keep going even in the face of diminishing chances of survival, and the hope—realistic or otherwise—on the part of patients, families, and the health care teams that things will improve, are all factors in such decisions. This being said, decision to limit treatment occurs relatively quickly, with the median time from ICU admission to the first decision to limit treatment occurring in a median of 2.8 days (range, 0.6 to 9.8) (10).

DECISION MAKING WITH CRITICALLY ILL PATIENTS

Communicating with intubated patients is particularly difficult and one of the most frustrating problems for patients and health care providers alike. Options include lip reading (difficult because the tape and endotracheal tube inhibit the formation of words), use of the alphabet (to spell out messages), word or picture boards, and writing (also challenging with arterial and intravenous lines in place

and the generalized weakness and fatigue that frequently accompany critical illness). Studies have shown that fewer than 5% of patients are able to communicate with the health care team at the time of decision making regarding withholding or withdrawing life support (11).

To participate in any decision-making process to consent to or refuse treatment, patients must first be capable; that is, they must have the ability to understand treatment options, risks, and benefits and must be able to appreciate how such options will affect them in view of their life goals, values, and beliefs. The challenges in communicating with intubated patients can make capacity assessments very difficult. Few critically ill patients are actually capable because the severe illness, the medications, and the lack of sleep all combine to reduce their ability to participate in decision making regarding their care. Critically ill patients have described extreme fear, inner tension, and a sense of isolation, all of which can be increased by seemingly trivial events (12). Nightmares, hallucinations, and delusions are common (13). A patient's recall of previous conversations and ability to concentrate may be reduced. As in other settings, capacity may be variable, and decisions may change from one day to the next. The challenge in the ICU is to ensure that differences in decision making are real and are not clouded by confusion, "transient" emotional states, or incapacity. Consistency of decisions over time is important.

An additional challenge is to explain life-sustaining interventions in the depth required to facilitate decision making. Patients with borderline capacity may be able to understand and appreciate some but not all of this complex information. In these situations, their decision making, if any, would not meet ethical or legal standards of practice. Because the stakes can be very high, it is crucial to be certain of a patient's capacity before engaging him or her in any decision making. Indeed, faced with the discomforts inherent in life-sustaining interventions, many patients request withdrawal of such therapies only to change their minds when they are informed of the impact on their chance of survival. In practice, only 0.5% to 5% of ICU patients are deemed capable to participate in such decision making (13). In a large French study, only 27% were deemed capable of understanding the decision to limit therapy (14).

Although decision making with critically ill patients is rare, when it is possible, a specific set of communication skills is required. Information must be conveyed in a clear, consistent way, with frequent checks of understanding. Unlike in other settings, the health care provider will, by necessity, have to do most of the talking. The ICU team has to have a clear picture of and stay focused on what the patient needs to know, compared with what would be nice to know, without becoming overly paternalistic. In general, the following information must be conveyed:

1. An explanation of the illness that brought patients to the ICU, and treatments and response to date
2. Life-sustaining interventions, what they entail and what they can and cannot potentially achieve
3. The current and future goals of therapy
4. What needs to be done to try to achieve these goals
5. The alternatives
6. The chances of success
7. The reasons for recommendations regarding the future course of therapy, including that of withholding or withdrawing life-sustaining interventions

Although some of this information may have been discussed in prior conversations, it is important to recapitulate, even briefly, when facing major decisions because research has shown that critically ill patients, even those that seemed capable at the time, have very significant problems recalling their stay in the ICU. Even capable patients may be able to concentrate for only short periods. Expressing empathy while trying to be clear and brief can be especially challenging (Box II–11–1). By necessity, the ICU physician will need to do most of the talking to make the process easier on the patient. However, everyone present, including the patient and family members, should be made aware that interruptions for questions or clarifications are expected at any time. Health care teams need to be prepared and committed because facilitating decision making is going to take time, and the communication process may be frustrating for all involved.

If the patient consents, the family may also be present during these discussions. Although the family can offer tremendous support, when the news is bad, they may also require significant support themselves. Moreover, a natural desire to shield the patient may also exist and may hinder discussions. Having the family present while the patient is gently informed can help ease their anxiety and can facilitate future discussions and expression of emotions and support. For these reasons, it may be a good idea to prepare the family for the news they are about to hear and the decisions that need to be faced before the bedside meeting occurs.

Because critically ill patients are rarely capable, the burden of trying to grasp the severity of illness and the prognosis and then to consent to or refuse the proposed treatment plans rests with the surrogate, who is most often a member of the family.

BOX II–11–1 *DECISION MAKING WITH CAPABLE CRITICALLY ILL PATIENTS*

Agree on a convenient time, decide who will be present, and make participants as comfortable as possible in the intensive care unit room, by ensuring as much privacy as the environment will permit.

- State the purpose of the meeting.
- Explain the meeting format.
- Recapitulate current the illness and explain goals and current life-sustaining interventions.
- Give information in small, clear, straightforward, and simple chunks, and check frequently for understanding.
- Be supportive and sensitive to emotional, psychological, cultural, and spiritual needs, especially fear and a sense of isolation.
- Avoid giving inappropriate hope and avoid the inappropriate destruction of hope.
- Avoid euphemisms: If the expected outcome of a decision is death, the patient needs to be told as gently and empathetically as possible, but it must be clear.
- Be patient when and if questions arise.
- Move the discussion into the future: Where do we go from here?
- Ask how these treatment options would fit with the patient's values, wishes, goals, and beliefs.
- Facilitate the development of realistic goals, and make a recommendation regarding future treatment plans.

DECISION MAKING WITH SURROGATES

Most surrogates are family members or people who are very close to the critically ill patient. The role of a surrogate is thus very difficult. On the one hand, surrogates have to deal with a myriad of emotions engendered by seeing their loved ones in a state of profound illness. On the other hand, they have to find a way through these emotions to understand the illness, the life-sustaining interventions used, and the treatment options, and to be able to participate in decision making with the health care team. The decision making standard is not what the surrogate would want; rather, it is what the patient would want if still able to speak for himself or herself. These two concepts may not agree. The lack of an advance directive or of some prior indication from a loved one results in significantly increased stress levels. In addition, surrogates and families frequently have difficulty eating and sleeping and are commonly physically and emotionally exhausted. Different coping styles may lead to misunderstandings, hurt, and intrafamily conflicts. Depending on the level of critical care required and the resources available, surrogates may have to travel great distances to be with their loved one. In these situations, their support network may be fragmented or lacking altogether.

Not surprisingly, the prevalence of anxiety and depression in family members is high: 69.1% and 35.4%, respectively. Significant symptoms of at least one—anxiety or depression—are seen in 84% of spouses and in 72.7% of family members of critically ill patients (15). Factors that increase anxiety include the absence of prior chronic disease in the patient, a spousal relationship, female gender, the absence of regular meetings with the ICU team, the absence of a quiet room for such meetings, and a desire for or actual professional psychological help. Factors that increase symptoms of depression are younger patient age, a spousal relationship, female gender, the lack of a meeting room, and the provision of seemingly conflicting information. When faced with decisions to withdraw life support, the stress is increased greatly, and high levels may persist 6 months later (15, 16).

Such psychological distress may seriously affect the ability of family members to fulfill their role as surrogate decision makers. In one study, only half of family members, acting as surrogates, understood the information regarding diagnosis, prognosis, and treatment that was conveyed by the health care team, yet most family members in North America prefer a shared decision-making model with the health care team (17). Even though one family member may be officially designated as the surrogate, most decisions are made in consultation with others. For these reasons, the ICU team must regard the patient and the entire family as a unit of care.

Overall family satisfaction with the care received by the patient in the ICU is high (84%), and most (77%) are satisfied with their role in the decision-making process. There appears to be a direct correlation between satisfaction with care and role in the decision-making process (18). Family satisfaction also increases with the provision of greater amounts of information, with the amount or level of care received, and in proportion to the degree of respect and compassion shown to the patient and family member. However, studies have also shown that ICU family meetings often fail to meet the needs of families. Even though the decisions to withdraw life support are weighty, one study revealed that these meetings are relatively short (32 minutes (SD, 14.8 minutes; range, 7 to 74 minutes), and the

average time allocated to listening to the family speak was only 29% (SD, 15%; range, 3% to 67%). As the proportion of time spent listening to the family increased, so did the family's satisfaction (19, 20). Allowing the family greater time to speak does not increase the duration of the meeting, a finding that ICU teams need to be aware of because quality of care can be easily improved even when time is in short supply.

Although the total meeting time was not associated with family satisfaction, other studies have shown that meetings that last longer than 10 minutes are associated with increased understanding. There appears to be a need for families to identify and speak with the physician "in charge," usually the staff intensive care specialist, because they look to this individual for comfort, information, and reassurance. Failure of the staff physician to establish such a relationship may be perceived as a sign of a lack of caring.

Conflicts regarding decisions to withdraw life-sustaining interventions are not uncommon. Whether between family members or with the health care team, conflicts are very draining for all involved. The effects on families can be profound and include increased stress, anxiety, grief, complicated bereavement process, and difficulties in future interactions with the health care system. Conflicts are also sources of frustration, secondary intrateam and interteam conflicts, and burnout.

Misunderstandings and forgetting or mixing up information are common, and repeated explanations may be required over the course of several meetings. In practice, some family members appear to become fixated on the data generated by the ICU, sometimes without really understanding them. Although this may be a way of coping for some, focusing on a few laboratory results, the fraction of inspired oxygen, or hemodynamic parameters on the monitor, may not provide an accurate picture of the course of illness or its prognosis. In these situations, gently explaining the limitations of such an approach and refocusing on the larger picture can be very helpful. Families also need to be reassured that any pain and distressing symptoms will be alleviated and that comfort will be ensured no matter what decisions are made.

In the end, the approach to meeting with a surrogate is not all that different from meeting with a capable patient (Box II–11–2). Three important added dimensions are: facilitating communication between family members and their critically ill loved one, facilitating communication among family members, and alleviating the burden of decision making as much as possible by acknowledging how difficult the tasks are and placing decisions into a shared decision-making model. Even if the critically ill patient is unconscious, encouraging the family to talk to their loved one, to express emotions, to resolve any conflicts and misunderstanding, and to provide support is important because this approach can often help to improve their own abilities to cope in the days ahead.

PAIN AND SYMPTOM MANAGEMENT

To help improve the quality of care and to address issues of pain and symptom control, in 1995 the Society of Critical Care Medicine established practice parameters for administering analgesia and sedation to critically ill patients (31). Still, problems remain.

BOX II–11–2 *DECISION MAKING WITH SURROGATES*

Choose a convenient time and ensure that all who need or want to be present are there.

- Introduce the ICU team members, and establish the relationships of all present.
- State the purpose of the meeting.
- Explain and recapitulate; avoid euphemisms. Clarify any misconceptions and miscommunications.
- Explore previously expressed patient values, goals, and beliefs, and explore concepts of patient's best interests AND
- Discuss potential future goals of therapy.
- Acknowledge the difficulties of the substitute's situation, normalize the experience, and be supportive and sensitive to emotional, psychological, cultural, and spiritual needs. Be prepared to explain that different coping styles are not a sign of lack of caring.
- Pay particular attention to the needs of younger children (if any). Additional resources may be needed.
- Encourage and respond to questions, either during the meeting or those that arise later, in an open and clear way.
- Explain to the best of your knowledge the experience of the patient while in the ICU. Acknowledge times of distress if they occurred, and explain how pain and symptoms will be alleviated and comfort ensured no matter what decision is taken.
- Encourage the ICU team's involvement during the meeting.
- Place decision making into a shared team framework.
- Address potentially hidden issues such as anger, blame, or guilt they may be experiencing toward the patient, the team, or themselves.
- Facilitate the development of realistic goals, and make a recommendation regarding future treatment plans.
- Facilitate conversations between family members and the critically ill patient: Encourage them to speak and to express love and support.

ICU, intensive care unit.

Pain and other distressing symptoms are very common in the ICU (see earlier). Recognizing them and evaluating the response to treatment are challenging: difficulties in communication and decreased levels of consciousness resulting from critical illness and medications often lead to reliance on facial expressions and nonspecific physiological parameters such as tachycardia or bradycardia, tachypnea with accessory muscle use, and hypertension or hypotension. In view of these inherent difficulties, it is concerning that most health care providers fail to recognize or underestimate the severity of the patient's pain and distress (32). Others refused to administer more medications when asked, for fear of exacerbating hemodynamic instability and causing respiratory depression. Yet, in the ICU, hemodynamics can be supported with increasing doses of inotropes or vasopressors, and fears of respiratory depression have repeatedly been shown to be unfounded. Even when the goal is curative, it is unacceptable not to alleviate pain and distress even if doing so means increasing the amount of support required. Certainly, based on the current literature, the need for concerted efforts to improve pain and symptom control using nonpharmacological and pharmacological means in the ICU is undeniable.

In the ICU, continuous infusions of narcotics and sedatives are used to alleviate pain and symptoms caused by the illness itself, to allow the assumption of

greater control of respiratory function with mechanical ventilation, and to decrease the discomforts inherent in being on life support. Intermittent bolus doses of medications are used to supplement the infusions in anticipation of and in response to interventions that would be expected to increase pain and suffering. The use of continuous infusions results in better pain control and lower total doses of medication overall, yet many patients do require moderate to high doses of opioids and sedatives. In multisystem organ failure, these medications and their metabolites can accumulate, resulting in very prolonged sedation and decreased levels of consciousness. This has led some to recommend daily interruptions in such therapy, and although such actions may lead to earlier discharge and fewer investigations, the effects on the patient's experience of pain, anxiety, and distress are not known.

In the last hours of life, when life support is being withdrawn, the ICU team has to be prepared to manage dyspnea, pain, and any other signs of distress acutely. Knowledge of the difficulties in assessing and subsequently treating pain and suffering is important, and the current literature indicates that the lack of success in doing so effectively in survivors seems to suggest a need to err on the side of being more aggressive in palliating such symptoms in dying patients. Many health care providers feel that pain and suffering are undertreated during withholding and withdrawal of life support (33).The one-to-one nurse-to-patient ratio is a great advantage in ensuring that patients are continuously assessed and medications are given quickly when needed. Indeed, anticipation and understanding of the effects of withdrawing life support, the frequency of reevaluation, and the immediate availability of the team should result in the ICU's being a leader in palliating symptoms at the end of life and ensuring comfort during the dying process.

Sedated patients are usually too ill to be "woken up" to speak to family members one last time. This can be a significant source of distress for the family and should be gently explained. In practice, if the patient is receiving continuous infusions of medications, these are continued and increased as required. Those patients not receiving infusions may have them started: such infusions will provide a baseline level of comfort, and many nurses find it easier and less disruptive to the family during this time to provide any needed boluses through the infusion pumps rather than through a syringe. Intravenous boluses of opioids, sedatives, or both are usually needed as the ventilator is withdrawn (see earlier). Boluses may also be given every 5 minutes for any signs of pain, dyspnea, agitation, or anxiety. When boluses are given, the infusions may also be increased to maintain symptom control. Infusions should not be increased without bolus dosing: the time to reach steady state from an increase in the infusion rate alone and hence for the patient to perceive any benefit is far too long. To achieve comfort, most patients are sedated into unconsciousness. In the current literature, such a practice may be viewed as terminal sedation, a practice some have questioned as being euthanasia in disguise. In the ICU, continuous infusions of opioids and sedatives while a patient is dying are simply a continuation of that way in which pain and distress are managed on a daily basis and constitute, without question, palliative care.

The amount of narcotics and sedatives required is variable and may be quite high. Doses given may be 5- to 10-fold higher than during the curative phase of treatment. The amount of medication needed depends on the level of distress and is different for each patient. The patient's baseline requirements of narcotics and sedatives before the withdrawal process also determine both the amount needed for bolus doses and the total dose. The average dose of morphine is 16

to 20 mg/hour and 7.5 mg/hour of lorazepam equivalents from 1 hour before ventilator withdrawal to the time to death (34, 35). The range in other studies was 0.5 to 350 mg/hour morphine and 0.5 to 95 mg/hour midazolam. No hastening of death has been seen in relation to doses of opioids or sedatives. Any difference has, in fact, been inverse: higher doses result in increased time to death.

The *principle of double effect* is used to permit the administration of analgesics and sedatives to alleviate the dying patient's distress, even though such administration could hasten his or her death. Although the current literature would seem to refute that any hastening actually occurs, fears still exist that the administration of opioids and sedatives may shorten the time to death. The principle of double effect was given legal sanction in a US Supreme Court decision that stated if the intent in administering analgesics and sedatives is clearly to palliate, physicians do not need to fear being charged with murder or assisting suicide. Fears of being misunderstood—of having an intent to palliate mistaken for an intent to kill—are currently being exacerbated by debates and articles in the medical literature in which the legalization of euthanasia is promoted by misappropriating the principle of double effect to diminish the fundamental and very real differences in intent that exist between the practices of palliation and euthanasia An unintended consequence may be to increase the reluctance on the part of health care providers to administer adequate analgesia and sedation and thus risk undertreating their dying patients. For these reasons, recently developed consensus guidelines clarifying palliative care in the ICU, distinguishing it from assisted death, and building understanding between medical and legal groups may help to improve the quality of end-of-life care.

WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING INTERVENTIONS

At least 70% of deaths in the ICU follow decisions to withhold or withdraw life support. Withholding and withdrawing are believed to be ethically and, for the most part, legally equivalent. In practice, the two do not feel the same. By the time a decision to withdraw life support has been reached, the relationship among the patient, family, and team may be more established, and the withdrawal is more emotionally difficult. Additionally, withdrawal decisions in general have a more acute, direct, and profound effect on the need to realign hope from that of survival to that of a peaceful death.

Excluding patient wishes, recommendations to withhold or withdraw life support are based on the intensive care specialist's assessment of the likelihood of surviving the current acute illness, the likelihood of long-term survival, premorbid cognitive function, patient age, length of ICU stay, and quality of life both before and after the course in ICU. Diagnostic categories such as cirrhosis, cancer, severe cardiac and respiratory failure, multisystem organ system failure, acute neurological diseases, and cardiac arrest are also associated with recommendations to withhold or withdraw support. System issues such as available resources, costs in relation to perceived patient benefit, and potential to help others play an increasing role as well in these current times when health care budgets become strained and physicians are placed in a gate-keeping role.

It is well recognized that physicians' assessments of likelihood of survival and quality life are influenced by their own prior experiences and by their ethical, moral, cultural, and religious beliefs. Such inherent differences can result in considerable variability in their recommendations regarding withholding or withdrawing life support. Other factors idiosyncratic to intensive care specialists and their practice environment also come into play: the years since graduation, the location and number of beds in the ICU, and their assessment of the likelihood that they would withdraw life support in comparison with their colleagues. Such variability can be a source of considerable distress both for other members of the involved health care teams and for families. Intensive care specialists need to be conscious of these disparities in practice and must work together to ensure more consistent decision making to improve the quality of end-of-life care provided.

Although the increasing focus on patient autonomy and rights has led to a shared decision-making model, intensive care specialists still make unilateral decisions to withhold or even to withdraw life-sustaining interventions on the basis of futility. There is no ethical or legal obligation to offer treatments that are deemed futile. However, the concept of futility is troubling. Many definitions have been proposed, none without serious flaws. In the ICU, knowledge of the patient's goals and beliefs will result in the withholding of some treatments without discussion and maybe even without informing the patient or surrogate and family, who are already overwhelmed with information and emotions. Such lack of discussion *may* not be inappropriate as long as the benefits of such treatments are evaluated in the context of patient goals and beliefs. Other treatments may be withheld if a given patient is imminently dying and the treatment would not be of any benefit in attempts to save his or her life. Again, discussion of such decisions with surrogates and families would not serve any purpose except to increase their distress and risk provoking a sense of abandonment. Such discussions may also be burdensome in that they would almost seem to be a search for absolution rather than an effort to respect autonomy and shared decision making.

Unilateral withholding or withdrawing of life support without knowledge of the patient's goals or when death is not imminent is more troubling because such decisions are prone to bias, as discussed previously. If life support is only prolonging the dying process, the standard of care would be to withdraw such interventions with the surrogate's consent. In cases when life support is serving only to prolong the dying process but the surrogate objects to its withdrawal and the conflict cannot be resolved, intensive care specialists, bioethicists, and the courts are split over whether unilateral withdrawal is acceptable. To date, most courts have been unwilling to make decisions that would result in the death of a patient whose wishes are unknown, and rulings have supported the families' wishes to continue life support (21). As resources become scarcer and the public and courts become more educated about life-sustaining interventions, the rulings and opinions may change.

The first therapy to be withheld is usually cardiopulmonary resuscitation. In view of the very poor survival rates after cardiac arrest in critically ill patients, instituting a Do Not Resuscitate order is an understandable and appropriate first step. Subsequent withholding decisions involve instituting limits to levels or numbers of inotropes, to escalations in ventilator settings, or limiting the introduction of new life-sustaining interventions such as dialysis. Placing such limits has been

translated into Do Not Escalate (DNE) orders on patients' charts. Such orders may be vague to other team members, especially for team members who were not present during the family meeting. To ensure clarity, DNE orders should be followed by a detailed explanation. Decisions to withdraw life-sustaining interventions are usually the last to be made.

After decisions are made to withdraw life support, variability exists in what is withdrawn and how. Therapies most likely to result in a more immediate death, those whose withdrawal will not increase pain and distress, those that have been more recently instituted, and those that are more invasive, expensive, and scarce are usually the first to be discontinued. For patients receiving multiple life-sustaining interventions, withdrawal may be sequential or simultaneous. There is no difference in time to death based on sequential or simultaneous approaches to withdrawal. It is not known whether one method of withdrawal is better than another, nor can such a question ever be answered. The most important goal is that the patient be kept comfortable no matter how the withdrawal is accomplished.

HOW TO WITHDRAW A VENTILATOR

With the foregoing considerations in mind, inotropes and vasopressors are simply turned off without being weaned. Mechanical ventilation was generally the last measure to be removed. However, more recent research reveals that mechanical ventilation is withdrawn completely in 75%, is reduced in 15.5%, and is not withdrawn at all in 9.2% of patients (20). Most commonly, the ventilator is quickly weaned in stages. The fast, stepwise approach allows the team to control and quickly alleviate any signs of dyspnea, agitation, or distress with a combination of opioids and benzodiazepines because these medications have known synergistic effects (20–22, 26–33). Initial bolus doses of an intravenous opioid (usually morphine or fentanyl) and a benzodiazepine (usually midazolam or lorazepam) are commonly given, and infusions of these medications are increased in anticipation of increased dyspnea as the ventilatory support is decreased. If the patient is already sedated with propofol, it may be used instead of benzodiazepines. The ventilatory support is then decreased, and further bolus doses are administered and infusions are increased as required. Once the patient appears comfortable, further reductions in support are made. The speed of weaning the ventilator varies based on patient comfort and the experience and practice of the intensive care specialist and respiratory therapist. In general, if the ventilator is to be weaned, a guiding principle is that it should occur as fast as possible to avoid prolonging the dying process and as slowly as required to ensure comfort. In practice, withdrawal of ventilatory support generally occurs over a period of 15 to 30 minutes.

Sixty-three percent of patients who undergo withdrawal of mechanical ventilation are extubated (20,33). Removal of the endotracheal and nasogastric tubes and of all the accompanying tape eliminates two more sources of discomfort. It has added the benefit of allowing the family to get closer and to see the face of their loved one finally unencumbered once again. An oral airway may be required to maintain the airway and to prevent choking. Secretions in the posterior pharynx may become audible and can be decreased with anticholinergic agents such as scopolamine, given intravenously to ensure absorption.

If the patient has an excessive amount of secretions and requires very frequent suctioning or if he or she is in florid pulmonary edema, extubation is probably not a good choice because in these situations, anticholinergic agents are usually insufficient, and patients can be helped by suctioning through the endotracheal tube. Patients who are pharmacologically paralyzed and hence are unable to breathe at all without ventilatory support should not have mechanical ventilation completely withdrawn and should definitely not be extubated because these acts will directly and immediately cause death. The difficulty is that sometimes in the presence of multisystem organ failure, metabolites can accumulate; therefore, these drugs take a long time to wear off, and the effect cannot always be reversed. In these situations, the fraction of inspired oxygen can be reduced to room air, and the level of assist and the respiratory rate can be significantly decreased. However, programming a minimal respiratory rate and level of assist from the ventilator must always be provided. Complete withdrawal of a ventilator from a paralyzed patient, one who is unable to breathe because of neuromuscular blocker drugs, is not condoned (30). An added challenge is that pharmacological paralysis eliminates the usual signs of distress, such as facial grimacing and respiratory effort. Ensuring comfort in a paralyzed patient as ventilatory support is reduced requires greater reliance on following hemodynamic parameters and erring on the side of being liberal with narcotics and sedatives.

The ways in which the ventilator is withdrawn and whether or not the patient is extubated have not been associated with any differences in time to death, the families' perceptions of comfort, or the use of morphine. Most families who have been through this process believe that their loved one was totally or very comfortable during the withdrawal and had a good death. Once life support is withdrawn however, the time to death is out of the control of the ICU team and may be difficult to predict. Patients receiving extensive support may die within minutes, sometimes before life support is removed in its entirety. Others may take hours to die.

THE LAST HOURS

Whenever the transition is made in primary goals from cure to palliation, efforts must be made to ensure therapeutic coherence. Therapies aimed at curative plans should be stopped, and only those aimed at palliating symptoms should be continued. Many therapies and all diagnostic tests are no longer indicated. This is one aspect of end-of-life care in the ICU that needs serious improvement: one study even showed that 67% of patients being withdrawn from life support continued to have blood drawn until their death (22).

Some have suggested and found success with end-of-life care protocols designed to bring some standardization to the withdrawal process and to serve as a reminder of what needs to be done (23-25). It is hoped that any need for protocols would subsequently diminish as their components become integrated into the team's standard care. Although such protocols may help to improve the quality of care, they should never replace the sharing of humanity so needed at this time. Others have suggested formally involving palliative care teams in the care of dying ICU patients. Although these efforts have also succeeded in improving end-of-life care in some studies, palliative care teams need to understand the effects of

withdrawing life support and adapt their practice to meet the acuity of pain and symptom management in the ICU.

CARING FOR THE FAMILY

An important part of providing quality palliative care in the ICU during the withdrawal process is to explain to the family what is happening. Death in the ICU has been portrayed in the media as one of the worst possible situations anyone could ever experience. The common term "pulling the plug" leads many to picture an abrupt removal of interventions that were instituted to alleviate distress in the first place. Hence, families commonly fear a death filled with pain, dyspnea, and suffering. Requests for euthanasia are not uncommon at this time and generally are a reflection of such fears. Explicit, clear, and straightforward explanations of how each life-sustaining intervention in use will be stopped, how pain, dyspnea, and any other signs of distress will be assessed and palliated, how the family can help, and how they can be with their loved one are absolute necessities. The ICU team should be prepared to offer gentle and straightforward explanations of the changes the family will observe in their loved one, changes that will occur in both their hemodynamics and respiratory patterns. Families will need reassurance that any signs of distress will be quickly alleviated, that changes are a normal part of the dying processes, and that the team will ensure that their loved one will not be distressed by these changes. Families need to be clear that the ICU team will not abandon them and that no matter how long their loved one survives after the withdrawal, he or she will be kept comfortable. Family members should be encouraged to ask questions and to express their fears. Particular attention should be paid to the needs of children, both in explaining death and dying and in helping them cope during and after the occurrence.

In the last days or hours, some ICUs are able to accommodate the family by designating a room to their private presence with the patient, limiting interruptions by staff, and even allowing a spouse to sleep next to the patient in a bed drawn up for the purpose. Efforts should be made to respect any wishes for ceremonies or religious and cultural rituals during and after death. Providing the family with emotional, psychological, and spiritual support and listening to and addressing their concerns throughout this time are crucial to providing high-quality end-of-life care. Support after the death of a loved one, help with funeral arrangements, and information on available bereavement support are also valued.

PEARLS

- Inform the patient and family early on that many health care teams will be involved in the care of a critically ill patient, and explain that this may cause communication challenges because different people may use different words to convey the same message.
- Make it clear to families that the course of critical illness can be unpredictable and that, although the initial hopes and efforts are for survival, life and death are precariously balanced in the ICU.

- Share humanity in the midst of technology: Ask about the patient as a person, and normalize the experience as much as possible by acknowledging the severity of illness, its accompanying emotions, and the complexities of decision making.
- Health care providers have an ethical, professional, and legal obligation to involve patients who are capable in the decision-making process, no matter how difficult such conversations may be.
- Place decisions in the context of goals, values, and beliefs, and discuss short- and long-term quality of life implications as best as they can be predicted.
- Ensure that treatment options, their risks, benefits, and the consequences of any decisions are crystal clear.
- Never forget that life-sustaining interventions can both cause and alleviate pain and distress. Ensure that such symptoms are evaluated and promptly treated throughout the course in the ICU.
- Ensure that treatment plans, patient and family goals, concerns, fears, and means of coping are communicated to all members of the health care team.

PITFALLS

- Using the technological environment to distance oneself from the patient as a person. Although this is an understandable coping mechanism, it can hinder the ability to provide high-quality end-of-life care.
- Failing to clarify consequences of decisions to ensure agreement with the proposed treatment plan or to spare the patient or family grief and suffering.
- Failing to engage in decision making with a patient in the rare situation when he or she is capable of doing so, to avoid difficult conversations that involve death and dying and to spare patients distressing decisions, especially when decisions involve withholding or withdrawing life-sustaining interventions.
- Failing to prepare families (and patients, if they are capable) about what to expect as life-sustaining interventions are withdrawn.
- Failing to explain how pain and distress will be palliated during the withdrawal process.
- Failing to return to the bedside during the withdrawal of life-sustaining interventions to ensure that symptoms are well palliated, support the family, and support the ICU team.
- Failing to provide initial bereavement support and information on how additional support can be obtained, if needed, after the patient's death.
- Forgetting the invaluable roles of other team members in helping to communicate with patients and families, in facilitating decision making, in providing emotional and spiritual support, and in ensuring comfort.

SUMMARY

Few other fields in medicine have endeavored as much as critical care medicine to improve the quality of care they provide at the end of life. Death in the ICU

should not be feared any more than, and perhaps even less than, death in other settings. Certainly great improvements have been made in the last 4 decades, but there is still a need for more. Ongoing education is needed to ensure that all members of the ICU team are consistently taught to communicate with patients and families, to negotiate the goals of treatment, and to evaluate and manage pain and distress. Efforts are still needed to legitimize research and assign funding. Future research to identify ongoing problems, to develop outcome measures, to assess the success or failure of improvement initiatives, and to translate this knowledge into practice is the only way to ensure that the level of care provided to those who are dying is as high as that provided to those who will survive.

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Emergency Medicine and Palliative Care

12

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CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

The emergency department (ED) cares for people with conditions all along the spectrum of illness and injury: those with chronic, progressive illness and those with or without good support systems. Although the primary role of the ED is to care for the critically ill and injured, many patients and families with nonemergency, urgent needs are nonetheless in crisis. The ED serves as a vital access point for medical care for people who are suffering, and it is a way station for those in need of crisis intervention.

UNDERSTANDING THE EMERGENCY DEPARTMENT MODEL

Perspectives for Non-Emergency Department People

Evaluate and treat, admit or discharge—this is the mantra of the ED clinician. Patients with palliative care needs present to the ED for an array of reasons, often crisis driven; their symptoms or pain may have escalated or perhaps the caregiver has panicked. Exceptional symptom management and procedural skills are critical in the ED. A fundamental understanding of how most EDs operate and knowledge of common barriers to palliative care are important first considerations.

Triage

After a visit to the ED, a clinician or relative may reasonably ask: Why was my patient with cancer and uncontrolled pain in the waiting room of the ED for hours before being seen? How quickly a patient's needs are met is one factor in the minimization of suffering. EDs serve a unique role in our society as a 24-hour safety net for the suffering, the underserved, and those with limited social or economic resources to access primary care. This is true of palliative care as well as other types of care. That said, ED overcrowding is well described across the world and is best documented in the United States, Britain, Canada, and Australia, with the resultant fact that patients may wait for long periods.

When patients arrive in the ED, they undergo triage. *Triage* means "to sort." The general purpose of a triage system is to classify patient presentations in a way that determines the potential for deterioration and the urgency with which evaluation by a physician or nurse is needed. This is typically done using a combination of factors that includes a patient's appearance, vitals signs, and underlying conditions that present a possibility of a threat to life. Under established emergency triage systems, patients who present with mild to moderate exacerbations of chronic illness are triaged to lower priority and therefore often have longer ED waits. Common triage systems generally assign patients who have no immediate threat to the respiratory or cardiac system to a semiurgent or nonurgent level. This results in potentially very long waiting room times and can cause discomfort to the patient and family. For instance, under the Canadian Triage and Acuity Scale, a patient with moderate to severe pain (4 to 7 on a scale of 0 to 10) would have a time-to-physician wait of more than 1 hour, and a patient with constipation would be triaged at the lowest triage priority level five with an "ideal" wait time of up to 2 hours before even being assessed by a nurse.

Health care professionals who interact with the ED should be aware of the resource constraints and priorities of the emergency setting and should not confuse this with a lack of caring by emergency personnel. Because the focus is on rapid identification of life threats, stabilization of vital signs, and airway management, relief of physical symptoms distress may sometimes take a lower priority than is desired. Psychosocial aspects of a patient's needs may also not be adequately explored and may, in fact, be detailed only if they relate to the triage decision.

Environmental and Systems Barriers

The setting of the ED typically lacks both privacy and the extended spiritual and psychosocial resources that would be more readily available to patients and families

in the inpatient or outpatient setting. When available, these resources are typically crisis oriented. The significant time pressure, general lack of privacy and seating, and high level of noise and distractions make the ED environment especially challenging. In the emergency setting, a practitioner must often forego his or her vision of optimal palliative care to meet the patient and family in the midst of crisis. Because of the never-ending stream of patients, the essential focus is on disposition: Where does this patient need to go next? Emergency providers are in search of critical pieces of history, physical findings, laboratory tests, or radiography that determine the disposition—admit, discharge, or transfer.

How to Assist Emergency Personnel

Emergency physicians and nurses operate in an environment of information deficits. Time constraints allow for very little time per patient, yet the doctor and nurses are expected to decide the vital next steps for the patient. Actively calling the ED staff, responding to them rapidly (by phone or in person), and letting the ED providers know what to expect are extraordinarily useful. Referring clinicians can be especially helpful if they are familiar with and explicitly communicate a patient's previously stated goals of care or treatments preferences because this knowledge can aid in targeting the correct disposition.

Perspectives for Emergency Medicine Clinicians

Bedside Rapid Trust Building

In view of the dynamics and workings of an ED, it is important to build trust rapidly, but this can be a particularly difficult task. ED patients with a variety of diagnoses have identified several factors as important for building trust, specifically the following:

1. Being treated as an individual
2. Not having reason to see the clinician as someone who is too busy to see them
3. Having reason to expect clinician's compassion at the bedside
4. Clinician sensitivity and concern
5. Having reason to expect clinician honesty
6. Having open discussion about treatment options
7. Having confidence that the patient's interests come first.

Surprisingly, factors rated as less important for trust building included the patient's perception of clinical competence, the clinician's expression of hopefulness or empathy, and the clinician's ability to use laymen's terms (1). To foster this trust and to honor these considerations, special trust building skills are necessary. Some key skills are suggested in Table II–12–1.

Magical Thinking Regarding the Effectiveness of Cardiopulmonary Resuscitation

Patients, surrogates and providers can, like all humans, engage in magical thinking and may be misinformed about the effect of cardiopulmonary resuscitation (CPR) on a chronic medical condition. Resuscitations should not be described in gruesome or gory terms, but families should be aware of the facts of CPR, including

Table II–12–1 ■ Rapid Trust Building in the Emergency Department

Emergency Department Provider Should:	Suggestions/Script
Avoid seeming too busy	Lean over the gurney and maintain eye contact when no chair is available.
Use nonrushed body language	Hold the patient's hand during the initial contact/discussion.
Be compassionate at the bedside	Maintain eye contact.
Use affirmative phrases that acknowledge the patient is human, not a number	"With so many distractions in the emergency department, I know it is difficult to discuss things...but you have my full attention now." "This can be a difficult setting to get your needs met, but we will do our best." "If I am called away suddenly, it is not because your problem is not important, and I will be back as soon as I can."
Show sensitivity and concern	"I know it is hard to speak with a perfect stranger regarding these issues, but it is how I can help you best."
Be honest	"I want to be honest with you regarding how long things will take. ..." "I want to be honest with you regarding what I see happening, even if it is difficult to talk about."
Use open discussion regarding treatment options	"Based on what I know medically, this is what the options are...this is what I would recommend."
Keep the patients' interests beyond all others	"I am most concerned with what is right for you."

those that pertain to futility when this is relevant. Perhaps influenced by what can be seen on television, more than 95% of laypersons feel that CPR is effective. Because 75% of patients on television survive initial resuscitation and 67% survive until discharge, this view is understandable (2,3). In spite of the stress and pressure that exist in the ED and in discussions of CPR, when providers talk to patients and families, they should acknowledge the difficulty of talking about the outcomes of CPR and not avoid the conversation. Studies have shown that patients in the ED are willing to hear news of a life-threatening illness (4).

CORE PALLIATIVE CARE SKILLS IN THE EMERGENCY SETTING

Core skills in the ED setting include "big picture" prognostication, recognition of sentinel ED presentations, noninvasive management of an impending cardiorespiratory arrest, noninvasive management of respiratory failure, management of severe uncontrolled pain, family-witnessed resuscitation, and death disclosure. All these skills require excellent, rapid communication and trust building.

"Big Picture" Prognostication

Consider the case of an 85-year-old man with stage IV lung cancer who presents in respiratory failure with no advance care plan regarding resuscitation. How should the emergency provider advise the patient and family regarding CPR without knowing the details of the patient's history and treatments?

Many patients and families with palliative care needs have limited understanding of their prognosis and do not have advance care plans. Because of the information deficit, the emergency provider will not be able to estimate life expectancy easily, but can more accurately define "the big picture." For example, the typical patient with cancer who is on a dying trajectory and who presents with a new urinary tract infection may recover from the infection but will still have terminal cancer after the infection is treated. If this information is communicated directly to patients and families, they may elect to treat the symptoms associated with the infection, but not the infection itself, and may regard the infection as a natural opportunity to die. A corresponding decision may be made to forgo resuscitation attempts. If the patient and family still need to fully realize that the patient will still have cancer even if resuscitation is successful, this is an important "big picture" communication that will allow an optimal decision for all concerned.

Important steps in rapid prognostication include the following:

1. Define the chronic, progressive, life-limiting illness.
2. Define the "new event."
3. Communicate the "big picture:" treatment of the new event will not reverse the chronic illness.

Sentinel Emergency Department Presentations that Indicate the Onset of Active Dying

Some sentinel presentations suggest terminal decline in a patient with chronic, progressive illness and signal that an important decision point may have arrived. Sentinel presentations include the inability to eat or drink, generalized weakness, a new illness or injury that would require major intervention (e.g., acute myocardial infarction, fracture, intracranial hemorrhage), and syndrome of imminent death. Such presentations should alert the ED clinician to the potential need for hospice, inpatient palliative care service, or preparation for a death in the ED. Patients often present with a new constellation of symptoms that are related to the natural progression of the underlying disease.

The inability to eat or drink and generalized weakness may signal progression of illness with or without an acute underlying event. The inability to take nutrition or reaching a point of critical weakness is often a pivotal point for families and caregivers. The ED response is typically to initiate artificial hydration and search for an underlying cause. What should be considered at that juncture is whether the search for a precipitating diagnosis is helpful in view of the relevant risks, benefits, and alternatives. Some patients and families are not willing to undergo invasive testing or painful procedures to give a name to, or even to attempt to reverse the course of, a new illness. Although an artificial feeding device may be appropriate in some cases of inability to eat or drink, patients and proxy decision

makers should be empowered to decline these types of interventions if they wish to do so.

Patients who present with a diagnosis that could potentially be treated with acute surgical or medical interventions (e.g., an orthopedic or neurosurgical operation) or neurologic or cardiac thrombolysis should not have the procedures until the goals of care are discussed with the patient and family. Before committing to specialty services, the ED provider should formulate a "big picture" prognosis (perhaps in conjunction with the specialist), assess possible goals of care for the patient, and discuss possible recommendations with the family.

The syndrome of imminent death deserves special attention, and the issue of CPR must be addressed. A proactive assessment of goals of care may avoid unwanted and futile resuscitations. Cardiovascular collapse can be anticipated within hours or days in many cases, so proactive discussion should be attempted if relevant plans and doctor's orders are not already in place. In patients with cancer, for example, studies have shown the survival rate of CPR to be 0% when clinicians anticipate that a patient with cancer may experience cardiopulmonary arrest because of the clinical state (sepsis, shock, multisystem organ failure) (5). Even though the provision of futile care is upsetting to emergency providers, studies show that providers will perform advanced cardiac and respiratory life support even when it will not change the outcome because they fear litigation, anger, and criticism by the patient or family (6). This is generally not helpful for providers, patients, or families.

Noninvasive Management of Severe, Acute Respiratory Failure

Conversations about resuscitation with patients at high risk for pulmonary decompensation, such as those with chronic obstructive pulmonary disease and congestive heart failure, often revolve around endotracheal intubation. Emergency physicians need to ask patients with chronic obstructive pulmonary disease or congestive heart failure about ventilation. This conversation should include the possible use of mechanical or noninvasive ventilation (NIV). NIV is an increasingly common modality in the emergency setting as a safe and effective rescue therapy. NIV may represent an intermediate step to endotracheal intubation, but it may also help to avoid endotracheal intubation altogether (7, 8). When the issue of resuscitation has never been discussed or no conclusion has been reached, NIV can give the provider and patient or surrogates time to discuss the potential risks, benefits, and recommendations of endotracheal intubation and resuscitation. NIV can also temporarily relieve dyspnea during the period when other palliative therapies for breathlessness or terminal dyspnea are being initiated. Candidates for NIV should be hemodynamically stable, conscious, alert, and cooperative, even though fatigued (increased respiratory rate, use of accessory muscles, paradoxical breathing, or the subjective feeling of being tired). Patients commonly excluded from a trail of NIV include those who wish no type of artificial support to extend life and those who are obtunded, uncooperative, lack a gag reflex, or are hemodynamically unstable (9). Failure to improve within 30 minutes of NIV signals the possible use of endotracheal intubation or medical management of symptoms. These are decisions that should be considered in the context of a discussion of goals of care. When NIV is used, the patient should still receive pharmacologic and nonpharmacologic therapies to relieve dyspnea.

Rapid Management of Severe Pain

Emergency physicians frequently treat pain and other symptoms. Like other specialists, they often undertreat pain and may not use a full range of therapies for symptoms other than pain.

Many emergency providers use a single standard 0.1 mg/kg morphine dose without frequent reassessment and without considering that a patient may be opiate tolerant (10). For instance, ED physicians and staff may be unfamiliar with basic equianalgesic dosing for opiates and especially unfamiliar with the use of methadone for pain control. Many patients present at the ceiling of analgesia provided by oral acetaminophen with opiate preparations. Although some protocols exist for rapid titration of pain control in opiate-exposed patients, it is unknown how frequently these algorithms are used. Several dosing strategies for cancer pain have been described, but there is less research with opiate-naive patients in the emergency setting. Several published protocols for patients with cancer in the emergency setting include rapid titration protocols with morphine or fentanyl (11, 12) (Figs. II–12–1 and II–12–2). However, there are no published articles on short stays in the ED in which patients are transitioned from intravenous to long-acting, oral opiates.

ED patients who have improvement of severe uncontrolled pain and who are discharged from the ED in less than 24 hours (which is usual) should be discharged with intermediate-release preparations of an oral opiate in the equivalent dose of the intravenous preparation received in the ED. They should be instructed on how the dose can be titrated by the patient or family so the dose is safely limited by patient somnolence to avoid respiratory depression. Careful attention should be paid to the appropriate opiate choice for patients with renal or hepatic insufficiency.

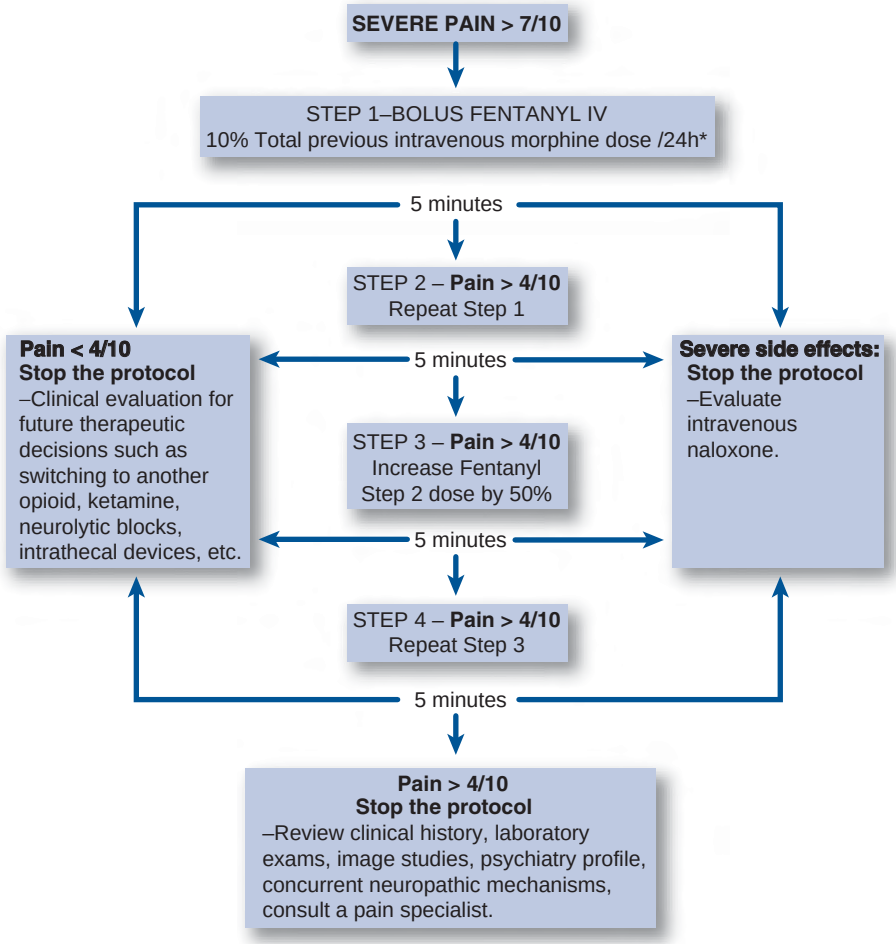
In general, when patients come to the ED from a palliative care environment, ED providers may be hesitant to administer analgesics for fear of causing respiratory depression. These fears should be acknowledged, and the proper educational support should be given to ED staff so patients do not suffer needlessly.

Family-Witnessed Resuscitation

In the event of cardiac arrest, most patients will die. Although still controversial, review of the available evidence suggests that inviting the family to be present (with support and supervision) during the resuscitation effort may be of benefit for survivors and patients (13). Few protocols have been published regarding family-witnessed resuscitation, but studies of this topic support the following conclusions:

1. Most family members would prefer to be given the option to be with the patient at the time of death during the resuscitation efforts.
2. Although such experiences are painful and emotionally draining, they may assist the family in the bereavement period.
3. Although doctors and nurses are sometimes initially reluctant, most soon become convinced of the value of family involvement.
4. A multidisciplinary approach should be used to develop a protocol.

Providers' attitudes may represent a barrier to having the family in the resuscitation area. Providers are concerned that family involvement could cause distress for survivors, interfere in the resuscitation, intimidate the team, bring greater pressure



*Convert oral morphine to intravenous morphine using a ratio of 3:1, and then to fentanyl using a ratio of 1:100.

Figure II–12–1 ■ Rapid titration with fentanyl. (From Soares LG, Martins M, Uchoa R: Intravenous fentanyl for cancer pain: A "fast titration" protocol for the emergency room. *J Pain Symptom Manage* 2003;26:876–881.)

to prolong the code, and cause anxiety in calling an end to the procedure. Physicians are more likely than nurses to oppose having survivors in the resuscitation area (14). Physicians-in-training are the most resistant and the most concerned that family presence could have a negative impact on patient care or could prove to be a negative experience.

Successful family-witnessed resuscitation requires appropriate preparation and training of the care team to increase receptiveness to the concept and practice of survivor participation (Table II–12–2). Medical and nursing staff should discuss the impact of having family members present during resuscitation attempts before

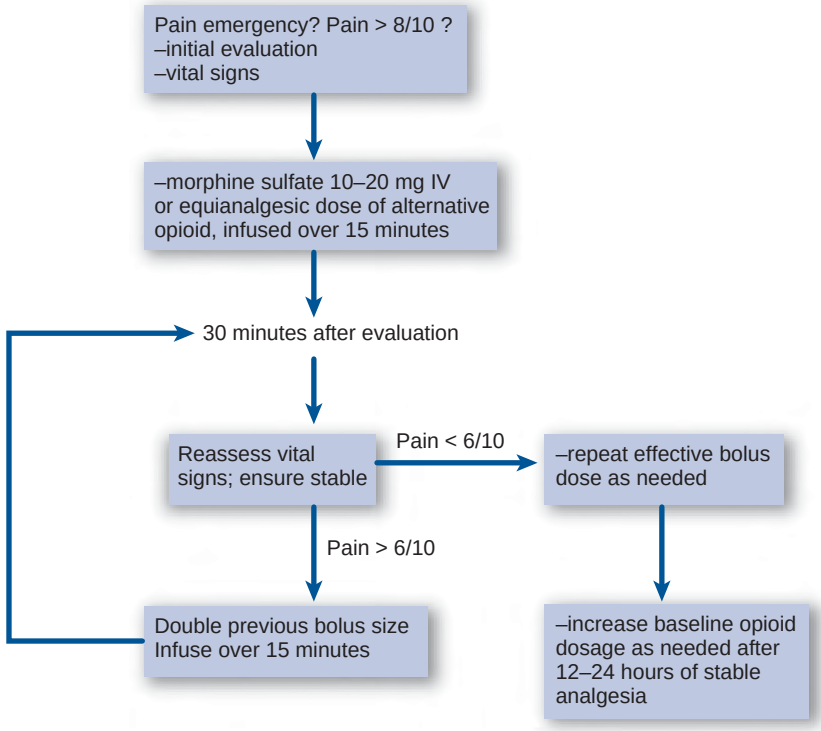


Figure II–12–2 ■ Rapid titration with morphine. (From Hagen NA, Elwood T, Ernst S: Cancer pain emergencies: a protocol for management. *J Pain Symptom Manage* 1997;14:45–50.)

Table II–12–2 ■ Family Witnessed Resuscitation (21)

Guidelines for establishing a Family Witnessed Resuscitation Protocol
- Multidisciplinary team
- Address fears and concerns of staff
- Protocol to address:
  - How many family members?
  - Key staff needed to be present
  - Roles and responsibilities of staff
  - Follow-up plan for family and staff
- Training of family facilitator (RN, SW, Chaplain)

Implementation
- Specific area for family
- Obtain consent of the physicians for family to watch
- The family facilitator helps and monitors family

bringing a spouse or other family member into such an emotional situation. Advance role playing by resuscitation team members in a number of situations is recommended by hospitals. Resuscitation team members should be sensitive to the presence of family members during resuscitative efforts. One team member should be assigned to answer questions, provide support, clarify information,

and offer comfort to family members. Ideally, quality monitoring procedures should be used to assess adherence to prescribed procedures, family and health professional satisfaction with the process, and close monitoring for adverse effects. As part of a systematic evaluation for symptoms of unresolved grief or depression, follow-up assessments should elicit family members' accounts of both positive and negative effects of the witnessed resuscitation attempt.

Death Disclosure

Although there are various methods to inform families of a sudden death, some core considerations apply (15–17). Most family survivors who experience a formal death disclosure in the emergency setting have not been a part of a family-witnessed resuscitation protocol because, in such a case, notification is typically done at the bedside. Delivering the news of death to a surviving family member can be devastating, whether or not the patient was expected to die. It can also be stressful for hospital and prehospital care providers. For both, the difficulty is increased because no relationship exists with the family and there is heightened anxiety about what kind of news is coming. Depending on the culture, a provider may go to meet the family and be asked "Is he or she alive or dead?" before the provider has had a chance to speak. A critical difference in the emergency setting is that the provider should take a leading role in delivering the news of death without using the "tell me what you know" approach because that approach typically does not help the survivors hear or accept the news. The provider should use empathic disclosure techniques to deliver the news that the patient has died. The provider should use the word "dead" or "died" rather than euphemism such as "passed on." It is important to review terminology in advance with a hospital-based translator when the disclosure will be done in a language unfamiliar to the provider. The provider may start the disclosure with something like, "I am afraid I have bad news." After a pause, continue: "I am not sure if you know what happened today." Proceed to give a very short summary, in layman's terms, of the known events prior to the death. Then say something gentle but direct and simple, such as: "This may be difficult to hear, but Mr. X died." Stay with the family for a little while; expect emotional responses. Quiet presence and then an invitation to either leave the family alone for a while or to arrange for them to see the body is usually appropriate.

SPECIAL ISSUES

Hospice Patients

ED personnel may not always be familiar with hospice rules and protocols (18). When hospice patients and families present to the ED, it may be because the patient and caregivers did not understand the dying process or because they were fearful that the patient had uncontrolled symptoms. Signs and symptoms of infection and changes in mental status are often difficult for patients and surrogates to negotiate, and short lengths of stay in hospice may make it difficult for hospice staff as well. The after-hours on-call nurse for the hospice may be unfamiliar with a particular issue, but may have other important information, such as previously

established resuscitation status and medications. Some patients and families may be in denial of the dying process and may be in search of additional opinions regarding treatment. These are all very difficult, often tense situations for the emergency provider. Emergency providers should treat the presenting symptoms but call the hospice before initiating invasive testing and detailed evaluations.

Loss of Support Devices

Among palliative care patients who present in the ED, the support devices most commonly lost include gastrostomy tubes and tracheal airways. Both losses can cause panic for patients and families. It is not uncommon for the device to be lost as a result of actions, by lay or even professional home care providers, such as moving the patient. Before acting, it is important for the provider to assess whether the patient or surrogate thinks that the device is still necessary. Presentation for care should not be assumed to mean that the patient or surrogate wants to continue using the device. A large amount of energy could be invested in the attempt to replace a device, only to learn that the patient or surrogate now wishes to discontinue its use. The patient or surrogate may view the occasion as an opportunity to explore the effectiveness of the device. The provider should give the patient or surrogate permission to discontinue using the support device if it is not meeting the patient's goals.

Enteral Feeding Devices

Numerous types of enteral feeding devices are available, and the percutaneous gastrostomy tube is the most commonly used in palliative care patients. However, patients with head and neck cancer may have pharyngostomy or esophagostomy tubes, and patients with more complicated resections may have gastroenterostomy, duodenostomy, or jejunostomy tubes. The emergency palliative care clinician cannot tell what kind of enteral tube is in use by physical examination alone. The presence of a skin incision near the ostomy site suggests that the tube is not easily removable. Nonoperative tube replacements should be done only in patients who have well established and granulated tracts. Gastrostomy tubes come in different styles and materials, including rubber, silicone, and polyurethane. Many gastrostomy tubes are designed with a flange or a crossbar (bumper) to anchor them in the stomach and to prevent migration into the small bowel. Although a Foley catheter may be used as a replacement tube, it is more temporary and difficult to secure to the skin. The latex in the Foley balloon may be weakened over time by stomach acid. A Foley catheter can always be used temporarily in the ED (after which more definitive arrangements can be made) or permanently if life expectancy is limited (Fig. II–12–3).

If the tube is still present in the ostial lumen, contrast injection should be done to determine the final resting place of the tube and to determine patency. When radiographic services are not available, nonpatent tubes should be flushed gently with saline. When the device cannot be flushed and is more than 1 to 2 weeks old, a Foley catheter can be used to replace the feeding tube.

Airway/Tracheotomy Support Devices

Common complications of tracheostomies include tube dislodgement, occlusion, and fracture. These patients may present in acute respiratory distress, and this

Figure II–12–3 ■ *A,* A Foley catheter can always be used as a temporary feeding tube replacement. The thin-walled Foley balloon usually only remains inflated for a month or so. A bolster can be made to prevent inward migration of the tube. *B,* In this case the previously removed Foley catheter was used to make the bolster for the new one. (From Roberts JR, Hedges J [eds]: Clinical Procedures in Emergency Medicine, 4th ed. Philadelphia: Saunders, An Imprint of Elsevier, 2004.)

can be a very frightening experience for the patient, family, and care providers. A patient with a tracheostomy who is in respiratory distress should be considered to have a partially or fully obstructed device. *Plugging of the trachea* is usually the result of dried respiratory secretions, blood, or aspirated materials. Secretions may act as a ball valve that allows air in but restricts outward ventilation, thus causing the patient to appear in acute respiratory distress with agitation and fear. Granuloma formation just distal to the tube may also cause obstruction. Emergency management includes attempts to clear the trachea, high-flow oxygen, and immediate exchange of the tracheostomy (Fig. II–12–4). *Dislodgement or shifting* of the tracheostomy tube can occur when the patient is intermittently ventilated and the tip of the tracheostomy is moved forward or when the head is flexed, causing the tube to be obstructed. Extension of the patient's head may solve the problem, or pulling back on the tracheostomy may help. *Bleeding* is a common complication; more than 20% of patients who present to the ED with tracheostomy difficulties have bleeding. Erosion of a major vessel from the cuff or tip of the tube is responsible for 10% of all tracheostomy hemorrhage and for most tracheostomy-related deaths. Minor bleeding is often postsurgical or the result of granuloma. Brisk bleeding from the tracheostomy, hemoptysis, or a history of either complaint should alert the clinician to the possibility of a life-threatening hemorrhage. Many patients experience "sentinel" bleeding hours or days before catastrophic bleeding. Some patients may report only a new cough or retrosternal pain. Any history or evidence of 10 mL or more of blood should be presumed to be arterial. Acute treatment in the ED includes an attempt to tamponade bleeding with a digit in the airway, a procedure that can cause significant discomfort to the patient. A discussion should be held regarding goals of care and all palliative options before more invasive therapy is initiated.

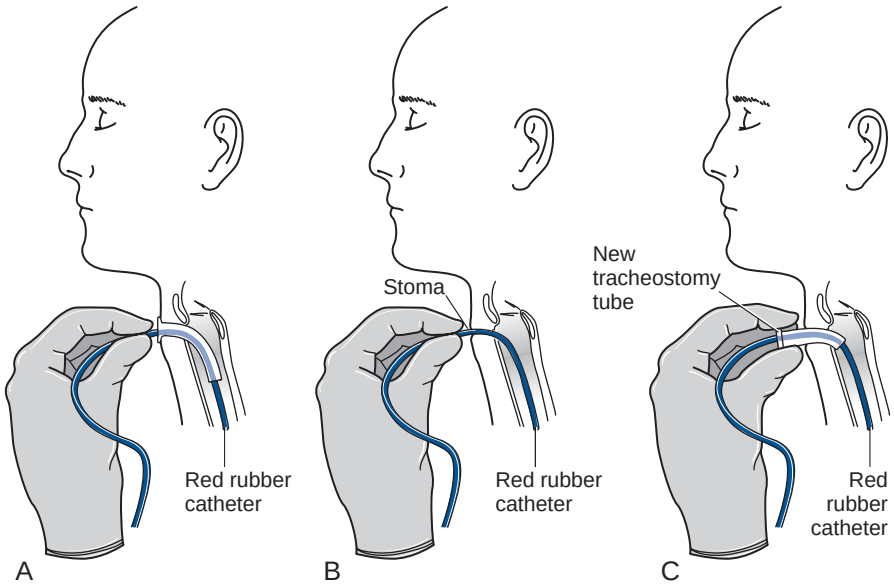


Figure II–12–4 ■ Changing a tracheostomy tube. *A,* Before the old tube is removed, a small red rubber catheter (or other guide catheter) is passed into the proximal trachea. *B,* The tracheostomy tube has been removed over the catheter, and only the catheter remains in the trachea. The catheter serves as a guide for easy and atraumatic insertion of a new tube. The neck should be slightly hyperextended. *C,* A new tracheostomy tube, without the obturator is threaded over the guide catheter; once the tube is in place, the catheter is removed. Similarly, if the tracheostomy tube has already been removed, the catheter may be passed through the stoma before a new tube is advanced. An obturator or inner cannula is not used when changing a tube with this technique. (From Roberts JR, Hedges J [eds]: Clinical Procedures in Emergency Medicine, 4th ed. Philadelphia: Saunders, An Imprint of Elsevier, 2004.)

PEARLS

- Time is the enemy. Anything that can be done faster that leads to greater patient and family satisfaction is warmly embraced.
- Emergency clinicians are typically willing and ready to provide comfort care when supported in appropriate guidelines or expertise. The de facto clinical practice is one of integration of many disciplines. Hence, these clinicians are receptive to sound evidence or clinically based recommendations from those with more expertise.
- Culturally, emergency clinicians are taught to evaluate, treat, and make disposition secondary to limitation in resources and to be respectful and helpful with this mindset.
- Emergency clinicians are very comfortable with procedures and may be able to temporize difficult airway or enteral feeding issues until dealt with more permanently.

PITFALLS

- Time is the enemy. Evaluate what is and what is not possible in the ED setting. It is often unrealistic to expect that the emergency provider will be

able to make a significant impact on communication, symptom burden, or caregiver support in the short window of time in which disposition must be made.
- Because emergency clinicians do not follow their patients, they may intentionally underdose patients with analgesics (opiates in particular) for fear of respiratory depression.
- Symptom research is sparse in emergency medicine. Hence, ED clinicians may be unfamiliar with otherwise common symptom medications such as haloperidol for vomiting.
- Emergency providers work 24 hours a day when all information systems are not available. As a result, emergency providers may err on the side of caution, typically when life is at stake, because of the paucity of clinical information available to them.

SUMMARY

Palliative care patients who present in the emergency setting are a challenge because the practice setting emphasizes rapid disposition and because the patient and caregiver population tend to present in crisis. Practitioners in the emergency setting must be able to build trust rapidly and to deliver a "big picture" prognosis. A focus on sentinel ED presentations may more clearly identify the most appropriate treatment and disposition options for patients. Providers must be competent in death disclosure and must be familiar with the pros and cons of family-witnessed resuscitation. Skills in specific minor procedures are needed to care for the patient with support devices.

Resources

Education on Palliative and End-of-life Care–Emergency Medicine (EPEC-EM): Available at http://www.epec.net

Society for Academic Emergency Medicine Interest Group: Available at http://www.comfort911.org

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SECTION III

Service Delivery

The Interdisciplinary Team

1

Judith A. Paice

CHAPTER OUTLINE

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INTRODUCTION

The team approach is crucial to palliative care, but there has been little research on the optimal structure and function of an interdisciplinary team that is responsible for caring for those with a life-threatening illness. The interdisciplinary team approach to care is not unique to palliative care. Other disciplines that emphasize teamwork include rehabilitation, critical care, mental health, and geriatrics. Interdisciplinary teams include professionals from multiple disciplines (e.g., nurses, physicians, social workers) who work collaboratively and make group decisions about patient care. The primary difference between multidisciplinary and interdisciplinary care is the role of collaboration and consensus building that is present in interdisciplinary care. Regular meetings serve as the forum for this collaboration and consensus building, and each member contributes the knowledge and skills drawn from his or her own unique training and education (1). This optimal approach to care, incorporating collaboration and interdependence, has been an historical cornerstone for hospice and palliative care and is the focus of this chapter.

Differences do exist regarding the definition of the interdisciplinary team, the criteria for an effective team, and methods for building and strengthening teams. A Medline search using the term "interdisciplinary" yields more than

10,000 citations; "multidisciplinary" generates more than 15,000 references. Nevertheless, significant overlap and confusion exist regarding the meaning and use of these and other related terms, such as transdisciplinary, interprofessional, and integrative teams. *Multidisciplinary teams* may consist of multiple disciplines, optimally working toward a common goal. Each individual team member performs his or her role within a formally defined scope of practice. The team members may function in parallel and, in less than ideal circumstances, with undefined or diverse goals. To add to the confusion, this term has also been used to describe teams that consist of multiple specialties within the same discipline who work together to provide patient care. An example of this model is the multidisciplinary pain clinic that includes an anesthesiologist, a neurologist, and a psychiatrist, all of whom work to address the complex needs of individuals with chronic pain. Another example is a team of internists and gynecologists who work to provide the health care needs of women. These individuals are all of the same discipline (physicians), but they are trained in different subspecialties.

Other terms have been used which may result in confusion. *Interprofessional* is synonymous with interdisciplinary and has also been proposed as an alternative to avoid the confusion associated with teams that include collaboration among medical specialties. *Transdisciplinary* is used to denote a system in which one team member acts as the primary clinician and other members provide information and advice. The *integrative model* consists of an interdisciplinary team approach that incorporates conventional medicine with complementary and alternative health care. For purposes of this chapter, the term *interdisciplinary* is used to describe a team composed of members from multiple disciplines who work collaboratively to provide palliative care.

Despite the confusion regarding terminology, there is strong agreement that an interdisciplinary team approach is needed to address the complexities of today's health care system. The 1999 Institute of Medicine report, *To Err is Human: Building a Safer Health System,* identified "promoting effective team functioning" as one of several key principles necessary to create a safe health care environment. The Institute of Medicine's subsequent report, *Crossing the Quality Chasm: a New System for the 21st Century*, reiterated the critical need for collaboration to respond to the complex demands inherent in the current health care system and recommended that better opportunities be provided for interdisciplinary training. A recent appraisal of the progress made in this area acknowledged the slow pace of change and continued to endorse the need for team training as a means to improve patient outcomes. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) issued their 2006 National Patient Safety Goals, which include a critical objective to improve communication among caregivers. Additionally, this organization endorsed the need for interdisciplinary participation as teams and organizations develop a patient safety plan in the clinical setting.

Professional organizations support the role of interdisciplinary teams. The Society of Critical Care Medicine includes "belief in the multidisciplinary, multiprofessional critical care team" in their mission statement. The American Geriatrics Society also espouses the role of interdisciplinary care in their mission and goals statement. Although not explicitly stated in their mission statements, interdisciplinary care is clearly endorsed by the primary professional organizations devoted to palliative care. Such organizations include the American Academy of Hospice and Palliative Medicine, the Hospice and Palliative Nurses Association,

the International Association for Hospice and Palliative Care, and the National Hospice and Palliative Care Organization.

INTERDISCIPLINARY TEAMS IN PALLIATIVE CARE

Interdisciplinary team membership is widely defined in palliative care. Palliative care team members can comprise a variety of disciplines, including art therapists, chaplains, home health aids, nurses, nurse aides, nutritionists, pharmacists, physical and occupational therapists, physicians, psychiatrists, psychologists, social workers and speech therapists (2). The hospice core team members must include at least one physician, a nurse, and one other member from a psychosocial discipline (3). Unique settings or populations may require specialized members (4). These may include, for example, a neonatologist when providing palliative care in the special care nursery or an infectious disease specialist when addressing the needs of patients with human immunodeficiency virus infection.

Other members of the interdisciplinary team in palliative care can include volunteers and informal caregivers (5). Even though both hospice and palliative care team members and patients and families find volunteers to be invaluable, few studies have evaluated the common or optimal role of these individuals within the team. In a survey of palliative care volunteers, investigators found the primary motivations for volunteering included the ability to ease the pain of those with a life-threatening illness. Other studies of palliative care teams reveal that volunteers were the least likely (37%) to consider leaving hospice work, compared with nurses (60% had considered leaving) and physicians (40%).

Informal caregivers include family members and friends of the patient who provide physical, emotional, and spiritual support. Numerous studies have documented the physical and psychological impact of providing care for loved ones who are dying. These include time constraints, physical tasks, financial costs, emotional burdens, and physical health risks. Rabow and colleagues suggested ways in which physicians can address the needs of informal caregivers, including good communication, encouraging appropriate advance care planning and decision making, supporting care within the home, demonstrating empathy, and attending to grief and bereavement needs (6). Although directed to physicians, these recommendations apply to all interdisciplinary team members. Much research is needed to articulate fully the way informal caregivers optimally work together with the interdisciplinary team and how the team can best assist in meeting the caregivers' needs.

Although difficult to investigate, some evidence correlates improved outcomes with palliative care provided by interdisciplinary teams (7). One controlled clinical trial of an outpatient palliative medicine consultation service revealed significant improvements in dyspnea, anxiety, sleep, and spiritual well-being when compared with patients who received standard care. Furthermore, patients who received palliative care from this interdisciplinary team experienced fewer visits to their primary care physician or at an urgent care setting. Other studies indicate improved relief of symptoms, improved use of advanced directives, more time at home, and reduced costs when care is delivered by interdisciplinary palliative care teams. A comprehensive review of the literature related to palliative care teams who care

for dying patients in the intensive care unit (ICU) revealed high levels of family and staff satisfaction, as well as cost savings to the institution.

CRITERIA FOR EFFECTIVE TEAM FUNCTIONING

As a result of limited research, few clear criteria are available to guide those attempting to build a strong and successful palliative care team. Experience suggests, however, that collaboration and communication are critical components to effective team functioning. Goals and roles must be clear and focused on the patient and family, and trust must be established. Leadership functions may be shared, and the strengths and contributions of all team members must be fully incorporated. The functioning and cohesiveness of the team should be viewed as more important than the individual identities of team members. Accepted signs of effective team function include strong rates of retention and satisfaction, trust among all members, participation by all members in leadership decisions, consistent attendance at meetings, successful attainment of quality indicators, and high satisfaction scores by patient and families (8).

THREATS TO TEAM FUNCTIONING

There are inherent internal threats to the successful functioning of any group. Turnover of group members, along with role overload and conflict, can jeopardize team performance. This situation can be exacerbated by the stress of providing care to vulnerable patients and families with complicated needs, in a complex environment that may not provide sufficient fiscal and other support to allow effective team function.

Instability of Team Membership

In the optimal situation, there is little staff turnover on an interdisciplinary team, but membership still changes at some point. Staff members may decide to leave for positive reasons (e.g., academic advancement or a partner who relocates out of town) or negative reasons (e.g., burnout). The program may decide that additional roles and positions are needed, and the resultant newcomers can produce temporary team instability. Furthermore, diverse settings present unique challenges to team solidarity. For example, when instituting palliative care in an ICU, some team members are based in the ICU, some visit the ICU, and some are consulted on a case-by-case basis (9). This arrangement also occurs in dedicated palliative care units, where there may be a core interdisciplinary team based on the unit, personnel who visit the unit (e.g., the hospice chaplain whose patient is admitted for respite care), and members who are consulted for their expertise (e.g., psychiatry for assisting with a patient with complex mental health disorders). In each of these situations, the composition of the team changes in subtle ways, and team function may be altered.

In his classic studies of team function, Tuckman described four phases of team development: forming, storming, norming, and performing (10).

Forming describes the setting of goals and objectives as the team begins its task. *Storming* occurs when group members express discord in their approach to the task. Interpersonal conflicts may become apparent at this stage. *Norming* occurs when effective communication results in cooperation. *Performing* is achieved when the task is accomplished through collaboration and conflict resolution. Each time a new member is introduced to the team, some level of forming and storming takes place, and norming and performing follow these stages. Frequent staff turnover and repeated substitutions can be a significant burden and a threat to the stability of the team and its function.

Role Conflict

Disparities and conflict among clinical disciplines are common, but little research specific to palliative care has been conducted. Furthermore, most of the existing literature focuses on physician and nurse conflict and neglects potential sources of conflict among other members of the palliative care team. For example, in a survey of 90 physicians and 230 nurses who worked in the ICU setting, 73% of physicians rated collaboration and communication with nurses as high or very high. Conversely, only 33% of the nurses rated the quality of collaboration and communication with physicians at the same level. Specifically, the nurses in this study reported difficulties in speaking up to physicians, complained that conflict was often not resolved, and felt that their input was not valued (10). The investigators concluded that some of this disparity in perceived effectiveness in collaboration and communication may be the result of differences in gender (most of the nurses were female and most physicians were male), status, authority, training, and responsibilities.

In a study of the role of various professionals working within a team, second-year postgraduate residents, advanced-practice nurses, and master-level social work students participated in the Geriatric Interdisciplinary Team Training. They were asked to respond to a survey regarding their beliefs about the roles of all team members (11). Interprofessional differences appeared to be greatest for beliefs about the physician's role. For example, 73% of residents, but only 44% and 47% of social work and advanced practice nurse trainees, respectively, agreed that the team's primary purpose was to assist physicians in achieving treatment goals for patients. Compared with the advanced-practice nurses and social work students, twice as many residents believed that physicians had the right to overturn care plans developed by the team (11). As in the previous study, differences in age, ethnicity, and gender among these groups may have correlated with the inconsistencies.

This theme of divergence and assumptions as a possible cause of impaired team functioning was echoed in another study of geriatric interdisciplinary team training (12). The authors call the phenomenon "interdisciplinary split" and believe that attitudes and cultural traditions are important contributory factors. Physician trainees were the least enthusiastic about the interdisciplinary training. Specifically, physicians who were farther along in their training were more likely to perceive other team members as incompetent. The nature of the problem, according to the authors, was not incompetence but rather the clinical inexperience of some of the trainees. Thus, successful interdisciplinary training may need to consider the level of education and experience of the team members from different disciplines.

Other investigators have also identified cultural differences as threats to interdisciplinary care. The Council on Graduate Medical Education and the National Advisory Council on Nurse Education and Practice held a joint meeting to discuss collaborative education models to support patient safety. They defined culture as the language, ideas, beliefs, customs, codes, institutions, and tools used by physicians and nurses in their practices. The panel members concluded that existing professional cultural norms do not support the interdisciplinary team approach and believed that cultural change will be a critical factor in fostering interdisciplinary care.

Cultural differences exist among other disciplines as well. For instance, some disciplines are action oriented and focus on fixing a problem or performing a task. Medicine and nursing generally fall into this category. Other disciplines are more relationship oriented, processing interactions and interpreting their meaning. Social work and psychology provide examples of this approach. Similar divergent approaches may occur between members of one discipline. Teams may need to consider these cultural differences when analyzing specific instances of role conflict.

Role blurring refers to overlapping competencies and shared responsibilities (13). This blurring can serve as a potential barrier to effective team function, particularly if resentment occurs because the skills of some team members are underutilized. Staff nurses, in particular, experience role blurring in interactions with advanced-practice nurses. Blurring also occurs when a physician's expectation of the nursing role differs from the nurse's expectation. Role blurring can be countered with clarification of the function of each team member. Williams and colleagues found that a clear definition of the roles and responsibilities of hospice chaplains was associated with less perceived stress (14). Conflict resolution and unambiguous communication within a team can address this confusion regarding roles. Other strategies to address role blurring are listed in Box III–1–1.

Aussman addressed the issue of role conflict and competition among health care professionals in an editorial, in which he charted the more recent history of medical care (15). He described the demise of the era of solo practice in medicine, exemplified by the kindly family doctor (such as the television character Marcus Welby). A newer metaphor for the practice of the health care team is a symphony orchestra, with all musicians playing together with their own special instruments at the right time. The salient, and unanswered, question in palliative care teams is "Who should serve as the conductor?"

BOX III–1–1 *STRATEGIES TO ADDRESS ROLE CONFUSION AND BLURRING*

Clarify role perceptions and expectations of each member.
Have each professional list his or her own competencies and the competencies of other team members, then compare these lists.
Discuss overlapping responsibilities and in what situations this overlap is most likely to arise.
Modify roles and expectations within the team based on these discussions.

Role Overload and Burnout

Although not well characterized, role overload (pressures related to the job) and burnout are potential barriers to the functioning of palliative care and other interdisciplinary teams (16). Studies suggest that related components of role overload, including a lack of institutional support, a heavy workload, and a shortage of staff, contribute to reduced efficacy of palliative care team functioning. Conversely, a study of the effectiveness of an interdisciplinary team in long-term care found greater apparent resource availability (e.g., improved staffing) to be associated with increased perceived team effectiveness (17).

Compassion fatigue occurs when health care professionals are constantly exposed to human suffering, and it is evidenced by fatigue and the absence of energy. Cumulative grief, related to and often a component of compassion fatigue, is a particular risk in palliative care and should be assessed (18). If left unattended, compassion fatigue and grief can lead to burnout. Burnout has been described as a set of behaviors and responses to stressful environments and has been well characterized in oncology and ICU settings, among other places. Although burnout is common among all staff members, house staff members experience the greatest degree of burnout, according to a study of house staff, nurses, and medical oncologists who worked in a cancer hospital. Strategies used by the staff to counteract burnout included talking with friends and using humor. Nurses working in an ICU described experiencing burnout related to the stress of transitioning from cure to comfort care and particularly in providing what they perceived as "futile" care or "torturing" the patient. These nurses also experienced distress when witnessing or becoming involved in the family discord surrounding a patient in the ICU. Strategies that assisted them in addressing this sense of burnout included feeling accepted as a professional member of the team and the use of cognitive, affective, and behavioral techniques to address this stress. Hospice nurses reported that the most important strategy for ameliorating the impact of witnessing unrelieved patient suffering was informal support from work colleagues. House officers rotating through hospice described their post as stressful, primarily as it related to staff conflict and caring for young patients. Almost one fourth of those surveyed had elevated scores on a test of psychological distress.

Of concern is the lack of self-awareness that can occur when burnout develops. A study of Scottish anesthesiologists found that many did not recognize the debilitating effects of stress and fatigue on their performance. This can lead to individual physical and mental health problems and can ultimately have a negative impact on team functioning. Strategies for managing burnout include lifestyle changes and self-care measures and are detailed in Box III–1–2 (19).

BUILDING AND STRENGTHENING TEAMS

Although much research is needed to guide the construction of effective interdisciplinary teams, experience has generated several recommendations. These include careful selection of team members, appropriate education and training of professionals regarding interdisciplinary approaches, and team building through effective communication. A creative exercise for the palliative care team may include

BOX III–1–2 *STRATEGIES FOR ADDRESSING BURNOUT AMONG TEAM MEMBERS*

Get sufficient sleep.
Take breaks throughout the day.
Plan vacations.
Engage in regular physical activity.
Develop and cultivate hobbies.
Seek balance between your professional and personal life.
Learn time-management strategies.
Create a personal space that allows reflection.
Incorporate mindfulness exercises into daily life.
Laugh.
Keep a journal.
Listen to music or view art.
Talk with colleagues.
Learn to grieve.
Initiate grand rounds or other venues devoted to psychosocial issues (e.g., Schwartz Center rounds—see www.theschwartzcenter.org/ for specific information).
Advocate for change when the system promotes factors that lead to burnout.
Seek counseling to address unresolved concerns; do not self-medicate.

reviewing literature, theater, or music, to compare situations within myth and the arts with the function of an interdisciplinary team.

Careful Selection of Team Members

In developing a palliative care interdisciplinary team, selection of team members is crucial. Team members must be skilled within their discipline and aware of their own limitations, as well as those of their specialty. In a provocative article regarding network theory, computer modeling was used to determine the attributes of effective teams (20). The most productive teams (broadly defined and drawing from business, science, and the arts) consist of individuals with the most skill who have experience in collaboration and are able to develop fresh ideas (20). The model discourages including people with whom the team has worked before—"friends"—because this will eventually mar performance. Rather, the model encourages including the most qualified individuals.

Interdisciplinary Education

The literature supports the need for both early interdisciplinary training of all professionals and interdisciplinary teamwork education. Interdisciplinary education will ultimately instill respect for and understanding of the role and benefits of teams. Although these educational efforts are increasing, they remain relatively uncommon. In surveys of Canadian and US medical schools, fewer than 30% had formal training related to interdisciplinary teamwork, and most of these

courses were elective. The lack of interdisciplinary education leads to diminished understanding of the roles of other team members and can result in isolation (8).

One study of the outcomes of a day-long interdisciplinary palliative care course yielded high satisfaction rates. However, fewer medical students were involved when compared with other disciplines (21, 22). Early experience suggests that the timing of interdisciplinary educational efforts is critical and should occur within the first 2 years of education. Students must, however, have at least beginning competencies in their field to participate in and contribute to this education adequately (22). Creative teaching strategies are necessary when providing palliative care education to interdisciplinary groups, including problem-based education, case studies, clinical experiences, and role playing, although some educators report that physicians are often reluctant to participate in these types of teaching methods (23).

Team Training

Along with providing interdisciplinary education during basic training, ongoing education is necessary to advance team function and growth (1). Group interaction skills, communication techniques, and conflict resolution are all topics that teams must address (8). Interestingly, much understanding of team training comes from other industries, particularly aviation. For example, a program called Crew Resource Management (CRM) was developed to ensure aircraft safety by fostering appropriate team attitudes among pilots and cockpit crews. This training has been successfully adapted to the health care setting. In a study of 489 physicians, nurses, technicians, and hospital administrators (most from the trauma unit and the emergency department) at Vanderbilt University Medical Center, in Nashville, Tennessee, who completed the Crew Resource Management training, most reported improvements in key areas such as addressing fatigue, creating and managing a team, recognizing adverse situations, cross-checking and communication techniques, decision making, and giving and receiving performance feedback.

In another example of successful interdisciplinary team building efforts, the Downstate Team-Building Initiative included students of medicine, nursing, physician assistants, physical therapy, occupational therapy, and diagnostic medical imaging. The students received training in group decision making, conflict mediation, and alliance building, along with multicultural skills. Team atmosphere improved 48%, group teamwork skills improved 44%, and interdisciplinary understanding improved 42% after the training.

Although focused on a single discipline, one study incorporated anesthetists who were asked to respond to simulated anesthesia scenarios to develop team skills. The program, Anaesthetists' Non-Technical Skills, included task management, team working, situation awareness, and decision making. Early trials established beginning validity and reliability of the simulated educational program. This is a creative program that may one day be adapted to enhance interdisciplinary team communication and to foster more efficient, productive interdisciplinary team meetings in palliative care.

An essential component of team training is communication, including conflict resolution. In studies of interdisciplinary teams in the ICU, clear and honest dialogue supported team functioning, in part by allowing team members to acknowledge differences regarding ethical issues. In other palliative care settings, communication training and the development of conflict management procedures

have been found to support team building. A practical exercise that enhances communication and clarifies the work of the interdisciplinary team includes writing a mission and purpose statement and clarifying the roles of all team members. Conflict resolution should include respectful negotiation and avoidance of negative behaviors such as dominance, negativity, distraction, and avoiding blame (19).

An interesting challenge to effective communication has been the introduction of electronic communication methods. Although intended to streamline communication, voice mail and e-mail can result in misunderstandings and, occasionally, hurt feelings. Strategies include projecting a courteous tone, reviewing content before sending a message, avoiding jargon, and being as brief as possible (19).

Institutional Support

Institutional support is absolutely critical for effective interdisciplinary team function, yet recent trends in health care threaten this support. Time, the most valued resource, is needed to foster group process (19). Adequate space, another precious commodity in today's environment, and physical proximity of team members, privacy, noise control, and comfortable seating are all necessary for interdisciplinary interaction.

In addition to physical attributes, the environment must support the work of the interdisciplinary team through unit level policies that support and value team (4). The leadership structure within the institution should be interdisciplinary, and individual leaders must role model interdisciplinary communication (4). Rewards offered for collaborative team work, rather than for individual achievements, will also serve to demonstrate the institutional support for this approach to care. The culture of the workplace must change to reduce unacceptable, intimidating behaviors, through improved dialogue, modeling of behaviors, and rewards for teamwork. Finally, the institution must foster and support an environment that allows the integration of interdisciplinary palliative care teams with existing services.

PEARLS

- The interdisciplinary team approach is crucial to palliative care. The Institute of Medicine, the Joint Commission on Accreditation of Healthcare Organizations, the Society of Critical Care Medicine, and others endorse the need for interdisciplinary care to address the complexities of today's health care system.
- Signs of effective team functioning include strong rates of retention and satisfaction, trust, attendance at meetings, attainment of quality indicators, and high satisfaction scores by patients and families.
- Careful selection of team members, interdisciplinary education, and institutional support are key to building successful teams.

PITFALLS

- Little research exists to define the criteria for an effective team, team structure, and methods for building and strengthening teams.
- Threats to effective team functioning include staff turnover, role conflict, role overload, and burnout.

SUMMARY

Interdisciplinary teams are essential in the care of patients with life-threatening illnesses and their families. Interdisciplinary approaches to care also assist the professional in preventing stress and burnout. Obstacles to effective interdisciplinary team function include frequent change in team composition, as well as role conflict or blurring. Building or strengthening teams depends on careful selection of members, interdisciplinary education, and team training in communication techniques and conflict resolution, as well as appropriate institutional support. Cultural disparities among disciplines complicate effective communication and collaboration. Future research is needed to elucidate optimal interdisciplinary team functioning in palliative care.

Resources

Center to Advancer Palliative Care: Available at http://64.85.16.230/educate/content/elements/interdisciplinarycare.html This Web site provides practical information specific to interdisciplinary palliative care, including core and expert competencies for physicians, nurses, chaplains, social workers, and volunteers, as well as strategies for recruiting in interdisciplinary team.

Conflict Resolution Information Source: Available at http://v4.crinfo.org/ This Web site provides a wider variety of resources to learn about and address conflict.

Geriatric Interdisciplinary Team Training: Available at www.gitt.org. Sponsored by the John A. Hartford Foundation, Inc., this Web site provides information regarding interdisciplinary team training, videos, tools to assess team function, and many other resources.

National Consensus Project for Quality Palliative Care: Available at http://www.nationalconsensusproject.org/ The Clinical Practice Guidelines for Quality Palliative Care are available on this Web site, highlighting the need for interdisciplinary teams and defining the core components of these teams.

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Palliative Care Nursing

2

Jeanne M. Martinez

CHAPTER OUTLINE

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INTRODUCTION

The (nursing) profession taught me so many lessons about the fragility of life, the importance of being mindful about the way you live, the need for appreciation of life's beauty and bounty while you are still healthy, and perhaps, most importantly, the worth of "unconditional positive regard," which is the way we were taught to approach our patients.
Elizabeth Berg, RN

The nursing specialty of palliative care has recently emerged, and its goal is to improve the care of the dying and of those who are living with chronic illness. Nursing has provided leadership in the development of this specialty, by defining the scope and standards of palliative nursing practice at both the generalist and advanced practice levels. The standards of palliative nursing practice can be applied to any care setting; they can be integrated into general patient care or used to guide a specialist palliative care consultant or practitioner. Hospice programs currently provide the best example of structured, regulated palliative care. Future trends include the continued development and standardization of palliative care in inpatient and ambulatory care settings, and these trends will drive a need for more advanced practice palliative care nurses (APNs) and for more palliative care nursing.

NURSING CONTRIBUTIONS

Dame Cicely Saunders, who started her career as a nurse, was the founder of the modern concept of hospice care; she opened St. Christopher's Hospice in Great Britain in 1967. She was instrumental in developing most of the principles that provide the basis of all palliative care today. Her interest in care of the dying began when she was a volunteer nurse. Dame Cicely subsequently obtained a degree in social work and went on to become a physician before directing St. Christopher's Hospice. Florence Wald, a nurse, brought hospice care to the United States in 1974; she founded Connecticut Hospice in Branford, Connecticut, the first US hospice. A former Dean of the Yale University School of Nursing in New Haven, Connecticut, Florence Wald heard Dame Cicely lecture at Yale in 1963 and was so inspired by her work that she subsequently visited St. Christopher's to learn about hospice care. Connecticut Hospice was the first hospice to have a building designed specifically for hospice care, and it remains unique in other ways. It is licensed as a hospital and is identified primarily as an inpatient facility (as is St. Christopher's), although Connecticut Hospice is integrated with home care services that are provided throughout Connecticut. By contrast, most US hospices use a home care model and contract with inpatient facilities for services when patients cannot be cared for at home.

In 1984, the (then) Joint Commission on Accreditation of Hospitals developed its first standards for hospice programs (1). Anne Rooney, RN, MS, MPH, was instrumental in defining these hospice standards, and she was one of the first Joint

Commission hospice surveyors. She is a former director of the Joint Commission's Home Care and Hospice Accreditation Program. In 1992, many of the original hospice standards were incorporated into the (renamed, and at time of printing still named) Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards and applied to the care of dying patients in hospitals. Since that time, the JCAHO has continued to incorporate palliative care standards into all patient care populations and settings. The best example of this is the JCAHO standard asserting that pain management is a right for all patients (2).

Madolon O'Rawe Amenta, PhD, RN, was another influential nurse in hospice development. She founded the Pennsylvania Hospice Network and was a founding member of the Hospice Nurses Association (HNA) in 1986. That same year, she coauthored one of the first nursing textbooks on end-of-life care, *Nursing Care of the Terminally Ill,* with Nancy Bohnet. Dr. Amenta served as the first HNA Executive Director from 1993 to 1997 (3). The HNA changed its name to the Hospice and Palliative Nurses Association (HPNA) in 1997 (4).

In May, 2004, the National Consensus Project for Quality Palliative Care (NCP), a collaboration of five major US palliative care organizations, published its comprehensive guidelines to promote consistent, high-quality palliative care by establishing a consensus on clinical practice guidelines. Five organizations participated in the development of these evidence-based palliative care guidelines: the HPNA, the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, Last Acts/Partnership for Caring, and the National Hospice and Palliative Care Organization. The NCP provides this definition of palliative care:

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such it can be delivered concurrently with life-prolonging care or as the main focus of care.

Within a year of publication, more than a dozen nursing organizations endorsed the NCP guidelines, as well as the American Alliance of Cancer Pain Initiatives and the Society of Critical Medicine (5).

DEFINING A SPECIALTY

According to the NCP, "Specialist Palliative Care providers are professionals whose work is largely or entirely involved with palliative care and who have received appropriate training and credentialing in the field." The American Board of Nursing Specialties (ABNS), the only accrediting body dedicated specifically to nursing certification, accredits specialty nursing certification programs if the organization has demonstrated compliance with rigorous standards for certification. The ABNS

considers "specialty nursing certification THE standard by which the public recognizes quality nursing care." Of the eighteen ABNS accreditation standards, the first ABNS Standard 1 requires a definition and written scope, describing the nursing specialty, along with evidence of a distinct body of scientific knowledge that is unique and distinct from that of basic nursing. Hospice and Palliative Nursing has been approved by ABNS as a distinct nursing specialty (6).

In 2000, the HPNA published their statement on the scope, standards of care, and standards of practice of the specialty of hospice and palliative nursing (4).

Scope

The defined scope of the specialty of hospice and palliative nursing includes the following:

- Pain and symptom management
- End-stage disease process care
- Psychosocial and spiritual care of patient and family
- Culture-sensitive care of patient and family
- Interdisciplinary collaborative practice
- Loss and grief care
- Patient education and advocacy
- Bereavement care
- Ethical and legal considerations
- Communication skills
- Awareness of community resources

Standards

The Standards of Hospice and Palliative Nursing Practice are authoritative statements that describe the responsibilities for which practitioners are accountable. They are divided into the Standards of Professional Performance and the Standards of Care.

The Standards of Professional Performance, which reflect the consistency of language and structure recommended by the American Nurses Association 1998 Standards of Clinical Practice (7) are as follows:

Standard I: Quality of Care. The hospice and palliative nurse systematically evaluates the quality and effectiveness of nursing practice.

Standard II: Performance Appraisal. The hospice and palliative nurse evaluates own nursing practice in relation to professional practice standards and relevant standards and regulations.

Standard III: Education. The hospice and palliative nurse acquires and maintains current knowledge and competency in hospice and palliative nursing practice.

Standard IV: Collegiality. The hospice and palliative nurse contributes to the professional development of peers and other health care professionals as colleagues.

Standard V: Ethics. The hospice and palliative nurse's decisions and actions on behalf of patient and family are determined in an ethical manner.

Standard VI: Collaboration. This use of interdisciplinary team and other resources includes collaborating with patients and family in developing the care plan and supporting team decisions.
Standard VII: Research. The hospice and palliative nurse uses research findings in practice, identifies research issues, and supports research studies.
Standard VIII: Resource utilization. The hospice and palliative nurse considers factors related to safety, effectiveness and cost in planning and delivering patient and family care.

TYPES OF CARE ACTIVITY

Beyond the standards of professional performance, the Standards of Care describe palliative nursing care activities for all patients and their families. The processes encompass all significant actions taken by nurses when providing care, and they form the foundation for clinical decision making (4). They are described below.

Standard I: Assessment—The Hospice and Palliative Nurse Collects Patient and Family Health Data

Whether assessing a newly admitted hospital patient with severe pain, caring for someone who is actively dying, performing intake at home for hospice services, or responding to a palliative care consultation, a nursing assessment is often the initial act of care in the nursing specialty of palliative care. In every circumstance, the patient's evaluation needs to be holistic and should identify current problems that encompass the physical, emotional, social, and spiritual care realms. It is essential that patient and family care goals be identified and communicated to the health care team. Problems need to be responded to according to the patient's identified priorities (or the family's priorities if the patient is unable to communicate). When palliative care is provided by a specialist in a consultative role, it is critical for the palliative care nurse to communicate with the patient's current care team, respond to the initial consultation, elicit their concerns, and provide a model of excellent team work.

Caring for patients with end-stage disease and for those who are actively dying entails the challenge of ensuring that the assessment itself does not pose a burden on patients or significant others. Because a thorough physical assessment may sometimes exacerbate symptoms, determining the cause of a symptom may not be realistically possible. Empirical symptom management, titrated to patient relief, may be the best option, along with intense intervention for immediate physical, emotional, and spiritual needs and immediate needs of the family. For actively dying patients, family support needs related to grieving must be assessed and should particularly identify those at risk for complicated grieving or those with a history of poor coping skills.

Standard II: Diagnosis—The Hospice and Palliative Nurse Analyzes the Assessment Data in Determining Diagnosis

Diagnoses are derived by the analysis of multidimensional assessment data and the identification of problems that may be resolved, diminished, or prevented. Whenever possible, diagnoses are validated with the patient, family, and other interdisciplinary team members and health care providers, and they should be consistently communicated to other team members.

Standard III: Outcome Identification—The Hospice and Palliative Nurse Develops Expected Outcomes

Realistic, derived outcomes are mutually formulated with the patient, family, and (as appropriate) other members of the interdisciplinary team. Expected outcomes should be attainable, given the prognosis of the patient; they can provide direction for continuity of care across all care settings and from the time of admission through bereavement. When possible, expected outcomes are documented as measurable goals.

Standard IV: Planning—The Hospice and Palliative Nurse Develops a Plan of Care that Prescribes Interventions to Attain Expected Outcomes

Care is planned in collaboration with the patient, family, and other interdisciplinary team members within the context of patient and family goals of care. It is individualized to the spiritual, emotional, physical, social, psychological, and cultural needs of the patient and family. The plan of care is dynamic and should be updated regularly as the status, goals, and priorities of the patient and family change. If goals of care are not clarified, the plan of care may go in the wrong direction.

Standard V: Implementation—The Hospice and Palliative Nurse Implements the Interventions Identified in the Plan of Care

All interventions need to be weighed by a benefit versus burden calculus that is, ideally, determined by or negotiated with the patient or surrogate decision maker. Although a palliative care approach generally focuses on symptom management, the nature of a particular symptom may lead a clinician to consider aggressive treatment to eradicate the cause, similar to an acute care approach. However, consideration must be given to the impact on the patient's quality of life, the patient's desire for intervention, and the potential for the intervention to cause further suffering. In patients with end-stage disease, the timeliness of the effect of an intervention must also be weighed against the amount of time an individual may have. Another important aspect of nursing intervention is timely referral to other health care disciplines and services and coordination of care to facilitate the interdisciplinary team expertise that is often required to meet the needs of the patient and family.

Many routine nursing interventions other than treatment can also be burdensome to patients with end-stage disease, particularly in inpatient settings. These

include such routine tasks as daily weights, blood pressures, blood draws for laboratory studies, and even bathing and feeding. Inpatient facility routines, often designed for efficient diagnosis and disease management procedures, can also be burdensome to frail patients or those with end-stage disease. Care needs to be individualized and designed to optimize symptom management, to allow patients to maintain as much control as possible, and to enhance quality of life.

Standard VI: Evaluation—The Hospice and Palliative Nurse Evaluates the Patient and Family's Progress toward Attainment of Outcomes

The effectiveness of the plan is evaluated in relation to achievement of the intended or acceptable outcomes. Palliative care interventions must consider the response of the patient and family to care as one of the most critical measures of effectiveness. The plan of care should be reviewed and revised according to the effectiveness of interventions at the time and according to the patient's current priorities.

PATIENT EDUCATION

Throughout the nursing process, a critical role of the nurse is to guide the patient and family through all the information that is needed to understand care options. The emotional context of coping with illness, of grieving the many losses, and of anticipating death can make education and learning a challenge. Nurses in palliative care and hospice roles often need to tell people information that they may not want to hear. They also need to provide or reinforce a great deal of information in a short amount of time. The need for frequent repetition of information to patients and families should be expected, and the use of written educational materials to reinforce information can be helpful. Common education needs for patients and families include information related to the following:

- Disease, expectations for disease progression, and prognosis
- Treatment options, including realistic, expected outcomes of treatment
- Advanced care planning information and tools
- Patients' rights, especially as related to decision making and pain management
- Care options, including hospice services and experimental treatments
- How to provide physical caregiving (for family caregivers)
- Signs of impending death
- Community regulations related to dying at home
- The grieving experience
- Resources for grief counseling and bereavement services

The HPNA provides patient teaching sheets that address many of the foregoing needs. These can be accessed at www.hpna.org.

EFFECTIVE COMMUNICATION

Because the emotional aspects of care can often be intense, it is critical that the care team be clear, consistent, and empathetic communicators throughout assessment,

care, and evaluation. Nurses need to anticipate the difficult and common themes that accompany serious illness and end-of-life care. These themes include the meaning of illness, the desire to know when death will occur, truth telling among family members, and fears about suffering at the time of death. Other common fears are fear of pain and other physical symptoms, loss of control, and fear of the unknown. Palliative care practitioners need to anticipate these issues, feel comfortable discussing them, and develop competency in using clear and comforting verbal and body language.

To attain patient goals and to ensure continuity of care, effective communication must extend to colleagues. All involved members of the interdisciplinary team must be able to provide input in care planning, and they need to be cognizant of patients' goals of care. Another critical part of the communication process is for every team member to give a consistent message to patients and families, who are often struggling with difficult and emotional care decisions. Receiving mixed messages from members of the health care team can create anxiety and can add to distress.

SPIRITUAL DIMENSIONS

A spiritual assessment, which includes cultural aspects of beliefs and values, is the first step in addressing spiritual needs. Nurses need to elicit important spiritual beliefs and needs, which can vary greatly among patients and their family members. It is important for nurses to understand some of the common beliefs, values, and rituals of cultural backgrounds of patients and families that may differ from their own. However, rather than making assumptions based on the culture of the patient and family, beliefs must be assessed individually. Some common spiritual needs include exploring the meaning of suffering, the existential issues of patients and families, and resolving unfinished issues or life tasks. Spiritual distress may exacerbate physical suffering, and it can greatly affect quality of life. Helping patients and families work through spiritual issues can also have a positive impact on the family's grieving after the patient's death.

Spiritual distress may be a concern for many patients and their family members, but nurses also need to be open to cues and opportunities for spiritual growth. For example, patients can be empowered to guide their family's communication by being open about feelings, take the opportunity to resolve problem relationships, and explore religious beliefs.

Although some experienced nurses may be able to address spiritual issues and guide patients and families through spiritual tasks adequately, they need to ensure that patients and families have access to the appropriate providers who can address spiritual needs. Ideally, this is a chaplain, community clergy member, spiritual guide, or other counselor who is also competent in addressing suffering for persons with serious and end-stage illness.

Nurses need to be aware of their own beliefs and values and ensure that they do not impose them on patients and families. It is important to be open to diverse ways of coping, grieving, and dying, rather than holding preconceived notions of how others should feel or behave.

PRESENCE AND SUPPORT

In providing care, there are many instances when physical presence is the most effective supportive nursing intervention. It may be a silent presence that allows the patient and family to express emotion, or it may be companionship during times of anxiety, loneliness, despair, dying, and intense grieving. The value of presence is to be in the moment and to model the importance of "being" rather than "doing" for families, friends, and other caregivers.

ETHICAL ISSUES

Professional Boundaries

Providing hospice and palliative care can be an intense, intimate experience, and boundaries between the patient and nurse can become blurred. Violating professional boundaries may be a greater risk for home care and hospice clinicians who are unaccompanied during visits in the patient's environment. Highly functioning interdisciplinary teams help to provide the support and perspective necessary to prevent individual clinicians from crossing boundaries. Professional caregivers who have had their own losses or suffer from unresolved grief may also find themselves at risk of overidentifying with patients and families or unintentionally seeking to have their own needs met. Nurses should be aware of signs of their own or a colleague's overinvolvement. These include the following, as set forth by the National Council of State Boards of Nursing (7):

- Excessive self-disclosure: The nurse discusses personal problems, feelings, or aspects of his or her intimate life with the patient or family.
- "Super nurse" behavior: The nurse believes that only he or she understands and can meet the patient's needs. Other members of the team are not utilized in the usual way.
- Secretive behavior: The nurse keeps secrets with the patient or becomes defensive when someone questions his or her interactions with patients or family.
- Selective communication: The nurse reports only some aspects of patient care or patient behavior.
- Flirtations: The nurse communicates in a flirtatious manner, perhaps employing sexual innuendo or off-color jokes.

Nurses may need help from a supervisor or other team member to set limits with some patients and families and to explore the reasons for their behavior. Crossing boundaries can be harmful to patients and families and, ultimately, can be a source of burnout for the nurse.

Withholding/Withdrawing Therapy

The withholding and withdrawing of life-prolonging or life-sustaining therapy or treatment are governed by the ethical principle of *autonomy,* which is an individual's right to refuse or accept treatment. However, the emotional component of

deciding not to initiate treatment and of withdrawing treatment can feel very different. Nurses need to be clear that withholding therapy and withdrawing therapy are legal and ethical equivalents. However, the knowledge of this equivalency may not make the decision to withdraw therapy easier for family members or, at times, professional members of the health care team. This issue should, therefore, be a consideration when recommending trials of life-sustaining or life-prolonging treatments that are unlikely to be effective or may need to be withdrawn in the future. When treatment trials are proposed, it is helpful to establish success or failure markers and a time frame for achieving success in advance of the trial so the groundwork is laid for withdrawal.

The difficulty in many of these decisions depends on who is making the decision and what therapy is being withheld or withdrawn. The decision is usually easier when a person is able to communicate clearly his or her wishes about refusing treatment. There is particular emotionality associated with withholding or withdrawing artificial food and fluids (8). The very public 2005 case of Terri Schiavo, a 41-year-old woman who had been in a persistent vegetative state for more than 15 years, provides an extreme example of the volatility of such decisions. Ms. Schiavo's parents fought with her husband (the legal surrogate decision maker) for many years to prevent removal of her feeding tube. This situation presented the combination of a young person who could not speak for herself and the decision to withhold artificial nutrition and hydration (9).

Palliative Sedation

Palliative sedation (formerly called terminal sedation) refers to the intentional use of pharmacological agents to induce sleep for relief of distressing symptoms that cannot be controlled by other means. Sedation is used in home and inpatient palliative care settings for relief of refractory symptoms, both physical and existential. The most common reasons for palliative sedation include pain, vomiting, terminal delirium, dyspnea, and psychological distress. This intervention is usually reserved for use at the very end of life. The pharmacological agents used in palliative sedation vary but include opioid analgesics, benzodiazepines, anticholinergics, and neuroleptic classes of medication. Indications for palliative sedation are rare, and it should be used only within the context of specialty palliative care to ensure that optimal, current symptom management has been provided, including nonpharmacological interventions such as assessment of spiritual distress, psychosocial support, and environmental alterations. Although governed by the ethical principle of *double effect,* palliative sedation practice varies and is rare enough that not every team member will feel comfortable with every intervention (8). Professional team members may have different opinions about whether palliative sedation is indicated, particularly when it is used for psychological distress. One question that arises in the practice of palliative sedation is whether the patient will be allowed to become conscious again or whether the sedation continues until death. Some team members may feel that continual sedation is too similar to euthanasia, eliminates patient control, and does not allow the patient to continue to consent. Nurses should become involved in developing and revising protocols for defining the practice of and indications for palliative sedation in their practice settings and should ensure that palliative care specialists are available to guide the intervention.

An ethics committee consultation should always be requested when team members are concerned about the use of palliative sedation.

Individual Competency

For nurses to improve palliative care, they need to take responsibility for their individual practice, including self-assessment of knowledge and skills, to identify areas where competency needs to be attained or improved. Although most nurses practice within a nursing specialty, palliative care needs are present in all care settings and most nursing practices. Areas of competency may include updating knowledge of symptom management, improving communication skills, assessing spiritual needs, and learning better methods of teaching patients and families. Another method for self-assessment is evaluating individual outcomes of practice. This can occur through quality improvement studies, medical record reviews, and clinical supervision.

SELF-CARE

The emotional nature of working with patients and families who are living with, and dying of, chronic and end-stage illness can be stressful for many practitioners. Nurses need to acknowledge that they and other professional caregivers will also experience feelings of loss and helplessness during the course of providing palliative and end-stage care. Individual nurses need to expect these feelings, to acknowledge them, and to find healthy strategies for coping with their feelings. A nurse's stress can affect his or her quality of life, as well as the ability to give optimal patient care. Some strategies that have been shown to be effective are as follows: relaxation, using a variety of techniques such as guided imagery, meditation, and passive relaxation; self-reflection; teaching or mentoring others; exercise; yoga; and journaling. Each nurse needs to monitor his or her own stress level and to find the most effective, individual coping strategies.

Every member of the palliative care team should be sensitive to any coping difficulties experienced by colleagues. Some hospice and palliative care programs offer formal support mechanisms for professionals, such as support groups or debriefing sessions for the team. Many organizations also provide individual, confidential counseling services through employee assistance programs that employees can access at any time. Many team members find it helpful to seek out individual colleagues who understand their work and with whom they can debrief and explore feelings when needed.

NURSES INTEGRATING CARE

Nurses have the opportunity to affect the organizations where they practice by integrating palliative care into all care settings. Initiatives can come from a variety of mechanisms. Organizational quality improvement measures, such as improving utilization of advanced directives, are often a good way to initiate palliative care

because these indicators already have organizational support and are recognized as both important and needing improvement. Another helpful mechanism for improving palliative care in organizations is to seek out and join others in the organization with interests in improving specific aspects of palliative care. These may include departments or groups such as pharmacy, pastoral care, ethics committees, and pain consultation teams. In addition, other nurses (including advance practice nurses who function in specific roles in pain management), educational and quality care departments, and specialties such as geriatrics, oncology, care of acquired immunodeficiency syndrome, pediatrics, and critical care often welcome support in improving patient comfort, decision making, and symptom management.

For all patient care, the benefits and applicability of integrating palliative care concepts into nursing practice apply to diverse care settings, including ambulatory care, intensive care, pediatrics, and emergency departments and cover areas such as pain and symptom management, advance care planning, bereavement care, and optimizing care at the time of death. In 1997, the American Association of Nursing Colleges identified 15 nursing competencies necessary for the care of patients during the transition at the end of life (Table III–2–1). Enhancing the care environment is another way to affect an organization by facilitating changes that will improve palliative care. Some examples are furniture designed for family comfort, a designated space for family cell phone use, lighting that can be softened and controlled by patients, and calming colors and art work in patients' rooms.

THE APPROACH

In some organizations, palliative care has been integrated so nurses in general care units or ambulatory settings routinely assess patients from a holistic perspective and identify palliative care needs, thus establishing an optimal, individualized care plan. In other organizations, palliative care (including the transition from acute care to comfort care at the end of life) often does not occur without a specialty palliative care consultation. The ideal nursing care model incorporates both: palliative care standards integrated into all patient care *and* the availability of specialty palliative care consultations for complex patients. Complex patients can include those with intractable symptoms, difficult symptoms of dying such as terminal delirium, suffering related to psychosocial or spiritual needs, and ethical concerns, such as requests for euthanasia from the patient or family. A nurse who is competent in providing palliative care will be able to do so in any role and for any patient population. Some general guidelines that illustrate a palliative care approach are listed in the following subsections. The nurse will always assess or establish these elements from the assessment of other team members when beginning care with a patient.

Establish What They Know

The nurse begins each patient assessment by ascertaining what the patient and family members understand about the patient's disease status and prognosis. Not only does this provide insight into the patient's and family's knowledge base, but also it often provides clues about how each person is coping emotionally.

Table III–2–1 ▪ Competencies Necessary for Nurses to Provide High-Quality Care to Patients and Families During the Transition at the End of Life

Recognize dynamic changes in population demographics, health care economics, and service delivery that necessitate improved professional preparation for end-of-life care.
Promote the provision of comfort care to the dying as an active, desirable, and important skill, and an integral component of nursing care.
Communicate effectively and compassionately with the patient, family, and health care team members about end-of-life issues.
Recognize one's own attitudes, feelings, values, and expectations about death and the individual, cultural, and spiritual diversity existing in these beliefs and customs.
Demonstrate respect for the patient's views and wishes during end-of-life care.
Collaborate with interdisciplinary team members while implementing the nursing role in end-of-life care.
Use scientifically based standardized tools to assess symptoms (e.g., pain, dyspnea [breathlessness] constipation, anxiety, fatigue, nausea/vomiting, and altered cognition) experienced by patients at the end-of-life.
Use data from symptom assessment to plan and intervene in symptom management using state-of-the-art traditional and complementary approaches.
Evaluate the impact of traditional, complementary, and technological therapies on patient-centered outcomes.
Assess and treat multiple dimensions, including physical, psychological, social and spiritual needs, to improve quality at the end of life.
Assist the patient, family, colleagues, and one's self to cope with suffering, grief, loss, and bereavement in end-of-life care.
Apply legal and ethical principles in the analysis of complex issues in end-of-life care, recognizing the influence of personal values, professional codes, and patient preferences.
Identify barriers and facilitators to patients' and caregivers' effective use of resources.
Demonstrate skill at implementing a plan for improved end-of-life care within a dynamic and complex health care delivery system.
Apply knowledge gained from palliative care research to end-of-life education and care.

From American Association of Nursing Colleges: A Peaceful Death. Washington, DC: American Association of Nursing Colleges, 1997.

Determine the Legal Proxy

The nurse needs to determine whether the patient has the capacity to make decisions and who the surrogate decision maker will be should the patient be unable to make decisions. Even a weak or dying patient who has capacity has the right to make decisions for himself or herself. Patients may delegate decision making to another, but they need to be aware of the laws that guide medical decision making if they wish to delegate to someone who is not the legal next of kin, unless previous legal arrangements have been made. The health care team needs to be aware of and to document these arrangements to honor them when the patient can no longer participate in decisions. Patients with capacity who verbally delegate medical decisions or information flow to another person should still be asked by members of the health care team, periodically and in private, whether they wish to continue to delegate in this way. When patients have a language barrier with their caregivers, medical translators who are not friends or family need to be provided when critical information is communicated and when decisions are needed.

When patients lack capacity, the nurse needs to determine the legal decision maker and to provide the name and contact information to other members of the health care team so communication and decisions are directed to the correct person.

Identify Priorities

Patients and family members are asked to identify current concerns, unaddressed issues, and priorities of care. The nurse begins a plan to address any immediate needs identified by the patient and family and to discuss the reason for the referral, if it resulted from a hospice or palliative care consultation. The nurse identifies or clarifies any goals of care that the patient and family may articulate.

Determine the Patient's Prognosis

Information from the patient's primary care provider and other health care consultants, and the patient's current status, will provide information about the likely prognosis. If it is probable that the patient is imminently dying, assessments and individualized interventions must be accelerated to facilitate a peaceful, comfortable death that honors the values of the patient and family. Counselor members of the team such as social workers, chaplains, and the patient's community clergy, if applicable, should be alerted to the patient's imminent dying, to assist in planning care and support at the time of dying.

Assess Pain and Other Symptoms

The nurse assesses the level of distress and meaning of symptoms to the patient and formulates a care plan based on the patient's priority for symptom management on an ongoing basis. Pain and symptoms need to be assessed using standardized assessment tools that are tailored to the patient's cognitive abilities, developmental stage, and preference. For example, a patient with mild dementia may not be able to use a 10-point visual analog pain scale but may be able to describe pain as mild, moderate, or severe. It is essential to communicate with the health care team about which assessment tools are best suited to the individual patient to ensure consistency in the use of tools among all team members.

A palliative care approach includes anticipation of symptoms related to disease progression and the dying process so these symptoms can be prevented or minimized. For example, a dying patient may lose the ability to swallow. Nurses need to collaborate with the medical team about which medications could be discontinued and should provide for alternate administration routes for medications needed to manage symptoms. Nurses also need to assess continually for any burdensome interventions that may cause discomfort or negatively affect the patient's quality of life, such as decreased checking of routine vital signs and discontinuation of blood draws and other diagnostic tests when they cease to provide information that will influence the patient's care.

Assess Emotional Issues

The nurse needs to be competent at discussing difficult topics related to prognosis and questions or fears about dying that patients and family members need to pro-

cess. The nurse should review any previously identified preferences related to advanced care planning and should listen for values and beliefs expressed by the patient and family members. The competent nurse will be emotionally prepared and comfortable discussing psychosocial and spiritual concerns and will be able to anticipate many of the questions patients and families may ask. This often means listening to expressions of sadness and grief in situations where there are no real answers and understanding the value of empathetic presence and support.

Make Referrals

After assessment of the patient's status, the nurse collaborates in a timely manner with the primary physician and other professional team members to communicate the need for medical orders and referrals to address the patient's needs. The team reviews the patient's and family's goals of care and determines what other goals need to be discussed or clarified. The team then determines who will document goals and plans in the medical record, who will communicate what to the patient and family, and, if necessary, who will communicate with any other professional caregivers.

Facilitate Grieving

The nurse should be prepared to provide spiritual support and grief resources before and at the time of the patient's death, in addition to the support provided by the patient's own clergy, counselor, or the professional counseling members of the health care team. The nurse ensures that written information about normal grief reactions and sources for grief support and counseling are also provided.

Foster Quality of Life

A goal of the art of palliative nursing is to assist patients in the identification and accomplishment of remaining life goals. This may mean helping patients move to the place where they wish to die, helping to complete a task, or communicating some important information to loved ones. Some patients wish to plan or have input in their funeral arrangements and may look to members of the health care team for help with this task. Enhancing the patient's immediate environment impacts quality of life, especially for the bed-bound person. For inpatient facilities, this may mean moving furniture to accommodate better window views, providing a quiet environment, with dimmed lighting, music of the patient's preference, and items from home. Whether at home or in an inpatient setting, the nurse should collaborate with family and caregivers to create or enhance ways to help the patient have some control over his or her own environment and daily routine.

Facilitate a "Good Death"

At the time of dying, the nurse facilitates privacy for the patient and family and any other changes to the patient's immediate environment that may enhance the comfort of the patient or family. At the time of dying, it is critical for inpatient routines

to be altered and tailored to the needs of the patient and family. Space to rest and sleep in the patient's room, areas outside the room for consultation, family respite, and telephone calls are helpful to visiting family members. Nurses need to provide a balance between support and privacy and should check frequently to ensure that the patient and family feel cared for and supported, not abandoned. An increase in the frequency of professional visits may be necessary for patients who are dying at home. Family members should be assured of a timely, knowledgeable, and sensitive response from the health care team, including the on-call team members.

Nurses and other members of the health care team should encourage family expressions of grief, even when their loved one can no longer communicate. Family members will need information about the dying process, what to expect at the time of death, and information on local laws regarding funerals and burial. Nurses need to assess for cultural and religious practices and rituals that may be important to families and should act as facilitators. Nurses should be a role model of compassionate, respectful patient care. The biggest impact on the family's grieving is to ensure that the patient's death "went well" from their perspective.

PROFESSIONAL ASSOCIATIONS

Membership in local, regional, and national nursing and other professional organizations provides opportunities for nurse networking, peer support, and education. Nurses who become involved in professional organizations at the committee or board level can directly affect specialty nursing practice through policy development, professional presentations, and committee work. Professional organizations depend largely on the volunteer expertise of professional nurses. The rewards to the individual nurse are enormous in enhancing their individual, professional development.

The HPNA has grown to represent more palliative nurses than any other organization in the world. The HPNA provides special interest groups in the areas of pediatrics, advanced practice geriatrics, administration, and research. Technical assistance is available to regional HPNA groups to give hospice and palliative care nurses local networking opportunities, as are resources and expertise from the national organization. HPNA has provided a variety of educational opportunities for nurses through their journal (the *Journal of Hospice and Palliative Nursing*), an annual clinical conference, teleconferences, and many educational publications. In addition, the HPNA hosts train-the-trainer conferences throughout the year, the End-of-life Nursing Education Consortium, and the HPNA Clinical Review to provide curricula and teaching strategies that allow professional nurses to teach their colleagues.

In 2003, the HPNA participated in the formation of a new coalition organization, the Alliance for Excellence in Hospice and Palliative Nursing. The Alliance is the formalization of three major hospice and palliative nursing associations: the HPNA, the National Board for Certification of Hospice and Palliative Nurses (NBCHPN), and the Hospice and Palliative Nurses Foundation.

Specialty Certification for the Nursing Team

In 1994, the first specialty certification examination in hospice nursing was offered by the (then) National Board for Certification of Hospice Nurses. In 1996, a role delineation study conducted by this organization demonstrated a common core of practice for hospice and palliative nurses. This provided the validation for broadening the specialty beyond those who practice in hospice programs to include palliative care nurse specialists in nonhospice settings. Subsequently, The National Board for Certification of Hospice Nurses and the HNA changed the names of their organizations by adding "palliative," to reflect the expanded scope of the specialty.

The NBCHPN has expanded specialty certification for other members of the hospice and palliative nursing team. Specialty certification for nursing assistants began in 2002 and in September 2004 for Licensed Practical and Vocational Nurses. The NBCHPN collaborated with the American Nurses' Credentialing Center in 2003 to create the first Advanced Practice Palliative Care Certification. In 2005, the NBCHPN became sole proprietor of the certification for APNs. Successful candidates who attain specialty certification earn the credentials identifying their specialty (Table III–2–2).

FUTURE TRENDS

Palliative Care Specialists

The need for palliative care specialists will continue to increase as the population ages and more people are living with chronic, serious illnesses. The success of treatments that allow people to live longer also creates an increased need for symptom management for diseases that can be managed but not cured. Because palliative care services are not currently regulated, there is an inconsistency in the ability to meet the needs of patients and families comprehensively and holistically. Palliative care programs need to standardize care by adhering to the recommended standards developed by the NCP, regardless of the palliative service practice model (5).

Advanced Practice Palliative Nurses

APNs are increasing in number and are poised to assume a variety of necessary roles in palliative care. In 2003, the first certification examination for APNs was

Table III–2–2 ▪ Credentials for Hospice and Palliative Certified Members of the Nursing Team

Advanced Practice Nurse (APN): ACHPN
Registered Nurse (RN): CRNH
Licensed Practical Nurse of Licensed Vocational Nurse (LPN/VN): CHPLN
Nursing Assistant (CNA, HHA): CHPNA

offered through a collaborative effort between the American Nurses Credentialing Center and the NBCHPN. APNs are prepared at the master's degree level or beyond and are either nurse practitioners or nurse clinicians. APNs are prepared for leadership roles in clinical care, education, consultation, and research (10).

Palliative Education

Palliative care practice will improve on a large scale only when undergraduate nursing programs incorporate palliative care education into their curricula and more graduate level programs in palliative care become available. The End-of-life Nursing Education Consortium project originally designed its curriculum to allow undergraduate programs to adapt and learn from it. Madonna University in Michigan offers interdisciplinary hospice education programs. The Breen School of Nursing at Ursuline College in Ohio was the first program to prepare advanced practice nurses in palliative care. New York University was the first in the United States to offer a Palliative Care Nurse Practitioner Program (11). Many more graduate and postgraduate programs will be needed to fill future needs.

Nursing Research

In addition to the common barriers in nursing research (e.g., lack of research funds and a limited number of nursing researchers) research in end-of-life nursing care faces a set of unique issues. Some of these research challenges include study accrual issues related to rapidly declining subjects and late referrals to hospice and palliative care programs. In addition, there are the ethical considerations (e.g., the ability of subjects to provide consent) and the challenge of conducting research on emotionally and physically vulnerable patient and family populations. Research tools need to be designed that balance scientific rigor and potential burden to the subject, and they must be sensitive to the fact that, for these subjects, time, especially quality time, is a limited commodity (11). Conversely, it is my experience that many seriously ill patients and their families respond positively to requests for participation in research studies. Some patients see this as a way to contribute to science and the well-being of others, providing some sense of purpose and allowing them to feel that they are giving as well as being cared for.

The National Institute of Nursing Research (NINR) developed an end-of-life research agenda after the publication of the Institute of Medicine report on the scientific knowledge gaps about end-of-life care. In August 2000, the NINR was joined by the National Cancer Institute, the National Center for Complementary and Alternative Medicine, the National Institute of Allergy and Infectious Diseases, the National Institute of Dental and Craniofacial Research, and the National Institute on Aging to collaborate on the theme of "Quality of Life for Individuals at the End of Life." The NINR has since funded more than 22 research projects and 7 training and career development awards related to end-of-life care (12).

PEARLS

- Careful listening is a key skill for every palliative care practitioner.
- At the end of life, patients may have capacity for decision making at some times, but not others. Patients should always be assessed for capacity and should be allowed to make decisions when they are able.

- Conflicting goals among the patient, family members, and health care team require respectful negotiation and clear communication.
- Nurses should appreciate the value of therapeutic presence, even when traditional nursing interventions are not needed.
- The nurse should anticipate what family members need to know, because most will not know what to ask or be able to articulate all their needs.
- The dying experience can be improved in *any* care setting.

PITFALLS

- All members of the health care team should communicate with the designated decision maker, rather than the most convenient family member or caregiver.
- Do not avoid discussion of imminent dying with family members who do not appear "ready" to hear the information. They still need to be informed, supported, and coached through their grieving.
- Decreasing medications and burdensome interventions should not be equated with decreasing care. Nurses need to ensure that patients are frequently monitored for comfort needs, and families are well supported by the entire health care team.
- The nurse needs to rely on the entire team to meet the needs of the patient and family and should not assume that he or she is the only one with the expertise or relationship that is needed.

SUMMARY

Nursing has been instrumental in the recent evolution of palliative care, by developing and defining this nursing specialty to meet the needs of a modern society where people are living longer with chronic, serious illnesses and wish to die on their own terms. In many ways, palliative care is an ideal nursing practice because it combines the art and science of nursing within the context of interprofessional collaborative practice, thus positively affecting patients, families, and society.

Resources

Educational resources can be found at http://www.supportivecarecoalition.org/EducationalOpportunities/elnec.htm

Two respected curricula on palliative care for nursing are provided by TNEEL and ELNEC which can be found, respectively, at http://www.tneel.uic.edu/tneel.asp and http://www.aacn.nche.edu/elnec/curriculum.htm

Two associations that provide educational materials and other resources are: The Hospice and Palliative Nurses Association and The National Board for Certification of Hospice and Palliative Nurses.

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3

Social Workers: The Connective Tissue of the Health Care System

Matthew J. Loscalzo

CHAPTER OUTLINE

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SUMMARY

AN HISTORICAL PERSPECTIVE

Social work is a younger profession than either medicine or nursing. Although some form of social work has been present wherever social systems have been in place, social work as a health care profession has it roots in the early 20th century. Social work has always been closely aligned with underserved populations and with the interplay between individuals and society. The identification with the underserved has been both a calling and a liability for the social work profession. Fighting for fairness and social justice always means having a brutally honest look at reality within a context that goes beyond the expeditious reflex of blaming the victim. It is always easier to blame an individual than to look at the underlying causes of the complex problems that confront people.

In many ways, the unconditional acceptance that all life has value both to the individual and to society (while not supporting behaviors that are destructive and harmful to self and others) has been influenced by the fact that social work evolved from a feminine perspective. Whether from feminine or feminist perspectives, it cannot be denied that women experience unfair treatment and oppression. The importance of the female perspective in the evolution of professional social work is discussed elsewhere (1). Although it is always difficult to make generalizations about gender differences, women generally place a higher value on fairness, justice, allocation of resources, interpersonal relationships, and the personal internal experience of the individual, especially as it relates to the *processes* of communication and interaction. The impact of women in medicine and surgery will be manifested most dramatically in the next 10 to 15 years as women move into key leadership positions. Social work, as a female-dominated profession, will probably feel a greater sense of shared values and goals when there are more female physicians in leadership roles who will affect policy and practice, but this may not necessarily translate into shared methods. As it relates to gender, society is slowly changing as rigidly prescribed boundaries give way to more opportunities for women and men to manifest behaviors and attitudes that more accurately reflect the true continuum of the human experience. This counterpoint and (one would hope) better balance to the male-dominated model of strategic activity toward technological *fixes* has the potential to challenge the value systems of society generally and medicine specifically (2). Physicians tend to be *outcome* focused, whereas social workers greatly value *process*. The desire for enhanced shared responsibility that nurses and social workers want from physicians is not likely to be resolved by gender alone. Palliative care has the potential to integrate the very best that diversity and technology offer while putting the spirit of sharing and healing back into the uniquely human experience of making prolonged efforts to protect people from unnecessary suffering and dangers beyond their control.

DEFINITION OF SOCIAL WORK

Although numerous formal definitions of social work have been proposed, the *International Federation of Social Workers* provides an understanding of social work that is broad enough to cover all social work settings:

The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work (3).

However, this general definition is far too broad to include a working definition of palliative care social work that adequately reflects the richness and nature of the services provided. At present, there is no single definition of palliative care

social work. The following definition is still evolving, but it begins to capture some of the richness and potential of palliative social work:

A patient's experience of serious life-threatening or debilitating illness is influenced by at least 4 characteristics that are a target for professional social work: 1) personality, 2) coping, 3) family system patterns and 4) practical resources. The palliative care social work clinician is expert at assessing and implementing strength-based approaches within a systems perspective to maximize the well being and functioning of the patient/client, family, and society in the biopsychosocial, practical, cultural, and existential domains of the human experience. Based on a set of clearly defined humanistic values, social workers: discover new knowledge through research, develop educational programs, and advocate for social change that insures skilled and respectful care for all members of a diverse society.

PSYCHOSOCIAL CONTEXT OF PALLIATIVE CARE

Social workers provide for the psychological, social, practical, educational, and existential needs of patients with serious debilitating illness and their committed caregivers by supporting efforts to maximize their well-being, independence, and problem-solving abilities. Attachment, commitment, challenge, loss, grief, death, reintegration, resolution, and growth characterize the continuum of the human experience throughout life. It is within the psychosocial context, not the disease, that people truly live their lives. In a study that reviewed the patient's perspective at the end of life, patients with chronic obstructive pulmonary disease, cancer, or acquired immunodeficiency syndrome were asked what their physicians could do to improve the quality of care they provided. For all three diseases, the importance of emotional support, communication, accessibility, and continuity was emphasized (4). These features are all essential elements of the psychosocial domain. People need to be listened to and feel that they have been heard. Social work has always understood the importance of assessing the person in context at any time to establish a therapeutic alliance that can withstand situational challenges.

Inevitably, all people, at different ages, regardless of socioeconomic status, will experience disruptions to their daily activities that challenge their sense of safety, control, predictability, and the ability to live a life relatively free from suffering. Serious life-threatening or debilitating illness will eventually come to all people. Most individuals (70% to 80%) in industrialized nations will die in their later years from a known chronic, degenerative disease that may last for years (5). For the effective management of prolonged illness, the psychosocial implications are multilevel and have repercussions for the health care system and for society. In the Unites States, especially for the rural and urban poor, coping with loss and bereavement may be disproportionately experienced as a consequence of violence. This acute sense of unanticipated loss requires specialized support and management, and the psychosocial interventions, where and when they exist, are highly condensed. Other clearly definable disenfranchised segments of society must also bear the unequal and added burden of having to understand and navigate a patchwork health care system that is poorly organized, reactive, inefficient, and

sometimes unable to meet their needs. There is an increasing awareness that the expenditures for those at the end of life and for the elderly are the result *not* of the increasing numbers of the elderly overall, as has been highly politicized, but rather of overuse of new medical technologies, slow integration of new information systems, inefficient processes, inappropriate care, administrative costs, profit taking, questionable values, and poor choices by political leaders for resource allocation (6). Social workers provide services to people who need help or who are having difficulty accessing supportive systems, or both.

Social workers do not see their patients and clients as separate and distinct from the social milieu in which they exist. Social workers help people to solve problems and to make hard decisions, often in the face of great uncertainty. Social workers serve as the connective tissue of the health care system by supporting, advocating, informing, educating, sensitizing, counseling, and synergizing all available resources and inherent strengths to the benefit of the patient, family, and society. Social workers have an ethical duty to go beyond direct services to patients and families, a responsibility that always includes awareness of the greater good to society. Social workers see all challenges and opportunities from a systems perspective.

People with chronic life-threatening illness and their committed family members are generally not a group with the time, focus, energy, or resources to foment structural systems change. Although many of the barriers to living a meaningful life are not caused by the individual, the individual must ultimately manage the problem. Social workers promote self-reliance and independence while ensuring that a realistic assessment of the situation is made and clearly communicated. Social workers, regardless of the practice setting, value and actively work to promote social justice. For example, ignoring the reality that more than 45 million US residents are uninsured and double or triple that number are underinsured is itself a barrier that is not surmountable by any individual or group. Although many people find the call for social justice unpleasant, social workers do not have the luxury of ignoring the social context of the patient and family situation. In the absence of acute physical distress or immediate threat to survival, it is within the social context (family, friends, spiritual affiliations, work, and community) that people truly live. Palliative care highly values and maximizes the benefits of the supportive social milieu of the patient and family in a way that modern medicine has long forsaken. It is not by accident that palliative care services are often provided in the home. The home is the territory of the patient and the family. Palliative care provides an opportunity to change not only how health care is practiced but also how society as a whole treats its members. Because health care professionals are active in virtually every part of society, there is the potential to institute humanistic values that strike a much better balance than currently exists. Social workers provide services in the most diverse of settings (Tables III–3–1 and III–3–2). Regardless of the setting, to varying degrees, all social workers have to help their clients to manage the realties of difficult situations related to loss and the need to adapt.

Palliative care is built on a bold value system that has the potential to change not only health care but also society overall, a system that is at the heart of social work values. Given that most of the early palliative care programs were started by nurses and social workers outside the traditional health care system, it is not surprising that practical, psychosocial, and spiritual issues were emphasized.

Table III–3–1 ▪ The Many Settings of Social Workers

Adoption agencies	Homeless shelters
Adult protective services	Immigration offices
Assisted living	Legal and court system
Child welfare	Mediation centers
Community centers	Mental health centers
Disease-specific advocacy groups	Military centers
Financial counseling services	Morgues
Funeral homes	Places of worship
Health care settings (e.g., home health care, nursing homes, hospices)	Poverty relief organizations
Schools	Prisons
Social supportive agencies	Private counseling practices
Substance abuse clinics	Rehabilitation programs
	Relief organizations responding to natural disasters and terrorism
	Research foundations

Table III–3–2 ▪ Social Work Roles

Advocate	Group leader
Change agent	Information giver
Clinician	Program developer
Colleague	Problem solver
Consultant	Researcher
Communicator	Role model
Counselor	Systems expert
Educator	Teacher
Ethicist	Team builder and catalyst

COPING WITH LOSSES

As a result of the normal aging process and life circumstances, people must learn to live with increasing levels of loss. The degree of physical deterioration, the number of internal resources, and social support factors are key interacting variables in how people manage challenge and live meaningful lives throughout the life cycle. Social workers are knowledgeable about biological developmental and social processes while focusing on encouraging the psychosocial processes that maximize quality of life and wellness for individuals, family caregivers, and society.

Social workers are highly informed about the need to identify and advocate for vulnerable groups, especially people who are socially isolated, such as the chronically ill and dying. Within the context of palliative care, social workers are attuned to the potential meanings ascribed to the inherent sense of loss related to chronic debilitating illness and how it is manifested at all developmental stages, from the beginning to the end of the life cycle. For example, social workers are aware that Medicare recipients with life-threatening illness are more likely to access higher-quality medical centers and to spend less time in the hospital if they are married (compared with Medicare recipients who are widowed) (7). People who are

married are less likely than unmarried people to spend the end of their lives in a nursing home (8). Because men often die at least 5 years earlier than women, women are at particular risk at the end of life of being unmarried and alone. People are particularly vulnerable at the end of life, given the level of ongoing effort necessary to manage the myriad of complex and ambiguous demands related to the need to understand multilevel information, important decisions that must be made, and the implications of these decisions for the person and the family. Although managing the demands of chronic illness is a challenge to all patients and families, certain factors significantly increase vulnerability and undermine the ability of an individual to receive adequate medical care and social support. Being financially disadvantaged is one of the most important risk factors for inadequate medical care and premature death. Social workers provide services to all people, regardless of social or financial status.

According to the Institute of Medicine's report of 2001, "A major problem in palliative care is the underrecognition, underdiagnosis, and thus undertreatment of. . .significant distress. . .ranging from existential anguish to anxiety and depression" (9). Psychiatric symptoms of depression, anxiety, and delirium in the chronically ill and in the final stages of life are frequently overlooked, and problems in the spiritual, psychosocial, and existential suffering domains are virtually ignored. Psychosocial concerns of the dying patient include the following:

- Not prolonging death
- Maintaining a sense of control
- Relieving burdens and strengthening ties (10)

The family caregivers of people with advanced disease can also be affected by disabling psychiatric problems, although fewer than half these caregivers ever access mental health services (11). Social workers are trained to identify psychiatric and social problems because this is their primary focus, and they usually have more communication with the families than does the rest of the health care team. In cancer settings, social workers are estimated to provide approximately 75% of the mental health services overall (12). Because families know the patient best, they are able to see changes that a busy physician may not perceive. Patients and family members are also more likely to share information about emotional and family problems with the social worker because they perceive this to be a social work function and also because they do not want to "bother" the doctor with their personal problems. Patients and families perceive the delineation of duties in their own minds and act accordingly. These perceptions are reinforced by the environment and by the attitudes of health care professionals. Social workers may also have the time, interest, and skills to talk about emotions, family problems, and psychosocial concerns, whereas most physicians and nurses do not. Ultimately, managing the sense of loss and sadness inherent in having a serious chronic illness or intractable noxious symptoms comes down to trying to put a life into an overall context and staying connected to loved ones even as the reality of separation and loss becomes evident. Within this context, loss is an ongoing process of not being able to control those things that are most valued.

Social work focuses on the strengths of individuals, families, and systems to find the resources necessary to manage challenges of daily living. Unlike the traditional pathology model (now being challenged by the palliative care paradigm) that

focuses on the origin of disease, the psychosocial model is more interested in the genesis of processes that maximize the inherent strengths of people and their systems (13). Although the techniques of social workers across settings differ according to what is required, the underlying set of humanistic values remains constant. Social workers always see people as part of a system. Within this context, many opportunities for assistance, support, and problem solving become apparent. Social workers are best known for their practical problem-solving skills and their ability to identify, link, and actively engage supportive resources.

CREDENTIALING

Medicine has recently made significant progress in credentialing in palliative care. At present, there is no formal process to credential, board certify, or license social workers specifically in palliative care, but this may be changing. As with other professions, there is an increasing consensus that credentialing in palliative care is necessary. Social work organizations and other interprofessional organizations are all highly invested in ensuring the quality of services provided by psychosocial professionals within palliative care. In addition, series of comprehensive books and journals focusing on encouraging social work credentialing and progress in standardizing the knowledge and skills necessary to provide quality social work services in palliative care are now available. The National Association of Social Workers (NASW) in the United States now has on-line courses on care at the end of life available to its membership of more than 160,000. There are now many opportunities for social workers to gain knowledge and skills in palliative care.

Most social workers have a 2-year master's degree from an accredited school of social work. Bachelor's degrees in social work (BSW) are also awarded and are especially helpful in underserved areas where MSW-educated social workers are not available. Increasingly, the doctorate in social work is what will be expected to practice social work in the future, especially in academic institutions. Because social work is present in so many settings, schools of social work are hard pressed to prepare social workers for specialty areas. Palliative care has gained a lot of momentum in universities in recent years, and training for social workers has improved significantly.

Social workers differ from other professions in that so many social workers come to the field in the middle of their careers or in midlife, to do something that gives them greater meaning than what they were doing previously. Many of these social workers have experienced significant loses in their own lives and know how to support people as they manage the emotional and practical aspects of healing. The wisdom, maturity, and experience that social workers bring to palliative care are a great resource for them and for the people they serve.

SOCIAL WORK VALUES IN PALLIATIVE CARE

In 1993, the NASW produced the "Client Self-Determination in End-of-Life Decisions," a policy statement that delineated the necessity for social workers

to assume responsibility to work actively to ensure that the client's rights are respected, that clients are fully informed, and that quality of life be valued as an end in itself (14). A comprehensive discussion of ethical issues relating to social work in palliative care leads to the conclusion that this position supports the ethical principle of autonomy (15).

Autonomy, as it is practiced, is of increasing concern in palliative care. At present, there is no standardized method to measure autonomy. The potential for conflict to the practicing social worker in trying to meet potentially differing standards is obvious. In addition, social workers are acutely aware of the danger of the slippery slope of supporting patient choice as it relates to making autonomous decisions about hastened death because so often the weakest and most vulnerable members of society have been seen as the most expendable. Therefore, there is the concern that the *right* to make conscious and thoughtful choices about hastened death will lead to the social expectation of feeling *obliged* to expedite one's own death to relieve family and society of the burdens of care. Because money is a metaphor for control, finances are almost always a major concern of the dying. Social workers are particularly sensitive to the importance of recognizing and making obvious the specific impact of oppression on vulnerable groups.

In 2003 the NASW reinforced the natural synergies and values between palliative care and social workers:

The hospice and palliative care movements in recent decades are reactions to the emphasis on cures, providing more caring and compassion to those in pain or at the end of life. It is in this area of caring for the whole person and nurturing him or her not only through the direct medical interventions, but also the psychosocial-spiritual consequences of illness that offer an opportunity for social workers (16).

In their 1999 position paper on euthanasia, the Association of Oncology Social Work reflected this position of supporting the client's right to make informed choices while at the same time clearly limiting the level of social work participation to supporting open discussion, information gathering, and advocating for best services available, but not assisting the act of hastening death. Inherent in these statements was the acknowledgment that to begin to address the needs of the chronically ill and the dying, social workers were frequently put in emotionally laden situations of great ambiguity, without adequate training, and within a health care system in dire need of reform. In 1999, using a survey supported by the Project on Death in America, Christ and Sormanti documented the lack of training opportunities in palliative care for social workers, including education, clinical care, and research (17).

SOCIAL WORK COMPETENCIES IN PALLIATIVE CARE

A consensus statement of the Social Work Leadership Summit on End-of-Life and Palliative Care 2002 (18) outlined the need for standards of practice and discussed the opportunities for and challenges to social workers. Knowledge competencies, skills competencies, and practice values and attitudes were used as the three organizing concepts for social work competencies across practice settings. Clearly, the

summit conference developed a core value system that drives the functions of all social workers regardless of the setting.

The social worker should have awareness of and management skills in the areas discussed in the following subsections.

Knowledge Competencies

- Patient and family as the focus of care
- Biological, psychological, social, emotional, spiritual, practical, informational, and financial variables
- Care and setting options
- Common biopsychosocial disease and treatment-related symptoms throughout the illness experience
- Cognitive-behavioral, psychodynamic, crisis, and environmental interventions that manage distress
- Signs and symptoms of imminent death
- Clinical and culturally aware information about death and related expectations of particular patients and families
- Religious, spiritual, and cultural values and rituals and beliefs
- Ethical and legal principles
- Experience of grief, loss, bereavement
- Equity in access to care
- Insurance, entitlements, and financial process and challenges
- Community resources
- Standards of care established by professional and legislative organizations

Skills Competencies

- Assessment seen as the foundation of social work practice
- Consideration of physical, functional, financial, social, emotional, spiritual, and psychological factors
- Strengths and coping resources maximized
- Family functioning
- Cultural expectations in communication and decision making
- Spiritual and religious beliefs
- Emotional issues
- Body integrity and functioning and level of dependences
- Barriers to maximizing health and quality of life
- Legal and ethical principles used to make health care decisions
- Safety issues, abuse or neglect, suicide, requests to hasten death

Treatment Planning and Interventions

- Treatment plans revised according to ongoing needs and tailored according to race, age, culture, religions socioeconomic, educational, lifestyle, for example
- Education, information, communication enhancement, supportive counseling, Gestalt techniques, brief therapies, life review, stress management, problem solving, family counseling and therapy, cognitive-behavioral therapy, spiritual

support, crisis intervention, conflict resolution, advocacy, case management, expressive therapies, for example
- Varied modalities including groups, families, couples, and individuals
- Team work by fostering communication, suggesting enhancements, documenting information and suggestions, sharing patient and family concerns, role modeling the management of team conflict, supporting self-awareness and self-care
- Program planning to include research, education, and clinical care
- Community outreach and education
- System change to enhance functioning and services at all levels
- Psychosocial research to identify and meet community needs
- Advocacy for human and dignified care for all populations, especially the most vulnerable

Practice Values and Attitudes

- Client-centered care that is compassionate, sensitive, respectful with an openness to diversity at all levels
- Recognition of personal attributes and attitudes as opportunities and challenges
- Demonstrated respect for values and desires of patients and family
- Active support to work with others on team and in the community
- Support for an environment of support and hope
- Commitment of personal growth and to advance new knowledge in the field through research

This information represents a step forward for social workers in palliative care. The clarification of roles and duties will be very helpful in developing clinical, educational, and research programs. An omission in the outline is screening for high-risk groups, currently considered to be the "gold standard" in many settings and in the mental health professions overall (19). Given that timely referral to palliative care is a problem, it is even more unfortunate that universal prospective biopsychosocial screening of patients was not given support.

EMERGING ROLE OF PALLIATIVE CARE SOCIAL WORK

Both palliative care and social work build on personal strengths and encourage people to maximize their abilities to live a meaningful life that benefits society. Both fields share the view of the human being as having inherent worth, regardless of the situation, and share a focus that looks beyond and above the myopia of disease diagnosis, while actively and relentlessly nurturing those qualities that have meaning for a particular individual. The very aspects of the human experience that create complexity and ambiguity also create the greatest opportunities to forge new relationships, to deepen existing ones, to review a life lived, and to decide how to live and be in the moment.

The United States Medicare Hospice Benefit, enacted in 1982, recognized the importance of psychosocial factors at the end of life and mandated social work coverage in the care of the dying. Although there have been attempts to reduce the costs of palliative care programs by deprofessionalizing the social work role, they have been obviated by the benefits of social work services. In 1999, the Social Work

Section of the National Hospice and Palliative Care Organization conducted the National Hospice Social Work Survey. Their findings can be summarized as follows:

1. Social work services supported hospice outcomes.
2. Social workers were an important part of the intake and assessment process.
3. Frequent contacts by social workers were highly supportive of the hospice mission.
4. Social workers were instrumental in preventing crises.
5. Experienced social workers with a master's degree had better client outcomes.
6. Social workers who were supervised by a social worker also had better outcomes.
7. Increased social work involvement led to decreased hospitalizations, fewer home health aide visits, and higher patient satisfaction scores.
8. Greater social work involvement resulted in lower hospice costs (20).

Social workers value team work. Palliative care had a new model that shifted the power structure and recalibrated the values, a very powerful combination, to a population of patients who demanded much more control over their lives. What palliative care lacked was legitimacy within the health care system, connections with the hospitals that would be their primary referral source, good science, and resources. The very fact that physicians, nurses, social workers, chaplains, and others could effectively function as a team where consensus supplanted hierarchy was in itself quite revolutionary at the time. The palliative care team values joint decision making and open communication and, importantly, recognizes that people should not have to be dying to receive adequate care for chronic, intractable symptoms. In addition, although the services provided by the early programs were quite uneven, the consumers of these services were very satisfied with the model and quality of care provided. This was much less true of people who received complex chronic or terminal care in the acute care setting. It is still universally accepted that acute care settings lack the basic continuity of care and coordination needed by people with chronic debilitating illnesses.

The values of autonomy and self-determination can be realized only when they are based on a sound foundation of honesty and open communication. Social workers are very strong in both these areas. Although people are resilient, they require accurate and honest information to make rational decisions and to begin integrating the emotional realities of their lives. There are serious long-term costs to ignoring reality, borne mostly by the patient and family. The patient and family lose invaluable time, trust in the health care system is eroded, and futile procedures are performed. Palliative care workers and social workers believe that caring honesty, tailored to the ability of the individual to integrate the implications of the information and emotional content, is the basis for all meaningful and healthy relationships. Regardless of the nature of the life-threatening disease, having confidence that the health care team is acting in the best interests of the patient has consistently been identified as being very important to those who are receiving care at the end of life. This is especially true of African Americans, who have a long-documented history of abuses by the health care system. Social workers are skilled at discussing taboo topics as a bridge to enhancing therapeutic relationships and well-informed decision making.

The conflicting expectations placed on physicians (who are encouraged to limit medical care and testing) go well beyond the obvious reward structure in

highly managed for-profit insurance schemes. For example, if research is perceived to be an important part of an institution's mission, there may be an inherent conflict in timely referrals to palliative care services. Patients and family members frequently need assurances that their trust in the health care team is well placed and that appropriate referrals will be made, especially when levels of stress and vulnerability are high. Generally, it is the ongoing demonstration of the quality of *both* the medical services and psychosocial support that leads to a relationship of trust and confidence of intent. Some ongoing innovative palliative care studies are attempting to bridge the unfortunate schisms that exist among science, medicine, and psychosocial care. For example, in the Simultaneous Care Study (funded by the National Cancer Institute), a physician-nurse-social worker team teaches problem solving to enable cancer patients, family members, and health care professionals who are participating in clinical trials to make key transitional decisions together (21).

MAXIMIZING QUALITY OF LIFE: THE ROLE OF SOCIAL WORK

Patients who are receiving palliative care tend to have many complex medical and psychosocial problems. Five to 10 years after the initial diagnosis of cancer, even those patients who were considered to be in remission or cured were often sicker and had more symptoms than a general population of carefully matched patients who did not have cancer (22). This finding is important because so many of the struggles of the chronically ill are invisible to a harried health care system strongly leveraged to reactive, intense, and episodic interventions focused on cure rather than thoughtful continuity of care based on the reality of the situation of any one individual. Social workers are the connective tissue of the health care system, the bridge between disease-directed treatment and the inherent human capabilities and strengths to maximize well-being in the presence of serious debilitating disease.

Social workers play an essential role in palliative care because of the many key functions they provide to patients and concerned family caregivers. The most efficient way to identify barriers to quality of life is through prospective universal biopsychosocial screening of patients and families. Screening has been shown to be an efficient way to identify problems in a manner that does not stigmatize patients. It allows for triage to the appropriate person or resource and communicates that the health care team cares for and about the patient (23).

As it relates to the knowledge and skills essential for social workers in palliative care, a quality of life perspective is highly informative and has the added benefit of clarity and specificity. Social workers have essential functions in all areas of quality of life.

Physical Quality of Life: Education, Advocacy, and Skills

Social workers play a crucial role by educating patients about the importance of easing the impact of physical symptoms and clarifying their expectations for effective management. This can be achieved by the following:

- Encouraging the patient to share perceptions about what is happening to their bodies and what caused these changes or problems

- Communicating physical symptoms and side effects in real time with their rest of the health care team
- Teaching those who lack the verbal skills or cognitive abilities to communicate effectively
- Alerting the team that the patient has physical problems that they not able or willing to share with the team

For a variety of reasons, patients and families may be reluctant to share information about physical symptoms and other relevant vulnerabilities openly with the health care team. Social workers are highly adept at helping people overcome their hesitancy to share relevant information when appropriate.

Social workers also have a crucial role to play in advocating for relief of physical distress (e.g., fatigue, stress, pain, nausea, agitation, disfigurement) by confronting the team in an open and supportive manner when team members fail to address the physical problems of the patient or the concerns of the family. Palliative care patients and family members highly value the ability to control pain and unnecessary suffering, so any contribution to minimizing fear and uncertainty are of great importance. When assistance is not readily available in the immediate setting, the social worker's advocacy efforts expand. The social worker may frequently be called on to identify symptom management experts in the community when skill or motivation is lacking in the present setting. As with all health care professionals, the primary commitment is first to the patient and then to the institution. When this is not the case, the patient and family should be fully informed.

The social worker's role is to increase the sense of entitlement as it relates to management of physical discomfort and to advocate for what is possible. Given the concerns that patients, family members, and health care professionals commonly share about the use of narcotics and fear of addiction, the social worker has an essential role to play in clarifying the issues. Underserved groups and minorities are at particular risk for undertreatment of pain, so it is essential that social workers be thoroughly informed about the issues and skills in advocating for these groups.

Finally, social workers should be skilled in at least some interventions that directly reduce physical distress and tension, such as problem solving, supportive counseling, distraction, relaxation, mediation, hypnosis, La Maze breathing, and guided imagery (24). For most patients, these skills can be readily taught and reinforced by integrating family members or by audiotaping the exercises and skills. Thus, within the physical realm of quality of life, the social worker has an essential role in education, advocacy, and skills training, all focused on maximizing participation of the patient and family while promoting a sense of function, comfort, and control.

Practical Quality of Life

Social workers are problem solvers and experts at identifying the practical needs of the patient and their family members. The importance of the practical needs of people is invisible to the health care system until it interferes with care or follow-up. Housing, transportation, finances, health insurance, food, and comorbidities in the family are all powerful influences on the ability to access health care and the ability to live a meaningful life free from unnecessary suffering.

Social workers are adept at identifying relevant unmet needs and at making linkages to appropriate supportive resources where and when they exist. If there is an absence of adequate resources, social workers are able to work within the system to make whatever adjustments are necessary to maximize the benefit of medical and psychosocial care.

Psychological Quality of Life

Fear, anxiety, depression, confusion, psychic numbing, lack of a sense of control and predictability, vulnerability, and feelings of being lost and adrift are examples of common experiences in palliative care. Information, skills training, supportive counseling, advocacy, and referrals are used by socials workers to help patients and family members find a sense of direction, maintain hope, and focus on function, comfort, and meaning.

Social Quality of Life

Debilitating or life-threatening illness creates an intense sense of isolation, exposure, and vulnerability. The social milieu of the patient and family is the reference point for their lives, *not the hospital or the health care team.* Family, close friends, work relationships, and other support systems are where and how people function. Family members are often more distressed than the patient. In most situations, by actively supporting the family and social structure, the health care team can significantly help the patient and family to create an environment of empowerment and meaning that will continue after the death of the patient.

The social worker's role is to maximize existing social supports and to create new ones for people with debilitating illness. It is also the social worker who is most focused on the existing support system of the patient and family and who actively guides the rest of the team to strengthen these interactions best.

Spiritual Quality of Life

Most people have some sense of spiritual or existential yearnings and a connection that extends beyond the boundaries of their lives. Although most people also have an identified religious or spiritual belief system, there are also many atheists at the very end of life. The ability to find a place in the universe where one's existence can have meaning is a powerful balm and a respite from the many biopsychosocial insults experienced by people with debilitating or life-threatening illness. Understanding how the individual uses his or her religious or spiritual belief system is essential in being able to help maximize a sense of well-being and connection to others.

The role of the social worker is to support existing adaptive belief systems that enable people to stay connected to something bigger than they are. This is usually best accomplished by encouraging people to communicate their beliefs openly, to stay connected to support systems, and to strive to make a contribution to those around them. Giving to valued others is always a healing experience, especially when time is limited and life is emotionally condensed.

PEARLS

- Frail voices may belie the clarity of the condensed wisdom of a lifetime that offers great potential benefit to all society's children.
- The value system of palliative care has the potential to effect changes in the health care system and in societal norms.
- It is within the psychosocial context, *not the disease*, that people truly live their lives.
- Resources and resiliency should be explored early in the relationship to allow the health care provider, the patient, and the family to see beyond the illness and suffering.
- From the first encounter, stress the importance of psychosocial variables and family integrity as an essential element of medical care.
- Social work focuses on the strengths of individuals, families, and systems to find the resources necessary to manage the challenges of daily living.

PITFALLS

- The emotional impact of psychosocial concerns of patients on health care professionals can be underestimated.
- One may fail to recognize that the connection between mental health and social injustice is amplified in vulnerable persons.
- The social milieu of the patient and family is their reference point for their lives, *not the hospital or the health care team.*

SUMMARY

Social workers in palliative care provide for the biopsychosocial needs of individuals with life-threatening or debilitating illness and their families, based on a value system that recognizes the worth of people regardless of the setting or individual situation. Social workers understand that it takes responsibility, knowledge, and courage to speak for those whose voices are too frail to be heard. Social workers also realize that if they do not actively speak for the vulnerable, without apology, the silence will eventually deafen and deaden the better parts of all of us. The angels within us will cease to exist. Frail voices may belie the clarity of the condensed wisdom of a lifetime that offers great potential benefit for all society's children.

Because of the incredibly broad range of settings in which social work services are provided, it is not possible to delineate the true scope of practice in a manner that would be truly reflective of even most social workers. However, this discussion of palliative care social work does provide an initial and evolving paradigm that can serve to stimulate a higher level of discussion that identifies the common values of social work and palliative care and the contributions social work will make in the future. Social work has played a key role in the evolution of palliative care and has clearly defined the contributions and relevance of the psychosocial perspective as practiced by highly trained social work clinicians and administrators. It is now essential that social work research and educational programs also be developed that clearly define a research agenda that fosters an environment where

interprofessional programs can discover new knowledge that leads to a deeper sense of caring and respect for all individuals with life-threatening or debilitating illness, their families, and society overall.

Resources

American Academy of Hospice and Palliative Medicine: Available at http://www.aahpm.org. This organization is dedicated to the advancement of palliative medicine through prevention and relief of patient and family suffering by providing education and clinical practice standards, fostering research, facilitating personal and professional development, and by public policy advocacy.

American Psychosocial Oncology Society: Available at http://apos-society.org. This group includes all health care professionals who seek to advance the science and practice of psychosocial care for people with cancer.

Association for Death Education and Counseling: Available at http://www.adec.org. This interprofessional group is dedicated to promoting excellence in death education, care of the dying, and bereavement counseling.

Association of Oncology Social Work: Available at http://www.aosw.org. Social work services are designed to assist individuals, families, groups, and communities through counseling, stress and symptom management, care planning, case management, system navigation, education, and advocacy.

NASW Standards for Social Work Practice in Palliative and End of Life Care: Available at http://www.socialworkers.org/practice/bereavement/standards/default.asp. This is the most comprehensive overview of social work role in palliative care.

National Family Caregivers Association: Available at http://www.nfcacares.org. This group supports, empowers, educates, and speaks up for the more than 50 million US residents who care for a chronically ill, aged, or disabled loved one.

People Living With Cancer: Available at www.plwc.org. This patient information Web site of the American Society of Clinical Oncology provides oncologist-approved information on more than 50 types of cancer and their treatments, clinical trials, coping, and side effects.

Wellness Community: Available at www.thewellnesscommunity.org. This national nonprofit organization is dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones.

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Spiritual Care

Melissa J. Hart

4

CHAPTER OUTLINE

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INTRODUCTION

At some point, people who are diagnosed with a life-limiting condition or illness generally realize that they are in transition to something unknown, either to the process of living differently with the condition or perhaps to the process of dying with it. Their time during this transition is precious. It may be a last opportunity to live as fully as one can, to be authentically oneself, to communicate meaningfully with loved ones, or to experience life in a different way.

The spiritual questions and concerns of people in this kind of life transition are often universal in scope. It appears to be inherent to the human condition to ask, "What has my life been about? What will it be about now?" Understanding our beliefs and finding a purpose can help to strengthen, calm, and root us when we are feeling knocked about by life or victimized by circumstance. This is true for patients as well as for those involved in their care, including loved ones, hired caregivers, and medical professionals.

Until they breathe their last breath, people are frequently still growing, appreciating, seeing things from a new perspective, and making meaning. They are engaged in the last developmental stage of life as we know it, and being with people at this stage in their development can be an amazing, invigorating experience. Our society in the United States focuses on death and dying as a tremendously negative and painful experience. We dismiss our last phase of life as a terrible series of losses that is devoid of value. It does not have to be so.

The physical, emotional, and spiritual challenges that people face at this stage can be met with respect, compassion, and guidance. A closely knit palliative care team that is devoted to the dignity and comfort of both patients and families can facilitate a positive, meaningful experience of illness, dying, death, and bereavement. By valuing and being present at the last developmental stage of life, we open ourselves to the wonder and opportunity that lies therein. Part of that opportunity is to find a sense of comfort, contentment, and completeness by the time death occurs.

How do we help people get there? How do we make our way toward a greater sense of wholeness as we move toward the end of life?

Clinicians who specialize in palliative care are trained to combine highly effective medications with complementary therapies to address physical concerns. So, too, effective tools and guides are available to help lead a person toward a place of emotional and spiritual comfort at this critical time in his or her life.

COMMON FEARS

Change is usually stressful for human beings—not just unwanted change, but even changes that we desire. People may deem as positive a new job, marriage, or children. Changes we may judge as negative include the diagnosis of a life-limiting illness, going through treatment, or losing a loved one. Why are both kinds of changes taxing? Change represents loss. After integrating the change, we will not be the same person and are thus called on to form a new identity. Such an invitation may be perceived as both a curse and a blessing, and moving toward this unknown can be extremely frightening.

Why does fear of death seem larger than fear of other unknowns? First, the other unknowns, such as marriage, childbirth, and the diagnosis and treatment of a life-limiting illness, have usually been survived by and reported by others. Because dying is the only unknown that has no survivors who can report the experience, it is harder to comfort those who may be moving closer to death. Witness the human fascination with near-death experiences—we are looking for reassurance from those who have gone before us.

In addition, if change inherently brings loss, then death is the ultimate change, the loss of everything as we know it and the integration of a new understanding of ourselves and the greater world. Some people think of it as the ultimate leap of faith; others describe it as the greatest letting go they will ever experience.

Individuals express fears around illness and dying in three principal ways: physical concerns, emotional concerns, and spiritual concerns. People often wonder about the actual, physiologic process of becoming sicker and dying: Will it hurt? Will it be awful? People often form a graphic picture in their mind of specific, uncontrolled symptoms overtaking their bodies. For some individuals, the only image of dying they have comes from the sensationalism of movies and television. Others may have watched an elderly loved one experience illness or death without symptom relief years ago.

Individuals often describe their emotional concerns in terms of worry—worry about burdening loved ones and, later, about the possibility of leaving loved ones behind. People with life-limiting illness sometimes wonder what they will be missing and how loved ones will function without them.

In terms of spiritual concerns, a person with a serious illness tends to reflect on some combination of the following questions:

What is happening to my body? Will I die?
Why have I been afflicted?
Do I believe in an organizing intelligence or connectedness in the universe? Do I believe in God? What *kind* of greater world do I believe in?
What has my experience of the foregoing been thus far? Does my experience match what I say I believe?
What has my life meant?
What gives my life meaning right now?
What will give my life meaning in the future?
How have I treated people and the world at large?
Do I live true to my values? Do I live true to my beliefs?

In general, at critical life junctures in which spiritual counsel is offered, it seems to be inherent to the human condition to ask the following:

Where have I been?
Where am I standing right now?
Where am I going?

PURPOSE OF SPIRITUAL CARE

Illness is a highly personal experience that no one else can have for us; no one can adjust to the limitations and losses incurred from illness but the person himself or herself. Life-limiting illness can be an extremely lonely experience.

Thus, spiritual care has two aims: to address the deep sense of isolation that accompanies serious illness and to help patients and loved ones find their own internal sense of comfort, strength, and balance. When these goals are achieved, the person may unearth a broader or deeper understanding of his or her relationship with the larger world. Patients and caregivers often describe this discovery

process with words of wonder and relief, finding a quiet, inexplicable gift hidden within their illness.

DEFINITIONS

There are countless ways to describe spirituality and religion, and admirably rigorous works that set out the issues have been well set out elsewhere (1). Simply put, spirituality is about a relationship between ourselves and the greater world, whereas religion is an expression of this relationship by a particular group. Spiritual care addresses both the universal and the particular—the interior awareness of our connection to the world at large and the specific form that relationship takes. Both may influence some or even all aspects of a person's daily life, thus presenting a person with abundant resources in which to find solace.

METHODS OF SPIRITUAL CARE: THE ROLE OF THE CHAPLAIN

Reviews of the role of clinicians in providing spiritual care are excellently provided elsewhere (2). Deeper spiritual work usually is provided by a chaplain. There are three primary roles for a spiritual care professional in palliative care. One is simply to be with the patient in the experience of transition and hope to alleviate some of the patient's isolation. Another is to connect the patient with clergy from a particular tradition, if they that is what the patient desires. A third role is to be present for the patient's exploration of spiritual concerns and questions.

Presence

First, it is of utmost importance to offer a humane, compassionate presence. Although we cannot take away the deep sense of isolation that patients and caregivers tell us they experience, we do aim to lessen it to the extent possible. How do we do this? Simply by being present with people as they struggle through their challenges. They may not have any interest in discussing religious, spiritual, or emotional matters and may, in fact, describe themselves as "areligious," "nonbelievers," or "not spiritual." This should not be a deterrent to the spiritual care professional in palliative medicine. We are there to provide a quiet, supportive presence for those who desire to be accompanied, to meet people on a path they may never have walked before, and to hold their hand, figuratively or literally. If watching a baseball game with a patient brings comfort to him or to her, that is how the relationship begins to be built.

Even if a patient is comatose, spiritual care professionals visit the bedside to talk, or meditate, or sing, or hold a hand. We hope that, with the sound of the human voice, or the touch of the human hand, such a patient may feel a bit less alone.

Tradition and Community

The second role for the spiritual care professional is to facilitate connection between patients (or caregivers) and their religious tradition. We do this by

offering to contact clergy and congregations from each individual's particular faith tradition. Even when an individual or family tells us that he or she has a lapsed or nonexistent relationship with the institutional form of his or her religious tradition, we offer to arrange for clergy or congregants of the faith tradition to visit. Such a visit may allow individuals or families to take part in religious observance through ritual, prayer, holiday celebration, story telling, or conversation. Although a person's interest in religious observance may have lapsed during adulthood, he or she will often find a significant, new relevance in participating, much to the surprise of loved ones.

If the prospect of a visit seems too much to bear or feels too invasive and the person still desires some form of connection with his or her own faith tradition, we also offer the opportunity to be included on a prayer list of a particular religious community. In either case, experiencing the link to the heritage and rituals and community of one's own faith tradition brings some people a sense of belonging and relief, relief at remembering one's connection to a larger community of faith.

Reflection

The third role for the spiritual care professional is to invite individuals and families to bring their spiritual joys and concerns to light. Spiritual counselors are trained to facilitate the exploration of one's inner experiences of meaning and faith, as well as one's understanding of being as it relates to the greater world. Such exploration may uncover both spiritual strengths and stressors, areas of vigor and unease. By helping an individual to hold the fullness of these, the person's interior experience is received in total with respect and compassion. The person may begin to feel less isolated by his or her circumstances and may begin to move toward a greater sense of wholeness and integration.

PATHS TO MEANING

Traditional forms of spiritual care include prayer, the holy scriptures of one's faith tradition, and spiritual reflection. Sitting in silent companionship may also provide a supportive presence that feels comforting to some people. Sometimes people with a life-limiting illness may not wish to (or be able to) expend precious energy on speaking. Even facial reactions require a certain amount of vigor that may not be available to the very sick.

There are other, very simple ways to provide care for the human spirit when a person is seriously ill. The list is limitless, really, but several ideas follow that may start the reader thinking. They show how each of us is touched in different ways, some visual, some auditory, some kinesthetic.

Location, Location, Location

First, a bed-bound person may find the bedroom setting too isolated from the rest of the household. Consider moving the bed to a more central location, such as the living room, where the person may become integral to the natural flow of household activity, rather than being set apart. Physical proximity to the daily bustle

of life may increase the bed-bound person's sense of participation and connection and can often result in a boost in spirit.

Nature: The Five Senses

Next, many people experience an increased sense of well-being when they are in the presence of nature. Some relate that they feel most connected to the universe or God, most peaceful and whole, when they are outdoors in the natural world.

Moving a bed close to a window with a view of the natural world can work wonders for the spirits of such individuals. One attentive family I met even installed a special bird feeder in the window that attracted birds within the patient's view, and the patient delighted in the variety of lively, petite birds that visited her window each morning.

When this is not possible, a video or audio recording of the natural world can bring the sights and sounds of nature to the bedside. Watching sapphire blue waves lapping at a sandy beach bathed in the glow of an orange sunset, or listening to the chirping of tiny, soft birds atop tall, green trees swaying in the wind can be very calming and soothing to the human spirit.

Aroma can also help people feel connected to the larger world. The fragrances of incense and spice are part of some religious traditions, and favorite scents of flowers and foods can delight the hearts of those who love them. One daughter I met told me of peeling the thick skin of a fresh orange beneath her mother's nose, because the bright fragrance released by the natural oils in the orange peel had been one of her mother's daily joys in life when she was well. Another person described her happiness and memory of wholeness simply at having the taste of coffee put on her tongue.

The pleasure of touch can also revive the spirit. For those who are seriously ill, touch is often a neglected sense, yet it is one that can return people to an early memory of wholeness, caring, and value. The warmth of a gentle, furry animal or even the soft squishiness of a velvety stuffed animal can help people to remember their connection to love, security, and comfort. Light massage can help people regain a memory of wholeness and contentment as well and can remind people that they are still fully human and part of the larger world.

Art

Some people feel intimately connected with the greater world through art. Consider Kim. Kim had her bed moved to the living room, beside her favorite window view, and then asked that her favorite painting be hung close to her new location. She had fond memories of complete absorption in that painting and knew that she needed its familiar comfort with her now. For other individuals, creating art or watching art be made at the bedside may feel nourishing to the spirit.

Music

Similarly, some individuals experience a deep sense of connectedness to the larger world through music. Hearing live music played at the bedside, singing, or listening to recorded music can help to enhance a person's sense of inner strength and

balance. Consider Tim, a gentleman with lifelong medical problems of increasing acuity, who felt fortified and at ease after regular visits from the music therapist. The therapist nurtured Tim's love and knowledge of classical music with discussion, live performance, and recordings specific to Tim's musical interests.

Creating a Spiritual Legacy

Some people wish to record what they have experienced, what they have learned in life, and their wishes for the future. Those who are inclined to write may put their thoughts down on paper, in a form of their choosing, such as journal entries, poetry, short stories, a biography, a letter, or an ethical will. Others may dictate their thoughts aloud to someone who will write for them. Some may wish to relay the meaning they have found in life by speaking directly to loved ones or making a recording. Still others may desire assistance in making a scrapbook or photograph album that captures something of their life that they would like to have remembered in years to come.

Ethical Wills: Staying Connected after Death

What is an ethical will? Basically, all wills are sets of instructions. A will of inheritance directs distribution of one's material property at death and is a set of financial instructions. A living will directs which treatments a person wishes to accept and refuse near death and is a set of medical instructions. An ethical will encapsulates the wisdom a person has gleaned in life and is a set of spiritual instructions for those they leave behind.

An ethical will summarizes a person's journey in life, their values, and their closing wishes. It can be general or specific, short or long. There are no rules for developing an ethical will, but there are simple guidelines. Although ethical wills are classically thought of as written documents meant to be shared with loved ones, the wisdom they hold may also be disseminated verbally (as in the Bible). In today's world, this often takes the form of audio and video recordings, without being formally named as such. In any form, creating an ethical will gathers and names the wisdom acquired over a lifetime. Leaving this spiritual legacy for heirs, friends, or caregivers can have a positive impact on all involved. Both patients and loved ones may benefit from the decreased feelings of loss and isolation, as well as the increased sense of meaning, connection, and well-being.

Ancient Roots of Ethical Wills

For many people, the concept of an ethical will is appealing, even when it is not named as such. Leaving behind closing wishes, values, and spiritual instructions for heirs is an ancient practice and early examples are described in the Bible. For those who would like to learn more about these roots, several Biblical references follow:

In *Genesis: 48–49*, Jacob offers parting words about what he sees for the life ahead of each of his sons, as well as burial instructions for himself. In *Deuteronomy: 33*, Moses speaks to the tribes of Israel. Moses discusses the journey of the people, with God accompanying them, and he blesses each of the tribes individually. In *I Kings 2: 2–4*, King David speaks to his son Solomon and gives him

instructions for spiritual and moral fortitude. Today, ethical wills are used for these same purposes—to pass on wishes, guidance, values, and life lessons—to bless those that follow.

Sample Questions for Ethical Wills

- What have you learned from life?
- What values, wisdom, or life lessons would you like to pass on?
- What is important to you?
- What would you want your loved ones to remember about you? About life? About themselves?
- What do you want your grandchildren and great-grandchildren to know about your life?
- What are your hopes and dreams?

Energy Work

Some people experience their spiritual connection to the greater world in a physical way, through their body. Many who meditate and pray or practice physical disciplines such as running, yoga, knitting, or tai chi, report a feeling of calm, clarity, and wholeness permeating their body both during and after the activity. For those who no longer have the capacity to engage these forms of spiritual connection but who still desire a way to be filled with the sense of balance and strength they bring, there is energy work, experienced through the laying on of hands.

As far back as the Bible, there are myriad examples of the healing power of touch, or the laying on of hands. Today's medical world offers treatments based on this real phenomenon. Continuing education programs in nursing teach healing touch and many health professionals, including physicians and chaplains, study the art of Reiki. (Although other types of energy work abound, only two are named here.) Practitioners are trained to place hands either very lightly on the patient or even slightly above the patient. During and after treatments, patients often report an internal sense of wholeness and balance returning. Other benefits patients express include feelings of soothing, calm, and well-being.

When does energy work seem appropriate for spiritual care? Consider Susie, a woman in her 40s who has cancer. Susie was raised in a religious home and attended private religious schools, but she never related to the beliefs and practices she was taught. As an adult, she did not find herself drawn to any faith traditions. Now very sick and home-bound, conserving energy by limiting her movement and speaking, Susie longed for a way out of her spiritual isolation. When she described the feeling of wholeness she used to feel when exercising outdoors, and how she wished desperately to return to that feeling, I asked Susie whether she would like to try energy work. Anxious to try anything that would not drain her resources (as she found that talking did) and wanting physically to feel the comfort she described as "prayer flowing through her body," Susie readily agreed. A Reiki practitioner (who was also a registered nurse) was dispatched to her home to work with a laying on of hands, both directly on and slightly above the body. Susie felt spiritually connected and calmed during the first treatment and asked the nurse to return for regular treatments. During the second and third visits, Susie began to describe her fears about the stage she had been so surprised to reach with her

illness—one of watching her body fragment and disintegrate. The practitioner continued the treatments and witnessed Susie's return to wholeness in spirit.

Susie was someone who connected to her spirituality kinesthetically, had extremely limited energy for talking, and did not relate to traditional religion. This made her an excellent candidate for at least a trial with energy work. Although individuals differ in *how* they experience their spiritual connection to something larger, the longing for that connection is virtually universal. Chaplains creatively seek to access and provide resources that facilitate meaningful connection to that which is greater, for everyone.

Dignity Therapy

Allowing a person's spiritual life its place in the fullness of a person's being as they near the end of life can be thought of as a way to maintain that person's dignity. Based on this view, some have developed a form of therapy known as dignity therapy (3,4). Psychotherapists have also developed something of a specialty for tending to the psychological needs of the dying; these can overlap with spiritual needs. Therapy can be practiced in individual or group sessions.

SPIRITUAL ASSESSMENT AND CASES

Spiritual assessment can be thought of as analogous to physical assessment in palliative care, that is, "Where/when/how does the patient hurt? Where/when/how is the patient at ease?" The health care practitioner assesses these basics, through history taking and physical examination, to create a care plan best suited to the unique person before him or her. The clinician can also screen for spiritual distress so that a specialist may be called in if need be. To do so, he or she may use questions from one of the published screening instruments designed for the purpose (5,6).

In the same way that a clinician takes a thorough history pertaining to physical aspects of an illness, the spiritual care practitioner takes a thorough history of an individual's spiritual strengths, vulnerabilities, and proclivities. The goal of the assessment is to begin building a spiritual care plan that is tailored to be most helpful to a particular individual. When a person's spirit is tended to, walking through the unfamiliar territory of life-limiting illness may feel just a bit less lonely or less impossible.

In palliative medicine, the chaplain attends to the spiritual life not only of the patient, but also of the entire system involved in the patient's circle of care. This may include hired caregivers, beloved friends, and family members, each of whom may be deeply challenged by the patient's illness. All are equally important in the eyes of the visiting palliative care team, and whoever desires spiritual care may receive it.

As with physical assessment, spiritual assessment is usually done by a specialist (in this case by a chaplain) and elucidates one of the following three circumstances: well-being, distress, or camouflage for psychological or emotional struggles. In addition, spiritual assessment may note a person's lack of apparent connection to

spirituality or meaning, which also guides a chaplain in building an appropriate care plan.

Although an initial assessment (physical or spiritual) may point to the overall direction for a care plan, assessment is ongoing. As the relationship between practitioner and patient develops, additional information may present itself, either spoken by the patient or hinted at in the patient's body language or demeanor.

Many people have fears and anxieties about the actual process of living and dying with a life-limiting illness that they may or may not verbalize. Physically, what will it be like? Will it be painful or scary? Spiritually, what will the process of dying be like? Will it be painful or scary? If I am not in control, who or what is?

If the team senses unacknowledged concerns in persons they are serving, they may attempt to assess further to discern the underlying nature of the perceived disquiet. In the example of the unease described earlier, the appropriate team member (in this case, the physician or the chaplain, respectively) may then begin to address the individual concerns directly. This can prove immensely reassuring and comforting to patients, who may have been suffering silently with their wonderings.

Spiritual Well-Being

Virginia was a traditional and deeply religious woman in her middle 50s who suffered with cancer pain. Until the palliative team was able to control her pain, the chaplain focused on prayer, hand holding, and quiet companionship. Day by day, Virginia's physical comfort improved.

Virginia was very sure of her religious beliefs and her prayer life, and this certainty gave her a spiritual comfort that she began to discuss. Still, even without saying so, she appeared to be quite frightened about the actual process of dying. Sensing this, the chaplain asked Virginia whether she would like to hear about his experience of sitting with individuals as they are dying. Eagerly and with surprise in her eyes, Virginia nodded her head. The chaplain described what he most often beheld: a peaceful, quiet, beautiful, and sacred experience. A great sense of peace and relief came over Virginia's face and her body relaxed into her bed.

Bess was a strong woman in her 90s with old-fashioned values of home and hearth, and she described herself as having a private, personal spirituality. She did not discuss her beliefs. She did not want to see a clergyperson, nor did she relate to institutional religion, and her family was of a similar mind. Chaplaincy visits to Bess and her family were intended to build and maintain a supportive relationship. When Bess' pain suddenly became uncontrolled while she waited for new medications to take effect, her nephew Brian tried to cheer her up with vibrant, joyous, reggae music, which Bess used to enjoy. It now made her shriek. The palliative team educated Brian about using silence or gentle, calming music to help lower Bess' rising level of internal stimulation (from the pain). Opportunities to help Bess and the family cope better presented themselves week after week, and because a supportive relationship had been built, the chaplain was able to make a difference in the comfort level of both the patient and the family.

In the foregoing situations, both Virginia and Bess came to their illness with a foundation of spiritual well-being. Proper assessment allowed the chaplain to build a care plan around this strength and to be of increasing assistance as needs arose. Sensitivity, respect, and a genuine desire to learn what would be most supportive for each individual patient facilitated the assessment process.

Spiritual Distress

Catherine was a pillar of her religious community. She had dedicated herself to years of committed service, by leading task forces for worthy causes while raising a large, participative family. After describing her deep religious involvement to the hospice chaplain, Catherine asked to see a clergyperson from her faith tradition, but not one from her own places of worship. Rather, she liked the idea of finding clergy from a local university, where they were "smarter about discussing the tough questions."

After Catherine met with university clergy, she confessed to the hospice chaplain what she had intended to discuss with the clergyperson, but found herself unable to do so. "What if, all this time, I've been kidding myself? What if I die and there's really no heaven, no God waiting for me with open arms, nothing else for me?" The hospice chaplain talked and prayed with Catherine, acknowledging the paradox of belief amidst nonbelief as part of the human condition, citing many scriptural examples. Catherine found relief from her distress in her honest expression of doubt alongside faith.

The initial spiritual assessment for Catherine may have pointed to spiritual well-being, but it also may have begun to hint at spiritual distress when Catherine wanted to meet with university clergy, rather than her own. By being sensitive to Catherine's request and staying close to the evolving assessment process, the chaplain was able to support Catherine in her distress in a way that was meaningful to Catherine.

Religious Camouflage for Psychological Struggles

Debra was extremely anxious about dying. A woman in her 70s, she had lived a very active life within the stability of a long, loving marriage. Debra described herself as a religious person who relied on the tools of her faith tradition to help her with life's challenges, but she did not seem to be using them in this situation. Although Debra did not have clergy or a religious community, she agreed to meet with clergy from her tradition to talk about her concerns and to receive partnership for working with the tradition's prayers and meditations. The chaplain on the palliative care team arranged and attended the first meeting with the clergy and Debra. After the meeting, Debra stated that she did not want to work any further with the specifics of her religious tradition. When asked, she told the palliative team's chaplain of her underlying emotional and psychological concerns.

Debra acknowledged that the she derived her self-esteem only from her competence in the external world and that she had little awareness of the internal world (her own heart and mind) that needed her attention and care as well. The chaplain worked with Debra in two primary ways: broadening Debra's concept of compassion to include compassion for herself as well as for others and awakening Debra's awareness to the fact that, although she may have learned how to give during her life thus far, she perhaps did not yet know how to receive. Debra had spent a lifetime in compassionate action for others, but she seemed to fight the possible opportunity provided by her illness to receive love, gentleness, and honor, from others and from herself. The chaplain was then able to create prayer and meditations with Debra that were specific to Debra's unique world view, lifelong fears,

and persistent psychological struggles. Debra finally found peace and rest as her enormous tensions dissolved into meditations created specifically for her.

The initial spiritual assessment for Debra indicated emotional distress. When the chaplain attempted to draw on Debra's stated religious foundation to alleviate some of her emotional distress, the foundation seemed metaphorically to fall away, leaving nothing to support Debra. Ongoing assessment, as well as consultation with the team's social worker, allowed the chaplain to discern where Debra was in her own emotional and spiritual development. This process of ongoing assessment and consultation was critical in designing an appropriate care plan for Debra, one that supported her as she finally found her way to the balance, comfort, and strength waiting inside her.

Lack of Apparent Connection to Spirituality or Meaning

Joseph was a gentleman in his late 90s who relayed that, although he was born to a particular religion, he had lived his life without it. Like so many others, he had been working, and working hard. He had neither the time nor the patience for religion, and he did not have anything to discuss. Did he believe in God? Maybe, maybe not, but there was no need to talk about it. Nothing was going to change his circumstances.

Joseph had a very off-putting manner in describing his lack of need for chaplaincy and social work visits, yet both the chaplain and the social worker agreed that there was something inexplicable in his manner that kept them wanting to try again. After all, he was all alone in the world—as with so many others his age, he had outlived friends and relatives, and Joseph had never raised any children.

At first, Joseph used his abrupt manner to try to get rid of these friendly faces, but gradually, seeing them return again and again, he began to tolerate their gentle, nondemanding presence. Over time, Joseph quietly began to come out of his shell and started talking about different phases of his life. He slowly developed relationships with the entire palliative team and allowed them glimpses into his mind and heart while his body gradually deteriorated. The care team threw Joseph birthday parties, helped him to hire caregivers, and brought him his favorite foods.

One day, Joseph told the story of his involvement with his religious tradition as a youth, and what prompted him to leave and never return. Joseph began telling the story over and over to the team, across many weeks, as though he were attempting to integrate a long-lost part of himself. Joseph wept at the loss. The chaplain invited him to restart his religious studies and prayer life, and Joseph spent the next months and years enjoying his "return to God." At his senior residence, he came to be known as a person of strong character who quietly lived a life of gentleness and kindness toward all. Staff and residents alike spoke to the visiting palliative team about how they admired the genuine and inspiring way in which Joseph conducted himself. He became a role model for the other seniors with whom he lived. Joseph seemed to die a happy, religious man.

In this instance, the team followed their instincts at initial assessment and attempted to provide a nondemanding presence in Joseph's life. Because this was well tolerated, ongoing assessment guided the team to stay in step with Joseph and try to provide him with a sense of family. Joseph seemed to feel so safe and cared for in his relationship with the team that he eventually brought to the team's

attention a painful part of his spiritual life that he had jettisoned, but dearly missed. With the team's support, he reclaimed his religious heritage and his relationship with God.

Attending to Current and Former Religious Needs

Although some adults may adopt a religious practice that differs from the tradition into which they were born, in palliative care we find that the person is often holding the full circle of their life experience, remembering all the phases of their life. Thus, the chaplain may consider offering to bring in clergy from a person's current faith practice as well as their initial faith. Depending on circumstance, comfort or healing may be found in the rituals and prayers of one's childhood.

Similarly, if a seriously ill person has lived his or her adult life without interest in religion or spirituality, family members may decline chaplaincy visits for that person. It is probably best for the chaplain to offer to visit anyway and explain to the family that the purpose of the visit is not to press spiritual matters, but simply to assess. The family is often not aware of how the ill person was raised as a small child, and they may not realize that comforting rituals and prayers, music, and language from a very young age are still lodged in an older person's mind. Even if someone is nonresponsive or lives with dementia, the earliest parts of memory can often be engaged, producing visible pleasure for the ill person and sometimes enormous surprise for family members.

Possible Problems

In all assessments, it is vital that practitioners engage the person before them with the awareness that they do not know fully that person's story and that they desire to learn more. Entering the life of a patient with respect and sensitivity for the complete person is of paramount importance. A genuine posture of humility and openness on the part of the practitioner is necessary to be able truly to serve the person before him or her.

When assessment is approached from this premise, practitioners may then have the highest likelihood for designing a care plan that is uniquely supportive and meaningful to that individual. In that vein, team members and consultants should not be allowed to bring a preconceived spiritual care agenda to the palliative patient. The resultant assessment and care plan could then become skewed toward a particular end in spiritual care, regardless of whether that end is experienced as meaningful, helpful, or even relevant by the individual patient. At worst, the patient may experience the interaction as disrespectful, destructive, or even traumatizing. When patients are already the most vulnerable as they try to live with serious illness, there is no room for risking harm.

WHO PROVIDES SPIRITUAL ASSESSMENT AND CARE?

Chaplains, pastoral counselors, spiritual counselors: These are all terms that may be used interchangeably for the person on the palliative team who facilitates spiritual care. Pastoral counseling began as an effort to help persons who had experienced a

crisis and were trying to make sense of it within the context of their religious beliefs and their experience of God. Persons who are braving a life crisis or major personal change often find themselves in startling and unfamiliar territory. Sometimes this leads to a crisis of meaning or faith, perhaps because the new realities can seem to challenge an unexamined or basic assumption. Pastoral counselors are guides who help navigate these dark and rocky waters.

There are several ways to become a chaplain, two of which are described here. Both combine theology and psychology, spirituality and counseling. One path consists of attending seminary in one's own religious tradition, becoming ordained clergy, and then taking additional training in counseling (which may not be emphasized in seminary). However, one need not be clerical to receive the proper training needed to provide spiritual care. Another path is a graduate degree in pastoral counseling, a program that integrates counseling with issues of meaning and faith. Professional associations for chaplains oversee requirements, equivalencies, and credentialing to maintain high standards of spiritual care.

How the Team Can Help

Any member of the palliative team should be able to refer individuals to the chaplain for spiritual assessment and care. The entire team visits patients and families, and any team member may notice opportunities where spiritual care could be helpful. For example, a physician making early rounds or a nurses' aide bathing and dressing patients each morning may be the first to hear a patient describe vivid dreams from the night before—with distress, joy, or, contentment.

Why may dreams be noteworthy for the team? Dreams can provide rich spiritual imagery for individuals throughout life, perhaps taking on even greater significance as people move toward meaningful milestones, such as the end of life. For a person rooted in scripture, dream connections to present life circumstances may be of even deeper, religious interest, because the Bible, for example, is replete with examples of the spiritual content of dreams. In any case, a team member who hears from a patient about a particularly distressing or strengthening dream is encouraged to contact the chaplain for a possible spiritual care referral. Similarly, when a physician hears a patient, loved one, or hired caregiver discussing concerns about purpose, meaning, or faith and the team is unaware, it is a good time to give the chaplain a call.

Even though a trained chaplain will have attempted a thorough, initial spiritual assessment at, or soon after, every palliative care admission, some individuals may decline spiritual support at the start of their care, by citing lack of concern, interest, or need. As serious illness progresses, however, patients, caregivers, or loved ones may find themselves flooded with unexpected experiences, thoughts, and feelings for which they have no context. When this window of opportunity opens, however slightly, the team should be ready to reintroduce the idea of spiritual support and should alert the chaplain to a possible point of reentry.

The team is also fortified when each professional is in close touch with his or her own spiritual strengths and vulnerabilities. Consider how your personal spiritual beliefs affect you in your work. Do they help to increase your sense of balance, comfort, and strength with the struggles you face in caring for patients? Do they help to decrease your own sense of isolation with the challenges you encounter in medicine?

Consider, too, how you will respond when a patient asks you to pray with him or her? There is no right answer here; the question just requires some thought on your part before the situation arises. Whatever your response, deliver it with integrity and kindness, honoring both your own beliefs and those of your patient. And call the chaplain.

PEARLS

- Remember that people may still be developing spiritually, even as they decline physically and mentally.
- Accompany people through life-limiting illness. This may reduce a deep sense of isolation and help people to find their own internal sense of comfort, balance, and strength.
- Realize that people tend to find meaning in relating to a greater world beyond themselves; this appears to be a virtually universal human need.
- Alert the chaplain to possible spiritual developments discovered during routine care.
- Stay in close touch internally with your own spirituality, and note where it strengthens you and renders you vulnerable in your life and in your work.
- Practice from a genuine posture of humility and openness. Desire to learn what will provide the most meaningful support to the person before you.

PITFALLS

- Discounting or dismissing the last stages of life as devoid of value
- Not seeing beyond brokenness of body and mind to the wholeness of the person
- Thinking that someone who is not religious will not be helped by spiritual care
- Thinking that a person's initial decline of spiritual care has to be static throughout the progression of an illness
- Not being in close touch with one's own spiritual beliefs
- Bringing a preconceived spiritual care agenda to the person for whom you are caring.

SUMMARY

How does spiritual care help people who are facing life-limiting illness to find courage and equanimity? How does it help people find balance, comfort, and strength?

The added dimension that spiritual care brings to palliative medicine has enormous capacity to improve the quality of life for patients, for families, and for physicians. Attending to the needs of the spirit can bring great comfort to the palliative care patient and to his or her entire circle of care. If spiritual care is offered with respect, sensitivity, and a supportive disposition, and if it is not agenda driven, it should rarely present any disadvantage.

By being present with people and attending to them in a way that is meaningful to them, the palliative team shows patients that they are valued as fully

human—that the team *sees* the whole of them, no matter how broken the physical body. When patients seemingly no longer have control over their circumstances, the palliative team gives them control wherever possible by respecting their needs and wishes. The care team functions with the understanding that all of us want to know we are loved, we belong, and we are not alone.

This is the condition of being fully human. Spiritual care helps people to remember this.

Resources

American Art Therapy Association: Available at www.arttherapy.org
American Music Therapy Association: Available at www.musictherapy.org
Association of Professional Chaplains: Available at www.professionalchaplains.org
Ethical Wills: Available at www.ethicalwill.com
Healing Touch: Available at www.healingtouch.net
International Center for Reiki Training: Available at www.reiki.org
National Association of Catholic Chaplains: Available at www.nacc.org
National Association of Jewish Chaplains: Available at www.najc.org

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Palliative Care in Long-Term Care Settings

5

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CHAPTER OUTLINE

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INTRODUCTION

The world's population is aging. Worldwide, one in every 10 persons is more than 60 years old. By year 2050, the number is expected to increase to one in every five persons. Palliative care clinicians will increasingly be confronted with providing end-of-life care for frail, older persons who are dying with multiple chronic illnesses. Palliative care clinicians must therefore develop expertise in the evaluation and treatment of geriatric patients.

This chapter provides an overview of three fundamental issues in the care of chronically ill, older patients: long-term care options and the possibility of including hospice or palliative care within the long-term care setting, the challenges of prognostication in chronically ill older adults, and the indications for and alternatives to artificial nutrition and hydration.

LONG-TERM CARE

Clinicians who care for chronically ill, older patients who are near the end of life need to be aware of the community resources and sites of long-term care that

are available for those who can no longer live independently. This section describes long-term care options, including home care, assisted living, nursing home care, day care, programs such as Programs for the All-Inclusive Care of the Elderly, and integrated programs such as the Edmonton Regional Palliative Care Program. Although this information may not be universally applicable, the aim is to provide examples of the diverse options that may be available in different communities.

Home Health Care

Many chronically ill patients wish to remain in their own homes as long as possible. Home health care aims to provide health and social services for older adults in their own homes to improve and maintain their function and to prevent institutionalization. Services may include skilled and psychiatric nursing, physical and occupational therapy, home health aide assistance, and social work support.

Although more research is needed to define the most effective strategies for providing palliative care in a patient's home, numerous benefits of home palliative care are described in the international literature and include increased satisfaction of the family caregivers with the care provided, decreased time spent in the hospital at the end of life (1), and improved general practitioner knowledge of symptom management. Another study has shown that incorporating a palliative care program into an existing home care program results in improved satisfaction with care, fewer emergency room visits, and decreased costs.

Daycare and Other Programs for Elders

Adult daycare programs are designed to provide daytime care for patients who have minimal personal care needs and have caregivers who are able to provide care only at night. Adult daycare offers a range of supportive and social services in the United States, the United Kingdom, Canada, Italy, and other countries. Most centers provide recreation, socialization, meals, some social services, personal care, and transportation. The medical care provided varies from site to site, however. Some centers offer specialized services such as dementia programs and incontinence programs. Although some may offer pain management, they rarely offer comprehensive end-of-life care.

One notable daycare program is found in the United States, the Program for the All-Inclusive Care for the Elderly (PACE) (2). PACE is a community-based, comprehensive care program funded by Medicare and Medicaid dollars. PACE programs enroll older persons who would otherwise be eligible for nursing home placement and provide them with comprehensive medical, rehabilitative, social, and personal services delivered by an interdisciplinary team. In the evening, the members return home to be cared for by families and friends. Care is provided in a daycare environment and in the participant's home, tailored to the participant's needs and social resources. PACE programs commit to caring for patients until the end of life, and these patients are no longer eligible for the Medicare hospice benefit while they are enrolled in PACE (2).

There are no published national standards for the provision of palliative care by PACE, and research suggests wide variation among programs. However, PACE may help clinicians, patients, and families to address important palliative care goals. Specifically, patients enrolled in PACE are more likely to die at home,

to avoid the use of invasive medical technology in the last months of life, and to have documented advance planning conversations, compared with Medicare recipients who are not enrolled in PACE. In addition, because the same interdisciplinary team follows patients from primary care to hospitalization to long-term care, the errors and distress that accompany transitions of care may be minimized under PACE. To improve the quality of palliative care provided, many programs have developed educational programs. However, research is needed to determine the specific needs of this group and how best to meet those needs (2, 3).

Another model of care that integrates a home palliative care program is the Edmonton Regional Palliative Care Program in Alberta, Canada. This program was created with the goal of increasing the access to palliative care services, decreasing the number of cancer-related deaths that occur in acute care facilities, and increasing the participation of primary care physicians in the end-of-life care of their patients. In the pilot program, four interdisciplinary teams provided consultative services for patients enrolled in a palliative care system that integrated several sites of care, including hospital-based services, inpatient palliative care units and hospices, and continuing care facilities, as well as a regional home care program. During the study period from 1992 to 1997, there was a decrease in the number of patients who died in the acute care facility and a significant decrease in the average length of stay in the acute care facility and the cancer center. It is likely that these outcomes not only met the goals of patients and families for a "good death," but also resulted in significant cost savings. Further research is needed to define both these benefits of home palliative care programs.

Assisted Living

Individuals who are less ill and more functionally intact may choose to reside in an assisted living facility. Typically, these facilities provide a combination of housing, personalized support services, and health services. Personal care homes, board and care homes, residential care homes, and domiciliary care are all examples of assisted living housing. In the United States, as well as other countries, assisted living facilities are quite heterogeneous, reflecting divergent regulations and variable institutional practices and levels of care offered (4).

Staffing and payment sources vary considerably among facilities. The most complete description of this can be found in literature from the United States. Although they are not required to do so by law, many assisted living facilities provide on-site physician visits and 24-hour nursing care. However, a national study of assisted living facilities in the United States reported that only 30% to 40% were staffed with a full-time registered nurse (40 hours/week) (5). In addition, only 15 of 50 states have minimum staffing laws, 22 of 50 states allow unlicensed staff members to distribute medications, and only 11 of 50 states require training for the nurse's aides.

Palliative care delivery in assisted living facilities may be hindered by a variety of factors, including lack of 24-hour coverage by a nurse, lack of an interdisciplinary care team, difficulty dispensing opioids because of limited nursing care or a lack of secure storage, insufficient numbers of physician visits, and minimal staff education about end-of-life issues. However, some assisted living facilities are piloting programs to improve care at the end of life in an attempt to provide adequate care for dying individuals (4). One study compared the dying experience

in assisted living facilities with that in nursing homes. In the last month of life, the assisted living residents were more likely to report untreated pain (14.8% versus. 1.8%; $P = .013$) and inadequately treated shortness of breath (12.5% versus. 0%; $P = .004$) compared with nursing home residents. Despite these inadequacies in symptom management, however, family and staff members reported greater satisfaction with end-of-life care in assisted living facilities compared with nursing homes (6). Although this study reported high satisfaction with care by both the families and the staff, this study also found substantial unmet palliative care needs. More research is needed to understand potential care interventions for assisted living residents. With the aging of the population, it is likely that the number of persons who will receive care in an assisted living facility will grow substantially.

Nursing Home Care

Nursing home care is available to patients who develop significant functional and physical impairments during the course of their illness and can no longer live at home or in an assisted living facility. Broadly defined, nursing homes are long-term care institutions that provide inpatient, 24-hour nursing care, as well as medical, social, and personal services to persons in need of short-term nursing and rehabilitation or long-term maintenance.

Increasingly, nursing homes have become the site of death for frail, older persons. It is projected that by the year 2020 approximately 40% of Americans will die in a nursing home. Given this trend, nursing home clinicians will likely assume an increasingly important role in the provision of end-of-life care.

Palliative care in nursing homes is frequently suboptimal. Recent research has highlighted important concerns with the quality of care in nursing homes from untreated pain (7), family dissatisfaction with the quality of care, and care that is not consistent with the disease trajectory or patient preferences (8). Research indicates that 33% to 84% of residents have ongoing pain that impairs ambulation, reduces quality of life, and increases the incidence of depression (7). In one study, 29% of nursing home residents with cancer reported daily pain, and only 26% of those with daily pain were treated with daily analgesics.

In another study, pain was reported by 69% of nursing home residents who were able to communicate. In 34% of these cases, however, the attending physician failed to recognize and treat the resident's pain. In a large study of 15,745 nursing homes, the staff reported that 3.4% of the residents had experienced daily excruciating pain during the previous week (7). Many dying nursing home residents with daily pain are either not receiving adequate pain management treatments or are receiving treatments that are inconsistent with pain management guidelines (9). Experts have identified barriers to the provision of excellent palliative care, including frequent staffing turnover, lack of palliative training and knowledge among the staff, and tension between goals of restorative care and those of palliative care.

Nursing home staffing issues may create a barrier to palliative care delivery. Staffing and services can vary substantially among nursing homes. Physician visits may be infrequent. A large portion of direct patient care is provided by nursing assistants, who usually have no formal training in geriatrics or palliative care.

The level and types of palliative care services provided vary among nursing homes. For example, some nursing homes have separate palliative care units or

beds and specialized dementia care units. Some may be able to administer intravenous medications and complete frequent pain assessments, but others may not. Nursing home residents at one institution may have immediate access to clinicians such as physicians, social workers, and chaplains, whereas others may have infrequently available contacts.

The quality of care also depends on staff turnover. It is known that higher staff-to-patient ratios are associated with higher quality of care, and longer relationships with staff result in greater satisfaction with care. However, many facilities experience frequent staff turnover. High turnover of nurse aides has been associated with inadequate staffing and stressful working conditions. Organization-wide efforts to improve quality of end-of-life care are difficult to sustain without a stable staff. Lack of continuity care has the potential to affect the quality of pain assessments and other end-of-life care adversely (10). Therefore, efforts to retain staff are particularly important. Additional education and training may be one strategy to decrease staff turnover.

Data describing educational and quality improvement programs that target physicians, nurses, and other nursing home staff members report an increase in family satisfaction with end-of-life care, increases in patient comfort (i.e., decreased pain intensity), and increases in job satisfaction among the nursing home workers (11,12). Thus, staff education may lead to improved care because of an augmented knowledge base, as well as a more stable staff.

Another challenge to the provision of palliative care in nursing homes may be related to regulatory environments. In the United States, experts in both long-term care and palliative medicine note that regulations and reimbursement systems may be at odds with the use of hospice and palliative care in nursing homes (10, 12, 13). In the United States, the 1987 Omnibus Budget Reconciliation Act (OBRA) stated that a major goal for nursing homes is to maintain or improve physical functioning (OBRA 1987) and mandated comprehensive assessments of all residents using the Minimum Data Set (MDS). The MDS, which includes 400 items that assess health and functional status, is used for clinical assessment and quality improvement. The information is also used to determine levels of reimbursement. Therefore, nursing homes with negative findings on their residents' MDSs are at risk for financial losses, as well as deficiency citations from state surveyors and possible decertification.

The desire to optimize the measures included in the MDS may be at odds with high-quality end-of-life care that is consistent with patient preferences. For example, weight loss secondary to dysphagia is a common terminal event in persons with dementia. Nursing home staff may believe that they will be cited or perform poorly on quality indicators if they respect a patient's wish not to have a feeding tube. It is important that these concerns be addressed with the nursing staff that cares for actively dying persons and that appropriate documentation outlining goals of care be noted in the medical record. Current reimbursement policies and the professional culture of many nursing homes focus on restorative care and the use of life-sustaining treatment such as artificial nutrition and hydration. Such financial incentives are one of the reasons cited for the underuse of and late referral of nursing home residents to hospice services or a focus on palliation in the nursing home setting. Palliative care clinicians need to be aware of these tensions to understand the decision-making process at the institution where they practice.

In Canada, limited funding for nursing home patients and similar staffing issues may also interfere with appropriate provision of quality end-of-life care.

Research in Canada over the past decade has shown that the quality of care in for-profit nursing homes is lower than that in not-for-profit nursing homes in many areas including the following: staffing levels and turnover; increased use of restraints, catheters, and tube feeding; and more unwanted outcomes such as pressure ulcers, infections, and hospitalizations.

One way to improve end-of-life care in nursing homes is to increase access to palliative care or hospice involvement for appropriate nursing home residents. Nursing home residents who died with hospice care in place had improved pain assessment and management, a greater likelihood of receiving an opioid for pain, and lower rates of hospitalization, restraint use, and artificial nutrition and hydration. Furthermore, in nursing homes with a larger proportion of residents enrolled in hospice, the nonhospice residents, as well as the hospice residents, experienced lower rates of hospitalization, higher frequency of pain assessment, and higher rates of opioid use for control of pain or dyspnea, when compared with decedents from nursing homes with limited or no hospice presence.

Nonrandomized, case-controlled studies have shown that families rated symptom management as significantly improved after the addition of hospice services to US nursing home care, and overall family satisfaction with end-of-life care was higher. Hospice or palliative care teams can teach family members and other caregivers to care for the dying patient and can offer emotional, psychological, and spiritual support to the patient and family, as well as bereavement care and counseling to family and friends before and after the patient's death.

A major factor cited for the low rate of hospice involvement in nursing homes is the difficulty in prognostication, especially in residents with a noncancer diagnosis because they have a less predictable illness trajectory (14). Other barriers to hospice referral include poor recognition of terminal illness, lack of knowledge within the facility about hospice, and the presence of artificial nutrition or expensive palliative care treatments (10).

Given that hospice involvement can improve the quality of end-of-life care, many residents will benefit from efforts to increase enrollment in hospice programs. One study found that a quality improvement intervention, involving the development of palliative pare leadership teams who taught a structured curriculum to all nursing home staff in selected nursing homes, led to increases in hospice enrollment, pain assessments, nonpharmacologic pain treatment, and discussions about end-of-life care from baseline (12). A randomized controlled trial of 205 residents demonstrated that those residents who received a "case-finding" intervention (including "jump-starting" conversations about hospice) were more likely to enroll in hospice within 30 days, had fewer acute care admissions, spent fewer days in an acute care setting, and had families who rated care more highly than the families of those who received the usual care (15).

Proactive discussion may minimize any conflict that may arise if the nursing home staff members believe that the hospice team members do not respect and value their opinions and care, or if nursing home staff members see the hospice as duplicating or interfering with their work or as another source of criticism and oversight. Nursing homes should focus more on care of the dying as part of their mission. Regulators need to recognize that caring for the dying is part of the nursing facility's mission, and that these populations require different services and measures of quality of care than those who are receiving custodial care. Nursing facility staff and regulators need training in appropriate means of caring for the dying.

ARTIFICIAL NUTRITION AND HYDRATION

Malnutrition and dehydration are serious and common problems among older people in nursing and residential care homes, especially among those at the end of life. Malnutrition is highly prevalent in the elderly populations in long-term care facilities, with estimates ranging from 30% to 85%. In addition to resident factors, specific barriers in long-term care staffing may contribute to poor nutrition, such as a lack of training, responsibility for the care of too many residents, poor food quality, and a lack of teamwork between nurse and nursing assistant. More than half of nursing home residents need feeding assistance. In addition, 40% to 60% of nursing home residents may have some degree of dysphagia. Higher staff levels have been associated with a reduced risk of malnutrition.

The prevalence of artificial nutrition and hydration for nursing home residents with dementia is higher in the United States than in many other countries. In one cross-sectional cohort study, approximately 6.6% of older nursing home residents in the United States received long-term artificial nutrition by feeding tubes, compared with 6.4% in Ontario, Canada. Of the two, the US cohort was almost three times as likely to have a diagnosis of dementia (16). In a 1999 study of all US Medicare- and Medicaid-certified nursing homes, more than one third of severely cognitively impaired residents had feeding tubes. The prevalence of artificial nutrition and hydration was associated with the residents' clinical features and the nursing home's demographic, financial, and organizational features. Palliative care clinicians may be asked to assist patients and families in making decisions about artificial nutrition and hydration.

Evidence Summary: Risks and Benefits

Most literature about artificial nutrition and hydration in the long-term care setting focuses on patients with advanced cognitive impairment. Although there are no randomized, controlled studies that compare tube feeding with hand feeding, little evidence indicates that artificial nutrition and hydration prolong life, improve nutritional status, prevent aspiration, decrease development or promote healing of pressure ulcers, or improve a patient's comfort (17). A large retrospective study showed that nursing home residents with dysphagia and advanced dementia did not have any survival benefit from receiving artificial nutrition and hydration, even after correcting for medical comorbidities. Another study reported that the median survival among elderly patients after percutaneous gastrostomy tube placement was 5.7 months, with 1-month mortality of 24% and 1-year mortality of 63% (18).

A prospective cohort study of relatively younger residents (mostly without dementia) and observational studies of nursing home residents with advanced dementia found that artificial nutrition did not provide consistent improvement in weight or serum albumin. There is no evidence from existing studies that artificial nutrition and hydration via gastrostomy tube prevents aspiration (17). Cohort studies have failed to demonstrate any benefit of artificial nutrition and hydration on prevention or healing of pressure ulcers.

In addition to this lack of evidence of improved outcome, artificial nutrition and hydration have adverse effects at the end of life. There are complications related to the placement of a gastrostomy or jejunostomy tube, such as local

infection, perforation, and aspiration secondary to sedation. Long-term complications can include tube dislodgement or clogging, diarrhea, aspiration pneumonia, *Clostridium difficile* colitis, and the use of restraints to prevent removal of the tube.

Costs of Tube Feeding

A small prospective cohort study examined US health care costs associated with gastrostomy tube feeding over 1 year. The average daily cost of tube feeding was $87.21 (median, $33.50). The estimated cost of providing one year of feeding via gastrostomy is $31,832 (median, $12,227). The main components of this cost include the initial tube placement (29.4%), enteral formula (24.9%), and hospital charges for rare but costly major complications (33.4%).

Another small study examined the cost of caring for 11 severely demented US nursing home patients with artificial nutrition and hydration versus another 11 patients without artificial nutrition and hydration. Items assessed included nursing time, physician assessments, food, hospitalizations, emergency room visits, diagnostic tests, treatment with antibiotics and parenteral hydration, and feeding tube insertion. Costs of nursing home care were higher for the residents who were not receiving artificial nutrition and hydration (i.e., receiving hand feeding) than for those receiving artificial nutrition and hydration ($4219±1546 versus $2379±1032, $P = .006$).

Ethical Issues Regarding Artificial Nutrition and Hydration

Ethical issues surrounding artificial nutrition and hydration often involve decision-making conflicts between the health care provider and patient's surrogates about the decision to initiate and the eventual decision to withdraw artificial nutrition and hydration. When a resident's wishes about artificial nutrition and hydration are known, it is reasonable to respect them, unless doing so will bring about obvious harm, such as increased respiratory distress or pain. Unfortunately, a resident's advance directive regarding wishes for artificial nutrition and hydration is often not available. When a patient's preferences are unknown, the surrogate should make a decision based on substituted judgment or knowledge of the patient's probable wishes. When the patient's probable wishes are not known, the surrogate must consider how a reasonable person would make a decision under the same circumstances. When artificial nutrition is being considered, clinicians should prepare patients and surrogates to consider a trial of therapy with eventual withdrawal if it does not achieve the desired effects.

Education of a resident's surrogate decision makers can greatly aid the process of decision making, but this education is often limited or nonexistent. Routine education at the time of nursing home admission may be helpful. Proactive education of decision makers about the lack of known benefits for tube feeding in advanced dementia may lead to more informed decisions, to greater satisfaction with decisions, and possibly to decreased tube placement in patients with advanced dementia (19, 20).

Education should focus first on general goals of care instead of technical options and should involve listening to the patient's or surrogate's perspective and addressing any disagreements with a mutual exchange of information. Disagreements are more likely to arise when patients or surrogates have unrealistic

goals, if they have received mixed messages or mistrust the medical establishment, if they are in denial about the poor prognosis, or if the surrogate feels guilt about his or her own involvement in the patient's care. Language barriers and sociocultural differences can exacerbate the challenges of communication.

A critical question for discussion is whether the particular treatment or intervention will restore or enhance the quality of life for the patient. For example, artificial nutrition and hydration may meet goals of care in some long-term care populations, such as patients in the acute phase of a stroke or head injury, those receiving short-term critical care, or those with certain bowel conditions, but artificial nutrition and hydration in other populations, such as patients with advanced dementia, may not achieve any of the mutually determined goals of care.

The value systems of patients and surrogates should play a role in decisions. Although most available evidence suggests that artificial nutrition does not improve survival or quality of life in many situations and, in fact, may worsen outcomes, this evidence conflicts with beliefs that many people have that all nutrition is basic care and must be provided, just as patients must receive shelter and basic personal care. This view may be linked to cultural or religious beliefs or a belief that forgoing artificial nutrition results in suffering and "starvation." In this sense, artificial nutrition sometimes represents more to patients and families than simply another medical treatment.

Specifically, cultural differences in perceptions of feeding may account for discrepant care. In Japan, physicians sometimes institute tube feeding in older patients with dysphagia out of consideration for strong family emotions, religion, public opinion, and social customs. Japanese physicians may agree to use feeding tubes out of fear that they will be accused of refusing such treatment for economic reasons. However, 90% of family members caring for tube-fed patients would not want to receive a feeding tube themselves in a similar situation. US data suggest that African American patients with advanced dementia receive feeding tubes at higher rates than do white patients. Regional differences also exist in the United States, with higher rates of use in urban settings and lower rates of use in rural settings. Physicians must acknowledge these cultural differences and accept that sometimes a well-informed surrogate will choose tube feeding for a nursing home resident with advanced dementia or other end-stage disease. To provide artificial nutrition in such cases can provide relief of psychological, spiritual, or social distress in the dying process for the patient and family. Conversely, adequate education of risks, benefits, and alternatives to tube feeding may allow patients legitimately to refuse a feeding tube if they do not want tube feeding but feel societal pressure to accept it. National standardization of practice through the use of guidelines that are based on evidence from trials may be one method of eventually changing societal norms.

In developing countries, cost may be a major additional consideration. Decision making may also be influenced by health care settings and clinical circumstances; for example, decisions about artificial nutrition and hydration are more likely to occur in a nursing home than in an acute care hospital. Standardized methods of capturing patient preferences may assist facilities in documentation.

If artificial nutrition and hydration are already in place, then ongoing discussion of the goals of care should occur. The same ethical principles apply to withdrawal of artificial nutrition and hydration as to its initiation. Artificial nutrition can be withdrawn if it is no longer consistent with mutually determined goals of care.

Patients who forego or request the withdrawal of artificial nutrition and hydration should receive high-quality palliative care.

Alternatives to Artificial Nutrition and Hydration

Extrapolation from other situations of impaired eating at the end of life suggests that discomfort from not eating is rare and, when it occurs, can be improved by measures other than artificial nutrition and hydration (21). It is important to reassure patients and families that decreased food and fluid intake at the end of life is normal and is an expected part of the dying process and that, in fact, it usually leads to a more comfortable death by minimizing secretions, urine output, and edema. This information will minimize guilt that families may feel and will decrease the assumption that a needed treatment, nutrition, is not being given.

Family members who attend meals and who bring in favorite foods from a restaurant or from home can help to restore pleasure in eating. At visits, the family can offer snacks in a nonpressuring manner. Other practical interventions include the following: creating an atmosphere that promotes mealtime as a pleasurable social activity; providing smaller portions more frequently; offering lactose-free nutritional supplements between meals as well as with medication passes; encouraging favorite foods; and avoiding diabetic, low-salt, low-fat, and low-cholesterol diets. In residents with dysphagia, a change in food texture and thickened liquids or changes in body positioning can improve swallowing. However, patients may dislike the modified food because the food can be less tasteful and thus makes eating less enjoyable, and this could inadvertently lead to further weight loss. For patients who do not take adequate fluids and who appear to have dry mouth, good oral care can improve comfort, and moistening the mouth can decrease the sensation of thirst.

In addition, residents should be assessed for unrecognized and inadequately treated medical conditions that can contribute to decreased appetite, including the following: certain medications; dental caries or infection; poorly fitting dentures; dry mouth; pain; constipation or fecal impaction; urinary retention; and burden of symptoms, such as nausea, vomiting, sedation, agitation, and dyspnea. The benefits and burdens of a comprehensive workup must be determined, by taking into account the patient's condition, family expectations and desires, and any health care directives.

Patients should be assessed and treated for anxiety, insomnia, and depression, and the use of antidepressants with appetite-stimulating effects, such as mirtazapine, should be considered. If improved appetite meets mutually determined goals of care, the clinician should consider the use of other appetite-stimulating medications, such as dexamethasone, 1 to 2 mg twice/day, prednisone, 10 to 20 mg twice/day, or megestrol, 80 to 400 mg twice/day (for a typical trial of 6 to 8 weeks). The efficacy of dronabinol and oxandrolone as appetite stimulants is controversial.

PEARLS

- Know your local long-term care options, including home-care, assisted living, nursing home care, daycare, programs such as Programs for the All-Inclusive Care of the Elderly (PACE), and any integrated programs such as the Edmonton Regional Palliative Care Program.

- Use home health care services to improve and maintain function and to prevent institutionalization.
- Use home palliative care to increase caregiver satisfaction, decrease hospital and emergency department visits, and decrease costs.
- Use adult daycare programs for patients with minimal personal care needs whose caregivers are able to provide care only at night.
- Use assisted living facilities to provide a combination of housing, personalized support services, and health services.
- Provide decision makers with alternatives to tube feeding, such as good palliative care.

PITFALLS

- Failing to consider hospice or palliative care in appropriate nursing home residents
- Overestimating prognosis, especially when not using objective signs and symptoms that can help to identify patients with poor prognosis (e.g., albumin, agitation, pressure ulcers, functional status, weight loss)
- Not recognizing the lack of evidence for use of artificial nutrition in patients with advanced dementia
- Not recognizing the ethical issues surrounding artificial nutrition and hydration, especially conflicts in decision making between health care providers and patients' surrogates
- Failing to respect a resident's known wishes about artificial nutrition and hydration
- Failing to acknowledge cultural differences in attitudes toward artificial nutrition and hydration
- Failing to accept that sometimes a well-informed surrogate will choose tube feeding for a nursing home resident with advanced dementia or other end-stage disease

SUMMARY

In summary, there is a dearth of evidence supporting the use of tube feeding in nursing home residents at the end of life. There should be advance care planning on every admission to the nursing home to determine the resident's or surrogate's wishes regarding this issue, with clear discussion of the lack of evidence of benefit in most situations, especially in advanced dementia. Despite this lack of evidence, many decisions about tube feeding are based on a patient's values, which often vary based on cultural and religious backgrounds. In this light, any well-informed decision regarding tube feeding should be respected. Good palliative care provides many alternatives to tube feeding.

As the population ages, there will be a greater need for palliative care physicians who are expert in determining the level of care an older, functionally impaired individual will require to be comfortable and safe near the end of life. In addition, families and patients will need advocates and guides to help them make difficult

decisions regarding goals of care and treatments, particularly regarding the use of artificial hydration and nutrition.

Resources

European Association for Palliative Care: Available at http://www.eapcnet.org/index.html
International Association for Hospice & Palliative Care: Available at http://www.hospicecare.com/
International Observatory on End of Life Care: Available at http://www.eolc-observatory.net/

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Integrating Palliative Care into Disease Management

6

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CHAPTER OUTLINE

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INTRODUCTION

The principal objectives of clinical practice guidelines are to improve medical care quality, to reduce variation in physician performance, and to enhance the cost effectiveness of care. Guidelines document recommendations based on expert analysis of available evidence and consensus of expert opinions. The proliferation of clinical guidelines for disease management has produced variation in the quality of guidelines themselves and, at times, confusion for the conscientious clinician who is willing to adopt authoritative recommendations.

Palliative care guidelines are different from disease management guidelines because they address a comprehensive approach to care, rather than focus on a particular condition. Like disease management recommendations, palliative care guidelines are based on widely accepted consensus. Recently, a generic template has been developed to encourage the intercalation of important palliative care principles into all disease management guidelines that deal with life-threatening illnesses. Even though these steps have occurred, many physicians have been slow to adopt such innovations or are unaware of their availability.

This chapter is intended to help clinicians who are involved in palliative care guideline development and implementation to become familiar with the ideal characteristics of guidelines, the process for guideline development, and several significant examples of palliative care guidelines. The chapter also highlights the limitations of guidelines and outlines suggestions from the field of diffusion studies to overcome these limitations in changing practice patterns. These involve a variety of organizational and technological strategies to influence the adoption of innovations, such as the recommendations of national palliative care consensus panels.

PURPOSE, POTENTIAL USES, AND AVAILABILITY OF CLINICAL GUIDELINES

The primary purpose of clinical guidelines is to help clinicians provide high-quality care to patients with specific health problems. Guidelines have multiple applications, depending on who is using them (e.g., clinicians, patients, payers, educators, policy makers) and on how they are designed. Clinical guidelines may

- Facilitate clinical decision making by communicating best practices.
- Inform physicians about medical research pertinent to the subject of the guideline and support the introduction of recently established findings into clinical practice.
- Provide summaries and recommendations in undergraduate, graduate, and postgraduate medical education programs.
- Improve the accountability of care by evaluating actual practice against accepted clinical standards.
- Provide a basis for pay-for-performance initiatives.
- Help reduce unnecessary and cost-inefficient practices such as the inappropriate use of high-cost technology.
- Provide a useful resource to patients and other consumer groups who want to participate in medical decisions by informing them about current medical opinion regarding the best available care.
- Identify important gaps in evidence and help to set research agendas.

Since the mid-1980s, the numbers of clinical practice guidelines in general, and those for palliative care in particular, have proliferated exponentially. Guidelines are now widely circulated in most health care settings and via the Internet in comprehensive databases (e.g., the National Guideline Clearinghouse http://www.guideline.gov).

The quality, applicability, and utility of individual guidelines vary considerably, and for practicing community clinicians the task of sorting through the literature to find practical and applicable tools for individual clinical circumstances can

be daunting. A challenge that faces guideline writers and other stakeholders who are trying improve health outcomes is the design of effective guidelines that can be disseminated and adopted throughout the care delivery system.

The purpose of this chapter is to provide an overview of the methods used to design guidelines, the elements that determine the quality of guidelines, and the steps necessary to disseminate and implement guidelines successfully in everyday practice across care settings. For purposes of illustration, specific examples of palliative care guidelines are mentioned in the text or are cited in the Resources section of this chapter.

DEFINITION OF TERMS

Various terms are used to describe consensus statements about clinical practices. This section examines how these terms are generally used.

Practice policies are recommendations intended to be applied to populations of patients with a particular condition within a specified medical context. Eddy described three types of practice policies: standards, options, and guidelines (1). He distinguished these practice policies by the degree of flexibility with which they should be applied in clinical practice and the degree to which patients would agree on their recommendations.

Standards are considered best practices backed by well-documented research and experience. Standards are those practices that are virtually unanimously desired by patients, and failure to follow standards would be considered malpractice. Standards are not flexible and should be strictly followed by clinicians.

Options are neutral in their flexibility and are more complicated because they can represent interventions for which outcomes are unknown or for which outcomes are known but patient preferences vary (preferences unknown, indifferent, or evenly split for or against the intervention).

Guidelines are more flexible than standards and are intended to aid or guide clinical decision making. The Institute of Medicine defines clinical practice guidelines as "...systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances" (2).

Guidelines are based, at least in part, on known outcomes of a particular intervention and reflect best practices. However, guidelines are intended to serve only as aids and may not necessarily be appropriate for all patients or agreed to by all physicians. Deviations from guidelines are common, and in many cases these deviations are appropriate when a physician's clinical judgment and patient-specific variables and preferences are factored into clinical decision making.

Rating the strength of evidence and recommendations for a guideline depends on the quality and consistency of underlying evidence supporting the recommendations and the likely benefit to the particular population of patients to which the guideline is applied (3). A system for rating the strength of evidence was first codified by the Canadian Taskforce on the Periodic Health Examination in 1979. After some modification, the US Preventive Services Taskforce accepted this approach of rating the quality of the evidence on which recommendations are then made and grading the strength of the recommendations. Although there is considerable

variation among the actual grading schemas used by guideline authors, well-formulated guidelines have an explicit description and evaluation of the kinds of evidence used, the potential benefits and harms, and the resulting grade of recommendations made. However, different guidelines for a particular condition can be in conflict because of differences in how the guidelines were developed, the interpretation of data used, the individuals involved, and how the lack of definitive information was handled.

Clinical practice guidelines, protocols, clinical pathways, critical pathways, care maps, clinical algorithms, and similar terms are generally used synonymously. For the balance of this chapter we employ "clinical guidelines" or "guidelines," for short.

DESIRABLE ATTRIBUTES OF CLINICAL GUIDELINES

The Institute of Medicine defined eight "desirable attributes" of clinical practice guidelines (4):

- Validity
- Reliability and reproducibility
- Clinical applicability
- Clinical flexibility
- Clarity
- Documentation
- Development by a multidisciplinary process
- Plans for review

Eddy (5) recommended focusing on five criteria:

- Accuracy: Explicit and objective evaluation of evidence
- Accountability: Documentation of assumptions and evidence considered, how estimates were made of pros and cons of benefits so the underlying reasoning can be evaluated
- Predictability: The expected outcome of following the guideline
- Defensibility: How disagreements and conflicts with other policies and evidence were reconciled
- Usability: How the guideline can be intelligently tailored to the unique characteristics of each patient or those in similar risk groups

PROCESS OF GUIDELINE DEVELOPMENT

The fundamental process of guideline development is a systematic review and synthesis of the best available evidence pertaining to a clinical question with explicit criteria for evaluating the strength of evidence. However, the methodology for guideline development is not standardized, although there have been proposals to do so.

Woolf described four methods for developing practice guidelines: informal consensus development, formal consensus development, evidence-based development, and explicit guideline development (6).

Informal consensus development is based on *expert opinion*: A group of experts makes recommendations based on clinical experience and a subjective assessment of the available evidence. They reach agreement without necessarily providing documentation of the methodology used to reach the conclusions or to ensure that the literature was reviewed without bias or that the recommendations are actually evidence based. This methodology is familiar to most practitioners, and informal consensus type guidelines are widely available. Recommendations may not be based on systematic clinical studies. The main advantage of informal consensus guidelines is that they are relatively easily produced. The problem is that they are often influenced by the biases of the panel members who formulate them, and they lack the systematic methodology to ensure that the recommendations are based on the best available science and research. This may also limit acceptance of informal consensus guidelines by large numbers of physicians.

By contrast, *formal consensus development* methods introduce a systematic approach to assess expert opinion and reach consensus. This approach was first developed in the late 1970s (7). Although formal consensus guideline development brings more structure to the analytic process of assessing expert opinion than does informal consensus, both methods lack explicit criteria that link the recommendations contained in the guideline to the quality of the underlying evidence.

Evidence-based development ties the recommendations contained within the guideline to the best available research and provides a description of the evidence. This process begins with a clear definition of the specific clinical question to be answered by the guideline and establishes explicit criteria and systematic methods for appraising the quality of the pertinent scientific evidence. The grade or strength of its recommendations is based not only on the quality of the available scientific evidence used, but also on the magnitude of the likely benefits and risks of the intervention (e.g., health benefits and side effects, cost of the intervention, practicality of implementation in clinical practice) (3). This grading allows for a more explicit evaluation of the guideline. The primary disadvantage of this approach is the relative lack of well-designed studies, particularly randomized controlled trials, which provide the highest grade of evidence. Another disadvantage of evidence-based guidelines is that they are derived from studies with highly selected cohorts of patients. As a result, particular guidelines may not be applicable to many individual patients because of their unique clinical characteristics and preferences.

The *explicit method* of guideline development builds on the evidence-based model employing firmer scientific evidence, as well as an approach developed by Eddy. The latter includes both a systematic evaluation of the benefits, harms, and costs of potential interventions, with estimates of the probability of each outcome *(outcomes-based approach)* and a process for incorporating patients' preferences for interventions *(preference-based approach)*. The information is presented in the format of a *balance sheet* with an estimation of the probability of each outcome (8, 9). This allows the reader of the guideline to judge the value of alternative interventions and to link multiple options and outcomes. The primary advantage of this approach is that it provides a framework for practitioners and patients to evaluate the consequences of the different options presented in the guideline prudently and to tailor the intervention to the individual patient's preferences and values. Thus, explicit guidelines may potentially be most consistent with an optimal palliative care philosophy because they focus on consequences of interventions and consider patients' preferences and goal assessment in care planning. The disadvantage of this

approach is that it is complicated and time consuming to develop and may not be practical.

ROLE AND LIMITATIONS OF EVIDENCE-BASED MEDICINE IN CLINICAL PRACTICE

The last two methods just described involve evidence-based approaches, which have been defined as

...the conscientious, explicit, and judicious application of the current best available evidence in the care of patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research (10).

There are four essential steps to practicing evidence-based medicine:

1. Defining the clinical question to be addressed
2. Accessing the information pertinent to answering the clinical question in an efficient and comprehensive way
3. Judging the credibility of the literature retrieved
4. Applying the study results to the care of patients

Although this process seems straightforward and is preferable to expert opinion alone, the last step is the most problematic. As noted earlier, this is primarily because study cohorts may not match many of the characteristics of patients in the clinical settings where the guidelines will be applied. In addition, the label "evidence-based" is used in medical literature in various ways. In general, the term applies to studies that avoid "systematic bias, non-systematic bias and inferential error" (11). Although randomized controlled trials may be least subject to bias, these are usually not feasible in the palliative care setting. Nonetheless, the quality of evidence in a study can be said to be relatively strong if the interventions and outcomes are observed in the same study. Inferences in such studies are said to be direct, as opposed to indirect, in which multiple sources of evidence are required to infer outcomes.

Woolf and colleagues noted that, "Many, if not most, evidence-based clinical practice guidelines are based on indirect evidence because they rely on a chain of reasoning that is based on several distinct bodies of evidence" (12). Therefore, evaluating evidence in guidelines is particularly difficult because it requires assessing the appropriateness of study designs employed in multiple studies and then making judgments about their implications for practice in general. This is inevitable because the evidence-based studies were limited to defined cohorts that met specific inclusion and exclusion criteria. This decreases their generalizability, so recommendations within guidelines are more the result of clinical judgment and experience than of simple conclusions from the underlying science.

Palliative care compounds the difficulty in evaluating evidence because there are significant barriers to measuring the outcomes and efficacy of interventions. These include the following:

- The multidimensional aspect and comprehensive scope of palliative care. This makes it difficult to measure the effects of multiple interventions across various domains of patient suffering (e.g., physical, emotional, existential).
- The unavailability of the ultimate recipient of care to provide feedback on the success of the intervention. Close relatives and caregivers can provide a proxy, however.
- The blinding in randomized trials. Although intended to eliminate patient and provider expectation biases, this study design may be antithetical to many types of palliative care research because patients' preferences, values, and expectations help to determine appropriate interventions and are important aspects of the patient-centered values of palliative care.
- The reluctance of many patients with advanced illness to participate in research. The limited stamina and functional incapacity in frail and vulnerable patients can create ethical challenges in obtaining informed consent.

Despite these limitations and the absence of large randomized trials in palliative care, leaders within the field have reached significant agreement about the principles of quality palliative care.

STATUS OF GUIDELINES IN PALLIATIVE CARE: BROAD PROFESSIONAL CONSENSUS

All palliative care guidelines highlight either specific features of or a broad range of palliative care's goal to optimize symptom management and the quality of life for patients with life-limiting conditions. This approach involves attending to the physical, psychosocial, practical and spiritual needs of these patients, employing patient-centered communication, and sensitively delivering bad news. Palliative care decision making should reflect an iterative process of clarifying goals throughout the progression of the patient's condition. Finally, attention to the needs of caregivers and bereavement support are also addressed.

One of the largest representative efforts to codify practice guidelines for palliative care was the National Consensus Project for Quality Palliative Care (13). Its guidelines were developed and agreed on by five major palliative care organizations in the United States: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, Last Acts Partnership, and the National Hospice and Palliative Care Organization. It referred to prior efforts of the Institute of Medicine reports (*Approaching Death*, *When Children Die*, and *Crossing the Quality Chasm*), the American Association of Colleges of Nursing report, *Peaceful Death*, and the National Hospice Work Group and the Hastings Center in association with the National Hospice and Palliative Care Organization monograph, *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*. It was noted that all these reports

...call for substantive changes to improve access to palliative care across the life span, in all health care settings, during all stages of debilitating chronic or life-threatening illness or injury. These changes include enhancements in the quality of care, restructuring of health care system regulations on service, education of health care professionals and research to support evidence-based palliative care practice (13).

Fourteen national specialty societies and the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) have adopted recommendations and policies that embrace the core principles of palliative care, and palliative care is now a recognized specialty with a well-defined set of practice standards. Numerous resources are available to clinicians to facilitate the development of these skills (see the Resources section at the end of this chapter).

Therefore, although there is broad agreement about the principles and practice of palliative care, workers in the field also agree that changes in the health care system need to address the following:

- Broader access to palliative care in all stages of life-limiting conditions
- A focus on high-quality of end-of-life care
- More professional education in palliative care
- More research to enhance the scientific basis for palliative care practice and guidelines

Although clinical guidelines can expect to make a contribution to several of these goals, they are not sufficient to achieve all the above aspirations. Moreover, guidelines are not likely to be effective in changing traditional practice patterns unless they are effectively disseminated to more physicians, and the physicians are motivated to adopt such guidelines and be held accountable for performance consistent with the guidelines (14). How this may occur is more fully addressed in the next section. Disseminating palliative care through disease management guidelines is one important step.

IMPROVING THE PALLIATIVE CARE CONTENT WITHIN DISEASE MANAGEMENT GUIDELINES

The very nature of palliative care is integrative and comprehensive. Ideally, it should be intercalated in all disease management guidelines that focus on a life-limiting condition. Studies indicate that this is not the case. Mast and coworkers surveyed 91 guidelines representing nine significant life-limiting conditions for palliative care content and found that only 10% had significant palliative care content, whereas 64% had minimal content (15). The absence of palliative care content in such guidelines may undermine the perception of the importance of palliative care in the eyes of generalists and specialists who manage such diseases.

As described previously, experts in palliative care have addressed guidelines for specialists in their own field. Nonetheless, there is a critical need for palliative care principles to be disseminated more broadly, especially to nonpalliative care physicians who may be using disease management guidelines in their clinical practices, as teaching aids, and for identifying areas of research development. The American Hospice Foundation Guidelines Committee recognized the lack of sufficient recognition of end-of-life issues in most chronic disease management guidelines and developed a template that recommended how guidelines could better integrate palliative care principles into the initial assessment, diagnosis, treatment, and concluding phases of managing life-limiting diseases (16).

Strategies to Address Challenges of Incorporating Guidelines

The gap between existing evidence-based recommendations and actual clinical practice is well documented. Numerous interventions to close this gap (e.g., medical record audits and feedback, academic detailing, chart-based reminders, computer decision support, benchmarking) have been studied and tried, although no one intervention has been shown to change behavior among health care professionals consistently across all settings. What is clear is that passive dissemination alone, such as traditional continuing educational efforts, is one of the least effective techniques (17).

CHALLENGE OF CHANGING BEHAVIOR IN MEDICINE

Diffusion of Information and Training

Diffusion studies comprise a field that analyzes the processes that contribute to or inhibit the dissemination of innovation. Innovation is

an idea, practice, or object that is perceived as new by an individual or another unit of adoption. ...Diffusion is the process by which an innovation is communicated through certain channels over time among the members of a social system. ...The four main elements are the innovation, communication channels, time, and the social system. These elements are identifiable in every diffusion research study, and in every diffusion campaign or program (18).

Innovation, including the adoption of comprehensive, high-quality palliative care in clinical practice, embodies a set of valuable principles that should be readily embraced by all physicians. Nonetheless, lack of familiarity with advances in palliative care generates indifference or resistance or may raise questions about its value to patients, compared with how generalists or specialists usually deal with end-of-life issues. Some more innovation-oriented physicians are early adopters and appreciate the relative advantage of palliative care over the standard medical model. Others note its complexity and extensiveness and may be discouraged by this. For example, the previously cited National Consensus Project for Quality Palliative Care takes more than 25 pages to describe 8 separate domains of care and 19 guidelines and their 120 associated criteria that should be addressed. Much can be done to overcome this barrier of complexity by using electronic health records and personal digital assistants, as discussed later.

Communication channels to educate physicians about palliative care exist in many venues and are important tools for the dissemination of information about a field's general ideas. Some examples include the following: the Education in Palliative and End-of-Life Care Project, whose mission is to educate all health care professionals on the essential clinical competencies in palliative care (www.epec.net); the End of Life/Palliative Education Resource Center at the Medical College of Wisconsin (www.eperc.mcw.edu); and the End-of-Life Nursing Education Consortium (www.aacn.nche.edu/ELNEC/index.htm).

In addition, the Liaison Committee for Medical Education, which establishes undergraduate medical education requirements, and the Accreditation Council

on Graduate Medical Education, which defines requirements for residency and fellowships programs in the United States, have both recognized training in end-of-life care issues in their review criteria.

Despite these efforts, deficiencies continue to be prevalent. For example, in a 2003 survey that evaluated the experiences of medical students, residents, and faculty, Sullivan and coworkers found that fewer than 18% of students and residents received formal end-of-life education, 39% of students reported were unprepared to address patients' thoughts and fears about dying, and nearly half felt unprepared to manage their own feelings about patients' deaths or to help bereaved families (19). In addition, palliative care has not been adequately represented in medical textbooks (20).

Physicians have also relied on other continuing medical education resources to maintain and improve their skills and knowledge. Traditional formats, such as attending lectures and reading textbooks, journals, and published clinical guidelines, are supplemented by newer methods that are more learner centered and self-directed. The latter include computer-based interactive technologies. Conclusions about which educational methods are most effective in influencing clinical practice and in improving outcomes may be determined by factors unique to the individual targeted, such as review of actual records. This becomes more practical with the installation of electronic health records.

Despite the ease and availability of the Internet and the variety of traditional continuing medical education venues, innovation studies suggest that the most effective ways of influencing behavioral changes, especially those involving new patterns of practice, are interpersonal experiences, especially face-to-face contact. This approach allows a clear exchange about the key elements of the innovation, an opportunity to influence the initiate's attitude positively toward the innovation, and, ultimately, a chance to persuade physicians to try implementing these changes in their practice.

Diffusion investigations show that most individuals do not evaluate an innovation on the basis of scientific studies of its consequences, although such objective evaluations may be especially relevant to the very first individuals who adopt them. Instead, most people depend primarily on a subjective evaluation of an innovation that is conveyed to them from other individuals like themselves. The dependence on the experience of near peers suggests that the heart of the diffusion process consists of the modeling and imitation by potential adopters of their network partners who have previously adopted the innovation. Thus, diffusion is a very social process.

The availability of mini-residencies for community physicians or invitations to attend palliative care units and palliative care rounds as continuing medical education–creditable activities may therefore be important complements to courses, conferences, journal articles, books, and guidelines in palliative care.

The pace or rapidity with which those persons who are exposed to the concepts of palliative care actually adopt it will vary. Innovation studies consistently describe four groups: early adopters, an early majority, a late majority, and laggards.

The *social system* in which innovative ideas occur affects the likelihood of the adoption of innovations and the time or speed with which they are adopted.

Opinion leaders who are respected members of a peer group and a nexus of relationships that reinforce the acceptability and desirability of new changes have a high rate of influencing the rate of adoption of innovation.

The challenge here is threefold. First, the presence of fellowship-trained palliative care physicians in more institutions is a critical step to improve access to expert consultations and care and to influence the attitudes and practices of nonpalliative care physicians elsewhere in the hospital and in related institutions. At present, there are 50 hospice and palliative care medicine fellowship programs in the United States, and these programs are expected to graduate more than 100 fellows each year. This number falls far short of the need, and, therefore, all medical residents and fellows need to be trained in basic palliative care skills. This is part of the curriculum stipulated by the Accreditation Council on Graduate Medical Education, although the details of this aspect of the curriculum and the qualifications of the teachers of palliative care are not specified. Second, many physicians in practice may not define their core responsibilities as including principles of quality palliative care or early palliative care referral. It is therefore important to encourage specialty societies to include palliative care principles in their clinical guidelines, board examinations, recertification examinations, and residency program accreditation requirements. Major specialty conferences should include palliative care topics as should specialty journal. Specialty society leadership should explicitly stress the inclusion of palliative care responsibilities within the scope of professional expectations. Third, there is a need to reach relatively isolated physicians in rural practices or those without active hospital privileges and to find practical ways to invite such individuals into model palliative care centers so such physicians will learn to manage their patients more effectively and to make appropriate referrals.

Technology as a Tool for Diffusing Innovation

Technology also has an important role in the dissemination of palliative care. As previously mentioned, the comprehensiveness of palliative care generates hundreds of potential interventions in multiple domains of care. When viewed from the standpoint of paper-based guidelines and paper-based medical records, the translation of these guidelines into practice is indeed daunting. Digitizing health information is crucial for many reasons, not least of which is that electronic health records will allow programming of prompts or reminders to clinicians about needed care for individual patients. These rules-driven reminder systems incorporate evidence-based guidelines and help busy physicians to adhere to even complex sets of recommendations.

The initiative of the US and British governments, managed care, and pharmaceutical firms to subsidize the development of network infrastructure, computer purchasing, and, in some cases, the full cost of electronic health record software will make such prompting systems more prevalent. The ease with which guidelines can be downloaded to hand-held personal digital assistants should also facilitate the diffusion of the important principles of palliative care into everyday practice, in both hospital and office settings.

Adherence to Quality Guidelines and Pay-for-Performance Incentives

National attention to improving quality of care and patient safety has spurred the development of pay-for-performance (P4P) initiatives by large health plans and the Centers for Medicare and Medicaid Services (CMS). In these programs, the quality of care is measured and monitored, and financial incentives for physicians and hospitals are linked to performance measures. Well-established metrics are now used in these pay-for-performance models to assess quality based on preventive care and longitudinal care for a variety of chronic diseases. The primary focus of these incentive programs is to increase physician compliance with evidence-based clinical guidelines. Although these programs hold much promise for improving quality of care in a variety of areas, pay-for-performance models for palliative care delivery are problematic and, to our knowledge, have not been implemented. Challenges in the design and implementation of such incentives include development of standardized, validated measures, adjusting payments with a severity case mix index, and building in financial incentives that are significant enough to encourage providers to focus on quality (21). Ethical considerations must be addressed to ensure that financial incentives would not encourage inappropriate care.

Role of Hospital Evaluation and Accrediting Organizations

JCAHO is a national accrediting body that can foster practice changes in hospitals. The audits by this organization are based on practice standards. Current standards recognize the patient's right to refuse care, the patient's wishes relating to end-of-life decisions, and the patient's right to pain management, along with comfort and dignity, during end-of-life care. JCAHO has not incorporated other elements of palliative care principles in its audits, although the Center to Advance Palliative Care has developed a "Crosswalk" of JCAHO Standards and a broad spectrum of palliative care policies, procedures, and support tools (www.capc.org/jcaho-crosswalk).

The Leapfrog Group (www.leapfroggroup.org) is a well-recognized employer-driven organization that is using evidence-based standards in the areas of safety, quality, and affordability of health care. Its goal is to inform health care consumers and to provide recognition for excellence in hospital performance. It has developed incentive programs to encourage hospitals to adopt its standards. These initiatives are supported in part by the Agency for Healthcare Quality and Research. The Leapfrog Group could influence the rate of availability of palliative care within hospitals if it were to accept certain structural standards, such as the importance of staffing hospitals with palliative care teams to improve access to quality end-of-life care.

Role of Managed Care Accrediting Organizations

The National Committee for Quality Assurance (NCQA) is the most widely accepted accrediting organization for managed care organizations. It has not adopted standards for quality palliative care. This suggests an opportunity for palliative care leadership to further their goals by influencing the priorities of this accrediting organization. Unfortunately, the few palliative care standards within JCAHO accreditation process and the lack of any NCQA standards convey to those being audited that either there are no evidence-based standards on which to base

audits or palliative care is not a priority for assessing quality of care. The former is not the case, nor should the latter be. Nonetheless, the politics of insinuating more standards is a slow but crucial step for the further diffusion of palliative care within the practice of medicine across all settings.

PEARLS

- Clinical practice guidelines have the potential to crystallize large bodies of scientific evidence into actionable recommendations to improve the quality of clinical outcomes, to reduce unnecessary and harmful care, and to reduce the cost of care.
- Ideally, guidelines are evidence based, include objective evaluation of risk-stratified outcomes, and also incorporate patients' preferences.
- Most guidelines do not fulfill the ideal characteristics, and this is true of many elements within palliative care guidelines. This characteristic of palliative care guidelines is understandable, given the multifaceted nature of palliative care's scope (as opposed to a single-disease focus) and the difficulty doing scientific research with a frail and vulnerable population that may be unwilling or unable to cooperate with strict research protocols.
- Despite these limitations, there is a broad consensus about what quality palliative care entails.
- It is critical that the curricula for medical students, residents, and postgraduate students incorporate palliative care more extensively. This should be reinforced through accreditation bodies and certification examinations.
- Templates have been developed to help specialty societies and other organizations incorporate key principles of quality palliative care into their guidelines that deal with life-limiting conditions.
- Diffusion studies suggest a variety of strategies for reaching those slow to adopt innovations such as palliative care: interactions with one-on-one near-peer role models in mini-residencies or rounds, technology such as electronic prompting systems within electronic health records, pay-for-performance incentives that reinforce palliative care best practices, and JCAHO, Leapfrog, and NCQA standards that stress palliative care.

PITFALLS

- Guidelines that employ informal or formal consensus among subject matter are more subject to bias, especially if the scientific evidence on which opinions are based is not well documented.
- Guidelines that do not take into account expected patient outcomes for various subgroups are problematic, because they make it difficult for both physicians and patients to apply the recommendations confidently.
- The effect of patients' preferences should also be incorporated into guidelines, especially guidelines that involve palliative care.
- These ideal attributes are rarely characteristic of clinical practice guidelines and contribute to the lack of widespread adoption of clinical practice guidelines.
- Changing clinical practice patterns and widely diffusing innovations such as high-quality palliative care must involve changes in many dimensions of medicine as a social system. As a result, we cannot expect to see the goals of palliative care fully realized in the near term.

SUMMARY

Clinical practice guidelines have the potential to improve the quality of care and patient outcomes, to decrease the variation in clinical practice, and to reduce the cost of care. They can help to educate clinicians at all levels about evidence-based recommendations on the best available practices.

There has been broad acceptance about the attributes of ideal guidelines and the process for creating effective guidelines. In addition, broad consensus exists among palliative care organizations about what constitutes high-quality palliative care. The guidelines that derive from this consensus are extensive and form a necessary but insufficient foundation for making palliative care more accessible.

There is a need to expose doctors to more training in palliative care. Medical schools, residency accreditation, and board examinations should reinforce this position. In addition, templates have been formulated to help incorporate palliative care into guidelines developed by specialty societies and interdisciplinary groups that address the care of life-limiting conditions. Dissemination of guidelines alone cannot be expected to change practice patterns, especially among the majority of physicians who had little or no exposure to palliative care during their training.

Diffusion studies suggest several changes that will be needed to ensure that recommendations about high-quality palliative care are more broadly instituted by those physicians who treat the many patients who could benefit from such guidelines. These include the influence of one-on-one near-peer teaching, reinforcement of the importance of palliative care by opinion leaders, and the use of technology to facilitate the translation of comprehensive guideline recommendations into electronic prompting systems in hospital and office settings. Pay-for-performance incentives and the incorporation of palliative care standards into the JCAHO, Leapfrog, and NCQA would also help those who are slower at integrating palliative care into their practice patterns.

Resources

General Guideline Database

National Guideline Clearinghouse, Agency for Healthcare Research and Quality (US): Available at http:www.guideline.gov/

Current List of Recognized Comprehensive Palliative Care Guidelines

At present, four general categories of palliative care guidelines meet these requirements:

1. General palliative care policy guidelines that deal with palliative care from a comprehensive perspective

Examples:

Fisher R, Ross MM, MacLean MJ: A Guide to End-of-Life Care for Seniors. Available at http://www.rgp.toronto.on.ca/iddg/eol.htm National Consensus Project: Available at http://www.nationalconsensusproject.org/Guidelines

2. Integrating principles of palliative care into disease management guideline development

Example:

Emanuel LL, Alexander C, Arnold R, et al: Integrating palliative care into disease management guidelines. *J Palliat Med* 2004;7:774–783.

3. Guidelines specifically intended for health care practitioners who provide palliative care

Example:
TIME: A Toolkit of Instruments to Measure End-of-life Care. Available at http://www.chcr.brown.edu/pcoc/choosing.htm

4. Disease management based guidelines for life-limiting conditions that include aspects of end-of-life care

Examples:
American College of Cardiology and American Heart Association: Guideline for CHF (ACC/AHA Pocket Guidelines: Evaluation and Management of Chronic Heart Failure in the Adult). Available at http://www.acc.org/clinical/guidelines/failure/pdfs/HF_pocketguide.pdf National Comprehensive Cancer Network: Clinical Practice Guidelines in Oncology v2. 2005. Available at http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

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Palliative Care Services and Programs

7

Alexie Cintron and Diane E. Meier

CHAPTER OUTLINE

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SUMMARY

INTRODUCTION

In this chapter, we discuss the types of palliative care services that are available in the United States and Canada. Palliative care services are most often provided in one of two settings: the hospital and the patient's home. Hospital-based palliative care programs include palliative care consult teams, palliative care units, and ambulatory palliative care services. Non–hospital-based programs include hospice care, home care, and bridge programs. A major criticism of hospice programs and some bridge programs is that enrollment is restricted to those individuals with a terminal prognosis. Provision of palliative care services should be based on need, not on prognosis. Conflating palliative care with end-of-life care can lead to late referrals to palliative care services.

Although primary palliative care can be provided by all health care professionals and is part of the basic competency of individual practitioners, secondary and tertiary palliative care encompasses a set of specialist services that exceed the skills of primary care providers and are therefore provided by providers with specialty training in palliative care. Palliative care providers should have skills and training in complex medical evaluation, pain and symptom management,

professional-to-patient communication, addressing difficult decisions regarding goals of care, sophisticated discharge planning, and providing bereavement support while adhering as closely as possible to clinical practice guidelines such as those put forth by the National Consensus Project for Quality Palliative Care. Certification for hospice and palliative care nursing is granted by the National Board for Certification of Hospice and Palliative Nurses (NBCHPN), and certification of physicians is granted by the American Board of Hospice and Palliative Medicine (ABHPM), although this will likely shift to the American Board of Medical Specialties (ABMS) over the next several years.

Palliative care can be provided to patients with advanced serious illness by a variety of services in numerous settings. In North America, palliative care services are most often provided in one of two settings: the hospital and the patient's home. This chapter discusses the types of palliative care services that are available. The types and availability of palliative care services are discussed within the context of Medicare, the major payment system for palliative care in the United States. We then end with an overview of training core skills necessary to provide palliative care, as well as training requirements for obtaining certification in hospice and palliative care.

LEVELS OF PALLIATIVE CARE DELIVERY

As with general medical care, palliative care can be delivered at three levels: primary, secondary, and tertiary. Primary palliative care can be provided by all health care professionals in any setting where patients receive care and should be part of the basic competency of individual practitioners (1). Moreover, primary palliative care is an expected part of primary care service models, and primary care physicians can acquire the knowledge, attitudes, and skills needed to provide palliative care to their patients. Local and national policy initiatives can ensure that providers demonstrate palliative care competencies. For example, a recent initiative of the Joint Commission on Accreditation of Healthcare Organizations on pain aims to ensure that pain control is part of the primary care of all patients in its accredited institutions (1). Accreditation of health care institutions in Canada by the Canadian Council on Health Services Accreditation now includes a specific section on palliative and end-of-life care.

Secondary palliative care is a set of specialist services that exceeds the skills of primary care providers (1, 2). These services are provided through specialized consultation teams. Although the recommendations made by palliative care consultation services may overlap with care that every physician should be able to provide, providers with special interest and training in palliative care possess attitudes, knowledge, and skills not yet acquired by most physicians. Palliative care specialists are equipped to handle the very time-consuming and complex interventions required by some patients with serious illness. Examples of secondary palliative care are hospices, palliative care teams and specialists, home palliative care services, and palliative care units. Pain specialists are not considered secondary palliative care providers because their practice patterns and target populations are generally different from those of palliative care specialists (1). Standards for specialist palliative care training have been developed and are discussed later in this chapter.

Tertiary palliative care exceeds the ability of secondary palliative care and is provided by referral centers with expertise in difficult problems (1, 2). Providers of tertiary palliative care are responsible for educating and conducting research in palliative care.

HOSPITAL-BASED PROGRAMS

Hospital-based palliative care teams have evolved from the modern palliative care movement as a result of national initiatives in the United States and Canada that called for improved pain and symptom management and for psychosocial, social, and spiritual support for patients and families living with serious illness (3, 4). These programs aim to improve hospital care for patients living with serious illness, care that is often characterized by untreated physical symptoms, poor communication between providers and patients, and treatment decisions in conflict with prior stated preferences. Patients with serious illness spend at least some time in a hospital during the course of their illness. These patients need expert symptom management, communication and decision-making support, and care coordination. Consequently, the number of hospital-based palliative care programs has grown rapidly in recent years (5, 6). Various secondary and tertiary palliative care models have developed in hospital settings, including palliative care consultation teams, palliative care units, and ambulatory palliative care services.

Palliative Care Consultation Team

The palliative care consultation team is the predominant hospital-based, specialist-level palliative care delivery model (2, 6). The goal of such a service is to assess the physical, psychological, social, spiritual, and cultural needs of patients with advanced, serious illness. The consultation team then advises the consulting provider on how to address these needs, thus providing support and supplementing the care of other physicians for their most complex and seriously ill patients, as well as providing direct care collaboratively with the referring care team. Effective palliative care teams understand that the referring team is also a client and that, although the work of the palliative care consultation team directly benefits the patient, the team should demonstrate a benefit to these clinicians. The team roles include educating clinicians about the components of care and the benefits of palliative care, generating visibility and awareness of the program and the need for better quality end-of-life care, and building clinical partnerships and support for its services. Evidence exists that palliative care consult services improve outcomes (7).

The design of a successful palliative care program should fully reflect the unique mission, needs, and constraints of the hospital it serves, as well as nationally accepted standards. It also adjusts to accommodate shifts in hospital priorities and patients' needs (8). Ideally, palliative care consultation services should consist of an interdisciplinary team that includes a physician, an advanced nurse practitioner, and a social worker. Other team members may include chaplains, volunteers, rehabilitation professionals, psychologists, and psychiatrists. Many programs have adopted a solo practitioner model that consists of a physician or an advanced nurse

practitioner. The choice between starting a program with a solo practitioner or a full team often depends on the availability of trained palliative care staff. However, as more trained staff becomes available, the model can transition from a solo practice to a full team model (7, 8).

Everyone on the team is responsible for assessing and following patients referred by an attending physician and contributing to the care plan. The team then provides advice to the referring team based on the assessment, care plan, and follow-up. On occasion, the team may assume all or part of the care of the patient, including writing the patient's orders. Other functions of the consultation team are to participate in conferences about patient and family needs, to refer the patient to needed services, to discharge the patient to appropriate care settings, and to communicate the plan of care with all the patient's providers (7).

Palliative care consultations are ordered by the responsible physician. In some institutions, nurses, social workers, and even family members may initiate a consultation request if approved by the responsible physician. Once the consultation is ordered, the first task of the palliative care consultation team is to elicit the specific reasons for consultation from the primary service. Reasons for palliative care consultation include relief of pain and other symptoms, assistance with communication about goals of care and support for complex medical decision-making, provision of psychosocial and bereavement support, and assistance with care coordination and continuity (9).

The approach to the patient and the family begins with a comprehensive assessment of any physical and psychological symptoms and other social, spiritual, and cultural aspects of care using validated assessment instruments whenever possible. Any active symptoms should be treated first because a discussion of realistic goals and overall goals of care cannot be held until the patient is comfortable enough to do so. The team can then elicit from the patient and the family their understanding of the disease, its treatment, and the patient's opinion about what constitutes an acceptable quality of life. The consultation team can coordinate a family meeting to discuss goals of care and to address advance care planning. The formulation of an appropriate plan of care and a discharge plan should take into account the family's support system and financial resources and should be consistent with the established goals of care. Throughout this process, the consultation team maintains a close working relationship with the referring team. The consultation team should encourage participation from the referring service at family meetings, should encourage participation from nursing and support staff in the formulation of the patient's care plan, and should educate the medical, nursing, and support staff in particular aspects of the patient's management and care plan. The team should also provide staff with support regarding difficult patient situations and treatment decisions (7).

This consultation process is time consuming. Because an initial evaluation can take more than 2 hours, the process often requires several visits over several days. Most of this time is spent communicating information and providing counseling (7).

Palliative Care Unit

Palliative care consultation services advise the primary providers on how best to provide palliative care to patients with serious illness. In contrast, palliative care units become the primary providers for these patients. Palliative care units provide

expert clinical management to patients who have severe symptoms that have been difficult to control, to patients who are imminently dying, and to patients with advanced serious illness that cannot be managed in any other setting. When staff members in other settings are untrained, uncertain, uncomfortable, or unable to formulate and implement a suitable palliative care plan for a patient with serious illness, it is appropriate to admit this patient to a dedicated palliative care unit where expert and trained staff and consistent-quality care plans can be ensured. The palliative care unit can also be a place where interdisciplinary training in palliative care practice can take place and a venue for conducting research projects that require careful monitoring of patients with serious illness (1).

Palliative care units often have a physical environment that is much different from that of other parts of the hospital. The staff is more experienced in providing palliative care and is more attentive to palliative care issues compared with the rest of the hospital staff. Patients and families can find a more cheerful, comfortable, and "homelike" environment that affords privacy, peace, and quiet. Ideally, palliative care units provide a room for family meetings and educational resources, such as computer access and printed literature. Finally, dedicated palliative care units allow for expanded or unrestricted visiting hours so family, children, and even pets can spend quality time with their loved ones (1).

Palliative care units have been organized in a variety of ways to meet the particular needs of distinct hospitals and surrounding communities. These units have consisted of scattered hospital beds, dedicated palliative care beds on another inpatient unit, and dedicated inpatient palliative care units. Table III–7–1 describes various palliative care unit models available (1).

Table III–7–1 ■ Palliative Care Unit Models

Unit Model	Model Characteristics
Acute palliative care beds or units	Operated under hospital license Rules that govern the operation of the unit are the same as the rules that apply to other in-hospital units Third-party payer covers if patient meets criteria for being in an acute care hospital Available in both academic and community hospitals
Subacute units	Provide postacute care where the focus is on providing treatment for problems identified during acute hospitalization Focus on short-term rehabilitation and discharge Beds not exclusively used for palliative care; possible conflicts in overall goals of care under the reimbursement rules or the unit's philosophy
Hospice units	Beds may be scattered in the institution, located in a dedicated unit, or located within a limited area of the hospital, such as an oncology unit May operate under the hospital's or hospice's license If the patient has opted for the Medicare Hospice Benefit, then the hospice is responsible for the overall plan of care and is reimbursed under a Medicare hospice inpatient fee schedule; in turn, the hospice reimburses the hospital under a negotiated contract Usually for short-term care

Ambulatory Palliative Care

Ambulatory services are an important aspect of the continuum of palliative care. Ambulatory palliative care programs are available on a consultation basis to ambulatory patient with serious, complex, or life-threatening illness. These practices can offer a range of services from ongoing symptom management to follow-up for patients discharged from inpatient services. They can also address the various needs of patients and families through a multilevel, interdisciplinary practice. In general, patients seen in such clinics are seen earlier in the course of their illness, and they may be receiving palliative care in conjunction with active, disease-modifying therapy (1).

Ambulatory palliative care may be provided as a stand-alone service, or it may be incorporated into another clinic such as oncology, infectious disease, geriatrics, or general internal medicine. Programs are staffed by physicians and nurses with specialized skills in palliative care. Therefore, this model allows for the following: assessment and management of symptom control problems; provision of psychosocial support, information, counseling, and bereavement services; continuity of care and contact with the medical system; triage of patients to other specialty services offered by the institution or community; and 24-hour access to care providers on call via telephone. When appropriate, patients seen by the ambulatory palliative care practice can be admitted directly to an inpatient palliative care unit if hospitalization is required to manage intractable symptoms or complex medical situations (1).

NON–HOSPITAL-BASED PROGRAMS

Throughout history, most people spent their last days at home surrounded by their loved ones. As hospitals increasingly became places of care in Western countries, more people were dying in these institutions rather than at home. Renewed interest in helping dying persons spend their last days at home, rather than in the hospital, gave rise to the field of home palliative care.

Hospice Care in the United States

Hospice care is specialized care designed to relieve the suffering of people facing life-limiting illness. Through an interdisciplinary approach, hospice aims to alleviate physical, psychological, emotional, and spiritual distress and provides support that specifically addresses the needs and wishes of the patient and his or her loved ones. The focus of hospice care is to improve the patient's quality of life rather than pursuing curative therapy for the life-limiting illness. Most hospice care, approximately 90%, is provided at home, but hospice is available wherever the person lives, including hospitals, nursing homes, and assisted living facilities (10).

How does hospice care work? In general, the care of the patient is primarily managed by a family member, and this family member also helps make decisions on behalf of the patient. Members of the hospice staff make regular visits to the patient's home to assess and treat the patient's symptoms and to provide

support and other services. A member of the hospice staff is available to patients and family 24 hours a day, 7 days a week, by phone or pager. The hospice staff usually consists of the patient's primary physician, a hospice physician or medical director, nurses, home health aides, social workers, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists (11).

What services does hospice provide? The following is a list of services provided by hospice staff:

- Assess and manage the patient's pain and other symptoms.
- Provide support to the patient and family for emotional, psychosocial, and spiritual concerns.
- Provide medications, medical supplies, and durable medical equipment.
- Coach the family on how to care for the patient.
- Deliver speech, physical, and occupational therapy when needed.
- Make short-term inpatient care available when pain or other symptoms become too severe or too difficult to manage at home or when the patient's primary caregiver needs respite.
- Provide counseling and bereavement support to surviving loved ones (11).

Besides the patient's home, hospice care can be provided by a nursing home hospice unit, a freestanding hospice unit, or a residential hospice (1). Hospice programs in nursing homes may provide routine home care or continuous home care services to residents because the nursing facility is considered to be the resident's home. However, because nursing home legislation has focused on promoting maintenance of function and prevention of premature death, residents who elect hospice care must be cared for by a certified hospice program that has a contract with the nursing facility (1). Moreover, the Medicare Hospice Benefit does not cover the cost of room and board. Consequently, a nursing home resident who receives partial or full room and board coverage under Medicare Part A (usually during the first 120 days of the nursing home stay) is suddenly responsible for all the room and board expenses should he or she choose to enroll in the hospice program while continuing to live in the nursing home.

Freestanding hospice units provide inpatient care, respite care, and residential care. Individual units provide one, two, or all three levels of care. A hospice unit must be Medicare certified so patients can use the Medicare Hospice Benefit in this program. Freestanding hospice programs have made arrangements with hospitals to provide patients with certain services, such as radiation therapy for spinal cord compression resulting from metastatic cancer, that are not available in the freestanding unit (1).

Community Volunteer Hospices in Canada

The term *hospice* in Canada has most often referred to community volunteer hospices that provide a range of volunteer services for patients and families that complement formal professional palliative care programs. These services include trained volunteers to provide part of the care team at home, grief programs, complementary therapy, spiritual counseling, and other services (12). Some services labeled hospices actually have full interdisciplinary teams that usually concentrate on care in the home.

Residential Hospices

Some hospice programs provide care in a residential setting where patients go to live the last days, weeks, or months of their lives (1). Residential hospices are still scarce in the United States and Canada, yet they embody the image that many people have of hospice. For residents of these hospice units, the costs of room and board are generally covered by Medicaid programs, managed care or other commercial insurance, private pay, philanthropy, or, in Canada, even by some government funding. If patients require a more intense level of care to treat symptoms, the residential hospice can intensify staffing or can transfer the patient to a hospital or palliative care unit.

Home Palliative Care Programs in Canada

Depending on the province and its organization of palliative care and home care, home palliative care programs may provide comprehensive palliative care on a local or regional basis. These are usually interdisciplinary and consist of physicians, advance practice nurses, primary palliative nurses, and others. These programs often are attached to organizations that provide institutional palliative care and collaborate extensively with community volunteer hospices. These home palliative care services provide around-the-clock care. Funding comes from a combination of hospital and government funding and donations (12).

Home Care Agencies

Home care agencies provide a wide range of assistance to patients who wish to receive care at home for their acute, chronic, or advanced illness. Home care agencies can provide skilled nursing care, home health aide and personal support worker services, and physical, occupational, or speech therapy to supplement the caregiving of the family. They can also provide practical guidance on planning for the illness as well as counseling to the patient and the family. Finally, home care services can be available to the patient and the family 24 hours a day, 7 days a week, to provide rehabilitative, maintenance, or palliative care at the home (1).

In the United States, Medicare reimburses the home care agency under a prospective payment system that is related to severity of illness and medical need. Coverage for these services can also be provided by Medicaid and commercial insurance, although these benefits vary widely. Medicare covers physicians' services at home. As more of these agencies have developed palliative care programs for patients with serious illness, home care programs have become an alternative for patients who are unable to access hospice services, who do not qualify for hospice, or who are not yet willing to forgo life-prolonging treatment for the terminal illness (1).

In Canada, home care is a benefit under provincial health care schemes, but the provinces vary with respect to services covered, copayments, and drug coverage. There has been a recent provincial and federal accord to increase home care services to dying patients (12).

Bridge Programs in the United States

Home care programs in the United States, however, are often limited because they restrict eligibility to those patients who are home bound, those who need skilled

nursing services, and those whose needs are episodic, with a potential for restoration of function (13). As mentioned earlier, hospice is limited by the requirement that a physician certify that the patient has 6 months or less to live and that the patient forego curative treatment for the illness in favor of symptomatic treatment for the illness. Because of the regulatory limitations of both hospice and home care services, an alternative mode of providing palliative care has emerged: prehospice or bridge programs (ideally, these programs provide a smooth transition, or bridge, to hospice) (13, 14).

Bridge programs provide some of the services provided by hospice without requiring a 6-month prognosis or that patients forego life-prolonging treatment. These programs provide interdisciplinary supportive care to patients with advanced serious illness and their families concurrent with potentially curative or life-prolonging therapy. They are also able to provide advanced palliative care treatments that may be too expensive for hospices to cover under the current per diem reimbursement scheme. Unlike the usual home health programs, whose staff may not have much experience caring for patients near the end of life, bridge programs provide access to hospice-trained nurses. An interdisciplinary team provides treatment of pain and other physical symptoms, care management and coordination services, support with advance care planning, and other psychosocial, spiritual, and bereavement support (13, 14).

Services from bridge programs are covered by Medicare Part B or Medicare Advantage (formerly Medicare + Choice) managed care plans, which are private health plans for Medicare beneficiaries and include both coordinated care plans and private fee-for-service plans at costs that are usually at lower for the beneficiary (15). Although the scientific literature does not currently provide much evidence of their effectiveness, bridge programs provide an opportunity to extend the benefits of hospice care to a wider population and spare patients the difficult choice between curative or life-prolonging treatment and high-quality palliative care.

TRAINING AND CERTIFICATION

Ideally, palliative care should be provided by an interdisciplinary team that consists of at least a physician, a nurse, and a social worker with appropriate training and education in palliative care. Other team members may include chaplains, rehabilitation professionals, psychologists, and psychiatrists. The team should have skills and training in: complex medical evaluation, pain and symptom management, psychosocial care, professional-to-patient communication, addressing difficult decisions about the goals of care, sophisticated discharge planning, and providing bereavement support. The team should provide coordinated assessment and services adhering as closely as possible to accepted guidelines of care and accepted practice standards. In the United States, the National Consensus Project for Quality Palliative Care has identified eight domains as the framework for its clinical practice guidelines (16). These domains are as follows:

- Structure and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care

- Social support
- Spiritual, religious, and existential aspects of care
- Cultural considerations
- Care of the imminently dying patient
- Ethics and the law

The Canadian Hospice and Palliative Care Association's Norms of Practice form the basis for both institutional and professional practice in the area of palliative care. The components of care are summarized by the "square of care" depicted in Figure III–7–1 (12).

Proper adherence to guidelines and standards requires that members of the team have special training or work experience in palliative medicine, hospice, or nursing home settings, as well as familiarity with the demands and standards of the acute hospital culture. Equally important is the team's ability to work well and communicate effectively with each other and with other health professionals (1).

How do health care providers develop these core skills? The Education on Palliative and End-of-Life Care (EPEC) project educates professionals by combining didactic sessions, videotape presentations, interactive discussions, and practical exercises (17). The curriculum is geared to an interdisciplinary audience and teaches fundamental palliative care skills such as comprehensive assessment, symptom management, communication, and ethical decision-making, thus preparing professionals in the provision of primary palliative care. The complete EPEC curriculum is available as online learning for continuing medical education credit. The American Academy of Hospice and Palliative Medicine provides courses (1, 2) in the United States. In Canada, education of primary care providers is available through a variety of government- and organization-sponsored comprehensive courses, as well as presentations at appropriate conference. Preceptorships, involving primary care providers who work with expert palliative care providers, are also available.

The End-of-Life Nursing Education Consortium (ELNEC) provides a comprehensive education program to improve end-of-life care by nurses in the United States. The ELNEC core curriculum was developed to prepare educators to disseminate the information to nursing schools and health care agencies (17).

Nursing staff members who wish to seek certification in hospice and palliative care nursing can do so at one of four levels: hospice and palliative advanced practice nurse, hospice and palliative care nurse, hospice and palliative licensed practical/vocational nurse, and hospice and palliative nursing assistant. The NBCHPN is responsible for determining eligibility, administering the examination, and awarding certification credentials. The purpose of the examination is to "test the ability to apply the nursing process in helping patients and their families toward the goal of maintaining optimal functioning and quality of life within the limits of the disease process, while considering factors such as fear, communication barriers, economic issues and cultural issues" (18). Table III–7–2 summarizes the eligibility requirements and the examination content for each of the four levels of nursing certification (18). In Canada, the Canadian Nurses Association now offers a certification examination for registered nurses in palliative care.

In the United States, physicians who seek subspecialty training in hospice and palliative medicine generally do so through one of two avenues: experiential practice for at least 2 years following residency or fellowship training or completion of

Square of Care			History of issues, opportunities, associated expectations, needs, hopes, fears Examination–assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity. Goals of care Requests for withholding/potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/develop plan of care–address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning,emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions
			Assessment	**Information sharing**	**Decision-making**	**Care Planning**	**Care delivery**	**Confirmation**
			PROCESS OF PROVIDING CARE					
Primary diagnosis, prognosis, evidence Secondary diagnoses-dementia, substance use, trauma Co-morbidities-delirium, seizures Adverse events-side effects, toxicity Allergies	Disease Management	COMMON ISSUES	*Patient/Family*					
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits–alcohol, smoking	Physical							
Personality, behavior Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	Psychological							
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconcilation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guadianship, custody issues	Social							
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual							
Activities of daily living Dependents, pets Telephone access, transportaiton	Practical							
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	End of life/ Death Management							
Loss Grief–acute, chronic, anticipatory Bereavement planning, mourning	Loss, Grief							

Figure III–7–1 ■ The square of care. (From Ferris FD, Balfour HM, Bowen K, et al: A Model to Guide Hospice Palliative Care. Ottawa, Canada, Canadian Hospice Palliative Care Association, 2002, with permission from the U.S. Cancer Pain Committee.)

Table III–7–2 ■ Summary of Eligibility Requirements and Examination Content for Each of Four Levels of Nursing Certification

Level of Nursing Certification	Eligibility Requirements	Examination Content
Hospice and Palliative Advanced Practice Nurse	1. Hold currently active Registered Nurse license 2. Graduated from accredited institution having didactic and clinical component leading to graduate-level academic credit 3. Hold one of: Master's or higher degree from an advanced practice palliative care program; post-Master's certificate with supervised clinical practice in palliative care; Master's, post-Master's, or higher degree from advance practice program as Palliative Care Clinical Nurse Specialist or Nurse Practitioner	Nine domains of practice tested: clinical judgment, advocacy and ethics, professionalism, collaboration, systems thinking, cultural and spiritual competence, facilitation of learning, communication, and research
Hospice and Palliative Care Nurse	1. Hold current license as Registered Nurse 2. Have at least 2 years experience in hospice and palliative nursing practice (recommended)	Seven domains of practice tested: end-stage disease process in adult patients, pain management, symptom management, care of patient and family (including resource management, psychosocial, spiritual, and cultural aspects, and grief and loss), education and advocacy, interdisciplinary practice, and professional issues
Hospice and Palliative Licensed Practical/Vocational Nurse	1. Hold current license as Practical/Vocational Nurse 2. Have at least 2 years experience in hospice and palliative Licensed Practical/Vocational Nurse practice (recommended)	Eight domains of practice tested: end-stage disease process in adult patients, pain and comfort management, symptom management, treatments and procedures, care of patient, family, and other caregivers (including resource management, psychosocial, spiritual, and cultural aspects, and grief and loss), education and advocacy, interdisciplinary practice, and practice issues
Hospice and Palliative Nursing Assistant	1. Documentation of at least 2000 practice hours under supervision of Registered Nurse in past 2 years 2. Have at least 2 years experience in Hospice and Palliative Nursing Assistant practice (recommended)	Four domains of practice tested: patient and family care, psychosocial and spiritual care of patient and family, interdisciplinary collaboration, and ethics, roles, and responsibilities

an accredited fellowship in palliative medicine. The ABHPM is the body responsible for credentialing physicians in the practice of hospice and palliative medicine. Eligible candidates for board certification must hold a current unrestricted medical license in the United States (or equivalent in other countries) and must be certified by an ABMS-approved board, an osteopathic medicine equivalent, or the equivalent in other countries (19). Those who choose to apply for board eligibility through the experiential track must have been in the clinical practice of medicine for at least 2 years following residency or fellowship, must have directly participated in the active care of at least 50 terminally ill patients (the requirement for pediatricians is 25 terminally ill and 25 severely chronically ill pediatric patients) in the preceding 3 years for whom palliative medicine was the predominant goal of care, and must have worked as a physician member of an interdisciplinary team for at least 2 years. Those who choose to apply through the postfellowship track must have successfully completed an accredited fellowship in palliative medicine or completed a fellowship program that "substantially complies with" the latest version of the standards for fellowship programs in palliative medicine (19). The examination covers the following nine content areas: hospice and palliative approach to care, psychosocial and spiritual issues, impending death, grief and bereavement, pain management, nonpain symptom management, communication and teamwork, ethical and legal decision making, and prognostication. ABHPM certification is valid for 8 years (19). The ABMS has recently granted specialty status to palliative medicine.

In Canada, a 1-year residency program in palliative medicine is offered at most medical schools. This is a joint program between the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada (12). Fellowships and preceptorships are also routes to achieving advanced knowledge. There is no certification examination. The Canadian Society of Palliative Care Physicians provides opportunities for advanced learning for palliative medicine physicians.

PEARL

- Provision of palliative care services should be based on need and not on prognosis.

PITFALL

- Conflating palliative care with end-of-life care can lead to late referrals to palliative care services.

SUMMARY

Whereas primary palliative care can be provided by all health care professionals and is part of the basic competency of individual practitioners, secondary and tertiary palliative care encompasses a set of specialist services that exceed the skills of primary care providers and are therefore provided by providers with specialty training in palliative care.

Hospital-based palliative care programs include palliative care consult teams, palliative care units, and ambulatory palliative care services; non–hospital-based programs include hospice care, home care, and bridge programs.

Palliative care providers should have skills and training in complex medical evaluation, pain and symptom management, professional-to-patient communication, addressing difficult decisions regarding goals of care, sophisticated discharge planning, and providing bereavement support while adhering as closely as possible to clinical practice guidelines such as those put forth by the National Consensus Project for Quality Palliative Care.

In the United States, certification for hospice and palliative care nursing is granted by the NBCHPN, and certification of physicians is granted by the ABHPM although this will shift to the ABMS over the next several years since specialty status has been granted to palliative medicine. In Canada, there is no certification examination.

Resources

American Academy of Hospice and Palliative Medicine: Available at http://www.aahpm.org
Canadian Hospice Palliative Care Association: Available at http://www.chpca.net
Center to Advance Palliative Care: Available at http://www.capc.org
Centers for Medicare and Medicaid Services: Available at http://www.cms.hhs.gov
National Consensus Project for Quality Palliative Care: Available at http://www.nationalconsensusproject.org

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SECTION IV

The Social Context

1 The Economic Burden of End-of-Life Illness

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CHAPTER OUTLINE

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Impact of Serious Illness on Patients' Families: Findings of the SUPPORT Project
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INTRODUCTION

The economic domain is not often a priority for clinicians; however, economic issues permeate the health care experience of clinicians, patients, and their families and caregivers. For example, reimbursement policies can affect the choice of treatment options available to patients, and caregiver employment status can affect the types of informal support that are available to patients. Prescription drug compliance can be related to insurance coverage, and the social care supports available to the caregiver can determine levels of strain that, in turn, affect caregiving quality and productivity at work. These issues are especially important to patients at the end of life and to those families on the lower end of the socioeconomic spectrum, but the lessons learned in providing high-quality care and support are applicable to all patient populations.

Palliative care is a movement and a philosophy dedicated to holistic patient care. In contrast to the biomedical model of medicine, this type of care has as its

"trademark" a comprehensive assessment of the different domains of illness-related human experience, including the physical, psychological, social, and spiritual (1). Illness-related suffering can have its origins in any of these domains and can threaten the identity and humanity of the patient, as well as the caregiver (2). Another important feature of palliative care is that caregivers and family members are considered part of the unit of care. This perspective recognizes the support networks the patient may have, as well as the knowledge that life continues for other individuals after a patient dies. Support for caregivers and family members is important both for the patient and as good preventive care for these other individuals.

This chapter focuses on how economic burdens may contribute to the suffering of the patient and relevant third parties and how these burdens are expressed in various domains of the human experience. Through adequate assessment and treatment of the problems in economic domains, the interdisciplinary team in palliative care can help to alleviate the associated effects of economic burden. We first examine what constitutes the economic domain with respect to end-of-life illness and care. Following that, we review the empirical evidence about the economic impact of illness, with special attention given to dementia and cancer. Finally, we provide brief, practical guidance for dealing with the economic issues that may arise in treatment of patients.

UNDERSTANDING THE ECONOMIC DOMAIN

The economics of end-of-life and palliative care need to consider the variety of costs borne by the patient and the caregiver, as well as the possibilities that palliative care interventions can provide economic benefits. Costs and benefits can be categorized first in terms of whether they affect the patient or the family, including nonfamily informal caregivers. When dealing with resources such as family savings that may pertain or belong to the patient as well as the family, this line may become blurred. However, a change in the health status of a caregiver has a clear effect on the family.

The second distinction is between medical and nonmedical costs and benefits. Medical costs and benefits are those that affect the cost of health care or health status for the patient or family. These costs can be monetary, coming in the form of insurance premiums or out-of-pocket costs for medical care. However, health status is also included here because economists use measurements of quality of life or health utility to calculate the cost effectiveness of interventions through a quality-adjusted life year (QALY) analysis. This is a reminder that even abstract health effects can have economic implications. Nonmedical costs and benefits are those that affect areas such as workplace productivity or school absenteeism. These are measured in terms of job wages or time lost while taking care of a sick relative.

ECONOMICS OF END-OF-LIFE ILLNESS

Anecdotal evidence suggests that end-of-life illness can have substantial burdens on patients and their families. However, because most cost-of-illness studies focus on the cost to health systems and insurers, surprisingly little is known about the costs

of terminal illness to patients and families. Over the past decade, several studies have begun to fill the gap, by providing clear empirical evidence that the economic burdens of end-of-life illness are substantial. To illustrate this point, we summarize evidence from several sources: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), the Commonwealth-Cummings Study of the burdens of terminal illness, and studies of labor market and economic burdens of dementia and cancer.

Impact of Serious Illness on Patients' Families: Findings of the SUPPORT Project

The SUPPORT project was a landmark study of prognoses, preferences, and decision making in patients with one of nine serious life-threatening illnesses (3). One of the goals of the SUPPORT project was to develop a better understanding of the impact of serious illness on the families of patients. Surrogate and patient interviews about the impact of illness on the family were obtained for 2129 patients who survived an index hospitalization. The interviews were obtained between 2 and 6 months following the hospitalization. Patients represented a wide age range (15% <45 years, 45% >65 years).

Table IV–1–1 describes the frequency of burdens described by SUPPORT subjects. Families noted several severe burdens. For example, 20% reported that a caregiver made a major life change to care for the patient, and this often included quitting or taking time off from work. In 31% of cases, most of the family savings was lost, whereas in 29% of cases, a major source of family income was lost. Seventeen percent reported a major change in family plans, such as moving to a less expensive home, delaying medical care for another family member, or altering educational plans for another family member. At least one major burden was reported by more than half (55%) of families.

Table IV–1–1 ■ Burdens Described by SUPPORT Families

Burden	Percentage (%)
A family member made a major life change to care for the patient	20
Quit or took time off from work	11
Other major life change	9
Others in the family became ill or unable to function normally because of the stress of the illness	12
Most of the family savings was lost	31
A major source of family income was lost	29
A major change in family plans was made because of the cost of the illness	17
Moved to a less expensive home	6
Delayed medical care for another family member	6
Altered educational plans for another family member	4
Other change	4
Suffered any of the above adverse impacts	55

SUPPORT, Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.

Although rates of burdens were high for all patient subgroups, several characteristics defined families most likely to suffer adverse financial impacts. For example, loss of most of the family savings was more common in families of patients with severe functional dependence than in those without severe functional dependence (37% versus 29%) and in families with incomes higher than $25,000/year than in those with lower incomes (35% versus 22%). Young patient age was, however, the strongest predictor of loss of family savings. Loss of savings was reported for 43% of families of patients younger than 45 years compared with 25% for patients older than 75 years. There are probably several reasons families of younger patients were at higher risk than families of older patients. Because most older patients receive Social Security, their income is less likely to be threatened by severe illness. In contrast, it is more likely that younger patients and their caregivers will need to give up work as the result of severe illness. Moreover, older patients are more often eligible for social and other support services than younger patients, and it is possible that some of these services offer some measure of protection.

The SUPPORT study did not identify the mechanisms of these burdens. However, because 96% of patients in SUPPORT had health insurance, it is likely that many of these burdens were the result of expenses not covered by insurance. Undoubtedly, a major source of financial burden is the loss of employment income for patients and caregivers. Many illness-related costs associated with terminal illness are not covered by most health insurers. This includes the costs of home health aides and assistance with basic activities of daily living (ADLs), home modifications, and long-term care costs. Although some of these costs are covered by hospice, many terminally ill patients are never enrolled in hospice, and those who are enrolled usually enter hospice for the last few weeks of their illness.

Commonwealth-Cummings Study

The Commonwealth-Cummings Project shed some more light on the mechanisms of burden that the SUPPORT project did not identify (4). Within 6 selected regions, 988 terminally patients (identified by their physicians as having a life expectancy of <6 months) and 893 of their caregivers were chosen for interviews. Fifty-nine percent of the subjects were more than 65 years old. Overall, 35% of patients had at least moderate need for nursing home care, home making, or personal care. Eighteen percent had unmet needs for nursing care, and 23% had unmet homemaking needs. Greater functional burdens, older age, and low income were associated with greater care needs. Substantial care needs, female gender, and African American ethnicity were associated with unmet care needs.

The study strongly suggested that substantial care needs were a key contributor to economic and other burdens. For example, significant depressive symptoms were reported by 31% of caregivers of patients with high care needs, compared with 25% of caregivers of patients with few needs. Similarly, caregivers of patients with high care needs were more likely to report that caregiving interfered with their personal needs (36% versus 24%). Interestingly, having an empathic physician seemed to buffer these burdens. Among caregivers of patients with high caregiving needs, those who reported that the needs and opinions of the caregiver were addressed by the physician were less likely to be depressed (28% versus 42%) and less likely to feel that caregiving interfered with their personal life (32% versus 48%).

The results of this study suggest an explanatory model for the burdens critical illness places on caregivers. In this model, factors such as poor performance status, older age, incontinence, and low income lead to high caregiving needs. These high caregiving needs lead to both economic burdens and health burdens such as depression.

Economic Impact of Dementia

Dementia differs from other end-of-life conditions because the later stages of the disease are often protracted, and the prognosis is unpredictable. Dementia also imposes special challenges on a patient's family because patients often require extensive caregiving assistance. This caregiving assistance is generally required because of a combination of memory impairments, behavioral disturbances, and impairments in physical functioning. Although dementia is the leading cause of nursing home placement, most patients with dementia are cared for at home by family members. However, although it seems probable that dementia care would impose high costs on families, only a limited number of studies have addressed the economic costs of dementia care.

One of the most important economic costs of dementia caregiving may be on the ability of caregivers to work. Because many caregivers need to provide continuous supervision, the ability to be employed is often compromised. In a study of patients newly enrolled in the Program of All-Inclusive Care for the Elderly (a new capitated benefit authorized by the Balanced Budget Act of 1997 that features a comprehensive service delivery system and integrated Medicare and Medicaid financing), 25% of patients with dementia had at least one caregiver who either quit working or reduced the number of hours worked to care for the patient (5). Loss of employment was considerably more common in patients of African American and Hispanic ethnicity, as was the case in the Commonwealth-Cummings Study of terminally ill patients, a finding suggesting that this economic burden of caregiving may be disproportionately endured by minority communities. Loss of employment was also more common when the caregiver was a woman.

One method of estimating the value of the time family members spend caring for patients with dementia is to estimate the opportunity cost of caregiving. *Opportunity costs* of caregiving generally represent the estimate of how a caregiver's time would be valued if they could provide their services within the labor market. Using this approach, Langa and colleagues used the Asset and Health Dynamics (AHEAD) study, a nationally representative sample of community-dwelling elderly persons, to conduct a study of the cost of informal caregiving for elders with dementia (6). The market value of caregiving was estimated using the average wage of a home health aide. In 2001, Langa and colleagues determined that patients with mild, moderate, or severe dementia required an additional 8.5, 17.4, and 41.5 hours of caregiving per week compared with elders without cognitive impairment. The yearly opportunity cost of this caregiving was $3600, $7420, and $17,700, respectively, in these 3 groups. This represented a national annual opportunity cost of more than $18 billion. This estimate is striking because the total national expenditure for all paid home services (for all conditions) was $29 billion in 1998. Because the $18 billion cost estimate considers only one condition, it seems almost certain that the economic cost of family caregiving (generally unpaid) exceeds the current economic cost of paid home care.

Caregiving also has substantial personal costs. Although these costs are incurred in many end-of-life illnesses, they are best documented for caregivers of patients with dementia. In particular, caregivers of patients with dementia have repeatedly been found to be at higher risk for depression. In a study of more than 5000 patients with advanced dementia, for example, 32% of caregivers were classified as depressed based on a high number of depressive symptoms (7). Rates of depression varied depending on patient and caregiver characteristics. Patient characteristics associated with higher rates of caregiver depression included younger age, white or Hispanic ethnicity (compared with black), low education, dependence on the caregiver for activities of daily living, and behavioral disturbances. Caregiver characteristics associated with high rates of depression included low income, female gender, more hours spent caregiving, and poor functional status. Thus, caregiver depression appears to be a complex process that is influenced by ethnicity, as well as by patient and caregiver characteristics. Depression is also associated with labor productivity losses. In one study, workers with depression had 5.6 hours per week of lost productive time compared with an expected 1.5 hours per week. Most productivity costs were explained by reduced performance while at work (8).

Some evidence suggests that caregiving for a frail elder is sometimes associated with more global health effects. For example, Schulz and colleagues demonstrated that caregivers who reported emotional strain while caring for disabled spouses had a 63% higher risk of death than nonspousal caregivers (9). Because spousal caregivers who did not have strain were not at higher risk for death, this study illustrated the importance of identifying caregivers who are experiencing adverse emotional outcomes from caregiving. There is also evidence suggesting that dying a "good death" by receiving palliative care services in the form of hospice may also have positive effects for spouses. Christakis and Iwashyna retrospectively matched 30,838 couples, in which the decedent in one group used hospice while the matched decedent in the other group did not (10). Bereaved wives whose husbands had used hospice showed a significantly lower mortality than those wives whose husbands did not use hospice after 18 months. This finding suggests that high-quality palliative care has the potential to soften the blow of widowhood.

Economic Impact of Cancer

Cancer is a leading cause of death, particularly among elderly persons. Although cancer affects all ages, the studies on the economic costs of cancer to patients and their families have focused on the elderly. Although initial studies used small convenience samples to examine the out-of-pocket costs related to cancer, more recent studies have exploited the data available from the 1995 AHEAD study. A study by Langa and colleagues examined the relative out-of-pocket medical expenditures of community-dwelling elderly persons who were more than 70 years old and who had cancer (11). In this sample of 6370 respondents, 84% reported no cancer or history of cancer, and 13% reported a history of cancer but no current treatment regimen, whereas 3% reported a history of cancer and current treatment. Adjusted mean annual out-of-pocket expenditures were significantly different at $1220, $1450, and $1880 for each of the groups, respectively. The major sources of costs were prescription medications and home care services. Low-income individuals undergoing cancer treatment spent 27% of their yearly income on

out-of-pocket expenses, a demonstration of the staggering effect that cancer can have on low-income individuals and their families.

Pain is a frequent and feared symptom of patients with cancer. Optimizing pain management remains an important clinical goal. However, considering pain as a mere physical symptom ignores the social and economic effects it can have on the patient and the family. In a study of 373 outpatients with cancer, investigators estimated the direct and indirect costs of cancer pain (12). Sixty-nine percent of patients had a direct medical cost associated with cancer pain, be it an emergency room visit or cost of analgesic medication. These costs are absorbed by insurance after copayments and deductibles; however, patients without insurance shoulder the whole cost, which was, on average, $825 per month, or almost $10,000 per year. Excluding productivity losses, 57% reported at least one indirect cost associated with cancer pain. These expenses are borne almost entirely by the patient and family and totaled $61 per month, or more than $700 per year. The most frequently cited expense was transportation, followed by the costs of purchasing over-the-counter medication. The largest predictors of both types of costs were pain intensity, pain interference, and breakthrough pain. This finding indicates that high-quality pain management in palliative care not only frees the patient from physical ailments, but also aids in the reduction of economic costs.

Although the previous study excluded labor costs, further analysis of the first wave (1993) of AHEAD data using similar methods to calculate the costs of dementia caregiving provides estimates of these numbers (13). Even though the informal caregiving costs for elderly patients with cancer are less than those with dementia, they are still significant at $1200/year per patient, for a total of nearly $1 billion annually.

HANDLING THE ECONOMIC DIMENSION OF CARE

As the empirical evidence has demonstrated, economic issues permeate many different dimensions of illness and care. Clinicians should recognize that economic distress can be one of the consequences of end-of-life illnesses. Economic costs can be paired with physical symptoms such as pain, or they can be associated with psychological ailments suffered by caregivers, such as depression. Economic costs can come in the form of transportation expenses, deductibles for insurance, or loss of income due to work absenteeism. These effects are not limited to the patient; they affect caregivers, spouses, and children as well. There are steps the clinician can take to help alleviate these economic burdens. We suggest several steps that a clinician can employ.

Economic Assessments

Comprehensive assessment should involve a simple screening question about the financial burden of end-of-life illness. End-of-life screening tools such as the Needs at the End-of-Life Screening Tool contain a question about the financial burden ("How much of a financial hardship is your illness for you or your family?") that can help to guide this process (14). Those performing the assessment should be aware of the cultural differences with respect to money and health status that may exist with the patient or the family members, including variability about when

financial hardship is identified and articulated. Clinicians should avoid implying that the patient is a burden to the family or that the family is unwilling to support the patient financially. Assessments can be conducted in informal conversations with the family or in planned formal family meetings. Assessment of the economic situation of the patient and caregiver or family should be a continuous process because it may be common to have economic situations "flare up" at different points during the course of the illness.

Making Use of the Interdisciplinary Team

One of the benefits of palliative care is the emphasis on care by the interdisciplinary team, which is associated with increased quality of care and satisfaction of the patient and family (15). If the patient demonstrates a significant financial burden, it may be appropriate to make a referral to a social worker who may be adept at providing financial guidance and finding sources of support for the patient and family. There are often sources of support, from the government, nonprofit organizations, or religious community organizations that the clinician can help mobilize to help the family to cope with caregiving stresses or economic burdens.

Other members of the interdisciplinary team may be useful in preventing economic burdens. For instance, a chaplain may help family members to deal with the existential issues surrounding death, which could have the impact of increasing work productivity and adjustment to loss after the patient dies. If the patient is still able to work and has the desire to do so, an occupational therapist may be able to alter the work environment of the patient and may help to navigate issues of accommodations with employers. In addition, the ability to provide self-care may be enhanced by rehabilitation, particularly for patients with cancer who have lost mobility (16).

Reimbursement

All clinicians should have some rudimentary knowledge of the different funding streams for palliative care. Although the main form of palliative care funding comes in the form of the Medicare Hospice Benefit, this benefit does not necessarily provide coverage for elements of palliative care provided in hospitals and nursing homes. In these settings, palliative care services may be limited by the internal budgets of the organization or by the priorities that have been set for care. However, early referral to hospice may be beneficial to patients and their families because it gives families access to some benefits, such as health aides and pain medications, that may not be available otherwise. Medicaid, through specialized state waiver programs, may provide services that can enable the patient to stay at home. This may reduce the costs of institutionalization. In addition, for those younger clients who lack Medicare, clinicians should inquire and work with the patient and family to ensure that the medical services provided to the patient that are not justified by the benefit do not cause financial harm to the family because they are not reimbursable under the patient's private insurance.

Empathy and Communication

As demonstrated in the Commonwealth-Cummings study, simple interventions such as clinician empathy can buffer the burdens of caregiver stress. As a result,

simply asking about economic burdens can help to stem depressive symptoms of informal caregivers. The trajectory of bereavement is highly influenced by the type of care that was provided before the death of the patient (17).

Inequities in Access to Palliative Services

Despite the successful growth of hospice programs in the United States, there has been limited success in providing equal access to palliative care services in vulnerable populations, including patients with low income and members of minority groups. As indicated in a review by Brenner (18), hospice programs have been most successful "in addressing the needs of middle class, white, elderly persons with cancer who have family members able to care for them at home." It has been a challenge for hospice programs to serve low-income, nonwhite, non–English-speaking individuals without health insurance. Additionally, some of the initial admission criteria to hospice may continue to have an impact. Some of the following examples highlight this fact:

1. To be admitted, patients must have supportive families with a primary caregiver.
2. Patients must agree to a do-not-resuscitate order.
3. Patients must discontinue certain therapies before admission to the program.
4. Patients must live in a safe neighborhood.

Since 1995, many of these criteria have been changed substantially to reduce barriers to hospice and palliative care (19). Nevertheless, access to hospice and palliative care remains an issue, and recent studies have shown that several of the foregoing criteria are the very reasons that certain minority groups do not enter hospice programs. The issue of access, however, is not simple. It is not simply economics, and yet many of the barriers that prevent individuals from different racial-ethnic minority backgrounds from accessing good end-of-life care are intricately linked to economics.

Studies of access have been predominantly of white populations. Therefore, little is known about the use of hospice care by individuals of different racial and ethnic groups. However, in a secondary analysis of the 1993 National Mortality Followback Survey, Greiner and colleagues (20) examined hospice use by minorities in the last year of life and found that African Americans were 34% less likely to use hospice than white Americans, even after controlling for socioeconomic status. Other studies have shown that individuals of Hispanic/Latino descent use hospice less often than white individuals (5). Greiner and colleagues concluded that "economic, educational, and access-to-care differentials between African Americans and white [Americans] are not the primary explanation for the variations in hospice use between these groups" (20). Indeed, many studies of seriously ill hospitalized patients have indicated that African American individuals have fewer do-not-resuscitate orders, receive cardiopulmonary resuscitation more frequently, tend to have written advance directives less often, and prefer more aggressive care for terminal illness. Although it is still not entirely clear why these differences exist, they continue to influence access to hospice care for African American and other racial-ethnic groups.

In 2003, Ngo-Metzger and colleagues (21) performed a study using the Surveillance, Epidemiology, and End Results program data to examine hospice use

Table IV–1–2 ▪ Barriers to Hospice Use among Minorities

Barrier	Impact
Medicare Hospice Benefit requirement for a full-time (≥19 hours/day) personal caregiver to care for the patient	Low-income patients and minority patients have working family members, which may lead to reduced work hours or job loss
Physicians are primary sources of referral to hospice	Physicians may be less likely to refer Asian Americans to hospice because of assumptions about cultural preferences
Linguistic barriers	Preclude adequate communication between patients and physicians
To be eligible for hospice services, informed consent is required, which requires knowledge and acceptance of a terminal diagnosis and prognosis	In contrast with the principles of patient autonomy and informed consent, many Asian American and Pacific Islanders may value filial piety, indirectness in communicating bad news, and family-centered model of decision making (studies have shown that African American and Mexican American patients also favor a less individualistic and more family-centered model of decision making)

by patients of Asian and Pacific Islander descent compared with white patients and to assess whether hospice use differs by birthplace (United States versus abroad). These investigators found that Asian American and Pacific Islander patients used hospice 33% less often than did white Americans, and that those who were foreign-born were especially less likely to enroll in hospice. The authors highlighted several important possible reasons why Asian Americans and other racial and ethnic minorities use hospice less often, including sociocultural factors (Table IV–1–2) (21).

In summary, access to hospice and palliative care among racial and ethnic minority patients is a complex issue and requires consideration not only of economic factors but also of the relationships among economic, social, and cultural factors. Overcoming inequities to hospice use will require major efforts from physicians, researchers, policy makers, and hospice and palliative care organizations.

PEARLS

- Make sure the comprehensive assessment includes a screening question about economic burdens of end-of-life illness.
- Know about the insurance status and coverage of patients, including details of reimbursement.
- Maintain awareness of the informal supports available to the patient.
- Involve a social worker early in the process to help the patient and family members deal with complex financial matters.

PITFALLS

- Presenting the ill patient as a burden on the family or other caregivers

- Avoiding or ignoring cultural differences in discussing and dealing with money and end-of-life illness
- Forgetting to perform a continuing assessment of economic status (it may have changed because of loss of employment or other "shocks")
- Assuming the economic status or preferences of the patient or family members
- Missing the signs of caregiver stress and its associated health effects

SUMMARY

Advanced illness is often costly to patients and families. The economic costs to families are frequently different from those measured in traditional analyses of health care costs because they often include expenses not reimbursed by insurance (e.g., informal home supports), the patient's lost income, and the opportunity cost of foregone employment on the part of the caregiver. It is important that clinicians and policy makers recognize that economic costs can be an important component of the burden experienced by patients and families facing end-of-life illness.

Resources

Agency for Healthcare Research and Quality: Publication no. 05-E004–2. Evidence Report/Technology Assessment, no. 110: End-of-Life Care and Outcomes, Available at www.ahrq.gov.

Americans for Better Care of the Dying: Available at http://www.abcd-caring.com/mainpagemain.htm

Good Endings: Available at www.goodendings.net

Promoting Excellence in End-of-Life Care: Available at http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=1

StopPain.org/Department of Pain Medicine and Palliative Care: Available at http://www.stoppain.org/for_professionals

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Palliative Care in Developing Countries

2

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CHAPTER OUTLINE

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INTRODUCTION

With the exception of the United States, developed countries registered either a decline or no change in population during the last decade, whereas 99% of population growth took place in developing countries. As a result, by 2050, industrialized nations will record a population increase of only 4%, and the population in developing countries will expand by 55% (1). Overall, the world population will reach approximately 9 billion by midcentury.

This population growth will burden developing countries with a greater demand for health care services. More individuals will require palliative care services, but funding is limited, infrastructures are inadequate, and there is limited access to preventive and curative measures.

The World Health Report published by the World Health Organization (WHO) indicates that 57 million deaths occurred worldwide in 2004. Most of these deaths occurred in developing countries, where more than three fourths of the world's population lives. Infectious diseases such as human immunodeficiency virus (HIV), malaria, tuberculosis, and respiratory infections caused more than half of the cumulative deaths in developing countries.

CANCER

Currently, 24.6 million people are living with cancer, and by 2020 it is projected that there will be 16 million new cancer cases and 10 million cancer deaths every year. Cancer is among the major noncommunicable causes of death worldwide, and it accounted for more than 12% of the total deaths in 2004, or more than 7 million cases (2). The International Agency for Research on Cancer projects that global cancer rates will increase by 50% from 10 million new cases worldwide in 2000 to 15 million new cases in 2020, primarily because of the aging of the population and increases in smoking. Fifty percent of the world's new cancer cases and deaths occur in developing countries, and approximately 80% of these patients already have incurable cancer at the time of diagnosis (3).

HIV/AIDS

The number of people living with HIV has been rising in every region, with the steepest increases occurring in East Asia, Eastern Europe, and Central Asia. The increases in Asia are mostly the result of the growing epidemic in China. More than 60 million men, women, and children have been infected with HIV. More than 22 million people have died of acquired immunodeficiency syndrome (AIDS), and it is now the primary cause of death in Africa. Approximately 8% of the adult population is infected with HIV in sub-Saharan Africa, and global AIDS deaths totaled 3.1 million during 2003 (4). Initial efforts were aimed at prevention as the most realistic approach to reduce morbidity and mortality, but there is now an increased focus on care and treatment that stresses the importance of integrating prevention and treatment approaches into national health policies and priorities. Under this new approach, several government officials and activists have called for improving access to highly active antiretroviral therapy, prophylaxis, and treatment of opportunistic infections in people living with HIV/AIDS in developing countries. In addition, several authors have indicated that this should also include palliative care, pain relief, and support to families of patients who

do not respond to the treatment or who do not have access to these expensive therapies (5).

PALLIATIVE CARE

WHO encompasses a broad definition of palliative care that includes the needs of patients, families, and caregivers, and also addresses the physical, emotional, and spiritual needs of those involved. The organization promotes a public health approach to palliative care and recommends that comprehensive palliative care programs be integrated into the existing health care systems and adapted to the cultural and social context of nations. Palliative care can be provided simply and inexpensively in tertiary care facilities, community health centers, and at home.

The key components of a national comprehensive palliative care program, as recommended by WHO, include policy development, education and training, the provision of good quality care, and drug availability (5, 6). To address the needs of patients with advanced disease, the World Health Assembly recently adopted a resolution that gives special emphasis to the development and reinforcement of comprehensive national cancer control programs that, for the first time, include palliative care as a main component of cancer control strategies (7).

OPIOID CONSUMPTION

For several years, morphine consumption has been used as an indicator of adequate access to pain relief. In 1986, the WHO developed the WHO analgesic ladder (6) for the relief of cancer pain. The method relies on the permanent availability of opioid analgesics, including morphine, codeine, and others. The WHO ladder has been widely disseminated throughout the world. Still, opioid analgesics are insufficiently available, especially in developing countries, prescription of morphine is limited to a small percentage of physicians, and the drug is unavailable in many countries of the world.

The International Narcotics Control Board (INCB) collects consumption data from government reports on a yearly basis. Although the supply of narcotic drugs for medical purposes remains inadequate, the consumption trends recorded by INCB indicate improvement. The global consumption of morphine has been doubling every 5 years since 1984. In 2002, global consumption amounted for 27.3 tons (8). The trend is, however, mainly the result of increasing consumption in a few countries. For 2002, 82% of the total global consumption of morphine occurred in six countries: the United States, France, Canada, Germany, the United Kingdom, and Australia. The remaining 18% was consumed in the other 133 countries for which data are available. There are 51 developing countries with no registered morphine consumption at all. For that same year, the global mean of morphine consumption was 6.56 mg per capita. Figure IV–2–1 shows the consumption of morphine in selected countries of the world (9). Highlighted

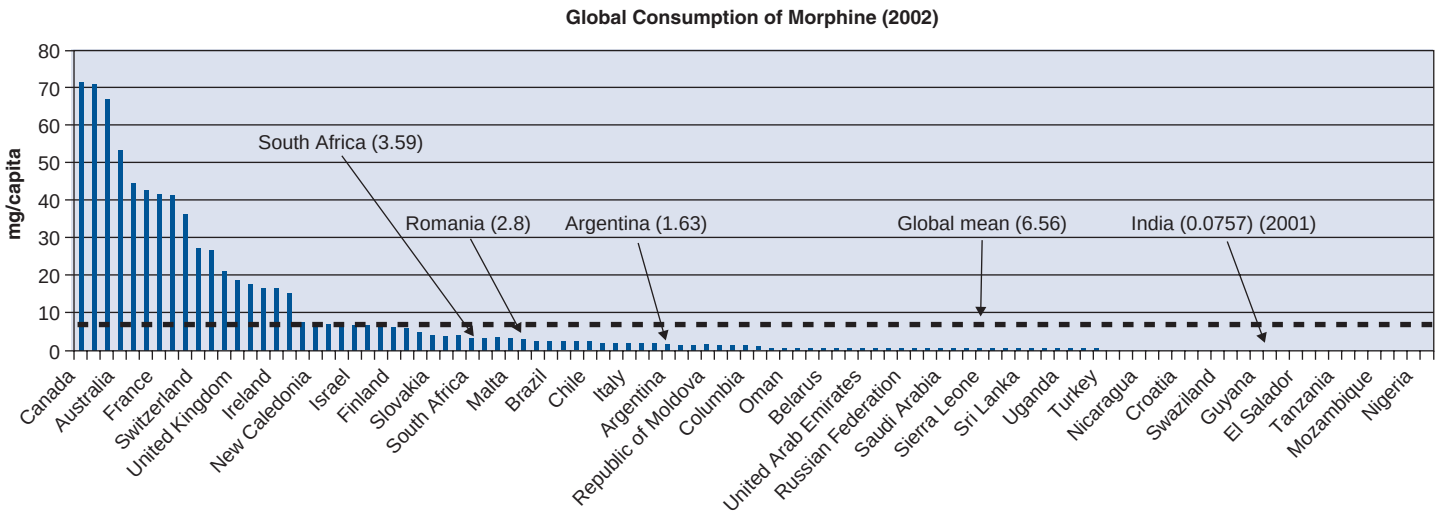

Figure IV–2–1 ■ Global consumption of morphine (13). (From the Pain and Policy Studies Group, 2005. International Narcotics Control Board and United National Demographic Group, 2002.)

are consumption rates for Argentina, India, Romania, and South Africa, countries discussed individually later in this chapter.

PALLIATIVE CARE IN THE DEVELOPING WORLD

Barriers to the adequate provision of palliative cancer care include the following: poverty; inadequate health care coverage; bureaucratic and inefficient processes related to the production or importation of opioids; restrictive laws and regulations related to the prescribing of opioids; centralized, ineffective opioid distribution methods that fail to reach rural regions adequately; insufficient drug availability; lack of knowledge and training related to palliative cancer care and pain management among health care workers; and insufficient support from national health authorities or low levels of political will to establish palliative cancer care programs (10).

The cost of opioids has been identified as a significant barrier to adequate care in developing nations. A recent study of developing and developed nations demonstrated that the median cost of opioid medication was twice as high in developing countries. In US dollars, a 30-day prescription was US $112 in developing countries, compared with US $53 in developed countries. Cost as percent of gross national product (GNP) per capita per month was 10-fold higher in developing countries, where patients have to spend more than one third of their salaries to cover pain therapy. Median cost was 31% of GNP per capita per month in the developing countries, compared with 3% of GNP per capita per month in the developed countries. Half of the opioid preparations cost more than 33% of monthly GNP per capita in developing countries compared with only 4% in developed countries. There were also fewer programs to offset medication costs in developing countries. Only one of the five developing nations (20%) had a subsidization program or socialized medicine, compared with four of seven (57%) of the developed nations (11).

A Latin American survey on advanced cancer care involved 667 physicians and demonstrated that, compared with other facilities or at home, most of the care given to persons with advanced cancer occurs in hospitals. However, the study also demonstrated that when the time of death approaches, most patients are discharged and die at home without receiving any type of medical care (12). Several authors have called for the development of palliative care models fit to meet population needs and financial constraints. Home palliative care can be a cost-effective approach when relatives are able to provide care and there is sufficient capacity to train them to provide the required nursing care.

A large body of knowledge has emerged on the assessment and management of the physical and psychosocial problems that occur in patients who develop cancer and other progressive incurable illnesses. Most of the available written material refers to the delivery of palliative care for diseases that occur mostly in the developed world and the use of resources available mostly in developed countries. However, patients in developing countries die younger and of conditions different from those in the developed world. In addition, certain socioeconomic and cultural issues pose particular challenges for the health care team.

Most of the research and advances published in the literature deal with medications or approaches that are not readily available in developing countries.

Several treatment strategies and inexpensive technologies can be adopted and implemented in the developing world. Some of these include the following:

Proctoclysis: This simple and inexpensive alternative method of hydration may be helpful in situations where resources are limited. A small nasogastric nutrition catheter is inserted in the rectum for hydration daily or every other day. It utilizes the colon's intrinsic ability to absorb normal saline or tap water. Assessments of comfort showed that this technique is well tolerated, and family members can successfully administer proctoclysis at home (13). This method may be especially helpful when technical difficulties make intravenous or subcutaneous infusion difficult or expensive. Such settings may include developing countries, a rural setting, or situations where nursing care is limited.

Edmonton Injector: This simple, nondisposable, very low-cost device allows patients to self-administer injections of opioids, metoclopramide, or other drugs intermittently into a subcutaneous needle. A bag contains 50 or 100 mL of medication, and pharmacists can prepare the medication from powder at a minimal cost. By a simple mechanical movement, patients are able to inject medication safely. The device does not require batteries, and little training is required for patients and families. The cost of this treatment is less than $1.00/day, and the device is not patented, thus allowing groups in developing countries to manufacture their own apparatus (14). Unfortunately, in some countries this device is not available or has not been approved by health care authorities, mostly because of its extremely low cost, which makes it unattractive to manufacturers.

Methadone: A synthetic opioid and N-methyl-D-aspartate antagonist, methadone is a potent analgesic in treating cancer pain. Its characteristics include excellent absorption, high lipid solubility, high potency, long half-life, lack of known metabolites, decreased opioid cross-tolerance, and very low cost, thus making it suitable for developing countries. However, overly restrictive regulations do not permit access to methadone in many of these countries (15).

CULTURAL ASPECTS

Recent publications address these issues and highlight the importance of a global approach sensitive to the different conditions, cultures, religious beliefs, ethnic backgrounds, and settings. Some of these include *Palliative Care in the Developing World: Principles and Practice* (16) and *Pain and Palliative Care in the Developing World and Marginalized Populations: A Global Challenge* (17).

Communication, disclosure of the diagnosis, active participation in decision making and treatment, discussion of end-of-life issues, and other matters are all influenced by the context in which these occur. Research has shown major differences in attitudes and beliefs regarding issues such as the role of patients and families in the decision-making process, amount of information disclosed in the diagnosis and prognosis, spiritual aspects, discussion of end-of-life issues, and other related topics (18). Professionals need to be aware of the need to recognize these differences, especially in multicultural environments or when traveling abroad to teach or work in another country.

The following are summaries of the status of palliative care in four different developing countries: Argentina, India, Romania, and South Africa. These sections were written by palliative care physicians who are actively working in their countries and are constantly facing many of the barriers discussed previously.

ARGENTINA

Health care development in Argentina varies considerably. Some areas have excellent medical facilities, whereas others have insufficient basic primary care. A high percentage of the population, especially among the lower socioeconomic classes, has difficulty obtaining qualified and efficient medical attention. The economic resources allocated for public health are insufficient to solve the sanitary problems. In addition, poor administration and bureaucracy at the professional and administrative levels aggravate the problems (19).

Status of Palliative Care

According to preliminary information from the National Directory of the Argentine Association for Medicine and Palliative Care (Asociación Argentina de Medicina y Cuidado Paliativo) there are approximately 90 palliative care teams in the private and public system, and they are located mostly in urban areas.

Most programs provide partial care and consist of small teams from different disciplines with varying levels of participation. The care is provided either at home through home care services or by family members who receive training in patient care and follow up via phone calls, in outpatient facilities, or institutions where patients can be hospitalized, although there are no beds dedicated to palliative care (mobile advisory teams) (20). Comprehensive palliative care programs with interdisciplinary teams that provide full-time care—in the consulting room, at home, in daycare, or at inpatient facilities—account for approximately 10% of the programs in the country.

Socioeconomic and Administrative Challenges

In 2002, the mortality rates from cancer and AIDS were 126.6 and 4.4 per 100,000, respectively (21). Despite the progress made in the last few years, the quality of assistance during the dying process is poor and has resulted in uncontrolled suffering and poor communication among professionals, patients, and families. Although there is limited information on the percentage of patients who receive palliative care, it can be estimated to be lower than 5% of the patients in need. Some of the reasons for this lack include insufficient support from health authorities, lack of rewards and incentives, and insufficient education. These are discussed in the following subsections.

Insufficient Support from the Health Authorities

Palliative care is not recognized as a specialty in Argentina, it is not incorporated within the health system, and no resources are assigned to the development of palliative care. In spite of the resolution adopted in 2000 by the Medical Obligatory

Program, which established that all the country's health institutions must offer free palliative care (including opioid analgesics) for patients with cancer, the government has failed to implement this resolution (22).

Lack of Rewards and Incentives

Palliative care workers, teams, and programs face financial constraints because the health system does not cover or underpays for the services. Many programs end up requesting donations from charity, hire workers on a pro bono basis, enroll volunteers, and request out-of-pocket pay from those patients who can afford it. A few private insurance programs in the country include palliative care in their coverage plans.

Palliative Care Education

Curricula for graduate health professionals are inconsistent, varied, and often inadequate. The results are predictable: some professionals without training provide inadequate palliative care to patients; some clinicians are unable to recognize the final stages of illnesses or to provide effective interventions; the role of different specialties is performed by many, without regard to quality or standards of care; many palliative care workers still feel uncomfortable discussing end-of-life issues; and many clinicians are incapable of working in multidisciplinary teams.

A few programs offer teaching opportunities with clear objectives and methods targeted to practice and improve the teamwork approach. A sign of progress is the creation of concurrency posts (nonpaid training positions) and residency positions (paid training positions) in palliative care for recently graduated clinicians. In 2003, two concurrency positions per year for physicians were established in the Hospital Tornú in Buenos Aires. In 2005, five residency positions per year were established for clinicians at the Hospital Tornú and the Hospital Udaondo in Buenos Aires.

Opioid Availability and Accessibility

Although the use of opioids has increased in Argentina during the last 10 years, the registered consumption in 2002 was 1.63 mg per capita, much less than the global mean of 6.5 mg per capita (see Fig. IV–2–1). Several opioids are available in urban areas, but high prices are a barrier to access (11). The monthly cost of 180-mg equivalent doses of immediate-release oral morphine, methadone, and sustained-release oxycodone is US $136; US $57, and US $412, respectively (23), whereas the minimum monthly salary in Argentina is currently equivalent to US $155.

INDIA

Socioeconomic and Administrative Challenges

In India, where 1 million people are diagnosed with cancer every year (2), fewer than 1% of needy patients have access to palliative care. A few have access to curative treatment, but most either experience futile aggressive treatment modalities that are continued late into the course of the disease, or they are told: "There is nothing more we can do." There is no government-sponsored social security system. The overwhelming social problem of poverty is worsened by the cost of

treatments. By the time the patient dies, families are often homeless, and children may have dropped out of school.

In 1991, the Government of India declared palliative care an essential component of cancer care, but health care delivery remained the onus of individual state governments. Policy did not become reality, and even now, very few cancer centers in India offer palliative care services. Even if they did, these services would still be grossly insufficient because most Indians live in rural villages with no access to cancer centers. Unless palliative care permeates primary health centers, coverage will continue to be inadequate.

Palliative Care Education

Only about 5 out of 200 medical colleges in India teach any palliative care to undergraduate students, and the situation is equally abysmal in nursing education. Preliminary educational efforts by many enthusiasts resulted in improved awareness of palliative care in at least in some pockets of the country. In addition to sensitization programs, short courses and distance education programs also have been started. In 2004, the only residential postgraduate course in palliative care started in the Amrita Institute of Medical Sciences, Kochi. It is a 2-year diploma course that offers a Diploma in Pain and Palliative Medicine, the first university-approved postgraduate course in the subject in the country. The International Association for Hospice and Palliative Care has supported this program with a faculty development grant. Pallium India, a nongovernment organization that emphasizes education, was instrumental in persuading the National Board of Examinations (a government body that conducts national-level postgraduate examinations) to accept Pain and Palliative Medicine as an independent postgraduate discipline.

Opioid Availability and Accessibility

Although India legally grows poppy and exports opium to many parts of the world, most suffering patients in India have no access to morphine. According to the INCB data, the consumption per capita in the country in 2001 was 0.07 mg (see Fig IV–2–1), lower than that of many countries with no palliative care programs. Fear of addiction among the public caused administrators to enact unrealistic narcotic regulations that effectively prevent medical use of the drug. The Narcotic Drugs and Psychotropic Substances Act of 1985 stipulated such strict penalties for even minor infringements that pharmacists all over the country stopped stocking potent opioids (24). Because multiple licenses are required from different state agencies, it is not uncommon finally to obtain one license only to find that another has expired. To add to the confusion, individual states within the country have different narcotic regulations. Even where oral morphine is available, fear of addiction and respiratory depression prevent professionals from using it. The resulting downward trend in consumption of morphine in India means a progressive increase in unnecessary pain burden for millions.

Government efforts, unfortunately, have had limited success. Between 1991 and 1996, several workshops were conducted by the Government of India in an attempt to improve access to opioids, but opioid consumption figures kept plummeting until the WHO Collaborating Center at Madison-Wisconsin joined forces with administrators and local organizations (including Indian Association of Palliative Care) to improve opioid availability (25). Today, narcotic regulations

have been simplified in 13 of India's 28 states, and morphine consumption has been rising steadily since 1999.

India has many systems of indigenous medicine, predominant among which is Ayurveda. Homoeopathy is also widely practiced. Theoretically, the availability of multiple systems of medicine should work to the patient's advantage, but there is seldom any scientific evaluation of the efficacy of these approaches, and they often add to patient's problems. Patients find it impossible to achieve a state of acceptance because there is always someone who offers a cure, no matter how hopeless the situation, and this contributes to the patient's emotional, physical, and financial burden.

The Last 2 Decades

There has been a positive change in the last 2 decades. Inpatient hospices in some parts of the country have acted as beacons of care and have contributed to educational efforts. However, they did not have the potential for wide area coverage, and later efforts based on care at home reached more people. In the South Indian state of Kerala, a model of care generated by the Pain and Palliative Care Society in Calicut has now grown to a network of about 60 palliative care centers in the state, many of them in rural areas (26). "The Calicut Model," as it came to be called, was a low-cost system designed to achieve coverage while maintaining quality. An extension of the model, called Neighborhood Network in Palliative Care, has taken it one step further by encouraging a greater role for volunteers and for getting closer to patients (27). It seeks to ensure increased involvement of laypersons in ensuring the health of the community. Neighborhood Network in Palliative Care is currently being systematically evaluated.

The Way Forward

So far, development in India in palliative care has been mostly driven by Nongovernmental Organizations (NGOs); government participation has been minimal. This situation has resulted in programs and projects run by very committed groups and individuals, but they do not have the ability to reach many patients. As coverage improves, there is always a concern that the service is spread too thinly, thus compromising quality of care. To reach the length and breadth of India, it is necessary to integrate palliative care with both mainstream medical practice and the health care system. NGOs in India have repeatedly asked the government for a pragmatic palliative care policy; but change is often slow.

Pain relief and palliative care also need to be incorporated in the basic education of physicians and nurses. This requires the support and endorsement of the Medical and Nursing Councils of India.

ROMANIA

Socioeconomic and Administrative Challenges

Palliative care was introduced in Romania through an initiative of Graham Perrols, Chairman of the Ellenor Foundation in the United Kingdom. In 1992,

a conference was organized with a group of supporters from the United Kingdom, and Romania's first service hospice, Casa Sperantei, was opened in Brasov.

Romania is an Eastern European country with 22.81 million inhabitants. Since the fall of the Communist dictatorial regime in 1989, it has struggled to overcome the consequences of 45 years under a totalitarian system and still faces problems such as a centralized economy, centralized distribution of funding, centralized decision making, a dictatorial political party, and extreme poverty.

The economy is going through a process of gradual reform, and, since 2000, there has been a modest increase in the gross domestic product (GDP) (28). Romania has had 10 health ministers since 1992. This instability has seriously hindered coherent development in all areas, including palliative care services. The medical health care system is funded through a national state insurance body, and approximately 80% of the population is insured (29). Despite the new legislative framework issued with the aim of decentralizing the health care system, most decisions are still largely under the responsibility of the Ministry of Health. In 2005, 4% of the GDP was allocated to health.

The leading causes of mortality are cardiovascular disease and cancer. These diseases are responsible for more than 50% of deaths in the persons up to the age of 64 years and for more than 85% of deaths among those older than 65 years. Two thirds of patients with cancer are diagnosed in the late, incurable stage of the disease (2). AIDS is a problem, particularly in children, although there has been a steady fall in the number of new cases per year because of improvements in blood testing and safety measures.

Cultural aspects and traditions must also be considered for a complete picture of the founding of palliative care in Romania. According to the 2001 nationwide census, 87% of Romanians are predominantly Christian Orthodox. Traditional families with three generations living under the same roof are now rarely found in Romania because of the migration and emigration of young couples. Community cohesion and rituals and traditions that surround major events in life (birth, marriage, death, grieving) are mainly preserved in the rural areas. Approximately 54% of the population lives in rural areas.

The main problems encountered in developing and providing palliative care services are lack of financial resources, lack of an appropriate legislative framework, low priority in the health care system for patients with incurable and terminal diseases, lack of trained staff, a hierarchical system that hinders team work, and lack of structures where these services could be provided.

Palliative Care Education

Since it opened in 1998, more than 2000 professionals, including health care professionals, managers, authorities, volunteers, and fund raisers from all over the country, have attended introductory or advanced courses at the Education Centre attached to the Hospice in Brasov. In 2000, palliative care was recognized as a medical subspecialty (30). A 12-week program for doctors was nationally accredited by the Ministry of Health and is run by Hospice Casa Sperantei Education Centre. To facilitate access to courses involving a longer period of training, in 2004 Hospice Casa Sperantei opened branches of the training center in four other cities: Bucharest, Cluj, Oradea, and Tg. Mures. Most of the theoretical training is done at these regional centers, and the practical training takes place at the hospice in Brasov. To date, 128 doctors have received a diploma in palliative care.

Because nurses are vital members of the team, nursing education was another priority. On the national level, the Association of Nurses is in the process of reorganization. A continuing medical education system with credits was introduced in 2004 and has proved an ideal opportunity to offer introductory courses in palliative care. The nursing diploma is still in negotiation, and, although the 6-week course for nurses was accredited nationally, it has not yet received the status of a diploma. Two universities offer optional palliative care courses at the undergraduate level for medical and nursing students in their final year: Brasov and Tg. Mures.

Opioid Availability and Accessibility

Romania is one of the countries in Europe with the lowest consumption of morphine (2.8 mg per capita in 2002), less than the regional mean and global average (see Fig. IV–2–1). This is the result of several existing barriers: the restrictive opioid law, inadequate training of physicians, patients' fears, and reluctance to use this medication. Legislation dates from 1969 and allows prescription of strong opioids only for patients with incurable cancer, peripheral vascular disease, and dyspnea resulting from terminal cardiac insufficiency. The procedure of obtaining the medication is lengthy and requires authorization, approval from the local health board, prescription with a dry stamp, and a triplicate prescription from the family doctor. Only one or two pharmacies per district dispense morphine and other strong opioids, and prescriptions must be renewed every 10 to 15 days. Because only one potent opioid is allowed at a time, patients receiving long-acting opioids cannot have breakthrough medication. A new authorization is required for any change in dosage or route of administration. General fear of morphine and lack of understanding by the general population are commonly encountered: morphine "equals death", "causes addiction", and is seen and used by doctors as a last resort.

Because of the interest the government showed toward pain control and palliative care, in 2002 Romania was selected to participate in a project by the Pain and Policy Studies Group at the University of Wisconsin. The old law was analyzed using WHO guidelines (31), and a new law and regulations were drafted. The new law was passed by Parliament in the autumn of 2005. An implementation program was proposed, which includes dissemination (via booklets, news, and media) and an education program targeted to physicians, pharmacists, and the general public. The group of national and international experts will continue to work together to ensure smooth implementation of the new law. Most of the other drugs needed for palliative care are available.

Adopted and Proposed Measures

Legislative changes have been proposed to foster the development of new services. The law regarding patients' rights was changed in 2003 and now includes articles about the rights of patients with advanced and terminal illnesses to receive appropriate care.

Since 2003, the health insurance law includes provisions that allow reimbursement through the insurance system for general home care services. Although palliative care services offered in inpatient units are included in the contract, no

practical provisions were enacted to ensure that actual funding is made. As a result, funding for inpatient services is not possible from this source. The law also stipulates that hospitals can provide curative treatments, rehabilitation, and palliative care.

The Minister of Health appointed the National Palliative Care Commission in 2004 with the aim of developing palliative care services at the national level. The commission drafted the Regulations for Palliative Care Services after researching international documents, but it also took into account the national standards that were proposed in 2000 by the Romanian National Association for Palliative Care. The document includes several sections, including beneficiaries, type and level of palliative care services, requirements (staffing and equipment) for the authorization of palliative care services, authorization and accreditation process, national data collection, regional coordination of development, and funding for palliative care services. The document has not yet been adopted.

Despite all these obstacles, there has been considerable development of palliative care in Romania in the last 10 years, but a long, untraveled road is ahead. Hospice Casa Sperantei was and is the one institution leading the palliative care movement in Romania. The task now is to integrate palliative care into the main health care system to offer access and coverage for patients in need.

SOUTH AFRICA

Since 1980 in South Africa, the hospice movement has provided palliative care to patients and families faced with the diagnosis of life-threatening illness. Hospices started as volunteer organizations that filled the gap by providing palliative care and especially end-of-life care that was not available in formal health care services. The Hospice Palliative Care Association (HPCA) of South Africa was established in 1987 and has facilitated further development of hospices to provide professional palliative care services through an accreditation process and mentorship of member hospices to adopt recognized policies and procedures for clinical palliative care, management, and good governance.

Specific Problems in the Provision of Palliative Care

There are two significant challenges in the provision of palliative care. The first is the lack of financial resources. Hospices in South Africa are NGOs that rely on donations and grants to finance the service. Since 2003, the government has started providing grants to some hospices for the palliative care of patients with AIDS, but not for those with cancer and other terminal illnesses. On average, this contribution amounts to 10% of the hospices' budgets. Health insurance has generally been used for oncology treatment before patients come into the hospice service, where care is offered free of charge. With the emphasis on providing professional palliative care, HPCA has encouraged hospices to employ professional staff at market-related salaries. This has resulted in some tension in the local hospices because many hospice directors still feel strongly that hospice should be a volunteer service.

The second significant challenge is the lack of human resources. In South Africa, 31% of all health professional posts were vacant in 2003. Significant numbers of

professional nurses and doctors have left the country to work in developed countries where salaries are higher. Another concern is the impact of the HIV epidemic on health care workers, which is estimated to have 16% prevalence (32, 33). As antiretroviral programs are being implemented in South Africa, posts are being created in antiretroviral clinics for health care professionals, and staff shortages in palliative care are more pronounced as personnel move into these posts.

Socioeconomic and Administrative Challenges

Until recently, palliative care in South Africa was provided only in hospices, and because these are NGOs, they depend on donations from the communities they serve, from corporate organizations, and from other funding sources. This means that hospices have been established in communities that are able to support the service financially and are capable of providing volunteer resources. Established hospices have expanded their services to include poor communities in their geographic areas, but many poorer areas have no palliative care services. Communities that identify a need for hospice services start the process by holding a public meeting to gauge public support for the project. Once financial support has been secured, a management committee is established with representation from health care professionals, management, and fundraisers. South African hospices provide home-based palliative care services, and a few hospices have also established inpatient facilities. It is an ongoing challenge to obtain sufficient funding to maintain hospice services, especially inpatient facilities.

International funds have recently become available for AIDS care, in particular funding from the US government from the President's Emergency Plan for AIDS Relief. In South Africa, these funds have been granted to the HPCA to build capacity in member hospices. The Department of Health has identified the need to integrate palliative care into the formal health care system and has formed a collaborative partnership with the HPCA to develop further palliative care services. This collaboration with the Department of Health may promote sustainability of hospice services.

Hospices do not have their own pharmacies or medication supplies, but they have always worked closely with the local hospitals and clinics to provide medication for their patients through the local hospitals. Hospice services are nurse driven, and medical support is available only in the larger metropolitan hospices in South Africa. There are no full-time medical posts in palliative care. Physicians are employed seasonally, or they donate their time to support professional nurses and do not see many hospice patients. Nurses also work closely with the patient's general practitioner or oncologist.

Palliative Care Education

Medical schools and nursing colleges are integrating palliative care into the undergraduate curricula, and practical training takes place in local hospices. Before this recent initiative, many qualified professionals did not receive training in palliative care. In 1989, the HPCA developed a palliative nursing curriculum. The curriculum is accredited by the South African Nursing Council and is a 6-month day-release program that includes 132 practical training hours. Nurses qualify with a certificate in palliative nursing. Seven hospice training centers have been set up

for professional nurses. The Cape Town Technical College initiated a degree program in palliative nursing in 2002.

The University of Cape Town offers postgraduate training in palliative medicine. These are distance-learning programs, an 18-month diploma course, and a 2- to 3-year Master's program in palliative medicine. HPCA also has an introductory course in palliative care for the interdisciplinary team, a 6-month distance-learning program, and is developing training programs in psychosocial palliative care and pediatric palliative care.

Availability and Accessibility of Opioids

South Africa has a limited number of opioids available, but the South African Essential Drug List has medications available for each step of the WHO three-step ladder, and many adjuvant analgesics are also included on the list. Codeine is the most commonly used step 2 analgesic, and morphine (mist morphine, slow-release morphine tablets and morphine sulfate injections) is the most commonly used step 3 analgesic. Tramadol and fentanyl are also available as alternate step 3 analgesics.

A recent study of the availability of essential palliative care medications in the state health system was very encouraging in that most recommended medications are available on the Essential Drug List. More medications are available in the private health system, although the only strong opioids available are morphine and fentanyl. Nonpharmacological treatments are available but are not covered by medical insurance.

The Pain and Policy Studies Group at the University of Wisconsin reported that, in 2002, the South African consumption of morphine was 3.6 mg per capita, and the global average was 6.56 mg per capita (see Fig. IV–2–1), whereas pethidine consumption was 5.1 mg per capita.

Proposed or Adopted Solutions

The following are the adopted or proposed solutions to the implementation of palliative care programs in South Africa:

- Increase public awareness in palliative care
- Education, training, and research in palliative care
- Collaboration with medical and nursing schools
- Collaboration with the formal health care sector and emerging palliative care services
- Establishment of provincial palliative care development teams
- Access to funding
- Mentorship for developing palliative care services

PEARLS

- Palliative care should not be regarded as a luxury available only in developed countries but rather as right of every patient, regardless of his or her socioeconomic situation, geographical location, creed, race, or disease.

- Access to palliative care includes access to treatment services, medications, and adequate professional care.
- Palliative care providers in resource poor countries need to develop their treatment protocols, research agendas, and strategies based on the needs of the population they serve and not on models developed elsewhere.
- Palliative care will become a reality only when politicians and policy makers in countries of the world recognize its benefits and include it in their national health care agendas.
- Developing multiregional and multinational programs requires the help and support of several organizations. No one single organization is capable of doing the work of all the existing ones.
- Funding will always be limited. Adopt and select strategies that will maximize the use of resources.

PITFALLS

- Believing that a single model of care is applicable globally
- Developing national or regional plans that do not include opioid availability, education, and changes in policy
- Failing to involve local and regional health care providers and organizations in the development of regional or multinational strategies

SUMMARY

The fact that a very large part of the world's population has either inadequate or no access to palliative care (including medications needed to alleviate pain and other symptoms) results in unnecessary suffering, especially among the poor and underprivileged. It has been estimated that one third of the world's population lacks access to the most essential medicines and curative treatments. Palliative care is and will continue to be the most cost-effective and, in many cases, the only possible care option for patients in developing countries. Governments, policy makers, health care professionals, and legislators should take the necessary steps to implement palliative care models suitable to fit the needs of the population. It is only through the designation of resources, allocation of space and beds, adoption of policies, education of health care workers, and increased awareness that patients will be able to have adequate care throughout the course of disease. The application of existing knowledge and resources is paramount to reach the majority of the population and patients around the world.

Resources

African Palliative Care Association: Available at http://www.apca.co.ug/
Eastern and Central Europe Palliative Care Task Force: Available at http://www.oncology.am.poznan.pl/ecept/emenu.php
European Association for Palliative Care East: Available at http://www.eapceast.org/
Hospice Palliative Care Association of South Africa: Available at http://www.hospicepalliativecaresa.co.za/

Indian Association for Palliative Care postal address:
Indian Association for Palliative Care Secretariat
DNHP Memorial Palliative Care Clinic
Bhuban Road, Uzan Bazar
Guwahati-781001 Assam
India
Email: goswamidcg@sify.com and painassam@rediffmail.com.
International Association for Hospice and Palliative Care: Available at http://www.hospicecare.com
International Observatory in End of Life Care: Available at http://www.eolc-observatory.net/
Latin American Association for Palliative Care [Asociación Latinoamericana de Cuidados Paliativos]: Available at http://ww.cuidadospaliativos.org

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Formulary: Medication Tables

Adapted from the EPEC-Oncology formulary by
S. Lawrence Librach and Kim Stefaniuk
S. Lawrence Librach and Kim Stefaniuk

The medication tables that follow list medications commonly used in palliative care. They are intended as a reference tool for clinicians in the United States and Canada.

Important Points

1. The list of dosage forms may not be complete and may change over time.
2. Not all drugs and dosage forms are available in each country.
3. Only the common adverse effects (AEs) and drug interactions are listed.
4. The listed trade names either represent the only product available or one that is commonly known.
5. Dosages may need adjustment for intercurrent conditions such as hepatic or renal failure.
6. Always refer to the Physicians' Desk Reference (PDR) in the United States or the Compendium of Pharmaceuticals and Specialties (CPS) in Canada for a complete, up-to-date list of the products available, adverse effects, and drug interactions.

Adverse Effects

AEs may be allergic, idiosyncratic, or dose-related extensions of known effects. They may increase with the number of different medications and the dosage. In the presence of liver or renal failure, AEs may emerge if dosage or frequency is not adjusted downward. If AEs occur, reduce or stop offending medications and provide appropriate antidotes.

Because medications may have many effects, they may also produce many different adverse effects. In some instances, they occur frequently enough to be grouped as in the table that follows.

Table App–1–1 ▪ Adverse Effects of Drugs

Adverse Effect Group	Possible Adverse Effects
Anticholinergic (AC)	Dry mouth, decreased gastrointestinal motility, constipation, tachycardia, urinary retention, mydriasis (pupil dilatation), cycloplegia (paralysis of ciliary muscle, of accommodation → blurred vision); may lead to restlessness, confusion, hallucinations, memory impairment, and delirium; may precipitate acute glaucoma
Central nervous system excitation (CNS)	Euphoria, restlessness, agitation, vivid dreams, nightmares, hallucination, myoclonus (jerks/twitches), and focal motor or grand mal seizures
Extrapyramidal (EPS)	Early effects (usually dose related): Acute dystonic reactions: torticollis (cervical muscle spasm → unnatural twisting of head), opisthotonos (a tetanic spasm with head and heels bent backward, body bowed forward), tics, grimacing, dysarthria, oculogyric crisis. Prescribe diphenhydramine, 25–50 mg PO, IM, IV q4h PRN Parkinsonian reactions: tremor, bradykinesia, rigidity, abnormalities of gait and posture. Prescribe benztropine (Cogentin), 1–2 mg IV, IM acutely then 1–2 mg PO daily–bid Akathisia: sense of constant motor restlessness. Prescribe benztropine, 1–2 mg PO daily–bid Late effects: Tardive dyskinesia: involuntary movements of lips, tongue, jaws, extremities; may persist indefinitely after medication is stopped. Antidopaminergic drugs may suppress these movements
Hypersensitivity	Rash, urticaria, bronchospasm, laryngeal or angioneurotic edema; in extreme cases, anaphylactic shock
Signs of electrolyte imbalance, dehydration	Dry mouth, thirst, weakness, lethargy, drowsiness, restlessness, muscle pain/cramps, muscle fatigue, hypotension (may be orthostatic), oliguria, tachycardia, nausea/vomiting
Upper gastrointestinal (GI)	Nausea, vomiting, dyspepsia; may include erosions, ulceration, bleeding. Prescribe misoprostol, 200 μg PO q6h or histamine H_2-receptor antagonists (see Antacids)

Abbreviations and Symbols

Table App–1–2 ▪ Abbreviations

Routes of Administration	
PO	Per os, by mouth
PR	Per rectum, by the rectum
IM	Intramuscular
IV	Intravenous
SC	Subcutaneous
SL	Sublingual
TD	Transdermal
IT	Intrathecal

Other Abbreviations

ac	Before meals
bid	Twice daily
CPS	Compendium of Pharmaceuticals and Specialties (Canada)
COX-2	Cyclooxygenase-2 selective inhibitor. may have less gastrointestinal, renal, and antiplatelet adverse effects
EC	Enteric coated
ER/SR	Extended/sustained release (extended-/sustained-release tablets must be taken intact, never broken or crushed)
EPS	Extrapyramidal symptoms
GI	Gastrointestinal
hs	At bedtime
Inj	injectable
IR	Immediate release (tabs are IR unless noted)
ODT	Orally dissolving tablets
MAOI	Monoamine oxidase inhibitor
NA	Not available
NS	Normal saline
NSAID	Nonsteroidal anti-inflammatory drug
PDR	Physicians' Desk Reference, Medical Economics Company, Inc., 1999 (US)
pc	After meals
PRN	As needed
qid	Four times daily
soln	solution
SSRI	Selective serotonin reuptake inhibitor
supp	Suppository
tab	Tablet
TCA	Tricyclic antidepressant
tid	Three times daily
↑	Upper dose limited only by need and adverse effects
†	Fixed-dose combinations not recommended in young children
††	Dose varies depending on condition being treated
☺	Insufficient experience in the pediatric population; if these drugs are needed, consultation is appropriate
☺☺	Insufficient experience in the pediatric population for this indication, although the drug may be used for other reasons; if these drugs are needed, consultation is appropriate

Medication Information Resources

American Hospital Formulary Service: Drug Information 2005. Bethesda, MD: American Society of Health-System Pharmacists, 2005.

Hardman JG, Limbird LL, Gilman AG (eds): Goodman and Gilman's The Pharmacologic Basis of Therapeutics, 10th ed. New York: McGraw-Hill, 2005.

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WEB SITES AND ONLINE DRUG RESOURCES

www.palliativedrugs.com
www.Epocrates.com
www.PEPID.com
www.pharmwell.com

Table App–1–3 ▪ Analgesics

Generic name	Dosage Forms Available	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Usual Dosing	Recommended Maximum Dosing
Acetaminophen	Tabs: 325, 500, 650 mg Elixir: 80 mg/0.8 mL, 60 mg/5 mL Supp: 120, 325, 650 mg, 81 mg chew	PO: 1–2 hr PR: 107–288 min	2–4 hr in normal individuals	Liver metabolism: 25% on first pass through the liver Renal excretion: 1%–4% unchanged	325–650 mg PO PR q4h routinely or PRN	650 mg PO PR q4h (4 g/24 hr)
Acetylsalicylic acid (ASA) (salicylic acid derivative)	Caplets, tabs: 325, 500, 650 mg Children's tab: 80 mg EC tabs: 81, 325, 500 mg Elixir: 80 mg/ Supp: 300, 600 mg	PO: buffered tablet: 20 min	4.7–9 hr (average 6 hr) Half-life is dose related	Liver metabolism Renal excretion: 5.6%–35.6%	325–650 mg PO, PR q4h routinely or PRN	650 mg PO PR q4h (5 g/24 hr)
Celecoxib (COX-2 selective)	Cap: 100, 200, 400 mg	PO: ≈3 hr	11 hr	Liver metabolism: extensive Renal excretion: 27% Less than 3% of a dose is eliminated as unchanged drug Feces: 57%	100–200 mg PO bid	200 mg PO bid
Choline magnesium trisalicylate (salicylic acid derivative) US only	Tab: 500, 750, 1,000 mg salicylate Elixir: 500 mg/5 mL	PO: tab: 1.5–2 hr Elixir: 3.5 hr	2–12 hr Dose dependent; higher doses produce longer half-life	Hydrolysis in GI salicylates Liver metabolism Renal excretion: 5.6%–35.6%	1–1.5 g PO q12h or 0.5–1.0 g PO q8h	1.5 g PO q8h (4.5 g/24 hr)

Table continued on following page

Table App–1–3 ▪ Analgesics (Continued)

Generic name	Dosage Forms Available	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Usual Dosing	Recommended Maximum Dosing
Diclofenac (acetic acid derivative)	IR tabs: 25, 50 mg ER tabs: 50, 75, 100 mg Supp: 50 mg (with 200 μg misoprostol: Arthrotec 50, 75 mg)	IR (diclofenac potassium): 1 hr (range, 0.33–2hr) ER (diclofenac sodium): 2 hr (range, 1–4 hr) PR: 30 min	2 hr	Liver metabolism: extensive first-pass Renal excretion: 65% Bile: 35%	IR: 50–75 mg PO PR q6–8h or ER 75–100 mg PO q8–12h	50 mg IR PO q6h or 75 mg ER PO q8h (225 mg/24 hr)
Diflunisal (salicylic acid derivative)	Tabs: 500 mg	PO: 2–3 hr	8–12 hr Half-life is dependent on the dose	Liver metabolism: extensive Renal excretion: 80%–90% Feces: <5%	250–500 mg PO q8–12h	500 mg PO q8h (1.5 g/24 hr)
Etodolac (acetic acid derivative)	IR tabs: 200, 300, 400, 500 mg ER tabs: 400, 500, 600 mg	PO IR: 1–2 hr PO ER: 3–12 hr	6–7 hr	Liver metabolism: extensive Renal excretion: 72% Feces: 16%	200–500 mg PO 6–12h	400 mg PO q8h ER: 1,200 mg/day
Flurbiprofen (propionic acid derivative)	Tabs: 50, 100 mg	PO: 1.5–2 hr	5.7 hr	Liver metabolism: extensive Renal excretion: 95%	50–100 mg PO q12h	200–300 mg/24 hr
Ibuprofen (propionic acid derivative)	Tabs: 200, 400, 600, 800 mg Elixir: 40 mg/mL, 100 mg/5 mL	PO: 1.4–1.9 hr	1.8–2 hr	Liver metabolism: extensive Renal excretion: Major route	200–800 mg PO q6–8h	800 mg PO q6h (3.2 g/24 hr)
Indomethacin (indole)	IR tabs: 25, 50 mg Supp: 50 mg Liquid: 25 mg/5 mL	PO: 2 hr	4.5 hr	Liver metabolism: extensive Renal excretion: 60% ≈26% eliminated as unchanged drug Feces: 33%	25–75 mg PO q8–12h or 75 mg ER PO q12–24h	50 mg PO q6h (200 mg/24 hr)

Ketoprofen (propionic acid derivative)	Cap: 50, 75 mg ER tabs: 100, 150, 200 mg Supp: 100 mg (Can)	PO IR: 1.2–2 hr PO ER: 6.8–9.2 hr	2–4 hr ER is 5.4 ± 2.2 hr	Liver metabolism Renal excretion: 80%; Bile: ≤40%	150–200 mg PO/24 hr IR: q6–8h ER: q12–24h	75 mg PO q6h (300 mg/24 hr)
Ketorolac (acetic acid derivative)	Tab: 10 mg Inj: 15, 30 mg/mL	PO: 44 min IM: 30–45 min IV: 1–3 min	5.6 hr	Liver metabolism Renal excretion: 92% excreted in the urine; 60.6% as unchanged drug Feces: 5.9%–6.3%	10 mg PO qid or 60 mg IM, IV loading dose, then 10–30 mg IM, IV q6h	40 mg PO/24 hr or 120 mg IM, IV/24 hr
Nabumetone	Tab: 500, 750 mg	PO: 3–6 hr	Nabumetone (prodrug): unknown Active metabolite (6-methoxy-2-naphthylacetic acid): 24 hr	Liver metabolism: extensive Renal excretion: 80% Feces: 10%	1–2 g PO q12–24h	1 g PO q12h (2 g/24 hr)
Naproxen (propionic acid derivative)	IR tabs: 250, 375, 500, 550 mg ER tab: 750 mg EC: 500 mg Liquid: 125/5 mL	PO IR: naproxen: 2–4 hr, naproxen sodium: 1–2 hr PO ER: 3 hr Topical, gel: 24 hr	12–15 hr	Liver metabolism: extensive Renal excretion: 95%	250–500 mg PO q8–12h	500 mg PO q8h (1.5 g/24 hr)
Piroxicam (oxicam)	Caps: 10, 20 mg	PO: 3–5 hr	50 hr; range: 30–86 hr	Liver metabolism: extensive Renal excretion: moderate; 5%–10% of a dose is eliminated as unchanged drug Feces: small	10–20 mg PO q12–24h	20 mg PO q12h (40 mg/24 hr)

Table continued on following page

Table App–1–3 ▪ Analgesics (Continued)

Generic name	Dosage Forms Available	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Usual Dosing	Recommended Maximum Dosing
Salsalate (salicylic acid derivative; US)	Tabs: 500, 750 mg	PO: 1.4 hr	1 hr	Liver metabolism: <1% appears as unchanged salsalate; remainder excreted as salicylic acid or metabolites of salicylic acid	1,000–1,500 mg PO bid	3,000 mg/day
Sulindac (indole)	Tabs: 150, 200 mg	PO: 1 hr	Sulindac: 7.8 hr Active metabolite: 16.4 hr	Liver metabolism: extensive Sulindac has no pharmacologic activity and must be metabolized to the pharmacologically active metabolite Renal excretion: 50% Feces: 25%	150 mg PO q12h	200 mg PO q12h (400 mg/24 hr)
Codeine (alone) (methylmorphine, naturally occurring opioid metabolized into morphine)	IR tabs: 15, 30, 60 mg Elixir: 5 mg/mL Inj: 15, 30 mg/mL ER 50, 100, 150, 200 mg (Can)	PO: 1–2 hr IM: 30/min PR: 30/min	2.5–3.5 hr	Liver metabolism:24–89% (metabolized to morphine) Renal excretion: 90% (3–16% of unchanged drug) Feces: ~5%	15–60 mg PO, SC, IM q4h routinely or q1h PRN	600 mg/24 hr then consider potent opioid
Codeine + acetaminophen combinations	Tabs: 15, 30, 60 mg codeine + 325 mg acetaminophen (may include caffeine, butalbital)	Codeine: PO: 1–2 hr Codeine PR: 30 min APAP: PO: 1–2 hr APAP: PR: 107–288 min	Acetaminophen: 4 hr Codeine: 2.5–3.5 hr	Codeine and acetaminophen: Same as codeine and acetaminophen	1–2 tabs PO q4h routinely or PRN	Limited to 12 tabs/24 hr by acetaminophen

Fentanyl	Patch: 12, 25, 50, 75, 100 μg/hr Lozenge: 200, 400, 600, 800, 1,200, 1,600 μg US only Inj: 50 μg/mL	Epidural: 30 min Transmucosal: 20–40 min Transdermal patch: 24–72 hr	≈4 hr Transdermal patch: 17 hr	Liver metabolism: to inactive metabolites Renal excretion: 75% (metabolites); 10% (unchanged drug) Feces: 9%	Patch: 25–↑ μg/hr q72h Lozenge: 200 μg q1h titrate PRN	Limited only by need and adverse effects
Hydrocodone + acetaminophen (US only)	Tabs: 5/500, 5/325, 7.5/325, 7.5/500, 7.5/750, 10/325, 10/500, 10/660 Elixir: 7.5/500 in 15 mL	PO: 1.3 hr for hydrocodone	Hydrocodone: 3.8–4.5 hr Acetaminophen: see above	Liver metabolism: Acetaminophen: see above Hydrocodone: extensive active metabolites Renal excretion: 26%	1–2 tabs PO q4–6h routinely or PRN	Limited to 4 g acetaminophen in 24 h
Hydrocodone + ibuprofen (US only)	Tab: 7.5/200	PO: within 2 hr (both components)	Hydrocodone 3.8–4.5 hr Ibuprofen 1.8–2 hr	Liver metabolism: see above Renal excretion: see above	1–2 tabs PO q4–6h routinely or PRN	Limited to 2,400 mg ibuprofen in 24 h
Hydromorphone	IR tabs:1, 2, 4, 8 mg ER capsules: 3, 6, 12, 18, 24, 30 mg Elixir: 1 mg/mL Inj: 1, 2, 4, 10 mg/mL Powder: 250 mg/vial Supp: 3 mg	PO IR: 48–60 min PO ER: 12–16.5 hr Epidural: 8 min IM/SC 30 min	IR: ≈3–4 hr	Liver metabolism: extensive Renal excretion: as hydromorphone 1.3%–13.2% Conjugates: 22%–51%	1–↑ mg: PO q4h routinely or q1h PRN, SC, IM q3h routinely or q30min PRN SC, IV q1h via infusion + breakthrough q30min PRN	Limited only by need and adverse effects
Levorphanol	Tab: 2 mg	PO: 1 hr	11 hr; with chronic PO dosing, half-life can be as long as 30 hr	Liver metabolism: extensive Renal excretion: extensive as conjugate	2–↑ mg PO q6–8h	Limited only by need and adverse effects

Table continued on following page

Table App–1–3 ▪ Analgesics (Continued)

Generic name	Dosage Forms Available	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Usual Dosing	Recommended Maximum Dosing
Meperidine (pethidine)	Tabs: 50, 100 mg Inj: 50, 75, 100 mg/mL Syrup: 10 mg/1 mL, 25 mg/1 mL, 50 mg/5 mL	PO: ≈ 1 hr IM: 25 min	Meperidine: 3.2–3.7 hr Active metabolite: 24–48 hr	Liver metabolism: 50% first pass through the liver Renal excretion: 0.5%–5.2% (average, 2.2%) unchanged Active metabolite, normeperidine, excreted 0.6%–21% (average, 6.2%) unchanged in the urine	50–150 mg PO IM, SC, IV q4h PRN NOT RECOMMENDED FOR CHRONIC DOSING because active metabolite, normeperidine, may produce adverse effects	150 mg q3–4h, 900–1,200 mg/24 hr
Methadone	Tab: 1, 5, 10, 25, 40 mg Elixir: 1, 2, 10 mg/mL Powder for injectable forms	PO: 2–4 hr	Methadone: 23 hr Metabolite: 39.8–48 hr After a single PO dose, half-life biphasic with an initial phase range of 12–24 hr and a secondary phase of ≤55 hr	Liver metabolism: four times greater after PO administration than after IM administration	5 mg PO q8h Titrate dose q3–5 days because of delayed clearance	Limited only by need and adverse effects

Morphine, IR	IR tabs: 5,10, 15, 25, 30, 50 mg Elixir: 1, 2, 10, 20 mg/mL Supp: 5, 10, 20, 30 mg Inj: 1, 2, 10, 15, 25, 50 mg/mL	Buccal: 5 hr (range, 4 hr, 1.5–12 hr) Epidural/ intrathecal: 5–10 min IV/IM/SC: 10–60 min PO IR: 1 hr PO ER: 8.4 hr PR: using PO ER: 5.4–6.7 hr PR: supp IR: 0.75–1 hr SC: 30 min	Liver metabolism: ≈90% of a given dose is conjugated morphine-3-glucuronide (M3G) and morphine-6-glucuronide (M6G-active) Renal excretion: 90% (metabolites and free drug) within 24 hr; altered in renal failure: clearance decreased; M3G and M6G accumulate severalfold with associated risk of toxicity Feces: 7%–10%	1–↑ mg: PO PR q4h Routinely or q1h PRN SC, IM q3h routinely or q30min PRN, or SC, IV q1h via infusion + breakthrough q30min PRN	Limited only by need and adverse effects
Morphine, ER	Kadian capsules: 20, 50, 100 mg (q12–24h) MS-Contin Tabs: 15, 30, 60, 100, 200 mg (q8–12h) Ora-Morph-ER tabs: 15, 30, 60, 100 mg (q8–12h)			10–↑ mg: PO/PR q8–24h routinely only (depending on product) Provide breakthrough doses using IR morphine q1h PRN	Limited only by need and adverse effects

Table continued on following page

Table App–1–3 ▪ Analgesics (Continued)

Generic name	Dosage Forms Available	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Usual Dosing	Recommended Maximum Dosing
Oxycodone (alone)	IR tabs: 5, 10, 15, 30 mg ER tabs: 10, 20, 40, 80 mg Elixir: 1 mg/mL (US)	PO IR: 1.6 hr PO ER: 2.1–3.2 hr	PO IR: 4 hr PO ER: 4.5–8 hr	Liver metabolism: extensive Renal excretion: extensive with ~20% unchanged	5–↑ mg IR PO PR q4h routinely, or q1h PRN or 10–↑ mg ER PO q12h	Limited only by need and adverse effects
Oxycodone + acetaminophen combinations	5 mg oxycodone + 325 mg acetaminophen 5/500, 7.5/325, 7.5/500, 10/325, 10/650 (may include caffeine)	See above	4 hr for oxycodone 2–4 hr for acetaminophen	Same as oxycodone and acetaminophen	1–2 tabs PO q4h routinely or PRN	Limited to 12 tabs/24 hr by acetaminophen
Oxycodone + aspirin combinations	5 mg oxycodone + 325 mg ASA (may include caffeine)	See above	Oxycodone: 4 hr ASA: 4.7–9 hr	Renal excretion: approximately 20% unchanged Same as oxycodone and acetaminophen	1–2 tabs PO q4h routinely or PRN	Limited to 12 tabs/24 hr by ASA
Tramadol	Tab: 50 mg	PO: 2 hr	Tramadol: 6.3 hr Metabolite: 7.4 hr	Liver metabolism: extensive Renal excretion: 30% excreted in the urine as unchanged drug, 60% of the dose excreted as metabolites	1–2 tabs PO q6h	2 tabs PO q6h

Table App–1–4 ■ Equianalgesic Doses of Opioid Analgesics

Oral/Rectal Dose (mg)	Analgesic	Parenteral Dose (mg)
120–150	Codeine	50
—	Fentanyl	0.050
15	Hydrocodone	—
3	Hydromorphone	1–1.5
2	Levorphanol	1
150–200	Meperidine (pethidine)*	50
15	Morphine	5–7.5
10	Oxycodone	—

*Not recommended for chronic pain.

IMPORTANT POINTS

These are guidelines only. Patients vary in their sensitivity to opioid effects and in the bioavailability of the drug. See Chapter I–7 for further information.

Table App–1–5 ■ Conversion to Methadone

Morphine Equivalents (mg)	Methadone/Morphine Ratio
<100	1:3
101–300	1:5
301–600	1:10
>600	1:15 to 1:20

Table App–1–6 ■ Dosage Equivalence for Transdermal Fentanyl*,†

Morphine Equivalents Dosage(mg)	Transdermal Fentanyl Dose (μg/hr)
30–59	12
60–134	25
135–224	50
225–314	75
315–404	100
405–494	125
495–584	150
585–674	175
675–764	200
765–854	225
855–944	250
945–1,034	275
1,034–1,125	300‡

*Not recommended for opioid-naive patients.
†From manufacturer's data.
‡Doses higher than this are not recommended.

Table App–1–7 ▪ Other Medications Used in Palliative Care

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Anorexia (Appetite Stimulants)								
Megestrol acetate Progestin for appetite stimulation	Megace: Tabs: 20, 40, 160 mg Suspension: 40 mg/mL	PO tablet: 1–3 hr PO suspension: 3–5 hr	13–105 hr (mean 34 hr)	Liver metabolism: 5–8% Renal excretion: 57%–78% Feces: 8% and 30%	Doses up to 800 mg PO daily may be useful	☺	Gynecomastia Deep vein thrombophlebitis Pulmonary embolism Alopecia Hyperglycemia Dyspnea Vaginal bleeding following withdrawal	None significant
Oxandrolone Anabolic steroid for weight gain	Various, Oxandrin is an example: Tabs: 2.5, 10 mg	IM: 24 hr	6–8 days	Liver metabolism: Renal excretion: unchanged Oxandrolone, 29%	2.5 mg bid–qid for 2–4 wk, then intermittently to maintain weight	≤ 0.1 mg/kg	Cholestatic jaundice Elevated liver function tests Virilization	Anticoagulants
Anxiety (Anxiolytics)								
Alprazolam Benzodiazepine	Various, Xanax is an example: Tabs: 0.25, 0.5, 1, 2 mg	PO: 0.8 to 2 hours	11.2 hours	Liver metabolism: extensive Renal excretion: 80% Feces: 7%	0.25–0.5 mg bid-tid (max 4 mg/24 h)	☺	Drowsiness Ataxia Fatigue Confusion Weakness Dizziness	CNS depressants Disulfiram Cimetidine Levodopa Anticonvulsants Psychotherapeutic agents
Clonazepam Benzodiazepine Long half-life	Various, Klonopin is an example: Tabs/wafers: 0.125, 0.25, 0.5, 1, 2, mg	PO: 1–4 hr PR: 10–30 min	30–40 hr	Liver metabolism: highly metabolized Renal excretion: 0.5%–1%	0.25–3 mg PO q8–12h (max 20 mg/24 hr)	☺☺	Nausea Rash	CNS depressants

Diazepam Benzodiazepine Long half-life	Various, Valium is an example: Tabs: 2, 5, 10 mg Elixir: 1, 5 mg/mL Inj: 5 mg/mL PR gel: 5 mg/unit PR supp: compounded	PO: 0.89–1.32 hr IV: 8 min IM: 1 hr PR gel:1.5 hr	0.83–2.25 days Active metabolites 40–194 hr	Liver metabolism extensive Renal excretion: 75%	2–10 mg PO, IM, IV q6–8h seizures: 5–10 mg IV q5–10min PRN	0.1–0.8 mg/kg/24 hr PO 6h	Drowsiness Confusion	CNS depressants
Lorazepam Benzodiazepine Intermediate half-life	Various, Ativan is an example: Tabs: 0.5, 1, 2 mg SL tabs: 0.5, 1, 2 mg solution: 2 mg/mL Inj: 2, 4 mg/mL	PO: 2 hr IM/SC: 1–3 hr SL: 60 min	12 hr Metabolites: 12–18 hr	Liver metabolism: 75% Renal excretion: 88% Feces: 7%	Sleep: 1–4 mg PO nightly PRN anxiolytic: 0.5–1 mg PO q6–8h (max 6 mg/24 hr) sedation: 1–4 mg PO q1–4h PRN (may require 20–50 mg/24 hr or more) seizures: 3–4 mg IV, SC, SL q5–10min PRN	☺☺	Drowsiness Confusion	CNS depressants
Midazolam Benzodiazepine Short half-life	Generic Inj: 1, 5 mg/mL	IM/SC: 45 min PR: 20–50 min	1.8–6.4 hr	Liver metabolism: extensive Renal excretion: 45%–57%	1–5 mg SC, IV, IM q3h PRN or 0.5–5.0 mg/hr SC continuous infusion seizures: 1–5 mg SC, IV, IM q1h PRN (generally used as an IV or SC infusion due to short half-life)	☺☺	Drowsiness Confusion	CNS depressants
Oxazepam Benzodiazepine Moderate half-life	Various, Serax is an example: Tabs: 10, 15, 30 mg	PO: 2–3 hr	2.8–8.6 hr	Liver metabolism: moderate Renal excretion: 50% unchanged drug	30–120 mg PO/24 hr (in divided doses)	☺☺	Drowsiness Confusion	CNS depressants

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Ascites (Diuretics)								
Furosemide Loop diuretic	Various, Lasix is an example: Tabs: 20, 40, 80 mg PO soln: 10 mg/mL Inj: 10 mg/mL	PO: 60–120 min IV: 6–10 min	30–120 min	Liver metabolism: ~10% Renal excretion: 60%–90% Bile: 6%–9% Feces: 7%–9%	20–240 mg PO/IV daily–bid	Initial dose: 1–2 mg/kg/24 hr PO ÷ q6–8h (may increase up to 8 mg/kg/24 hr)	Bloating Epigastric distress Nausea/vomiting Hypersensitivity Gynecomastia	Antihypertensives Indomethacin Aminoglycosides Alcohol
Metolazone Diuretic	Various, Zaroxolyn is an example: Tabs: 2.5, 5, 10 mg	8 hr	8–14 hr	Metabolism: site unspecified Renal excretion: 56.1%	2.5–20 mg PO daily	☺☺	Tinnitus	Barbiturates Opioids
Spironolactone Diuretic	Various, Aldactone is an example: Tabs: 25, 50, 100 mg	PO: 1–3 hr	1.3–1.4 hr Active metabolite: 8.9–23 hr	Liver metabolism: extent not reported Renal excretion: 47%–57%	50–250 mg PO daily–bid	1–4 mg/kg/24 hr in 1, 2, 3, or 4 divided doses	Gynecomastia	Salicylates

Constipation (Laxatives)								
Magnesium hydroxide Osmotic laxative	Many tabs and liquids available over the counter	Onset of action: dependent on the ability of the antacid to solubilize in the stomach and react with the hydrochloric acid Aluminum hydroxide: Slow Magnesium hydroxide: Fast	Duration of action in fasting patients may range from 20 to 60 min. When given 1 hr after meals, the acid-neutralizing effect may be prolonged up to 3 hr	NA	15–30 mL or 1–2 tabs PO q2h PRN (avoid mg if renal failure present, use Al)	Infant: 2.5–5 mL PO q1–2h Child: 5–15 mL PO pc and nightly	Alkalosis Mg can → diarrhea Al can → constipation Hypophosphatemia	Direct binding or elevated gastric pH may alter drug absorption, i.e., angiotensin-converting enzyme inhibitors, benzodiazepines, cephalosporins, chlorpromazine, histamine H_2-receptor antagonists, corticosteroids, digoxin, hypoglycemics, PO: iron, isoniazid, ketoconazole, metronidazole, nitrofurantoin, NSAIDs, quinidine, salicylates, phenytoin, tetracycline, theophyllines, valproic acid, vitamins C and D
Bisacodyl Laxative	Various, Dulcolax is an example: Tab: 5 mg Supp: 5, 10 mg	Initial response: PO: 6–12 hr PR: 15–60 min	NA	Renal excretion: minimal Feces: extensive	5–10 mg PO/PR daily–tid	5–10 mg PR or 0.3 mg/kg PO PRN	Diarrhea Cramps Dehydration Electrolyte depletion Nausea/vomiting	None significant

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Docusate sodium or calcium Anionic surfactant that emulsifies, wets, and disperses feces	Various, Colace, Surfak are examples: caps, tabs: 50, 100, 240, 250 mg Syrup: 20 mg/5 mL, 50 mg/5 mL drops: 10 mg/mL	Initial response: PO: 1–3 days	NA	Excreted in bile/feces	100–200 mg PO daily–tid	5 mg/kg/24 hr PO as a single daily dose	Mild abdominal cramping Bitter taste	Mineral oil
Glycerin Contact irritant laxative	Various: Supp: 96% glycerin	Initial response: PR: 15–30 min	30–45 min	Liver metabolism: 80% Renal excretion: 10%–20%	1 supp PR daily–bid	1/2–1 supp PR PRN	Rectal irritation	None significant
Lactulose Osmotic laxative	Various: Syrup: 10 g/15 mL	Initial response: PO: 24–48 hr	NA	Colon: extensive: lactulose is metabolized by colonic bacteria Renal excretion: 3%	15–60 mL PO daily–tid	5–10 mL PO once daily	Flatulence Cramps Nausea	Antibiotics PO: neomycin Antacids
Magnesium citrate Osmotic cathartic laxative	Various, Citro-Mag is an example: PO solution: 168 mEq mg/240 mL	Initial response: PO: 0.5–3 hr	NA	NA	50–150 mL PO daily–tid (not recommended)	4 mL/kg PO	Large watery stools Cramps Caution in renal patients	None significant

Magnesium hydroxide Osmotic cathartic laxative	Phillips' Milk of Magnesia: Liquid: 400 mg/5 mL Tab: 311 mg	NA	NA	NA	15–30 mL PO daily–qid PRN	No information	Diarrhea	None significant
Mineral oil Irritant laxative that penetrates and softens feces	Various	Initial response: PO: 6–8 hr PR: 5–15 min	NA	Not absorbed	15–45 mL PO daily–bid	1 mL/kg PO nightly	Anal leakage Nausea Abdominal cramps Lipid pneumonia	Docusate salts Fat-soluble vitamins (A, E, D, K)
Psyllium Bulk-forming laxative	Various, Metamucil is an example: Fiber wafers: 3.4 g Unflavored powder: 7 g/tsp orange powder: 3.4 g/2 tsp	Not absorbed Initial response: PO: 12–24 hr (≤3 days)	NA	Not absorbed	1 packet (10 mL) daily–tid, or 1 tsp unflavored powder (2 of flavored) PO daily, or 2 wafers PO daily (must mix with at least 240 mL of water)	1/4–1/2 of adult dose	Ensure good fluid intake, dehydration will worsen constipation Hypersensitivity Not for use if impaired GI motility	None significant
Sennosides Contact cathartic laxative that stimulates colonic peristalsis	Various, Senokot is an example: Tab: 8.6 mg Supp: 30 mg Syrup: 1.7 mg/mL Granules: 15 mg/tsp	Initial response: PO: 6–12 hr PR: 0.5 –2 hr	NA	Fecal and/or renal	1–2 tabs PO daily–tid (available combined with docusate)	3–10 mL of Senokot syrup PO bid	Nausea Abdominal cramps	None significant
Sodium phosphate Osmotic cathartic laxative that draws fluid into the gut, distends the intestine, and results in increased peristalsis	Various, Fleet Enema is an example	Initial response: PR: 0.5–3 hr	NA	NA	1 enema PR daily–bid	One pediatric or adult Fleet enema PRN	Rectal irritation Abdominal cramps	None significant

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Sorbitol Osmotic laxative	Various: Syrup: 10 g/15 mL	Initial response: PO: 0.5–3 hr	NA	Liver metabolism: fructose	15–60 mL PO daily–tid	5–10 mL PO daily	Flatulence Cramps Nausea	Antibiotics PO: neomycin antacids
Cough (Antitussive)								
Dextromethorphan Antitussive	Various combination preparations: Cap: 30 mg Syrup: 30 mg/5 mL	PO: 2–2.5 hr	1.4–3.9 hr Metabolites: 3.4–5.6 hr	Liver metabolism: rate of metabolism varies among individuals Renal excretion: extensive	15–45 mg PO q4–6h PRN (max 120 mg/24 hr)	1 mg/kg/24 hr ÷ q6–8h	Nausea/vomiting Dizziness Sedation GI disturbances	CNS depressants MAOIs
Hydrocodone Antitussive opioid	Various, Hycodan is an example: Tab: 5 mg Syrup: 5 mg/5 mL	PO IR: 1.3 hr PO ER: 3.4 hr	3.8–4.5 hr	Liver metabolism: extensive Renal excretion: 26%	5–10 mg PO q4–6h PRN	0.1 mg/kg PO q4h PRN	Lightheadedness Dizziness Sedation Nausea/vomiting Constipation Hypersensitivity	CNS depressants TCAs MAOIs
Delirium (Antipsychotics and EPS antidotes)								
Chlorpromazine Dopaminergic antiemetic, sedating neuroleptic, hiccups	Various, Thorazine is an example: Tabs: 10, 25, 50, 100, 200 mg Liquid: 100 mg/mL Inj: 25 mg/mL Supp: compounded	PO: 2.8 hr IM: 1–4 hr IV: 2–4 hr	6 hr	Liver metabolism: extensive PO: undergoes extensive first-pass metabolism Renal excretion: 23%	PO, PR, IM, IV q6–12 h nausea, hiccups: 25–50 mg PO PR, IM, q8–12h PRN	Antipsychotic dose: ☺ Antiemetic: 2 mg/kg/24 hr PO, IV ÷ q4–6h	Haloperidol (not as sedating) Anticholinergic AE EPS sedation Hypotension Itching	CNS depressants Anticonvulsants Barbiturates Lithium

Diphenhydramine H_1-histamine receptor antagonist	Various, Benadryl is an example: Caplets: 25, 50 mg Elixir: 12.5 mg/5 mL Children's liquid: 12.5 mg/5 mL Inj: 50 mg/mL Cream: 1%, 2%	PO: 2–4 hr	4–8 hr Metabolites: 8.6–10 hr	Liver metabolism: 50% large first-pass effect	25–50 mg PO, IV tid–qid, or 10–50 mg IM, IV q4h PRN or Routinely (max 400 mg/24 hr)	5 mg/kg/24 hr PO IM, IV ÷ q4–6h PRN or routinely	Sedation Dizziness Confusion Nausea/vomiting Hypersensitivity Arrhythmias	CNS depressants Ephedrine MAOIs
Haloperidol Dopaminergic antiemetic, nonsedating neuroleptic	Various, Haldol is an example: Tabs: 0.5, 1, 2, 5, 10, 20 mg Liquid: 2 mg/mL Inj: 5 mg/mL	PO: 2–6 hr IM: 20 min	21 hr (range: 10–38 hr)	Liver metabolism: Renal excretion: 33–40% Feces: 15%	0.5–5 mg PO SC, IM q4–6h PRN or routinely	☺	Diarrhea Sedation Hypotension Hypersensitivity	Alcohol Anticholinergics Barbiturates β-Blockers Cimetidine Clonidine Disulfiram L-Dopa Lithium Metoclopramide Meperidine Phenytoin Pyrimethamine SSRIs TCAs Trazodone Valproate Vitamin C
Olanzapine Atypical neuroleptic	Various, Zyprexa is an example: Tabs: 2.5, 5, 7.5, 10, 15, 20 mg ODT: 5,10, 15, 20 mg Inj: 10 mg/vial	PO: 6 hr IM: 15–45 min	21–54 hr (mean 30 hr)	Liver metabolism: extensive Renal excretion: 57% Feces: 30%	2.5 mg PO daily and advance to 5–10 mg/24 hr	☺☺	Dizziness Hypotension Hyperkinesia Somnolence Nausea	Levodopa Carbamazepine

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Perphenazine Neuroleptic	Various, Trilafon is an example: Tabs: 2, 4, 8, 16 mg Concentrate: 16 mg/5 mL	PO: 4–8 hr	9.5 hr (range, 8.4–12.3 hr)	Liver Metabolism: extensive	8–16 mg PO bid–qid (max 64 mg/24 hr, 24 mg/24 hr in ambulatory patients)		Haloperidol (not as sedating) Anticholinergic AE EPS Sedation Hypotension Itchiness	CNS depressants Anticonvulsants Barbiturates Lithium
Quetiapine Atypical neuroleptic	Various, Seroquel is an example: Tabs: 25, 50, 100, 200, 300 mg	PO: 1.5 hr	6 hr	Liver metabolism: extensive first-pass Renal excretion: 70%–73% Feces: 20–21%	25 mg PO bid and titrate	☺☺	Dizziness Hypotension Hyperkinesia Somnolence Nausea	Levodopa Carbamazepine
Risperidone Atypical neuroleptic	Various, Risperdal is an example: Tabs: 0.25, 0.5, 1, 2, 3, 4 mg ODT: 1, 2 mg Syrup: 1 mg/mL	PO tabs: 1–2 hr PO solution: 1 hr	PO: 20–30 hr Metabolites: 21–30 hr	Liver metabolism: extensive	0.5 mg PO bid and titrate weekly	☺☺	EPS Dizziness Hypotension Hyperkinesia Somnolence Nausea	Levodopa Carbamazepine
Depression (Antidepressants and Stimulants)								
Amitriptyline TCA for neuropathic pain	Various, Elavil is an example: Tabs: 10, 25, 50, 75, 100, 150 mg	PO: 4 hr	15 hr (range: 9–25 hr)	Liver metabolism: ≈50% of dose is metabolized to nortriptyline Renal excretion:	Start with 10–25 mg PO nightly tid and if no adverse effect, increase q3–4 days in 25-mg increments	☺	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics

Bupropion Antidepressant	Various, Wellbutrin, Zyban are examples: Caps: 75, 100 mg ER: 100, 150, 200 mg	PO IR: 2 hr PO ER: 3 hr	14 hr Metabolites: 20–37 hr	Liver metabolism: considerable first-pass effect Renal excretion: 87% Feces: 10%	100 mg PO bid or 150 mg ER to start (max 300 mg/24 hr)	☺	Agitation Constipation Dizziness Dry mouth Headache Insomnia	Alcohol Anticoagulants PO: antidiabetic agents, antihistamines, benzodiazepines, β-blockers, carbamazepine
Clomipramine TCA for neuropathic pain	Anafranil Caps: 25, 50, 75 mg	PO: 2–6 hr	19–37 hr Metabolite: 54–77 hr	Liver Metabolism: extensive first-pass effect Renal excretion: 51%–60% Feces: 24%–32%	25 mg PO daily and titrate	25 mg PO daily up to 3 mg/kg or 100 mg daily, whichever is smaller	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics
Desipramine TCA for neuropathic pain	Various, Norpramin is an example: Tabs: 10, 25, 50, 75, 100, 150 mg	PO: 3–6 hr	14.3–24.7 hr	Liver metabolism: extensive first-pass effect Renal excretion: ≈70%	10–25 mg PO daily and titrate	☺	Anticholinergic AE Arrhythmias QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics
Dextroamphetamine Stimulant	Various, Dexedrine is an example: Tabs: 5 mg ER: 5, 10, 15 mg	PO IR: tablets: 60–180 min PO ER: capsules: ≈7–8 hr	7–34 hr, mean 12 hr	Liver metabolism: extensive Renal excretion: 17%–73%	5 mg PO q9AM and noon; start and titrate (avoid late afternoon and evening doses as these can interfere with sleep)	☺☺	Nervousness Insomnia Dizziness Nausea/vomiting Cardiac effects Delirium Hypersensitivity	MAOIs Pressor agents Guanethidine Bretylium Warfarin anticoagulants TCAs Phenylbutazone

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Doxepin TCA for neuropathic pain Prominent histamine H_1-receptor antagonist	Various, Sinequan is an example: Caps: 10, 25, 50, 75, 100, 150 mg	PO: 30–60 min	8–25 hr mean: 16.8 hr Metabolites: 33.2–80.7 hr (mean 51.3 hr)	Liver metabolism: to active metabolite Renal excretion: 0.5%	10–25 mg PO nightly and titrate	☺	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics
Fluoxetine SSRI antide-pressant	Prozac: Caps: 10, 20, 40 mg Liquid: 20 mg/5 mL	PO: 6–8 hr	4–6 days, chronic administr-ation Metabolites: 4–16 days	Liver metabolism: extensive active metabolite, norfluoxetine Renal excretion: 60% Feces: 12%	Start with 2.5–5 mg PO nightly if no side effects, increase gradually q1wk (max 80 mg/24 hr, may take 4–5 wk to realize effect, reduce dose for elderly, hepatic and renal failure)	☺	Asthenia Constipation diarrhea Dizziness Dry mouth Headache Insomnia Somnolence	Alcohol Anticoagulants PO: antidiabetic agents, antihistamines, benzodiazepines, β-blockers, carbamazepine
Imipramine TCA for neuropathic pain	Various, Tofranil is an example: Tabs: 10, 25, 50, 75, 100, 150 mg	PO: 1 hr	6–18 hr Metabolite: Desipramine 12–36 hr	Liver metabolism: extensive first-pass effect to desipramine Renal excretion: 0.05–0.1% (desipramine only) Imipramine metabolites are excreted in urine	10–25 mg PO daily and titrate	☺☺	Anticholinergic AE Arrhythmias QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants histamine H_2-receptor antagonists MAOIs Sympathomimetics

Methyl-phenidate Stimulant Antidepressant	Various, Ritalin is an example: IR tabs: 5, 10, 20 mg ER tabs: 20 mg ER caps: 10, 20, 30, 40 mg Concerta ER Tab: 18, 27, 36, 54 mg	PO IR: 1–3 hr PO ER: 6–8 hr	PO: 2–7 hr; mean 3 hr	Liver metabolism: rapid and extensive Renal excretion: less than 1% unchanged	5 mg PO q9AM and noon to start and titrate 20–40 mg/24 hr reported (avoid late afternoon and evening doses as these can interfere with sleep)	☺☺	Nervousness Insomnia Dizziness Nausea/vomiting Cardiac effects Delirium Hypersensitivity	MAOIs Pressor agents Guanethidine Bretylium Warfarin anticoagulants TCAs Phenylbutazone
Mirtazapine Atypical anti-depressant	Remeron: Tabs: 7.5, 15, 30, 45 mg ODT: 15, 30, 45 mg	PO: 1.5–2 hr	20–40 hr	Liver metabolism: extensive Renal excretion: 75% Feces: 15%	15 mg PO nightly	☺	Somnolence Dizziness Weight gain	Alcohol Diazepam
Nefazodone Antidepressant (US only)	Serzone: Tabs: 50, 100, 150, 200, 250 mg	PO: 0.5–2 hr	1.9–5.3 hr Metabolites: 2–33 hr	Liver metabolism: extensive first-pass metabolism Renal excretion: 55% Feces: 20%–30%	100 mg PO bid and titrate	☺	Dizziness Drowsiness Dry mouth Headache Nausea Constipation Blurred vision Hypersensitivity	Anticholinergics Antihypertensives CNS depressants Digoxin Cisapride Triazoloben-zodiazepines MAOIs Phenothiazines Phenytoin SSRIs
Nortriptyline Tricyclic anti-depressant for neuropathic pain	Various, Aventyl, Pamelor are examples: Caps: 10, 25, 50, 75 mg Solution: 10 mg/5 mL	PO: 1 hr	15–39 hr	Liver metabolism: extensive Renal excretion: 2%	10–25 mg PO daily and titrate	☺☺	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Paroxetine SSRI anti-depressant	Paxil: IR tabs: 10, 20, 30, 40 mg Suspension: 10 mg/5 mL	PO IR: 3–8 hr PO ER: 6–10 hr	15–22 hr	Liver metabolism: extensive Renal excretion: 65%–67% Feces 36%–37%	Start 20 mg PO nightly if no side effects, increase 10 mg PO q1–2wk (max 50 mg PO daily, may take 3–4 wk to realize effect, reduce dose for elderly, hepatic and renal failure)	☺	Asthenia Constipation, diarrhea Dizziness Dry mouth Headache Insomnia Somnolence	MAOIs (avoid) Neuroleptics Nifedipine Pentazocine Phenothiazines Phenytoin Theophylline
Protriptyline TCA for neuropathic pain (US only)	Vivactil Tabs: 5, 10 mg	PO: 8–12 hr	54–198 hr	Liver metabolism: extensive Renal excretion: slow rate of excretion (50% over 2 weeks)	5 mg PO tid and titrate	☺☺	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics
Sertraline SSRI anti-depressant	Zoloft: Tabs: 25, 50, 100 mg conc. soln: 20 mg/mL	PO: 4–8 hr	24 hr Metabolites: 62–104 hr	Liver metabolism: extensive Renal excretion: 40%–45% Feces: 40%–45%	Start with 50 mg PO nightly, if no side effects, increase gradually q1wk (max 200 mg/24 hr)	☺	Asthenia Constipation, diarrhea Dizziness Dry mouth Headache Insomnia somnolence	Alcohol Anticoagulants PO: antidiabetic agents, antihistamines, benzodiazepines, β-blockers, carbamazepine

Trazodone Antidepressant Sedative	Various, Desyrel is an example: Tabs: 50, 100, 150, 300 mg	PO: 0.5–2 hr	7.1 hr	Liver metabolism: extensive Renal excretion: 70%–75% Feces: 21%	Start with 50 mg PO nightly, if no adverse effects, increase q7days up to 400 mg/24 hr	☺	Dizziness Drowsiness Dry mouth Headache Nausea Priapism No risk of withdrawal Hypersensitivity	Anticholinergics Antihypertensives CNS depressants Digoxin General anesthetics MAOIs Phenothiazines Phenytoin SSRIs
Trimipramine TCA for neuropathic pain	Surmontil: Caps: 25, 50, 100 mg	PO: 2 hr	23 hr	Liver metabolism: extensive	25 mg PO daily and titrate	☺☺	Anticholinergic AE Arrhythmias, QRS prolongation Drowsiness Nausea/vomiting Orthostatic hypotension Seizures	Alcohol Anticoagulants Barbiturates Cimetidine Clonidine CNS depressants Histamine H_2-receptor antagonists MAOIs Sympathomimetics
Venlafaxine Atypical anti-depressant	Effexor: Caps: 25, 37.5, 50, 75, 100 mg ER: 37.5, 75, 150 mg	PO IR: 1–2 hr PO ER: 5.5 hr	5 hr Metabolite: 11 hr	Liver metabolism: extensive first-pass effect to active metabolite Renal excretion: 36%–60%	37.5 mg PO bid or 75 mg/24 hr ER; start lower in some patients	☺	Asthenia Constipation, Diarrhea Dizziness Dry mouth Headache Insomnia Somnolence	Alcohol Anticoagulants PO: antidiabetic agents, antihistamines, benzodiazepines, β-blockers, carbamazepine
Diarrhea (Antidiarrheals)								
Attapulgite Antidiarrheal	Kaopectate: Generic multiple strengths and formulations	Not absorbed	NA	NA	30 mL or 2 tabs PRN (max 6 doses = 12 tabs/24 hr)	Suspension: 3–6 yr: 7.5 mL 6–12 yr: 15 mL >12 yr: 30 mL	None significant	None significant
Bismuth subsalicylate Antidiarrheal	Various, Pepto-Bismol is an example: Liquid: 17.6 mg/mL Tab: 262 mg	PO: (salicylate): 1.8–5 hr	Bismuth: 21–72 days Salicylic acid: 2–5 hr	Intestinal wall, extent unknown Renal excretion: bismuth, 0.003%; salicylate 95% Feces: bismuth, 99%	30 mL or 2 tabs PO q½h PRN (max 8 doses = 240 mL or 16 tabs/24 hr)	<2 yr: ☺ 2–4 yr: 5 mL PO q½h PRN 5–9 yr: 7.5 mL or ½ tab PO q½h PRN 10–14 yr: 15 mL or 1 tab PO q½h PRN	Blackens tongue and feces Constipation	Direct binding or altered gastric pH may alter drug absorption, See antacids, Al or Mg hydroxide antacids

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Diphenoxylate Synthetic opioid, related to meperidine Inhibits excessive gastric motility	Various in combination with atropine, Lomotil is an example: Tabs: 2.5 mg with atropine 0.025 mg Liquid: 2.5 mg/5 mL	PO: 2 hr	2.5 hr	Liver metabolism: extensive Renal excretion: 14% Feces: 49%	2.5–5 mg PO daily–qid (max 20 mg/24 hr) (avoid in hepatic failure)	0.3–0.4 mg/kg/24 hr PO ÷ bid–qid	Uncommon	May potentiate the effect of phenothiazines, barbiturates, TCAs
Loperamide Synthetic opioid, related to meperidine	Various, Imodium is an example: Caplets: 2 mg Caps: 2 mg Liquid: 1 mg/5 mL	PO cap: 5 hr PO liquid: 2.5 hr	7–15 hr	Liver metabolism: significant first pass Renal excretion: 1% Feces: 25%–40%	4 mg PO first dose then 2–4 mg after each unformed stool (max daily dose 16 mg/24 hr)	2 yr or older: ≈0.2 mg/kg/24 hr PO ÷ bid–tid	Abdominal pain Constipation Dizziness Dry mouth Nausea/vomiting Hypersensitivity	Cholestyramine
Octreotide Synthetic octapeptide analogue of somatostatin; inhibits secretion of the gastroenteropancreatic endocrine system, reducing volume of intestinal secretions	Sandostatin: Inj: 50, 100, 200, 500 μg LAR: 10, 20, 30 mg	SC: 15–30 min	1.5 hr	Liver metabolism: extensive Renal excretion: 32%	100 μg SC q8h for 48h or 10 μg/hr continuous SC, IV infusion and titrate	1–10 μg/kg bid–tid	Generally well tolerated	Cimetidine Cyclosporine

Drying (Anticholinergic)								
Atropine Antimuscarinic anticholinergic	Various: Inj: 0.1, 0.3, 0.4, 0.5, 0.6, 1.0 mg/mL in multiple combination PO tablets	PO: 1 hour IM: 30 min	Biphasic: initial ~2 hr; final: 12.5 to 38 hr	Liver metabolism: 45% Renal excretion: 30–50% unchanged	0.4–0.6 mg SC, IM, IV q3–4h routinely or PRN	0.01–0.02 mg/kg SC, IM, IV	CNS and cardiac excitation (atropine only) Anticholinergic AE Photophobia Palpitations Tachycardia (atropine only) Constipation Difficulty urinating	Antacids Histamine H_2-receptor antagonists may interfere with absorption Amantadine Quinidine Haloperidol Phenothiazines MAOIs TCAs
Glycopyrrolate Anticholinergic	Robinul: Tab: 1, 2 mg Inj: 0.2 mg/mL	PO: 90 min IM: 10 min	2.2–33.4 min	Renal excretion: 48.5%	0.1–0.4 mg IM, IV q4–6h PRN	☺	Anticholinergic AE	Antacids Slow K Levodopa Digoxin Phenothiazines Amantadine Antiparkinsonian agents Glutethimide
Hyoscyamine Antimuscarinic anticholinergic	Various, Levsin, Cystospaz are examples: Tab: 0.125, 0.15 mg Drops: 0.125 mg/5 mL Inj: 0.125 mg/mL	PO SR: 2.5 hr	3.5 hr ER: ≈7 hr	Renal excretion: majority of hyoscyamine excreted unchanged in urine within 12 hr	0.125–0.25 mg PO SL q4h routinely or PRN (max 1.5 mg/24 hr)	2–10 yr: 0.25–1.0 mL PO q4h routinely or PRN	Drowsiness (scopolamine) Nausea/vomiting Delirium, coma	Some antihistamines Digoxin Ketoconazole

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Scopolamine Antimuscarinic anticholinergic	Various, Transderm-Scop is an example: Inj: 0.4–0.6 mg/mL Patch: contains 1.5 mg, releases 1.0 mg in 3 days	4 hr	9.5 hr	Liver metabolism: Extensive Renal excretion: 1% (oral), 34% (transdermal)	0.3–0.6 mg SC, IV, IM q4–8h PRN or by continuous SC, IV infusion, or 1–2 patch(es) behind alternating ears q72h (patch takes 12 hr to achieve maximum blood levels, and 12 hr after removal of last patch to clear scopolamine from the blood) (wash hands thoroughly after applying patch)	Not indicated for children	May precipitate acute confusion or dementia-like picture, acute glaucoma Discontinue immediately Contraindicated in the presence of dementia, delirium, or glaucoma Treat excess with physostigmine IV Hypersensitivity	Antacids Histamine H_2-receptor antagonists may interfere with absorption Amantadine Quinidine Haloperidol Phenothiazines MAOIs TCAs
Dyspnea (Bronchodilators)								
Albuterol Salbutamol (CA) Inhaled ß-adrenergic agonist	Various, Ventolin is an example: MDI: 6.8, 17-g canister = 100 μg/puff 0.5%, 0.83%, inhalation solution 0.5, 1, 2, and 5 mg/mL inhalation solution CA Syrup: 2 mg/5 mL Tab: 2, 4 mg	Aerosol Inhalation: 3–4 hr SL: 2–3 hr ER: 6 hr PO: 1–4 hr	3–6.5 hr	Liver metabolism: to active metabolites 64%–98% Feces: 1.2%–7% after PO dose 10.2%–12% after inhalation	2.5–5.0 mg solution diluted to 4.0 mL with NS nebulized q4h PRN, or 2–3 puffs metered dose inhaler q4h PRN 2–4 mg PO tid–qid	0.03 mL/kg in 3 mL normal saline via nebulizer PRN child >12 yr: 2 mg PO qid	Tremor Nervousness Tachycardia	CNS stimulants Levodopa Propranolol MAOIs TCAs

Theophylline Bronchodilator	Various, Theo-Dur is an example: Tabs: 100, 125, 200, 300, 450, 600 mg SR 400, 600	PO once-daily dosage form: 11 hr	6–12 hr, adults	Liver metabolism: extensive Renal excretion: 10%–13%, adults	Start with 200–300 mg PO q12h every 3 days, increase 50–100 mg q12h until response or toxicity (monitor blood levels)	6 wk–1 yr: 6–15 mg/kg/24 hr ÷ q6–8h 1–12 yr: 20 mg/kg/24 hr ÷ q8–12h 12–16 yr: 18 mg/kg/24 hr ÷ q12h	Nervousness Restlessness Dizziness Insomnia Palpitations Nausea/vomiting	Adenosine Barbiturates Carbamazepine Phenytoin Rifampin Cimetidine
Zolpidem Nonben-zodiazepine hypnotic	Various, Ambien is an example: Tabs: 5, 10 mg	1.6–2.0 hr	2–2.6 hr	Liver metabolism: extensive Renal excretion: <1% 96% of a dose appears as metabolites in the bile, urine and feces	5–10 mg PO nightly	☺☺	Drowsiness Dizziness Lightheadedness	CNS depressants
Nausea (Antacids, Antinauseants)								
Cimetidine H_2-receptor antagonist, antacid	Various, Tagamet is an example: Tabs: 200, 300, 400, 800 mg	PO: 45–90 min IM:15 min	2 hr Metabolites: 2.2 hr	Liver metabolism: extensive Renal excretion: 48%–75% Feces: 2%–3% Bile: <2%	300 mg PO qid ac + hs, or 400–600 mg PO q12h, or 800 mg PO nightly, or 300 mg IV q6h (max 2400 mg/24 hr, reduce dose for renal failure)	1–12 yr: 20–25 mg/kg/24 hr PO: IV ÷ q4–6h <1 yr: 20 mg/kg/24 hr PO: IV ÷ q4–6h (reduce dose for renal failure)	Cognitive abnormalities, especially if hepatic or renal function is impaired Leukopenia Thrombocytopenia	Ketoconazole Hypoglycemics Theophylline Food Antacids Sucralfate Propantheline
Dronabinol Synthetic cannabinoid antiemetic and appetite stimulant	Marinol: Caps: 2.5, 5, 10 mg	PO: 1 hr	19–36 hr Metabolites: 49–53 hr	Liver metabolism: extensive Renal excretion: 10%–15% Feces: 35%–50%	2.5 mg PO q8–12h and titrate	☺	Ataxia Blurred vision Depression Dizziness Vertigo Drowsiness Dry mouth Headache Hallucinations Cannabis "high" Hypersensitivity to marijuana	Alcohol Barbiturates Benzodiazepines Opioids

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Droperidol Dopaminergic antiemetic	Inapsine Inj: 2.5 mg/mL	IM: 2–4 hr IV: 2–4 hr	2 hr Metabolite: 8–12 hr	Liver metabolism: extensive Renal excretion: 75% Feces: 22% (11%–50%)	2.5–5 mg q3–4h	2–12 yr: 0.05–0.06 mg/kg/dose IV/IM q4–6h	Diarrhea Sedation Hypotension Hypersensitivity Arrhythmias	Alcohol Anticholinergics Barbiturates β-Blockers Cimetidine Clonidine Disulfiram Levodopa Lithium Metoclopramide Meperidine Phenytoin Pyrimethamine SSRIs TCAs Trazodone Valproate Vitamin C
Famotidine H_2-receptor antagonist	Various, Pepcid is an example: Tabs: 10, 20, 40 mg Inj: 10 mg/ mL	PO: 1–3.5 hr	2.6–4 hr	Liver metabolism: 30%–35% Renal excretion: 25%–70% Feces: 50%	20–40 mg PO daily, or 10–20 mg IV q12h	☺	Insomnia Headache Malaise Dizziness Vertigo Somnolence	Warfarin anticoagulants Benzodiazepines β-Blockers TCAs Cephalosporins
Lansoprazole Hydrogen, potassium, adenosine triphosphatase inhibitor	Prevacid: PO caps: 15, 30 mg Granule packets: 15, 30 mg (US only) ODT: 15, 30 mg IV: 30 mg/vial	PO EC granules: 1.5–3 hr ODT: 1.8–2.0 hr	0.9–1.5 hr Metabolites: 3 hr	Liver metabolism: extensive Renal excretion: 14%–25% Bile: 67%	15 – 30 mg PO daily	☺	Generally well tolerated	Phenytoin Warfarin anticoagulants Benzodiazepines Corticosteroids Digoxin Ketoconazole Sucralfate

Metoclopramide Dopaminergic antiemetic, prokinetic	Various, Reglan is an example: Tabs: 5, 10 mg Liquid: 1 mg/mL Inj: 5 mg/mL	IV: 15 min PO: 60–160 min PR: 1–3 hr SC: 30 min	5–6 hr	Liver metabolism: Renal excretion: 70%–85% Feces: 2%	5–10 mg PO IM, SC, IV tid–qid, ½ h ac and hs (reported as continuous SC, IV infusion)	0.5 mg/kg/24 hr PO tid–qid, ½ h ac + hs	Dizziness Gynecomastia Galactorrhea Amenorrhea Abdominal cramps ⇑ risk of perforation if bowel obstructed Hypersensitivity	Alcohol Anticholinergics Barbiturates β-Blockers Cimetidine Clonidine Disulfiram levodopa Lithium Metoclopramide Meperidine Phenytoin Pyrimethamine SSRIs TCAs Trazodone Valproate Vitamin C
Misoprostol Prostaglandin E_1 analogue for gastric protection from NSAIDs	Cytotec: Tabs: 100, 200 μg	PO: 9–15 min	20–40 min	Liver metabolism: extensive Renal excretion: 80% Feces: 15%	100–200 μg PO q6h, after food 200 μg PO bid may be sufficient for NSAID prophylaxis (reduce in renal failure)	☺	Diarrhea Abdominal pain Flatulence Nausea/vomiting Headache	Salicylic acid
Omeprazole Hydrogen, potassium, adenosine triphosphatase inhibitor	Losec (CA), Prilosec: Tab: 10, 20, 40 mg	PO: 0.5–3.5 hr	0.5–1 hr	Liver metabolism: extensive (inactive metabolites) Renal excretion: 77% Bile: excretion of metabolites (16–19%)	20–40 mg PO daily (do not exceed 20 mg/24 hr with liver failure)	☺	Generally well tolerated	Phenytoin Warfarin anticoagulants Benzodiazepines Corticosteroids Digoxin Disulfiram Phenytoin
Ondansetron Serotonin 5-HT_3 receptor antagonist antiemetic	Zofran: Tab: 4, 8 mg Inj: 2 mg/mL Soln: 4 mg/5 mL ODT: 4, 8 mg	PO: 1–2.2 hr IM: 0.38 hr IV: end of infusion (30 min)	3–5.5 hr	Liver metabolism: extensive Renal excretion: 44%–60% Feces: 25%	4–16 mg PO, IV q8h	☺	Headache Constipation Flushing/warmth in the head or epigastrium Hypersensitivity	CNS depressants Anticonvulsants Lithium

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Prochlorperazine Dopaminergic antiemetic, phenothiazine neuroleptic	Various, Stemetil (CA), Compazine are examples: Tabs: 5, 10 mg Liquid: 5 mg/5 mL Supp: 2.5, 5, 10 (CA), 25 mg Inj: 5 mg/mL	1.5–5 hr	6.8–9 hr	Liver metabolism: extensive	5–20 mg PO PR, IM, IV, PR q4h PRN or routinely	0.5 mg/kg/24 hr PO: PR ÷ bid–tid	Drowsiness Dizziness Hypotension EPS	Alcohol Anticholinergics Barbiturates β-Blockers Cimetidine Clonidine Disulfiram levodopa Lithium Metoclopramide Meperidine Phenytoin Pyrimethamine SSRIs TCAs Trazodone Valproate Vitamin C
Promethazine Histamine H_1-receptor antagonist antiemetic	Phenergan Tab: 25, 50 mg syrup 6.25 mg/5 mL Inj 25 mg/mL	IM: 2–3 hr	7–15 hr	Liver metabolism: extensive first-pass metabolism	12.5–25 mg PO/PR q4–6h	0.5 mg/lb PO/PR q4–6h	Drowsiness Dry mouth Blurred vision	CNS depressants Anticholinergics
Ranitidine H_2-histamine receptor antagonist antacid	Various, Zantac is an example: Tabs: 75, 150, 300 mg Inj: 25 mg/mL Syrup: 15 mg/mL	PO: 0.5–2 hr IM: 15 min	2–3 hr	Liver metabolism: Renal excretion: 30%–70%	150 mg PO bid or 300 mg PO daily (300 mg PO bid may be used for ≤4 wk to promote healing) 50 mg IV, IM q6–8h	2.5–3.8 mg/kg/24 hr PO ÷ bid	Nausea/vomiting Constipation Diarrhea Abdominal discomfort Drug-induced hepatitis Impotence Gynecomastia Hypersensitivity	Phenytoin Probenecid Procainamide Quinidine Acetaminophen

Sucralfate Polysaccharide that binds to ulcer tissue in the esophagus, duodenum and stomach to provide a barrier from acid	Various, Sulcrate (CA), Carafate are examples: Tab: 1 g Suspension: 1 g/10 mL	Initial response: 1 hr	Duration PO: 6 hr	Sucralfate is not metabolized; any amount of sucrose octasulfate and Al absorbed is excreted unchanged in the urine Renal excretion: 0.5–2.2% Feces: 90%	1 g PO qid ac + hs 2 g PO q12h (may add antacids, but do not use within ½ hr of sucralfate dose because acid is required to activate sucralfate)	☺	Constipation Diarrhea Nausea Gastric discomfort Dry mouth Pruritus Sleepiness Vertigo Al buildup may occur with renal failure	No antacids within ½ hr of dose No H_2-blockers Tetracycline Phenytoin Digoxin Ketoconazole Theophylline Ciprofloxacin Norfloxacin
Trimethobenzamide (US only) Antiemetic, unclear mechanism of action. Probably combination of dopaminergic and others	Tigan: Caps: 100, 250 mg Supp: 100, 200 mg Inj: 100 mg/mL	PO: 45 min IM: 30 min	7–9 hr	Liver metabolism: unknown Renal excretion: 50%–70%	250 mg PO q8h 200 mg PR q8h	30–90 lb child: 100–200 mg PO q6–8h <30 lb child: 100 mg supp PR tid	Drowsiness Dizziness Hypotension EPS	Alcohol Anticholinergics Barbiturates β-Blockers Cimetidine Clonidine Disulfiram Levodopa Lithium Metoclopramide Meperidine Phenytoin Pyrimethamine SSRIs TCAs Trazodone Valproate Vitamin C
Pain (Analgesics)								
Capsaicin Topical for neuropathic pain	Various, Zostrix is an example: cream: 0.025, 0.075%	Initial response: topical: 14–28 days	NA	NA	Apply lightly to affected areas at least 3–4 times/24 hr (wash hands immediately) (optimal response within 14–28 days of continued application)	≥2 yr: same as adults	Transient burning on application; avoid contact with eyes; do not apply to wounds or damaged skin; do not bandage	None significant

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Carbamazepine Antiepileptic, neuropathic pain	Various, Tegretol is an example: Tab: 100, 200 mg ER: 100, 200, 400 mg Suspension: 100 mg/5 mL	PO IR: 4–5 hr PO chew tablets: 6 hr PO ER: 3–12 hr PO suspension: 1.5 hr	12–17 hr	Liver metabolism: 98% Renal excretion: 72%	Seizures: 100 mg PO bid–400 mg PO tid Hiccups: 100–200 mg PO bid–tid (start low and increase q3–4days, monitor blood levels)	Initial dose: 10 mg/kg/24 hr ÷ bid–tid Increase dose if necessary, up to 30 mg/kg/24 hr	Aplastic anemia Cardiovascular effects Ataxia Blurred vision Confusion Drowsiness Vertigo Headache Hepatic effects Nausea/vomiting Hypersensitivity	Alcohol Calcium-channel blockers Corticosteroids Erythromycin, doxycycline Haloperidol Isoniazid Lithium MAOIs (avoid) Metoclopramide Other anticonvulsants Psychoactive agents Theophylline Warfarin anticoagulants
Flecainide Class 1C antiarrhythmic for neuropathic pain	Tambocor: Tabs: 50, 100, 150 mg	PO: 1.5–6 hr PO cap: 1–8 hr	7–22 hr	Liver metabolism: extensive Renal excretion: 81%–90% Feces: 4%–6%	Start with 50 mg PO q12h Increase 50 mg q12h every 4 or more days (max 300 mg/24 hr) (adjust for hepatic or renal impairment)	☺	May cause ventricular or other arrhythmias Congestive heart failure Dizziness Visual disturbances (blurred vision, diplopia, photophobia) Headache Nausea Dyspnea	Other antiarrhythmics Cimetidine Digoxin Propranolol Phenytoin Phenobarbital Rifampin Carbamazepine

Gabapentin Antiepileptic, for neuropathic pain	Neurontin and various Caps: 100, 300, 400, 600, 800 mg Syrup: 250 mg/5 mL	PO: 1.5–4 hr	5–7 hr	Not metabolized Renal excretion: 76%–81% unchanged in the urine Feces: 10%–23%	100–300 mg PO tid and titrate (3,600 mg/24 hr has been reported)	☺	Somnolence Dizziness Fatigue	Alter for renal function Cimetidine PO: contraceptives, antacids
Lidocaine Anesthetic to relieve pain from mucositis, oropharyngeal, perianal, and skin lesions/ulcers. Endotracheal spray may be used during painful dressing changes	Various, Xylocaine is an example: Topical liquid: 4% Viscous: 2% Oral and endotracheal spray: 10% Jelly: 2% Ointment: 5% Inj: 5, 10, 20 mg/mL IV infusion: 8 mg/mL in 5% dextrose in water	IM: 30 min–2 hr Initial response: topical 2% jelly: 3–5 min	1.5–2 hr Metabolites: 1–6 hr	Liver metabolism: 90% Renal excretion: ≈90%	Viscous: 15 mL PO q3h PRN, gargle, spit or swallow (mix 50/50 with antacid to make more palatable) Liquid/spray: apply to affected areas PRN Jelly: apply to urethra before catheterization (max 200 mg/24 hr)	5–15 mL swish and spit q4h PRN (max 3 mg/kg/24 hr)	No fluids or food within 60 min of PO: ingestion (interferes with second stage of swallowing) Systemic administration may cause CNS excitation or depression, ventricular or other arrhythmias Hypersensitivity	Bupivacaine if given systemically Other antiarrhythmics Amiodarone β-Blockers Cimetidine MAOIs Phenytoin Trimethoprim-sulfamethoxazole
Lidocaine + Prilocaine Anesthetic combination to relieve pain associated with local procedures	E mLA: Cream: 25 mg lidocaine and 25 mg prilocaine/g Patch: 1 g cream	Topical, cream: 2–4 hr Topical periodontal gel: 30 min	Lidocaine: 1–2 hr Prilocaine: 10–150 min	Liver metabolism: lidocaine (extensive), prilocaine (extent unknown) Renal excretion: lidocaine 90%	Apply patch, or a thick layer of cream Cover with an occlusive dressing for at least 1 hr before a painful procedure (may remain ≤5 hr)	Apply as for adults (not recommended for infants <6 mo or children 6–12 mo receiving drugs for methemoglobin)	Mild local reactions, i.e., edema, itching, transient paleness, erythema, initial burning	None significant

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Mexiletine Class 1B arrhythmic used for neuropathic pain	Mexitil: Caps: 150, 200, 250 mg	PO: 1–4 hr IM: 15 min–2 hr	6–17 hr	Liver metabolism: extensive Renal excretion: ≈8%–15%	Start with 100 mg PO q8h Increase 100 mg q8h every 3 or more days (max 1200 mg/24 hr) (adjust for hepatic impairment)	☺	May cause ventricular or other arrhythmias Upper GI distress Lightheadedness Tremor	Other antiarrhythmics Phenytoin Phenobarbital Rifampin Carbamazepine Cimetidine Theophylline Metoclopramide Avoid diets/medications that acidify urine Tobacco, smoking
Valproic acid Antiepileptic for neuropathic pain	Depakene, Depakote, and various Tabs: 125, 250, 500 mg Syrup: 250 mg/5 mL Caps 250, 500 mg	PO: valproic acid Capsules Depakene: 1–4 hr PO: divalproex tablet: 4–8 hr PO: divalproex sprinkle capsule: 3.3–4.8 hr PO: divalproex sodium ER tablet: 4–17 hr PO: sodium valproate soln: 1.2 hr IV, Depacon: At the end of a 1 hr infusion PR: diluted Valproic acid syrup: 3.1 hr	6–17 hr	Liver metabolism: extensive Renal excretion: 70%–80% Bile: 7% Lung: 2–18%	Seizures: start at 15 mg/kg/24 hr, increase wkly by 5–10 mg/kg/24 hr up to max 60 mg/kg/24 hr (>250 mg, divide into 3 doses/24 hr) Hiccups, neuropathic pain: 250 mg PO bid–qid	Same as adult dosing	Ataxia Tremor Sedation Inhibition of platelet aggregation Nausea/vomiting Thrombocytopenia Hypersensitivity	Alcohol Antacids ASA Barbiturates Clonazepam Phenytoin

Sedation (Barbiturate)								
Phenobarbital Barbiturate antiepileptic and sedative	Various: Tabs: 15, 30, 60, 100 mg Elixir: 20 mg/5 mL Inj: 30, 65, 120, 130 mg/mL	PO: 8–12 hr IM: 1 hr IV: 15 min	1.5–4.9 days	Liver metabolism: partial Renal excretion: 21% unchanged	Sedation: 100–130 mg PO, IM, IV q6h or by continuous infusion 1–5 mg/hr (starting low and titrating upward until sedation is achieved) Seizures: 60–120 mg IV, IM, PR q10–20min PRN	Seizures: initial dose 20 mg/kg IV Maintenance dose: Children <3 mo 5–6 mg/kg/24 hr ÷ bid children over 3 mo 3–5 mg/kg/24 hr ÷ bid	Drowsiness Headache Hypersensitivity Nausea/vomiting Diarrhea	CNS depressants Anticoagulants Corticosteroids Antidepressants Griseofulvin Doxycycline PO: contraceptives, anticonvulsants
Skin (Antibiotics)								
Metronidazole Topical and PO antibiotic particularly for malodorous skin ulcers	Various, Flagyl, MetroGel are examples: Tab: 250 mg Caps: 375, 500, 750 mg Cream: 10% Vaginal inserts: 500 mg Inj: 5mg/mL	PO: 1–2 hr IV: end of infusion PR: 3 hr Topical: 8–12 hr	6–14 hr	Liver metabolism: extensive Renal excretion: 60%–80% Feces: 6%–15%	For skin ulcers: apply layer of cream over affected area tid–qid and if extensive, 250–500 mg PO/IV q8h	Skin ulcers: same as for adults	Anorexia Diarrhea Dry mouth Furred tongue Nausea/vomiting Neurologic deterioration Peripheral neuropathies Unpleasant, metallic taste Hypersensitivity	Alcohol Astemizole (avoid) Barbiturates Warfarin anticoagulants Disulfiram Lithium Terfenadine (avoid)
Silver sulfadiazine Topical antibiotic particularly for malodorous skin ulcers	Various: Cream: 1%	NA	10 hr	Renal excretion: 60%	Apply layer of cream over affected area bid (use with caution in hepatic or renal impairment)	Same as for adults	Use with caution in patients sensitive to sulfa Leukopenia Hypersensitivity	PO: hypoglycemics, phenytoin, cimetidine

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Dexamethasone Glucocorticoid	Various, Decadron is an example: Tabs: 0.5, 0.75, 1, 4, 6 mg Elixir: 0.5 mg/mL Inj: 4, 10 mg/mL	PO cap: 3.17 hr PO Elixir: 10–60 min PO tabs: 1–2 hr	Plasma: 1.88–2.23 hr Biological duration of action: 36–54 hr	Liver metabolism: partial Renal excretion: up to 65% Bile: small extent	0.5–8 mg PO, IV, IM, SC daily–q6h (single doses of 40–100 mg IV may be used to effect an acute response (dosage may need to be tapered slowly to avoid adrenocorticoid insufficiency on withdrawal)	††	Increased risk of infection, particularly opportunistic infections Gastritis Gastric ulceration/bleeding Nausea/vomiting Pancreatitis Wasting, particularly proximal muscles Thinning of skin, bowel (possible perforation) Impaired wound healing Salt, water retention Hypertension Cushingoid state	Hepatic microsomal enzyme inducers Estrogens NSAIDs Potassium-depleting drugs Anticholinesterase agents PO: anticoagulants, cyclosporine
Fludrocortisone acetate Mineralocorticoid	Florinef: Tab: 0.1 mg	PO: 1.7 hr	3.5 hr	Liver metabolism: extensive	0.1–0.2 mg PO daily (may combine with glucocorticoid)	50–200 μg PO daily	Increased risk of infection, especially fungal, tuberculosis, other opportunistic infections Salt, water retention Hypertension Hypokalemia	Potassium-depleting drugs

Prednisone Glucocorticoid	Various: Tabs: 1, 2.5, 5, 20, 50 mg Soln: 1mg/mL	PO: 1.3 hr	Plasma: 2.6–3 hr Biological duration of action: 12–36 hr	Liver metabolism: extensive (metabolized to the biologically active steroid, prednisolone)	5–80 mg PO daily	††	Hyperglycemia Euphoria Insomnia Mood swings Personality changes: depression, psychosis Withdrawal may lead to adrenocortical insufficiency Flare in joint pain May suppress reactions to skin tests Not to be used in the presence of herpes zoster	Hepatic microsomal enzyme inducers Estrogens NSAIDs Potassium-depleting drugs Anticholinesterase agents PO: anticoagulants, cyclosporine
Miscellaneous Baclofen Muscle relaxant	Various, Lioresal is an example: Tabs: 10, 20 mg IT inj: 0.05, 0.5, 2 mg/mL	PO: 2 hr	3–6.8 hr	Liver metabolism: limited Renal excretion: 69%–85% Feces: 10 %	5–20 mg PO bid–tid (max 120 mg/24 hr)	☺	Nausea/vomiting Sedation Dizziness Weakness Neuropsychiatric disturbances Genitourinary effects	CNS depressants
Belladonna and opium Anticholinergic + opioid Relief of pain related to smooth muscle spasm	Various: belladonna/opium: Supp 16.2/30 mg and 15/65 mg	NA	NA	Renal excretion: Belladonna 33%	1 PR q6h PRN	☺	Anticholinergic AE Photophobia Constipation Difficulty urinating Somnolence	Antacids Histamine H_2-receptor antagonists may interfere with absorption Amantadine Quinidine Haloperidol Phenothiazines MAOIs TCAs

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Bethanechol Cholinergic stimulant	Various, Urecholine is an example: Tabs: 5, 10, 25, 50 mg	NA	NA	Unknown	10–50 mg PO tid–qid, or 2.5–10 mg SC tid–qid	☺	Cholinergic stimulation, including sweating, salivation, flushing, decreased blood pressure, nausea, abdominal pain, diarrhea, bronchospasm	Anticholinergic drugs Atropine Quinidine Procainamide Sympathomimetics
Cyclobenzaprine Muscle relaxant	Various, Flexeril is an example: Tab: 5, 10 mg	PO: 3.9 hr	18 hr	Liver metabolism: extensive Renal excretion: 1%	20–40 mg daily in divided doses (max 60 mg/24 hr)	☺	Drowsiness Dry mouth Dizziness Fatigue Nausea/vomiting Confusion	TCAs MAOIs CNS depressants Anticholinergics
Cyproheptadine H_1-receptor antagonist	Various, Periactin is an example: Tab: 4 mg Syrup: 2 mg/5 mL	PO: 6–9 hr	16 hr	Liver metabolism: 57% Renal excretion: 40% Feces: 2%–20%	4–20 mg PO ÷ q4–6h (max 32 mg/24 hr)	2–4 mg bid–tid depending on age and weight (max 16 mg/24 hr)	Sedation Dizziness Confusion Nausea/vomiting Arrhythmias Hypersensitivity	CNS depressants ephedrine MAOIs
Dantrolene Muscle relaxant	Dantrium: Caps: 25, 50, 100 mg Inj: 20 mg/vial	PO: 4–8 hr	8.7 hr	Liver metabolism: 80% of the absorbed dose as metabolites	25–50 mg PO daily–qid	☺	Muscle weakness Slurred speech Drowsiness Dizziness Diarrhea Nausea/vomiting Malaise Hepatic effects	Verapamil CNS depressants

Dicyclomine Anticholinergic antispasmodic	Various, Bentyl is an example: Tabs: 10, 20 mg Syrup: 10 mg/5 mL Inj: 10 mg/mL	PO: 60–90 min	1.8 hr	Renal excretion: 79.5% Feces: 8.4%	10–20 mg PO tid–qid	☺	Anticholinergic AE	Antacids Slow K Levodopa Digoxin Phenothiazines Amantadine Antiparkinsonian agents Glutethimide
Flavoxate Smooth muscle relaxant	Urispas: Tab: 100 mg	Initial response PO: 55 min–2 hr	NA	Liver metabolism: Renal excretion: 57%	100–200 mg PO tid–qid	☺	Nausea/vomiting Dry mouth Headache Drowsiness Confusion	None significant
Fosphenytoin Antiepileptic injectable prodrug of phenytoin	Cerebyx: Inj: dosed as phenytoin equivalents	IM: 30 min IV: immediate (at end of infusion)	Conversion half-life of fosphenytoin to phenytoin is 15 min Phenytoin: 12–28.9 hr	Liver metabolism: to phenytoin which is metabolized extensively (95%) Bile excretion	IM, SC, IV Consult pharmacy for phenytoin equivalent determination	IM, SC, IV Consult pharmacy for phenytoin equivalent determination	Ataxia Diplopia Dizziness Nystagmus Confusion Drowsiness Hallucinations Cardiovascular effects Constipation Depression Gingival hyperplasia Hematologic effects Hepatic dysfunction Hypotension Megaloblastic anemia Nausea/vomiting Hypersensitivity Avoid in pregnancy	Amiodarone Mexiletine Quinidine Antihistamines Benzodiazepines Carbamazepine Valproic acid Cimetidine Chloramphenicol Corticosteroids Salicylates Cyclosporine Disulfiram Doxycycline Folic acid Isoniazid Rifampin Methadone Phenobarbital TCAs Trazodone Theophylline

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Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Hydroxyzine Histamine H_1-receptor antagonist	Various, Atarax, Vistaril are examples: Caps: 10, 25, 50, 100 mg Inj: 25 mg/mL, 50 mg/mL Syrup: 10 mg/5 mL	PO: 2 hr	3–20 hr Cetirizine: 25 hr	Liver metabolism: to cetirizine, active	25 mg PO tid–qid PO/IV	2 mg/kg/24 hr PO ÷ tid–qid	Drowsiness Dry mouth Dizziness Headache Nausea/vomiting Bitter taste in mouth	CNS depressants Anticholinergics Epinephrine
Meclizine Histamine H_1-receptor antagonist	Various, Antivert, Bonine are examples: Tab: 12.5, 25, 50 mg	Initial response: PO: 1 hr	6 hr	Liver metabolism: probable Renal excretion: Metabolites Fecal: unchanged drug	25–100 mg PO daily–qid	Use ½ the adult dose	Drowsiness Dry mouth Blurred vision	CNS depressants Anticholinergics
Methocarbamol Muscle relaxant	Various, Robaxin is an example: Tabs: 500, 750 mg Inj: 100 mg/mL	PO: 1–2 hr	0.9–2 hr	Liver metabolism: extensive	500 mg PO tid–qid (max 6000 mg/24 hr)	☺	Drowsiness Dizziness Headache Blurred vision Nausea/vomiting Hypersensitivity	CNS depressants Anticholinergics Pyridostigmine
Nifedipine Calcium-channel blocker Hiccups	Various, Adalat, Procardia are examples: IR tabs: 10, 20 mg ER tabs: 30, 60, 90 mg	PO IR: 20–45 min PO ER: 6 hr SL: 60 min	2–2.5 hr	Liver metabolism: extensive Renal excretion: 70%–80% Bile/Feces: 20%	Hiccups: 10–20 mg PO, SL q8h or 30–60 mg PO daily ER	Hypertension: 0.5 mg/kg/24 hr PO: ÷ q8h, increase as needed up to 1.5 mg/kg/24 hr	Dizziness Lightheadedness Headache Insomnia Palpitations Nausea/vomiting	Cimetidine Ranitidine Propranolol
Orphenadrine Muscle relaxant	Norflex: Tab: 100 mg Inj: 30 mg/mL	PO: 2–4 hr IM: 1 hr	13.2–20.1 hr	Liver metabolism: Renal excretion: 60%	60 mg IM, IV q12h or 100 mg PO bid	☺	Anticholinergic AE Nausea/vomiting Headache Drowsiness	Propoxyphene CNS depressants

Oxybutynin For relief of urinary urgency, frequency, leakage, incontinence associated with a neurogenic bladder	Various, Ditropan is an example: Tab: 5 mg Syrup: 5 mg/5 mL Oxytrol Transdermal 3.9 mg	PO: 1 hr TD: NA	1.1–2.3 hr	Liver metabolism: primary site Renal excretion: less than 0.1%	5 mg PO bid–tid (max dose 20 mg daily) 3.9 mg TD twice weekly	<5 yr: 0.5 mg/kg/24 hr PO ÷ qid >5 yr: 10–15 mg/24 hr ÷ bid–tid	Anticholinergic AE	None significant
Phenazopyridine Anesthetic to relieve dysuria	Pyridium: Tabs: 100, 200 mg	NA	NA	Liver Metabolism: Renal excretion: 65%	200 mg PO tid	☺	Orange or red urine Mild upper GI upset Other AE rare, including headache, transient acute renal failure, methemoglobinemia, hypersensitivity	None significant
Phenytoin Antiepileptic	Various, Dilantin is an example: Caps: 30, 100 mg Infatabs: 50 mg Suspension: 30 or 125 mg/5 mL Inj: 50 mg/mL	PO ER capsules: 4–12 hr IV with loading dose: 20–25 min	PO: 7–42 hr; value is variable due to the saturation kinetics IV: 10–15 hr	Liver metabolism: extent unknown Renal excretion: 2% Bile: most of the dose	Seizures, hiccups: start with 100 mg PO/IV tid and adjust to achieve therapeutic blood levels (monitor blood levels) (if the person is unable to swallow and IV access is not possible, parenteral solutions may also be administered PR) (see fosphenytoin)	6 mo–3 yr: 7–9 mg/kg/24 hr ÷ bid–tid 4–6 yr: 6.5 mg/kg/24 hr ÷ bid–tid 7–9 yr: 6 mg/kg/24 hr ÷ bid–tid 10–16 yr: 3–5 mg/kg/24 hr ÷ bid–tid	Ataxia Diplopia Dizziness Nystagmus Confusion Drowsiness Hallucinations Cardiovascular effects Constipation Depression Gingival hyperplasia Hematologic effects Hepatic dysfunction Hypotension Megaloblastic anemia Nausea/vomiting Hypersensitivity Avoid in pregnancy	Amiodarone Mexiletine Quinidine Antihistamines Benzodiazepines Carbamazepine Valproic acid Cimetidine Chloramphenicol Corticosteroids Salicylates Cyclosporine Disulfiram Doxycycline Folic acid Isoniazid Rifampin Methadone Phenobarbital TCAs Trazodone Theophylline

Table continued on following page

Table App–1–7 ▪ Other Medications Used in Palliative Care (Continued)

Generic name	Trade Name(s), Dosage Forms	Time to Maximal Drug Concentration	Elimination Half-Life	Route of Elimination	Adult Doses	Pediatric Doses	Adverse Effects	Common Interactions
Quinine sulfate For nighttime leg cramps	Various: Tab: 260, 325 mg	PO: 1–3.2 hr	4.1–11.1 hr	Renal excretion: 12%–30%	200–300 mg PO nightly PRN	☺	Headache Nausea/vomiting Tinnitus Confusion hypersensitivity	Mefloquine Cardiac glycosides Cimetidine
Simethicone Antiflatulent, particularly for gastric gas	Various combinations with antacids Tab: 80, 125 mg Susp: 40 mg/0.6 mL	Inert: not absorbed	NA	Feces: unchanged	As per antacid directions 40–120 mg PO qid PRN pc + hs (max daily dose = 500 mg)	See directions on bottle	None significant	None significant

2

Coding for Physician Services Related to Palliative Care*

Linda L. Emanuel

Coding for physician services, whether the patient is enrolled under the Medicare hospice benefit or receives health care services through other funding mechanisms, almost always uses the same coding technique. Physicians code for their service to an individual patient in two parts: a procedure or service code and a diagnosis code.

Procedure or Service Codes

The physician selects a procedure code from the Current Procedural Terminology (CPT) codes published by the American Medical Association. For physicians involved in palliative care, the most frequently used codes are the evaluation and management (E/M) codes (code range, 99201 to 99499). There are evaluation and management codes for each of the usual settings in which physicians provide services: ambulatory outpatient, acute inpatient hospital, extended care institutions, and patients' homes. Within each general category of codes (by setting) is a hierarchy of codes from least intensive to most complex.

The Health Care Financing Administration (HCFA) has promoted extensive guidelines for the documentation that must support the use of each of the E/M codes. Related to palliative care, a little-known and underappreciated provision of current E/M coding guidelines often applies. When more than 50% of the patient-physician interaction is composed of counseling and/or information giving, then *time* becomes the factor that determines the level of service that is coded. Because palliative care consultations and services often incorporate extensive amounts of information giving and/or counseling as part of the physician-patient interaction, then the time it takes to complete the activity determines which E/M code will be chosen. Each of the E/M codes is associated with a time element for this purpose. Table App–2–1 indicates current codes with an amount of time associated with each.

When time is used to determine which E/M code to use, the documentation must indicate that more than 50% of the interaction was related to counseling or information giving. In the inpatient setting, the time is defined as floor or unit

* This Appendix is taken, with permission, from The EPEC Curriculum (www.epec.net)

Table App–2–1 ▪ Summary of Some Current Procedural Terminology Evaluation/Management Codes

Attending/Managing Physician			
New/Office	**Established Hospital**	**Initial**	**Subsequent Hospital Office**
99201 10 min 99202 20 min 99203 30 min 99204 45 min 99205 50 min	99211 5 min 99212 10 min 99213 15 min 99214 25 min 99215 40 min	99221 30 min 99222 50 min 99223 70 min	99231 15 min 99232 25 min 99233 35 min
Nursing Home-C	**Nursing Home-F**	**Home New**	**Home Established**
99301 30 min 99302 40 min 99303 50 min 99344 60 min 99345 75 min	99311 15 min 99312 25 min 99313 35 min 99350 60 min	99341 20 min 99342 30 min 99343 45 min	99347 15 min 99348 25 min 99349 40 min
Prolonged Service Face to Face		**Prolonged Service Face to Face**	
Office/Home		**Inpatient**	
99354 30 min 99355 each subsequent 30 min		99356 30 min 99357 each subsequent 30 min	

time, which includes the time that the physician is present on the patient's hospital unit and at the bedside rendering services for that patient. This includes time in which the physician establishes and/or reviews the patient's chart, interviews and examines the patient, writes notes, and communicates with other professionals and the patient's family.

Physicians who provide palliative care may also report codes for specific procedures or tests that they may perform (e.g., anesthetic injections, paracentesis, and thoracentesis). The time required to provide these procedures or tests is not included in the time used to establish the appropriate E/M code.

AN EXAMPLE

You are asked to provide palliative care consultation for an 86-year-old former schoolteacher who has been admitted to the hospital for exacerbation of congestive heart failure. The attending physician would like advice on managing her dyspnea. You spend an hour on the unit reviewing the chart and interviewing/examining the patient and an additional 20 minutes writing your note and conferring with the attending physician. The majority (>50%) of your interaction with the patient was related to eliciting her values and care goals, clarifying her understanding of her diagnosis and prognosis, and giving information and counseling. You had some specific suggestions about the use of morphine to relieve her dyspnea.

You would code 99254 for this initial consultation in the hospital. In the note documenting the consultation, you would indicate the name of the referring

physician, the reason for the consultation, the recommendations for medical management of the dyspnea, the fact that the majority of the interaction was related to counseling and information giving, and a summary of the situation and the information around which counseling or information giving was required. The note should indicate that the total time spent on the consultation, including the time spent in documentation and discussing the case with the referring physician, was 80 minutes.

Diagnosis Codes

Besides the CPT code, the physician describes the reason for the service by using one of the International Classification of Disease–Clinical Modification (ICD-9-CM) codes promulgated by the National Center for Health Statistics (NCHS). These diagnosis codes are published by several publishers, including the American Medical Association. The ICD-9-CM book contains not only disease codes but also many symptom codes. A few examples are indicated in Table App–2–2.

Many physicians, particularly internists, are concerned about reimbursement for concurrent care; that is, if they see a patient on the same day as another internal medicine specialist or subspecialist, only one of them will have their services reimbursed. In October 1995, the HCFA published new rules that permit concurrent care by two or more physicians on the same day, even if they are of the same specialty. To describe the legitimate differences in evaluation and management services

Table App–2–2 ■ Some Common International Classification of Disease–Clinical Modification (ICD-9) Codes Physicians May Use in Palliative Care*

Anorexia	783.0	Inanition	263.9	Pain: unspecified	780.9
Agitation	307.9	Mental status change	780.9	Pain: abdomen	789.0
Anxiety	300.0	Nausea	787.02	Pain: arm	729.5
Confusion	298.9	Nausea and vomiting	787.01	Pain: back	724.5
Coma	780.01	Vomiting	787.03	Pain: bone	733.90
Cough	786.2	Weakness	780.7	Pain: chest	786.50
Debility	799.3	Weight loss	783.2	Pain: foot	729.50
Dementia	298.9	Shortness of breath	786.09	Pain: hip	719.45
Dyspnea	286.6	Unconscious	780.09	Pain: leg	719.45
Depression	311			Pain: muscle	729.1
Delirium	780.09			Pain: sacroiliac	724.60
Diarrhea	558.9			Pain: throat	789.1
Fatigue	558.9			Pain: neck	723.1
Fever	780.6				
Headache	784.0				
Hemorrhage	459.0				

From Emanuel LL, von Gunten CF, Ferris FD (eds): The Education in Palliative and End-of-Life Care (EPEC) Curriculum: EPEC Project, 1999, 2003. Available at www.epec.net

*Refer to the full tabular list of ICD-9-CM codes to ensure coding at the highest degree of accuracy.

that multiple physicians may provide to a single patient, physicians need to use different ICD-9-CM codes for diagnosis as appropriate.

AN EXAMPLE

For the 86-year-old woman with congestive heart failure described earlier, if both her general internist and the palliative care specialist use the ICD-9-CM code for congestive heart failure, only one submission for reimbursement is likely to be accepted, and the other will probably be denied. However, if you are being consulted for advice related to management of shortness of breath, you would use the ICD-9-CM diagnosis code for dyspnea (286.6).

Reimbursement for Physician Services Related to Palliative Care

MEDICARE HOSPICE BENEFIT BACKGROUND

The Medicare hospice benefit was established in 1982 to pay for hospice services at home for Medicare beneficiaries. Provision is also made for brief periods of inpatient services. A patient is eligible to elect the Medicare hospice benefit if the patient is confirmed by two physicians to have a prognosis of 6 months or less if the disease follows its usual course. The patient must acknowledge the terminal nature of the illness and must sign election forms that indicate that care will be directed toward comfort, not cure of the disease. When a patient elects the Medicare hospice benefit, care for the patient that is related to the terminal illness is the direct responsibility of the hospice program. The benefit pays 100% for intermittent nursing, social work, chaplain, nurse aide, physical/occupational therapy, medication and therapy related to the terminal illness, and durable medical equipment. The hospice agency receives a per diem rate to cover these costs. This rate is set by the federal government and is not influenced by the particular treatments or services that the patient receives. As such, it is an example of capitated medical care. Many commercial payers have adopted similar approaches to covering home hospice care. If a patient needs medical care that is not related to the terminal illness, then that care can be provided and reimbursed by standard Medicare mechanisms. It is the responsibility of the hospice physician to determine whether care is related or unrelated to the terminal illness.

PAYMENT AND CODING FOR PHYSICIAN SERVICES UNDER THE MEDICARE HOSPICE BENEFIT

Administrative/Supervisory Activities

As a part of the benefit, the services of the hospice medical director that relate to the administrative and general supervisory activities of the hospice are included in the per diem rate. "These activities include participating in the establishment, review, and updating of plans of care, supervising care and services and establishing governing policies" (Medicare Regulations, Section 406). Therefore, the medical director should expect his or her administrative services to be reimbursed from the hospice program in addition to fee-for-service billing for direct patient care.

Direct Physician Services to Medicare Hospice Patients

Physician services related to direct patient care under the Medicare hospice benefit are not covered as part of the per diem rate. Any physician who provides direct care, whether the hospice medical director or other physicians caring for the patient, needs to code for his or her services separately. The precise mechanism for reimbursement depends on whether or not the physician is associated with the hospice program, either as an employee or as a volunteer.

Attending Physician, Not Associated with Hospice

At the time the patient elects the Medicare hospice benefit, the patient indicates who his or her attending physician will be. The attending physician for the patient who is not associated with the hospice continues to code for physician services using CPT and ICD-9-CM as described earlier and submits bills for reimbursement to Medicare under Part B (the federal Medicare program that funds physician services from payments made by beneficiaries). However, for paper claims, the physician must indicate on the HCFA-1500 claim form that he or she is the attending physician and not an employee of the hospice program caring for the patient when each claim is submitted. If this statement is not present, the services are likely to be denied. For physicians who submit bills electronically (EMC), an HC modifier must be appended to the CPT code. The fiscal intermediary will then telephone the physician's office for further information. When the carrier calls, the information they need is this: "This is a hospice patient; Dr. X is the attending physician and is not employed by the hospice."

Attending Physician Associated with Hospice

If the attending physician is associated with the hospice agency (e.g., medical director or hospice physician), as a salaried employee or even as a nonsalaried volunteer, then codes for physician services are submitted to the hospice agency and are submitted by the agency to Medicare under Part A (the federal Medicare program that covers institutional and nonphysician services funded by payroll deductions). This is a marked departure from other standard approaches to coding and billing for physician services. The hospice agency submits these bills and is paid at 100% of the usual and customary fee reimbursed under Medicare Part B schedules. The hospice agency then can pass this reimbursement on to the physician as part of his or her negotiated salary or fee-for-service arrangement.

Consulting Physicians

Consulting physicians who are asked to see the patient by the attending physician can also submit claims for the services they have provided to patients who have elected the Medicare hospice benefit. However, they must submit their code claims directly to the hospice agency, which, in turn, submits the claims for reimbursement under Part A. The consultants must have a contract with the hospice agency for this to occur.

PAYMENT AND CODING FOR PHYSICIAN SERVICES OUTSIDE THE MEDICARE HOSPICE BENEFIT

Hospice under Medicaid/Public Aid

Hospice care is reimbursed by many states for their indigent patients. The Medicaid and public aid budgets are administered by individual states, not the federal government. However, most states have adopted HCFA/Medicare guidelines for patients who are receiving hospice care. Consequently, the coding guidelines outlined for the federal Medicare hospice benefit also apply. In state-managed programs, it is important that practitioners become familiar with the rules and regulations in the individual states in which they are practicing.

Private Insurance

Most commercial payers (i.e., health plans, insurance companies) require physicians to code for their services by means of CPT and ICD-9-CM codes. Physicians code and submit their claims for reimbursement regardless of whether a patient is covered by a hospice benefit. Again, specific regulations regarding coding may apply for an individual payer. Information on these rules should be obtained before claims are submitted.

Palliative Care Services for Patients under Medicare

Physicians may see patients for purposes of delivering palliative care services when they are still covered under Medicare. Use the coding procedures outlined in the first part of this document and submit them to the Medicare fiscal intermediary in your area in the usual way.

Funding for Nonphysicians Providing Palliative Care Services

Under the Medicare hospice benefit, the per diem fee covers all services of nonphysician health care professionals who provide care to the patient and family. However, patients who are not eligible or appropriate for enrollment under the Medicare hospice benefit may have legitimate needs for interdisciplinary palliative care services. The challenge is how to pay for the nonphysician component of such services. Many health care professionals, such as nurse practitioners, clinical nurse specialists, social workers, and chaplains, can access fee-for-service billing for patients not enrolled in the Medicare hospice benefit. In many settings, this has not been explored but is available. More commonly, these services are included as part of a larger program of services. For example, when a patient is hospitalized, the hospital reimbursement rate includes nursing, social work, and chaplaincy services.

Consultation

A consultation is a type of service provided by a physician whose opinion or advice regarding evaluation and/or management of a specific problem is requested by another physician or other appropriate source. A physician consultant may initiate diagnostic and/or therapeutic services. The request and the need for consultation

must be documented in the medical record. The opinion and any services ordered or performed must also be documented. A "consultation" initiated by a patient and/or family but not requested by a physician should be reported by means of the codes for confirmatory consultation or office visits, as appropriate. *The follow-up codes should not be used* if the consultant assumes responsibility for management of a portion, or all, of the patient's condition (Table App–2–3).

Table App–2–3 ■ Coding for Consultations

Office/Home	Initial Hospital	Follow-up Hospital	Confirmatory
99241 15 min	99251 20 min	99261 10 min	99271
99242 30 min	99252 40 min	99262 20 min	99272 Low severity
99243 40 min	99253 55 min	99263 30 min	99273 Moderate severity
99244 60 min	99254 80 min		99274 Moderate to high
99245 80 min	99255 110 min		99275 Moderate to high

3 Resources for Palliative and End-of-Life Care

S. Lawrence Librach

Guidelines for the Use of this List

1. These Web sites have been visited, and information on them may be appropriate for patients, their families, and care providers.
2. Before recommending a site to patients, it would be prudent to visit the site and see the information available on it.
3. Many good downloads are available on the sites listed.

Agency for Healthcare Research and Quality

www.ahrq.gov/

The Agency for Healthcare Research and Quality is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, and broaden access to essential services.

ALS Association

www.alsa.org

A special section designed for health care workers contains information about new treatments, drugs, and clinical trials and provides access to brochures, books, and videos that health care workers can offer to their patients. There is a wealth of information on the site in general about amyotrophic lateral sclerosis as well as a special section for patients, their families, and caregivers in general.

American Academy of Hospice and Palliative Medicine

www.aahpm.org

The American Academy of Hospice and Palliative Medicine is an organization for physicians who are committed to furthering and fostering the practice of hospice and palliative care for the terminally ill and their families.

American Academy of Pain Management

www.aapainmanage.org

This resource provides the names of credentialed pain practitioners and pain management programs by zip code. It offers direct access to the National Pain Data Bank for outcome measurement, provides links to other pain-related sites, and has information about the agenda for the annual clinical conference in September of each year.

American Academy of Pain Medicine

www.painmed.org/

The mission of the American Academy of Pain Medicine is to provide for high-quality care to patients suffering with pain, through the education and training of all physicians, through research, and through the advancement of the specialty of pain medicine.

American College of Physicians–American Society of Internal Medicine

www.acponline.org/index.html

The American College of Physicians–American Society of Internal Medicine is a medical specialty society designed to enhance the quality and effectiveness of health care by fostering excellence and professionalism in the practice of medicine.

American Geriatrics Society

www.americangeriatrics.org/

The American Geriatrics Society is a professional organization of health care providers dedicated to improving and effecting change for the health and well-being of all older adults.

American Hospice Foundation

www.americanhospice.org

This site provides links to other hospices, palliative care organizations, and foundations all over the United States. It also has specific tools and resources that explore legal issues and a section geared specifically toward helping grieving children and teenagers.

American Medical Association

www.ama-assn.org

The American Medical Association is a membership organization of physicians. It serves as the patient's advocate, sets standards for the profession of medicine, medical education, policy matters, and much more.

American Pain Society

www.ampainsoc.org

The American Pain Society is a nonprofit multidisciplinary educational and scientific organization dedicated to serving people in pain, through research, education, treatment, and professional practice.

American Society for the Advancement of Palliative Care

www.asap-care.com

The American Society for the Advancement of Palliative Care is a personal effort to help expedite the reform of terminal health care practice.

American Society for Bioethics and Humanities

www.asbh.org

This professional society is composed of individuals, organizations, and institutions interested in bioethics and humanities.

American Society of Law, Medicine and Ethics

www.aslme.org

This organization provides high-quality scholarship, debate, and critical thought to the community of professionals at the intersection of law, health care, policy, and ethics.

Americans for Better Care of the Dying: ABCD

www.abcd-caring.org

ABCD is a nonprofit coalition of citizens and professionals united to ensure that public policy addresses the needs of individuals and families coping with a fatal illness.

Approaching Death: Improving Care at the End of Life

www2.nas.edu/hcs/21da.html

This report, from a committee of the Institute of Medicine, calls for changes to improve end-of-life care, better training of health care professionals, reform of outdated laws that inhibit the use of pain-relieving drugs, and testing of new payment options.

Association of Cancer Online Resources, Inc.

www.medinfo.org

The Association of Cancer Online Resources, Inc. is a nonprofit patient advocacy organization founded to develop, support, and represent Internet-based resources providing high-quality, up-to-date information and support to patients

with cancer and to provide open communication channels between and among patients, health professionals, and research scientists.

Better Health

www.BetterHealth.com/

Better Health is an online interactive forum offering support and help on a variety of medical concerns and conditions.

Biomed Central

www.biomedcentral.com/bmcpalliatcare

This free online journal offers limited numbers of articles but has a search function.

Brave Kids

www.bravekids.org

This is an excellent network of links to books, videos, Web sites, and services for parents of children with chronic life-threatening illnesses. Separate message boards are available for both the parents and the children themselves. A handy search is available at the top that is organized by resource type, disease, or condition.

Canadian Hospice Palliative Care Association

www.chpca.net

The Canadian Hospice Palliative Care Association is the national association in Canada for hospice palliative care. The site provides important information about Canadian palliative care and its programs. It has a marketplace function and a number of resources available for patient and care provider information.

Canadian Virtual Hospice

www.virtualhospice.ca

This new resource is intended for health care professionals, patients, family, and palliative care workers. The information available for patients and family is sensitive but addresses key issues. Some online advice is available but not to care providers in the United States.

Cancer Net

www. cancernet.nci.nih.gov/

Cancer Net is a wide range of accurate, credible cancer information from the National Cancer Institute. The comprehensive cancer database includes summaries on cancer treatment, screening, prevention, and supportive care as well as information on ongoing clinical trials.

Caregiver Network

www.caregiver.on.ca

Based in Toronto, Canada the goal of the Caregiver Network is to be a national single information source to make your life as a caregiver easier.

Caregiver Survival Resources

www.caregiver911.com/

Caregiving is becoming a significant issue for many people. This resource provides help to others to cope with the demands of caregiving.

Caring Connections

www.caringinfo.org

This is a resource for health care professionals to offer patients and families. There are sections on advanced care planning, financial planning, grief, caregiving, pain, and hospice. The site contains an extensive amount of information on each of these topics as well as many external links to other useful resources.

Catholic Health Association of the United States

www.chausa.org

Roman Catholic–sponsored health organizations provide the aged and chronically ill population with a broad spectrum of high-quality professional services.

Center for Medical Ethics and Mediation

www.wh.com/cmem

The Center for Medical Ethics and Mediation is an educational association dedicated to providing high-quality training, research, consultations, and mediations for health care professionals and organizations.

Center to Advance Palliative Care

www.capc.org

The Center to Advance Palliative Care is dedicated to increasing the availability of high-quality palliative care services in hospitals and other health care settings for people with life-threatening illnesses, their families, and caregivers.

Center to Improve Care of the Dying

www.gwu.edu/~cicd

This organization consists of an interdisciplinary team of committed individuals engaged in research, public advocacy, and education activities to improve the care of the dying and their families.

Centers for Disease Control and Prevention

www.cdc.gov/

The mission of the Centers for Disease Control and Prevention is to promote health and quality of life by preventing and controlling disease, injury, and disability.

Children's Hospice International

www.chionline.org

This is a resource for hospice services globally and in the United States for services specific to children. It has several books for adults regarding children's death and dying and some especially for children. Membership is available at a minimal fee.

Choice in Dying

www.echonyc.com/~choice/

This nonprofit organization provides advance directives, counsels patients and families, trains professionals, advocates for improved laws, and offers a range of publications and services.

Chronicle of Philanthropy

www.philanthropy.com/

This is the newspaper of the nonprofit world.

Clinical Care Options–HealthCare Communications Group

www.healthcg.com/

This is a state-of-the-art medical resource for health care professionals.

Commonwealth Fund

www.cmwf.org/index.html

The Commonwealth Fund engages in independent research on health and social policy issues.

Death, Dying, and Grief Resources

www.katsden.com/webster/index.html

This Web site represents a large and comprehensive collection of Internet resources with a holistic perspective of the death process.

Department of Health and Human Services, Healthfinder

www.healthfinder.gov

Healthfinder is a consumer health and human services information Web site that links to selected online publications, Web sites, and not-for-profit organizations.

Dying Well

www.dyingwell.com/

By defining wellness through the end of life, this Web site provides resources for patients and families facing life-limiting illness.

Edmonton Regional Palliative Care Program

www.palliative.org

The site makes available clinical assessment tools, clinical practice guidelines, and a useful section on practical solutions for common problems in the terminally ill. A very useful palliative care manual contains chapters on pain management, mood disorders, confusion, eating disorders, and many other common symptoms encountered in palliative care. The site also contains a PDF version of a very useful document entitled *Alberta Hospice Palliative Care Resource Manual.*

Education in Palliative and End-of-life Care Project

www.epec.net

The Education in Palliative and End of Life Care Project is a national education program that is based on a train the trainer model. Modules are available on-line for a fee. Special programs in oncology and emergency medicine have been developed.

End-of-Life Care for Children

www.childendoflife.org

This site provides easy to access videotaped interviews with doctors, nurses, and parents who share their experiences and answers questions about the death of a child. An "active glossary" defines terms as the reader peruses each section. There is an option to download a printable version of the majority of the content of theWeb site. The Web site contains extensive resources detailing the health care professional's role in the death of a child in terms of both medical care and psychological support of the child and the family. The Web site also contains resources that openly discuss the feelings that may arise in a health care professional during the dying process of a child.

End of Life/Palliative Education Resource Center

www.eperc.mcw.edu

The purpose of this organization is to assist physicians and other educators involved in all aspects of physician end-of-life education through: Brief abstracts describe peer-reviewed instructional and evaluation materials. A list of core resources is available for end-of-life educators and opportunities for training, extramural funding, and pending conferences. Educational materials can be submitted for peer review and potential inclusion on the site.

Epocrates

www.epocrates.com

This site is partly commercial. Free entry allows access to and downloading to a PDA of an extensive list of drugs and alternative medications. The site explains adult dosing, pediatric dosing, drug interactions, contraindications and adverse reactions. The premium edition is available for a fee.

Foundation Center

fdncenter.org/index.html

This center collects, organizes, analyzes, and disseminates information on foundations, corporate giving, and related subjects.

Foundation For Accountability

www.facct.org/

This organization works to ensure that Americans have clear, accurate information about quality that they can use to make better health care decisions.

Growthhouse

www.growthhouse.org/

This Web site is an international gateway to resources for life-threatening illness and end-of-life issues.

Hospice and Palliative Nurses Association

www.hpna.org

This organization provides information and courses about pain management, caring for dying people. The site also has many links to hospices and care centers in the United States.

Hospice Net

www.hospicenet.org

This site is useful for the general public, including family, friends, and dying persons themselves. It contains a section geared specifically addressing concerns about how to live with the diagnosis as well as pain management issues. It also includes a section on explaining death to young children and specific ways of dealing with grief in children, as well as an exhaustive general description of hospice.

Ian Anderson Continuing Education Program in End of Life Care

www.cme.utoronto.ca/endoflife/

Thirteen modules on end-of-life care for health care provider education include cases. The download is free and includes teaching points and slides.

International Association for the Study of Pain

www.iasp-pain.org

This organization is open to scientists, physicians, dentists, psychologists, nurses, physical therapists, and other health professionals actively engaged in pain research and to those who have an interest in the treatment of pain.

Medicare Rights Center

www.medicarerights.org

The Medicare Rights Center provides free counseling services to Medicare beneficiaries who cannot afford private assistance for Medicare-related issues.

Nathan Cummings Foundation

www.nathancummings.org

The Nathan Cummings Foundation seeks to build a society that values nature and protects ecological balance for future generations, promotes humane health care, and fosters arts to enrich communities.

National Association for Home Care

www.nahc.org/

This organization is committed to serving the home care and hospice industry, which provides services to the sick, the disabled, and the terminally ill in the comfort of their homes. Information is provided about details of hospice and home care in the United States including what it is, who provides it, how it is paid for, and what can be done if you have a problem with the services.

National Center for Health Statistics

www.cdc.gov/nchs

The National Center for Health Statistics provides statistical information that will guide actions and policies to improve the health of the people of the United States.

National Conference of State Legislatures

ncsl.org/programs/pubs/endoflife.htm

The National Conference of State Legislatures report helps state lawmakers to make informed decisions regarding assisted suicide, pain management, and other end-of-life care policies.

National Family Caregivers Association

www.nfcacares.org/

This organization is predicated on the belief that caregivers who choose to take charge of their lives, and who see caregiving as but one of its facets, are in a position to be happier and healthier individuals.

National Hospice and Palliative Care Organization

www.nhpco.org/

Founded in 1978, the National Hospice and Palliative Care Organization is the oldest and largest nonprofit public benefit organization devoted exclusively to hospice care. It is dedicated to promoting and maintaining high-quality care for terminally ill persons and their families and to making hospice an integral part of the health care system in the United States.

National Institute on Aging

www.nih.gov/nia/

The National Institute on Aging promotes healthy aging by conducting and supporting biomedical, social, and behavioral research and public education.

OncoLink

www.oncolink.com

The University of Pennsylvania Cancer Center provides easy access to a wide variety of cancer resources including current clinical trials, financial issues for patients, and more.

Oregon Health Sciences University Center for Ethics in Health Care

www.ohsu.edu/ethics/

The Center for Ethics combines the perspectives of health professionals, patients, and families to improve teaching, research, and clinical consultation about ethical issues in patient care and health policy.

Palliative.info

www.palliative.info

This site offers an organized, up-to-date collection of links to palliative care resources on the internet, as well as locally developed palliative care materials.

Palliative Care Australia

www.pallcare.org.au

This site provides a range of information, including general standards for providing palliative care, palliative care for children and teenagers, and palliative care for the aged. It offers free online access to a book called *Journeys,* which is

an excellent resource for families and caregivers about palliative care for children and teenagers.

PalliativeDrugs.com

www.palliativedrugs.com

This free site requires the user to register. It has a monthly e-newsletter. It is searchable for drugs, but it has a definite UK flavor.

Pediatric Pain: Dalhousie University

pediatrics.medicine.dal.ca/clinical/palliative.htm

This site provides professional, research, and self-help resources for health care workers, researchers, and parents caring for children in pain.

Project on Death in America

www.soros.org/death/

The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts and to foster innovations in the provision of care, public education, professional education, and public policy.

Resource Directory for Older People

www.aoa.dhhs.gov/aoa/dir/intro.html

This resource serves older people and their families, health and legal professionals, social service providers, and others with an interest in the field of aging.

Robert Wood Johnson Foundation

www.RWJF.org

This foundation, the nation's largest philanthropic group devoted exclusively to health and health care, has made more than $2 billion in grants.

SeniorScape

www.seniorscape.com/

SeniorScape is a source for information on elder law, community resources for elders, senior health and nutrition, lobbying efforts, geriatric care, financial management in later years, and much more.

Stoppain.org (Beth Israel Hospital)

www.stoppain.org

Various Powerpoint presentations, including a script for the presenter, can be downloaded about pain management and can be altered to fit specific needs.

Numerous online continuing medical education modules are available for physicians and for registered nurses after a quick and free registration process. Some very useful links are also on the Web site, including one to a manual outlining clinical practice guidelines for quality palliative care.

University of Wisconsin Pain and Policy Studies Group

www.painpolicy.wisc.edu

This group studies public policy in relation to pain management and identifies and addresses the barriers to medical use of opioid analgesics.

When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context

www.health.state.ny.us/nysdoh/provider/death.htm

The New York State Task Force on Life and the Law published a 217-page report entitled *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context,* which has been made available electronically.

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