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Psychosocial Issues in Palliative Care

A COMMUNITY BASED APPROACH FOR LIFE LIMITING ILLNESS

THIRD EDITION

EDITED BY MARI LLOYD-WILLIAMS

WITH A FOREWORD BY Stein Kaasa

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A community-based approach for life-limiting illness

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Edited by

Mari Lloyd-Williams
Professor and Consultant in Palliative Medicine
Academic Palliative and Supportive Care Studies Group
University of Liverpool

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To my parents, sister, husband, children and friends for all their love,
care, support and guidance and for forgiving me for probably spending
far too much time on my work.

Foreword

The discipline of palliative care is primarily focusing on the patient who has the disease –whether it be cancer or other chronic diseases. It is crucial to take psychosocial issues into consideration in order to deliver optimal palliative care. The patient centered approach ought to be combined with a disease centered approach in order to deliver optimal care. This combined approach is expected from the patients, the family and from the society.

Most textbooks in medicine focus mainly on the disease approach. The approach is well covered, including new knowledge about the pathology, the epidemiology, the diagnosis and the treatments of the disease. However, knowledge and competence in psychosocial issues are needed in order to combine the disease and patient centered approach; this combination is seen in "early integration of palliative care".

Already in 2002 WHO changed some of the content of their definition of palliative care. It clearly states some fundamental issues related to organization, content and competence in palliative care:

- For patients and families "facing the problems associated with life threatening illness"
- From an organizational perspective: "palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life."
- It should be performed "through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment"
- It constitutes a broad approach to the patients "assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

Four main issues are debated today with background in the content of the WHO definition. These issues are also relevant for the need of psychosocial care:

- Integration of palliative care early in the disease trajectory
- A correct use of diagnostic tools , and methods to identify patients in need of treatment
- Family involvement – a life threatening disease will also have impact on the family
- Patients with life threatening diseases are often suffering from several symptoms and signs in parallel of physical, psychosocial and spiritual nature.

Psychosocial issues in palliative care is content wise one of the main pillars of modern palliative care.

This book covers main areas of psychological and social care. Many of the chapters give excellent updates, and more than that; the book is discussing fundamental approaches to patient care and health care. The need for a community based approach is necessary in order to reach a basic goal in palliative care – to give the patients the possibility to stay at home as much and long as possible, and to die at home if desired. The latter goals will probably need to be facilitated by involving end of life care in community care as well as a part of the national public health policies. This book is therefore highly relevant for clinicians in general and even more for palliative care specialist.

Preface

I feel privileged to be writing a preface to the third edition of 'Psychosocial Issues in Palliative Care: A community based approach', and to be editing an edition that truly reflects the huge changes that have taken place in palliative care since the first edition was being prepared for production in 2002.

In 2002, palliative care was still a fairly new speciality and unheard of by many people including clinicians. At that time the definition of palliative care was as it is now, but the reality was that palliative care was confined in the vast majority of cases to those dying of cancer.

In the last fifteen years we have seen a much needed shift in understanding and acceptance that palliative care can offer so much to patients living with all life limiting conditions and provide much needed support for their families. This new edition contains chapters exploring neonatal palliative care to supporting usually older patients living with dementia and frailty.

The global increase in longevity brings with it increasing demands on health and social care and the realisation that what many people need within our communities is a compassionate neighbour who is there to support, help and guide and by empowering volunteers to work alongside health and social care professionals within communities, palliative care in its broadest sense can be extended to more people with a possible reduction in demand for professionally provided health and social care as a consequence. The pioneering work of Suresh Kumar in Kerala shows clearly how community volunteers can deliver total palliative care within their community.

However much still needs to be done—the majority of those training in health and social care will have some exposure to palliative care, yet we still have situations where palliative care is not considered or considered too late to make a difference and where families are distressed and humiliated by the care, or lack of care given to family members in the last days and weeks of life. Yes, this lack of care is often due to palliation of physical symptoms but frequently also due to the lack of consideration and attempt to palliate the myriad of psychosocial aspects that make for good palliative care not only at the end of life but to all those living with life-limiting illness. It is with all of these situations in mind that the third edition of Psychosocial Issues in Palliative Care: A community based approach has been written and the aim is that the book is accessible to patients, families, volunteers as well as health and social care professionals.

Within this book there are a number of colour plates which are the work of people who attend the Waen Outreach Day Care, near St, Asaph in North Wales. In 2011, a group of volunteers linked with a very small welsh chapel, decided to try to help and support those in their rural community who due to illness or older age had become isolated. Support is offered to all in need and from the first day in June 2011 when precisely two people attended (and were cared for by four volunteers!), it has grown to offer two days a week of day care to an average of fifteen people each day, all supported by volunteers with no paid staff, and has also extended to a practical befriending service supporting those living with life limiting illness but who are too unwell to leave their homes.

In 2012–2013, the group were able to have an accomplished artist, Rhian Catrin Price to attend the group weekly and to support people with Dementia, Cancer and many other life-limiting conditions, along with some family members to use art as a way of expressing thoughts and feelings and to have fun and laughter as they painted and developed their ideas. The project culminated in an exhibition in 2012 and Waen Outreach is delighted that Rhian still inspires and encourages the day care groups in addition to those at home as part of the befriending service, to gain so much from art in all its forms. I am humbled to be able to include this art work and particularly grateful to Mrs Hafwen Roberts, Henllan, who has very kindly allowed her wonderful art work to be used as the cover for this third edition.

I am very grateful to so many people for their support and guidance for this third edition. My research team at the Academic Palliative and Supportive Care Studies group have helped shaped its format; the service users who are engaged in our research programme gave perspectives and insights on what aspects would be invaluable for patients and family carers; all the contributors who so kindly agreed to write a book chapter in addition to hugely busy timetables and for delivery the chapters on time and to all my clinical colleagues and academic colleagues at the Hospice and the University of Liverpool who are so ready to give wise counsel and advice on many aspects of this book.

Despite a busy academic workload, I consider myself first and foremost a clinician and it is in my weekly clinics that I learn so much about what did and what would make a difference to the patients' care. To all my patients who over the years have taught me so much and compelled me to strive for excellence in academic and clinical psychosocial care, I give my heartfelt thanks.

Professor Mari Lloyd-Williams
Professor and Director of Academic Palliative and Supportive Care Studies
Group, University of Liverpool and Consultant in Palliative Medicine

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Contributors

Paula Abramson
Head of Training, Child Bereavement UK, Saunderton, UK

Rosangela Caruso
Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, School of Medicine, University of Ferrara, and University Hospital Psychiatry Unit University Hospital and Health Trust, Ferrara, Italy

Mark Cobb
Clinical Director of Professional Services, Sheffield Teaching Hospitals NHS Foundation Trust, UK

Luigi Grassi
Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, School of Medicine, University of Ferrara, and University Hospital Psychiatry Unit University Hospital and Health Trust, Ferrara, Italy

Karen Harrison Dening
Head of Research and Publications, Dementia UK, London; Honorary Research Fellow, University of Liverpool, and Honorary Assistant Professor, School of Health Sciences, University of Nottingham, UK

Nigel Hartley
Chief Executive Officer, Earl Mountbatten Hospice, Isle of Wight, UK

Matthew Hotopf
Director, NIHR Maudsley Biomedical Research Centre, South London and Maudsley NHS Foundation Trust, and Professor of General Hospital Psychiatry, Institute of Psychiatry Psychology and Neuroscience, King's College London, and Honorary Consultant Liaison Psychiatrist, St Christopher's Hospice, UK

Aliki Karapliagou
Associate Fellow, Faculty of Health Sciences, University of Southampton, and Research Fellow in Applied Health Research, Faculty of Health Studies, University of Bradford, UK

Allan Kellehear
50th Anniversary Professor (End of Life Care) and Academic Director for the Digital Health Enterprise Zone (DHEZ—Academic), Faculty of Health Studies, University of Bradford, UK

David W. Kissane
Professor and Chair, Department of Psychiatry, School of Clinical Sciences at Monash Health, Monash University, Victoria, Australia, and Professor of Psychiatry, Weill Medical College of Cornell University and Memorial Sloan-Kettering Cancer Center, New York, NY, USA

Philip J. Larkin
Professor of Clinical Nursing (Palliative Care), UCD School of Nursing, Midwifery and Health Systems and Our Lady's Hospice & Care Services, and Associate Dean for Taught Graduate Studies, UCD College of Health Sciences, Dublin, Republic of Ireland

Wendy Lichtenthal
Assistant Attending Psychologist and Director, Bereavement Clinic, Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

Alexandra Mancini
Pan London Lead Nurse for Neonatal Palliative Care, Chelsea and Westminster Foundation Trust, London and The True Colours Trust

Allison M. Marziliano
Pre-doctoral Fellow, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY, USA

Susan McClement
Professor, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, Canada

Linda McEnhill
Head of Supportive Care, St Joseph's Hospice, London, UK

Maria Giulia Nanni
Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, School of Medicine, University of Ferrara, and University Hospital Psychiatry Unit University Hospital and Health Trust,
Ferrara, Italy

Holly G. Prigerson
Professor of Sociology in Medicine, Joan and Sanford I. Weill Department of Medicine, Weill Cornell Medical College, New York, NY, USA

Genevieve Thompson
College of Nursing, Rady Faculty of Health Sciences
University of Manitoba
Winnipeg, Manitoba, Canada

Klaus Wegleitner
Assistant Professor, Institute for Palliative Care and Organizational Ethics, Faculty of Interdisciplinary Research and Continuing Education (IFF Vienna), University of Klagenfurt, Austria

Chapter 1

The public health end-of-life care movement: history, principles, and styles of practice

Aliki Karapliagou, Allan Kellehear,
and Klaus Wegleitner

Introduction to the public health end-of-life movement

This chapter provides an introduction to a growing professional movement in end-of-life care that specifically aims to address the *social* dimensions of care and revises our understandings of community action. Most palliative care activity is based upon direct service provision and face-to-face professional encounters with medical, nursing, and allied health professions. The idea of the 'social' has often been subsumed under the idea of psychosocial care. However, in this style of psychosocial care health services merely work with social care services—it is care understood as care by the professions and not as community care in all its civic dimensions. Other community work has so often been defined and confined to actions by hospice volunteers.

Public health ideas have been adopted by a diverse and international range of palliative care programmes for many years now but both their theoretical origins and practice strategies remain poorly understood, or worse, misunderstood. In the following discussion we provide some background to the public health end-of-life care movement encapsulated by the framework known as *Compassionate Cities*, a description of some of its basic principles, and a brief outline of the main practice approaches and challenges associated with this new approach to social care at end of life. We begin with some historical and conceptual background and then discuss the major forms of social actions that have arisen from palliative care that have reflected these principles in some form or another.

Modern public health: from disease management to health in all policies

All public health concerns itself with health on a population level. It involves the application of scientific knowledge upon organized efforts to improve the health of citizens. Public health as a discipline in its own right was established during industrialization, when a rapid process of urbanization led to the overcrowding of modern cities. Poverty and the lack of sanitary measures and hygiene led to contamination risks, and the spread of infectious diseases, such as cholera, tuberculosis, and malaria epidemics. Public health aimed to alleviate those risks, improve health, and restore economic productivity.

A set of measures (Poor Laws) were taken to support those who could not work due to ill health, and investigations on the causes of disease took place. At this stage, poverty was linked to ill health for the first time, but it was believed that disease causes poverty, rather than poor health being the outcome of social conditions and living standards (Hamlin, 1994). The value of preserving the health of citizens through the application of scientific knowledge and civic mobilization was justified in terms of the financial benefits of improved health for industries and national economies.

The legislative development and sanitary reform that ensued led to dramatic changes. Since the middle of the nineteenth century, control over contagion was achieved, and mortality rates significantly reduced. One of the main achievements of the first wave of public health development was its ability to integrate different sets of knowledge emerging from life sciences (bacteriology, physiology, and social statistics) into 'a coherent and comprehensive model of health and disease' (Potvin and McQueen, 2007). At the same time, the engagement of civic society in the effort to transform health, led to the incorporation of public health into the bureaucratic regulatory system of nation-states (Porter, 1999). In this way, public health was established out of what some authors (Susser and Susser, 1996; Terris, 1983) call a 'revolution'. Potvin and Chabot (2002) justify this characterization in terms of radical transformations in the system, its knowledge base, and practice.

Once the risks of contagion were contained, infant mortality was reduced, and people lived to old age, the attention of the public health movement shifted towards the cure of chronic conditions. In the twentieth century, public health became synonymous with medicine and their services, and a growing professional culture of physicians, nurses, and other health-care professionals concentrated their efforts upon further extending the population's lifespan. Changing lifestyles due to improved living conditions and nutrition patterns, greater prosperity, and the introduction of food manufacturing, significantly improved health and wellbeing, but did not alleviate the effects of the simultaneous reproduction of inequality and poverty, as well as the lack of awareness about new health hazards. The health needs of populations changed, and diabetes, obesity, smoking, and the simple facts of ageing now triggered chronic conditions, and presented new threats to life. Terris (1983) refers to the process of professionalization of health as the second revolution in the history of public health, but within this approach death was perceived as failure of the efforts to preserve life (Illich, 1976).

A yet more recent direction in public health—what commentators (Breslow, 1999; Potvin and McQueen, 2007) call the third revolution of public health—provides methods and models that emphasize 'health and wellbeing', and not simply disease or illness. Under a 'new regime of total health' (Armstrong, 1993), the view of health as a 'resource' led developments. Advanced governance systems, established health-care systems, the professionalization of health based on broad multi-disciplinary scientific knowledge, and a population involved in political debates and decisions, changed the way in which health and its care is approached in the twenty-first century. Citizens are becoming increasingly engaged in their own health—as a population and citizen-led responsibility—within health ecologies constructed by the media and business (Kickbusch, 2007a). Current public health issues appeal to an educated consumer society that develops health literacy (Kickbusch, 2009), within an expanding health market. In 'health societies' the development of policies and practices that promote health and wellbeing crosscut all social sectors and are participatory, collaborative, and citizen-led. These developments witness a shift away from 'health policy' by health-care professions alone, and a move towards 'health in all policies' and social environments (Kickbusch, 2007b).

Public health in contemporary societies aims to empower citizens to see health as a central personal aspiration in life. Health is no longer exclusively a matter of good health-care provision, treatment, and control. It is a 'resource for everyday life' (Breslow, 1999) that can be promoted by empowered citizens. Participatory methods driven by large public campaigns and the media have been central in health promotion that signals a shift away from a focus on disease to a focus on health and its maintenance (Adshead and Thorpe, 2009). The reduction of co-morbidities, illness prevention, and active ageing, drive current health promotion efforts. The understanding of health issues as global and environmental (WHO, 1978; 1986) also shaped the direction of the second revolution in public health. It invited the development of sustainable solutions and ecological interventions (WCED, 1987; Brundtland, 1989).

The third revolution of public health turned towards health because disease has boundaries, while health knows no limits—whether disease is present or absent. However, in practice, public health and health promotion continue to make provisions primarily for a situation where disease is absent, or at best curable. A content analysis of academic and professional published titles carried out by Karapliagou and Kellehear (2016) indicated that public health in Britain prioritizes issues arising from smoking, obesity, and diabetes, while marginal experiences that generate their own co-morbidities such as dying, bereavement, caregiving, being in prison, or homeless are largely neglected. Contemporary public health paradigms could be effectively applied to care for the wellbeing of every citizen, whether they are healthy, or have end-of-life care needs. Health care and medical innovations prolong the lifespan of people with life-limiting conditions, while populations are generally expected to die in old age affected by multiple morbidities. Given these recent demographics, the promotion of health among the frail and vulnerable would be vital to the new 'wellness revolution' in complete 'health societies' interested in creating independent and empowered citizens.

Public health and health-promoting palliative care

The incorporation of end-of-life and palliative care considerations in public health potentially transforms its practice and impact (Kellehear, 2004). The latter becomes a necessity given the centrality and range of end-of-life care experiences in our societies. End-of-life care now starts much earlier in a serious illness because technological innovations and medical improvements prolong its trajectory through earlier diagnosis and prognosis. This is a common observation among the elderly who are disproportionately affected by multiple morbidities and life-limiting conditions. In the UK, 75% of people aged 75 years or more have more than one long-term condition, rising to 82% among those aged 85 years or more (Barnett et al., 2012). Inadequate support systems and care networks lead to unplanned hospital admissions that exhaust the resources of urgent care. Health, social, and technological innovations aim to address the challenges of an ageing population expected to double from 11.7% in 2013 to 21.1% by 2050 (United Nations Department of Economic and Social Affairs, 2013). Public health programmes aim to mobilize communities to develop sustainable frameworks of care that accommodate increasing needs. In this context, the inclusion of end-of-life care considerations in the public health agenda could propose solutions on sustainability, and drive a larger transformation of attitudes towards health and wellbeing that supports the needs of an ageing society.

The incorporation of end-of-life care in the public health agenda has equal value for those who are well and healthy. Citizens in contemporary societies are becoming increasingly aware of mortality risks, and are socialized into feeling empowered to promote their own health and wellbeing. Large media campaigns raise awareness about the risks of communicable disease, HIV contagion and treatment, and the threats that smoking and obesity pose to life. Simultaneously, there is growing understanding that social inequalities and exclusion present significant morbidity and mortality risks (Sengupta, 2009). Characteristically, we now know that lack of social relationships is the most important contributing factor to mortality (Holt-Lunstad and Smith, 2012). The incorporation of end-of-life care in the previously discussed considerations would destabilize the view of 'a perfect ecology of health'. It would counteract its death-averse attitude, attend to experiences that challenge one's health status, promote broader awareness about health and wellbeing, and restore resilience. End-of-life care is about living, and living with one of the most unavoidable but universal experiences—mortality.

A public health framework called *Health-Promoting Palliative Care* (Kellehear, 1999) serves the purpose of acknowledging the significance of end-of-life care in our societies. It draws attention to the broader social issues implicated in health and illness, and attempts to reorient the traditional approach of the palliative care movement from the 'psychosocial' to the explicitly social determinants of health and wellbeing at the end of life. A health-promoting palliative care departs from past formulations of the 'psychosocial' by restoring (and to some extent rehabilitating) substantive concepts of the 'social' shifting the emphasis away from social psychology to matters properly community, civic, and ecological. It is a public health lifespan-focussed framework for social transformation that includes end-of-life care.

Past psychosocial and psycho-educational programmes that have driven palliative care support, tended to have focussed upon personal reactions to crisis such as anxiety, depression, fear, disorientation, anger, or financial difficulties, the burden of care, and the management of illness (Hudson et al., 2008; Grov et al., 2006; Harrison et al., 2009). Their evaluation often minimizes the impact, lessens the links to and upon social support and social networks (Hudson et al., 2008), and in some instances social support is perceived as burdensome (Wittenberg-Lyles et al., 2014). Rather than providing any guidance about the development of social strategies to address the inadequacies of support, efforts commonly focus instead on the personal ability to 'cope'. To that end, psychosocial and psycho-educational programmes in palliative care are largely driven by service delivery and disease management models and incentives. Limited within institutional or direct health service provision settings, psycho-social approaches often under utilize or reflect upon the challenges of social, cultural, or economic interactions that make-up end-of-life care experiences.

Phenomenological studies on dying and caring at the end of life commonly report 'existential' concerns when there is lack of social integration within the neighbourhood, as well as communication difficulties with family, relatives, friends, colleagues, and professionals in caring roles (Sjolander and Ahlstrom, 2012). These influences weaken peoples' resilience, encourage one to question their sense of identity and belonging, and withdraw from their social environment (Dahlborg Lyckhage and Lindahi, 2013). As a consequence of social isolation, their health, wellbeing, and independence can be further compromised. And yet, psycho-educational services are unlikely to replace the role that meaningful relationships and social networks play in promoting health and wellbeing even at the end of life itself. There is, and has been, a long-term need for actions that address the health-promoting social environments of people living, caring, and grieving at the end of life. The public health end-of-life care movement represents an attempt to address just these challenges.

Public health end-of-life care

The development and implementation of a coherent public health end-of-life care framework has a number of benefits for public health. Firstly, public health end-of-life care identifies a range of experiences of death, dying, grief, loss, and caring with implications for palliative and end-of-life care, and makes an effort to include related considerations in preventive and health-promoting interventions. For example, public health end-of-life care intervenes in all policies and strategically aims to influence practices that enable the social inclusion of marginal experiences caused by social inequalities and lack of cohesion (poverty, social isolation, loss of homeland, and a safe cultural location, for example). Such conditions are known to compromise health and wellbeing, and may cause co-morbidities and premature mortality (early deaths, sudden deaths, or suicides, for example). Public health end-of-life care also prescribes a number of planned interventions in social settings, makes an early intervention, and offers valuable care in the form of social support at the outset of life-limiting illness. In this way, a number of illnesses (mainly associated with age and ageing), such as dementia, heart disease, and stroke are included in care. Finally, public health end-of-life care promotes greater awareness about mortality, death, dying, loss, grief, and caring, and a broader understanding of experiences that may cause the above. It cultivates a culture of compassionate care, responsibility towards oneself and others, and willingness to prevent but also accommodate the above experiences in everyday life.

Public health end-of-life care makes a large contribution to public health by integrating an orientation towards death, dying, loss, grief, and caring in its approaches and directions. As a result, a public health approach to end-of-life care is able to address population care needs along the entire life course. It recognizes dying as valuable part of life and promotes well-being in the end of life (see Figure 1.1).

For example, health literacy, which is used as a main prevention and health-promotion measure is complemented by death literacy. In doing so the perspective of healthy living includes 'healthy dying'. The traditional focus upon healthy active ageing is complemented by considerations of elderly care and its overlap with end-of-life care. Finally, the current focus upon palliative and health-promoting palliative care is expanded by a decisive turn towards the end of life and its care in social and institutional settings as a civic care approach that makes an early investment, and engages whole societies in related matters.

The driving principle and coordinating force behind all the activities, practices, and policies of public health end-of-life care is *Compassion.* Community attitudes are reoriented towards end-of-life care by cultivating an ethic of compassion and sharing in suffering and in pain. Etymologically, 'compassionate' means to possess an attitude that allows one to accompany another in their suffering (Funk, 1963), to experience empathy, and share the journey. During the last decade, Compassionate Communities emerged around the world in an attempt to implement the basic principles of public health end-of-life care. They were inspired by Compassionate Cities—a model presented in *Compassionate Cities: Public Health and End-of-Life Care* (Kellehear, 2005).

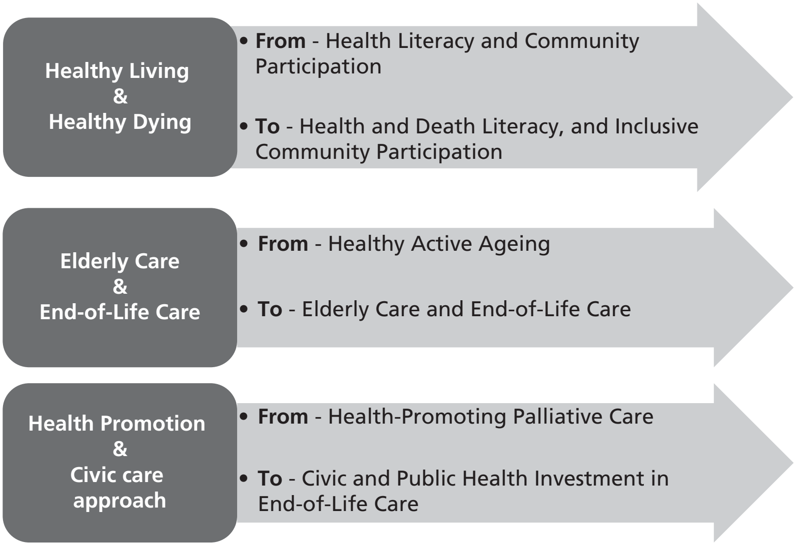


Figure 1.1 Extensions and shifts through public health end-of-life care

Compassionate Communities

Sectors within the hospice movement and community organizations that work with people with end-of-life care needs are concerned about patients' and carers' lack of trust in their own abilities to care, and tendency to ask professionals for help in the first instance (Sallnow et al., 2016; Abel and Townsend, 2016; Horton et al., 2016). By the end of the twentieth century, it became apparent that palliative care was challenged by an increasingly professionalized culture that disempowered people with end-of-life care needs, and marginalied their lived experiences. The role of the local community lacked conceptual understanding, and people who are more likely to withdraw due to suffering (Cassel, 2009) became excluded from care and social life.

The professionalization of palliative care poses additional challenges in urbanized and ageing societies; the services of which will struggle to meet increasing demand (Sallnow et al., 2016). By the middle of the century all regions of the world will be predominantly urban and occupied by an ageing population (UN Habitat, 2010). Palliative care already struggles to be inclusive—people from ethic minority groups (Coupland et al., 2011), lesbian, gay, and bisexual groups (Harding, 2012), and low socio-economic classes (Kessler et al., 2005) are underrepresented, while cancer patients are overrepresented in specialist palliative care services (The National Council for Palliative Care, 2013).

The publication of *Compassionate Cities* (Kellehear, 2005) provided options and solutions to the previously discussed challenges. The emphasis of the approach on social needs and relationships involved in end-of-life care was something that some communities and organizations working in palliative care were already experimenting with. The Compassionate Cities approach gave them a firm direction within a public health framework that makes health-promoting strategies central, and is community building and partnership oriented.

Compassionate Communities employ the basic principles of Compassionate Cities—as health promotion and community development initiatives, and hold compassion as an ethical imperative (Wegleitner, Heimerl, and Kellehear, 2016). These social values and aspirations often translate into neighbourhood befriending programmes, social networking schemes, and community engagement initiatives. Different from traditional hospice volunteering, these initiatives are commonly directed, controlled, and maintained by the communities themselves, and are not volunteer 'services' sent from hospices. Though they may often be *initiated* by local palliative care services, Compassionate Communities grow out of local cultures, caring networks, voluntary resources, and the outreach activities of *other* community trusts and organizations.

Community volunteering

Community volunteering is the most commonly used method of community development in public health end-of-life care. The pitfall of this approach is that stakeholders who are not familiar with the purpose of Compassionate Communities risk conflating their offer of voluntary services in the community with community development in end-of-life care. For this reason, it is worth highlighting the unique features and objectives of community volunteering in Compassionate Communities.

Volunteering in hospices and palliative care settings takes several forms. In the UK there are 125,000 volunteers (Help the Hospices, 2014), mainly occupied in supportive roles in specialist palliative care settings. Evidence from North American research suggests that the ability of volunteers to befriend and meet the social needs of people at the end of life and their caregivers is limited (Planalp and Trost, 2008; Berry and Planalp, 2009). Strict institutional procedures, health and safety regulations, and ethical guidelines contain their activity and communication avenues. As a result, volunteers may be confused or frustrated about their role, or they may feel unappreciated (Claxton-Oldfield and Claxton-Oldfield, 2008). There may also be tension in their relationships with health-care staff (Claxton-Oldfield et al., 2008).

On the other hand, there is evidence to suggest that volunteers are best suited in social roles. They can facilitate meaning-making processes of life review and re-identification following loss. They also help people experiencing loss, gain a sense of belonging, and support their communication with family, relatives, friends, and professionals (Burbeck et al., 2014). In short, they 'help them live until they die' (Seigny et al., 2009). Community volunteering in Compassionate Communities takes this last quality a step further.

Community volunteers are actively encouraged to develop relationships based on empathy and compassion. Employing their strong social observation skills and needs identification training, they explore with the people they support their needs and wishes. In this way, they provide people who are frail and vulnerable with a renewed sense of identity, and make them feel secure in their social environment. In some instances they give them access to the practical support they need to enhance their independence by enabling better communication with social and health-care services.

Community volunteers are also actively encouraged to extend and apply their compassion in everyday situations that they will encounter in the community. Community volunteering starts formally within a community development programme with specified training and standard procedures. However, it cultivates independence in the volunteer, and the ultimate purpose is to embrace an attitude of compassion and develop additional compassionate relationships in the community, where needs arise. In this sense, volunteering in Compassionate Communities takes an informal character and prioritizes the natural social relationships between citizens, rather than the goal-oriented nature of the encounter in a volunteer-led programme.

The ability of community volunteering to influence a larger societal change, however is often challenged by strict organizational boundaries and procedures, and a risk averse professional culture within palliative care settings. In addition, community volunteering alone is not enough to lead a public health reorientation towards the end of life and its care. Community and other charitable organizations that lead similar initiatives may have more flexibility, and the ability to diversify and be creative with their community development programmes in order to more effectively reach the citizens they serve. However, they are constantly challenged by lack of sustainability in the methods used to implement community development, firm political support, and a stable funding base.

Social networking

Social networking involves the process of identifying a *supportive* social network, which is likely to help during the end of life and its care. Where necessary roles and responsibilities are assigned within the network, or rearranged as required to support people with end-of-life care needs. The purpose of the social networking technique in end-of-life care is to reorient attitudes, and shift focus away from professional services and towards naturally occurring supportive networks, as a starting point of acquiring help. The social networking approach has been used as a community development method in its own right, but it has also been employed as a community engagement technique within community volunteering (Abel and Townsend, 2016).

Social networking was developed and applied in palliative care in Australia to support caregivers (Leonard et al., 2015). In the UK, it was adopted by Weston Hospice to support similar purposes (Abel and Townsend, 2016). The model used distinguishes between inner and outer links within a person's network (Abel et al., 2013). Formal family ties may provide direct physical care and/or companionship, as well as a sense of trust and safety. Community ties are no less important and can provide practical support, recognition as a citizen who needs and deserves help, a sense of belonging in the wider community, and a renewed sense of identity, all of which can save the caregiver from breakdown and exhaustion.

To mobilize the social network and formation of inner and outer links, a key principle within the approach is 'to just say yes' to offers of help (Abel and Townsend, 2016). In the evaluation carried out at Weston Hospice, it was observed that in time, people fell into habitual patterns of providing support, adopted consistent roles, and were organized into supportive teams around the unit that needed help. The organization of the network gave credit and value to the life experience of the caregiver.

Social networking is a dynamic method of community development that can be applied in everyday situations to alleviate suffering. However, grief is isolating, and bereavement is the long process of re-identification after death has taken place (Walter ,1999). Therefore, the risk of withdrawal is ever present even within supportive and understanding networks. Characteristically, the caregivers that participated in the Weston networking project withdrew following the death of their loved one. To sustain support we need to saturate all social spaces with compassion towards the end of life and its care, and influence a larger ecological change. Social networks are made and unmade by circumstances and losses, but it is our ethical responsibility within Compassionate Communities to proactively support fellow citizens in their need.

Community engagement

Community engagement is the process of involving community members in end-of-life care by giving them opportunities to reflect upon death, dying, loss, grief, and caring. The purpose of community engagement in end-of-life care is to empower community members to become involved in matters they are likely to encounter at the end of life. For example, advance care planning, wills and inheritance, existential concerns, family relationships, psycho-social issues, how one would like to live at the end of life, and preparations for death and dying can all be discussed at anytime during the life-course.

Talking about end-of-life care matters reorients community attitudes towards related experiences. Conversations sensitize the community and create environments in which people can articulate their worries in times of need, seek support, find understanding and compassion, or simply acquire information and settle their affairs. For this purpose we need spaces and opportunities for conversations and ethical reflection to take place in the context of interactions between individuals and collective experiences, ideas, and concepts. It involves a method of a practicing ethics (Schuchter and Heller, 2016). Community engagement in end-of-life care entails health and death education, and aims to empower citizens to take control of their health and wellbeing at the end of life. Knowledge and active involvement in end-of-life care matters early on in life (or early on in the dying process) can be conducive to healthy living, and/or a good death with one's wishes fulfilled.

In the UK, the National Council for Palliative Care initiated a campaign that aims to address the social taboo present in conversations about death and dying. Towards this end, it published *The Dying Well Community Charter: Principles of Care and Support* that provides policy directions for engagement in end-of-life care in community settings. The Dying Well Community Charter focuses upon recognition and respect for end-of-life care needs, active communication about possibilities of involvement and support, and action plans for their delivery. To contextualize those policy directions and implement its community engagement programme, The National Council for Palliative Care introduced the Pathfinders and Buddies Scheme. Selected communities applied The Dying Well Community Charter in their local communities, and are in the process of evaluating its impact (for more information and to view The Dying Well Community Charter visit http://www.ncpc.org.uk/communitycharter).

The Scottish Partnership for Palliative Care also runs a very active community engagement programme with the *Good Life, Good Death, Good Grief* campaign at its forefront (for more information visit https://www.goodlifedeathgrief.org.uk). The Scottish Partnership for Palliative Care has a number one priority to promote health and wellbeing at the end of life in its population, and sponsors numerous arts projects and community engagement initiatives around the country. It has gone as far as to propose a rational for a national public health approach to palliative care through the Scottish Public Health Network (ScotPHN) briefing papers (Patterson and Hazelwood, 2015; Gillies, 2016).

Compassionate community in Sandwell

The Compassionate Community of Sandwell (Patell, 2016) is part of a larger community development programme that aims to address inequalities that impact upon people's health and wellbeing at any life stage. The Borough of Sandwell has a population of less than 30,000 inhabitants, and is one of the most deprived in the UK. As a site of industrial revolution, the region has a historical record of poor health and above average death rates compared to national standards. Murray Hall Community Trust is a public health and community development body set up in 1994 to improve the health of the region's population. One of the Trust's key aspirations is to raise citizens' self-determination and cultivate their agency in matters that affect them. Their aim is to use social capital in order to create opportunities for care and support, and increase access to information and services. A community development project called Bridges was formed out of the need to bridge the gap that separates the community from health-care services. People with end-of-life care needs felt disoriented and turned to the Trust's information desk for help. The Bridges programme identified and aimed to address the following: information needs; emotional support, practical support, and spiritual needs. Murray Hall developed a narrative-based assessment method that emphasizes listening to one's story to extract their meanings, worries, and anxieties. It is on the basis of what cannot be rationally articulated that needs are identified. A team of coordinators then work with health and social services to deliver the care that people mostly need. A team of community volunteers provide emotional support and practical services such as driving people to and from hospital appointments. As a community development organization, Murray Hall Community Trust engages in numerous and varied other activities in which the ethic of compassion is primary. Health and death literacy takes place within support groups, or in the context of art projects and other participatory and networking activities. What is distinctive about Murray Hall Community Trust is that it recognizes that death can take place at any life stage, and creates possibilities for inter-generational learning and exchange of support. The Trust throughout it life has undergone radical transformations. Although Murray Hall has influenced health-care services and public health directions in the region, the recognition and inclusion of end-of-life care in public health would provide firm support for their local projects, and formal representation in health policy directions.

Compassionate Cities

Compassionate Communities have been successful in transforming the cultural fabric of local communities, and reorienting attitudes towards end-of-life care in certain neighbourhoods (Wegleitner, Heimerl, and Kellehear, 2016; Kellehear, 2016). Their community development approach and methods borrow from established public health interventions; but their implementation designs are skilfully crafted to utilize social capital, and in this way, meet local needs. As Sallnow and Paul (2015) observe the degree of community engagement that community development programmes in end-of-life care mobilize varies considerably, depending upon the locus of control, and goals set. Some programmes aim to inform citizens, simply consult them on matters that affect them, co-produce solutions, collaborate in the delivery of outcomes, or empower them to take control, make decisions, and influence their health and wellbeing. Compassionate Communities utilize all of these principles to achieve their ultimate goal, which is the empowerment of local communities. They may have to go through multiple cycles of community engagement and focus upon different outcomes, before local communities become independent and empowered.

Despite their empowering potential and impact upon the health and wellbeing of people with end-of-life care needs in local settings, Compassionate Communities cannot support a large-scale societal transformation. At best, they will reach those affiliated with the coordinating organization. If empowerment leads to community networking, it will engage people who are volunteering or use social services, and participate in neighbourhood activities, and for this reason, actively seek out information and participatory action on local issues. Community development programmes cannot reach everyone in a given society. They may be suitable for homogenous towns and villages, but for diverse urban centres we need alternative public health paradigms.

To achieve large-scale societal impact we need a national public health campaign that will utilize the media to influence popular knowledge and perceptions, settle consensus on the priority of the end of life and its care, and initiate parallel actions in all social sectors and public institutions. These activities will lead to the reorientation of policy, practice, and social/physical environments. We also need collaborative actions between science, research, business, and social enterprize in order to develop and implement systematic innovations that will transform citizens' relationship to the end of life and its care.

The most profound way in which public health transforms attitudes and promotes health and wellbeing in advanced societies employs the operational mechanism of nation-states, and particularly the concept of citizenship that moderates social life. By introducing the values of health and wellbeing in the arena of civic responsibilities, and cultivating the ethic of care in embedded and sustained social relationships, public health succeeds in reorienting attitudes and preserving social systems. In this way, health becomes part of the governance apparatus, and wellbeing offers itself as a valuable resource that guarantees effectiveness and sustainability. Public health priorities are translated into actions that promote health and wellbeing in all sectors and institutions of a given society. These actions involve the development of policies and practices that deliver measurable outcomes on particular health issues. The coordination of activities in social settings is oriented towards overall wellbeing. Compassionate Cities employ the same mechanisms to introduce and incorporate the end of life and its care in the public health domain.

Compassionate Cities (Kellehear, 2005) borrow inspiration from Healthy Cities (WHO, 1986; Hancock, 1997). Healthy City is a form of urban public health design that develops policies to impact upon health and wellbeing. Healthy Cities target the social determinants of health such as income, housing, food security, employment, and quality of life. This form of social innovation addresses social inequalities to support health, create healthy environments, sanitation, and ensure access to health care. It relies upon the commitment and engagement of the local community through participatory action, and the involvement of multiple stakeholders in policy-making with a clear vision, empowerment, and a sense of ownership. The definition of Healthy City prescribes the use of natural and social resources in collaborative and participatory development that serves and maximizes society's full potential. Demonstrable benefits for health and wellbeing prescribe the accumulation of 'community capital` as a precondition and a challenge in developing healthy and sustainable communities in the twenty-first century (Hancock, 2001).

Compassionate Cities attempt to redress the imbalance and emphasis of Healthy Cities upon health, and include illness and social disadvantage in its considerations. The approach proposes an alternative framework of social action that is better able to accommodate social inequalities, marginal experiences, and the social determinants that cause morbidity and mortality.

A Compassionate City has several mechanisms in place that empower citizens to engage with the full range of end-of-life care experiences, and develop resilience and coping as a means to health and wellbeing. A basic ingredient in this process is the acknowledgement that people can die due to hardship, grief, and sorrow. For this purpose, Compassionate Cities engage in a wider social transformation achieved in the context of public articulation of diverse cultural narratives of loss and traditions of grief, and their integration in our understanding of social factors that undermine health, and determine death, dying, loss, grief, and caring. The culture of compassion is cultivated through informed empathy towards suffering. Policies translate into established cultural practices that prescribe a widespread commitment towards the aged, and those who experience marginality and social disadvantage. Compassionate Cities are inclusive societies that offer their inhabitants a range of opportunities to representation in care—beyond care offered by professional services. Policies are owned by citizens, and a range of services including palliative care services are easily accessible and designed for an empowered population in control of their end-of-life care.

The Compassionate City Charter

Social change and the reorientation of the physical and cultural environment are necessary in the development of public health policies that serve end-of-life care purposes. A Charter for Action drives policy and practice development, and environmental reorientation processes. It involves a set number of actions that Compassionate Cities need to facilitate in order to achieve their objectives:

1. Schools have annually reviewed policies or guidance documents for dying, death, loss, and care.
2. Workplaces have annually reviewed policies or guidance documents for dying, death, loss, and care.
3. Trade unions have annually reviewed policies or guidance documents for dying, death, loss, and care.

4. Places of religious worship have at least one dedicated group for end-of-life care support.
5. Hospices and nursing homes have a community development programme involving local area citizens in end-of-life care activities and networks.
6. Cultural institutions (such as museums and arts centres) hold annual exhibitions on the experiences of ageing, dying, death, loss, or care.
7. An annual peacetime memorial parade represents experiences of loss, such as any life-limiting condition, child loss, suicide survivors, loss of animal companion, loss of emergency workers, and accident loss.
8. An incentives scheme celebrates and highlights the most creative compassionate organization, event, and people in the community.
9. A public media campaign showcases local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns'.
10. An annual art competition helps raise awareness about death, dying, loss, caring, and other marginal experiences.
11. Institutions, organizations, and communities that support socially disadvantaged populations (homeless, imprisoned, refugees, immigrants, and ethnic minorities, women's groups, mental health groups, and economically deprived communities) have plans in place for end-of-life care, including loss and bereavement.
12. The understanding of difference and diversity drives policy, practice, and cultural development in end-of-life care. Work in partnership with community organizations and social institutions must steer policy and practice development in directions that are representative, inclusive, and alleviate social inequalities present in end-of-life care, loss, and bereavement.

Local councils as civic authorities commonly hold the responsibility for supervising and overlooking the implementation of the public health end-of-life care intervention in the city. They ensure that all social sectors and public institutions are involved in the delivery of actions and intervene to provide support, guidance, additional resources, and exchange of expertise between actions. The design and delivery of actions is the product of participatory co-creation and engagement of citizens who own the policies, practices, and embody the desirable ecological reorientation in the city. Compassionate Cities can be developed incrementally and according to local needs. Consultations on their design and evaluation involves a collaborative and iterative process between development and practice among multiple stakeholders from all walks of life, social sectors, professions, and communities under the auspices of the civic authority.

The Compassionate City Challenge

A number of cities in Britain and Europe have expressed interest in becoming Compassionate Cities. Limerick in Ireland, Seville in Spain, Londonderry, and Sheffield in England are among recent examples. The challenge for cities that aspire to become Compassionate Cities is multi-dimensional—the process involves social change, during which our beliefs and perceptions of death, dying, loss and grief evolve, our attitudes towards care transform radically, and our relationship to governance changes.

The transition to a co-produced and participatory model of care in community settings cannot materialize unless we confront our fears, and let go of our belief in our inability to care—that makes us invest all our hopes and trust in professional care. A critique of community development in end-of-life care by Stajduhar et al. (2010) summarizes this challenge by simply asserting that caregivers in end-of-life care want to be looked after by professionals, and are fearful of empowerment. The critique also claims that it is actually hazardous to force carers into roles that carry responsibility and deprive them of health-care services. A Compassionate City does not deprive its citizens of professional health and social care. On the contrary, services adapt to the individualized needs of an educated, involved, and empowered clientele that has a clear vision of its rights and responsibilities, and owns the decisions that affect their experiences of end-of-life care. Compassionate Cities foster continuity of care before, during, and after healthcare services. Professional health services and public health (end-of-life) care are complementary approaches because they have always been policy and practice partners. Compassionate Cities serve to cultivate a different relationship to power and governance—they represent an evolved way of thinking about health and death that requires system-wide, collaborative, and participatory solutions.

To implement Compassionate City models we need to deliver innovation action designs based upon the co-creation of policies and practices that coordinate end-of-life care in urban centres. An integral element of this new public health revolution will be the incorporation of end-of-life care considerations in *all policies*, rather than solely the development of policies in the end-of-life care field (for example, in policies for homeless populations, caregivers, and other groups which are at risk of morbidity and mortality, as well as in policies that regulate everyday life in schools, workplaces, and other social settings).

This brings us to our final challenge—the reconsideration of what we think of as public service provision. Ultimately, Compassionate Cities will challenge our perceptions of professional services through the introduction of a co-produced and participatory model of care delivered by citizens themselves in collaboration with professionals and other stakeholders. Policies will be flexible and embedded within everyday processes of negotiation of complex experiences that intersect multiple areas of life. The adoption of an incremental and reflexive approach to development that builds upon partnerships and focuses upon positive outcomes for health and wellbeing in end-of-life care will safeguard the success of the transition.

Conclusion

Palliative care has always been about 'whole person' care. This approach has identified the major components of the 'whole person' as encompassing the physical, psychological, spiritual, and social dimensions of being. As professionals, our care mission has been to address these with a service that has targeted all forms of distress at the end of life. We have usually confined our attempts to address social distress with professional services. We have worked with hospice volunteers to help with issues of quality of care, continuity of care, and balancing professional care with community participation. Public health end-of-life care takes this much further. Public health practices represent a change from recent ways of working with communities. In public health approaches we see a stronger and more radical emphasis on community partnerships and participation moving from neighbourhoods to the wider civic institutions that govern and shape not only palliative care but everyone. This is recognition that if palliative care is to succeed in its ambition to care for the 'whole person' it must do so *earlier*, inside *and outside* of formal care, and *create alliances* with social institutions that participate in the creation and maintenance of the whole person—as citizen and not solely as patients—at the centre of our care. Therefore, public health end-of-life care aspires to strengthen the community and build new relations and partnerships. Professionals and care organizations can make a major contribution to this by expanding their self-conception as important hubs and actors in local care networks, and by recognizing that strengthening compassionate cities and communities could be a core mission of their behaviour, as professionals and fellow citizens. The history of public health demands that we recognize that end-of-life care—like current health care itself—is everyone's responsibility.

References

Abel J. and **Townsend D.** (2016). Developing community support networks at the end of life in Weston-super-Mare, UK. In K. Wegleitner, K. Heimerl, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Abel J., **Walte, T.**, **Carey L.B.**, **Rosenberg J.**, **Noonan K.**, **Horsfall D.**, **Leonard R.**, **Rumbold, B.**, and **Morris, D.** (2013) Circles of care: Should community development redefine the practice of palliative care? *BMJ Supportive and Palliative Care*, **0**: 1–6.

Brundtland G.H. (1989). Global change and our common future. *Environment*, **31**(5): 16–43.

Adshead F. and **Thorpe A.** (2009). Modern public health. In F. Wilson and M. Mabhala (eds) *Key Concepts in Public Health*. London: SAGE Key Concepts, pp. 11–14.

Armstrong D. (1993). From clinical gaze to a regime of total. *Health Education Journal*, **52**(3): 114–19.

Barnett K., **Mercer S.W.**, **Norbury M.**, **Watt G.**, **Wyke S.**, and **Guthrie B.** (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, **380**(9836): 37–43.

Berry P. and **Planalp S.** (2009). Ethical issues for hospice volunteers. *American Journal of Hospice and Palliative Medicine*, **23**(6): 458–62.

Breslow L. (1999). From disease prevention to health promotion. *JAMA*, **281**(11): 1030–3.

Burbeck R., **Candy B.**, **Low J.**, and **Rees R.** (2014). Understanding the role of the volunteer in specialist palliative care: A systematic review and thematic synthesis of qualitative studies. *BMC Palliative Care*, **13**: 3.

Cassel, E.J. (2009). Suffering. In T.D. Walsh, A.T. Caraceni, R. Fainsinger, K.M. Foley, P. Clare, C. Goh, M. Lloyd-William, J.N. Olarte, and L. Radbrush (eds) *Palliative Medicine*. Philadelphia: Elsevier, pp. 46–50.

Claxton-Oldfield S. and **Claxton-Oldfield, J.** (2008). Some common problems faced by hospice volunteers. *American Journal of Hospice and Palliative Medicine*, **15**(2): 121–6.

Claxton-Oldfield S., **Hastings E.**, and **Claxton-Oldfield, J.** (2008). Nurses' perceptions of hospice palliative care volunteers. *American Journal of Hospice and Palliative Care*, **25**(3): 169–78.

Coupland V., **Madden P.**, **Jack R.H.**, **Moller H.** and **Davies E.A.** (2011). Does place of death from cancer vary between ethnic groups in South East England? *Palliative Medicine*, **25**(4): 314–22.

Dahlborg Lyckhage E. and **Lindhahi B.** (2013). Living in liminality—Being simultaneously visible and invisible: Caregivers' narratives of palliative care. *Journal of Social Work in End-of-Life and Palliative Care*, **9**(4): 272–88.

Funk, I.K. (1963). *Funk and Wagnalls New Standard Dictionary of the English Language*. New York: Funk and Wagnalls.

Gillies, M. (2016). *Palliative and End of Life Care in Scotland: The Rational for a Public Health Approach*. Scottish Public Health Network (ScotPHN).

Grov E.K., **Fossa S.D.**, **Sorebo S.D.** and **Dahl A.A.** (2006). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Sciences and Medicine*, **63**(9): 2429–39.

Hamlin C. (1994). State medicine in Great Britain, in Porter, D. (ed.) *The History of Public Health and the Modern State*. Amsterdam: Rodopi.

Hancock T. (1997). Healthy cities and communities: Past, present, and future. *National Civic Review*, **86**(1): 11–21.

Hancock T. (2001) People, partnerships and human progress: building community capital. *Health Promotion International*, **16**(3): 275–80.

Harding R., **Epiphaniou E.**, and **Chidgey-Clark J.** (2012). Needs, experiences and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *Palliative Medicine*, **15**(5): 602–11.

Harrison J.D., **Young J.M.**, **Pric, M.A.**, **Butow P.N.**, and **Solomon, M.J.** (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer*, **17**(8): 1117–28.

Help the Hospices (2014). *New exhibition showcases rich legacy of hospice volunteering*. Press Release, February. Accessed at: http://www.ehospice.com/ArticleView/tabid/10697/ArticleId/9258/View.aspx

Holt-Lunstad J. and **Smith T.B.** (2012) Social relationships and mortality. *Social and Personality Psychology Compass*, **6**(1): 41–53.

Horton S., **Zammi, R.** and **Nio Ong B.** (2016). Community partnerships: A public health approach to ageing, death, dying and loss. In K. Weigleitner, K. Heimerl, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Hudson P., **Quinn K.**, **Kristjanson L.**, **Thomas T.**, and **Braithwaite M.** (2008). Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliative Medicine*, **22**(3): 270–80.

Illich I. (1976). *Medical Nemesis: The Expropriation of Health*. New York: Pantheon Books.

Karapliagou A. and **Kellehear A.** (2016). The forgotten people in British public health: A national neglect of the dying, bereaved and caregivers. *BMJ Supportive and Palliative Care*, **6**(2): 153–9.

Kellehear A. (1999). *Health Promoting Palliative Care*. Melbourne: Open University Press.

Kellehear A. (2004). Third-wave public health? Compassion, community, and end-of-life care. *International Journal of Applied Psychoanalytic Studies*, **1**(4): 313–23.

Kellehear A. (2005). *Compassionate Cities: Public Health and End-of-Life Care*. New York: Routledge.

Kellehear, A. (2016), The Compassionate City Charter: Inviting the cultural and social sectors into end of life care. In K. Weigleitner, K. Heimerl, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge, pp. 76–87.

Kessler D., **Peters T.J.**, **Lee L.** and **Parr S.** (2005). Social class and access to specialist palliative care services. *Palliative Medicine*, **19**(2): 105–10.

Kickbusch I. (2007a). Innovation in health policy: Responding to the health society. *Gaceta Sanitaria*, **21**(4): 338–42.

Kickbusch I. (2007b). Adelaide revisited: From healthy public policy to Health in All Policies. *Health Promotion International*, **23**(1). Doi:10.1093/heapro/dan006.

Kickbusch I. (2009). Health literacy: Engaging in a political debate. *International Journal of Public Health*, **54**: 131–2.

Leonard R., **Horsfall D.**, and **Noonan K.** (2015). Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Supportive and Palliative Care*, **5**(2): 153–9.

Patel M. (2016). Compassionate Communities in Sandwell, West Midlands, England. In K. Weigleitner, K. Heimerl and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Patterson R. and **Hazelwood M.** (2015). *Palliative and End of Life Care in Scotland: The Rational for a Public Health Approach*. Briefing Paper 5: Good Life, Good Death, Good Grief. Scottish Public Health Network (ScotPHN).

Planalp S. and **Trost M.R.** (2008). Communication issues at the end of life: Reports from hospice volunteers. *Health Communication*, **23**(3): 222–33.

Porter D. (1999) *Health Civilization and the State*. London: Routledge.

Potvin L. and **Chabot P.** (2002). Splendour and misery of epidemiology for evaluation of health promotion. *Revista Brasileira de Epidemiologiao*, **5**(1): 91–103.

Potvin L. and **McQueen D.V.** (2007). Modernity, public health, and health promotion. In D.V. McQueen and I. Kickbusch (eds) *Health and Modernity: The Role of Theory in Health Promotion*. New York: Springer, pp. 12–20.

Sallnow L., **Bunnin A.**, and **Richardson H.** (2016). Community development and hospices. In K. Weigleitner, K. Heimerl and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Sallnow, L., and **Paul, S.** (2015) Understanding community engagement in end-of-lfie care: Developing conceptual clarity. *Critical Public Health*, **25**(2): 231–8.

Schuchter P., and **Heller A.** (2016). Ethics from the bottom up. In K. Wegleitner, K. Heimerl and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

Seigny A., **Dumont S.**, **Cohen S.R.**, and **Frappier A.** (2009). Helping them live until they die: Volunteer practices in palliative home care. *Nonprofit and Voluntary Sector Quarterly*, **39**(4): 734–52.

Sengupta S. (2009). Determinants of health. In F. Wilson and M. Mabhala (eds) *Key Concepts in Public Health*. London: SAGE Key Concepts.

Sjolander C., and **Ahlstrom G.** (2012). The meaning and validation of social support networks for close family of persons with advanced cancer. *BMC Nursing*, **11**: 17.

Stajduhar, K., **Funk, L.**, **Jakobsson, E.**, **Öhlén, J.** (2010) A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving. *Nursing Enquiry*, **17**(3): 221–230.

Susser M., and **Susser E.** (1996). Choosing a future for epidemiology: Eras and paradigms. *American Journal of Public Health*, **86**(5): 674–7.

Terris M. (1983). The complex tasks of the second epidemiologic revolution: The Robert Cruikshank Lecture. *Journal of Public Health Policy*, **4**(1): 8–24.

The National Council for Palliative Care (2013). *National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2011–2012*. The National Council for Palliative Care: London.

United Nations Department of Economic and Social Affairs (2013). *World Population Ageing*. New York: United Nations.

United Nations Habitat (2010). *State of the World Cities 2010/2011: Bridging the Urban Divide*. United Nations Human Settlement Programme: Kenya.

Walter T. (1999). *On Bereavement: The Culture of Grief*. Maidenhead: Oxford University Press.

Wegleitner K., **Heimerl K.**, and **Kellehear A.** (2016). *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.

WCED (World Commission on Environment and Development). (1987). *Our Common Future*. Oxford, UK: Oxford University Press.

World Health Organization (WHO) (1986). Ottawa charter for health promotion. In: *Health Promotion***1/4**: i–v.

World Health Organization (WHO), UNICEF (1978). Primary Health Care: Report of the International Conference on Primary Health Care. Alma-Ata USSR. 6–12 Sept. 1978. WHO. Genf.

Wittenberg-Lyles E., **Washington K.**, **Demiris G.**, **Oliver D.P.** and **Shaunfield S.** (2014). Understanding social support burden among family caregivers. *Health Communication*, **29**(9): 901–10.

Chapter 2

Communication and psychosocial issues within neonatal palliative care

Alexandra Mancini and Paula Abramson

Background to neonatal palliative care

In the United Kingdom (UK), over 90,000 infants are admitted to specialist neonatal intensive care units every year as a result of being born prematurely, born with congenital conditions, or following a significant insult at the time of delivery, however just over 2,000 babies who die are likely to require palliative care (Bliss, 2017). The neonatal period is recognized as the first 28 days of life irrespective of gestation, however some infants requiring neonatal care, have had conditions diagnosed within the antenatal period, therefore parents may receive palliative care even before birth. There may be some infants who spend many weeks, even months, on a neonatal intensive care unit, whilst receiving active treatment alongside palliative care.

One cannot underestimate the impact that the quality of care towards the end of life of an infant can have on families; an impact that can last for many years after the infant has died (Papadatou, 2009; Woodroffe, 2013). The British Association of Perinatal Medicine (2010) defines palliative care for the fetus, neonate, or infant with life-limiting conditions as 'an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death, and beyond. It is the holistic management of supportive end-of-life care following multidisciplinary agreement on eligibility'. The philosophy and principles of palliative care integrated into routine neonatal care, can enhance the quality of care infants and their families receive (Murdoch et al., 2013), furthermore the integration of relevant services ensure the best possible care and experience for the infant and their family during life and support after death.

Recent studies by Fraser et al. (2012) further identify that significantly more than the original estimated number of children with life limiting conditions are living within the UK, and the most significant increase is in the under one year olds. This phenomena has been attributed to the rise in survival rate of extremely premature infants, as well as the advancements in technology supporting infants with life-limiting conditions (Wilkinson et al., 2006; Costeloe et al., 2008; Ramnarayan et al., 2007). In recent years, there has been increasing recognition of neonatal palliative care within the routine clinical neonatal environment and it s emerging as a specialty in its own right (Mancini et al., 2013).

For parents and families being given the news that their baby has a life-limiting condition and may die is extremely harrowing and this can be a very difficult and confusing time in their lives. Branchett and Stretton (2012) led a study with parents of infants on a neonatal unit who were not expected to survive. Key findings included the way in which health-care professionals communicate with families at this time is of the utmost importance and must be approached sensitively and compassionately. The focus of care is on maximizing the quality of life for that infant, in accordance with their family's wishes; encompassing every aspect of the family structure, whilst ensuring families have the relevant information available to support their decision-making process.

In recent years, national professional agencies and bodies such as the British Association of Perinatal Medicine (BAPM), Bliss, Together for Short Lives (TfSL), Department of Health (DH) and the Royal College of Paediatrics and Child Health (RCPCH) have supported the growing need for good quality palliative care during the perinatal period via educational interventions. Several national publications including frameworks of care and pathways are recognized and highlight good standards of practice (ACT, 2009; BAPM, 2010; BLISS, 2011; Mancini et al., 2014; Sands, 2016; TfSL, 2017). These documents provide a foundation on which health-care professionals can develop local education and training initiatives, and emphasize the need for individualized care plans and family centered care, where family choice is given a high priority. However, it has been widely documented, that the knowledge and skills of neonatal staff and their attitudes towards neonatal palliative care is variable and inconsistent (Gallagher et al., 2012; Twamley et al., 2012; Mancini et al,. 2013).

Following evidence to support the benefits of palliative care, the Nuffield Council of Bioethics (2006) introduced recommendations that specified all professionals working within the field of neonatology must have mandatory training in the principles of palliative care for infants. More recently, the importance of appropriate and consistent training for professionals within this specialist area this has been further supported in national publications (DH, 2009; and Bliss, 2011). Whilst it is important to recognize that there is evidence of effective local training programmes in neonatal palliative care (Soni et al., 2011; Mancini, 2011; and Gallagher et al. 2012), training and education in the principles of neonatal palliative care remains variable and fragmented.

National mapping surveys (Soni et al., 2011; Bliss, 2011; Together for Short Lives 2011) identified inconsistencies and fragmentation in neonatal palliative care provision and access to training for professionals, resulting in inequitable palliative care for infants and their families. Price et al. (2013) reinforce that it is imperative that health-care professionals receive appropriate training in a highly specialized and complex field such as neonatal palliative care, where it is rapidly expanding, and professionals need to respond to the demands on an expanding and developing service by focusing on appropriate education for health-care professionals (Downing and Ling, 2012).

Education and training are an integral part of the provision of high quality neonatal care which includes complex and palliative care (Mancini et al., 2013; Mancini et al., 2014) and assists professionals in developing and enhancing the skillset required to deliver excellent holistic care.

Evaluation of a recent educational model (Morris and Cookson, 2017) identified that neonatal nurses are crucial in communicating with parents on a neonatal unit, however they require the confidence and skills to do so. The overarching aim is that all families are treated with compassion and difficult information is shared as sensitively as possible, with all the relevant and appropriate information about additional services and options for care planning offered, so that families are offered choice, and supported with the decisions they make, providing equity of information and care for all families.

In order to deliver high-quality neonatal palliative care, it is fundamental to identify, assess, and plan care appropriately in partnership with the parents and family.

Why is neonatal palliative care different to adult palliative care?

There are similarities within adult and neonatal palliative care such as the focus of support given to family and loved ones. However, there are also many differences which include:

- With the advancements of technological investigations, parents may receive an antenatal diagnosis that their baby has a life-limiting condition or a significant surgical condition, which may mean they are eligible/identified for palliative care support before the baby is born.
- New parents, who have never had their baby at home, may be faced with preparing for the birth of their new baby at the same time as preparing for their baby's death.
- Infants requiring palliative care are usually cared for in a noisy, busy neonatal intensive care unit, where their clinical condition may deteriorate or improve suddenly within a short space of time.

- There may have been a multiple pregnancy, where subsequently, there may one or more babies being cared for in different hospitals. The parents may have to care for a critically unwell baby whilst grieving the death of another baby.
- The father may be extremely anxious in worrying about the uncertainty of the future of the baby, whilst his partner may be unwell following delivery requiring medical care of her own.
- There may be a very short amount of time which families can spend with their baby before death.
- There are limited opportunities to create memories with their baby and other family members, particularly siblings.
- Multiple teams and services may be involved, across professional boundaries, requiring excellent clear communication and documentation.

Identify

In recent years there have been increasing challenges in identifying which infants may require palliative care. It can be challenging for health-care professionals to define and categorize infants who may be eligible for palliative care as infants don't fit neatly into groups or categories. With these challenges in mind, the British Association of Perinatal Medicine in their report document (BAPM, 2010) have detailed five broad categories to aid identification (Box 2.1).

Assessment

In accordance with recent guidance provided by Together for Short Lives, the national organization for paediatric palliative care (2017), an integrated framework has been developed building on previous work (ACT, 2009).

Health-care professionals can utilize this framework when assessing and planning palliative care for the infant and continuing support for their family.

Figure 2.1 illustrates a tool which will support and encourage health-care professionals to offer families choices and empower them in planning care for their babies (TfSL, 2017).

There are six standards: sharing significant news; planning for choice in the location of care; a multi-agency assessment of the family's needs; co-ordinated multi-agency plans; an end-of-life care plan and then continuing bereavement support and care across three main stages within the trajectory of care which is provided.

Box 2.1 Candidate conditions eligible for perinatal palliative care in 5 broad categories

1. An antenatal or postnatal diagnosis of a condition which is not compatible with long-term survival.
2. An antenatal or postnatal diagnosis of a condition which causes a high risk of significant morbidity or death.
3. Birth at the margins of viability, where intensive support has been deemed inappropriate.
4. Postnatal clinical condition with a high risk of impairment of quality of life and the baby is receiving or may require life support.
5. Postnatal conditions which result in the baby experiencing 'unbearable suffering' (BAPM, 2010).

Source: data from British Association of Perinatal Medicine (BAPM), *Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine, Report of the Working Group*, August 2010, Accessible from: http://www.bapm.org/publications/

To be truly effective and inclusive, it is imperative that there is a multi-agency approach delivering comprehensive and integrated care planning following a collaborative assessment (NICE, 2016; Larcher et al., 2015; Mancini et al., 2014; TfSL, 2017).

A thorough comprehensive assessment should include:

- What are the infant's immediate clinical needs?
- What is important for the family at that point in time?
- What are their wishes for the uncertain future?
- Who is caring for the other children?
- Consider social aspects such as financial difficulties, maternity leave.
- Use language which the family can understand.
- Are there language barriers which may impede communication and understanding? Is an interpreter required?
- Consider briefing the interpreter beforehand and after the discussion. Sensitive information may be lost in translation.
- Are all the services and organizations who could provide support to the family involved?

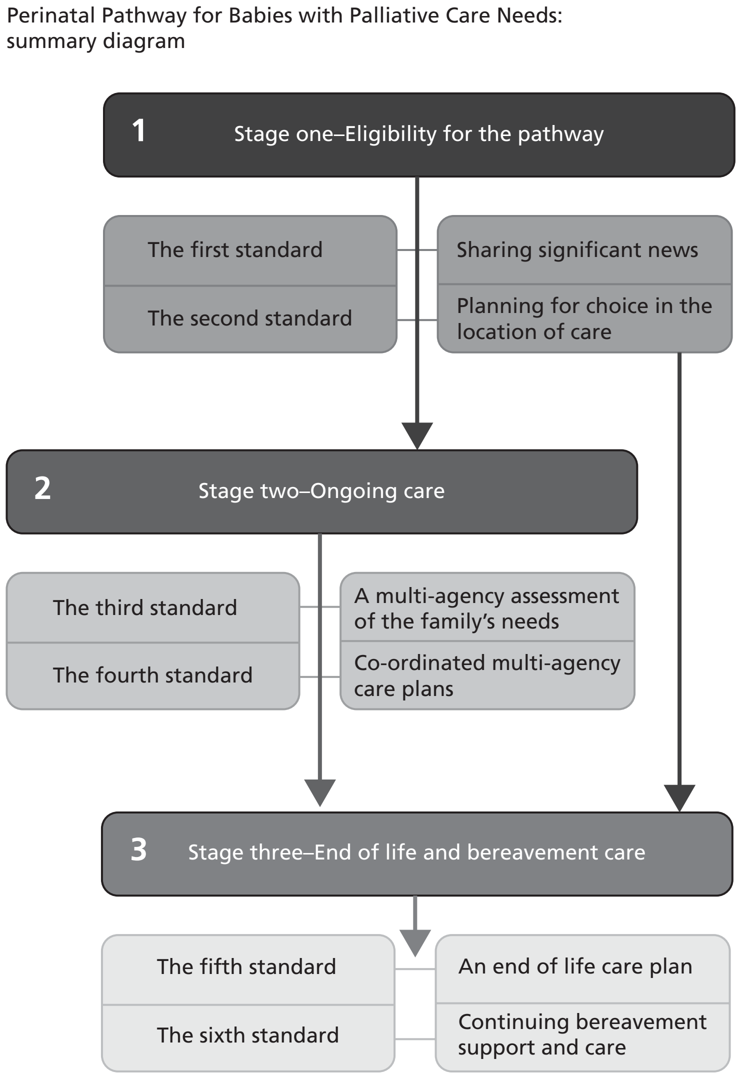


Figure 2.1 Perinatal pathway for babies with palliative care needs: summary diagram Reproduced with permission from Together for Short Lives (2017) *A Perinatal Pathway for Babies with Palliative Care Need*, Second edition, Bristol: Together For Short Lives, p. 12, Copyright © Together for Short Lives.

Family-centred care planning

Gallagher and Franck (2012) in recent work explore the value parents feel when working in partnership with professionals which echoes Casey's (1995) work over 20 years ago. The importance and value of the nurse considering the whole family, whatever the dynamics may be to include the baby, the family, health of the family, the environment, and the nurse herself (Brykczynska and Simons, 2011).

Brown (2007) discusses the importance of an advance care plan for the baby and family; placing the family at the centre of making decisions and what they feel is appropriate for their baby. Parents should be respected and listened to by all the professionals involved in the planning of care. Parents may be empowered in formulating plans in anticipation of their baby being born and not surviving. A study led by parents who had babies on a neonatal unit reported that they value health-care professionals; respecting them by listening, showing compassion, and allowing them to feel supported in their difficult decision making (POPPY, 2009).

Advance care planning for the family ensures they can be at the centre of making decisions regarding the level of treatment they feel is appropriate for their child: including the medications used in the event of deterioration. This partnership involves the entire family; empowering them in formulating plans in advance of potential deterioration, whilst meeting the emotional, spiritual, and social needs of the child and family, (Brown, 2007).

The National Service Framework (2004) stresses the importance of parents being given clear and concise information in relation to their babies and children. Education and partnership between professionals and parents are fundamental to ensure that parents are able to make informed decisions and choices for their children. Parents are the best advocates for their baby or child, however they rely on professionals sharing key important information with them.

Family-centred care is the epitome of effective neonatal palliative care focusing on maximizing the quality of life a neonate and their family experience; including information sharing, respecting beliefs and wishes, and symptom management whilst working in partnership with families and ensuring the neonate is central to care planning (TfSL, 2017).

Cultural and spiritual care

The spiritual aspect of care for the family is a shared responsibility within the multidisciplinary team. Culturally appropriate care is integral to high-quality family-centred care and addresses specific cultural practices regarding decision making, death, dying, and continuing bereavement. It is important not to make assumptions about cultural beliefs and rituals, but to recognize individual needs, as members of the family may have different beliefs, cultural, and religious backgrounds (Mancini et al., 2014). It is also vital that staff respect that the mother and the father may have different religious or cultural beliefs. It is helpful for staff to have some knowledge of the beliefs and rituals associated with death and dying within different faiths, particularly in relation to issues immediately following death and in care of the body (Children's Hospices UK, 2009).

Some parents or carers can find it reassuring and helpful to discuss their beliefs and values, but remember that some may find these discussions difficult or upsetting. There may be differences in these discussions within each family and indeed between the mother and father (Mancini et al., 2014).

For many parents of preterm and sick newborns, there is often a sense of loss and grief even if their baby does not die. In this chapter we will be considering the role of staff within a neonatal intensive care unit (NICU). Specifically we will consider how to assist staff to have a heightened level of awareness of how a parent may be feeling, and to increase the levels of staff confidence in communicating with and supporting these families.

Advance planning and care after death

There have been many developments in recent years with regards to whole organ donation and minimally invasive post mortems, thereby offering families greater choice in planning for after the death of their baby. Whilst it remains a rare occurrence, whole organ donation is now possible in infants who meet the required criteria (RCPCH, 2015; Charles et al., 2014).

Families are also able to consent to a minimally invasive post mortem, which may seem more acceptable to them than a traditional full post-mortem with minimal cosmetic consequences (Sebire et al., 2012).

There is a paucity of literature to support the use of 'cool bedrooms' within a children's hospice after the death of a baby, however parents report that this additional support has helped their grieving, particularly that it is in their own time. The 'cool bedroom' allows the baby's body to be maintained at a required temperature in preparation for the funeral, but in an environment more acceptable to the family (TfSL, 2017). It is important that this information is shared as honestly and at the earliest opportunity to allow the family time to make the right decision for them. This option will ensure that the family have a safe place to 'be' together as a family for whatever time they need (Davis D., 2014).

Time spent with their baby after death can help the parents be reassured that their baby has normal aspects of their appearance like family resemblances; take time to bathe and dress them, all the 'normal' aspects of parenting. It will be the parents who set the pace for spending time with their baby, and it is they who will slowly draw themselves away from the body when they are ready to do so. This will help the families feel a sense of control, rather than it being the health-care professional who sets the time and the distress of taking the baby to the hospital mortuary. Families should also be aware that they can take their baby home after death, and all the appropriate information should be offered, as families may not know what is possible (Mancini et al., 2014).

When a woman discovers that she is pregnant, she will have an idea of what lies ahead. She might imagine the perfect pregnancy followed by a text book birth and then a few hours later going home to begin her new life with her healthy, new baby. She may even imagine her child's first words, first day at school. Perhaps she may start to think about whether her child will become a doctor, a nurse, a teacher … and within moments she may be imagining herself as a grandmother.

Adjusting to a new reality

For the vast majority of people this is exactly what will happen, but for some parents, the reality is not what they had expected. Very few parents expect to find themselves on a neonatal intensive care unit with their baby fighting for life. Some parents may experience many months on the neonatal unit living with the uncertainty of the future for their baby and their family. They may feel a sense of loss for the healthy full-term baby they had been expecting. It is important for health-care professionals working on a neonatal intensive care unit to consider the needs of the family and the impact on parents, and to bear in mind that for many of these families, the NICU is an alien and confusing environment.

Here, a mother shares her experience when she went into labour at just 24 weeks gestation (full term is considered at 37 weeks gestation and above):

> … I was literally willing my body to hold onto our baby, hoping that if I concentrated hard enough, I could give him those precious extra day. The doctors from the neonatal unit explained that our baby would be taken straight to intensive care. When our baby was born, we heard a cry but all we could see were the doctors, nurses and midwives exchanging worried looks. It was four hours before we got to see him. We were parents but we couldn't touch him or hold him and we didn't know what challenges he would have to face. Suddenly my baby was no longer inside me, but in a room I had never seen and I didn't know what was happening to him.

Feelings of uncertainty and loss

Parents often share their feelings of uncertainty and loss with the health-care professionals caring for their infant: not knowing whether to celebrate the arrival of their longed for child, or to feel sadness and a sense of loss for the full term, healthy baby they were expecting and hoping for. Mothers in particular may talk of feeling guilty, that somehow it must be something that she did, or something that she should have done, that caused this to happen.

Fathers often feel afraid to get too close to their baby for fear of how they will cope if their baby does not survive. There are often parallels drawn between the feelings that parents experience after the death of a baby to that of the feelings they have when their baby is very sick with an uncertain future:

> … the guilt that I have felt since his birth, the fact that I feel that I let him down.

Secondary losses

Parents with a baby on a neonatal intensive care unit, often feel prohibited from doing all of the things they are supposed to be doing for their newborn baby, feeding, washing, caring, and nurturing. Parents often report feeling disempowered when having a baby on a NICU. With medical teams looking after their baby around the clock, it is often difficult to 'feel' as if you are a parent. These feelings are often referred to as secondary losses (see Figure 2.2). Examples of secondary loss are:

- Loss of identity—am I a parent?
- Loss of hope for the future.
- Loss of goals and dreams.
- Loss of self-confidence.

Secondary losses may also be on a much more practical level:

- Loss of income.
- Loss of financial security.
- Loss of support network.

It is well recognized that compassionate care combined with sensitive communication is an important component of effective care and can make a huge difference to the impact on families (SANDS, 2016).

Cockburn and Walters (1999) describe effective communication between health-care professionals and parents of the baby, as an integral component within the context of continued high-quality care.

> [C]ommunication is probably the single most important component of effective care. It underpins and colours everything that staff can offer. Excellent clinical care can be overshadowed by poor communication … parents who are shocked, stressed and frightened are likely to be particularly sensitive to the way that staff communicate with them. (Cockburn and Walters, 1999)

Parents are acutely aware and familiar with the different layers of communication, not just between parents and staff, but also amongst staff. One mother highlighted the importance of this:

> when there was a good flow of communication through the team, that's when our baby got the best possible care.

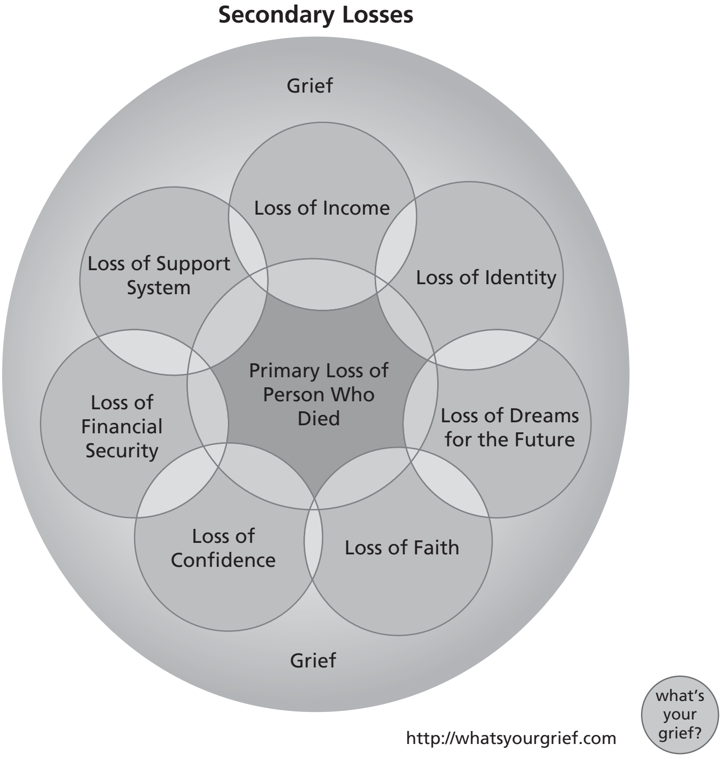


Figure 2.2 The affected person is in the middle of the circle, experiencing all the secondary losses (accessed 25th March 2017)
Reproduced courtesy of What's Your Grief, www.whatsyourgrief.com

This is further supported by Mancini et al. (2014) emphasizing the importance of all members of staff being included in discussions of the planning of care the baby, whilst also being given the opportunity to attend regular unit meetings including multidisciplinary team consultations. Health-care professionals must be aware of how to access sources of support for their own wellbeing, which can foster and nurture team cohesiveness and opportunities for reflection and assist in building resilience.

Good communication includes acknowledging that parents know their baby best and that parents may notice the subtle changes in the baby's clinical condition. Parents often spend hours sitting beside their baby's incubator or cot observing their behaviour (Redshaw et al., 2014). It is therefore important that staff, wherever possible explain how and why they are doing things. Often parents say they feel disempowered to 'be' parents, as the nurse may appear to be the 'expert' in their baby's care.

Staff interaction and comments may influence how parents interact with their baby. Parents have reported how they 'hang on' to every word a doctor or nurse says about their baby. It is therefore important for health-care professionals to think about how they communicate in all of their interactions with parents.

Recognizing their baby as an individual, and not referring to the baby by their medical condition or the referring hospital, is a consistent theme that emerges when talking to parents about their lived experience on a neonatal unit. It is hugely important for parents to see that staff recognize their baby as a unique and individual person.

> … on one occasion, when the doctors were doing their rounds, I heard him say 'that's the Milton Keynes baby, we don't need to discuss that one'. When you are a parent, in that moment that is not what you want to hear. In my head I was screaming 'he's my baby and his name is James' but I didn't say anything, I just wasn't capable of saying anything …

It is well recognized and accepted that nursing and medical teams can have a list of numerous tasks and procedures which they need to complete. Sometimes, the baby and human being at the centre of the care may be forgotten.

One father says:

> if he was an adult patient, they would ask before taking bloods or carrying out other tests. If a parent is with their baby, it makes sense to ask. Good nurses and doctors would ask, 'is this a good time?'.

This father continues:

> even when our baby was very poorly and things were so intense, it was really positive when staff asked us questions about him and took an interest in him as an individual. They seemed to value what we had to say, and that built trust in those professionals immediately. It was good for us to feel a part of the team, and for us to be involved in his care.

Confusing communication or mixed messages

It is also important to consider the terminology that is used on a neonatal intensive care unit. Confusing communication and mixed messages will only add to the distress and psychological impact on parents:

Whilst being on a neonatal intensive care unit may be 'normal' for staff, for parents who find themselves unexpectedly thrown into this alien and confusing world, it is far from normal. It may be helpful to consider how parents might be feeling. This is probably the most traumatic experience of their lives so they may be feeling disempowered, afraid, and vulnerable.

> All I could do was look at our tiny little boy through the window in the incubator door. Tears of happiness fell because he was here and he was so beautiful, but then when I got

> back to the delivery room, I crumbled and sobbed with pain because I didn't know when I was going to get to touch him let alone hold him. All the things your body and your heart are screaming at you should be happening … that your baby needs you, wasn't the reality, and I had to somehow make sense of that.

Parental suggestions for effective communication

When asked about effective communication parents often report that it is important for them to know that their baby is seen as a unique and individual person. They also say that it is important that health-care professionals do not give mixed messages, this can be confusing and can sometimes add to the day-to-day stresses of being a parent with a sick baby in a hospital. With this in mind, here are just a few suggestions:

- Do try to use the baby's name at all times.
- Do at least try to get the baby's gender correct.
- Don't refer to the baby by his or her medical condition.
- Do ask parents how they think their baby is—they are often the people who know their baby best.
- Don't refer to the baby you are looking after as 'my baby' this can be upsetting for parents to hear.
- Don't assume that parents want you to refer to them as 'mummy' or 'daddy'—it's always best to ask first.
- Don't move their baby without informing parents at the earliest possible time.
- Don't dress their baby for the first time without parents being present—it is such a special moment to miss out on.
- Do ask: 'Is this a good time?' before doing things to their baby. Do try to include parents in discussions.
- Do try to encourage parents to be present when their baby gets weighed—it is one of the few moments when the baby is not attached to wires and looks 'just like a normal baby'.
- Don't give false reassurances to parents—describing a very sick baby as 'poorly' can be very confusing and misleading.
- Do try to use language/terminology that parents will understand—gauging their level of understanding is not always easy but is an essential part of effective communication.
- Do try to be clear, open, and honest in all communications with parents, particularly if you are giving bad news.

Janvier and Lantos (2014) provide a perspective of being a health-care professional and a parent of a baby on NICU, and suggesting that health-care professionals sometimes may not completely understand how disorientating this experience can be. It may be assumed that there is an etiquette of 'good manners' on the neonatal unit which may be helpful for staff to observe. Echoing the previous statements, but also including guidance and recommendations such as:

- Introduce yourself using your name, and do not assume parents know already. Include your profession and what your role is.
- Listen to parents: sit down next to them, rather than standing over them and ask how you think baby is doing.

There are many other helpful recommendations suggested by Janvier and Lantos (2014), which are easily embedded in practice and can help staff gain confidence in how they communicate with families. They may seem common sense, however, by not addressing parents' specific needs can result parents voicing their dissatisfaction, and can lead to poor relations between the parents and the health-care professional.

Model for breaking bad news

When communicating with parents, particularly if bad or significant news is being shared, it is important to gauge what type of language to use. An established model for breaking bad news is 'Ask-tell-ask' (Back et al., 2005)

Ask—'How do you think your baby is doing? Tell me what your understanding is. . . .'

This will give a clear understanding of what the parents' understanding is, do they appreciate just how sick their baby is? It will also help to gauge what language and medical terminology can be used, in other words, what is right for this family at this time.

Tell—This is the time to tell them how their baby is using clear and concise language, with no space for misunderstanding.

Ask—This is an opportunity for clarification; to ensure that they have understood what they have been told. It may be helpful to invite them to ask any questions 'do you have any questions, is there anything else that you would like me to explain . . .?

Health-care professionals often feel hindered and inexperienced when having to break bad news. It is only natural to feel a sense of reluctance to deliver bad news, many professionals feel a huge burden of responsibility, and perhaps a fear of a negative response. It is always best to avoid euphemisms such as:

- 'We've come to the end of the road.'
- 'We think we are going to lose your baby.'

- ‘There’s nothing more we can do.’
- ‘There isn’t long to go.’

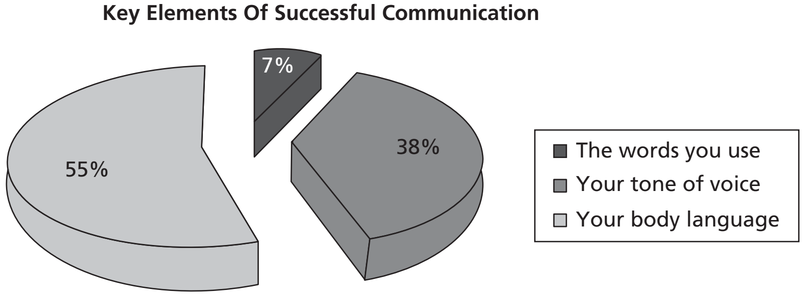
Figure 2.3 demonstrates how so much of our communication takes place at a non- verbal level. Mehrabian and Weiner (1967) suggest that the tone of our voice and our body language represents over 90% of our communications with each other.

Other research suggests that when parents are being given bad news, they are only able to retain between 30–40% (Kessels, 2003) of the information being given, of which most is inaccurate. It is therefore really important that we communicate clearly and effectively, particularly when breaking bad news (Kessels, 2003). With this in mind, it is always advisable to offer a follow up meeting later the same day, or to suggest that parents might like to record the meeting and they can play it back at their leisure. If parents do choose to record the meeting this must be done explicitly and transparently, with the permission and consent of all involved.

There will of course be times when even the most experienced of us will want to ‘swallow back’ the words that have just been spoken. That is okay; we are, after all, only human and we will sometimes make mistakes.

Feelings of isolation

Remember as well, that during this time parents are often feeling alienated from their family and friends. For parents life may become fragmented, often juggling the needs of their other children at home, visiting their baby on the NICU, and



Albert Mehrabian (1967)

Figure 2.3 Example of key elements of successful communication
Reproduced with permission from Mehrabian A. and Weiner M., ‘Decoding of inconsistent communications’, *Journal of Personality and Social Psychology*, Volume 6, Issue 1, pp. 109–14, Copyright © 1967 American Psychological Association, DOI: 10.1037/h0024532

having to deal with difficult circumstances at the same time. Existing children 'lose' their parents to the alien world of the NICU and a baby that they may never have met. It may be that, due to the specialist care they need, their baby is in a NICU far from home (Bliss, 2015). Although officially the neonatal period refers to the first 28 days of life, the reality for many parents is that their baby may spend weeks and often months on a neonatal unit before being discharged home, or to a children's hospice (Craig and Mancini, 2013) Some hospitals may offer parents accommodation onsite, but for many this is not an option., due to no facilities available and limited resources (Poppy Project, 2009)

> … our baby was in NICU for seven months. We were fortunate to be offered accommodation on the hospital site so we could be close by. We are both self employed and neither of us were able to work much during this time. Eighteen months on, we are still struggling with the financial repercussions, still trying to get back on track, it hasn't been easy for us.

The impact on staff

It must also be acknowledged that professionals may experience difficult and sometimes painful feelings after the death of a baby. Murray Parkes (2006) suggests that 'Grief is just as normal a reaction for staff as it is for parents and relatives'.

Furthermore, if we take it as a given that for parents with a baby on an intensive care unit are in the midst of a traumatic experience, then might it also be true that those who work alongside these families, often caring for five or six babies in one nursery, may in some way feel the effects of this trauma (Gallagher et al., 2012; and Kain, 2007)?

This is known as Secondary Traumatic Stress, where the health-care professional witnesses the suffering and distress experienced by the baby, their parents, and family, and are therefore at risk of becoming distressed (Melvin, 2015). Some might say that it is impossible not to be affected when a baby or child dies. It is therefore important that all members of staff are aware of what support is available (Papadatou, 2009).

In recent years phrases such as compassion fatigue and secondary traumatic stress disorder have begun to emerge when thinking about the physical and emotional effects on health-care professionals who care for the most seriously ill or dying patients.

It is widely recognized that caring for babies and children in an intensive care setting can be particularly draining. In recent years, managers and leaders within the health-care profession are acknowledging the need for both formal and informal support to be available to staff. Asking for and receiving support should no longer be considered a sign of weakness, but rather a sign of strength.

It is vital that staff are made aware of and are able to easily access support when they are affected by the death of a child.

This support may come in a variety of ways, and will depend on the individual trust or unit. Different types of support structures may be in place:

- Staff debriefs
- Reflective practice
- Schwartz Round
- Peer support
- Staff counselling service

> [C]aring for parents and children in an intensive care setting can be particularly draining and relentless. It is extremely important that the stresses and demands of the job are acknowledged and that senior staff and management make it clear that it is legitimate for all staff to ask for and get help when they need it. (Jennings, 2002)

Conclusion

Palliative care within the specialty of neonates is relatively new, however it is being recognized as a vital component of family centred care. High quality sensitive and effective communication between health-care professionals and families is paramount during at this time. The neonatal unit can be an alien world where the future is uncertain, alongside the beginnings of life and the possibility of a premature death, emotions are heightened significantly impacting on effective communication.

Inevitably there will be challenges in communication between the health-care team and families where there may be different approaches to care from a variety of different professional groups.

Good quality care for the infant and their family is multi-faceted and focuses on the life the family want for their baby and the whole family at that point in time. Therefore, it is critical that neonatal staff who care for these babies and support their parents through such a distressing time have the training, understanding, and the appropriate and relevant information to share with families, whilst acknowledging what is important to the family.

Key Points:

- Ask the parents what is important for them at that time, and be mindful that this can change.
- Be mindful of previous experiences of the parents and family.
- Use clear language that the family can understand at all times utilizing an interpreter if required.

- Consider recording the conversation.
- Do try to use the baby's name at all times.
- Ask the parents what they understand of their baby's condition.
- Consider the whole family, particularly the siblings.
- Be aware of the urgency in creating memories.
- Involving other services at the earliest opportunity, so that the family may benefit from additional support.
- Clear and concise documentation throughout care assessment and planning.

Acknowledgements

The quotation attributed to Cockburn J., and Walters, W.A.W., was reprinted with permisison from 'Communication between doctors and patients', *Current Obstetrics and Gynaecology*, 9(1): pp. 34–40. Copyright © 1999 Published by Elsevier Ltd. http://www.sciencedirect.com/science/article/pii/S0957584799900719. The excerpt credited to Jennings, P. was reproduced from 'Should paediatric units have bereavement support posts?', *Archives of Disease in Childhood*, **87**(1), pp. 40–2, Copyright © 2002 BMJ Publishing Group Ltd and the Royal College of Paediatrics and Child Health, with permission from BMJ Publishing Group Ltd.

References

ACT (2009). Association for Children's Palliative Care. *A Neonatal Pathway for Babies with Palliative Care Needs*. Bristol.

Back A., **Arnold R.**, **Baile W.**, **Tulsky J.** and **Fryer-Edwards K.** (2005). Approaching Difficult Communication Tasks in Oncology. *Cancer Journal for Clinicians*, **5**(3).

Bliss (2017). Neonatal care and admissions www.bliss.org.uk/neonatal-care-and-admissions (accessed 28 March 2017).

Bliss (2015). Bliss baby report 2015. *Hanging in the balance*. London.

Bliss and Together for Short Lives (2011). *The mapping of palliative care provision on neonatal units in England using the together for short lives neonatal service self assessment tool*. London.

Branchett, K. and **Stretton, J.** (2012). Neonatal palliative and end of life care: What parents want from professionals. *Journal of Neonatal Nursing*, **18**(2): 40–44.

British Association for Perinatal Medicine (BAPM) (2010). *Palliative Care (supportive and end of life care). A framework for clinical practice in perinatal medicine*. The report of a working party.

Brown, E. (2007). *Supporting the Child and the Family in Paediatric Palliative Care*. London: Jessica Kingsley Publishers.

Brykczynska G. and **Simons J.** (2011). *Ethical and Philosophical Aspects of Nursing Children and Young People*. London: Wiley-Blackwel.

Casey A. (1995). Partnership nursing: influences on involvement of informal carers, *Journal of Advanced Nursing*, **22**(6): 1058–62.

Charles E., **Scales A.**, and **Brierley J.** (2014). The potential for neonatal organ donation in a children's hospital. *Archives of disease in Childhood, Fetal Neonatal Ed.* London.

Charters D. and L. (2012) Conversation with a parent. Steele P (2012).

Cockburn J. and **Walters W.A.W.** (1999). Communication between doctors and patients. *Current Obstetrics and Gynaecology* **9**(1): 33–40.

Costeloe K., **Hennessey M.**, **Haider S.**, **Stacey, F.**, **Marlow N.**, and **Draper E.** (2012). Short term outcomes after extreme preterm birth in England: comparison of two birth cohorts in 1995 and 2006. *BMJ*, 345.

Craig F. and **Mancini A.** (2013). Can we truly offer a choice in place of death in neonatal palliative care? *Seminars in Fetal and Neonatal Medicine*. **18**(2): 93–8.

Davis D. (2014). Providing after-death care at home when a baby dies. *Pyschology Today*.

Department of Health (2015). *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values*. London.

Department of Health (2009). *Toolkit for High-Quality Neonatal Services*. London

Downing J. and **Ling J.** (2012). Education in children's palliative care across Europe and internationally. *International Journal of Palliative Nursing*, **18**(3). doi: org/10.12968/ijpn.2012.18.3.115.

Fraser L., **Miller M.**, **Hain R.**, **Norman P.**, **Aldridge J.**, **McKinney P.**, and **Parslow R.** (2012). Rising National Prevalence of Life-Limiting Conditions in Children in England. *Pediatrics*, **129**(4): 171–9.

Gallagher K., **Marlow N.**, **Edgley A**,. and **Porock D.** (2012). The attitudes of neonatal nurses towards extremely preterm infants. *Journal of Advanced Nursing*, **68**: 1768–79.

Gallagher K., and **Franck L.** (2012). Ten lessons from 10 years of research into parental involve-ment in infant pain management. *Infant* **8**(3): 78–80.

Janvier A., and **Lantos J.** (2014). Ethics and Etiquette in Neonatal Intensive Care. *JAMA Pediatrics*, **168**(9): 857–8.

Janvier A., **Barrington K.**, and **Farlow B.** (2011). Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Seminars in Perinatology*, **38**(1): 38–46.

Jennings P. (2002). Should paediatric units have bereavement support posts? *Archives of Disease in Childhood*, **87**: 40–2.

Kain V. (2007). Moral distress and providing care to dying babies in neonatal nursing. *International Journal of Palliative Nursing,* **13**(5): 243–8.

Kain V.J. (2006). Palliative care delivery in the NICU: what barriers do neonatal nurses face? [Review]. *Neonatal Network*, **25**(6): 387–92.

Kessels R. (2003). Patients' memory for medical information. *Journal of the Royal Society of Medicine*. **96**: 219–22.

Larcher V., **Craig F.**, **Bhogal K.**, **Wilkinson D.**, and **Brierley J.** (2015). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives Disease Childhood*, 100.

Mancini A. (2017). Neonatal palliative care: Together we can optimise support for infants and their families to live life. *Journal of Neonatal Nursing*, **23**: 47–8.

Mancini A., **Uthaya S.**, and **Beardsley C.**, **Wood D.**, and **Modi N.** (2014). *Practical Guidance For The Management Of Palliative Care On Neonatal Units*. Royal College of Paediatric and Child Health & Chelsea & Westminster NHS Foundation Trust.1st Edition: London.

Mancini A., **Kelly P.**, and **Bluebond-Langner M.** (2013). *Training neonatal staff for the future in neonatal palliative care*. Seminars in Fetal & Neonatal Medicine, 18: 111–5.

Mancini, A. (2011). Developing a neonatal palliative care education programme within the North West London Perinatal Network. *Journal of Neonatal Nursing*, **17**: 146–9.

Mehrabian A. and **Weiner M.** (1967). Decoding of inconsistent communications. *Journal of Personality and Social Psychology*, **6**: 109–14.

Melvin C. (2015). Historical review in understanding burnout, professional compassion fatigue and secondary traumatic stress disorder from a hospice and palliative care nursing perspective. *Journal of Hospice and Palliative Nursing*, **17**(1): 66–72.

Morris S. and **Cookson J.** (2017). Preparing neonatal nurses for difficult conversations with parents. *Infant*, **13**(3): 111–14.

Murray Parkes, C. (2006). *Love and Loss: the Roots of Grief and it's Complications*. London and New York: Routledge.

Murdoch E., **Carragher P.**, and **McNamara K.** (2013). *Perinatal Palliative Care Framework for Managed Clinical Networks*. South East Scotland.

National Institute Clinical Excellence NICE, (2016). *End of Life Care for Infants, Children and Young People with Life-limiting Conditions: Planning and Management*. London.

National Service Framework for children, young people and maternity services (2004). *Medicines for Children and Young People*. London.

Nuffield Council of Bioethics (2006). *Critical Care Decisions in Fetal and Neonatal Medicine-Ethical Issues*. London.

Orfali K. (2004). Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science and Medicine.* **58**(10): 2009–2022.

Papadatou D. (2009). *In the Face of Death: Professionals Who Care for the Dying and the Bereaved*. New York: Springer Publishing Company.

POPPY Steering Group (2009). *Family-Centred Care In Neonatal Units*. A summary of research results and recommendations from the POPPY project. NCT: London.

Price J., **Dornan J.**, and **Quail L.** (2013). *Seeing is believing-reducing misconceptions about children's hospice care through effective teaching with undergraduate nursing students.* Nurse Education Practice 2013 **13**(5): 361–5

Ramnarayan P., **Craig F.**, **Petros A.**, and **Pierce C.** (2007). Characteristics of deaths occurring in hospitalised children: changing trends. *Journal of Medical Ethics*, **33**(5): 255–60.

Redshaw M., **Rowe R.**, and **Henderson J.** (2014). *Listening To Parents After Stillbirth or the Death of Their Baby After Birth*. Oxford: NPEU.

Reid T., **Bramwell R.**, **Booth N.**, and **Weindlign**. (2007). Perceptions of parent-staff communication in neonatal intensive care: The development of a rating scale. *Journal of Neonatal Nursing*, **13**(1): 24–35.

Royal College of Paediatrics and Child Health (2015). *The Diagnosis of Death by Neurological Criteria (DNC) in Infants Less Than Two Months Old*. RCPCH: London.

Royal College of Nursing (2013). *Breaking bad news: supporting parents when they are told of their child's diagnosis.* Royal College of Nursing: London.

Sebire N., **Weber M.**, **Thayyil S.**, **Mushtaq I.**, **Taylor A.**, and **Chitty L.** (2012). Minimally invasive perinatal autopsies using magnetic resonance imaging and endoscopic post-mortem examination ('keyhole autopsy'): feasibility and intial experience. *The Journal of Maternal-Fetal & Neonatal Medicine*, **25**(5).

Soni R., **Vasudevan C.**, and **English S.** (2011). *National survey on neonatal palliative care in the UK.* Arch Dis Child Fetal Neonatal Ed, 96.

Steele P. and **Mancini A.** (2013). The neonatal experience-loss and grief without a bereavement. *Infant*, **9**(3): 92–3.

Stephens B.E, **Tucker R** and **Vohr B.R.** (2010). Special health care needs of infants born at the limits of viability. *Pediatrics*, **125**(6): 1152–8.

Together for Short Lives (2017). *A Perinatal Pathway for Babies with Palliative Care Needs.* 2nd edition. Bristol.

Twamley K., **Kelly P.**, **Moss R.**, **Mancini A.**, **Craig F.**, **Koh M.**, and **Polonsky R.**, **Bluebond-Langner M.** (2012). Palliative care education in neonatal units: impact on knowledge and attitudes *BMJ Supportive & Palliative Care*, **00**: 1–8.

What's Your Grief-Secondary Losses (2017). www.whatsyourgrief.com (accessed 25th March 2017).

Wilkinson D. (2006). Is it on the best interests of an intellectually disabled infant to die? *Journal of Medical Ethics*, **32**(8): 454–9.

Wilkinson D., **Fitzsimons J.J.**, **Dargaville P.**, and **Campbell N.** (2006). Death in the neonatal intensive care unit: changing patterns of end of life care over two decades. *Archives of Disease in Childhood-Fetal and Neonatal edition*, **91**(4): F268–271.

Woodroffe I. (2013). Supporting bereaved families through neonatal death and beyond. *Seminars in Fetal and Neonatal Medicine*, **18**(2): 99–104.

Wool C. (2015). Clinical Perspectives of Barriers in Perinatal Care. *Lippincott Williams and Wilkins*. **40**(1): 44–50.

Further resources

BLISS—www.bliss.org.uk
Child Bereavement UK—www.childbereavementuk.org
Child Death Helpline—www.childdeathhelpline.org.uk
Contact a Family—www.contactafamily.org.uk
MBF—www.multiplebirths.org.uk
Newlife—www.newlifecharity.co.uk
NHSBT—www.nhsbt.nhs.uk
Organ Donation—www.organdonation.nhs.uk
Rainbow Trust—www.rainbowtrust.org.uk
Sands—www.sands.org.uk
SIBS—www.sibs.org.uk
TAMBA—www.tamba.org.uk
TFSL—www.togetherforshortlives.org.uk
WellChild—www.wellchild.org.uk
Free Online Perinatal Palliative Care Module—www.elearnicpcn.org

Chapter 3

The call to social inclusion: psychosocial care for the marginalized in society

Philip J. Larkin

Introduction to psychosocial care for the marginalized

For most people in society, the experience of being excluded is transient and relatively short-lived. Whatever the cause, people find a way through and resume their place within their social community. However, for some, exclusion and marginalization represent the totality of their experience. Koffman and Camps (2004) define this as 'no way in.' (p. 354). There is a broad literature defining the attributes of social exclusion and the need to reduce inequity is critical in health service delivery, not least in palliative and end-of-life care (Grande et al., 1998; Addington-Hall, 2000; O'Neill and Marconi, 2001, Connolly 2001). There is also a movement within palliative care to develop integrated programmes and services which extend coverage and equal access and early intervention, irrespective of disease and not focused only on the dying process (Gomez-Batiste and Connor, 2017). However, we tend to consider inequity in terms of access and care as an issue for developing countries and fail to appreciate that such inequity also exists within our own societies (Lamas and Rosenbaum, 2012). The recent WHA resolution '*Strengthening of palliative care as a component of comprehensive care throughout the life course*' (World Health Assembly, 2014) highlights inequality between different groups and their access to, experience of, and outcomes from palliative care. This pattern of inequality would seem to be replicated across the international palliative care community.

Social exclusion encompasses a plethora of problems: including unemployment, low income, poor housing, high crime, bad health, and family breakdown. Some of these hold true for people in receipt of palliative care services. An overriding theme is poverty; either in monetary terms or the poverty of spirit, which can be experienced through prejudice and ignorance. Tickle (2007), in his discussion of a UK community health service for patients described as 'those shunned by others' (p. 69) highlights how clients live in conflict situations with authority for many reasons, often addiction or mental health problems. Where communication breaks down and services seem unable or unwilling to respond, the need for statutory services to examine mutual values and motivations is as imperative as any attempt to alter potentially destructive behaviours.

For people who need palliative care, there is a growing body of evidence that not all citizens are treated equally. In this chapter the focus will be on those for whom evidence indicates that their experience of palliative care warrants a deeper consideration of reasons why exclusion occurs. These are:

- Martin—living with serious mental illness (SMI)
- Catherine—living with an intellectual disability (ID)
- Mark—palliative and end–of-life care needs of those in prison
- Lilian—a woman who is homeless
- Mary—living with a chemical dependency and/or addiction.

Through a series of case studies, the psychosocial dilemmas faced by this varied group of patients are described. Although embedded in one societal perspective, they offer insight into more global issues experienced across the health and social care spectrum in many countries. Key issues will be highlighted at the end of each section. To begin with, there are two questions to be considered. What do we mean by the 'marginalized' and how far is palliative care a human right?

What do we mean by the marginalized?

Marginalization is complex to define but reflects a range of social processes, both conscious and unconscious that can lead to a sense of a exclusion and isolation.Palliative care practitioners need to ask if their clinical discipline currently sustains a society that unconsciously divides its citizens. One good example of this is the fact that, despite a global shift in thinking and practice to palliative care as an international public health initiative, palliative care remains predominantly cancer-focused in its orientation and practice (Rosenwax et al., 2005;; Walshe et al., 2009). Therese Vanier described the parallel between the vision of L'Arche (faith communities for the intellectually disabled) and Cecily Saunders hospice movement as: 'somebody listening very carefully to some very fragile and vulnerable people'. Vulnerability, although challenging if applied to others as a label in itself, is a real issue in palliative care. Stienstra and Chochinov (2012) argue that vulnerability occurs when the system sustains attitudes, barriers, and policies that fail to be inclusive. People who exist in this fragile and vulnerable state live and die with the risk of lack of access to basic care needs, financial worries, and often sub-standard and inadequate quality housing at a time when increasingly, pressure is applied to family members to provide care where limited support is available in the community. This attributes to the concern that palliative care exists within an unequal system (Praill, 2000; Kang et al., 2000; Anderson, 2001; Lee et al., 2003; Van Kleffens et al., 2004; Anderson and Ravens, 2004; Muir-Chochrane et al., 2006).

Palliative care as a human right?

Palliative care as a fundamental human right is clearly articulated in the literature (Radbruch et al., 2007; Brennan, 2007; Brennan et al., 2007; Gwyther et al., 2009, Gwyther 2008). The need for national governments to consider palliative care as a part of universal health coverage for all citizens in need has been emphasized in the recent WHA resolution (2014) which advocates member states to:

> [D]evelop, strengthen and implement, where appropriate palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care. (WHA, 67.19, p. 3)

This resolution goes on to emphasize the primacy of a public health and primary care dimension to palliative care to meet the needs of those for whom palliative care remains out of reach. The right to pain management, essential medicines, and a dignified death have been championed by a range of international agencies and state bodies. Denial of these rights has been considered degrading and inhuman by the United Nations (Connor and Sepulveda, 2014; Human Rights Watch, 2012). Based on concepts of respect, dignity, and the need to address suffering and provide all efforts to enable patients to live fully until death, this discourse is both meaningful and appropriate to the philosophy and practice of palliative care. However, there are limitations to a human rights based approach (Brennan, 2007) when such an approach is undertaken in a structurally unequal society (Wilkinson and Pickett, 2009). There is also a tendency for the discourse of human rights around dignity, autonomy, and privacy to be reduced to ethical questions in the palliative care literature, which removes human rights from connections to wider socio-economic and politico-cultural contexts (Ko et al., 2011). Further, there is no clear responsibility on any agency to ascertain if human rights are violated and to respond. Human rights, though laudable, become an aspiration rather than a reality. It therefore serves to seek alternative models which situate palliative care in a real-world context.

A case for an affective equality approach to palliative care

Notwithstanding the important message that human rights approaches offer to palliative care, it is argued here that the fulfilment of a human right to palliative care for all in society is contingent on greater socio-economic equality. In effect, considering marginalization and inequity using a social justice framework strengthens the call for greater inclusion, accessibility, and equitable provision. A social justice lens allows a greater focus on human rights whilst drawing attention to the practical measures and conditions needed to realize human rights in palliative care. A social justice lens also provides a more structural, less individualized framework for understanding equality and inclusion in palliative care (Baker et al., 2004; 2009). This therefore allows the 'inequity in palliative care' discourse to move beyond an aspirational rights-based approach (as previously discussed) and/or clinical and practice-based analysis to a more social and structural analysis. In this way, our understanding of concepts such as suffering, poverty, and death are appreciated in a different way (Reimer-Kirkham et al., 2016; Krakauer, 2008).

Social justice focuses on issues of resources, respect, power, and care (Baker et al., 2004; 2009). It also emphasizes the importance of relationships between persons and gives focus to why inequalities arise when the system, consciously or sub-consciously, promulgates division and separation in society. The social justice model or framework proposed by John Baker and colleagues (Baker et al., 2004; 2009) is based on the premise that these four issues impact people's life experience in one of four ways; economically, politically, culturally, and affectively. Power is often seen as a precursor to inequalities in a political system so that citizens feel that they have no voice. Inequity in how resources are accessed and allocated is largely economic and the inequity in optimal care delivery resides within an affective system. The hidden expectation that women take on unpaid caring roles within families and for wider family members is one example. Baker and colleagues argue that the affective system has received least attention and where society fails to appreciate sustaining relationships of love, care, and solidarity among people; people can be without love or care, isolated, or abused (Baker et al., 2004; 2009).

This is an important message for palliative and end-of-life care. If people are deprived of or unable to access the care they need at a specific point of their life-limiting disease, this creates dependency and vulnerability. The delivery of palliative and end-of-life care cannot be alienated from its economic, cultural, and political dimensions, but care remains at the heart of its practice and so the affective domain holds a particular place in how we understand and promote access, equity, and inclusion (Lynch et al., 2009; Lynch 2010). In the cases which follow, it is argued that a deeper understanding of affective equality may lead to a more inclusive approach to the care of people who evidence suggests are excluded and marginalized in both society and in access to palliative and end-of-life care. Each case reflects a real-world clinical experience and the challenges posed and, where possible, how they are addressed will be considered and debated.

Case study

Living with serious mental illness (SMI)

Martin was a 45-year-old single man who lived with his elderly mother on their farm. Martin had a long-standing history of bi-polar disorder and was supported by local mental health services, although his mother had acted as his main carercarer for many years.

Following his diagnosis and treatment for rectal cancer, he was referred to the home care team who were able to provide guidance on his symptom management. Martin became increasingly withdrawn and reluctant to engage with the team, which his mother interpreted as part of his mental health disorder. His mother and the local mental health team wished him to be transferred to the hospice but the hospice were concerned about their ability to deal with his mental health issues.

The term Serious Mental Illness (SMI) reflects a range of mental health challenges: including schizophrenia, bi-polar disorder, and major depression (Morgan 2016). The global prevalence of mental disorders in adults may reach 48% by 2020 (World Health Organization, 2001. Depression is common in end-of-life patients (Lloyd-Williams and Payne, 2003; Meyer et al., 2003; Lawrie et al., 2004; Robinson and Crawford, 2005). Rates of depression in palliative care patients are variable which is attributable to the complexity of utilizing depression measurement instruments within an already frail and vulnerable population and a focus on physical rather than psychological symptoms in clinical assessments (Lloyd-Williams et al., 2004, Lloyd-Williams and Payne, 2003, Hoptof et al., 2002, Steifel et al., 2001).

Although mental health problems in the standard palliative care population may be exacerbated by metabolic disturbances, unrelieved symptoms, infection, or the progression of disease (Garssen 2004; Thewes et al., 2004), those with SMI may exhibit (or be assumed to have) challenging and demanding behaviours that palliative care practitioners are ill-equipped to deal with and hence are likely to be uncomfortable and question their capacity to provide optimal care (Bloomer and O'Brien 2013, Woods et al., 2008, McCormack and Sharp, 2006).

Palliative care and mental health practitioners share common skills to engage therapeutically with patients or clients (Cutcliffe et al., 2001a; 2001b) and there has been recent literature promoting the potential collaborative opportunity in nursing (Evanblij et al., 2016; Picot 2014) and the value of cross-disciplinary training and education (Taylor et al., 2012). A partnership approach is advisable between mental health and palliative care services to enhance mutual skills and knowledge to ensure that those with severe mental health problems receive equitable care. Picot (2014) demonstrates how a collaboration between two nurse practitioners for their respective mental health/palliative care disciplines can lead to better patient outcomes. Partnership has worked to alleviate clinicians' mutual concerns and consolidated strong relationships between practitioners from disparate disciplines (McCormack and Sharp, 2006). In the case presented here, palliative care concerns expressed about Martin's bi-polar disorder were ill-founded and based upon a limited knowledge of the treatment and maintenance of the disease. Equally, mental health practitioners were unfamiliar with the treatment that Martin had received for his cancer, how to deal with its side-effects, and compounded his mother's fears regarding the use of opiates. Martin's reluctance to engage with palliative care services was based on his belief that to do so would hasten his death. Evidently, the need for cross-communication and joint care planning were paramount; involving both Martin and his mother as far as possible. Offering a weekly palliative day care place to Martin and inviting his community psychiatric nurse to visit him at the hospice on that day created the structure where Martin could feel safe and secure and have both his palliative and mental health needs monitored. The issue of place of care at end of life for people with SMI is an important one (Lavin et al., 2017; Morgan, 2016), The need for better co-ordination here is essential. Once inpatient care was necessary, Martin had built up a significant relationship with staff to reduce his tension about the move. The mental health services were also able to provide an outreach support service to his mother through Martin's final illness and into bereavement, as they had built a strong relationship with her during the time span of Martin's mental health care.

Martin's case speaks to an inequity in care which results in an undue burden on the family carer (his mother) to take on a role with limited and sometimes fragmented access to services (Jones, 2007; Lynch et al., 2009; Iqbal et al., 2010; Ryan et al., 2011). Further the social isolation that Martin may face in terms of poor financial support, cultural stigma, and limited support mean that sterotypes of mental illness persist (McCasland, 2007). Better collaboration may open the dialogue to reduce inequity for people with SMI and see the future as an opportunity rather than challenge.

Key issues in caring for people with mental health problems at end of life

- There is a need to encourage liaison between the palliative care and mental health services beyond episodes of care to enhance mutual understanding of diverse perspectives.
- Close liaison with the local mental health practitioner who holds strong family knowledge is essential to securing trust with both family and mental health team.
- Be clear about role expectations, e.g. who will deliver bereavement support to the family.

Case study

Living with intellectual disability (ID)

Catherine was a 48-year-old woman with Down's syndrome in long-term residential care. She has lived in the same group home since the age of 19 and was employed in a workshop attached to the local day centre for young adults with ID. Catherine has received treatment for breast cancer, which has been largely unsuccessful and she is now developing clinical symptoms suggestive of extension of her disease and the need for palliative care. Catherine's parents are dead and she has one sister, Siobhan, who visits her occasionally. Catherine has a bright personality but evident speech and comprehension difficulties. She has strong attachments to her carers and this dependency has become increasingly problematic for the staff at her home. She is supported by the home care team and plans are being discussed for her care in the terminal phase of her life.

There has been a growing interest in the palliative care of people with ID, the challenges that it poses, and the ways in which access, care and death, and dying and bereavement could be managed (Tuffrey-Wijne and Rose, 2017; Tuffrey-Wijne et al., 2016; Vrijmoeth et al., 2016;; Bailey et al., 2014; Read, 2012; Dunkley and Sales, 2014; Ryan et al., 2011, Tuffrey-Wijne 2002). In the UK, up to 3% of the population have an ID, which may be severe or profound (Department of Health, 2001; Tuffrey-Wijne, 2003). Across the EU, almost 15 million citizens may fit within the category of having an intellectual disability (WHO, 2011). Given the complex spectrum of ID, there is a general agreement that ID is characterized by altered intellectual function before the age of 18 with concurrent limitations in at least two of the following areas (among others): communication and social skills, academic skills, utilizing community resources, and self-care (American Association on Intellectual and Developmental Disability, 2013; Michael, 2008; Tuffrey-Wijne et al.; 2008)

Increased life expectancy due to better medical treatment has led to an increasing incidence of progressive illness in this client group: including cardiovascular disease, Alzheimer's disease, and cancer (Coppus, 2013).

It is suggested that people with an ID are among the most marginalized in society and their dying has been described as a 'hidden transition' within the ID community (Todd and Read, 2006). People with ID face specific barriers in relation to treatment access, and care: including delay in diagnosis and managing transitions in care, poor knowledge within the palliative and hospice community, communication problems, and ethical concerns related to information-giving and consent (Bekkema et al., 2015; Wagemans et al., 2010; Friedman et al., 2012; Tuffrey-Wijne and McEnhill, 2008). There is also evidence that end-of-life care for people with ID is poorly managed (Heslop et al., 2013). This said, the evidence base in this field is growing including tools to identify distress in people with communication difficulties (Tuffrey-Wijne et al., 2006), service delivery and planning (Tuffrey-Wijne et al., 2006a), the specific issues of bereavement (Tuffrey-Wijne and Rose, 2017; Tuffrey-Wijne, 2012; Blackman, 2006) and the importance of user involvement (Tuffrey-Wijne et al., 2006). Research priorities for palliative care in ID have also been proposed including end-of-life decision-making, mapping, quality of care, and refined outcome measures and instruments (Tuffrey-Wijne et al., 2016). However, there still remains limited empirical evidence about the specific palliative care needs of people with ID. There are reports where ID has rendered someone ineligible for cancer treatment or symptoms are misinterpreted as attributable to their ID (Tuffrey-Wijne, 2003; Miki et al., 1999). People with ID needs are not always offered the same range of treatment options as others, nor involved in the decision-making about their care, leading to distress and fragmentation of care (Keenan and McIntosh, 2000; Northfield and Turnbull, 2001). This is compounded by palliative care practitioners concerns that they lack appropriate skills and confidence in the management of ID patients (McLoughlin et al, 2014; Bailey et al., 2014; Read, 2012; Dunkley and Sales, 2014; Ryan et al., 2010). Mild cases of ID may not be fully recognized by professionals (Cumella and Martin, 2000) and this in itself supports the assertion that to label all people with an ID as having communication and comprehension difficulties is erroneous (Read, 2012).

There is clear reference to the needs of this disadvantaged group in terms of access, information, and supportive care (Wagemans et al 2013, Department of Health, 2000; 2001; National Institute for Clinical Excellence, 2004). A key ethical premise of working with people with ID which reflects an equality argument is the belief that the life of all persons holds equal value (Tuffrey-Wijne, 2003). Similarity rather than difference, particularly at end of life, should be promoted (Read, 2012). The case history opens the debate on what we mean by family, the historical experience of institutionalization, and the need for models which promote greater societal integration. Blackman (2006) considers that people with learning disability are more likely to experience profound insecurity due to disrupted patterns of attachment in childhood, often through prolonged hospitalization and the poor experiences therein. This is exacerbated when, for example, transfer to a residential setting is required if the parents die or are unable to cope. In Catherine's case, her family ties had been redirected to the care staff and away from her sibling, Siobhan, which required the palliative care team to redefine the goals and objectives for 'family' meetings. The group home believed that Siobhan should make the decisions about her sister's care but she felt that the care staff were more sensitive and better placed to define Catherine's needs. In ID care settings, the bond between carer and resident can be very strong, which can have negative consequences when the need to involve a wider team of carers is warranted. Jacquemin (2006) describes this as balancing between active presence and respectful distance. In all cases assessing the palliative needs of the person with ID must include an understanding of emotional investment on the part of the person, family, and carer. The biological family may choose to withdraw and this should be respected. Carers may be overprotective and even though people may seek information, they lack education and training to impart this. Given the emphasis on open communication around end-of-life care for patients and families, people with ID should receive information, albeit in a framework that is understandable to them (Tuffrey-Wijne et al., 2006). A growing area of interest is the use of advance care planning in ID (Tuffrey-Wijne et al., 2016), as is breaking bad news (Tuffrey-Wijne et al., 2017; Tuffrey-Wijne, 2012). Research demonstrates that people with ID are likely to be excluded from the knowledge that someone close to them is going to die (Raji and Holmes, 2001; Dowling et al., 2003; Todd, 2004; Blackman, 2006), another example of exclusion rather than inclusion. For the other residents of Catherine's group home, it was important to prepare them for Catherine's final illness and death. In caring for Catherine in her own environment, the choice of the client's preferred location is essential. Catherine chose to stay in her group home and her carers undertook a short one-week palliative care course in the earlier days of her illness to equip themselves with additional knowledge and skills. Supported by the local GP and home care team, Catherine died peacefully in the presence of her sister and close friends from the group home.

Key issues in intellectual disability

- People with ID are likely to be excluded from knowledge about their disease and prognosis but have the right to be included and fully informed within the scope of their understanding.
- ID covers a broad spectrum and end-of-life care needs to be tailored to the individual's ability to understand and participate in their care; respecting their individuality and personality.

- The concept of family may need to be revised in terms of biological family versus 'meaningful family' to the person with ID.
- Grief support should be extended to the carers of the person with ID given the strength of long-term relationships developed in most cases.

Case study

Palliative and end-of-life needs of people in prison

Mark is a 58-year-old man, currently serving 25 years in prison for armed robbery and aggravated assault. His diagnosis of lung cancer and cerebral metastases was confirmed one year ago and despite two course of chemotherapy, his prognosis is extremely poor. He is currently in the prison infirmary following an exacerbation of breathlessness and back pain. The palliative care team were invited to offer consultation. Mark's wife has petitioned for compassionate leave for Mark to be allowed to return home for his final days.

Since the 2nd edition of this textbook, the issue of people with palliative care needs in the prison community has grown exponentially with a widening discourse and evidence base on the topic and international collaboration on best practice and care (Cloyes et al., 2017; Handtke et al., 2017; Wion and Loeb. 2016; Cloyes et al., 2015; Maschi et al., 2014a; 2014b; 2012; Phillips et al., 2011; 2009, Elkins and Olugundoye 2001).

Maddocks (2004) describes prisoners with advanced disease as a truly marginalized population and issues of equity and justice seem particularly pertinent here. Turner et al. (2011) posit that over 10 million people worldwide are incarcerated, the highest rates seen in the US. In the UK, the third highest in Europe, over 151 per 100,000 people are in prison. Rold (2002) considers that the care and treatment given to prisoners at end of-life is a reflection of the moral standing of a society and the dying prisoner is entitled to humane care, irrespective of the reasons for their incarceration. An opposing argument would suggest that the purpose of incarceration is to correct errant behaviour through segregation and punishment (Byock 2002). An important argument in Turner's 2011 paper is that policy often dictates a rehabilitation perspective rather than punishment, although the practice may well reflect the latter. There would also be a disparity in the way culture dictates the delivery of palliative care services (for example) between the US and the UK; the former favouring '*hospice*' in the prison and the latter, an '*in-reach*' model (Stone et al., 2011). Therefore, for the palliative care practitioner, an understanding of their own perceptions, values, prejudices, and beliefs in relation to the role of incarceration in society may assist in defining how to achieve best practice principles (Rich, 2013). Critical to this health-care challenge, although not specific to Mark's case, the ageing population in the prison system and concomitant health decline is significant

(Turner and Peacock, 2017; Maschi et al, 2014a, Maschi et al., 2014b; Maschi et al., 2012, O'Neill et al, 2002). Turner and Peacock (2017) argue that the turn towards neoliberalism in society is one reason that older people are likely to be incarcerated and to die in custody. The prison population demonstrates higher risk factors in terms of health and well-being. Up to 75% of inmates have a history of chronic alcohol and drug dependency, may age faster in physiological terms than people in the non-prison population, and be susceptible to health problems often associated with chronic disease (Bick, 2002). The structure of prison life divides family cohesion and relationships can breakdown leaving the prisoner isolated and without external social support.

Colleran and O'Síorán (2006) highlight the following as key issues of the complexity of palliative care provision in the prison system:

- Many prisons lack the infrastructure to care for dying inmates.
- The focus may be on extending life as far as possible as the death of an inmate can pose a threat to prison security (Dubler, 1998).
- Compassionate release to allow the prisoner home leave can be a lengthy bureaucratic procedure (Lum, 2004).
- Prison security measures such as 'lock-down' and the use of physical restraints mitigate against the ideal of death with dignity.
- Palliative caring can be limited by restricted access to the prison hospitals and medication and the continuing presence of prison officers by the patient's bedside on 'bedwatch' (Lum, 2004; Maddocks, 2004).

Just over ten years later, some of these issues remain although increasingly, efforts are made to develop stronger working relationships between palliative care and prison staff to manage the complexity of end-of-life care in prison (Turner et al., 2011). One example may be the lowered emphasis on the challenge of physical restraint of prisoners at end of life in the literature. Byock (2002) identified that more than 2,500 US inmates are manacled at the time of death. However, more recent research would include the use of inmate hospice 'volunteers' to manage care and support, which indicates some revisioning of how care is delivered (Cloynes et al., 2015). Continual liaison between the palliative care team and the prison service is needed to ensure that the dignity and appropriate treatment are afforded to the patient in the most appropriate manner. Both the palliative care team and prison service have a duty of care towards the prisoner, the latter having an additional duty of safe custody. This includes discretion in supervising the dying prisoner.

Most institutions offered spiritual and psychological counselling to dying prisoners and a relaxation of visitation rules for families, Yampolskya and Winston (2003). The degree of support for the family, particularly in the bereavement phase was variable. Given the nature of incarceration, and the separation and isolation experienced by both prisoner and family, this would appear to be an area in need of redress.

The management of prisoners at the end of life is a multifaceted concept that warrants careful consideration on how best to match the palliative team skills to patient needs. Descriptions of the prison environment as one of distrust and despair juxtaposes the essence of palliative care as a cohesive and supportive network for all at the end of life but also asks for a careful consideration of what justice and equity really mean in society. Palliative care practitioners need to practise their craft out of the defined ethical frameworks that govern best practice differently to non-clinical professionals. Confidentiality and sharing of information may have a very different meaning for a palliative care physician and a prison governor. In Mark's case, a twofold approach was needed: one to direct clinical management in the prison setting (as per the 'in-reach' model proposed by Stone et al., 2011) and the other to support the family in their struggle to obtain a compassionate release for him. Given his crime, home release was unlikely and the hospice was suggested as an alternative place of care following agreement with the hospice management team. However, the nature of decline in his health meant that Mark died in prison before the release could be sanctioned, a situation not uncommon, where the need for earlier communication could have led to a more favourable outcome.

Key issues in caring for people in prison at end of life

- The needs of prisoners are multifaceted and complex.
- Family and prisoner work involves addressing issues of despair, loss, and isolation.
- Bureaucracy can impact on the reality of palliative care service delivery.
- Mutual dialogue between the clinical team and the prison service is essential.
- The clinician's duty of care may exceed the containment and segregation requirements of the prison services and should be explicit at the outset.

Case study

A woman who is homeless

Lilian is a 72-year-old woman who has been homeless for over 20 years. Having left an abusive marriage and become estranged from her family, she lived 'rough' using hostels on occasion, preferring to avoid social service involvement and sleeping in derelict buildings or doorways in the city centre. She had a known alcohol dependency and had spent some time in prison for minor offences. She had sought help from a homeless shelter health-care provider which resulted in a diagnosis of advanced ovarian cancer. She did not seek treatment but rather disappeared only to re-appear about six weeks later, clinically unwell and clearly approaching the end-of-life stage of her illness.

As in the case of prisoners, there is a growing discourse about the palliative care needs of the homeless. Lilian's case can be considered at a number of levels; her age, her dependency, and her disease and place of care at end of life. Homeless people are one group who are largely underserved in palliative care (Håkanson et al., 2016). The challenges of co-morbidities, substance abuse, and mental illness in this group make the delivery of palliative care complex (Cagle, 2009). Moreover, the transitional nature of homeless living means that place of care in an institution, however well-meaning, can post specific challenges for the homeless person who may have had poor interactions with authority, systems, and health care. This said, palliative care for homeless people has been considered in terms of research into needs: staff, and service user views, design of care facilities, and more recently, the ageing (Tobey et al., 2017; Cagle, 2009;; Podymow et al,. 2006; Moller, 2005; Ahmed, 2004, Anderson and Rayens 2004, Anderson and Imle 2001).

Definitions and estimates of prevalence of homelessness are unclear. Notwithstanding the current migrant crisis, which is a related but different issue, the United Nations (2005) estimate that 100,000 people are homeless at any one time. Mortality is up to four times higher than in the general population (Geddes and Fazel, 2011) with a range of chronic life-limiting illness and untreated or poorly managed chronic disease related to lifestyle and poverty. Moreover, people who are homeless are likely to die without access to palliative care (Ahmed et al., 2004). The work of Song and colleagues (Song et al., 2007a; 2007b) offers evidence of the loneliness of death for homeless people and the risk of a death without dignity. A recent Canadian study would suggest that this death is likely to occur up to 30 years earlier than in the general population: with higher incidences of hepatitis, heart disease, cancer, and diabetes in this group (Huynh et al., 2015). The evidence would also suggest that socioeconomic disadvantage may be higher in males, people from non-white ethnicity, those who are single, those with lower educational achievement, and those without a home (Lewis et al., 2011; Walshe et al., 2009).

To address this disparity, models of palliative and end-of-life care need to be novel and innovative. Again, Canada has developed excellent examples of shelter-based palliative care and ambulatory services to meet the complexity of need (Baune et al., 2014; Podymow et al., 2006). An important study by McNeil et al. (2015 would propose that any initiative to bring palliative care to homeless people must begin from a point of harm reduction recognising the circumstances which have led to their life and developing trust strategies which foster engagement and collaboration wherever possible. Given the stigma associated with homelessness and the concern raised by hostel staff in being able to manage end-of-life scenarios (the hospice may offer a solution for Lilian's care. Speck (2006) cautions against the risk of 'chronic niceness' in palliative care where, for some, the impact of care-giving is overwhelming and fails to acknowledge the reality of their lives. For Lilian, the ability to accept help was a hurdle for staff, as was her need to be mobile and not supervised or contained within her room, both of which she found oppressive and frustrating. Håkanson et al. (2016), offer a useful framework in which to consider how best to approach palliative care for homeless people. They identify the need to build trust; including family where possible, to 're-dignify the person' (p. 1258), offer pragmatic solutions, and clear honest communication. For Lilian, one of the core skills that palliative care offered was the benefit of a multidisciplinary approach which enable her to re-engage with her family (social work), address her spiritual concerns (chaplaincy), and feel wanted and loved (nursing). Dying in hospice provided a space for Lilian to make sense of a life which had been traumatic and painful. For others who live with homelessness, the outcome may not be as positive which palliative care practitioners need to appreciate in practice.

Key issues in caring for people who are homeless

- Caring for people who are homeless in a hospice setting can be challenging.
- Establishing trust is an essential component of good practice.
- Respecting the value of the story which led to homelessness is important in supporting and understanding decision-making.
- Palliative care services need to be innovative in their community/outreach services to include homeless people and those who care for them.

Case study

Living with chemical dependency and/or addiction

Mary is a 35-year-old woman with an astrocytoma grade IV, which has left her with a left-sided hemiparesis. She has a long-standing history of heroin and alcohol addiction and has been supported by community addiction services and her local mental health team. She lives alone, but has some family support from her own siblings, some of whom are themselves in rehabilitation programmes or known addicts. Transfer to the hospice is imminent. Mary has two children in the care of social services who only have had limited contact with their mother and are currently fostered.

There is a notable link between illicit substance abuse, homelessness, and the challenge that these issues can pose at end of life (McNeil and Guirguis-Younger, 2011). Chemical dependency and substance abuse are defined as uncontrollable situations that results in adverse legal, health, and social consequences (Diagnostic and Statistical Manual for Mental Disorders, DSM-IV). Bruera et al. (1995) estimated that over 25% of patients admitted to a palliative care unit had alcohol addiction problems. Evident in addiction is an internal struggle between the 'high' of elation as effected and the isolation, loneliness, and depression of a life-seeking procurement of the drug, notwithstanding the trauma of withdrawal and rejection by family and society at large (Kirsch and Passik, 2006). There is a growth in literature on the topic of

Mary's case raises a number of issues from an affective equality perspective. The marginalization of people living with addition and dependency has clear ramifications for how they access resources, and how they experience respect, power, and care (Baker et al., 2004; 2009). How can her estranged children be part of her end-of-life care plan and is that possible? How do a palliative care team work with substance abuse at a family level and where do the boundaries overlap with other services? Even the language of palliative care may need to be adapted. Concepts such as physiological dependence and tolerance, which are clearly understood in palliative care terms may hold different meaning for patients and families living with addiction (Kirsch and Passik, 2006). Reticence in admitting addicted patients for end-of-life care is due to misconceptions that trying to manage such patients is too complex and intractable (Passik and Theobald, 2000).

Passik and Theobald (2000) illustrate the extent to which addiction can impact on palliative care interventions. They note the impact of addiction on the family, the suffering endured by the patient as they fluctuate between their continual need for the 'fix', and the increasing burden to family as symptoms proliferate. The complexities identified include:

- Increased suffering for the patient.
- Increased stress for the family.
- Difficulties in assessment, particularly the extent of symptom burden.
- Poor compliance (patient) and fear about prescribing (practitioner).

In addiction, cancer diagnosis can compound already negative emotions, such as loss of self-worth and hopelessness. A high level of co-morbidity with psychiatric disorders is also noted, (EMCDDA 2015, see emcdda.europa.eu/topics/pods/comorbidity-substance-usemental-disorders-europe).

The continual need to source drugs weakens the already compromised cancer patient and exacerbates symptoms of addiction, such as insomnia and fatigue as well as opioid tolerance (Walsh and Broglio, 2010; Kirsh and Passik, 2006). This can then confuse the palliative care practitioner who may misinterpret symptoms as related to cancer and not the addiction, or vice versa.

The successful transition to palliative care treatment may be best achieved through the construction of some degree of control over a potentially uncontrollable situation. Support of a multidisciplinary team; supplemented by specialist workers in addiction counselling or addiction work will help to create a cohesive plan of care that meets the patient and family need. A clear understanding of the existent family dynamic is essential before care is proposed: including relations between family members, and dependency and co-dependencies need to be identified. The family may harbour resentment, guilt, anger, or fear, which inhibit their ability to receive help and be a part of the care plan offered. They may clearly not wish to be part of the care team but find it difficult to move away from the situation. Families may have fears over the use of certain medications and specific safeguards may be necessary to ensure that drugs are safely managed outside the hospice setting. Palliative care staff have an educational role with families to enable them to understand the differences between dependence and addiction. Further, practitioners need to respond to families at the physical and emotional point in which they find themselves, which warrants specific supports for the practitioner. Families who are ‘burnt-out’ from living with an addicted family member need to hear that it is possible for them to withdraw from the situation and still play some part in being present for their family member at end of life.

As practitioners, key philosophical issues are addressed. For example, how do the goals of addiction ‘recovery’ fit with a model of palliative care? Patients at end of life are not likely to find the personal resources to seek recovery from their addiction and the best that may be achieved is a satisfactory degree of compliance with a treatment and care protocols. Patients and families need to believe that their suffering can be supported and that pain is not a necessary part of living. The safe surroundings of a hospice may be protective, or viewed as restrictive, where access to the drug is limited. Naturally, the decision to admit a patient with an addiction problem is a point of negotiation for the inpatient and community teams. As trust is a key determinant addiction management: there is a need to focus towards stability and reorientation; supporting an already fragile existence and equilibrium.

Mary’s initial needs were clearly based around the need to provide a regimen of sound symptom management, which kept her pain-free in order for her to address the psychosocial needs in her life, such as child care after her death. The complexity of addiction in other members of her family meant that stringent protocols were put in place to enable access in a controlled fashion. Ground rules were laid including the fact that any member who came to the hospice under the influence of drugs would not be admitted. Initial staff fears over theft of drugs were unfounded as the medication room was not accessible to the public. Mary was able to be part of discussions with social services over the future care of her children and although a planned visit from the children was not fulfilled, she died peacefully six weeks after admission.

Key issues in addiction

- A clear understanding of how team members' values around addiction is important.
- Symptom management can be complicated but possible given flexibility.
- Families may not be willing or able to act in capacity supportive capacity for the patient any longer.
- Addiction is about suffering and a palliative care response must encompass the context of suffering endured by the patient with dependency.

Conclusion

In this chapter, a number of possible scenarios have been explored that exemplify the complexities of providing palliative care to patients who either consider themselves, or are considered to be, marginalized. The expression of palliative care as a human right has an international significance (World Health Assembly Resolution, WHA 67.10). A case is made that a re-orientation towards a model of social inclusion and specifically affective equality which values relationality and care as a pre-requisite for palliative care-giving is both beneficial and essential to the enhancement of trust, collaboration, partnership, and best practice. For palliative care practitioners, the need to become 'contextually educated' would be an important factor in how patients such as those described here are supported in their final illness. Contextual education implies that textbook materials are only useful as resources for knowledge and not definitive guides to practice. Each case will be significant and unique and should open the opportunities for multi-agency working. This requires palliative care to demonstrate how it can contribute to this complex situation, so as to prevent transition to palliative care being perceived as a last resort. Neither can it be assumed that palliative care can provide all the resources to cater for such a wide and disparate group of people and again, the boundaries of practice need to be clearly defined at the outset so that all including the patient and family, understand what care is available to them.

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References

Addington-Hall J. (2000). *Positive Partnerships: Palliative Care for Adults with Severe Mental Health Problems*. London: National Council for Hospices and Specialist Palliative Care Services.

Ahmed, N., **Bestall, J.E.**, **Ahmedzai, S.H.**, **Payne, S.A**, **Clark, D.**, and **Noble, B.** (2004). Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med*, September 2004; **18**(6): 525–42.

American Association on Intellectual and Developmental Disabilities. (2013). Definition of intellectual disability. Available from: http://aaidd.org/intellectual-disability/definition (accessed 19 May 2017).

Anderson D.G.and **Imle M.A.** (2001). Families of origin of homeless and never-homeless women. *West J Nurs Res*, **23**(4): 394–413.

Anderson D,G., and **Rayens M.K.** (2004). Factors influencing homelessness in women. *Public Health Nurs*, **21**(1): 2–23.

Bailey M., **Doody O.**, and **Lyons R.** (2014) Surveying community support for persons with intellectual disability and palliative care needs. *Br J Learning Disability*, **44**(1): 24–34.

Baker J. Lynch K., **Cantillon, S.** and **Walsh, J.** (2004). *Equality: From Theory to Action*. Basingstoke, UK: Palgrave Macmillan.

Baker, J. Lynch, K. Cantillon, S. and **Walsh, J.** (2009). *Equality: From Theory to Action*, 2nd Edition. London: Palgrave Macmillan.

Baune L., **Leavens A.**, **Muskat B.**, et al. (2014). Poverty and Pediatric Palliative Care: What can we do? *J Soc Work End Life Palliat Care*, **10**(2): 170–85.

Bekkema N., **deVeer, A.J.E.**, **Hertogh C.M.P.M.**, and **Franke, A.L.** (2015). From activating towards caring: shifts in care approaches at the end of life of people with intellectual disabilities: a qualitative study of the perspectives of relatives, care-staff and physicians. *BMC Palliat Care*, **14**(33) doi: 10.1186/s12904-015-0030-2.

Bick J.A. (2002). Managing pain and end-of-life care for inmate patients: the California Medical Facility experience. *J Correctional Health Care*, **9**(2): 131–47.

Blackman N. (2006). Supporting bereaved people with intellectual disabilities. *Eur J Palliat Care*, **12**(6): 247–8.

Bloomer M, **O'Brien A** (2013) Aboriginal palliative care and mainstream services. *Aust Nurs J*, Jan **20**(6): 39.

Brennan F.P. (2007). Palliative Care as an International Human Right. *J Pain Symptom Management*, **33**(5): 494–9.

Bruera E., **Moyano J.**, **Seifert L.**, et al. (1995). The frequency of alcoholism among patients with pain due to terminal cancer. *J Pain Symptom Manage,* **10**(8): 599.

Byock I.R. (2002). Dying well in corrections: Why should we care? *J of Correctional Health Care*, **9**(2): 107–116.

Cagel J. (2009). Weathering the storm: palliative care for the elderly homeless. *J House Elderly*, **23**(1-2) : 29–46.

Cloyes K.G., **Rosenkrantz S.J.**, and **Supiano K**, (2017). Caring to learn and learning to care: Inmate vospice volunteers and the delivery of prison end-of-life care. *J Correctional Health Care*, **23**(1): 43–55.

Cloyes K.G., **Berry P.H.**, **Martz K.**, and **Supiano K**, (2015). Characteristics of prison hospice patients: Medical history, hospice care, and end-of-life symptom prevalence. *J Correctional Health Care*, **21**(3): 298–308.

Colleran M., and **O'Síoráin L.** (2006). Providing palliative care for prisoners. *Eur J Palliat Care*, **13**(6): 257–9.

Connolly M. (2001). The disadvantaged dying: care of people with non-malignant conditions. In: Kinghorn S., Gamlin R. (eds) *Palliative Nursing, Bringing Comfort and Hope*. Edinburgh: Baillière Tindall.

Connor S., and Sepulveda C. (eds) (2014). *Global Atlas of Palliative Care and the End-of-life*. Geneva/London: World Health Organisation/Worldwide Palliative Care Alliance.

Coppus A.M. (2013). People with Intellectual disabilities; what do we know about Adulthood and life expectancy? *Dev Disability Resesarch Rev*, **18**(11): 6–16.

Cumella S., and **Martin D.** (2000). *Secondary Healthcare for People with a Learning Disability*. London: Department of Health.

Cutcliffe J.R., **Black C.**, **Hanson E.**, and **Goward P.** (2001a). The commonality and synchronicity of mental health nurses and palliative care nurses: closer than you think? *J Psychiatric Ment Health Nurs*, **8**: 53–9.

Cutcliffe J.R., **Black C.**, **Hanson E.**, and **Goward P.** (2001b). The commonality and synchronicity of mental health nurses and palliative care nurses: closer than you think? *J Psychiatric Ment Health Nurs*, **8**: 61–6.

Dowling S., **Hubert J.**, **Hollins S.** (2003). Bereavement interventions for people with learning disabilities. *Bereavement Care*, **9**: 8–15.

Dubler N.N. (1998). The collusion of confinement and care: end-of-life care in prisons and jails. *J Law Med Ethics*, **26**: 149–56.

Dunkley S., and **Sales R.** (2017). The challenges of providing palliative care for people with intellectual disabilities: a literature review. *Int J Palliat Nurs*, **20**(36), 279–96.

Elkins M., and **Olugundoye D.** (2001). *The Prison Population in 2000: A Statistical Review*. London: The Home Office.

EMCDDA-European Drug Report 2015, downloaded 22.11.17 at http://www.emcdda.europa.eu/topics/pods/comorbidity-substance-usemental-disorders-europe.

Evanblij K., **Widdershoven G.A.M.**, and **Onwuteaka-Philipsen, B.D.** (2016) Palliative care in mental health facilities from the perspective of nurses: a mixed-methods study. *J Psych Mental Health Nurs*, **23**(6-7), 409–418.

Friedman S.L., **Helm D.T.**, and **Woodman A.C.** (2012). Unique and universal barriers: Hospice care for aging adults with intellectual disability. *Am J Intellect Dev Disabil*, **117**(6): 509–32.

Garssen B. (2004). Psychological factors and cancer development: evidence after 30 years of research. *Clin Psychol Rev*, **24**(3): 315–38.

Geddes J.R., and **Fazel S.** (2011). Extreme health inequalities: mortality in homeless people. *The Lancet*, **384**(9953): 2156–7.

Gomez Batiste X., and Connor S. (eds) (2017). *Building integrated palliative care programs and services*. Geneva: Technical Advisory Group (TAG) of the WHO initiative for Palliative Care.

Grande G.E., **Addington-Hall J.M.**, and **Todd C.J.** (1998). Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med*, **47**(5): 565–79.

Gwyther L. (2008). Just palliative care? Integrated models of care. *J Pain Symptom Manage*, **36**: (5) 17–9.

Gwyther L., **Brennan F**, and **Harding R.** (2009). Advancing palliative care as a human right. *J Pain Symptom Manage*, **38**(5), 767–74.

Håkanson C., **Sandberg J.**, **Eksted M.** et al. (2016). Providing palliative care in a Swedish support home for people who are homeless. *Qual Health Research*, **26**(9): 1252–62.

Handtke V., **Bretschneider W.**, **Elgar B.**, and **Wangmo T.** (2017). The collision of care and punishment; Ageing prisoner's views on compassionate release. *Punishment and Society*, **19**(1): 5–22.

Heslop P., **Blair P.**, **Fleming P.**, et al. (2013). *Confidential inquiry into premature deaths of people with learning disabilities* (CIPOLD). Avalaible from: http://www.bris.ac.uk/cipold/reports/index.html (accessed 18 May 2017).

Hoptof M., **Chidgey J.**, **Addington-Hall J.**, and **Lan Ly K.** (2002). Depression in advanced disease: a systematic review. Part 1: prevalence and case finding. *Palliat Med*, **16**(2): 81–97.

Human Rights Watch (HRW) (2012). 'Old age behind bars: the aging prison population in the United States'. Available from: www.hrw.org/sites/default/files/reports/usprisons0112webwcover_0.pdf (accessed 12 May 2017).

Huynh L., **Blair H.**, and **Dosani N.** (2015). Minding the gap: access to palliative care and the homeless. *BMC Palliat Care*, **14**(62). doi 10.1186/s12904-015-0059-2.

Iqbal J., **Francis L.**, **Reid J.**, **Murray S.**, and **Denvi, M.** (2010). Quality of life in patients with chronic heart failure and their carers: a 3-year follow-up study assessing hospitalization and mortality. *European Journal of Heart Failure*, **12**: 1002–8.

Jacquemin D. (2006). Caring for people with learning difficulties. *Eur J Palliat Care*, **12**(6): 249–50.

Jones A., **Tuffrey-Wijne I.**, **Bernal, J.**, **Butler, G.**, and **Hollins, S.** (2007). Meeting the cancer information needs of people with learning disabilities: experiences of paid carers. *British Journal of Learning Disabilities*, **35**(1): 12–18.

Kang M., **Alperstein G.**, **Dow A.**, **Van Beek I.**, **Martin C.**, and **Bennett D.** (2000). Prevalence of tuberculosis infection among homeless young people in central and eastern Sydney. *J Paediatr Child Health*, **36**(4): 382–4.

Keenan P., and **McIntosh P.** (2000). Learning disabilities and palliative care. *Palliative Care Today*, **9**(3): 11–13.

Kirsch K.L., and **Passik S.D.** (2006). Palliative care of the terminally ill drug addict. *Cancer Invest*, **24**(4): 425–31.

Ko, D.N., **Cruz-Perez, P.**, and **Blinderman, C.D.** (2011). Ethical issues in palliative care. *Prim Care Clin Office Pract*, **38**(2): 183–93.

Koffman J., and **Camps M.** (2004). No way in. Including the excluded at the end of life In: Payne S, Seymour J, and Ingleton C (ed.). *Palliative Care Nursing Principles and Evidence for Practice*. Bucks: Open University Press, pp. 364–84.

Krakauer E.L. (2008). Just palliative care: Responding responsibly to the suffering of the poor. *JPSM*, **36**(5): 505–13.

Lamas D., and **Rosenbaum L.**, (2012). Painful inequities-palliative care in developing countries. *NEJM*, **36**(3): 199–201.

Lavin K., **Davydow D.S.**, **Downey L.**, **Engelberg R.A.**, et al. (2017). Effect of psychiatric illness on acute care utilization at end of life from serious medical illness, *JPSM*, **54**(2), 176–85.

Lawrie I., **Lloyd-Willams M.**, and **Taylor F.** (2004). How do palliative medicine physicians assess and manage depression. *Palliat Med*, **18**(3): 234–8.

Lee B.A., **Spratlen-Price T.**, and **Kanan J.W.** (2003). Determinants of homelessness in metropolitan areas. *J Urban Affairs*, **25**(3): 335–56.

Lewis J.M., **DiGiacomo M.**, **Currow D.C.**, and **Davidson P.M.** (2011). Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *J Pain Symptom Manage*, **42**(1): 105–18.

Lloyd-Willams M., and **Payne S.** (2003). A qualitative study of palliative care nurses' perceptions on depression. *Palliat Med*, **17**(4): 334–9.

Lloyd-Williams M., **Dennis M.**, and **Taylor F.** (2004). A prospective study to compare three depression screening tools in patients who are terminally ill. *Gen Hosp Psychiatry*, **26**(5): 384–9.

Lum K.L. (2004). Palliative care behind bars: the New Zealand prison hospice experience. In: Rajagopal M.R., Mazza D., Lipman A.G. (ed.) *Pain and Palliative Care in the Developing World and Marginalized Populations: a Global Challenge*. New York: Haworth Press Inc., pp. 131–8.

Lynch K., **Baker J.**, and **Lyons M.** (2009). *Affective Equality: Love, Care and Injustice*. Basingstoke: Palgrave Macmillan.

Lynch K. (2010) *Affective inequalities: challenging (re)distributive, recognition and representational models of social justice*. Presentation at RCO2 Economy and Society Session 1 New Approaches to Understanding Inequalities and their Significance ISA XVII World Congress of Sociology. Gothenburg, Sweden.

Maddocks I. (2004). Commentary: prisoners with advanced disease—a truly marginalized population. *J Pain Palliat Care Pharmacother*, **17**(3-4): 139–40.

Maschi T., **Deborah V.**, **Harrison M.T.** et al. (2014a). Bridging community and prison for older adults: invoking human rights and elder and intergenerational family justice. *Int J Prisoner Health*, **10**(1): 55–73.

Maschi T., **Marmo S.**, and **Han J.** (2014b). Palliative and end-of-life care in prisons: a content analysis of the literature. *Int J Prisoner Health*, **10**(3): 172–97.

Maschi T., **Viola D.**, and **Sun F.** (2012), The high cost of the international aging prisoner crisis: well-being as the common denominator of action, *The Gerontologist*, doi:10.1093/geront/gns12.

McCasland L. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. *Journal of Hospice & Palliative Nursing*, November/December, **9**(6): 305–13.

McCormack P., and **Sharp D.M.M.** (2006). Palliative care for people with mental health problems. *Eur J Palliat Care*, **13**(5): 198–201.

McNeil R., **Kerr T.**, **Anderson S.**, et al. (2015). Negotiating structural vulnerability following regulatory changes to a provincial methadone programme in Vancouver, Canada; a qualitative study. *Soc Sci Med*, **I33**: 168–76.

McLaughlin D., **Barr O.**, **McIlfatrick S.**, and **McConkey R.** (2014). Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: a mixed methods study. *Palliat Med*, **28**(10): 1213–21.

McNeil R., and **Guirguis-Younger M.** (2011). Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals. *Palliat Med*, **26**(4), 350–9.

Meyer H.A.M., **Sinnott C.**, and **Seed P.T.** (2003). Depressive symptoms in advanced cancer. Part 2. Depression over time; the role of the palliative care professional. *Palliat Med*, **17**(7): 604–7.

Michael J. (2008). *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Aldrick Press.

Morgan B. (2016). 'No right place to die': Nursing attitudes and needs in caring for people with serious mental illness at end-of-life. *J Am Psych Nurs Assoc*, **22**(1): 31–42.

Miki M., **Ohtake N.**, **Hasumi M.**, **Ohi M** et al. (1999). Seminoma associated with bilateral cryptorchidism in Down's Syndrome: a case report. *Int J Urol*, **6**(7): 377–80.

Moller, M.D. (2005). Neurobiological responses and schizophrenia and psychotic disorders. In G.W.Stuart and M.T. Laraia (eds), *Principles and*

Practice of PsychiatricNnursing (8th ed.). St. Louis, MO: Mosby, pp. 334–68.

Muir-Chochrane E., **Fereday J.**, **Junedini J.**, **Drummond A.**, and **Darbyshire P.** (2006). Self-management of medication for mental health problems by homeless young people. *Int J Ment Health Nurs*, **15**(3): 163–70.

National Institute for Clinical Excellence (2004). *Supportive and palliative care services for adults with cancer: understanding NICE Guidance—information for adults with cancer, their families and carers and the public*. London: National Institute for Clinical Excellence.

Northfield J., and **Turnbull J.** (2001). Experiences from cancer services. In: Hogg J., Northfield J., and Turnbull J. (ed.) *Cancer and People with Learning Disabilties: the Evidence from Published Studies and Experiences from Cancer Services.* Kidderminster: BILD Publications, pp. 39–56.

O'Neill J., and **Marconi K.** (2001). Access to palliative care in the USA: why emphasize vulnerable populations? *J R Soc Med*, **9**(4): 452–4.

O'Neill J., **Akhter M.**, and **Poliquin L.** (2002). Terminally ill offenders: an international dialogue. *J Correctional Health Care*, **9**: 119–24.

Passik S.D., and **Theobald D.E.** (2000). Managing addiction in advanced cancer patients: why bother? *J Pain Symptom Manage*, **19**(3): 229–34.

Phillips, L.L., **Allen, R.S.**, **Harris, G.M.**, **Presnell**, et al. (2011). Aging prisoners' treatment selection: does prospect theory enhance understanding of end-of-life medical decisions? *The Gerontologist*, **51**(5): 663–74.

Phillips L.L., **Allen R.S.**, **Salekin K.**, and **Cavenaugh R.K.** (2009). Care alternatives in prison systems: Factors influencing end-of-life treatment selection. *Criminal Justice and Behavior*, **36**(6): 620–24.

Picot S.A., **Glaezer K.M.**, and **Myhill K.J.** (2014). Coordinating end of life care for individuals with a mental illness—–A nurse practitioner collaboration. *Collegian* **22**(1): 143—9.

Podymow T., **Turnbull J.**, and **Coyle D.** (2006). Shelter-based palliative care for the homeless terminally ill. *Palliat Med*, **20**(2): 81–6.

Praill D. (2000). Editorial: Who are we here for? *Palliat Med*, **14**(2): 91–2.

Raji O., and **Hollins S.** (2001). Exclusion for funerary rituals and mourning: implications for social and individual identity. In: Hubert J (ed.). *Madness, Disability and Social Exclusion: the Archeology and Anthropology of Difference*. London: BILD Publications, pp. 208–16.

Radbruch L., **Foley K.**, **De Lima L.**, **Praill D.**, and **Furst C.J.** (2007). The Budapest Commitments: setting the goals for the joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospices. *Palliat Med*, **21**(4): 269.

Rich B.A. (2013). Justice Mercy and the terminally ill prisoner. *Cambs Quart Health Care Ethics*, **22**: 382–8.

Robinson J.A., and **Crawford G.B.** (2005). Identifying palliative care patients with symptoms of depression: an algorithm. *Palliat Med*, **19**(4): 278–87.

Rold W.J. (2002). Introduction. *J Correctional Health Care*, **9**(2): 103–5.

Read, S. (2012). Palliative care for people with intellectual disabilities: Pitfalls and potential. *Palliat Med*, **27**(1): 3–4.

Reimer-Kirkham S., **Stajduhar** *K.* et al. (2016). Death is a social justice issue: perspectives on equity informed palliative care. *Adv Nurs Sci*, **39**(4): 293–307.

Rosenwax L.K., **McNamara B.**, and **Blackmore A.M.** (2005). Estimating the size of a potential palliative care population. *Palliat Med*, **19**(7): 556–62.

Ryan K., **McEvoy, J.**, **Guerin S.**, and **Dodd P.** (2010). An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. *Palliat Med*, **24**(6): 566–72.

Ryan K., **Guerin S.**, **Dodd P.**, and **McEvoy J.** (2011). End-of-life care for people with intellectual disabilities: Paid carer perspectives. *Journal of Applied Research in Intellectual Disabilities*, **24**(3): 199–207.

Speck P. (2006). *Teamwork in Palliative Care; Fulfilling or Frustrating*? Oxford: Oxford University Press.

Stiefel F., **Die Trill M.**, **Berney A.**, **Nunez Olarte J.M.**, and **Razavi D.** (2001). Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care. *Supportive Care Cancer*, **9**: 477–88.

Stienstra D., and **Chochinov D.M.** (2012). Palliative care for vulnerable populations. *Palliat Support Care*, **10** (1): 37–42.

Stone K., **Papdopolous I.**, and **Kelly D.** (2011). Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. *Palliat Med*, **26**(8): 969–78.

Taylor J., **Swetenham K.**, **Myhill K.**, **Picot S.** et al. (2012). IMhPaCT: an education strategy for cross-training palliative care and mental health clinicians. *Int J Palliat Nurs*, **18**(6): 290–4.

Thewes B., **Butow P.**, **Girgis A.**, and **Pedlebury S.** (2004). The psychosocial needs of breast cancer survivors. A qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-oncology*, **13**(3): 177–89.

Tickle S. (2007). Why we treat patients shunned by others. *Pulse Careers*, 69–70.

Tobey M., **Manasson J.**, **DeCarlo K.**, et al. (2017). Homeless individuals approaching the end of life. Symptoms and attitudes. *JPSM*, **53**(4): 738–46.

Todd S. (2004). Death counts:the challenge of death and dying in learning disability service. *Learning Disabil Pract*, **7**(10): 12–15.

Todd S., and **Read S.** (2006). Inclusion, exclusion and separation: a short history of death and disability. *J Appl Res Intellect Disabil*, **19**(2): 252.

Tuffrey-Wijne I. (2002) The palliative care needs of people with learning disabilities: a case study. *Int J Palliat Nurs*, **8**(5): 222–32.

Tuffrey-Wijne I. (2003). The palliative care needs of people with intellectual disabilities: a literature review. *Palliat Med*, **17**(1): 55–62.

Tuffrey-Wijne I., **Bernal J.**, **Jones A.**, **Butler G.**, and **Hollins S.** (2006a). People with intellectual disabilities and their need for cancer information. *Eur J Oncol Nurs*, **10**(2): 106–16.

Tuffrey-Wijne I. and **McEnhill L.** (2008). Communication difficulties and intellectual disability in end-of-life care. *Int J Palliat Nurs*, **14**(4): 189–94.

Tuffrey-Wijne I., **Whelton R.**, **Curfs L.**, and **Hollins S.** (2008). Palliative care provision for people with intellectual disabilities: A questionnaire survey of specialist palliative care professionals. *Palliat Med*, **22**(3): 281–90.

Tuffrey-Wijne I (2012) Palliative care for people with intellectual disabilities. *Int J Palliat Nurs*, **18**(6): 264–6.

Tuffrey-Wijne I., and **Rose T.** (2017). Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study. *J Intellect Disability*, **61**(8): 727–36

Tuffrey-Wijne I., **McLoughlin D.**, **Curfs L.** et al. (2016). Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care. *Palliat Med*, **30**(5): 446–55.

Turner M., **Payne S.** and **Barbarachild Z.** (2011). Care or custody? An evaluation of palliative care in prisons in North West England. *Palliat Med*, **25**(4): 370–7.

Turner M., and **Peacock M.** (2017). Palliative care in UK prisons: practical and emotional challenges for staff and fellow prisoners. *J Correctional Health Care*, **23**(1): 56–65.

United Nations (2006). *Convention of the Rights of Persons with Disabilities and Optional Protocol*. New York: United Nations.

Van Kleffens T., **Van Baarsen B.**, **Hoekman K.**, and **Van Leeuwen E.** (2004). Clarifying the term 'palliative' in clinical oncology. *Eur J Cancer Care (Engl)*, **13**(3): 263–71.

Vrijmoeth C., **Barten P.**, **Assendelft W.J.J.** et al. (2016). Physicians' identification of the need for palliative care in people with intellectual disabilities. *Res Develop Disabilities*, **59**: 55–64.

Walsh AF, and **Broglio K.** (2010). Pain management in advanced illness and comorbid substance use disorder. *J Hosp Palliat Nurs*, **12**(21): 8–14.

Walshe C., **Todd C.**, **Caress A.**, and **Chew-Graham, C.** (2009). Patterns of access to community palliative care services: a literature review. *J Pain Symptom Manage*, **37**(5): 884–912.

Wagemans A.M.A., **van Schrojenstein Lantman-de Valk, H.**, **Proot I.M.** et al. (2013). End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Pall Med*, **27**(8): 765–71.

WHO (2011). *World report on disability*. WHO: Geneva.

World Health Organization (2001) The World Health Report: Mental Health, New Understanding, New Hope, downloaded 22.11.17 from www.who.int/whr/2001/en

Wilkinson R., and **Pickett K.** (2009). *The Spirit Level: Why More Equal Societies Almost Always Do Better*. London: Allen Lane.

Wion R.K., and **Loeb S.J.** (2016). End-of-Lfe care behind bars; a systematic review. *Am J Nurs*, **116**(3): 24–36.

Woods A Willison K, **Kington K**, **Gavin C** (2008). Palliative care for people with severe persistent mental illness. Can J Psychiatry, **53**(11), 725–36.

World Health Assembly (WHA 2014). resolution 67.19. *Strengthening of palliative care as a component of comprehensive care throughout the life course*. WHO: Geneva.

Yampolskya S., and **Winston N.** (2003). Hospice care in prison: general principles and outcomes. *Am J Hospice Palliat Care*, **20**(1): 290–6.

Chapter 4

Psychosocial care in diverse communities and encouraging communities to support each other

Linda McEnhill

Introduction to psychosocial care in diverse communities

Despite a plethora of policy documents and legislation there are still significant numbers of people who are unable to access palliative care in general and specialist palliative care in particular (Dixon et al., 2015). One of the defining aspects of palliative care is the commitment to holistic care; the integration of psychosocial care alongside the physical care of the dying person and those important to them. Psychosocial care is concerned with the psychological, emotional, spiritual, and social aspects of care. The presentation of psychosocial needs at the end of life are unique to the individual patient or family member and arguably are shaped by all the life experiences which structure personhood. It is the uniqueness of these needs which presents the challenge even for 'specialist' palliative care providers in supporting the patient and their family members to experience a 'good' or 'good enough' death; one that will support the healthy grieving experiences of those left behind. It is no wonder then that although the United Kingdom (UK) has been recognized as leading the world in 'quality of death' there is still significant concern about the availability and quality of palliative care in the UK and that a significant number of complaints to and about the NHS (50% in 2008) are related to end-of-life care and/or bereavement. Faced with the challenge of getting basic end-of-life care right e.g. the identification of those who require palliative care and the ability to offer this in the place of the patient and family's choosing, it is reasonable to assume that the provision of psychosocial care at the end of life may present even greater challenges and particularly in the context of diverse communities.

This chapter seeks to identify some of the challenges, reflect on contributory factors, and share good practice in overcoming obstacles to encouraging diverse communities to provide psychosocial care at the end of life.

Defining diversity

Although the term 'diversity' has at its heart the sense of rich variation it has historically been used in the UK to describe minority racial/ethnic groups with this being the focus of early equality and diversity committees and training programmes that aimed to ensure public services and employers did not discriminate against people from these groups. Equality legislation has always focussed wider than this. In 2010 the Equality Act (2010) brought all prior equality legislation together and extended the groups considered most at risk of inequitable societal responses. The Act defines nine 'protected characteristics' which it is unlawful to discriminate against because of, and these are: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race, religion, and belief, sex, and sexual orientation. The Act makes it clear that both direct and indirect discrimination of people having one of these protected characteristics, or being associated with someone who has one of them (e.g. being discriminated against based on being the mother of a child with a disability) is unlawful.

Diversity as described within palliative care includes these aspects; how could it not as they potentially incorporate just about everyone under one or more categories? The concept of diversity however has been extended within some texts to include the concept of 'difference' or 'social difference' as factors which influence access to palliative care at the end of life (Monroe and Oliviere, 2004; Oliviere et al., 2011). This is particularly helpful for the purposes of this chapter in reducing the focus to those groups who have most difficulty in accessing psychosocial palliative care.

Access issues in palliative care for diverse communities

A recent publication on equity in palliative care provision in the UK (Dixon et al., 2015) identifies issues with access across the range of protected characteristics including ethnicity/race, sexual orientation, age (both the very young and the very old) and disability (in terms of having a non-cancer diagnosis, especially dementia). In addition, it highlights the issues for people from a range of other groups whose marginalization or 'social difference' renders them less likely to receive palliative care; these include people who experience deprivation or those who do not have a 'traditional' family structure (especially those who do not have a spouse), it also highlights the importance of one's normal place of care at the end of life for access to palliative care. Sleeman et al., have demonstrated similar findings with relation to hospice deaths (Sleeman et al., 2016).

Similarly, the CQC thematic review (CQC, 2016) extends the list to include people who have learning disabilities, mental health issues, are homeless, prisoners, or gypsies and travellers. Whilst the publication helpfully offers good practice case studies, it serves mostly to emphasize the scope of the challenge in ensuring that everyone who needs palliative care can access it. As Professor Steve Field, Chief Inspector of General Practice at the Care Quality Commission says in the publication:

> A person's diagnosis, age, ethnic background or social circumstances should not affect the quality of care they receive at any point, but certainly not at the end of their lives. What is important is that everyone receives care based on their individual needs, delivered with compassion and sensitivity by staff with the right skills, and that there is regular and effective communication between staff and the dying person and their family. (CQC, 2016)

Despite this sentiment, all these factors, as well as those of being asylum seekers, refugees, teenagers, vulnerable adults and, people who abuse substances, do impact on access to palliative care (see Monroe and Oliviere, 2004; Oliviere et al., 2011).

Access however is a complex and multi-factorial concept. The access that is referred to in most of these documents is what might be considered 'primary access' to services. This type of access is mostly, as Dixon et al., suggest, 'conceived of in narrow medical terms, even though health-care inequities are often grounded in wider social inequalities' (Dixon et al., 2015, p. 87). It may be typified as access to a referral for a generalist or specialist palliative care service. Sadly, there is evidence that many people fail to achieve even this primary level of access to palliative and end-of-life care services. Amongst these are people who are dying 'from' (rather than 'with') dementia, the frail elderly and people with mental health problems, the very old and the very young, to name but a few (Dixon et al., 2015).

In terms of psychosocial care, issues of 'secondary access' are crucially important. Secondary access can be identified by following someone's journey through a care service (such as may be done by undertaking a 'process map' (see glossary) of a service activity e.g. from referral to service allocation). This can identify that although a service appears to be offering open access to people from diverse communities, in that it accepts referrals from these groups to the service (i.e. primary access), thereafter the person's journey through the service may be significantly different from a 'mainstream' user. An example of this was highlighted in the research of Hogg et al. (Hogg et al., 2001) who discovered that; of those people with learning disabilities referred to cancer and hospice services, most received a community based service, few received an in-patient service, fewer still received complementary therapies, and very few received counselling and emotional support services. In other words, people from some diverse communities may appear to have overcome the considerable barriers to accessing palliative care but in essence are only accessing a stunted form of palliative care that is out of keeping with the philosophy of holistic end-of-life care. In the case of people with learning disabilities this has been suggested, by Professor John Swinton to be a kind of 'diagnostic overshadowing' whereby focus is only on the physical aspects of care to the exclusion of emotional and spiritual care (Swinton and Powerie, 2004).

Tertiary access to these services is also an issue for psychosocial palliative care. Tertiary access as defined by McEnhill (McEnhill, 2012) refers to services which accept referrals for all people, irrespective of their diagnosis or other defining factors, but the service which is offered thereafter is essentially characterized by a 'one size fits all' approach in that there is no modification of the service approach irrespective of the 'differences' between the needs of service users. On the surface this may be suggestive of an equality of service provision (staff may proclaim 'virtuously' that 'we treat everyone the same') but it is neither a virtue nor results in equitable service provision. Equity, as described by Aristotle, is the principle of 'treating equal things equally and unequal things unequally'. The concept of equity overriding equality has been difficult for many palliative care providers to grasp but the inability to do so can result in a failure to recognize the differing needs of service users or the requirement under equality legislation to make 'reasonable adjustments' to services to meet individual users' needs. The aim is not to ensure an equality of service provision but to ensure that all have an equality of outcome i.e. care which meets the specific needs of individuals and communities. This is perhaps best demonstrated by the failure of adult hospices to offer booked respite to young people in transition on the basis that they do not offer this service to their ordinary patients. This—even though the length of time spent caring—the complexity of caring; physically, emotionally, socially, and financially, presents a greatly unequal need for such respite as a core aspect of the palliative care required to support carers to continue to care, families to remain together, and the young person to continue to live in their preferred place of care. Additionally, the debate as to whether hospices should provide bathing services for any or all their service users has the same inherent issues in terms of equitable service provision.

Some people referred to palliative care services will experience more than one type of barrier to access. For instance people with learning disabilities have been referred to palliative care services in increasing numbers for more than a decade now but many of them experience not only the 'access within access' barriers of secondary access but also the wholesale failure to adapt bereavement counselling models to meet their needs is suggestive of tertiary access issues. Furthermore, many people in diverse communities inhabit more than one category of difference or disadvantage, which not only impacts on their physical health (as in the social determinants of health and the social gradient of ill health) but also on their ability to access services to meet their needs at the end of life.

Finally, a word about the themes, which arise from the literature on access to palliative care for people from diverse groups. One of the biggest issues for palliative care practitioners, however willing they are to open their services to all who need them, is the dearth of literature to form an evidence base on which to found care models. The most recent publication by Marie Curie (Marie Curie, 2017) on the end-of-life care of LGBT people demonstrates this powerfully having found only one systematic review of related literature prior to 2012 (which covered only 12 papers) and another in 2016. This is echoed in a number of other diverse groups and exacerbated by the fact that there can appear to be a significant body of literature but on closer investigation it merely describes the demographics of those groups (as in refugees) or the scope of the problem (e.g. end-of-life care of homeless people) but with little information that supports the development of care for the group in question. Thus, some groups are both 'invisible' in the literature and in services e.g. white asylum seekers/refugees and (lesbian, gay, bisexual and transgender (LGBT) people.

Perhaps most damaging of all are those service responses which cause people to be 'distanced' from themselves (McEnhill, 2012) as in the case of LGBT people who say that the heteronormative practices of hospices 'force them back into the closet', or those unquestioningly feminized forms of service (e.g. most forms of bereavement care) which when accessed by men render them distanced from their normal coping styles in contradiction to best practice literature (e.g. Stroebe and Shut, 1999).

Different is not 'deficient': redefining resilience

In society, generally and in palliative care specifically the concept of 'resilience' has gained increasing interest in the last decade. This resourceful concept is described as ' … a universal capacity which allows a person, group or community to prevent, minimize or overcome the damaging effects of adversity' (Newham, 2004 in Monroe and Oliviere, 2007). Beginning with a focus on the individual, stimulated by the observation that a group of people may experience the same adverse circumstances but have very different individual responses to them across a continuum; from being completely overwhelmed to coping, or even to posttraumatic growth as opposed to posttraumatic disorder. The structure of resilience offers us infinite opportunities to consider how to mobilize inherent strengths in individuals and communities challenged with serious illness, dying, and bereavement.

As such, the concept of resilience provides what Monroe and Oliviere call

> [A] unifying concept to both retain and sustain some of the most significant understandings of the last four decades of palliative care and to incorporate more effective investment in a community approach and a public health focus. (Monroe and Oliviere, 2007)

However, there are issues related to professional assessment of resilience in diverse populations, be they of individuals or communal groupings. As Monroe and Oliviere suggest 'Resilience is inextricably linked to risk in an interactive process occurring over time and influenced by individual and family variables, social context, and social structure.' (Monroe and Oliviere, 2007) Therefore, how professionals conceptualize vulnerability and resilience in the face of risk for individuals and communities is likely to be predictive of their assessment of such an individual and community's ability to cope, to share partnership and power in professional relationships construed around a terminal diagnosis.

The concept of 'difference' and 'social difference' as an element of diversity comes into play with powerful force in an understanding of resilience. A mapping of the palliative care workforce (both specialist and generalist) demonstrates the starkness of the 'difference' between individuals from diverse communities and individual palliative care practitioners. The contrasting demographics of both groups feeds the dichotomous 'us' and 'them' relationships which exacerbate limited understandings of each other's world views. Resulting, at times, in understandings of groups and individuals as inherently resilient or inherently vulnerable, a polarization that can have significant impact on both the care and the choices which people have at the end of life.

This is perhaps most clearly articulated in situations where a person who is dying or is the carer for someone who is dying has a learning disability. Envisaged by professionals as inherently vulnerable, the assessment of their ability to cope with risk may result in an over-protective response which disables the person from being able to die in their place of choice (i.e. home) or to continue to be the main carer for the dying person (even if that person is their spouse). Equally the over-estimation of resilience within middle class families sometimes results in overly optimistic perceptions of coping and minimized assessment of risk that place children and some patients at risk of harm.

Sadly, within the current resilience literature there are characterizations of factors which predispose resilience which, if taken seriously are predictive of poor outcomes for large swathes of the population e.g. the suggestion that for a child to be predisposed to resilience it requires: parents with higher education; socioeconomic advantage; to live in a quality neighbourhood, and to attend an academically effective school (Stokes in Monroe and Oliviere, 2007). This is more descriptive of privilege than resilience in that these elements arguably minimize adverse effects rather than enable someone to cope with them. Such models have little to offer people with disabilities or many individuals who comprise those diverse populations that are disadvantaged by the current structuring of society. There is a real need to begin to articulate what resilience looks like in individuals and communities who are stereotyped as inherently vulnerable. This is vitally important in end-of-life care where we have 'Only one chance to get it right' (Leadership Alliance, 2014) and where the failure to do so impacts on the lifelong grieving experiences of those mourning the person who died. One example of resilience in people considered inherently vulnerable is described in the case study below.

Case study

The GOLD group

The Growing Older with a Learning Disability (GOLD) group came together in 1998 to support a research project about getting older at the Foundation for People with Learning Disabilities, part of the Mental Health Foundation (The Foundation for People with Learning Disabilities 2002). The members at this stage were all people in their 50s with learning disabilities, until then a relatively uncommon experience given the increased mortality of people with learning disabilities. When the project ended in 2002, the group wanted to continue to both meet socially and talk about their experience of growing older. The group continue to meet until the present day, sometimes they have funding for specific projects and often they have not and are dependent on the group facilitators and a host charity (www.Respond.org.uk) to support them with a venue and the organization of meetings.

During the two decades in which this group have met, they have helped professionals and academics understand the realities of life as an ageing person with a learning disability in ways that would otherwise not have been possible (Ward, 2012). Inevitably the group have experienced loss through the death of some of its members and as they have done so they have worked through their grief together and shared it with other people with learning disabilities and their supporters to facilitate enhanced understanding of both the commonalities and unique aspects of bereavement for someone with a learning disability.

Through drama and workshops, they have helped many to explore the potentially lifelong experience of loneliness that many people with learning disabilities encounter. As two of their members declined into dementia they supported these friends until their deaths and went on thereafter to develop a video recorded play called 'Forget me not' which dramatically detailed the issues for people with learning disabilities who have dementia. The video became part of a training pack developed for the many care workers who face the epidemic of dementia in people with learning disabilities (Blackman and Brooks, 2008). An epidemic comprised of both the increased incidence of early onset dementia in people with Downs syndrome and the fourfold increased incidence in all people with learning disabilities irrespective of the aetiology of the learning disability. In 2011, the group became the reference group for the development of the content of the Department of Health, Route to Success publication on end-of-life care for people with learning disabilities (The National End of Life Care Programme, 2011). In doing so they have had to consider, with the consistent support of their facilitators, questions around what they would want if they had a diagnosis of a life-threatening illness, including whether they should be artificially fed, whether they should be resuscitated and where they would want to be cared for and by whom. Their contribution shaped not only the content of the document but the opinions of many of the professionals involved who might otherwise have assumed these questions were off limits for people with learning disabilities. Much of what is understood about the experiences of ageing and the consequent losses experienced for British people with learning disabilities is because of the undertakings of this diverse compassionate community.

One of my striking observations gained from working with this group has been to understand how little we appreciate or value the 'wisdom' of elderly people with a learning disability, despite their rich history and their experience of having lived through a vastly changing and changed world for people with a life-long disability. As one of the members has said often to me, 'You know I have seen a lot, I have been around a long time'. Indeed, she has as she enters her 70th year along with those few remaining members of the original group, who have taught us so much.

Assets-based approaches

The critique of previous overly professionalized (and medicalized) models of care are that they have taken what is described by many authors as a 'deficits' based model of care. This model focusses assessment on problems that can be solved by professionals and those things that the person being assessed, or the communities in which they are set, cannot do.

There is a growing understanding of the limitations of this way of thinking and the inhibiting effect it has on the utilization of individual and communal resources to 'prevent, minimize or overcome the damaging effects of adversity' (Newham 2004, in Monroe and Oliviere, 2007). The case study below demonstrates the impact of deficit thinking on the communication between a patient and palliative care professional and their attempt to overcome it.

Case study

Communication and deficit thinking

Anne was a 61-year-old white British woman: married with no children; she had been diagnosed four months earlier with advanced metastatic lung cancer. She also had a history of extreme anxiety and obsessive-compulsive disorder. She was referred to the hospice day services and attended for her initial assessment. She and her husband met with the lead doctor and nurse for the day hospice and myself.

Undertaking an initial assessment, the doctor started asking questions at which point Anne became distressed and said she was frustrated that each professional she met asked her the same questions. She had prepared a typed summary of her medical history and a list of her current medication, which she gave to the doctor. She hesitated and then handed the doctor a copy of her CV, there was a short pause, and then the doctor put it aside saying she would read it later.

When I met the woman in day hospice the following week she asked me if she had 'made a fool' of herself by giving the doctor her CV. She had felt totally overwhelmed by her patient status and wanted to remind us that the last four months were not an exclusive representation of her life, but it seemed all that people wanted to talk to her about.

(Patricia McCrossan, social work manager, personal testimony.)

By comparison, an assets-based approach to assessment would have been equally as concerned with the strengths and resources which the patient brought as a partner in responding to their current health situation. For example, the patient had demonstrated (in her typed medical history and medication list) abilities or strengths and inevitably within her CV (of which she seemed implicitly proud) would be other strengths, skills, and experience that could be drawn upon. Instead, she was embarrassed and disempowered by a response, which did not credit her with a vital part to play in securing best outcomes in her illness journey.

Legislation in the form of the Care Act (2014) legitimizes and indeed creates an expectation that public servants form asset-based relationships with service users: seeing them as partners (in Scotland, as citizens) with rights rather than passive recipients of care. This requires as Gollins et al. (Gollins et al, 2016) suggest, a change of culture.

Overcoming deficits-based models, the development of Patient Leaders

In stark contrast to the situation described in the previous paragraph is the aim of creating a 'patient and customer services revolution' 'Foundation of Patient Leadership' (FPM, 2013) by creating patient leaders. Patient Leaders are leaders who are patients as opposed to the previous generations of 'patients' who have displayed extreme passivity and low expectation of their involvement in the decisions related to their own health care. Patient Leaders are 'patients, service users and carers who work with, and for others to influence decision making at a strategic level'. Their leadership 'Creates a dialogue of equals between patient, clinical and managerial leaders' (FPM, 2013).

Gilbert crystalizes why we need to utilize the untapped resource of patient leaders; he says that patients have the drive and compassion to bring about positive change but are treated like 'units of data' by the NHS and viewed as 'potential complainants, questionnaire fillers, bed blockers or frequent flyers' (Gilbert, 2012). Sadly, although so much of what we do or have done as providers of psychosocial palliative care has been to help people come to terms with the content of the 'crucible' of their lives and 'reframe and build new identities', rarely until now have we considered that their new identity may include becoming a Patient Leader.

This significant 'outsider-inside' (Gilbert, 2012) leadership role requires the patient to be both a 'community channel' and a 'critical friend', giving rise to two types of Patient Leaders: those who transform and improve their health and social care system, and those who enable improved health and well-being in their community (Gilbert, 2012). However, Patient Leaders are continuously confronted with significant power imbalances as typified in that they require an organizational invitation to be able to express their leadership. As Doughty and Gilbert discuss, patients who access services are 'powerless' compared with professionals who provide the service and 'have control over decisions' (Doughty and Gilbert, 2012).

Providers of psychosocial palliative care have a unique opportunity to create platforms from which patients can express their acts of leadership or 'tip the balance'. Uniquely concerned as they are, with the narrative not only of the current illness but also of the person's life, their capacity for resilience and previous experiences of 'overcoming'. Within the multidisciplinary team, they can convey the person who is more than the patient: contextualising their 'feedback' and suggestions for improvement. Remembering that after all each palliative care professional (and even CQC inspectors) will face their own terminal journey and will want to be as fully involved in this as in every other aspect of their lives and that we should therefore expect nothing less from those people who we currently care for.

For those who have diminished patients by considering them to be 'non-experts' the work undertaken by the King's Fund in their 'Collaborative Pairs Programme' (Seale, B 2016) provides a catalyst for thought. In this programme, pairing clinicians with patients to co-design patient service achieved outstanding results e.g. pairing a consultant cardiologist with his patient resulted in a redesign of local heart failure pathways and services (Seale, B 2016). This demonstrates the benefit that patients, facilitated into leadership positions, can bring.

Over many years now palliative care has been charged with reducing psychosocial care down to its psychological aspects and neglecting the more practical and social aspects of this approach (Croft S, Beresford P, Adshead L. 2006). The involvement of service users in leading and developing their care and influencing the care of others offers an opportunity for palliative care professionals to reclaim this area of practice and to share the leadership of it with patient colleagues.

Ultimate access, co-production

In addition to those levels of access previously described, there is a final level (Ultimate Access) which is arrived at via co-production approaches. Co-production means

> … delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change. (Nesta, 2012)

Co-production moves beyond service user feedback and even most forms of service user engagement involving people at every stage of the patient journey including commissioning, design, delivery and evaluation, it is described by Watson who says: ‘It is about involving people not only in the rowing and the steering of the boat, but also in actually building it’ (2016).

Case study

Co-production

Co-production can begin at any age as was demonstrated by young people in a hospice-based bereavement group.

One young boy, Ian, was referred to be seen for some pre-bereavement work concerning his father who had an incurable condition, which was unpredictable in its progression such that he could live for many years or he may without notice experience a bleed in his brain that was likely to be fatal. Ian had been with his father when he had his first brain bleed and although only 11 years old he understood both the unpredictability and the seriousness of the condition and consequently was struggling emotionally: was unable to sleep, and thus was tired at school in the day which was interfering with his learning.

On a first meeting with the bereavement supporter Ian seemed deeply unimpressed by anything that was suggested for ways to spend the session. Ian told the supporter that ‘They keep getting people to talk to me but nobody seems to be able to help’ it was clear that he felt this helper to be the latest in the long line of people who would be no use at all to him.

The supporter had tried asking Ian what he felt would help him but to no avail and so she asked instead what did he think might help other young people in his situation. Ian thought about it and then decided that having a booklet to explain his father’s condition would be helpful to young people in this situation and so they agreed that the sessions would be used to create such a booklet. Ian took this task very seriously (including wanting to research incidence of the condition across Europe!). Whilst creating the booklet Ian was able to talk about his concerns: including that he may inherit the condition and his feelings of sadness that his father could no longer play sport with him.

Within the same service, a group of bereaved teenagers consulted on what would best meet the needs of young people in their situation decided that a bereavement app would support them in a way that was ‘cool’ and which did not draw attention to their bereavement when they were at school or out with friends. The young people worked with a technician to develop the app including the content, which had favourite songs to cheer you up, yoga for when you felt stressed and affirmations to support you when you felt lonely. The app was then developed for wider use with bereaved young people.

In each case although the professional supporters had a role to play the outputs and outcomes of the interventions were significantly enhanced by giving over the creative processes to bereaved young people who best understood their needs and how to meet them.

Encouraging communities to support each other

In one of the early definitions of psychosocial care, Field told us

> … the meaning, experience and expression of their terminal illness is shaped and influenced by the communities in which they live. The social fabric of their lives is central to how they make sense of their illness experiences, the meanings they draw upon to understand these, and the range of resources they can call upon to help them manage them. (Field 2000, quoted by Hartley in Monroe and Oliviere, 2007)

Historically the psychosocial care of people who are dying and their family members would have been seen to be the domain of one of a range of palliative care professionals. Borne partly out of the necessity that the increased population of dying people presents in the context of reduced resources and partly out of a growing understanding of the impact that loneliness and isolation have on physical and emotional health, public health approaches have gained increasing favour.

In end-of-life care Allan Kellehear has pioneered a health promoting, public health model which is characterized as a 'Compassionate Communities' approach (Kellehear, 1999; 2005). This model is based on the conviction that psychosocial issues such as loneliness, stigma, and other social problems are best 'tackled by friends or community members rather than health-care professionals' and that 'a strong community response augments rather than supplants the professional response' (Sallnow et al., 2016)

Enshrined within the *Ambitions for Palliative and End of Life Care* (National End of Life Care Partnership, 2015) is Ambition number six, 'each community is prepared to help' the development of Compassionate Communities is building community capacity to care compassionately for people at the end of their lives and their family members. The previous helper and helped dichotomies in this approach are blurred such that although the patient is the focus of help the helper also benefits and the community as is demonstrated by this case study.

Case study

Bereavement support and pilates in the park

As hospice care develops a more community-based approach, St Joseph's Hospice in Hackney, London has modelled a bereavement project providing bereavement support for and by local people. Volunteers are trained and supported to deal with complex bereavement referrals in Islington, one of the most 'unequal boroughs in the UK' as described by the Islington Fairness Commission in 2011.

The Community Commissioning Group commissioned the Islington Bereavement Service in April 2015, and offers peer-to-peer support for adults aged 18 and over living in the Borough. It is based on the 'Compassionate Communities' model and whilst run by St Joseph's Hospice, it is defined by the quality and commitment of the volunteers who offer timely emotional, social and practical bereavement support at home or a community venue. The following case study illustrates the reciprocal nature of the match.

Charles (bereavement support volunteer) is a 33-year-old Afro-Caribbean male, he has a background in youth work: mentoring and providing music workshops. He has set up his own company called 'Voices for Youth'. Charles is also undertaking a Level 2 counselling course. Charles has worked with gangs in Hackney and Tottenham previously but wanted to gain some experience in bereavement support and thus trained and volunteers with the Islington Bereavement Service.

Charles has been matched to Amelia, a white female 43-year-old. Amelia's ex-boyfriend committed suicide recently and she was referred by the Single Homeless Project to the Islington Bereavement Service. Amelia has been diagnosed with bipolar disorder and at the time of referral reported feeling 'depressed all the time'. Amelia's mother died of cancer when Amelia was 16 years old and she described herself as having had a nervous breakdown in her 20s whilst at university due to this loss. Amelia was detained under the Mental Health Act and described her mind as 'time travelling'; she has received counselling and group therapy for many years. Amelia stated she did not want to be a 'counselling junkie' and needed something different to help her this time, hence her referral to the Islington Bereavement Service.

During the initial meeting with the Community Development Manager Amelia also asked for support around her hoarding, she wanted someone to speak to about her grief and someone who could help her to clear her flat slowly. Amelia stated that she recognizes her hoarding is linked to the grief of losing her mother and would just like someone to help 'clear some of the stuff away' as she realizes 'these things are getting in the way of me living my life'.

Amelia has had over ten bereavement support sessions with Charles, during this time they have met in cafés, at the park, and in her home. During their first session, Amelia drew a sketch representing her goals for the next ten weeks, Charles took a photo of the sketch and they refer to it regularly. Amelia said she felt much better having someone to talk to but did not feel ready to show her flat to Charles until a few weeks later. Amelia is a pilates teacher and in the meantime has been teaching Charles pilates whilst they have chatted in the park, Charles has appreciated this as he has been working on his weight issues. Amelia said: 'It's nice to just have someone to talk to'.

Charles has helped Amelia with clearing her flat and attended a court hearing with her as support. Amelia has reached her goals during their sessions, which has included enrolling on a course and introducing some of her clothing designs in shops. Amelia stated: 'Charles is motivational and friendly, he reminds me I'm going forward and shows me what I've achieved'. Charles was keen to explain, 'Amelia has also helped me, she motivates me to keep believing in myself . . . I was going for interviews and she supported me through that, I've got a new job now as a Support Worker with people with Autism. We share experiences . . . we're like friends'.

Lourdes Colclough (Community Development Manager)

Several other projects nationally are similarly building community capacity such as is demonstrated in the evaluation report of the Dying Well Community Charter Pathway Report (National Council for Palliative Care 2016). Each of these projects have piloted different models of care utilising the Dying Well Community Charter (NCPC 2016) (which is based on the Compassionate Cities Charter, Karapliagkou and Kellehear, 2014) which states:

> Dying and death do not happen in isolation from the rest of life. People who are dying may not wish to be isolated and disconnected from their communities. There is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility. (NCPC, 2016)

One of the additional advantages of these projects and others like them is that they can be targeted to reach specific under-represented and marginalized groups as with the St Joseph's Hospice Namaste project described in the next case study.

Case study

Namaste Care Service

The Namaste Care programme developed by Professor Joyce Simard in the USA in 2003 is a therapeutic and person-centred model of care for people living with advanced dementia. The programme moves away from the traditional medical model and aims to improve quality of life for people living with advanced dementia through meaningful activities and sensory stimulation tailored to the person's need and preferences.

The Namaste Care Service at St Joseph's Hospice, a volunteer-led outreach service, offers practical, social, and emotional support to people living with advanced dementia: also support for their families and carers. Trained volunteers provide Namaste Care in various domiciliary settings across the ethnically diverse boroughs of Hackney, Tower Hamlets, and Newham: teaching family, friends, and carers how to engage with the person with dementia and incorporate Namaste Care into everyday activities.

In harnessing the creativity and skills of local volunteers, the Namaste Care Service promotes social action and encourages communities to come together to support people affected by dementia. The service is also offered to those living with dementia who have no family or limited support networks: enabling them to remain connected to their community, reducing their feelings of isolation, and resulting in improved mental and physical wellbeing.

This case study details an individual intervention.

Ms. Harris was referred to the Namaste Care Service through Age UK East London, an organization which commissions St Joseph's Namaste Care in the borough of Tower Hamlets. Diagnosed with advanced dementia, Ms. Harris had reduced mobility and lived alone, with carers visiting every day to assist with daily living activities. Ms. Harris was often tearful, withdrawn, and socially isolated.

Ms. Harris was matched with a Namaste volunteer, who visited her at home on Saturday afternoons and they got to know each other over the course of 12 months. The volunteer established quite early on in their interactions that she and Ms. Harris had a mutual love of classic movies and musicals from the 1940s—1960s. The volunteer visited her local libraries, second-hand shops, and charity shops sourcing classic musical DVDs starring Ms. Harris's favourite actors—including the likes of Doris Day, Judy Garland, Fred Astaire, and Howard Keel.

'I developed the concept of a movie club (which consisted of myself, Ms. Harris and her Age UK support worker) as a way of engaging with her and stimulating her memory through reminiscence activities. Every Saturday afternoon we would get together to eat popcorn and watch Ms. Harris's favourite movies: consisting of musicals such as 'Calamity Jane', 'High Society' and 'Annie Get Your Gun'.

Ms. Harris, whose short-term memory is very poor, sometimes has trouble constructing a sentence and often stumbles over her words; was able to recall the lyrics to all her favourite musical songs—some of which she hadn't watched in over 30 years!

'It's almost as though she had transported herself into the movie, she became so engaged, confident, animated, and happy'. (Namaste volunteer)

The Namaste service has also enabled those affected by dementia to remain connected to health and social care services, with volunteers and the Namaste Care team signposting, referring, and providing information on appropriate services available in the local community, helping to increase access to care and reduce health inequalities, particularly within hard to reach and marginalized groups.

Namaste Care volunteers reported a reduction in their own isolation; stating that the service has given them to opportunity to feel more part of the community, meet new people, and learn about different cultures and religious traditions, in addition to increasing their confidence, self-esteem, and skill set.

The Namaste volunteers, as ambassadors of the hospice, have helped to promote a socially cohesive and compassionate communities model of care. Through raising awareness of St Joseph's Hospice and engaging local people, they have assisted in building stronger relationships between the hospice and the local community.

Emma Quintal, Namaste Care Coordinator

Conclusion

Fifty years on from the beginning of the modern hospice movement we are caused by circumstance of population growth; diminished societal financial resources, alongside overly specialized, expensive models of care to reconsider the what, how, and who of psychosocial care at the end of life. Much in the same way as Dame Cecily intended that hospice care would not stay confined to hospice buildings or medical specialties but be part of the whole system of care for patients, we have an opportunity to free psychosocial palliative care back into the community. As Abel and Kellehear remind us '*It takes a village to raise a child and it takes a community to support death, dying and bereavement*' and also challenge us '*to remember that death, dying, caregiving and loss are social problems with medical aspects to them and not medical problems with social aspects*' (Abel and Kellehear, 2016). It is time to grasp that opportunity.

Glossary

Process map: A process map is a visual representation of the transactions that occur for a patient through a process of care. A process map is a pictorial tool that enables clinical staff to define and interrogate a care experience e.g. it is commonly used to understand the elements involved in an admission or discharge process.

By process-mapping a care experience staff can understand the complexity of a process and the interrelated parts they play in its delivery. It is possible to use a process map as part of an Equality Impact Assessment of a service (EqIA) to understand how the service impacts differentially on service users in relation to one or more of their protected characteristics under the Equality Act (2010). Examples of process maps can be found on the King's Fund website. See https://www.kingsfund.org.uk/projects/pfcc/process-mapping

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References

Abel J. and **Kellehear A.** Palliative care reimagined: A needed shift. *BMJ Supportive and Palliative care*, **6**(1): 21–6.

Blackman N., and **Brooks M.** in **collaboration with the GOLD group** (2008). *Dementia and People with Learning Disabilities: Valuing Relationships*. London: Respond.

CQC (2016). *A Different Ending: Addressing Inequalities In End Of Life Care*. England: Care Quality Commission.

Croft S., **Beresford P.**, and **Adshead L.** (2006). *Palliative Care, Social Work and Service Users: Making Life Possible*. London: Jessica Kingsley.

Department of Health, (2008). *End of Life Care Strategy: promoting high quality care for adults at the end of their life*. England: Department of Health.

Dixon J., **King D.**, **Matosevic T.**, **Clark M.**, and **Knapp M.** (2015). *Equity in the Provision of Palliative Care in the UK: Review of Evidence Personal Social Services Research Unit, London School of Economics and Political Science*. London: Marie Curie Cancer Care.

Doughty M. and **Gilbert D.** (2012). When patients become leaders. *Health Service Journal*, Foundation of Patient leadership, Centre for Patient Leadership. Bring it on- 40 ways to support Patient Leadership (2013) NHS Midlands and East.

Gilbert D. (2012) 'The Rise of the Patient Leader' *Health Service Journal*.

Gollins T., **Fox A.**, **Walker B.**, **Romeo L.**, **Thomas J.**, and **Woodham G.** (2016). *Developing a Well -being and Strengths—Based Approach to Social Work Practice: Changing Culture*. England: Think Local Act Personal.

Government. UK, (2010). London: Equality Act.

Hogg J., **Northfield J.**, and **Turnbull J.** (2001). *Cancer and People with Learning Disabilities*. BILD publications.

Karapliagkou A. and **Kellehear A.** (2014). *Public health Approaches to End of Life Care: A Toolkit*. Availalble from: www.ncpc.org.uk

Kellehear A. (1999). *Health Promoting Palliative Care* Oxford University Press: Oxford.

Kellehear A. (2005). *Compassionate Cities*. London: Routledge.

Leadership Alliance for the Care of Dying People. (2014). *One Chance to Get it Right.* London: UK Government.

Marie Curie (2017). *Hiding Who I am: The Reality of End of Life Care for LGBT People*.

McEnhill L. (2012). Unpublished dissertation for Masters in Hospice Leadership, Lancaster University 'A Narrative review of the literature on equity as it pertains to end of life care'.

Monroe B. and **Oliviere D.** (2004). *Death, Dying and Social Difference*, Oxford: Oxford University Press.

Monroe B. and **Oliviere D.** (eds) (2007). *Resilience in Palliative Care: Achievement in Adversity*. Oxford: Oxford University Press.

National Council for Palliative Care. *Dying Well Community Charter Pathfinder Project: Evaluation Report 2016*. Accessible from: www.ncpc.org.uk

National End of Life Care Partnership. (2015). *Ambitions For Palliative And End Of Life Care: A Framework For Local Action 2015–2020*. Accessible from: www.endoflifecareambitions.org.uk

Nesta (2012). *People Powered Health Co-Production Catalogue*. London: Nesta

Oliviere D., **Monroe B.**, and **Payne S.** (2011) *Death, Dying and Social Difference* (2nd Edition), Oxford: Oxford University Press.

Parliamentary and Health Service Ombudsman (2015). *Dying without dignity: Investigation by the Parliamentary and Health Service Ombudsman into complaints about end of life care*. London: Parliamentary and Health Service Ombudsman.

Sallnow L., **Richardson H.**, **Murray S.A.**, and **Kellehear A.** (2016). The Impact of new public health approach to end of life care: A systematic review. *Palliative medicine*, **30**(3): 200–11.

Seale B. (2016) Patients as partners: Building Collaborative Relationships among Professionals, Patients, Carers and Communities, Kings Fund, London.

Skills for Care (2014). *Skills Around The Person; Implementing Asset-Based Approaches In Adult Social Care And End Of Life Care*. London: Skills for Care.

Sleeman K.E., **Davies M.D.**, **Verne J.**, **Gao W.**, and **Higginson I.J.** (2016). The changing demographics of inpatient hospice death: Population-based cross-sectional study in England (1993–2012). *Palliative Medicine*, **301**(1): 45–53.

Stroebe M. and **Schut H.**, (1999). The dual process model of coping with bereavement: rationale and description, *Death Studies*, **23**(3): 197–224.

Swinton J. and **Powerie E.** (2004). *Why are we here? Meeting the spiritual needs of people with learning disabilities*. London: Foundation for People with Learning Disabilities.

The Care Act (2014). United Kingdom: HM Government.

The Economist Intelligence Unit (2015). *The 2015 Quality of Death Index Ranking palliative care across the world*. London: The Economist Intelligence Unit.

The Foundation for People with Learning Disabilities (2002). *Today and Tomorrow: The Report of the Growing Older with Learning Disabilities Programme*. London: The Foundation for People with Learning Disabilities.

The National End of Life Care Programme (2011). *The Route to Success in End of Life Care–Achieving Quality for People with Learning Disabilities.* United Kingdom: National Health Service.

Ward C. (2012). *Perspectives On Ageing With A Learning Disability*. York: Joseph Rowntree Trust.

Watson T. (2016). Available from: www.coproductionscotland.org.uk/

Chapter 5

Models of psychosocial care for patients and their families: the role of volunteers in supporting psychosocial needs

Nigel Hartley

Introduction the role of volunteers in psychosocial care

The role of volunteers in supporting the psychosocial needs of patients and their families living with dying has been evident since the opening of the first modern hospice, St Christopher's Hospice, in 1967. Over this time, although a renewed energy in developing and reforming the volunteer offer within Hospices is evident, there has been relatively little researched and reported on. The second edition of 'Volunteers in Hospices and Palliative Care' (Scott R., Howlett S., Doyle D., 2009) is now almost ten years old with a new edition awaited (Scott and Howlett, 2017). However, a thorough literature review published in the Journal of Palliative Medicine in 2013 (Wilmot A., Hill M., Ockenden N., and Payne S., 2013) outlines a growing number of individuals and organizations who have begun to question anew the role of volunteers in end-of-life care. We have therefore, in recent years begun to see a small number of studies which begin to question and to prove the benefits of developing those people who give their time for free as part of related organizations. In 2016, a multi-authored controlled trail study led by the International Observatory on End of Life Care in Lancaster (Walshe C., et al.) UK, highlights recommendations for a befriending type service model offering. In the results of a large qualitative research study, Diamond et al. (2012) have shown that bereavement volunteers in hospices scored higher on 'helpfulness' than psychotherapists. Armstrong J and McLeod J (2003) whilst researching into the organization and the training and effectiveness of counsellors who work for free, also show that they achieve clinical outcomes that are equal to or better than professionals who are fully trained and paid.

However, as we celebrate the fiftieth anniversary of the modern hospice movement and despite the fact that over one hundred thousand volunteers support UK hospices in some way, it could be argued that there is still a lack of clarity and organization with regard to the utilization of a large unpaid workforce across the system (Hospice UK, 2013).

This chapter will present some working examples of the benefits that volunteers can bring when supporting the psychological, social, and spiritual needs of both dying patients and their families and friends. Arguing the need for change and a new direction, examination, and exploration; the need for clear and organized recruitment, training, and support in order to enable success and sustainability of services will be presented.

Volunteering and attitudes towards it are deeply embedded into UK culture and many would say that the willingness to give ones time for free to support other people and causes is a long-standing part of British life. The latest data from the Institute of Volunteering Research (Institute of Volunteering Research, 2014/15) tells us that 42% of people living in the country had volunteered formally at least once during the previous year and that 27% of them had formally volunteered at least once a month. This equates to around 21.6 million people and 13.8 million people respectively. These figures show a 9% increase in volunteering since 2005. Many believe that the increase in the number of those people volunteering in the UK was boosted by the 2012 UK Olympics, which brought together over 120,000 volunteers who supported the event in a variety of significant ways which showcased a community that was re-pledging a commitment to giving time for free. However, the evidence of sustainability of this assumption still remains to be evidenced.

With regard to volunteering in hospices in the UK, it is telling that there is no accurate account for the number of people volunteering in order to support their cause. Hospice UK, the national umbrella body for hospices claims that there are over 120,000 volunteers supporting hospices in a number of different ways (Hospice UK, 2012). It is common that many hospices cannot articulate clearly how many volunteers they have supporting them at any one time, and what roles they are undertaking. This will be mainly due to the ‘ad hoc’ way in which volunteering has been commonly developed across UK hospices (Hospice UK, 2012). We do recognize, however, that volunteers assist the work of hospices in many different ways. At Earl Mountbatten Hospice on the Isle of Wight, thousands of volunteers promote fundraising events in support of the organization. An annual walk, ‘Walk the Wight’, attracts over 300 volunteers for this event alone, together with over 8,000 walkers. Many of these volunteers support this one event, once a year. It will be difficult to ascertain why these people support such an event. Many, of course, will have experience of family members or friends dying at the hospice and will want to support the cause. Others however may just enjoy walking or supporting the wider island community: showcasing the island's assets to a wide range of visitors from across the UK and beyond.

A large number of volunteers also assist hospice charity shops across the UK. Another example on the Isle of Wight is that our ten community shops are supported by hundreds of local volunteers who volunteer as shop assistants, or who collect and sort out donations which go on to be sold. In addition, the hospice also utilizes the support of hundreds of prisoners from the island prisons. Prisoners offer support through upcycling furniture, or by sorting through clothes, or making garden ornaments in their art and craft classes, which also go on to be sold. Uniquely, these prisoners are hospice volunteers. Again, it will be difficult to ascertain if there are any altruistic reasons for these prisoners supporting the work of the hospice. For many, the support will be part of a rehabilitation programme, whilst for others it will just be giving them something to pass the time.

It is clear therefore, that volunteers in hospices represent a 'community of the unlike', and because of this potentially bring a broadness in diversity of practice which is unusual (Saunders C., 1990).

David Field (2000) highlights that in order to support dying people within the communities that they live, those supporting them must realize that for the care they give to be effective; the meaning, experience, and expression of their terminal illness is shaped and influenced by the communities within which they live. One of the key aspects of utilising volunteers in supporting the work of hospices therefore, should include a focus on recruiting volunteers from within the communities within which people are dying. It is also clear that Cicely Saunders, when opening St Christopher's Hospice, put an important focus on this issue. She believed that when people came into the hospice for care, their communities should be reflected by utilising both staff and volunteers from the local community, so that the patients' social lives were reflected back to them in the very essence of those people who were caring for them (Clarke D., 2002).

In 2011–13 the Commission into the Future of Hospice Care put a specific focus on the role of volunteers in enabling the hospice movement to be sustainable for the future (Hospice UK, 2013). A working paper focussing on the future importance of volunteers argued that if hospices were to meet to growing demands for care and support, and were to successfully diversify into supporting currently excluded groups such as older people and those with dementia: growing a competent and confident future volunteer workforce would be crucial (Hospice UK, 2012).

One focus of the Commission into the Future of Hospice Care (Hospice UK, 2013) was the development and future of volunteering within hospices. The working paper (Hospice UK, 2012) reported on five recommendations:

1. Commitment to recruit a new wave of hospice volunteers
2. Establishing and evaluating training packages for local use
3. Hospice UK taking the lead on developing innovative and evaluated models of practice
4. National organizations testing more radical adaptations to current volunteering practice
5. More extensive research needed

Although the Commission into the Future of Hospice Care (Hospice UK, 2013) created a new energy with clear articulation of the issues and matters which need absolute attention for the survival and reformation of the modern hospice movement, it remains to be seen whether hospices on a local level are able to respond to the challenges set out within the report; finding creative and innovative ways of casting off the shackles of the past.

It has become clear that over the last 50 years that many volunteer groups supporting palliative care, including those in hospices, have grown and developed in mostly ad hoc ways, and in the most part have lacked robust recruitment, training, and support structures and systems (Hospice UK, 2012). This has led to ineffective services, inflexible behaviours and an unacceptable focus on supporting the few. The Commission into the Future of Hospice Care challenged the sector to place volunteer development as central and essential to any future strategy: to grow the volunteer workforce; to explore a more successful, effective, and extensive deployment of volunteers, and to cultivate packages of volunteer training which could be adapted and applied locally (Hospice UK, 2012). If volunteers are supporting people at one of the most vulnerable times of their lives, it is clear that they will need to not only discover an absolute emotional resilience and growing self-awareness, but that they will need to be invested in through appropriate training and ongoing support.

Although five years on from the publication of the report, there remains a lack of centrally co-ordinated volunteer development and direction in this respect, we do begin to see new and successful examples of locally led initiatives where organizations are investing in volunteer development and creating new models of support for patients, families, and their friends. This chapter highlights some critical and more formal responses to the Commission into the Future of Hospice Care report, which have been developed as part of the work of a hospice covering a population of around one hundred and fifty thousand people in the South of England. Following a brief introduction to the context, three important projects are discussed and shared:

1. Developing training and ongoing support for patient and family facing volunteers.
2. Setting up a new volunteer community support service.
3. 'Responsible Communities'—a new volunteer approach to engaging local communities in caring.

Earl Mountbatten Hospice

Earl Mountbatten Hospice has been the only hospice on the Isle of Wight, in the south of England, since 1982. It covers a population of around 1,500 people, supporting up to 650 people within the places that they live on any one day. The Isle of Wight has a growing older population with a growing number of older people living with dementia, and is 15 years ahead of the rest of the UK in this respect (Office of National Statistics, 2016). One in six households on the Isle of Wight are inhabited by a single person over the age of 65, and 25% of all people living on the Island are over 65 years of age. By 2035 we are told that three and a half million of the UK population will be aged over 85 and these will account for half of all deaths. One in three of these people will die with dementia and most with chronic multiple conditions. It is clear that these demographic changes are occurring sooner on the Isle of Wight and hospice services are being developed and evidence gathered regarding what support is most effective, for whom, and at what cost. It is clear that developing the competence and confidence of volunteers will be an important part of these developments (Hospice UK, 2013). The hospice's community-focussed holistic care is supported by a sixteen bedded inpatient unit as well as an innovative day, outpatient, and community centre which is open seven days a week, 12 hours a day, 365 days a year. The organization offers care and support to children, teenagers, and adults: has a team in the local hospital, including a rapid discharge service, as well as support to those who die in the local prisons. The hospice also houses and provides the island-wide bereavement service for children, families and adults, the local lymphoedema service, and is the lead provider of health and social care education across the local community. In order to respond to the growing older population and those coming to the end of their lives with dementia, a new specialist dementia service has been set up, together with a domiciliary care team who are able to put in packages of care within four hours of receiving a referral.

Developing training and ongoing support for patient- and family-facing volunteers

Over 500 volunteers support the care of patients and families across all service areas, as well as helping to sustain the operation of ten charity shops within the local community, and regularly reinforcing hundreds of fundraising and awareness-raising events. As part of a new five year strategy: volunteers training, development, and ongoing support were placed central to an aim of reaching more people who could benefit from support, particularly within their own homes. With regard to volunteers supporting patient and family service areas a new training programme consisting of six four-hour workshops begins to equip volunteers supporting patients in their own homes and as inpatients within the hospice and the local hospital with the competence and confidence needed to be useful in a variety of ways. It is clear that if volunteers are to be central to the future of our services, a significant investment and commitment is needed.

Starting a process to ensure that a volunteer group is fit for purpose: recruited, trained, and supported effectively, the hospice embarked on a bold and new volunteer development programme. In order for volunteers to remain competent and confident in dealing with a myriad of psychological and social issues: including being knowledgeable to provide practical and emotional support as well as being able to signpost appropriately which people face at the end of life, a six-workshop training programme was crafted for volunteers who provide direct support to patients and their careers. The workshops focus on developing a wide-ranging set of qualities and skills needed to sustain supporting the psychological, social, and physical needs of people coming to the end of their lives. The training programme includes a range of both face-to-face and multi-media techniques. The training is delivered by a range of experienced staff from different clinical teams and is facilitated by a trained psychologist. Each workshop opens with a time for reflection using experiences gained from a reflective diary process, which volunteers are asked to populate in between training sessions.

We have defined together five specific abilities needed in order to sustain volunteering with patients and families:

1. Commitment to the values, vision, and mission of the hospice through attendance and punctuality at training sessions and involvement in discussions and practice in training sessions.
2. Self-awareness with the ability to take note of your own behaviour: to take responsibility for it, and to change it where appropriate.
3. The ability to communicate and listen; being able to express yourself so that others understand you and that you understand and respond appropriately to what others express to you.

4. The ability to engage with other people, individually and within the group; being respectful of others however different or similar they are to you.
5. Willingness and flexibility to undertake a range practical duties and activities.

These qualities form the basis of the formal interview for all patient and family-facing volunteers and also continue forward into the training programme and the support sessions, and ongoing education offered during the ongoing volunteering process.

Feedback forms are completed at mid- and end-points of the six workshop programme. Volunteers are assessed by the programme facilitator and workshop leaders throughout the workshops. If there are any apprehensions during the workshops, these are raised directly with individual volunteers.

Completion of the workshops does not necessarily ensure that volunteers will go on to support patients and families. All volunteers who do go forward to support are followed up with regular and formal one-to-one meetings.

Ongoing evaluation has become an important part of the training programme: enabling an ongoing content analysis of the post-training evaluation forms highlights the these areas as important regarding the participants' experience of training:

- Gaining in confidence: 73% of volunteers tell us that their confidence in dealing with the psychological, social, and physical issues of dying patients and their families grows significantly when describing the impact of the volunteer training programme on themselves.
- Developing new skills and competences: 83% of volunteers report that they were able to develop new skills during the training programme. Most of this feedback is focussed around the significance of listening skills and a new confidence in making relationships.
- A fresh and clear understanding of what 'good quality care' looks like and changed perceptions of the work of the hospice: 69% of volunteers mention that they have developed a new or different understanding of the meaning of 'good quality care' and how they have grown in their understanding of the breadth of the work that the hospice does whilst changing their perceptions of death and dying.

Setting up a new volunteer community support service—'Volunteers@Home'

Many hospices in the UK utilize their buildings for only a small part of the work that they do (Hospice UK, 2013). At Earl Mountbatten Hospice, as already mentioned, over 650 people are supported within the places that they live on any one day. We therefore need to utilize the majority of our human resource in supporting those people as much as possible. Embarking on a new programme to shift the balance of our volunteers from supporting services within the hospice building to visiting people within their own homes in order to be helpful and supportive has been an important part of our strategic implementation plan over the past two years.

Following attendance at the six workshop training programme, volunteers are assessed for their interest and suitability in supporting patients and families in different ways. This could be on our inpatients unit, in our John Cheverton Self-Help and Rehabilitation Centre, as part of our Island-wide Bereavement Service, or as part of our new 'Volunteers@Home' service. Whichever area volunteers are selected to support within, further bespoke training follows. Those who go forward to support people within their own homes focus on a further set of competences and skills. Although, of course, much of the support is psychological through focussed listening and relationship building, and social through maintaining an important link with the local community, it has been important that volunteers develop some competency to support people physically, such as helping with eating and drinking and supporting to and from the toilet. The key areas for further training are:

- Further communication and listening skills
- Dealing with challenging conversations
- Safe moving and handling awareness
- Care of the patient in their own home—support with eating and drinking, helping to and from the toilet, food hygiene, use of equipment etc.
- Understanding of local community services and signposting
- Lone working awareness
- How to access support and other hospice services

Volunteers are supported as part of our Hospice Community Team, which is made up of clinical nurse specialists, registered nurses, health care assistants, and domiciliary carers. As well as supporting people within the places that they live, this group of volunteers are also available to visit and support people within our local hospital. In this instance, they will be supported by our hospital palliative care team.

Volunteers are matched with someone who lives within their own community, wherever possible. We have found that this proves useful, particularly with arranging visits, being available in a more flexible way, and also holding a knowledge about the local community which has been helpful for linking up further support when needed. The initial agreement is set up to encompass 12 visits, which can be made flexible over three months. At the mid-point and also at the end of 12 visits, an evaluation form is completed by the person being supported, the volunteer, and the member of the hospice community team who made the referral.

Continuous evaluation has been important and has given us fruitful information about both the success of the model, the challenges the model raises, and also potential developments for the future. Key evaluation themes have been

◆ Patients and families feeling supported

It is clear from feedback that patients and families feel supported 100% of the time. They talk of volunteers 'going the extra mile', of 'being endlessly kind' of providing 'much needed help and respite' and of providing a 'sense of still belonging to something bigger than themselves'. Interestingly many people talk about the 'Social Death' that comes with their illness and dying, and how a volunteer from their local community enables them to 'stay in touch' with their friends and neighbours.

◆ Volunteers feeling valuable and valued

Volunteers tell us that the visits give them a sense of 'feeling valued' and also of 'providing a valuable service to the local community'. Many volunteers tell us that they have become known in their community as being a hospice volunteer and this gives a positive view both of themselves and the work of the hospice. It has also been interesting to learn that many volunteers feel as if they are not giving enough. It has been common to hear that although patients and families have been overwhelmed by the support and kindness; volunteers find it hard to articulate what they have really done, other than 'just turning up'. This has helped us to realize that on many occasions 'being there' as a supportive person is more important than undertaking many or any other tasks.

◆ Community team feeling supported

Feedback from community nurses has shown that, despite feeling anxious at the beginning of the project, they have grown to trust that volunteers can be more useful than they had originally thought. Initially, there was a sense, particularly from health care assistants and domiciliary carers, that 'Volunteers@ Home' were going to take away their jobs, and the whole process was a way of saving money. Although part of the impetus came out of realising that would not be able to continuously afford to employ more support staff as we achieved scale, it was never our intention to replace paid staff with volunteers. Our community team members tell us that it helps them focus on the people who really need them, knowing that many people are 'supported and held' by competent volunteers. The evaluation continues to show that it has also been important to engage our community nurses in the training and support of volunteers; giving them both leadership and control of the process and service.

Case study

Jemima

Jemima is in her late fifties and is a widow. She is the mother of two children who are now at university. She moved to the Isle of Wight 15 years ago following the sudden death of her husband. Following her children heading off to university, she had heard about the work of the hospice and wanted to volunteer as she had heard about the training and is interested getting some experience so she can go back to work herself. Although in then past she had worked as an administrator, she was more interested now in going to the local collage and studying health and social care so she could become a carer. She wanted to volunteer with the hospice as an important step in this process.

Jemima says that she was a little sceptical of how long the training was going to take but was surprised by the content and how much she learned. She has been volunteering with us for almost 18 months, and is currently visiting someone who lives in the same village as herself. Reading through the evaluation forms, which were completed by the patient after the first six visits, Jemima was both astonished and moved by the impact that her support had had. The patient says that life before Jemima was lonely and isolating and that they spent most of the time alone and anxious. Jemima has helped them with shopping, driving them, and staying with them during hospital appointments, and supported them with cooking simple meals. He says that Jemima has "made life manageable again'. Interestingly, Jemima feeds back that most of the time she did not feel that she was doing very much. She says that she has learned that 'small things' that can make a big difference.

Case study

Benjamin

Benjamin is 19 and left school with minimal qualifications. He describes being at school and not knowing what he wanted to do with the rest of his life. He says that he wandered through his school years aimlessly and did not feel that he had enough guidance and support about thinking about future possibilities. His grandfather died under the care of the hospice when he was in his mid-teens and he says that he always admired the work of the staff and volunteers who supported both his grandfather and the entire family.

Benjamin had found it difficult to find work and decided when he was 17 to apply to be a volunteer at the hospice. He says that he did not want to volunteer in the hospice shops and was interested in learning how to support the people that we were caring for. Following interview and completion of the training workshops, Benjamin tells us that felt 'fired up' and wanted to support people within their own homes. He attended further training and for the past year has supported three people within the places that they live. During an evaluation interview, he described 'learning how to care' and particularly learning how to talk to people and, more importantly, how to listen. He tells us the story of Dan who had a grandson who lived in Australia and he missed being able to spend time with him. Talking with Benjamin, who was a similar age, Dan felt that he was able to pass on stories and advice to someone who was 'hungry to learn'. Benjamin points out that Dan's stories were powerful and that he learned so much from him. Benjamin has now enrolled on an introduction to Social Work course at the local college and he has decided that he wants to go on to train as a Social Worker.

Case study

Gladys

Gladys is 79 and lives in a rural, isolated village. Her husband died suddenly over five years ago. She tells us that after a couple of years of feeling sorry for herself, she applied to volunteer at the hospice. Initially she thought that she might help out with some administration, but following the six workshop training programme, she felt confident and motivated to support someone coming to the end of their life at home. Over the last year, she has been visiting an older lady called Suzannah who is living with dementia and also a cancer diagnosis. Suzannah has a daughter who lives and works 50 miles away who is only able to visit her mother at weekends. Suzannah is being cared for at home in a sheltered accommodation apartment within the same village that Gladys lives. Suzannah has carers from the hospice domiciliary care service three times a day. Working alongside the care team and taking support and advice from them, Gladys visits Suzannah regularly, helping her to eat and drink, supporting her to and from the toilet, and sitting and listening to her. Gladys tells us that she feels very useful, for the first time in her life since her husband died. As part of the evaluation of the work, the care team fed back that Gladyz is invaluable as she is able to feed back information to them that both informs and enhances their care of Suzannah. They tell us that Gladys 'fills a gap' and the fact that she has received training and support from the hospice gives them both confidence and trust.

It is clear that the 'Volunteers@Home' service is providing new recognition and increased confidence for the volunteers, as well as a myriad of psychological, social, and physical benefits for patients and their carers.

'Responsible Communities'—a new volunteer approach to engaging local communities in caring.

Developing our volunteer workforce through robust recruitment, training, and support mechanisms has led the way for us to rethink our relationship with our local community. We know that there are 30% of people who die across the Isle of Wight who do not have access to hospice services who might benefit from some of our support. As we cannot afford to give all of our services to everyone who might need it, we are needing to think a lot more creatively about what the hospice support of the future might look like, particularly for those who are earlier on in their illness journey. One of the major excluded groups within our local community are older people coming to the end of life with increasing frailty. These people will not have a formal 'diagnosis' and because of this will not have access to the health and social care system in the ways that people with more mainstream illnesses, such as cancer, dementia, and heart failure will have. We have recently developed a new community support project called 'Responsible Communities', which is still in its development stage. However, we already begin to see the potential benefits that such a programme might bring to older, frail people. Our aim is to re-engage local neighbourhoods in order to provide some much needed psychological, social, and physical support for frail, older, and vulnerable people. We aim to utilize our expertise and social capital to:

- Support beneficiaries not normally referred to the hospice, particularly frail, older people; through engaging, supporting, and training existing members of their local communities as community champions to provide companionship, kindness, communication, and information.
- A number of bespoke services will be delivered ranging from the reengaging of social networks through to befriending; signposting; enabling access to good information, and providing advice on sustaining well-being.
- Source individuals and existing community groups from within these areas to lead the project.

We know that frail older adults are vulnerable, have a lower ability for independent living, and often require assistance for daily activities (Torpy, 2006). More than half of people aged 75 and over live alone. 70% of older people admit that their only company is the television. These people will mostly not have been referred to a hospice or other mainstream health and social care services as they will be older people living and dying with frailty as opposed to a diagnosed illness. On the Isle of Wight, around one in six households are occupied by a single person over the age of 65 and we are told that loneliness has been observed as having a similar potential impact on survival rates as smoking (Holt-Lundstad et al., 2010). The inward migration of retired people, frequently without immediate family due to limited employment opportunities existing on the island and the outward migration of younger island-based people for the same reason has created a population imbalance where 23.8% of the island population is aged 65 and over against a national average of 16.4% (2016).

The scope of the project encompasses both urban and rural locations across the Isle of Wight. In each location Earl Mountbatten Hospice acts as the principal remote hub for the project but (particularly in the rural areas identified) uses a variety of locations working with existing groups: for training; support; and guidance ranging from village halls, pubs, and local post offices. Our main objective is to connect a number of 'local volunteer champions' to our local hospice shops, of which there are ten across the Isle of Wight, and to extend our supportive local community presence.

We have identified areas which fall into the 20% most deprived in England and are ranked within the top five of the 89 wards comprising our local community in terms of 'Income deprivation affecting older people'. Meeting places for groups are limited and high levels of crime are a barrier to older people being both mobile and confident within the community. Newman and Newman (2012) identified the three top concerns of older people as bodily pain, loneliness, and memory loss. The issue of social isolation on the Isle of Wight has been established (BLF, 2014) and frailty, loneliness, and lack of access to services in rural locations have also been identified by our Hospice Community Team, particularly through our 'Volunteers@Home' work, as an escalating concern.

In preparation for this work, we engaged with both urban and rural communities through our Hospice Community Team, our 'Volunteers@Home' service, professional multi-disciplinary outreach teams, and fundraising networks. Our hospice also offers community engagement activities that range from a concert series through to art classes and a community café at the hospice site. Like other organizations it is challenging to extend these services to other locations. We have gathered substantial evidence that attendees have identified friends and neighbours who would like elevated levels of social interaction but are too frail to travel to the hospice building or to engage in such activities other than at a local level.

Whilst there is some debate over ways in which to address social isolation (Davidson S. and Rossall P., 2014) there is general agreement that re-engagement with the local community is a key indicator. The hospice is a trusted name on the Isle of Wight and we are discovering that those who have engaged with us in the past or have knowledge of the hospice through past experiences are interested in supporting us in our 'Responsible Communities' project.

Earl Mountbatten Hospice has a track record of innovation and successfully rolling out new projects and ideas underpinned with solid evaluation and research and we have a formal relationship with the University of Southampton which supports us with any new initiatives. Prior to recently launching the project we consulted with all local stake holders including town and parish councils, other local voluntary organizations, and other potential beneficiaries. Existing trained hospice volunteers have been identified from within the pilot sites and the project has begun to identify local individuals and groups. Local communities are supported by local volunteers with operational oversight resting with the project co-ordinator who is based at the hospice.

Although the project has only been running a short time, and is still yet to achieve capacity, we are discovering a wide range of needs exhibited by beneficiaries; ranging from companionship, occasional transport and shopping, going for a walk, to more complex needs such as support with eating/drinking, and mobility, and listening to people's stories. Those individuals and groups trained and supported are able to signpost individuals onto more expert and appropriate services should they feel this is needed.

Developing a set of outcomes and key performance indicators has been key to the success of this work. The initial project will last 18 months, and our aim is to put in place ongoing support for community groups in order to sustain this work into the future with minimal support from the hospice. Some of the outcomes and indicators for the project are shared in Table 5.1.

Although the project is still in the development phase, it is clear that the hospice has a part to play in supporting communities to regain their responsibility for caring. Six local community groups are currently involved supported by 12 hospice volunteers, all of whom have previously given time for free as part of the 'Volunteers@Home' project. One of these volunteers, as part of the evaluation interview process shared these comments:

> I am beginning to see my village come together in a way I haven't experienced during the twenty or so years I have lived there. I am getting to know people I did not even know lived there, speaking with them and engaging with them in a positive and caring way. A group of us meet at the local post office every week and we identify older people who might need support in some way. We are fortunate that the District Nurse lives in the village and has become engaged with the group. It feels instinctively right that we support 'our own'. It is beginning to give a very different sense of community, and we hope that no-one will ever have to feel lonely and isolated due to our commitment.

Conclusion

This chapter has described how volunteers can support the psychological, social, and physical needs of members of the local community who are living with dying and all that this brings. It has highlighted the complexities of changing the very nature of how hospice volunteering schemes need to develop and reform if they are to be useful within the changing landscape of health and social care within the UK at the current time. In order to be able to offer worthwhile and relevant opportunities for volunteers both drawn from the local community and based within the local community, whilst meeting the changing needs of patients and families and addressing key drivers for those changes as part of both internal and external sources, we have been able to successfully and critically self-examine our past volunteer strategies and policies in order to create a more relevant present and potentially a more successful future. We have learned that change on a large scale is often difficult, but not impossible, and that if the needs of patients and families are matched carefully with both internal and external challenges, a critical examination can pay dividends in developing a more robust and fruitful volunteer service.

Taking volunteering seriously is both a strategic and ethical necessity. The whole Health and Social Care sector in the UK and Hospices in particular should scrutinize their past and current experiences in order to deliver a service which responds to the innumerable psychological, social, and physical needs of those living with death and dying as well as members of the local community who want to give something back to society.

Table 5.1 Outcomes and indicators for the 'Responsible Communities' project

Outcome	Indicator	Indicator level	Timescale
Beneficiaries feel less isolated through interacting with the project and have developed new social networks/ activities and self-confidence as a result	Number of new social interactions and increase in participation levels by beneficiaries	30 people participating in new social activities	By end of project
	Number less isolated	40 people feeling less isolated through interactions with volunteers and other groups to which they have been introduced	By end of project
	Increased self -confidence	20 people feeling increased self-confidence (as measured in Wellbeing questionnaire). 40 people feeling increased self-confidence (as measured in 'Wellbeing' questionnaire)	After six months By end of project
Beneficiaries will feel more a part of their local community, have increased visibility and an active voice on local matters that affect them	Activity in local issues	Five people involved in local forums or discussion groups. Five people confident to act as advocates for fellow group members	By end of project By end of project
Increased sense of well-being amongst beneficiaries	Increased participation in activities and general well being	20 people indicate increase in wellbeing in questionnaire. 40 people indicate increase in wellbeing in questionnaire	After six months By end of project
Earlier identification of unmet medical, social or other essential needs amongst beneficiaries	Increase in referrals and signposting to other agencies	Five people referred or signposted to health and social care services or other voluntary agencies. Ten people referred or signposted to health and social care services or other voluntary agencies	After six months By end of project

If this is addressed and achieved, hospices have a significant part to play: acting as a central training and service-provider exemplar for a range of opportunities for members of their immediate communities and other organizations working within the wider national landscape, including patients, families, and carers, as well as prospective volunteers with different desires and purposes for wanting to give their time for free.

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The five Hospice UK recommendations were reprinted with permission from 'Help the Hospices', *Volunteers: vital to the future of hospice care, A working paper of the Commission into the Future of Hospice Care*, November 2012, which is available at: www.hospiceuk.org.

References

Armstrong J. and **McLeod J.** (2003). Research into the organisation, training and effectiveness of counsellors who work for free. *Counselling and Psychotherapy Research*, **3**(4): 245–59.

British Lung Foundation (2014). Available from: www.lunguk.org/you-and-your-lungs/conditions-and-diseases/copd.htm (accessed May 2017).

Clark D. (2002). *Cicely Saunders: Founder of the Hospice Movement Selected Letters 1959-1999*. Oxford, UK: Oxford University Press.

Davidson S. and **Rossall P.** (2014). Loneliness Evidence Review. UK: Age UK >

Diamond H., et al. (2012). Helpful aspects of bereavement support for adults following an expected death: Volunteers and bereaved people's perspectives in death studies. *Death Studies*, **36**(6): 541–64.

Field D. (2000). *What Do We Mean by Psychosocial?: A Discussion Paper on Use of the Concept Within Palliative Care*. UK: National Council for Palliative Care.

Hartley N. (2012). *Bénévoles d'accompagnement au Saint-Christopher's Hospice: tendances actuelles et futurs défis*. Pedicine Palliative Sons de Support, Accompagnement, *Ethitique*, **11**: 252–61.

Holt-Lunstad J., **Smith T.B.**, and **Layton J.B.** (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Med*, **7**(7): e1000316.

Hospice UK (2013). Report from the Commission into the Future of Hospice Hospice UK: Care Publication.

Hospice UK (2012). *Volunteers: Vital to the Future of Hospice*. Hospice UK: Care Publication.

Newman B.M. and **Newman P.R.** (2012). *Development Through Life: A Psychosocial Approach*. Australia, Brazil, Mexico, Singapore, UK, USA: Lengage Learning.

Office of National Statistics (2016). *Overview of UK Population*. London: Published by the Office of National statistics.

Saunders C. (1990). *Hospice and Palliative Care: An Interdisciplinary Approach*. London: Edward Arnold.

Scott R., **Howlett S.**, and **Doyle D.** (2009). Volunteers in Hospice and Palliative Care Publ. Oxford: Oxford University Press.

Scott R. and Howlett S. (eds) (2017). *The Changing Face of Volunteering in Hospice and Palliative Care: An International Perspective*. Oxford, UK: Oxford University Press.

Torpy J.M. (2006). Frailty in older adults. *Journal of the American Medical Association*, **296**(18): 559–64.

Walshe C., **Dodd S.**, **Perez Algorta G.**, **Hill M.**, **Ockende N.**, **Payne S.**, and **Preston N.** (2016). *How to Provide a Volunteer Befriending Service: Reccomendations From a Wait-List Controlled Trial International Observatory on End of Life Care*. Lancaster, UK: 2 Institute for Volunteering Research, NCVO. 10.1136/bmjspcare-2016-001245.226.

Wilmot A., **Hill M.**, **Ockenden N.**, and **Payne S.** (2013). A narrative literature review of the contribution of volunteers in end of life care services. *Journal of Palliative Medicine*, **5**(7): 428–36.

Chapter 6

Dementia, multimorbidity, and frailty

Karen Harrison Dening

Introduction to dementia, multimorbidity, and frailty

More people are living longer in old age (WHO, 2012). The numbers of those reaching the oldest ages are increasing the fastest: in 2008 there were 1.3 million people in the UK aged 85 and over, with this expected to increase to 1.8 million by 2018 and to 3.3 million by 2033 (ONS, 2013). As life expectancy increases people often develop a range of conditions and disabilities in the years before death (Froggatt et al, 2006). These changes to the age structure of the population influence both the prevalence and incidence of age-related conditions such as dementia (Stephan and Brayne, 2008) and frailty.

In the UK it has been estimated that as many as 25 million people (42% of the UK population) will know a close friend or family member affected by dementia (Luengo-Fernandez et al., 2010). Exact figures for dementia are hard to obtain but the Dementia 2010 Report (Luengo-Fernandez et al., 2010) estimates that the number of people in the UK with dementia (both diagnosed and undiagnosed) is currently around 820,000. This figure equates to 1.3% of the entire UK population. Though these statistics have recently been challenged (Matthews et al., 2013; Norton et al., 2013) we know that increasing age appears to be the strongest risk factor for developing dementia (O'Connor, 2010) and that these numbers are forecast to rise.

Dementia

Dementia is not a disease in itself but a syndrome: a collection of symptoms; including a decline in memory, reasoning, and communication skills, and a gradual loss of skills needed to carry out daily living activities. These symptoms are caused by structural and chemical changes within the brain as a result of neurodegenerative changes. The cognitive changes arising in dementia are determined to a large extent by the areas of the brain that are affected by the underlying pathological processes. These processes include: tissue destruction, compression, inflammation, and biochemical imbalances. In other words, the process of dementia is the end stage manifestation of numerous brain disorders (Fratiglioni and Qiu, 2013). Alzheimer's disease remains the most common form of dementia followed by vascular dementia, mixed dementia, dementia with Lewy Body's, and front temporal lobe dementia, and in other conditions primarily or secondarily affecting the brain such as Parkinson's disease.

Thus the number of people dying with and from dementia and frailty will similarly increase. Estimates from the UK MRC-CFAS project, a large multicentre study looking at the health and cognitive function of 13,000 older people, suggest that people who died between the ages of 65 and 69 years had a 6% risk of dying with dementia, rising to a 58% risk of dying with dementia in those over 95 years. In the UK, one in three people over the age of 65 will die with or from dementia (Brayne et al., 2006). However, older people with dementia will often have several other co morbid conditions such as; frailty, diabetes, heart failure, etc.

Frailty

Frailty is a distinctive health state also related to the ageing process in which multiple body systems gradually lose their in-built reserves.

> … an aggregate expression of risk resulting from age- or disease-associated physiologic accumulation of subthreshold decrements affecting multiple physiologic systems resulting in adverse health outcomes. (Abellan van Kan et al., 2008)

Around 10% of people in the UK aged over 65 years have frailty: rising between 25% and 50% of those aged over 85 years (BGS, 2014). Older people with dementia and frailty are at risk of adverse outcomes such as dramatic changes in their physical and psychological well-being after an event that for a younger person may be a minor illness, such as an infection or the introduction of a new medication.

Frailty is defined as a combination of the natural ageing process and a variety of medical problems. It is possible to distinguish those older people who are fit and healthy from those displaying signs of frailty. Fried et al. (2001) suggest that if someone presents with three or more of the following factors they should be considered frail (see Box 6.1).

As with dementia, frailty also becomes more common with increasing age; by the age of 90 years 32% will be frail (Gavrilov & Gavrilova, 2001). Frailty is strongly associated with cognitive impairment and clinically diagnosed dementia among people of 75 years and over. Based upon the findings of a

Box 6.1 Signs of frailty

- Unintentional weight loss—ten pounds or more in one year
- General feeling of exhaustion
- Weakness, as measured in grip strength
- Slow walking speed
- Low levels of physical activity

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population study Kulmala et al. (2014) argue that such is the significance of the association of cognitive impairment and dementia in people with frailty that it should be included as a clinical feature within the frailty definition.

Frailty and dementia are multi-factorial in origin and share some common aetiological pathways. Smoking, obesity, lack of physical activity, and depression have been linked to the development of both frailty and dementia (Hamer and Chida, 2009; Kerwin et al., 2010; Ownby et al., 2006). Thus frailty and dementia have been conceptualized as final common pathways resulting from cumulative exposures over a number of years (Neale et al., 2001).

Both dementia and frailty have an adverse impact on a range of outcomes. People with dementia are at higher risk of acute hospital admission (Mukadam and Sampson, 2011), falls (Myers et al., 1991), and being placed in care homes (Harrison et al., 2017); crisis or transition points at which the diagnosis is often made for the first time. Frailty also increases the risk of emergency hospital admission, overnight hospital stays (Rodriguez-Pascual et al., 2017), falls (Fried, et al., 2001), and institutionalization (Harrison et al., 2017). These outcomes seem to be independent of physical co-morbidity and other potential confounders such as age or gender (Avila-Funes et al., 2009).

Multiple morbidity and long-term conditions

A long-term condition (LTC) is defined as a condition that cannot, at present, be cured but is controlled by medication and/or other treatment or therapies (DH, 2012). They are of one year's duration or longer, impact significantly on a person's life, and may require ongoing care and support (Scottish Government, 2015). The number of people with one long-term condition (LTC) is projected to be relatively stable over the next ten years, however, those with multiple LTCs is set to rise from 1.9 million in 2008 to 2.9 million in 2018 (DH, 2012). Dementia and frailty are now often framed within the context of being an LTC; with a very limited number of pharmaceutical treatments specifically for Alzheimer's disease that cannot cure the disease but temporarily alleviate symptoms or slow down the progression of the disease (Alzheimer's Research UK, 2016). Not surprisingly, people with LTCs and frail older people (including those with dementia) are the greatest users of health and social care (Kulmala et al., 2014). This rising demand on health and social care services has been of increasing concern and priority for policy development.

Dementia and diagnostic overshadowing

When two or more condition: as in dementia, multimorbidity, and frailty are present it is often possible that the diagnosis of dementia overshadows the others and makes their detection, assessment, and overall management more difficult. Diagnostic overshadowing is a term that is more commonly used within mental illness and learning disabilities and may arise due to the stigmatization of the mental health condition and negative attitudes among health and social care practitioners (Carling-Jenkins et al., 2012; Nash, 2013). However, there is very little written about diagnostic overshadowing old age and dementia. Because 80% of medical diagnoses are based upon what people tell their doctors, diagnostic overshadowing is most prevalent among those who have problems and difficulties in verbal communication. Communication becomes increasingly problematic as dementia progresses. Diagnostic overshadowing can increase the risk of treatment delay and thus, in turn, may increase the possibility of complications and morbidity having a profound and negative effect on frail, older people with dementia as they near the end of life. There is a challenge for practitioners to minimize or avoid misattribution of cognitive or behavioural changes to dementia but to respond to those symptoms which cause concern or distress (see case study); this is the essence of good palliative and end-of-life care for people with dementia, and indeed frailty.

Case study

Jean

Jean had advanced dementia of Alzheimer's type and was admitted to an acute hospital from a care home where she was staying whilst her husband and carer was being rehabilitated following a small stroke. Up until his admission to hospital, Frank had been Jean's main carer. Frank had cared for Jean for five years after her diagnosis of dementia and accepted little support, wishing to care for her himself. As well as dementia Jean also had osteoporosis and frailty and tended to have frequent urinary tract infections due to her immobility.

During the first week of her stay in the care home Jean became increasingly distressed and started to refuse care hitting out at care staff as they tried to support her with personal care. The GP was called and given a history of 'agitation' by the care staff, 'resistance to care' and 'shouting' and prescribed her an antipsychotic medication as it was felt that Jean was displaying behavioural and psychiatric symptoms of dementia (BPSD). Sadly Jean's diagnosis of dementia had overshadowed how her symptoms were being perceived. Rather than seeing Jean as a person who was unable to communicate her needs in any normal way expressed her sense of loss of her husband, not understanding where he was; being in a strange environment and having intimate and personal care provided by people she neither knew nor who knew her and all in a setting she did not recognize. Having no verbal communication Jean expressed her 'distress' through her behaviours' that resulted in her dementia being seen as the basis for her care refusal.

Dementia and frailty are life-limiting illnesses

Despite the impact that dementia and frailty have on older people and their families, they have not traditionally been conceptualized as 'terminal' or 'life limiting' syndromes, for example, care home medical and nursing staff consistently overestimate prognosis in advanced dementia. In one study of nursing home carers and physicians, at nursing home admission only 1.1% of residents were perceived to have life expectancy of less than six months however, 71% died within that period (Mitchell et al., 2004).

A population study in the UK gave a median survival time from diagnosis of dementia to death of 4.1 years (Xie et al., 2008). As would be expected, older people defined as being frail, also have a significantly increased risk of death (Klein et al., 2005). Identifying when a frail older person with dementia is reaching the end of their life can be challenging. Numerous studies have attempted to identify prognostic indicators that may guide clinicians to adopt a more palliative approach to care, however, these tools are more reliable at identifying people with dementia at *low* risk of dying rather than those at higher risk of death (van der Steen, et al., 2005). However, we know that acute physical illness requiring emergency hospital admission, such as pneumonia or urinary tract infection may be indicator of imminent death in people with advanced dementia (Mitchell et al., 2009; Sampson et al,, 2009). Similarly mortality is also very poor with 24% of those with moderate or severe dementia dying after acute unplanned medical admissions compared to 7.5% of those who did not have dementia (Sampson et al., 2009).

Clinical judgement and an understanding of the nature and progression of dementia, frailty, and multimorbidity towards the end of life can positively enhance care for this population. At times of intercurrent illness or care transition, such as to a care home or acute hospital admission, may present an opportunity to refocusing the goals of care where an active plan is not in place (van ser Steen, 2010). This may also lead to constructive discussions with families and carers, taking the opportunity to reassess or shift the goals of care and management towards a palliative approach, whether this be in the form of anticipatory or advance care planning.

Advance care planning in dementia

Advance care planning (ACP) is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future consider their wishes and preferences for care in certain circumstances. ACP has been available for a longer period and achieved success in conditions such as cancer. However, in the context of dementia, the mental capacity to make decisions can be lost fairly early on in the illness. There is a small growing literature on ACP and its application in dementia in the UK highlighting that its uptake is low and patchy and is still not a mainstream intervention (Harrison Dening, 2011). The EAPC white paper makes 57 recommendations for effective palliative care in dementia (van der Steen et al., 2013) and domain three focuses on ACP (see Box 6.2).

Wishes and preferences for future care are assumed to be based upon the principles of autonomy, whereby a person expects to retain personal control in making decisions. However, there is often a desire in older adults to consider family ties and so the collective process of family decision may be of equal importance (Whitlatch et al., 2009). Friedman et al., (2002) proposed that the individualistic sense or value of autonomy becomes more collectivist when considering health-care decisions of older people and found that participants had a preference for shared decision making with their families and carers. However, in the absence of ACP discussions family carers' ability to accurately predict the wishes and preferences of the person with dementia for whom they care for is limited, and concordance is often no better than chance (Harrison Dening et al., 2016) so people with dementia and their families require ongoing professional support in shared decision making.

Within the context of dementia and frailty, decisions about what to do or not range in importance: for example, from decisions to be made as a result of a health crisis, such as an intercurrent illness as previously discussed, to decisions to be made about to day to day needs. How decision making is best supported will vary with the circumstances and the complexity and seriousness of the issue in question (Whitlatch et al., 2009). Families affected by dementia often feel unsupported in decision making and in preparing for the progression of the disease (Harrison Dening et al., 2017a) and have little experience of shared health-care decision making before the onset and diagnosis of the dementia. Indeed, there is much debate on when is the best time to offer ACP

Box 6.2 Domain 3. Setting care goals and advance planning

3.1 Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.

3.2 Anticipating progression of the disease, advance care planning is pro-active. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs, and beliefs can be elicited.

3.3 Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.

3.4 In mild dementia people need support in planning for the future.

3.5 In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort.

3.6 Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.

3.7 Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Reproduced with permission from van der Steen J. T. et al., 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care', *Palliative Medicine*, Volume 28, Issue 3, pp. 197–209, Copyright © SAGE Journals, DOI: 10.1177/0269216313493685

to people with dementia; many professionals feel that entering into discussions about ACP for end-of-life care and is both too soon and insensitive within the diagnostic process. However, in dementia, end-of-life planning needs to take place early, while the person has sufficient mental capacity to consider their preferences and make decisions but, as discussed earlier when considering the potential shift in goals of care, there are certain junctures where ACP could be considered, whether that directly involve the person with dementia if able and in support of family decision making (see Box 6.3).

The process of ACP in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes

Box 6.3 Milestones which can act as triggers to engage in ACP

Transition points Healthcare events

- Time of diagnosis of dementia
- When undertaking a Lasting Power of Attorney (LPA) for finance (consider LPA personal welfare)
- Care plan/package review for community home care
- Changes of care setting; transfer to acute care or residential care setting, etc.
- Changes in family carer situation (illness, death, etc.)
- Deterioration or decline in the persons condition
- Person presenting with complex symptoms
- Person presenting with difficulty with nutrition and hydration
- Decreasing response to anti-biotic treatment
- When the question of a need for further medical investigations of treatments arise
- Discussions about attempting cardio-pulmonary resuscitation
- Changes to the health status of the family carer

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compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position whereby they are called on to inform, or directly make, decisions on behalf of the person with dementia. It is often assumed that carers know what the person with dementia's decisions might have been when capacity is lost even though wishes and preferences have not been articulated. We need to have greater confidence to initiate ACP conversations to directly involve the person with dementia themselves if we are to ensure their wishes and preferences are realized at a time where they have lost capacity to make these themselves in real time. Of equal importance is for professionals to support family carers to make decisions on behalf the person with dementia to enable them to effectively navigate the various transition points along the trajectory of dementia: such as seeking a diagnosis; access to support services, admission to a care home, end-of-life care options, etc.

Access to palliative care and end-of-life care

Older people have not always enjoyed access to palliative and end-of-life care services. As early as 2001 a call was made for equitable access to palliative and end-of-life care for older people in the National Service Framework for Older People (DH, 2001). The document set eight standards for improving the health and social care of older people, which aimed the first of the eight standards to ensure that older people are never unfairly discriminated against in accessing NHS or social care services as a result of their age. However, despite older people logically being nearer to death, palliative, and end-of-life care services are still very 'cancer focused', but we are seeing changes to their inclusiveness of people dying from other conditions with strong push to include people with dementia (Hospice UK, 2015).

Admiral Nursing: a model for palliative care in dementia

There is a growing interest in a 'case management' approach for families affected by dementia; this would entail detailed assessment and a coordination of care for both the person with dementia and their family carer in receiving support from health, social, and voluntary care sectors (Harrison Dening et al., 2017b). However, care that manages the illness throughout its progression: from diagnosis to death and beyond in supporting families in their loss; access to care management is patchy (Harrison Dening 2010). Admiral Nursing has a case-management approach in working with families affected by dementia with support offered throughout the trajectory of the illness; this support is of particular value during transitions from community to care home and towards the end-of-life of the person with dementia (Harrison Dening, 2010; Harrison Dening et al., 2017b). Admiral Nursing was established as a result of the experiences of family carers to uniquely join the different parts of the health and social care system and enable the needs of family carers and people with dementia to be addressed in a coordinated way (Rahman and Harrison Dening, 2016).

Admiral Nursing and hospice

Dementia care is an increasingly important strategic consideration for palliative, end-of-life and hospice services in the UK. In 2014 Hospice UK embarked upon a year-long project to explore current provision for families affected by dementia within the hospice movement and provide guidance for hospice providers to support people with dementia to live well in the community until they die. The findings revealed a number of UK hospices were already embracing dementia and palliative care in creative ways. However, where hospices did not provide care for people with dementia there were a number of factors that were perceived as barriers. Several felt that dementia was not within their remit, did not consider it to be a life-limiting illness and had no plans or intentions to include dementia in future service development or strategic planning. Conversely, some were considering including dementia but reflected they did not have the most suitable physical environments or that it may conflict with meeting the needs of their other patients. The guidance steers hospice from the very first steps of auditing and reviewing their current position, to implementing creative dementia friendly services (Hospice UK, 2015). A growing number of hospices have used the guidance to support their strategic planning in implementing dementia-specific services such as Admiral Nursing.

Many people with dementia find health and social care bewildering, and find the system difficult to navigate, especially as the person with dementia nears the end of life. The Admiral Nursing model was developed to provide case management (Harrison Dening et al., 2017b) for families affected by dementia to be better able to cope; enable people with dementia to stay at home and to live more independently and positively with their condition for as long as possible. Admiral Nurses work across a variety of NHS organizations (primary, secondary, acute, and community care) as well as in social care, care home, and hospice settings. Central to their role is case management using the Admiral Nurse Assessment Framework (an 18-domain assessment schedule of the needs of both the person with dementia and the family carer) to underpin their care of families affected by dementia. The 'gold standard' would be to case manage families affected by dementia throughout the disease trajectory. However, due to funding constraints and commissioning anomalies Admiral Nurses may work for a specific period or part of the disease trajectory. The model is proving to be very effective in meeting the needs of families affected by dementia as the diagnosed person nears the palliative and end-of life stages (Harrison Dening, Crowther, and Tolman, 2017).

Case study

Admiral Nursing

St Cuthbert's hospice was the first hospice in the UK to appoint an Admiral Nurse in 2014. The Admiral Nurse (AN) quickly perceived that the ethos of good hospice care chimed with the principles of good dementia care; seeing the person before the illness and involving and supporting all those around the person who may also be affected by the illness. Whilst hospice staff are very skilled in dealing with complex issues and patient/family distress, dementia still carries fear and stigma and a worry about what to do and hospice staff feeling they lack the confidence and skills to care. This can result in a reduced understanding of a person's needs. So, some of the ANs role has been in building staff's confidence and interest in caring for people with dementia. Teaching is important but changing culture and getting people to think differently and feel passionate about dementia care is required to embed best dementia care and practice with more sustainability.

The AN became involved in multidisciplinary meetings where the terminology used is beginning to change to embrace a more person centred ethos; for example, 'distress behaviours' are talked about now rather than 'challenging behaviours', the diagnosis of dementia no longer overshadowing other physical conditions. The AN acts as a resource for various issues such as: deprivation of liberty legislation (DoLs), capacity, and mental capacity assessments. She has also introduced tools to assess delirium and pain in dementia (Schuurmans et al., 2003; Abbey et al., 2004). A large part of the AN's work is community based: working mostly with people in the advanced stages of dementia and working with family carers to build their confidence, knowledge, and skills.

St Cuthbert's now hosts a cognitive stimulation group in its well-being centre aimed at people with mild to moderate dementia and also a Namaste Care (Simard, 2013) at home service for people with advanced dementia (see Box 4). The AN trains Namaste Care volunteers to visit people at home and provide sensory-based stimulation and interaction for people with dementia, showing family carers new or different ways of remaining connected with the person with dementia. Carers of people with dementia can now also access complimentary therapies that are offered routinely to other family carers by the hospice. The AN's role is to both plan and initiate these services and ensure the staff have the confidence and ability to take them forward, offering support where needed (see Box 6.4).

The AN feels the scope of possibilities to be endless and that it is a pleasure to work alongside these people highly skilled in palliative and end-of-life care and to have had the opportunity to grow the dementia service with them. The AN reflects that the palliative care approach reminds us all that dementia is a 'disease' of the brain and much of their work is in helping the wider health and social care community see dementia through a palliative lens which gains a completely different perspective, one that is fresh, hopeful, and thoughtful.

In support of family carers

As the number of people with dementia increases so the number of family carers will do so also; current estimations are 670,000 (Newbronner et al., 2013). Many carers are spouses and likely to be older and have physical or mental health needs of their own, to the extent that these may hamper their ability to provide care to the person with dementia (Harrison Dening et al., 2012).

However, the relationship that they had to the individual prior to their illness still remains, e.g. husband or son, but the changing nature of the relationship after diagnosis often requires physical and emotional adjustments throughout its course. Carers can experience a number of 'pre-death' losses that can cause

Box 6.4 Namaste Care

Namaste Care^{TM} is a seven day a week program designed to improve the quality of life for people with advanced dementia through providing sensory and meaningful activities, such as hand or foot massage through 'loving touch'. It is designed to take place in a designated space that helps to create a safe and comforting environment such as care homes and within a person's own home as part of a hospice programme.

Source: data from Namaste Care, *The End of Life Care Program for People with Dementia*, Available at: http://www.namastecare.com/

grief. Even when family carers are able to work through their pre-death grief, they cannot fully re-establish their lives until after the death of their relative (Chan et al., 2012).

Loss, grief, and bereavement in carers of people with dementia

Caring for a person with dementia is considered more burdensome and 'unrelenting' when compared with other long-term conditions (Sachs et al., 2004) with increased vulnerability to complex or abnormal grief reactions (Schulz et al., 2008). Some carers find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies yet others feel a further acute sense of loss when the person dies.

A sense of loss is one of the most powerful feelings that carers of people with dementia experience. This sense of loss and associated anticipatory grief can be felt whilst the person with dementia is still alive and depending on the relationship with the person with dementia, the carer may experience grief for many forms of loss, such as loss of future retirement plans, loss of spousal companionship in later life. The manner in which family carers experience and manage their grief reactions to the pre-death losses can influence not only care giving outcomes but also subsequent adjustment once those with dementia have died. It is therefore crucial that their grief is addressed (Almberg et al., 2000; Chan et al., 2012). In a systematic review Chan et al., (2012) describe grief in dementia carers as a complex reaction to losses occurring before and after death. Chan et al. argue that anticipatory grief is greatest in moderate to severe stage dementia and spouse carers, especially when the person with dementia is institutionalized. Evidence about the prevalence of grief is less robust with studies reporting anticipatory grief between 47% and 71%, and complicated grief after death is estimated around 20%. Carer depression increases with anticipatory grief. Being a spouse carer and being depressed are the strongest predictors of complicated and normal grief after death (Chan et al., 2012).

It is important that bereaved carers of people with dementia receive follow-up care in recognition of their loss and bereavement. Many carers feel a second and huge sense of loss and may also feel that their life no longer has the meaning that it has had for many years. Often the care services that were present in meeting the person with dementia's needs instantly withdraw leaving a void in the carer's life. Often carers are discharged from services that were related to the person with dementia and grief and abnormal grief are often not observed or addressed adequately.

Conclusion

Better access to palliative and end-of-life care for people with dementia are causes that have has been championed for nearly two decades. People with dementia often present with a variety of complex needs given their multi morbidity of several other life-limiting and long-term conditions and as such require care and interventions that have the capacity and ability to manage their care effectively. A combination of dementia, frailty, and multi morbidity is becoming common place and requires a skilled and appropriate response from health and social care to enable good palliative and end-of-life care. However, people with dementia do not 'travel alone' with their illness with many family carers also experiencing the profound effects of the diagnosis. Many older, spousal carers also experience multi morbidity and frailty so to provide emotional and psychological support to their caring role may only go part way to truly develop resilience to continue to care. Health and social care services are required to adopt a comprehensive case-management approach to meet the challenges faced by the whole family affected by the diagnosis of dementia in support of better outcomes.

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References

Abbey J., **Pillr N.**, **De Bellis A.**, **Esterman A.**, **Parker L.**, and **Lowcay B.** (2004). The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing*, **10**(1): 6–13.

Abellan van Kan G., **Rolland Y.M.**, **Morley J.E.**, and **Vellas B.** (2008). Frailty: toward a clinical definition. *Journal of the American Medical Directors Association*, **9**(2): 71–2.

Almberg B.E., **Grafstrom M.**, and **Winbald B.** (2000). Caregivers of relatives with dementia: experiences encompassing social support and bereavement. *Aging and Mental Health*, **4**(1) 82–9.

Alzheimer's Research UK. (2016). *About Dementia–Types of Dementia*. Available from: http://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/symptoms/ [Accessed 10 May 2017].

Avila-Funes J.A., **Amieva H.**, **Barberger-Gateau P.**, **Le Goff M.**, **Raoux N.**, **Ritchie K.**, **Carrière I.**, et al. (2009). Cognitive impairment improves the predictive validity of the phenotype of frailty for adverse health outcomes: the three-city study. *Journal of the American Geriatrics Society*, **57**(3): 453–61.

BGS (2014). *Fit for Frailty: Consensus Best Practice Guidance for the Care of Older People Living with Frailty in Community and Outpatient Settings*. London: British Geriatric Society, Royal College of General practitioners and Age UK.

Brayne C., **Gao L.**, **Dewey M.**, and **Matthews F.E.** (2006). Dementia before death in ageing societies—the promise of prevention and the reality. *PLoS. Med.*, **3**(10) e397 available from: PM:17076551.

Carling-Jenkins R., **Torr J.**, **Iacono T.**, and **Bigby C.** (2012). Experiences of supporting people with Downs syndrome and Alzheimer's disease in aged care and family environments. *Journal of Intellectual & Developmental Disability*, **37**(1): 54–60.

Chan D., **Livingston G.**, **Jones L.**, and **Sampson E.** (2012). Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry*, doi: 10.1002/gps.3795.

DH (2001). *National Service Framework for Older People*, London: Department of Health.

DH (2012). *Long Term Conditions Compendium of Information: Third Edition*. Accessible from: www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf [Accessed 10 May 2017].

Fratiglioni L. and **Qiu C.** (2013). Chapter 31: Epidemiology of dementia. In: Dening, T. and Thomas, A. (ed.) 2nd edition, *Oxford Textbook of Old Age Psychiatry*, Oxford: Oxford University Press, pp. 389–413.

Fried L.P., **Tangen C.M.**, **Watson J.**, **Newman A.B.**, **Hirsch C.**, **Gottdiener J.**, **Seeman T.**, et al. (2001). Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology. Series A, Biological sciences and medical sciences*, **56**(3): 46–56.

Friedman, M.R., **Bowden, V.R.**, and **Jones, E.** (2002) *Family Nursing: Research, Theory and Practice,* New Jersey: Prentice Hall.

Froggatt K., **McCormack B.**, and **Reed J.** (2006). End-of-life issues in long-term care–implications for practice. *International Journal of Older Peoples Nursing*, **1**(1): 44, doi: 10.1111/j.1748-3743.2006.00011.x.

Gavrilov L.A. and **Gavrilova N.S.** (2001). The reliability theory of aging and longevity. *Journal of Theoretical Biology*, **213**(4): 527–45.

Hamer M. and **Chida Y.** (2009). Physical activity and risk of neurodegenerative disease: a systematic review of prospective evidence. *Psychological Medicine*, **39**(1): 3–11.

Harrison J.K., **Garrido A.G.**, **Rhynas S.J.**, **Logan G.**, **MacLullich A.M.**, **MacArthur J.**, and **Shenkin S.** (2017). New institutionalisation following acute hospital admission: a retrospective cohort study. *Age and Ageing*, **46**(2): 238–44.

Harrison Dening K. (In press). Advance care planning and dementia, Chapter 12. In: Thomas, K., Lobo, B. and Detering, K. (eds) *Advance Care Planning in End of Life Care*. Oxford: Oxford University Press.

Harrison Dening K., **King M.**, **Jones L.**, and **Sampson E.L.** (2017a). Healthcare decision-making: past, present and future, in light of a diagnosis of dementia. *International Journal of Palliative Nursing*, **23**(1): 4–11.

Harrison Dening K., **Aldridge Z.**, **Pepper A.**, and **Hodgkison C.** (2017b). Admiral Nursing: Case management for families affected by dementia. *Nursing Standard*, **31**(24): 42–50.

Harrison Dening K., **Crowther J.**, and **Tolman S.** (2017c). Admiral Nursing: Combining specialist dementia and hospice care. *Nursing and Palliative Care*, **2**(3): doi: 10.15761/NPC.1000151.

Harrison Dening K. King M. Jones L., **Vickerstaff V.**, and **Sampson, E.** (2016). Advance care planning in dementia: Do family carers know the treatment preferences of people with early dementia? *Plos One*, **11**(8): e0161142, doi: 10.1371/journal.pone.0159056.

Harrison Dening K., **Greenish W.**, **Jones L.**, **Mandal U.**, and **Sampson, E.L.** (2012). Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. *BMJ Supportive and Palliative Care*, **2**(2): 103–7.

Harrison Dening K., **Jones L.**, and **Sampson, E.L.** (2011). Advance Care Planning in dementia: A Review. *International Psychogeriatrics*, **23**(10): 1535–51.

Harrison Dening K. (2010). Admiral Nursing: Offering a specialist nursing approach. *DementiaEurope*, **1**(1): 10–11.

Hospice UK. (2015). *Hospice Enabled Dementia Care: The First Steps, a Guide to Help Hospices Establish Care for People with Dementia and their Families*. London: Hospice UK.

Kerwin D.R., **Zhang Y.**, **Kotchen J.M.**, **Espeland M.A.**, **Van Horn L.**, **McTigue K.M.**, **Robinson J.G.** et al. (2010). The cross-sectional relationship between body mass index, waist-hip ratio, and cognitive performance in postmenopausal women enrolled in the Women's Health Initiative. *Journal of the American Geriatrics Society*, **58**(8): 1427–32.

Klein B.E., **Klein R.**, **Knudtson M.D.**, and **Lee K.E.** (2005). Frailty, morbidity and survival. *Archives of Gerontology and Geriatrics*, **41**(2): 141–9.

Kulmala J., **Nykänen I.**, **Mänty M.**, and **Hartikainen S.** (2014). Association between frailty and dementia: A population-based study. *Gerontology*, **60**(1): 16–21.

Luengo-Fernandez R., **Leal J.**, and **Gray A.** (2010). *Dementia 2010*, London: Alzheimer's Research Trust.

Matthew, F.E., **Arthur A.**, **Barnes L.E.**, **Bond J.**, **Jagger C.**, **Robinson L.**, **Brayne C.**, and **Medical Research Council Cognitive Function and Ageing Collaboration**. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet*, **382**(9902): 1405–12.

Mitchell S.L., **Kiely D.K.**, and **Hamel M.B.** (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*, **164**(3): 321–26.

Mitchell S.L., **Teno J.M.**, **Kiely D.K.**, **Shaffer M.L.**, **Jones R.N.**, **Prigerson H.G.**, **Volicer L.**, et al. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, **361**(16): 1529–38.

Mukadam N. and **Sampson E.L.** (2011). A systematic review of the prevalence, associations and outcomes of dementia in older general hospital patients. *International Psychogeriatrics*, **23**(3): 344–55.

Myers A.H., **Baker S.P.**, **Van Natta M.L.**, **Abbey H.**, and **Robinson E.G.** (1991). Risk factors associated with falls and injuries among elderly institutionalised persons. *American Journal of Epidemiology*, **133**(11): 1179–90.

Nash M. (2013) Diagnostic overshadowing: a potential barrier to physical healthcare for mental health service users. *Mental Health Practice*, **17**(4): 22–6.

Neale R., **Brayne C.**, **Johnson A.L.**, and **Medical Research Council Cognitive Function and Ageing Study Writing Committee** (2001). Cognition and survival: an exploration in a large multicentre study of the population aged 65 years and over. *International Journal of Epidemiology*, **30**(6): 1383–8.

Newbronner L., **Chamberlain R.**, **Borthwick R.**, **Baxter M.**, and **Glendinning C.** (2013). *A Road Less Rocky–Supporting Carers of People with Dementia*, Carers Trust: London.

Norton S., **Matthews F.E.**, and **Brayne, C.** (2013). A commentary on studies presenting projections of the future prevalence of dementia. *BMC Public Health,* **2, 13**:1.

ONS (2013) Population Estimates for UK, England and Wales, Scotland and Northern Ireland. Available from: http://ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk-england-and-wales-scotland-and-northern-ireland [Accessed 10 May 2017].

Ownby R.L., **Crocco E.**, **Acevedo A.**, **John V.**, and **Loewenstein D.** (2006). Depression and the risk for Alzheimer disease: systematic review, meta-analysis, and metaregression analysis. *Archives of General psychiatry*, **63**(5): 530–8.

Rahman S. and **Harrison Dening K.** (2016). The need for specialist nurses in dementia care. *Nursing Times*, **112**(16): 14–17.

Rodriguez-Pascual C., **Parades-Galan E.**, **Ferrero-Martinez A.I.**, **Gonzalez-Guerro J.L.**, **Homillos-Calvo M.**, **Menendez-Colino R.**, **Torres-Torres I.**, et al. (2017). The frailty syndrome is associated with adverse health outcomes in very old patients with stable heart failure: A prospective study in six Spanish hospitals. *International Journal of Cardiology*, **236**: 296–303.

Sachs G.A., **Shega J.W.**, and **Cox-Hayley D.** (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, **19**(10) 1057–63.

Sampson E.L., **Blanchard M.R.**, **Jones L.**, **Tookman A.**, and **King, M.** (2009). Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *British Journal of Psychiatry*, **195**(1): 61–6.

Schuurmans M.J., **Shortridge-Baggett, L.M.**, and **Duursma S.A.** (2003). The Delirium Observation Screening Scale: a screening instrument for delirium. *Research and theory of nursing practice*, **17**(1): 31–50.

Scottish Government (2015) *Long term conditions*. Available from: http://gov.scot/Topics/Health/Services/Long-Term-Conditions [Accessed 10 May 2017].

Simard J. (2013). *The End-of-Life Namaste Care Program for People with dementia*. 2nd Edition. Maryland: Health Professions Press.

Stephan B. and **Brayne C.** (2008). Prevalence and projections of dementia. In: Downs, M., and Bowers, S. (eds) *Excellence in Dementia Care: Research into practice*. Maidenhead: McGraw-Hill.

van der Steen J.T., **van der Wal G.**, **Mehr D.R.**, **Ooms M.E.**, and **Ribbe M.W.** (2005). End of life decision making in nursing home residents with dementia and pneumonia: Dutch physicians intentions regarding hastening death. *Alzheimer's Disease and Associated Disorders*, **19**(3): 148–55.

van der Steen J.T. (2010) Dying with dementia: what we know after more than a decade of research. *Journal of Alzheimers Disease*, **22**(1): 37–55.

van der Steen J.T., **Radbruch L.**, **Hertogh C.E.M.**, **De Boer M.E.**, **Hughes J.C.**, **Larkin P.**, **Francke A.L.**, et al. (2013). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, **28**(3): 197–209.

WHO (2012) World Health Statistics 2012 Indicator compendium. Available from: http://www.who.int/gho/publications/world_health_statistics/WHS2012_IndicatorCompendium.pdf [Accessed 10 May 2017]

Whitlach C.J., **Piiparinen R.**, and **Feinburg, L.F.** (2009). How well do family caregivers know their relatives' care values and preferences? *Dementia*, **8**(2): 223–43.

Xie J., **Brayne C.**, and **Matthews F.E.** (2008). Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ*, **336**(7638): 258–62.

Further resources

Brooker, D. (2007) *Person-centred dementia care: Making services better*. London: Jessica Kinglsey Press.

Hughes, J.C. (Ed) (2006) *Palliative Care in Severe Dementia*. London: MA Healthcare.

Pace, V., **Treloar, A.** and **Scott, S.** (2011). *Dementia: From advanced disease to bereavement*. Oxford: Oxford University Press.

www.hospiceuk.org

www.dementiauk.org

www.stcuthbertshospice.com/215/2/St-Cuthberts-Hospice-Dementia-Support

Chapter 7

Psychosocial care of families in palliative care

David W. Kissane

Introduction to psychosocial care of families

The stress and burden of illness reverberates throughout the family, challenging members to respond in some way: providing support, care, or understanding (Kissane, 1994). For many patients, the family is central to their experience of social support. The philosophy of palliative care has been patient- and family-centred from its early origins because this approach is both preventive and responsive to real needs. With the patient as the primary focus, the family members constitute a second-order level of clients in their own right. In this chapter, family-centred care is considered from the perspective of information provision, need recognition, and how to run a family meeting; through to the management of complex families who deserve the offer of family therapy, with continuity of care into bereavement.

Definition of family

Who is the family? While commonly defined by kinship relationships, in practice the patient defines their 'psychological' family as comprised of people who matter to them, have formed part of their world, and are essential to the information- and care-provision needs of the system (Boss and Dahl, 2014). Indeed, the psychological family influences the pattern of coping and adapting to the many losses and changes that illness brings; it does this through its traditions and pursuit of religious, cultural, and ethnic norms. Families can dictate when to be stoical, shed tears, or comfort one another. So strong may these patterns of behaving and relating be that therapists have referred to them as 'scripts' that families follow from one generation to the next (Byng-Hall, 2004).

Needs of the family and family goals of care

The appraisal of needs of the family is part of any comprehensive assessment whenever a patient enters a palliative care programme. Membership can be most simply displayed on a genogram, where the nature of relationships can be symbolized, key illness and loss events notated, and needs identified (Zaider, 2014). In addition to defining the goals of care for the patient, goals of care for the family are created in a comprehensive care plan. These goals of care for the family comprise both their perceptions of needs (informational, instrumental, and emotional support, and respite) and the clinician's appraisal of their coping capacities (primary caregiver abilities, family functioning, and recognition of individuals at risk of morbid outcomes, including during bereavement).

Empirical evidence of rates of psychiatric disorder among the families of patients in the palliative care setting have long suggested that whereas up to half of the patients have psychiatric disorders in the form of adjustment, anxiety, and depressive disorders, one third of partners and one quarter of children also carry psychiatric disorders (Kissane et al., 1994; Stenberg et al., 2010). The experience of caring for a sick relative can spoil the quality of life of caregivers (Weitzner et al., 1999); contribute to development of depressive symptoms (Braun et al., 2007; Tang et al., 2013a; Tang et al., 2013b) sleep disturbance (Brummett et al., 2006), fatigue and burnout (Hudson et al., 2010), social isolation (Robinson-Whelen et al., 2001), and eventually result in complicated grief once bereavement occurs (Applebaum and Breitbart, 2013; Garrido and Prigerson, 2014; Tomarken et al., 2008). The psychosocial morbidity afflicting members of families caring for a relative in the palliative care setting can be profound.

Two broad approaches have developed in response to this challenge: the first is psycho-educational in nature and aims to prepare and support caregivers within families; the second targets dysfunctional or families at greater risk and delivers more intensive therapeutic care. Let us consider each of these models in turn.

Preparing caregivers: education and communication

Levels of exposure to illness vary considerably within societies, with resultant differences in preparedness to provide care. The provision of information about the illness, its management, prognosis, and anticipated care needs is foundational to assist carers in their role (Harrop et al., 2014). The communication of this information is typically stepped and proportional to the phase of progression of the patient's illness. Families are often protective of their loved one and avoidant of causing distress, which can result from discussion of existential threats and uncertainty associated with death and dying. Asking permission of the patient and confirming readiness to more openly communicate about difficult topics brings relief to many families (Schumacher et al., 2007).

Studies of psycho-educational interventions to caregivers and families at the end of life have been effective in delivering information: reducing distress, and garnering a sense of support (Harding et al., 2012; Hudson et al., 2013; Harding, 2014). Whether delivered individually by palliative care nurses in the home, or offered to small groups of families in brief educational programmes, these efforts begin to open up communication, address unmet needs, and thus constitute the most basic form of family-centred care that needs to be offered to all. The development of a sense of competence to be a care provider and to feel rewarded by the process of caregiving are key outcomes (Henriksson et al., 2013; Hudson et al., 2013; Holm et al., 2016).

These psycho-educational interventions are theoretically based on delivering knowledge and skill development relevant to the needs of care providers; including anticipation of sources of symptom distress and ways to alleviate this. Preparation for caregiving is crucial to sustain comfort and emotional wellbeing in the role. Three to four two-hourly sessions can be cost-effectively delivered to groups of carers over as many weeks, with contributions from all members of the multi-disciplinary team. Manualized content ensures consistency, while educational brochures can be provided to attendees. Topics can be as broad as nutrition and exercise, and as specific as the management of syringe drivers and use of breakthrough pain medications.

Another successful model to enhance physician-patient-caregiver communication is the use of a question prompt list about end-of-life issues. While extending the consultation time by only an average of seven minutes (31 up to 38 minutes average consultation time), Clayton et al., 2007 showed in a randomized controlled trial that twice as many questions were asked by patients and their family caregivers who received a question prompt list, including questions about prognosis and end-of-life issues. Importantly, no differences in anxiety resulted from using this approach, yet the family's satisfaction with preparation for end-of-life care is enhanced.

Running a routine family meeting

Family meetings are employed most commonly in inpatient palliative care settings to review the goals of care with the family: optimize their support for the patient, consider discharge options, and resolve any differences of opinion about this care plan (Hannon et al., 2012; Kissane and Hempton, 2017). The common goals of such a family meeting are summarized in Box 7.1.

The content that is discussed in achieving these goals includes how relatives help to assess symptoms, administer medications, understand the trajectory of illness, know what to anticipate as the illness progresses, know how to liaise with the medical team, become able to talk about death and dying, and to

Box 7.1 Goals of a routine family meeting in the palliative care setting

(1) Educate the family about the illness and its management
(2) Assess family caregiver needs and respond to family questions
(3) Understand wishes about end-of-life care and views about place of death
(4) Address the pragmatics of advance directives and who are the decision-makers within the family
(5) Discuss discharge planning issues, including any home care needs
(6) Assess family coping and identify high-risk families or members so that appropriate referrals can be made

eventually say goodbye when this is possible (Ventura et al., 2014). Basic information about instrumental care and available support, respite, the contribution of home nursing and allied health services, volunteers, and spiritual support is grist for the mill. Challenges that need to be addressed to achieve all of this include opening up family communication, countering conspiracies of silence about prognosis, shifting protective or avoidant coping styles, building trust and bridging differences of opinion about the goals of care (Sullivan et al., 2015).

In training clinicians to conduct family meetings, three new skills, beyond basic communication skills training, and need to be aquired. These are: 1) agenda setting with families; 2) asking circular questions; and 3) providing integrative summaries. Each of these communication skills is defined and illustrated in Table 7.1.

The most common error that facilitators of family meetings make in establishing an agenda for the meeting is to begin to answer a query or problem-solve an issue before the agenda setting is fully completed. Much greater efficiency is achieved as a result of five minutes of formal agenda setting up front, before getting into the detail of any discussion. Further efficiency is achieved through harnessing the resilience of the family to mutually support one another. As they begin to talk openly about the illness, they place their fears and concerns on the table. In this manner, the clinician does not need to be the source of all the answers. Developing the art of asking circular questions and avoiding linear exchanges in family meetings is generally learnt through experiential role-play work with simulated patients and family members in communication skills training (Kissane and Hempton, 2017). Finally, the process of checking understanding of any issue is central to a successful dialogue and accomplished through the use of summaries by either a family member or facilitator as needed.

Table 7.1 Specific communication skills used in facilitating a family meeting

Name of skill	Definition	Illustration
Family agenda setting	A sequential process of inviting each family member to list their concerns and expectations from the meeting, alongside those of the facilitators, to empower the creation of an agenda that will structure the meeting, optimize efficiency, and ensure satisfactory coverage of all pertinent issues.	'We hope to review the status of X's illness, the goals of care, and the challenges that lie ahead. Before talking about this, it helps to set an agenda, so that we make sure we identify and respond to all the issues that you carry as a family. So let's take a moment to create a list of any concerns and questions that you want covered in our meeting. We can then address these in a logical order, and make sure we attend to all of your needs.'
Use of circular questions	Questions in which family members are invited to express their views about the coping and wellbeing of their relatives rather than talk directly about themselves. This avoids a linear dialogue between one person and the facilitator, reveals relational dynamics, and promotes the exchange of empathic interactions between family members.	'Let me ask each of you as adult children to say how each of your parents is coping emotionally with this illness?' 'How hard is it for your parents to talk openly about this illness? 'What do they worry about the most?' 'Who in the family do you hold the greatest concern for?' 'As parents, how do each of you see your children coping with this illness? Who causes greater/greatest concern to you and why?'
Integrative summaries	When a theme has been adequately discussed and before moving to the next topic, a summary is offered to check understanding and level of consensus, and gain permission to move to the next theme on the agenda.	'Thus far, we have reviewed the management of two key symptoms that X is experiencing and the recommended treatment of these. Before we talk about the next item on our agenda, can you please summarize how you will use these medications so that I can check that you understand this clearly?'

Recognition of dysfunctional or 'at-risk' families

The clinically-oriented approach to the recognition of families 'at-risk' of poor coping as a result of some level of relationship dysfunction is to ask questions about the three 'C's' of family relational life—communication, cohesion, and conflict resolution. Thus, 'How openly do you communicate as a family?' 'What is your teamwork and support of each other like?' 'How effectively do you deal with differences of opinion?' Any deficit in these dimensions creates a level of risk. Questions such as these can be asked in the early phase of a family meeting to help the clinician assess what family life is like.

An alternative approach to family assessment is through the use of a screening tool such as the Family Relationships Index (FRI), a 12-item, true–false, well-validated measure that includes four items about cohesion, four about communication and four about conflict (Moos and Moos, 1981). Scores of nine or less out of 12 carry a high level of sensitivity to identify family dysfunction (Edwards and Clarke, 2005). Such screening can be undertaken routinely when a patient is first admitted to a palliative care service, or immediately prior to a family meeting, when it could be completed independently by each attendee. Each person's perception of their family is valid, and so scores are not averaged—any individual's score of equal to or less than nine out of 12 is meaningful as a family 'symptom bearer' (Kissane and Bloch, 2002). Screening permits services to plan a preventive model of family-centred care by electing to work with families that are found to be 'at risk' on screening during palliative care. In doing this, families are never labelled negatively. However, it is possible to make simple reference to the FRI as a rationale to meet, such as, 'Some of you commented that talking openly about the illness is hard. We find it helpful to meet together as a family so that you can help us to care for (patient's name) and you all as you grapple with this illness.'

Empirical work has revealed the strongly significant associations between any level of family dysfunction and the development of psychiatric disorder among family members in the settings of both palliative care (Kissane et al., 1994a; Kissane et al., 1994b) and bereavement (Kissane et al., 1996a; Kissane et al., 1996b). This has been confirmed in other cohorts (Kissane et al., 2003) and cultural settings (Schuler et al., 2017). When palliative care services begin work with families to support their adaption and coping, a preventive approach is adopted that is sustained into bereavement with the aim of ameliorating complicated grief. Trials were needed to confirm this and these are described in the following section.

Types of families met during palliative care

Studies of family functioning during palliative care have revealed patterns of relating as a family that impact on our ability to help families when a member has advanced illness that will eventually lead to their death. These patterns form a typology of five broad clusters, which have now been replicated across several studies (Kissane et al., 1994b; Kissane et al., 1996a; Schuler et al., 2014; Nissen et al., 2016) and are shown in Table 7.2.

Table 7.2 Typology of family functioning based on the Family Relationships Index (FRI), which identifies the level of need for family-centred psychosocial care provision

Family type	Typical FRI Score[§] (out of 12)	Relational patterns displayed by FRI screening measure	Associations with psychosocial morbidity	Psychosocial care needs
Supportive	11–12	Optimal cohesion, communication, and conflict resolution	Very low to absent psychiatric disorders; resilient coping	Provide education and normal symptom management
Conflict resolving	10–11	Optimal cohesion and communication, but some conflict	Lowest rates of depressive disorders; little morbidity, and resilient coping	Provide education and normal symptom management
Low communicating	7–9	Low expression of thoughts and feelings; mid-range cohesion, and conflict resolution	Significant association with anxiety and depressive disorders; social isolation, poorer adaption	Recommend family therapy; six sessions minimum across at least six months
Uninvolved	5–6	Low cohesion and communication; some conflict, but more muted	Significant association with anxiety and depressive disorders; poorer coping, and social isolation	Offer family therapy to those willing to engage; ensure optimal individual psychosocial care for distressed members
Conflictual	0–4	Highest conflict	Significant association with anxiety and depressive disorders; poorer coping, social isolation, and high distress	Recommend family therapy; ten + sessions over 18 months, including six + months of bereavement care

[§] FRI = Family Relationships Index (Moos and Moos, 1981) with scores derived from empirical studies (Kissane et al. 1994, 1996, 2003); Treatment recommendations based on RCT studies (Kissane et al. 2006; Kissane et al. 2016)

Supportive and cohesive families: optimally supportive families are cohesive and open communicators, who lack conflict, are highly resilient, and their members remain free of psychiatric disorder (Kissane and Bloch, 2002). Their adaptive style empowers them to mutually grieve and cope well with both the illness during palliative care and also in bereavement. They will actively seek information and make sensible use of medical, nursing, and other community-based services. Recognition of their adaptive and well-functioning nature allows clinicians to affirm their support of one another, but not over-invest limited specialist psychosocial services in them.

Conflict-resolving and involved families: a second type of well-functioning family, which is also naturally resilient and carries little psychiatric disorder; has features of effective communication and strong cohesion that serve protectively to help them tolerate differences of opinion. So although the members of this type of family can argue and get angry with one another, any conflict is short lived and constructively resolved. Clinicians may observe their emotionally expressive style, but can draw confidence from their prominent teamwork, adaptive communication, and high levels of mutual support.

The prevalence of these two types of well-functioning families can vary across different cultures, proportionately with variance in emotional expressiveness, but generally two-thirds of families in palliative care fall into one or other of these clusters. In contrast, a third of families carry some level of dysfunctionality, need more service provision, and can be seen to fall into three distinct patterns of family dysfunction.

Low communicating families: the prominent characteristic of this cluster is restricted communication, whether based on lower interpersonal confidence, avoidant coping, or poorer educational opportunity, and lower-health literacy. As a result, they have mid-range levels of cohesion and some conflict, and their members develop anxiety and depressive disorders, as well as being at risk of complicated grief in bereavement. They are readily helped by family meetings that help them to safely communicate with one another as they learn more about the illness, prognosis, and the journey ahead. Some 20% of families in the palliative setting have this relational style. Their engagement during palliative care is usually possible through the simple acknowledgement that 'communication can be hard for them as a family' and it seems to help them to meet as a group with an allied health member of staff. But what is important from the perspective of family-centred care is that a plan of continued family meetings is put in place, with a frequency of sessions every one to two months; depending on clinical issues, prognosis, care demands and so forth. We will see later the preventive benefits of such care provision.

Conflictual families: these families fight openly and fracture readily, their conflict generally becoming quite obvious to service providers. Their family history, as illustrated on their family genogram, may show a number of separations, cut offs, or bitter divorces. Some 5–6% of families have these characteristics. They may be challenging to engage with allied health services, as each key relative may need to be personally phoned and invited to help with the ill family member. They may worry about meeting as a family for fear of conflict breaking out. It is the experience of the psychosocial clinician who can offer strong family facilitation skills and promise safety in an initial family session that can empower them to come together. Indeed, beneficial therapeutic work and healing is possible for a number of these families, with around ten sessions of family work being conducted across 18 months and, as we will see, preventive benefits resulting for the family-as-a-whole.

Uninvolved families: these families are characterized by poor cohesion, low communication, and moderate conflict, and they have adopted the solution of 'distance' as their way to survive. They see little of one another, sometimes residing deliberately in different states or counties, and generally being unwilling to meet together as a group. They employ avoidant coping as their modus operandi, and represent about 5–6% of families met by palliative care services. Our family therapy trials to date have not seen beneficial outcomes for this cluster in bereavement; suggesting that any individuals who are considered 'at risk' of poor coping may be best helped by individual psychosocial care. Sometimes the patient reports loss of contact long ago and does not consider reconciliation possible. On other occasions, clinicians make contact to invite them to visit, but meet resistance, excuses, or a frank declaration of disinterest. To recognize that they conform to a well-defined empirical pattern of family relationships can help multidisciplinary teams set realistic goals for care provision.

Evidence base from family therapy studies

The initial 'proof of concept' randomized controlled trial (RCT) was an efficacy study delivered to 81 families (363 family members) who received family therapy (with the patient present; commencing during palliative care, and continuing into bereavement) or usual care (Kissane et al., 1998; Kissane et al., 2006). Screening with the FRI was used to select families at risk. Treated families had reduced distress on the Brief Symptom Inventory at 13 months post death, with family members showing evidence of clinical depression on the Beck Depression Inventory at baseline revealing a significant improvement at six and 13 months post death (Kissane et al., 2006). Sixteen social workers were trained and supervised to deliver this therapy, which was shown to be faithfully adhered to (Chan et al., 2004). Families received up to 13 sessions, with low-communicating and uninvolved families averaging seven and conflictual families nine sessions.

Given the positive outcome of this initial RCT, a hybrid efficacy–effectiveness trial was conducted using a greater number of therapists and varying the dose of therapy offered to between six and ten sessions. Again screening was used to select families deemed to be at risk by an FRI which resulted in less than or equal to nine out of 12. In this RCT, 170 families were represented by 620 members and 32 therapists were able to faithfully deliver the model of therapy (Del Gaudio et al., 2012). Using the abbreviated Complicated Grief Inventory (Prigerson et al., 2009) as a primary outcome measure, a significant treatment effect ($p = 0.032$) and treatment by family-type interaction was found ($p < 0.001$). Better outcomes resulted from ten sessions when compared with standard care for low-communicating and high-conflict families, but not for families with low involvement (Kissane et al., 2016). For those receiving standard care, 15.5% of the bereaved developed a prolonged grief disorder at 13 months post death, compared with 3.3% of those who received ten sessions of family therapy. Evidence for this prevention of complicated grief was evident at six months post death. Although a main effect was not found for depression, 21% of those receiving standard care were BDI cases of depression at 13 months of bereavement, compared to 11% receiving the family intervention ($p = 0.047$, adjusted p on generalized estimating equations = 0.07) (Kissane et al., 2016).

These RCTs show a protective benefit of such family-centred care for high-risk families selected by screening, especially in preventing complicated grief, which is a disorder of attachment, and thus more understandably influenced by the quality of family relationships. The greater the level of dysfunction in the family, the larger the dose of therapy that will be needed to ensure clear benefits. Families with low communication are most amenable to being helped, while uninvolved families prove the toughest to help, perhaps because they have already chosen 'distance' from each other as their preferred solution to relational tension in family life.

Families with adolescent and younger children

The family therapy studies described previously included adolescent offspring and provided clear benefit to them through this model of intervention (Muriel, 2014). When children are potentially affected by the death of a parent, much good can be achieved by a psycho-educational approach with the parents: guiding them in how to openly communicate about the illness, while sustaining hope and normality in family life (Muriel, 2014). Education needs to be tailored to the developmental age of each child. The presence of parental depression and dysfunction in the family have been two key predictors of behavioural and emotional disturbance in children when a parent has a life-threatening illness (Thastum et al., 2009). Active treatment of parental depression is clearly a crucial goal of family-centred care. Once children are bereaved, an RCT of 12 sessions of group therapy for children aged eight to 16 years, combined with parental educational sessions, has proven benefits in promoting adaption in bereavement (Sandler et al., 2003).

When it comes to a child with cancer or another progressive and terminal illness, realistic family communication is crucial. This also applies to the neonatal setting, when a child is born with abnormalities not compatible with life. Parents will need an explicit physician recommendation to discontinue treatment once it is futile, so that parents are not left with a sense of responsibility for the child's death (Bluebond-Langner et al., 2007; Kreicbergs et al., 2007). Parents do not regret talking to their child about death, and older siblings can be drawn into this process (Wiener and Gerhardt, 2014). Facilitating family conversations is a powerful pathway to promote adjustment. When families can find meaning in the life of the child who is dying or deceased, more successful adaptation to the loss is achieved (Wiener et al., 2011; Schonfeld, 2012).

Families with older adults

When the very elderly are facing their dying, their sense of accomplishment from a full life, alongside growing awareness of bodily frailty, can lead to acceptance of death and family comfort at their departure. Nevertheless leaving a very elderly partner after many years of marriage brings deep sadness for the survivor and some care challenges for the family. Use of residential aged-care facilities is common, where staff often prove very helpful to the adult children involved in care. Loneliness, disenfranchisement, and social devaluation may be clinical challenges that arise for the elderly (Jeffreys, 2014). The use of storytelling, recognizing family realignments, and acknowledging the legacy of the deceased prove very helpful to the family. Similarly, affirming the care that was provided to the deceased is an important means of upholding the dignity of such an elderly care provider.

Families with disabled members

Whenever a family member has been chronically disabled, whether due to a mental illness such as chronic schizophrenia, physical incapacity such as cerebral palsy, or intellectual disability such as Down's syndrome, parents who have been long-term care providers are challenged as they face dying. Some will have made careful long-term plans for their offspring, with saying goodbye the key remaining task. Others may have avoided such preparation: whether due to emotional dependence, conflict with community systems, or some level of social deprivation. The latter subgroups need early recognition when a terminal illness is first diagnosed so that family meetings can be arranged and care plans developed appropriately.

Families in crisis at the end of life

Occasionally complex circumstances present which challenge the best of clinical teams. Consider, for example, a patient with familial Creutzfeldt–Jacob disease, where the genetics have been kept secret by one generation, and hospital admission with terminal illness brings the first realization of this predicament to the next generation. Anger, recriminations, uncertainty, and ambivalence can predominate. The family can appear in crisis as subsequent generations worry about obtaining genetic counselling, while also preparing to say farewell to the sick relative. Such circumstances invariably carry some level of family dysfunction and, while appearing dramatic at initial presentation, can be worked through by application of the principles of family care outlined in this chapter.

Conclusion

Families can bring complex issues and care needs to the palliative care team. Sometimes the illness has run a long and difficult trajectory bringing cumulative stressors to the family along the way. In other circumstances, these challenges can have resulted in enhanced resilience for a family that has adapted and responded with generosity, commitment to care, and mutual support of one another. Clinicians do well to differentiate families that are adaptive from those with high needs.

All families have basic educational and communication needs. A further subgroup carry relational dysfunction, which places them at special risk of morbid consequences such as complicated grief and depressive disorders. We now have an evidence base that such families can be identified by screening and supported with a programme of family therapy that is capable of preventing morbid mental health in bereavement. Such care is cost effective, and delivers continuity of psychosocial care to the family members, which is deeply appreciated by those involved.

A range of special circumstances can also exist, ranging from the death of a child to the death of the very elderly, to families with disabled or dependent family members, and these families also warrant additional family-centred care. Such work is rewarding, can harness the strengths of the family to foster a better level of adaptation, prevent morbid bereavement outcomes, and offer considerable assistance to families with increased needs.

References

Applebaum A.J. and **Breitbart W.** (2013). Care for the cancer caregiver: a systematic review. *Palliat Support Care*, **11**(3): 231–52. doi: 10.1017/S1478951512000594.

Bluebond-Langner M., **Belasco J.B.**, **Goldman A.**, et al. (2007). Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *J Clin Oncol*, **102**(5): 2414–19.

Boss P. and **Dahl C.M.** (2014). Family Therapy for the Unresolved Grief of Ambiguos Loss. In: Kissane DW and Parnes F (eds) *Bereavement Care for Families*. New York, NY: Routledge, pp. 171–82.

Braun M., **Mikulincer M.**, **Rydall A.**, et al. (2007). Hidden morbidity in cancer: spouse caregivers. *J Clin Oncol*, **25**(30): 4829–34.

Brummett B.H., **Babyak M.A.**, **Siegler I.C.**, et al. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychol*, **25**: 220–5.

Byng-Hall J. (2004). Loss and family scripts. In: Walsh F. and McGoldrick M. (eds) *Living Beyond Loss: Death in the Family*. 2nd ed. New York: W.W. Norton, pp. 85–98.

Chan E.K., **O'Neill I.**, **McKenzie M.**, et al. (2004). What works for therapists conducting family meetings: treatment integrity in family-focused grief therapy during palliative care and bereavement. *J Pain Symptom Manage*, **27**(6): 502–12.

Clayton J.M., **Butow P.N.**, **Tattersall M.H.**, et al. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol*, **25**(6): 715–23.

Del Gaudio F., **Zaider T.I.**, **Brier M.**, et al. (2012). Challenges in providing family-centered support to families in palliative care. *Palliat Med*, **26**(8): 1025–33.

Edwards B. and **Clarke V.** (2005). The validity of the Family Relationships Index as a screening tool for psychological risk in families of cancer patients. *Psychooncology*, **14**(7): 546–54.

Garrido M.M. and **Prigerson H.G.** (2014). The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. *Cancer*, **120**(6): 918–25.

Hannon B., **O'Reilly V.**, **Bennett K.**, et al. (2012). Meeting the family: measuring effectiveness of family meetings in a specialist inpatient palliative care unit. *Palliat Support Care*, **10**(1): 43–9.

Harding R. (2014) Caregivers of people at the end of life: emerging evidence. *Curr Opin Support Palliat Care*, **8**: 391–3.

Harding R., **List S.**, **Epiphaniou E.**, et al. (2012). How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliat Med*, **26**(1): 7–22.

Harrop E., **Byrne A.**, and **Nelson A.** (2014). 'It's alright to ask for help': findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care*, **13**: 22.

Henriksson A., **Arestedt K.**, **Benzein E.**, et al. (2013). Effects of a support group programme for patients with life-threatening illness during ongoing palliative care. *Palliat Med*, **27**(3): 257–64.

Holm M., **Arestedt K.**, **Carlander I.**, et al. (2016). Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care—results from a randomized control trial. *Psychooncology*, **25**(7): 795–802.

Hudson P., **Trauer T.**, **Kelly B.**, et al. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: short-term effects from a randomised controlled trial. *Psychooncology*, **24**(1): 1987–93.

Hudson P.L., **Remedios C.**, and **Thomas K.** (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliat Care*, **9**: 17.

Jeffreys J.S. (2014). Family-centered approach to helping older grieving people. In: Kissane D.W. and Parnes F. (eds) *Bereavement Care for Families*. New York, NY: Routledge, pp. 232–46.

Kissane D.W. (1994). Grief and the family. In: Bloch S., Harari E., Szmukler G.I., and Hafner J. (eds) *The Family in Clinical Psychiatry*. Oxford, UK: Oxford University Press, pp. 71–91.

Kissane D.W. and **Bloch S.** (2002). *Family Focused Grief Therapy: A Model of Family-centered Care During Palliative Care and Bereavement*. 1st ed. Buckingham: Open University Press, p. 252.

Kissane D.W., **Bloch S.**, **Dowe D.L.**, et al. (1996a). The Melbourne Family Grief Study, I: Perceptions of family functioning in bereavement. *Am J Psychiatry*, **153**(90): 650–8.

Kissane D.W., **Bloch S.**, **McKenzie M.**, et al. (1998). Family grief therapy: a preliminary account of a new model to promote healthy family functioning during palliative care and bereavement. *Psychooncology*, **7**: 14–25.

Kissane D.W., **Bloch S.**, **Onghena P.**, et al. (1996b). The Melbourne Family Grief Study, II: Psychosocial morbidity and grief in bereaved families. *Am J Psychiatry*, **153**: 659–66.

Kissane D.W., **Bloch S.**, **Patrick J.D.**, et al. (1994b). Perceptions of family functioning and cancer. *Psycho-Oncology*, **3**(4): 259–69.

Kissane D.W., **Block S.**, **Burns W.I.**, et al. (1994a). Psychological morbidity in the families of patients with cancer. *Psycho-Oncology*, **3**: 47–56.

Kissane D.W. and **Hempton C.** (2017). Conducting a family meeting. In: Kissane D.W., Bultz B., Butow P.N., et al. (eds) *Oxford Textbook of Communication in Oncology and Palliative Care*. 2nd ed. Oxford, UK: Oxford University Press, pp. 109–117.

Kissane D.W., **McKenzie M.**, **Bloch S.**, et al. (2006). Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement. *Am J Psychiatry*, **163**: 1208–18.

Kissane D.W., **McKenzie M.**, **McKenzie D.P.**, et al. (2003). Psychosocial morbidity associated with patterns of family functioning in palliative care: baseline data from the Family Focused Grief Therapy controlled trial. *Palliat Med*, **17**: 527–37.

Kissane D.W., **Zaider T.I.**, **Li Y.**, et al. (2016). Randomized controlled trial of family therapy in advanced cancer continued into bereavement. *J Clin Oncol*, **34**: 1921–27.

Kreicbergs U.C., **Lannen P.**, **Onelov E.**, et al. (2007). Parental grief after losing a child to cancer: impact of professional and social support on long-term outcomes. *J Clin Oncol*, **25**(22): 3307–12.

Moos R.H. and **Moos B.S.** (1981). Family Environment Scale. *Family Environment Scale Manual*. 1st Edition ed.: Consulting Psychologists Press: Palo Alto, CA, p. 38.

Muriel A.C. (2014). Care of families with children anticipating the death of a parent. In: Kissane D.W. and Parnes F. (eds) *Bereavement Care for Families*. Routledge: New York, NY, pp. 220–31.

Nissen K.G., **Trevino K.**, **Lange T.**, et al. (2016). Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer. *J Pain Symptom Manage*, **52**: 841–9.e841.

Prigerson H.G., **Horowitz M.J.**, **Jacobs S.C.**, et al. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med*, **6**: e1000121.

Robinson-Whelen S., **Tada Y.**, **MacCallum R.C.**, et al. (2001). Long-term caregiving: what happens when it ends? *J Abnorm Psychol*, **110**: 573–84.

Sandler I.N., **Ayers T.S.**, **Wolchik S.A.**, et al. (2003). The family bereavement program: efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. *J Consult Clin Psychol*, **71**(3): 587–600.

Schonfeld D. (2012.) Providing support for families experiencing the death of a child. In: Wolfe J., Hinds P.S. and Sourkes B.M. (eds) *Textbook of Interdisciplinary Pediatric Care*. Elsevier Saunders: Philadelphia, PA, pp. 223–30.

Schuler T.A., **Zaider T.I.**, **Li Y.**, et al. (2014). Typology of perceived family functioning in an American sample of patients with advanced cancer. *J Pain Symptom Manage*, **48**: 281–8.

Schuler T.A., **Zaider T.I.**, **Li Y.**, et al. (2017). Perceived family functioning predicts baseline psychosocial characteristics in U.S. participants of a family focused grief therapy trial. *Journal of Pain and Symptom Management* **54**(1): 126–31. doi: 10.1016/j.jpainsymman.2017.03.016.

Schumacher K.L., **Stewart B.J.**, and **Archbold P.G.** (2007). Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nurs Res*, **56**: 425–33.

Stenberg U., **Ruland C.M.**, and **Miaskowski C.** (2010). Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*, **19**: 1013–25.

Sullivan S.S., **Ferreira d.R.**, **Silva C.**, et al. (2015). Family meetings at end of life: A systematic review. *Journal of Hospice & Palliative Nursing*, **17**: 196–205.

Tang S.T., **Chang W.C.**, **Chen J.S.**, et al. (2013a). Course and predictors of depressive symptoms among family caregivers of terminally ill cancer patients until their death. *Psychooncology*, **22**: 1312–18.

Tang S.T., **Huang G.H.**, **Wei Y.C.**, et al. (2013b). Trajectories of caregiver depressive symptoms while providing end-of-life care. *Psychooncology*, **22**: 2702–10.

Thastum M., **Watson M.**, **Kienbacher C.**, et al. (2009). Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer: a multinational study. *Cancer*, **115**(17): 4030–39.

Tomarken A., **Holland J.**, **Schachter S.**, et al. (2008). Factors of complicated grief pre-death in caregivers of cancer patients. *Psychooncology*, **17**: 105–11.

Ventura A.D., **Burney S.**, **Brooker J.**, et al. (2014). Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers. *Palliat Med*, **28**(5): 391–402.

Weitzner M.A., **McMillan S.C.**, and **Jacobsen P.B.** (1999). Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*, **17**(6): 418–28.

Wiener L., **Alderfer M.**, and **Hersh S.P.** (2011). Psychiatric and psychosocial support for child and family. In: Pizzo P.A., and Poplack D.G. (eds) *Principles and Practice of Pediaric Oncology*. 6th ed. Philadelphia, PA: Lippincott, pp. 1322–46.

Wiener L. and **Gerhardt C.A.** (2014). Bereavement care after the death of a child. In: Kissane DW and Parnes F (eds) *Bereavement Care for Families*. New York, NY: Routledge, pp. 197–219.

Zaider T.I. (2014). Assessing bereaved families. In: Kissane D.W. and Parnes F. (eds) *Bereavement Care for Families*. New York, NY: Routledge, pp. 79–91.

Chapter 8

The meaning of dignity in psychosocial care

Susan McClement and Genevieve Thompson

Introduction

Palliative care is a type of health care for individuals facing life-threatening illness, with their families, that involves ongoing evaluation and management of a person's pain and other physical symptoms (Pastrana et al., 2008). It also involves the provision of psychosocial care—care that attends to a person's emotional, social, and spiritual well-being (Lloyd-Williams, 2008; Surbone et al., 2010). This whole-person approach to the care of individuals is concerned with addressing a range of needs that can improve quality of life. One such need is for patients to feel that they are treated with dignity during their interactions with health-care providers (Clark, 2010). The notion of dignity—and the extent to which health professionals can either bolster or erode it in the course of providing care—is the focus of this chapter. Firstly, the importance of attending to the dignity of those receiving care will be examined. Secondly, empirical work explicating the factors that can support and erode a person's sense of dignity will be reviewed. Finally, approaches that health professionals can use in their practice to support patient dignity will be discussed, and illustrated with case study examples.

What is dignity?

The term dignity is an oft used one in society today. It is the registered trademark for everything from funeral, cremation, and cemetery providers, incontinence undergarments, and transportation services for those with disabilities. It is a concept that is embedded in the United Nations Universal Declaration of Human Rights (1948), and the United Nations Educational, Scientific, and Cultural Organization's Declaration on Bioethics (2005). References to dignity pepper hospital and long-term care facility mission statements, and respect for human dignity is advanced as a central pillar in the debate between those on both sides of the euthanasia/assisted suicide debate (Ersek, 2004). Clearly, dignity appears to be something that is valued and needs to be respected (Schulman, 2008)—notions consistent with both the etymology of the word (the Latin dignitāt-em for 'merit' and 'worth',) and dictionary definitions describing it as 'the quality of being worthy or honourable; worthiness, worth, nobleness, excellence.' (Merriam Webster, 2017). It may be argued that dignity is something inherent in every human being; a sentiment captured in Dame Cicely Saunders' proclamation, 'you matter because you are you, and you matter until the end of your life' (Saunders, 1976, p. 1003). Dictionary definitions also suggest, however, that there is a conferring of evaluation or judgment about worthiness that accompanies dignity. It thus follows that one's sense of dignity is 'co-constructed' at least in part, through engagement with others. Health-care providers represent a very important group of 'others' with whom patients interact. Thus in a very real sense, 'the reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity' (Chochinov, 2004, p. 1339). How can health-care providers ensure that they meet this challenge? A willingness to understand patient experiences and perspectives about dignity is a critical first step in this regard. Such understanding provides a foundation from which to develop and evaluate dignity affirming approaches to care that can be implemented in practice (Johnston et al., 2015; McClement et al., 2004; Thompson, McArthur, and Doupe, 2016).

Why is it important to attend to patient dignity?

Psychosocial care (and by extension attending to patient dignity) may be characterized by some as a 'soft science', (Bultz, Jacobsen, and Loscalzo, 2017) resulting in its being relegated to the realm of a nicety as opposed to a necessity of care. Yet there is evidence that patients' perception about their sense of dignity (or lack thereof) can serve as the impetus to seek out death-hastening measures. Van der Maas and colleagues (1991) conducted a series of studies in a nationwide investigation in the Netherlands examining euthanasia and other medical decisions at the end of life. Interviews with physicians identified, out of 187 cases, 'loss of dignity' as the most highly endorsed reasons people sought out a hastened death (57%), followed by pain (33%), and tiredness of life (23%). Van der Maas' research did not present data to explicate what physicians understood patient declarations of loss of dignity to mean. Given that patient experiences and perceptions of loss of dignity are shaping the care decisions that patients make and clinicians offer, this lack of understanding is highly problematic. Seminal work to address this gap in empirical knowledge has been conducted by Chochinov and colleagues (2002) who systematically examined patients' perspective about the things that both support and erode their sense of dignity in the context of terminal illness. Thematic analysis of qualitative interviews with fifty people with terminal illness receiving care in either their home or the hospital generated an inductively derived empirical model that details those issues consistently identified by interviewees as influencing their sense of dignity. (See Figure 8.1.)

Firstly, people indicated that there were factors related to their illness that could influence their sense of dignity—specifically physical symptom distress, and the fears and uncertainties engendered by their illness. They were also concerned about the ways in which their illness could contribute to a decline in their cognitive and physical functioning. Secondly, patients identified that the ways in which they perceived themselves and their situation could influence their sense of dignity. These perspectives included questions and concerns about such things as feeling in control of their situation: identifying what their role and purpose in life was; whether or not they felt hope; had the will to go on, and the type of legacy they would leave behind. However, people also identified a repertoire of dignity-conserving strategies they used to help to ease their situation such as not dwelling on their illness: living in the moment, and seeking spiritual comfort. Finally, people identified the ways in which interactions with others might shape their sense of dignity. In this regard, it was important that others respected their privacy, treated them with kindness and respect, and avoided making them feel like their care requirements were burdensome.

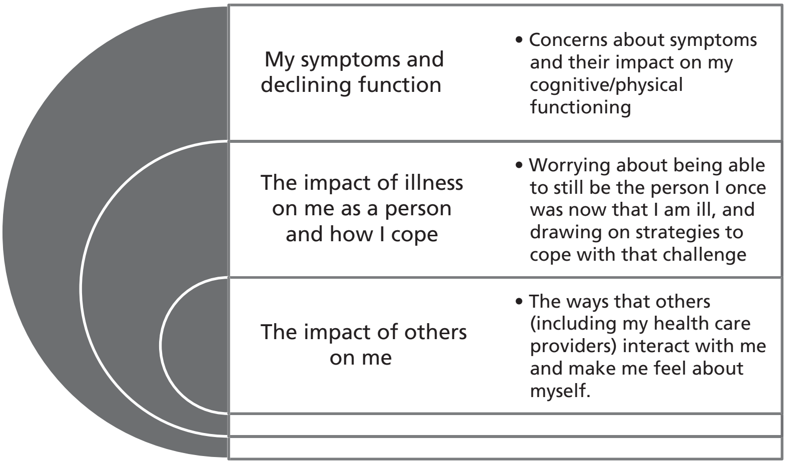


Figure 8.1 Issues influencing dignity in the terminally ill
Reprinted with permission from *Social Science and Medicine*, Volume 53, Issue 4, Chochinov H.M., Hack T., McClement S., Kristjanson L., and Harlos M., 'Dignity in the terminally ill: a developing empirical model', pp. 433–43, Copyright © 2002 Elsevier Science Ltd., http://www.sciencedirect.com/science/article/pii/S0277953601000843

Quantitative studies also inform our understanding of dignity. Cross-sectional cohort research conducted with 213 people with terminal cancer receiving care on specialized palliative care units examined the extent to which they believed they were able to maintain their sense of dignity, and the ways in which symptom distress and psychological well-being might influence their perception (Chochinov et al., 2002). Participants completed a battery of measures including a seven-point sense of dignity item: a symptom distress scale; the McGill pain questionnaire; an index of independence in activities of daily living; a quality-of-life scale, and instruments screening for anxiety, hopelessness, desire for death, will to live, social support, and burden to others. Sixteen of the 213 participants identified that loss of dignity was a significant concern for them. Though they constitute only 7.5% of the total sample, it is important to note that those whose dignity had been eroded were more likely to report increased levels of pain, difficulty with bowel functioning, and needing help with activities such as toileting and bathing. Patients experiencing loss of dignity were also more likely to report a decreased quality of life: loss of will to live; hopelessness, depression, anxiety, and a desire for death. These findings remind us that tending to patient dignity requires that health-care providers screen for and address physical and emotional distress; support functional independence in activities of daily living, and help people identify and engage in those activities and relationships that help them find meaning and purpose.

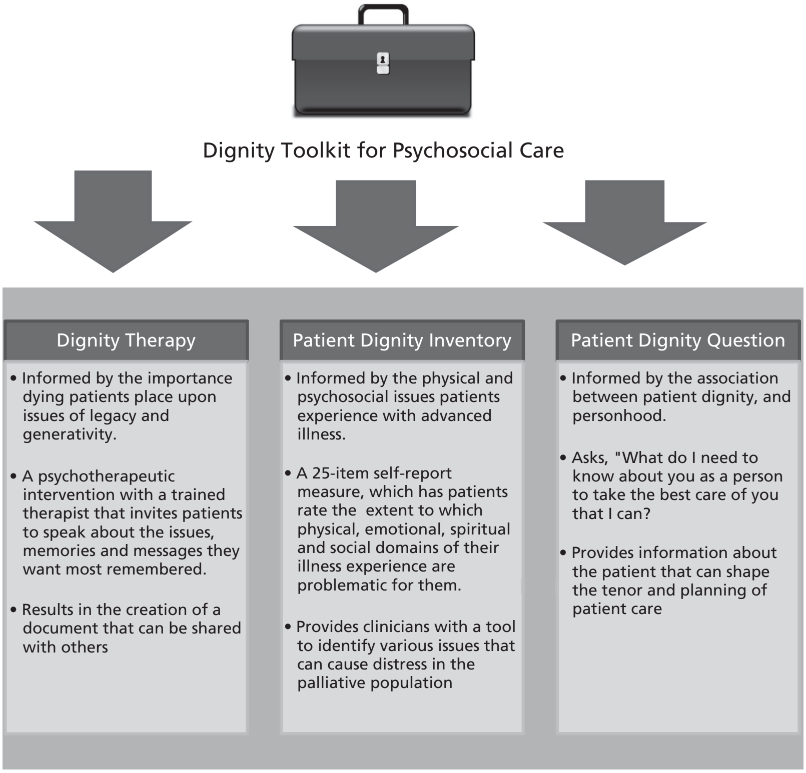
Supporting dignity in clinical practice

The domains identified in the empirical model of patient dignity previously described have informed the development of applications that health-care providers can add to their clinical 'tool kit' to help attend to this vital part of the patient's care experience. (See Figure 8.2.) Three specific applications will be detailed here. They include:

- Dignity Therapy
- The Patient Dignity Inventory (PDI)
- The Patient Dignity Question (PDQ)

Dignity therapy

The model of patient dignity clearly identifies that an important part of bolstering patient dignity concerns addressing the patient's generativity, sense of purpose, meaning, and worth. Dignity therapy (DT) is a manualized psychotherapeutic intervention informed by these needs (Chochinov, 2012). It involves an individual trained in DT guiding the patient in conversation about those facets of their life about which they feel most proud, that were most meaningful, and that they would want remembered. Questions explore such



Dignity Toolkit for Psychosocial Care

Dignity Therapy

- Informed by the importance dying patients place upon issues of legacy and generativity.
- A psychotherapeutic intervention with a trained therapist that invites patients to speak about the issues, memories and messages they want most remembered.
- Results in the creation of a document that can be shared with others

Patient Dignity Inventory

- Informed by the physical and psychosocial issues patients experience with advanced illness.
- A 25-item self-report measure, which has patients rate the extent to which physical, emotional, spiritual and social domains of their illness experience are problematic for them.
- Provides clinicians with a tool to identify various issues that can cause distress in the palliative population

Patient Dignity Question

- Informed by the association between patient dignity, and personhood.
- Asks, "What do I need to know about you as a person to take the best care of you that I can?
- Provides information about the patient that can shape the tenor and planning of patient care

Figure 8.2 Approaches for supporting patient dignity in practice
Source: data from Chochinov, H.M., *Dignity therapy: final words for final days*, Oxford University Press: Oxford. Copyright © 2012; Chochinov, H.M., et al. (2008) 'The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care', *Journal of Pain and Symptom Management*, Volume 36, Issue 3, pp. 559–71, Copyright © 2008 U.S. Cancer Pain Relief Committee, Published by Elsevier Inc., http://www.sciencedirect.com/science/article/pii/S0885392408002509; and Chochinov H.M., et al. (2015) Eliciting personhood within clinical practice: effects on patients, families, and health care providers, *Journal of Pain and Symptom Management*, Volume 49, Issue 6, pp. 974–80, Copyright © 2015 American Academy of Hospice and Palliative Medicine, Published by Elsevier Inc., http://www.sciencedirect.com/science/article/pii/S0885392414009142

things, but are not limited to: the person's most important accomplishments and things they feel most proud of; hopes and aspirations for loved ones, and lessons learned about life worth pass along to others. The content of the conversation will appropriately vary according to what the patient regards as the most meaningful aspects of their lives. Interviews are audio-recorded: transcribed;

edited to enhance flow and readability, and then returned to the person for review and approval. Further revisions suggested by the patient are made as required. The final version of the transcript—referred to as a generativity document—is provided to the patient to keep and/or share with others, as they wish. Dignity therapy was first evaluated in a single group study with a sample of 100 terminally ill Canadian and Australian patients receiving palliative care (Chochinov et al., 2005).

Ninety per cent of patients reported feeling satisfied or highly satisfied with dignity therapy, 76% endorsed a heightened sense of dignity as a result of participating in DT, and 47% reported an increase in the will to live. Family members (n = 60) of those who had participated in dignity therapy were contacted nine to 12 months after the death of the patient, and invited to complete a questionnaire evaluating their perspectives about the impact of DT on both themselves and their terminally ill relative (McClement at al., 2007). Ninety-five per cent of participants reported that Dignity Therapy helped their relatives: heightened their sense of dignity (78%), purpose (72%), and helped the patient prepare for death (65%), and reduced their suffering (43%). Family members also endorsed that DT was as important as any other aspect of the patient's care (65%), that the generativity document helped them during their time of grief (78%), and that the document would continue to be a source of comfort for their families and themselves in bereavement (77%). That dignity therapy appears to mitigate the suffering of terminally ill patients and help bereft family members speaks to its utility as an important psychosocial intervention for both patients and family members.

Case study

Dignity therapy

Mrs. F is a 64 year old woman with metastatic breast cancer who is receiving regular visits at home by the palliative care team. The nurse who sees Mrs. F in the community notes that the patient is expressing remorse that she will not be able to see her grandchildren grow up, and impart the wisdom that 'only grandmothers can'. The nurse identifies that Mrs. F may be someone who could benefit from dignity therapy, and explores her willingness to participate in it. Mrs. F agrees, and one of the psychosocial clinicians on the palliative care team who is trained in DT comes to the patient's home and guides the patient through the therapy. The generativity document produced from the DT intervention gave Mrs. F the opportunity to provide specific direction to each of her three grandchildren about the importance of putting family first before all else: being honest in their business dealings with others, and taking responsibilities for their mistakes. Mrs. F has given a copy of her document to the parents of her grandchildren for safekeeping. Though she knows her grandchildren are too young to understand all of these instructions just now, she is happy, and feels a great sense of relief and satisfaction that her words of wisdom will be available to them long after she is gone.

Mrs. F's daughters both have copies of her generativity document, and are glad that they will have their mother's words to share with her grandchildren when the time is right.

Subsequent single-group studies of dignity therapy have also reported high levels of patient and family satisfaction with the intervention (Bentley, O'Conner, Kane, and Breen, 2014; Rudilla et al., 2016). Less consistent, however, has been clear evidence of the beneficial impact of dignity therapy on primary palliative care outcomes in the context of controlled studies (Chochinov et al., 2011). A systematic review of dignity therapy conducted by Fitchett and colleagues (2015) advances some possible reasons to explain this. Firstly, studies may not have been sufficiently powered to detect changes between the intervention and standard care groups (Hall et al., 2011; Hall et al., 2012). Secondly, the use of outcome measures indexing symptom distress and physical functioning may not be appropriate given that areas discussed as part of DT do not broach these areas. Thirdly, DT may actually be tapping into issues related to existential issues and acceptance of death, and outcome measures used to date have not focused on these facets of patient experience. These issues notwithstanding, dignity therapy has been described as an overwhelmingly acceptable psychosocial intervention that can help enhance hopefulness (Hall et al., 2009), and decrease anxiety and depression when base rates of these symptoms are high (Juliao et al., 2013; Juliao et al., 2014).

The patient dignity inventory

Patients at the end of life suffer from various types of physical and psychosocial distress. The model of dignity in the terminally ill helped to identify what those potential causes of suffering might be, and provided the foundation from which to develop a tool called the Patient Dignity Inventory (PDI) —a tool designed to access the sources of dignity-related distress experienced by those with advanced illness that were problematic (Chochinov et al., 2008). Each item on the tool asks the patient to indicates his/her degree of concern on a five-point scale (1 ='not a problem' and 5 ='an overwhelming problem'). After vetting the prototype with palliative care patients and clinicians, a five-point, 25 item tool coined the Patient Dignity Inventory was administered to a sample of Canadian and Australian palliative care patients (n = 253) in order to evaluate its psychometric properties. The tool demonstrated excellent face validity, and people with advanced illness in hospital and the community could complete it without difficulty. The PDI also demonstrated high internal consistency (Cronbach's coefficient alpha = 0.93), temporal stability of ratings over a 24-hour time period (test–retest reliability, $r = 0.85$). Factor analysis resulted in a five-factor solution. Labels for extracted factors were: Symptom Distress, Existential Distress, Dependency, Peace of Mind, and Social Support, that accounted for 58% of the overall variance. Concurrent validity was evidenced by way of significant associations between PDI factors and concurrent measures of distress.

Cross-culturally, the PDI has been translated and validated for use with Italian and German patients with solid and hematological cancer receiving active treatment, (Ripamonti et al., 2012; Sautier, Vehling, and Menhert, 2014), patients with advance directives in the Netherlands (Albers et al., 2011), advanced cancer patients in Spain, (Rullán et al., 2015), and Italian patients hospitalized in a psychiatric ward (Di Lorenzo et al., 2017). These works suggest that items on Patient Dignity Inventory tap into issues that resonate universally in the evaluation of dignity for patients irrespective of culture or pathology.

The PDI may well identify issues about which clinicians were unaware, or may cue them for the need to revisit previous issues that have re-emerged for patients and are contributing to their distress. Future research using the PDI might examine the clinical utility of the instruments in practice from the perspective of health-care providers; be used as a tool for researchers to identify and compare the sources and prevalence of dignity related distress in palliative cancer patients across inpatient and outpatient settings, and invite communication with patients about the approaches they feel might mitigate the distress they are experiencing.

Case study

The Patient Dignity Inventory

Mrs. R is a 58-year-old woman with metastatic lung cancer who has been admitted to the in-patient palliative care unit for management of increasing dyspnea. The palliative care unit regularly administers the Patient Dignity Inventory (PDI) tool to all patients in an effort to identify and respond to those items endorsed by patients as contributing to dignity-related distress. When Mrs. R completes the PDI this morning, the nurse notices that she has ranked the item feeling anxious as being ‘a major problem’ for her. This is not an item on the PDI that has previously been problematic for the patient, and the nurse had not picked up on any verbal or non-verbal cues from the patient that anxiety was a problem. The nurse uses the information gleaned by way of the PDI to begin a conversation with Mrs. R about her feelings of anxiety. In doing so, the nurse learns that Mrs. R is very afraid that she will ‘die feeling like I am being suffocated, gasping for breath.’ The patient shares with the nurse how frightening the episode of acute dyspnea that precipitated her hospital admission was, and she can only assume that the moment of her death with be just like that, ‘only 1000 times worse!’. After acknowledging and normalizing Mrs. R’s experience and feelings, the nurse identifies the need to reassure the patient that the palliative care team is keeping a close eye on her symptoms, and to explain to Mrs. R what specific plans are in place to help manage further episodes of dyspnea that may occur. She also gently explores with the patient whether or not she wishes to discuss what she can expect as death draws near, and will follow the patient’s lead as to the type and amount of information she desires about that issue.

The patient dignity question

A person's sense of dignity is linked to them feeling known by their care-givers as a person as opposed to pathology. While health-care providers cannot conceivably know the detailed personal history of everyone for whom they care, they can become conversant with those specific details that the patient would want them to know that have the potential to shape the way health-care providers perceive and thus care for the patient. Chochinov and colleagues (2015) developed and evaluated the patient dignity question (PDQ) as a way of eliciting information regarding patienthood. The question: 'What do I need to know about you as a person to give you the best care possible?' was asked of palliative care in-patients (n = 66). Relatives (n = 60) were asked the question: 'What should health-care providers know about your family member to give them the best care possible?' where patients were too unwell to provide a response. Questions prompting respondents to elaborate on important roles, relationships, beliefs, or experiences they wanted staff to be mindful of can help expand initial responses to the PDQ. Question responses were summarized and typed up: vetted by patients/family members for accuracy, and with permission, placed on the patient's medical chart. Patient and family feedback about the PDQ endorsed the accuracy of the summaries (98%) felt the information was important for their health-care provider to be aware of (84.9%) and felt it could affect care (64.3%).

To examine factors that might influence their receptivity toward information contained in the PDQ summaries, health-care providers (N = 190) completed a demographic questionnaire, the Job Satisfaction Scale, the Empathy Questionnaire, the Meaningful Life Measure, and the Multidimensional Scale of Perceived Social Support. Each time they read a PDQ summary on one of their patients' charts, health-care providers were asked to complete an anonymous eight item survey (with individual items ranging from one [strongly disagree] to seven [strongly agree]) that examined the extent to which they were emotionally affected by the PDQ, had learned something new about the patient as a result the PDQ: whether it affected their attitude toward the patient; influenced the care they provided; as well as their respect, connectedness, empathy toward, and satisfaction in providing care for, the patient.

Females, nursing and medical students, and health-care providers with either a few years of experience, or experience in excess of 15 years were most likely to be responsive to information elicited by the PDQ. Responsiveness to information from the PDQ was also associated with high job satisfaction, and having a meaningful life. There is evidence that use of the PDQ can shape the tenor of care patients receive. Health-care providers reported that they were emotionally affected by the contents of the PDQ (64%), that their sense of connectedness to the patient was enhanced (63%), and that they felt more empathy for (59%), and respect (48%), toward the patient. Enhanced personal satisfaction in providing care to the patient, and feeling that information on the PDQ influenced care provided was endorsed by 49% of respondents. The salutary effect that the PDQ might have on health-care providers is noteworthy. Constant exposure to death and dying: time constraint; and inadequate resources are linked to clinician stress, burnout, decreased quality of care, and team work in palliative care settings (Sanchez-Reilly et al., 2013). Conversely, approaches that enable clinicians to develop the ability to empathize with others is believed to promote resiliency (Mehta et al., 2016)

Case study

Patient dignity question

Mr. A is a 68-year-old man who is living with metastatic colon cancer. He has been admitted to the palliative unit for management of a malignant bowel obstruction. As part of the regular admission process to the unit, each patient is asked the Patient Dignity Question: ‘What do I need to know about you as a person in order to give you the best care possible?’ Mr. A shares that his cancer diagnosis forced him to retire from a busy practice in internal medicine that was the focus of his life. He indicates that he likes to be in control of things, and is not comfortable ‘being on the other side of the hospital gurney’. He shares that he is unmarried, doesn’t have any close friends, and that his family live far away in another country. Though he goes to visit them occasionally, he does not describe his family ties as being particularly close. He indicates that he is interested in working on his spiritual development in order to try and make peace with all that has happened in his life, but that he eschews organized religion. Information obtained in response to the Patient Dignity Question helps the staff in caring for Mr. A. It sensitizes them to the challenges that the role reversal from physician to patient might create for him. His past role as a clinician is acknowledged and validated. The staff utilize a collaborative approach in care planning that works well with the patient, and affords him a feeling of control. Mr. A is made aware of the spiritual support services within the hospital, and expressed an interest in dialoguing with the hospital chaplain to exchange thoughts and ideas about the non-religious dimensions of spirituality.

Conclusion

American author John Steinbeck (1961) once pondered: ‘I wonder how many people I’ve looked at all my life and never seen?’ We as clinicians would do well to ask ourselves the same thing regarding the people for whom we care. The fast paced, highly technical milieu that characterizes much of modern health care more often than not privileges pathology over personhood and dignity—with deleterious consequences. Yet it is knowledge of both that allows for optimal therapeutic effectiveness. Application of the approaches to dignity-conserving care described in this chapter offer tangible ways of helping clinicians keep patient dignity squarely on their clinical radar.

References

Albers G., **Pasman H.R.**, **Rurup .M.L de Vet H.C.**, and **Onwuteaka-Philipsen B.D.** (2011). Analysis of the construct of dignity and content validity of the patient dignity inventory. *Health and Quality of Life Outcomes*, **9**: 45. Available from: http://doi.org.uml.idm.oclc.org/10.1186/1477-7525-9-45,

Bentley B., **O'Connor M.**, **Kane R.**, and **Breen L.J.** (2014). Feasibility, acceptability, and potential effectiveness of dignity therapy for people with motor neurone disease. *PLoS One*, **9**(5), Available from: www.plosone.org]

Bultz B., **Jacobsen P.**, and **Loscalzo M.** (2017). Screening for distress: A communication tool that highlights patient concerns and facilitates psychosocial programme development. In: D. Kissane, B. Bultz, P. Butow, C. Bylund S. Noble, and S. Wilkinson, (eds), *Oxford Textbook of Communication in Oncology And Palliative Care*. Oxford University Press: Oxford, pp. 287–92.

Clark J. (2010). Defining the concept of dignity and developing a model to promote its use in practice. *Nursing Times*, **106**: 16–9.

Chochinov H.M., **Hack T.**, **McClement S.**, **Kristjanson L.**, and **Harlos M.** (2002). Dignity in the terminally ill: a developing empirical model. *Social Science & Medicine*, **53**(4): 433–43.

Chochinov H.M., **Hack T.**, **Hassard T.**, **Kristjanson L.**, **McClement S.**, and **Harlos M.** (2002). Dignity in the terminally ill: a cross-sectional cohort study. *The Lancet*, **360**(9350): 2026–30.

Chochinov H. (2004), Dignity and the eye of the beholder. *Journal of Clinical Oncology*, **22**(7): 1336–40.

Chochinov H.M., **Hack T.**, **Hassard T.**, **Kristjanson L.J. McClement S.**, and **Harlos M.** (2005). Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, **23**(4): 5520–5.

Chochinov H.M., **Hassard T.**, **McClement S.**, **Hack T.**, **Kristjanson L.J.**, **Harlos M.**, **Sinclair S.**, and **Murray A.** (2008). The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of Pain & Symptom Management*, **36**(3): 559–71.

Chochinov H.M., **Kristjanson L.J.**, **Breitbart W.**, **McClement S.**, **Hack T.**, **Hassard T.**, and **Harlos M.** (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology*, **12**(8): 753–62.

Chochinov H.M. (2012). *Dignity Therapy: Final Words For Final Days*. Oxford University Press: Oxford.

Chochinov H.M., **McClement S.**, **Hack T.**, **Thompson G.**, **Dufault B.**, and **Harlos M.** (2015). Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *Journal of Pain & Symptom Management*, **49**(6): 974–80.

Di Lorenzo R., **Cabri G.**, **Carretti E.**, **Galli G.**, **Giambalvo N.**, **Rioli G.**, **Saraceni S.**, **Giulia Spiga G.**, **Del Giovane C.**, and **Ferri P.** (2017). A preliminary study of Patient Dignity Inventory validation among patients hospitalized in an acute psychiatric ward *Neuropsychiatric Disease & Treatment*, 2017, **13**: 177–90.

Ersek M. (2004) The continuing challenge of assisted death. *Journal of Hospice and Palliative Nursing*, **6**(1): 46–59.

Fitchett G., **Emanuel L.**, **Handzo G.**, **Boyken L.**, and **Wilkie D.J.** (2015) Care of the human spirit and the role of dignity therapy a systematic review of dignity therapy research. *BMC Palliative Care*, **14**(8): 10.1186/s12904-015-0007-1. eCollection 2015.

Hall S., **Chochinov H.**, **Harding R.**, **Murray S.**, **Richardson A.**, and **Higginson I.J.** (2009). A phase II randomized controlled trial assessing the feasibility, acceptability and potential effectiveness of dignity therapy for older people in care homes: study protocol. *BMC Geriatrics*, **9**(9) doi: 10.1186/1471-2318-9-9.

Hall S., **Goddard C.**, **Opio D.**, **Speck P.W.**, **Martin P.**, and **Higginson I.J.** (2011). A novel approach to enhancing hope in patients with advanced cancer: a randomised phase II trial of dignity therapy. *BMJ Supportive & Palliative Care*, Dec, **1**(3): 315–21.

Hall S., **Goddard C.**, **Opio D.**, **Speck P.W.**, and **Higginson I.J.** (2012). Feasibility, acceptability and potential effectiveness of dignity therapy for older people in care homes: a phase II randomized controlled trial of a brief palliative care psychotherapy. *Palliative Medicine*, Jul, **26**(5): 703–12.

Johnston B., **Gaffney M.**, **Pringle J.**, and **Buchanan D.** (2015). The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. International *Journal of Palliative Nursing*, **21**(2): 71–7.

Juliao M., **Barbosa A.**, **Oliveira F.**, and **Vaz Carneiro A.**, (2013). Efficacy of dignity therapy for depression and anxiety in terminally ill patients: early results of a randomized controlled trial. *Palliative & Supportive Care*, Dec, **11**(6): 481–9.

Juliao M., **Oliveira F.**, **Nunes B.**, **Vaz Carneiro A.**, and **Barbosa A.**, (2014). Efficacy of dignity therapy on depression and anxiety in Portuguese terminally ill patients: a phase II randomized controlled trial. *Journal of Palliative Medicine*, Jun, **17**(6): 688–95.

Lloyd-Williams M. (ed.) (2008). *Psychosocial Issues In Palliative Care*. Oxford: Oxford University Press.

McClemen S.E., **Chochinov H.M.**, **Hack T.F.**, **Kristjanson L.J.**, and **Harlos M.**, (2004). Dignity-conserving care: application of research findings to practice. *International Journal of Palliative Nursing*, **10**(4): 173–9.

McClement S., **Chochinov H.M.**, **Hack T.**, **Hassard T.**, **Kristjanson L.J.**, and **Harlos M.** (2007). Dignity therapy family member perspectives. *Journal of Palliative Medicine*, **10**(5): 1076–82.

Mehta D.H., **Perez G.K.**, **Traeger L.**, **Park E.R.**, **Goldman R.E.**, **Haime V.**, and **Chittenden E.H.** (2016). Building resiliency in a palliative care team: a pilot study. *Journal of Pain and Symptom Management*, **51**(3): 604–8.

Merriam-Webster, 2017, Dignity. On-line dictionary. Available from: https://www.merriam-webster.com/dictionary/dignity] [Accessed April 2017]

Pastrana T., **Jünger S.**, **Ostgathe C.**, **Elsner F.**, and **Radbruch L.**, (2008). A matter of definition–key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, **23**(2): 222–32.

Ripamonti C.I., **Bonaccorso L.**, **Maruelli A.**, **Bandieri E.**, **Pessi A Boldini S.**, **Prmi C.**, and **Miccinesi G.** (2012). Patient dignity inventory (PDI) questionnaire: the validation study in Italian patients with solid and hematological cancers on active oncological treatments. *Tumori*, **98**(4): 491–500.

Rudilla D., **Galiana L.**, **Oliver A.**, and **Barreto P.**, (2016). Comparing counseling and dignity therapies in home care patients: a pilot study. *Palliative & Supportive Care*, **14**(4): 321–9.

Rullán M., **Carvajal A.**, **Núñez-Córdoba J.M.**, **Martínez M.**, **Carrasco J.M.**, **García I.**, **Arantzamendi M.**, **Belar A.**, and **Centeno C.** (2015). Spanish version of the patient dignity inventory: translation and validation in patients with advanced cancer. *Journal of Pain & Symptom Management*, **50**(6): 874–81.

Sanchez-Reilly S., **Morrison L.J.**, **Carey E.**, **Bernacki R.**, **O'Neill L.**, **Kapo J.**, **Periyakoil V.S.**, and **deLima Thomas J.**, (2013). Caring for oneself to care for others: Physicians and their self-care. *Journal of Supportive Oncology*, **11**(2): 75–81.

Saunders C. (1976). Care of the dying—1. The problem of euthanasia. *Nursing Times*, **72**(26): 1003–5.

Sautier L.P., **Vehling, S.**, and **Mehnert A.**, (2014). Assessment of patients' dignity in cancer care: preliminary psychometrics of the German version of the Patient Dignity Inventory (PDI-G) *Journal of Pain and Symptom Management*, **47**(1): 181–8.

Schulman A. (2008). *Human Dignity and Bioethics: Essays commissioned by the President's Council on Bioethics*. Government Printing Office: London.

Steinbeck J., (1961). *The Winter Of Our Discontent*. New York: Penguin.

Surbone A., **Baider L.**, **Weitzman T.S.**,**Brames M.J.**, **Rittenberg C.N.**, **Johnson J.**, and **MASCC Psychosocial Study Group** (2010). Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Supportive Care in Cancer*, **18**(2): 255–63.

Thompson G.N., **McArthur J.**, and **Doupe M.** (2016). Identifying markers of dignity-conserving care in long-term care: A modified delphi study. *PLoS ONE*, **11**(6): e0156816.

United Nations General Assembly. *'Universal Declaration of Human Rights'*. (1948). United Nations 217 (III) A 1948 Paris, art. 1. Available from: http://www.un-.org/en/universal-declaration-human-rights/. Accessed April 2017.

Unesco. Universal Declaration on Bioethics and Human Rights. (2005). *Universal declaration on bioethics and human rights*, UNESCO. Retrieved at September 18, 2008, from the website temoa: Open Educational Resources (OER) Portal at http://www.temoa.info/nod. Accessed April 2017.

Van der Maas P.J., **Van Delden L.**, **Pijnenborg L.**, and **Looman C.W.N.** (1991). Euthanasia and other medical decisions concerning the end of life. *Lancet*, Sep **14: 338**(8768): 669–74.

Chapter 9

Diagnosis, assessment, and treatment of depression in advanced disease

Matthew Hotopf

Introduction to depression in advanced disease

Depression in palliative care is common, under-recognized, and has significant impacts for sufferers. There are effective treatments but in most settings, a shortage of staff to provide them. This chapter sets out a number of key issues to consider when assessing and treating individual patients, as well as exploring the way in which palliative care services can innovate to provide a population level response to depression.

Definitions

Depression has many meanings. First, it may be used to describe an *emotion*. We may say we feel 'depressed' because the wrong team won the match, or the wrong political party won the election. Depression used in this sense means virtually any negative emotion one can imagine—frustration, sadness, anger, disgust, irritation—all of which are a normal response to circumstances. And naturally these emotions might be anticipated in advanced disease.

Depression can also mean a *symptom*—'depressed mood'—which suggests a more prolonged state of sadness and loss of interest. Symptoms imply that the sensation is experienced to be abnormal, and is sufficiently troublesome to lead to some form of illness behaviour, for example visiting a doctor or withdrawing from day-to-day activities. Thus we might understand that a person with advanced disease is unhappy, but if that unhappiness is persistent, prolonged, and unwavering, and starts to dominate their life, we might consider it to have crossed a threshold from normal emotion to abnormal symptom.

Depression can also mean a *syndrome*—a collection of symptoms which frequently occur together, and when sufficiently prolonged, severe, and disabling meet criteria for a psychiatric disorder such as major depressive disorder, dysthymia, or a depressive episode in bipolar affective disorder.

Finally, a depressed mood can be a feature of virtually any other psychiatric disorders—including delirium, dementia, psychosis, and personality disorders, in which changes in mood are one feature among many, and the main approach to care is likely to be focussed elsewhere.

For each of these meanings of depression, the response is different. For example, it would be unhelpful to prescribe antidepressants for someone with an understandable emotional response to advanced disease. Most of the time, distress should be normalized rather than medicalized and the individual reassured that their emotions are not out of the ordinary. People not only feel relieved but also experience a greater sense of agency and independence when told they do not have to worry about yet another diagnosis. But there is a point along the spectrum from emotion to symptom to syndrome, when it is important to identify and manage the problem and provide treatment for it. There are few states more unpleasant and uncomfortable than experiencing a prolonged depressive disorders and unfortunately many people with significant depressive disorders languish too long without support or treatment.

Apart from the direct impact of experiencing depression, diagnosing depression matters because of the wider impacts of depression on clinical care. For virtually every physical illness in which depression has been studied, the impacts of depression (whether as a disorder or symptom) are significant (Hotopf and McCracken, 2014). People with physical illness who are unlucky enough to experience depression have poorer physical health outcomes, worse quality of life, higher mortality, increased length of stay, higher costs, lower satisfaction with care, and poorer adherence to treatments (Evans, Charney, and Lewis, 2005) and depression, when severe, can impact decision making capacity (Owen, et al., 2008). Depression is therefore an important component of the overall clinical state of the patient.

The diagnosis of depressive disorders

Depressive disorders consist of a pattern of symptoms which tend to occur together (see Box 9.1). The symptoms of major depressive disorder are shown in Table 1. Many are common in the general population and even more so in palliative care. Many of them (fatigue, poor sleep, loss of appetite, and weight) may be direct consequences of physical disease. Others (low mood, loss of interest in activities, and thoughts of death) may be direct emotional impacts of disease and disability.

This leaves us with a problem. Given that, in making the diagnosis of major depressive disorder one relies on the presence of symptoms which might be expected to be there already for the person with advanced disease, can we

Box 9.1 DSM5 symptoms of Major Depressive Disorder

A. Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful).
2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation.)
3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day.
4. Insomnia or hypersomnia nearly every day.
5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders.

E. There has never been a manic episode or a hypomanic episode.

Note: Criteria A–C represent a major depressive episode.
Note: Responses to a significant loss (e.g., bereavement, financial ruin, losses from a natural disaster, a serious medical illness or disability) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss noted in Criterion A, which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgment based on the individual's history and the cultural norms for the expression of distress in the contest of loss.

safely make the diagnosis at all? In DSM5 the symptoms of major depressive disorder do not 'count' if they are clearly related to another disorder. But the cause of a symptom is not always obvious. One approach to the problem has been substitution criteria, which were proposed by Endicott (1984). Here the diagnostic criteria of depression are adjusted in order to take account of these symptoms. When Chochinov and colleagues (1994), attempted to apply the Endicott Criteria to cohorts with depression and advanced disease, they found it made virtually no difference to the prevalence of disorders. More recently, we found that symptoms like loss of appetite were informative in that their absence had some negative predictive value—in other words, people who did not report appetite or sleep disturbance were unlikely to have depression (Rayner L. et al., 2006). Ultimately, questions of the validity of symptoms in making the diagnosis of a depressive disorder lead one to question the purpose of making the diagnosis itself. The key reason to make a diagnosis is to make predictions which are clinically useful—and in particular predicting whether someone will respond to a treatment. So debates about which symptoms matter need to be placed in the context of whether they are informative about making treatment decisions, and within the palliative care setting there is insufficient evidence to suggest that one set of symptoms are more predictive of treatment outcome than any other.

Depressive disorder overlap considerably with anxiety disorders—indeed overlap is the norm not the exception (Goldberg et al., 1997). The concept of common mental disorders (Goldberg and Huxley, 1992),—broadly speaking, depression and anxiety disorders—is useful, in that it lumps together these disorders which have similar epidemiology, similar impacts and similar treatments. Depression is also a core feature of bipolar affective disorder, which is an illness characterized by swings in mood, from severe depression through to intense elation and mania. The distinction between bipolar and unipolar depression is important because the treatment response is different.

Measurement of depressive symptoms

Many ways have been devised to measure systematically symptoms of depression. The main approaches are:

- Questionnaires where the patient responds to structured questions on paper or electronically. Such questionnaires may be designed either for screening (or identification) or for measuring severity of symptoms in an individual with diagnosed depression, or both:

  Beck Depression Inventory (1961)
  Patient Health Questionnaire (Kroenke K, et al. 2001)
  Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)
  General Health Questionnaire (Goldberg, 1972)

- Rating scales, which have typically been used to measure severity of depression in treatment trials. Such rating scales are completed by a clinician following an interview with the patient:

  Hamilton Depression Rating Scale (1960)
  Montgomery, Asberg Rating Scale (1979)
  Inventory of Depressive Symptomatology (Rush et al., 1986)

- Diagnostic interviews can be used to diagnose depressive disorders in research contexts by following a strict algorithm—these can be structured in which case the interviewer has little or no scope to change the questions, or unstructured, in which case the interviewer—usually a clinician—is able to use his or her training to guide the interview:

  Clinical Interview Schedule—Revised (Lewis et al., 1992)
  Composite international Diagnostic Interview (Division of Mental Health, 1990)
  Structured Clinical Interview for DSM (Spitzer et al., 1992)

Prevalence of depression in palliative care

Given that depression can be measured in many different ways, it is no surprise that reported prevalence estimates of depression vary considerably in palliative care. A methodological systematic review (Wasteson et al., 2009) found that there was enormous diversity in the way in which prevalence studies had categorized depression with 106 different assessments being used in over 200 included publications. There were relatively few studies which used structured diagnostic interviews. When these different designs are summarized, we found, unsurprisingly, that single item questions on the prevalence of the symptom suggested it was very common. When one uses a questionnaire designed to detect depression such as the Hospital Anxiety and Depression Scale, the prevalence is reduced to 29%, and when studies have used structured diagnostic interviews, the prevalence is lower still, about 15% (see Table 9.1) (Hotopf et al., 2002). All these summaries are simplifications: indicating median prevalence of multiple studies. A more recent review (Mitchell, Chan, and Bhatti, 2007) estimated a reassuringly similar combined prevalence of 16.5% for diagnostic interview diagnosed depression in palliative care settings and 16.3% in oncological and haematological settings. These figures are three to four times higher than the point prevalence of depressive disorders in the general population.

Associations of depression

In the general population, the peak onset of depression is in adolescence and early adult life (Kessler, et al., 2007). This has focussed attention on the processes leading to depression which starts still earlier. Most prevalence studies indicate that, with age, depression becomes less common. In palliative care settings this pattern is also seen, and it makes sense that people who are facing death in their 20s or 30s may be less resilient to depression than those in their 80s or 90s.

The other highly reliable association with depression is with female sex. Prevalence of depression is between one-and-a-half to two times higher in women than men in the general population (Seedat et al., 2009). The reasons for this may include biological predisposition; including the impacts of sex hormones, and social; including differential exposure to victimization and

Table 9.1 Prevalence of depression according to type of measure used

Criterion	Number of studies	Median (interquartile range) prevalence
Single depression question	14	40.5% (29–53.5%)
HADS ('Definite depression')	15	29% (20–29%)
Diagnostic interview	10	15% (5–26%)

Reproduced with permission from Hotopf M., Chidgey.J, Addington-Hall J., and Ly K. L., 'Depression in advanced disease: a systematic review Part 1. Prevalence and case finding', *Palliative Medicine*, 16(2), 81–97, Copyright © 2002 SAGE Journals, DOI: 10.1191/0269216302pm507oa the challenges childrearing places differentially on women. In palliative care, the evidence for a female preponderance in depression is absent, with some studies finding no gender difference (Mitchell et al., 2009) or even reversed gender differences, with more men affected (Rayner, et al., 2006). It seems that men are particularly affected by threats to their independence (Hayes, Lee, and Rayner, 2011).

The other socio-demographic risk factor reliably demonstrated for depression relate to material and social deprivation (Weich and Lewis, 1998). There is a considerable literature indicating that social status is strongly associated with symptoms of distress—whether this is framed in terms of educational status, occupational social class, or access to resources such as housing tenure or car ownership. These are not linear relationships—much depends upon context and culture: but unemployment and loss of work due to illness or disability are particularly potent associations with depression (Rayner et al., 1995; Hatch, Frissa, and Verdecchia, 2011). Social isolation is also strongly associated with depression. In palliative care, these associations play out via the network around an individual and their resources to recruit help. Studies indicate that social isolation is an important risk factors for depression and is associated with poor depression outcomes (Rayner, Lee, Price et al., 2005; Goodwin, Lee, and Price, 2011).

Early risk factors

Given the substantial evidence that peak onset of depression is in adolescence and early adult life, general population studies on aetiology focus on early risk factors. There is extensive evidence that depressive disorders are heritable with considerably greater monozygotic twin concordance than dizygotic concordance (Sullivan, Neale, and Kendler, 2000). As is the rule in psychiatric genetics, depression is driven by multiple genes of small effect—there is no single gene for depression. Whilst progress is being made in genome wide association studies to identify what will eventually be a long list of genes, the genomics of depression has no clinical utility thus far.

A stable and loving early environment is fundamental to mental health—the psychic equivalent to clean drinking water which is so critical in public health. Disrupted early environment is a strong risk factor for virtually all psychiatric disorders. This includes not only severe childhood abuse (physical, sexual, or emotional) but also patterns of unstable attachment—parents or carers who are inconsistent and at some level cannot be relied upon. Early adversity can have impacts on physical health: leading to changes in stress reactivity and to immune dysregulation. In palliative care, even if the patient has led a long life, childhood adversity may profoundly impact how the individual responds to receiving care.

If care-givers have been sources of danger in the past the same responses may be evoked by nurses or doctors caring for the individual in the present.

Later risk factors

Life events, particularly those which involve loss, are strongly associated with depression (Brown and Harris, 1978). The loss may involve a bereavement, the break up of a relationship, loss of employment or role. Also frequently associated with depression are life events characterized by some form of humiliation, or loss of face.

Physical illness is itself strongly associated with depression, not just in advanced disease but across a wide range of disorders (Evans et al., 2005). There is no exclusivity in the relationship—virtually all physical illness is associated. There is substantial evidence that inflammation is strongly associated with depression. This has been demonstrated elegantly in people undergoing immunotherapy—for example for hepatitis C, where interferon alpha is infused, kick-starting an immune response which reduces viral load, but also frequently precipitating a depressive illness (Pariante et al., 1995). Many of the classic feature of illness behaviour associated with inflammatory illness—sleep and appetite disturbance; reduced motor activity, fatigue, and poor concentration—which overlaps with depression. Many advanced diseases are associated with overwhelming inflammatory reactions and there is some evidence for immune mechanisms to depression in this context. The immune hypothesis of depression is exciting as it opens the possibility that anti-inflammatory agents may have antidepressant action, a proposal currently under investigation.

Physical illness is also, of course, a series of life events. Imagine one patient's cancer journey—she is first faced with symptoms which lead up to diagnosis. The symptoms may have been dismissed by her or misdiagnosed by her doctor. The diagnosis itself is followed by treatments which infringe her very sense of self: mutilating surgery, colostomy, or chemotherapy. Treatment may keep her busy, but when complete, she is faced with a new loss—the loss of roles. She takes early retirement, or someone else has been enlisted to look after her grandchildren. She may then be faced with recurrence: a new round of treatment; growing dependency on others, and the threat of the ultimate loss—her own mortality. It is surprising, perhaps, that not more people with cancer develop depression.

The assessment of depression in palliative care

Assessing mood involves taking a history: making observations, and critically talking to informants. The clinical interview needs time and privacy, but to people with advanced disease both may be scarce. Patients get tired, and it is sometimes necessary to make an assessment in a ward where conversations may be overheard. It is usually best to approach the assessment from the perspective of the patient, and focus on the history of the physical illness—this is less threatening than immediately asking about mood, and establishes rapport as the patient then knows the interviewer has a sense of what they have been through. The assessment should also include a past psychiatric history; indicating whether the individual had ever had previous episodes of depression or other psychiatric disorders, whether they had received treatment and whether they had ever felt suicidal, and key biographic information, which can be highly informative—including information on early upbringing. Some suggested questions in history taking are shown in Box 9.2.

In psychiatry, the mental state examination provides a useful way to structure observations about the patient. The key aspects of someone with depression are shown in Table 9.2. Finally, whenever possible, it is informative to speak to an informant. This might be a relative, or if the patient is in hospital or hospice, a member of nursing staff. Ask whether the mood lifts when visitors come, whether the patient engages in activities, and how their sleep and appetite appears.

Assessment and management of suicidal ideas

One consequence of depression is the risk of self-harm and suicide. Assessment of suicidal ideas is easy to do (see Box 9.3) and most patients when asked feel relieved these disturbing thoughts are being considered. The problem however is that, whereas suicide is a rare event, even in palliative care populations, suicidal ideas are very common. In the general population about 10–20% at any one time have thoughts that life might not be worth living. Rather fewer attempt self-harm, but it is still a common presentation to emergency departments. But suicide, even in the group who self-harm, is rare and unpredictable. Management of suicidality is discussed forthwith.

Ruling out alternative explanations for depression

There are many routes to depression and some lead to radically different treatment plans. Some of the differential diagnoses of depression in palliative care settings are outlined in Table 9.3. First it is important to rule out a direct impact of the physical illness causing depression-like syndrome. For example a patient in intense pain may appear to have severe depression, which miraculously lifts when the pain is addressed. Many organic brain syndromes, including delirium, arise directly out of physical disease or its treatment, and may present

Box 9.2 Useful questions to ask in history taking

Response to the illness

- When did you first realise something was wrong?
- How did you respond when you were given the diagnosis?
- What did you fear most?
- What do you now fear most?
- What's the most frustrating thing about having this illness?
- In caring for you, is there anything which you think it's important for the team to know?

Biographic information

- Can we draw a family tree so I can understand who is in the family?
- Who are you close to? Who is at home? Are you particularly worried about anyone in the family?
- What was life like before this illness started? Were you working? Were you planning retirement?
- Do you remember your home life when you were growing up? Was it a happy childhood? Did anyone ever mistreat you?
- How did you get on at school? Did you make friends easily? Were you bullied?
- What was the best job you ever had?

Past psychiatric history

- Do you recall if you've ever seen a doctor about an emotional or mental health problem? Did you have any treatment? Were you signed off work?
- Have you ever felt so bad you've felt life wasn't worth living? Did you ever try to harm yourself?
- How do you normally cope with difficulties—can you recall a particularly difficult time in your life and what you did about it?

with affective changes and agitation which can be mistaken for depression. And dementia, which is very common given the demographics of the palliative care population, is often undiagnosed and can present with behaviours which are frequently mistaken for depression. Other psychiatric disorders should also be considered: whilst psychotic illness or bipolar affective disorder are usually well known by the care-team, patients with personality disorders or substance use

Table 9.2 Features of the mental state examination in depression

Mental state feature	Presentations in depressive disorders (*severe)
Appearance and behaviour	◆ Appears downcast/looks sad or tearful ◆ Does not engage readily in the interview ◆ Appears slowed down/agitated* ◆ Poor self-care* ◆ Mask-like appearance*
Speech	◆ Slow, ponderous, lack of variation in tone ◆ Mute*
Mood	◆ Complains of low mood ◆ Loss of interest and enjoyment of activities which used to bring pleasure ◆ Feels empty ◆ Suicidal ideas
Beliefs	◆ Low self-worth ◆ Guilt ◆ Delusions of poverty, guilt* ◆ Nihilistic delusions*
Abnormal experiences	◆ Mood congruent auditory hallucinations
Cognitive assessment	◆ General slowing of responses ◆ Answers ‘don’t know’ frequently ◆ May appear as though has dementia*
Insight	◆ Lack of recognition of symptoms as abnormal, or that he or she has depression or of need for treatment*

disorders may notd be and these disorders impact care, particularly because they go unrecognized.

Management of depression

The mainstay of the management of depression is usually some combination of psychological therapy and antidepressants. However the key challenge is how to integrate depression care into the routine work of palliative care services.

Box 9.3 Questioning about suicidal risk

It sounds like things have been really tough for you lately. Is life worth living?

Have you wished you could go to sleep and not wake up?

Have you had any thoughts about harming yourself lately? What were these?

Have you ever harmed yourself in the past?

Table 9.3 Differential diagnoses of depression

Question	Differential diagnosis	How to ascertain
Is a component of the patient's medical illness directly impacting mood?	Delirium Intractable pain Opiate toxicity Cerebral metastasis Adverse drug reaction	History, cognitive testing History Drug chart and examination History, examination, imaging Review of drug chart
Is there evidence of cognitive impairment indicating a coincidental organic psychiatric disorder?	Dementia	History, cognitive testing, informants
Is there evidence of a previous history of major mental disorder?	Schizophrenia, other psychoses and bipolar affective disorder	Informants, medical records, history
Is there evidence of substance use disorder?	Alcohol or drug dependence	History, informants, medical records
Is there evidence of a personality disorder?	Personality disorder	History, informants
Is this a normal emotional response to circumstances?	Normal emotional response	History, mental state examination, informants

Following a consultation process (Rayner, Price, Hotopf, and Higginson, 2009; 2011) , the European Palliative Care Research Collaborative guidelines on the management of depression form a useful framework focussing on prevention, assessment, and treatment (Rayner, et al., 2003).

Prevention

Whilst there is no solid evidence base of preventive strategies for depression in advanced disease, there is evidence from a prospective study of depressive symptoms that one of the strongest risk factors for developing depression is poor social support, and one of the best prognostic factors for established depression is improved physical symptoms (Goodwin, Lee, and Price 2011). Palliative care, with its emphasis on the wider context of the patient including family and community, and expertise in symptom reduction, may well be a tool for prevention. Excellent listening and communication: providing accurate information, and supporting individuals with good symptom management and social support are all likely to be helpful in preventing depression (Goodwin, Lee, and Price, 2000).

Case finding

Much has been written about which screening tool is best in depression, and in palliative care, whether further adaptations are required to take account of the conditions of the patient. The Hospital Anxiety and Depression Scale, for example: has an item on feeling slowed down, which some have argued make it problematic in this population. In practice, however, there is relatively little to separate these measures (see Table 9.4).

There has been a debate in mental health about the use of screening (or more accurately case finding) to identify previously unrecognized depression. By asking all patients attending a service to complete depression screening tools it is possible to identify those with previously undetected depression, and to offer treatment and thereby improve outcomes. The first rule of screening, however, is that it is only justified when one can offer a credible response when a 'case' has been detected. If staff hand out questionnaires without knowing how to respond when the patient indicates significant symptoms, the process is unlikely to be helpful, and may simply raise expectations which are not met. Screening programmes in primary care do not work as stand alone interventions (Gilbody, Sheldon, and House, 2008; Mitchell, Vahabzadeh, Magruder, 2011).

By contrast, there is evidence from a number of settings that screening as a part of integrated, or collaborative care can improve outcomes. This approach involves systems change—staff have to be trained to respond appropriately to

Table 9.4 Commonly used depression specific screening tools[33]

Screening tool	Sensitivity	Specificity
Single-item 'Are you depressed?'	0.42–0.86	0.74–0.92
Two-item 'During the last month, have you been bothered by feeling down, depressed or hopeless?' 'During the last month, have you been bothered by having little interest or pleasure in doing things?'	0.91–1.00	0.57–0.86
Hospital Anxiety and Depression Scale (HADS) 14 items, seven for anxiety, seven for depression. Excludes somatic symptoms.	0.68–0.92	0.65–0.90
The Brief Edinburgh Depression Scale (BEDS) six items covering guilt, insomnia, fear, sadness, inability to cope, and thoughts of self-harm.	0.72	0.83

Reproduced with permission from Rayner L., Higginson I. J., Price A., Hotopf M., *The Management of Depression in Palliative Care: European Clinical Guidelines. London: Department of Palliative Care, Policy and Rehabilitation*, European Palliative Care Research Collaborative, Copyright © 2010 European Palliative Care Research Collaborative, www.epcrc.org, Available from: www.kcl.ac.uk/schools/medicine/depts/palliative patients who score high for symptoms of distress and treatments, which might range from brief psychological interventions, case management, cognitive behavioural therapy, or antidepressants.

Antidepressants

Broad considerations

There is substantial evidence that compared with placebo, there is a substantial short-term (6–8 week) treatment effect of antidepressants even when patients also have a physical illness (Rayner et al.,) and that this also applies to people with diseases likely to require palliative care (Sullivan, Neale, and Kendler, 2000). However there is a debate about the severity of depression necessary to reach before antidepressants are effective. Mild episodes of depression frequently improve spontaneously and there is a case for watchful waiting. In palliative care settings, around 50% of depression resolves within a month without specific treatment (Goodwin, Lee, and Price, 2011). The problem, however, is that antidepressants take time to work, and when time is limited there is a counterargument to start early and treat aggressively. The evidence suggests that most antidepressant use in advanced disease is too little too late (Lloyd-Williams, Friedman, and Rudd, 1999). Whether to start an antidepressant depends on the severity of the depression, the prognosis of the patient, the patient's preference, and the impact of potential side effects and interactions (Rayner et al., 2010).

Patients may be reluctant to start an antidepressant—possibly reflecting reluctance to accept the diagnosis, or concerns about side effects, being on yet another drug, addiction, or a loss of control. These concerns should not be dismissed—there is, for example, a significant body of knowledge indicating some people struggle to discontinue antidepressants (Fava et al., 2015) and a patient who has undergone chemotherapy may be reluctant to take a drug which causes nausea. It is usually possible to engage the patient in a conversation about risks and benefits, and assure him or her that the antidepressant can be stopped if side effects are a problem. Patients should be warned that antidepressants take at least two weeks to start to work and that they should expect to remain on the treatment for at least six months.

Choice of antidepressant

All antidepressants act on the monoamine pathway in the brain; impacting serotonergic and noradrenergic transmission. The main classes of antidepressants have broadly similar efficacy, but differing side effect profiles and toxicity. Monoamine oxidase inhibitors are rarely used because of their interactions. Tricyclic antidepressants may have a slight advantage in terms of effectiveness, but this is outweighed by their toxicity in overdose and side effect profile, except in cases where they are already being used for treatment of neuropathic pain, in which case it is often reasonable to increase the dose. Because of tricyclics' toxicity in overdose they should be avoided in patients who express strong suicidal ideas.

The selective serotonin reuptake inhibitors (SSRIs) are the main class of antidepressants now in use and are safe in overdose and usually well tolerated. Other newer antidepressants include the noradrenergic and specific serotonergic agent mirtazapine and duloxetine, a serotonin-norepinephrine reuptake inhibitor. A major systematic review by Cipriani and colleagues (2009) included a network analysis and found of the 'second generation' antidepressants, escitalopram and sertraline had the best balance of efficacy and side effects. Mirtazapine was also well tolerated and effective and is of particular interest in palliative care settings as it has a strong appetite stimulant effect which whilst problematic for physically healthy people is often appealing to cachectic patients. It is however sedating, and this may limit its use. Choice ultimately will depend upon the nature of the patient's disease, the side effect profile of the antidepressant, response to prior treatment and patient preference (Katon, Lin, Von Korff, 2015).

Patients started on an antidepressant should be monitored for treatment response using a validated rating scale. If the patient fails to respond: ask about treatment adherence, consider increasing the dose, or possibly switching antidepressant to a different class. A major pragmatic trial of antidepressant use, STAR*D, indicated that there is sometimes benefit from switching from one antidepressant to another, but this benefit is fairly modest (Rayner et al. 2011; Rush et al., 2008).

Other drug therapies for depression

Augmentation with lithium: combinations of antidepressants; switching to other drug classes with potential antidepressant effects such as the atypical antipsychotic quetiapine, are all treatment options, but should not be attempted before a careful reassessment of the patient and if possible specialist referral.

Psychostimulants such as amphetamines have been advocated as a potential treatment for depression in palliative care. Whilst there is some evidence that they may be effective and helpful in cancer-related fatigue (Sullivan et al., 2016), there is no credible evidence from trials that they act as antidepressants. A systematic review of trials of psychostimulants for depression indicated that they were effective in causing side effects but not in treating depression (Candy et al., 2008), and one trial of psychostimulants in depression in palliative care setting was negative, although it was probably too small to rule out a treatment effect (Sullivan et al., 2016).

Another novel treatment for depression which offers some promise in palliative care is the anaesthetic and glutamate receptor moderator ketamine, which has been trialled in treatment resistant depression and is one of the only treatments for depression, apart from electroconvulsive therapy, which seems to work virtually instantaneously. However a recent review suggests that effect sizes are limited and quality of evidence poor (Caddy et al., 2016) and trials are required in palliative care before this can be recommended.

Psychological treatments for depression

Psychological therapies range from brief self-help interventions through to intensive, long-term psychological interventions. There is some evidence that self-help interventions and guided self-help, particularly if they are theoretically driven, can be modestly effective in people with distress in the context of a physical disease (Uitterhoeve et al., 2004). There are very few good trials of psychological therapies for depression in advanced disease (Uitterhoeve et al., 2004). Most psychological therapies are delivered over a periods of months. In palliative care, brief interventions may be preferable for many patients due to their physical health status or poor prognosis. There is evidence that palliative care nurses and practitioners can be trained to deliver psychological therapy (Cort et al., 2009; Walker et al., 2009), but should have regular supervision to do so.

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy (CBT) is the most widely used and widely evaluated psychological therapy for depression, and focuses on identifying and restructuring dysfunctional thought patterns. People with depression typically have negative views of themselves, the world, and the future, the so called cognitive triad. These negative attributional styles are accompanied by cognitive distortions—errors in the way in which inferences are drawn. Examples include overgeneralization (where one negative event is seen as evidence for some more profound flaw in the person's personality) or selective abstraction, in which only one component of a complex situation is attended. Automatic thoughts are ever present, fleeting ideas which skim across our consciousness. In depression they betray the errors of thinking—so, when a depressed person notices that someone they know has not acknowledged them when walking down the corridor, their automatic thought might be: 'I'm boring' or 'he doesn't like me,' whereas many other interpretations might plausibly be applied. In cognitive therapy these errors of thinking are addressed and alternative hypotheses tested between the patient and therapist. Though there is a scarcity of studies in palliative care populations (Moorey et al., 2009) RCTs have demonstrated the effectiveness of CBT in physically ill people (Beltman et al., 2010).

Problem-solving and activity scheduling therapies

Problem solving and activity scheduling are both components of CBT which can be delivered as therapies in their own right: are simple, practical, and easy to learn. In problem solving the emphasis is in overcoming the learned helplessness which occurs in depression—depressed people become almost paralysed by their mood, and stop being able to use normal, healthy coping strategies. By working with a therapist to generate a list of problems: generate potential solutions to these, and then pick a small number of tractable problems to tackle, people with depression can take the first steps to re-discovering their natural coping strategies. There is some evidence for this approach in depression generally (Bell, and Zurilla, 2009). Activity scheduling is based on the observation that people with depression become inactive, and this inactivity worsens mood. The therapist encourages and supports the individual to engage in new activities. Both approaches have been successfully taught to oncology nurses as part of a broader package of effective care for depression in cancer (Walker , et al., 2010; Strong et al., 2008; Walkeret et al., 2008).

So called 'third generation' psychological theories and approaches to therapy have been applied. These include mindfulness and acceptance and commitment therapy (Powers et al., 2009). These approaches focus less on challenging errors in thinking, and more in distancing the individual from disturbing thoughts and emotions. The therapies borrow much from Eastern mediation, and encourage a state of interested detachment from emotions and thoughts. In ACT, there is also an emphasis on behaviour change. These approaches are attractive in palliative care settings because many of the disturbing thoughts and feelings which patients experience are realistic and the challenge of helping someone overcome severe emotional responses to their predicament is to find a way forward in spite of the difficulties they face. There is some evidence for their effectiveness at least for management of distress, rather than necessarily depressive disorder, in people with physical illness (Powers et al., 2009).

Dignity therapy

Dignity therapy has arisen from the work of Harvey Chochinov, (2002), who has focussed increasingly on the importance of the threat of loss of dignity to the individual's sense of self and wellbeing (Chochinov et al., 2012; Chochinov et al., 2012). In dignity therapy the individual participates in an interview with the therapist with the aim of generating a 'generativity' document—an account of their lives which could be handed on to close relatives. Dignity therapy has mainly been tested in unselected populations of people undergoing palliative care rather than specifically depressed subgroups. The trials indicate it is valued by patients and reduces symptoms of distress (Hall et al., 2009; Chochinov et al., 2002; Chochinov et al., 2012), but there is, as yet, no evidence of it as a specific treatment for depression.

When time is short

One of the greatest challenges is what to do for a patient whose distress is great and in whom the prognosis is very limited. The first consideration is diagnostic—if someone has become increasing agitated as their illness has deteriorated, is it really depression, or delirium? Secondly, focus on amenable sources of distress, in particular pain, but also unresolved social issues. Thirdly, agitation and severe distress can be treated symptomatically with benzodiazepines or neuroleptics (Rayner et al.,).

Managing suicidality

For palliative care services desire for death is a more natural feeling and a passive wish that death should come is not to be confused with suicidality. Such wishes are, for sure, strongly associated with depression and depression should always be assessed (Rayner et al.; Chochinov et al., 1995). However these wishes also fluctuate with clinical state (Price et al,. 2011) and the presence of pain (Chochinov et al., 2007). So how should palliative care services respond to individuals with active suicidal ideas or intent?

The key question in responding to suicidal ideas or acts of self-harm is to determine the presence of a psychiatric disorder to assess mental capacity. If risk is considered high and if a psychiatric disorder is impacting on capacity it may be appropriate to detain the individual and restrict their liberty in the hope that the crisis passes. However this situation is rare, and the patient's interests are usually best served without any threat of coercion. What suicidal patients need is a clinical team which can contain their destructive emotions and offer consistent, humane care. Threatened or real coercion may backfire if this leads to a breakdown in this protective therapeutic relationship. Instead, palliative care services should work with mental health services to manage and review the individual. Steps to reduce availability of means, including limiting supplies of opiates and other potentially lethal medicines, and engaging family members, are reasonable precautions. Patients should be provided with a care plan about what to do if they feel suicidal. Meanwhile any underlying psychiatric disorder should be treated.

Conclusion

Embedding depression care in health systems

Given that depression is common: under-recognized; distressing, and associated with a range of bad outcomes, there is an overwhelming case for devising systems of care in which depression management is routine. Because of historical splits between mental and physical health, which occur even in palliative care, there is often a skills gap. However depression, along with other sources of distress, must be everyone's business. Palliative care staff can be trained to deliver basic depression care: including CBT skills, problem solving, and activity scheduling; as well as following simple protocols to initiate, monitor and adjust antidepressant treatment. These approaches have been tested in trials in cancer care including individuals with cancers with a poor prognosis (Walker et al, 2009; Strong et al., 2008). The challenge is to take these approaches from research trials conducted in centres of excellence with good resources to other settings. One approach to do this, IMPARTS (Integrating Mental and Physical Healthcare: Research Training and Services) has attempted to do just that: with case finding; staff training, care pathway development, and self-help materials (Rayner et al., 2014). This approach can be applied to virtually all health care, truly integrating mind and body.

References

Beck A.T. and **Ward C.H.**, **Mendelson M.** (1961). An inventory for measuring depression. *Archives of general psychiatry*, **4**(6): 561–71.

Bell A.C. and **D'Zurilla T.J.** (2009). Problem-solving therapy for depression: A meta-analysis. *Clinical psychology review* **29**(4): 348–53.

Beltman M.W., **Voshaar R.C.**, and **Speckens A.E.** (2010). Cognitive-behavioural therapy for depression in people with a somatic disease: meta-analysis of randomised controlled trials. *The British journal of psychiatry: the journal of mental science*, **197**(1): 11–9.

Brown G.W. and **Harris T.O.** (1978). *Social origins of depression: a study of psychiatric disorder in women*. London: Tavistock Publications.

Caddy C., **Amit B.H.**, **McCloud T.L.**, et al. (2015). Ketamine and other glutamate receptor modulators for depression in adults. *The Cochrane database of systematic reviews*, **23**(9): CD011612.

Candy B., **Jones L.**, **Williams R.**, **Tookman A.**, and **King M.** (2008). Psychostimulants for depression. *Cochrane Database of Systematic Reviews*, **2**(2).

Chochinov H.M. (2002). Dignity-conserving care—a new model for palliative care. Helping the patient feel valued. *Journal of the American Medical Association*, **287**(17): 2253–60.

Chochinov H.M., **Hack T.**, **Hassard T.**, **Kristjanson L.J.**, **McClement S.**, and **Harlos M.** (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet*, **360**(9350): 2026–30.

Chochinov H.M., **Hack T.**, **Hassard T.**, **Kristjanson L.J.**, **McClement S.**, and **Harlos M.** (2005). Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, **23**(24): 5520–5.

Chochinov H.M., **Hack T.**, **McClement S.**, **Kristjanson L.**, and **Harlos M.** (2002). Dignity in the terminally ill: a developing empirical model. *Social science & medicine*, **54**(3): 433–43.

Chochinov H.M., **Kristjanson L.J.**, **Breitbart W**, et al. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *The Lancet Oncology*, **12**(8): 753–62.

Chochinov H.M., **Tataryn D.**, **Clinch J.J.**, and **Dudgeon D.** (1999). Will to live in the terminally ill. *Lancet*, **354**(9181): 816–9.

Chochinov H.M., **Wilson K.G.**, **Enns M.**, and **Lander S.** (1994). Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgements. *American Journal of Psychiatry*, **151**(4): 537–40.

Chochinov H.M., **Wilson K.G.**, **Enns M.**, et al. (1995). Desire for death in the terminally ill. *The American journal of psychiatry*, **152**(8): 1185–91.

Cipriani A., **Furukawa T.A.**, **Salanti G.**, et al. (2009). Comparative efficacy and acceptability of 12 new-generation antidepressants: a multiple-treatments meta-analysis. *Lancet*, **373**(9665): 746–58.

Cort E., **Moorey S.**, **Hotopf M.**, **Kapari M.**, **Monroe B.**, and **Hansford P.** (2009). Palliative care nurses' experiences of training in cognitive behaviour therapy and taking part in a randomized controlled trial. *International journal of palliative nursing*, **15**(6): 290–8.

Division of Mental Health. (1990).*CIDI-Core. Composite International Diagnostic Interview, Core Version 1.0*. Geneva: WHO.

Endicott J. (1984). Measurement of depression in patients with cancer. *Cancer*, **53**(suppl): 2243–8.

Evans D.L., **Charney D.S.**, **Lewis L.**, et al. (2005). Mood disorders in the medically ill: scientific review and recommendations. *Biological psychiatry*, **58**(3): 175–89.

Fava G.A., **Gatti A.**, **Belaise C.**, **Guidi J.**, and **Offidani E.** (2015). Withdrawal symptoms after selective serotonin reuptake inhibitor discontinuation: a systematic review. *Psychotherapy and psychosomatics*, **84**(2): 72–81.

Gilbody S., **Sheldon T.**, and **House A.** (2008). Screening and case-finding instruments for depression: a meta-analysis. *CMAJ*, **178**(8): 997–1003.

Goldberg D. (1972). *The Detection of Psychiatric Illness by Questionnaire*. London: Oxford University Press.

Goldberg D. and **Huxley P.** (1992). *Common Mental Disorders: a Biopsychosocial Approach*. London: Routledge.

Goldberg D.P., **Bridges K.**, **Duncan-Jones P.**, and **Grayson D.** (1987). Dimensions of neuroses seen in primary care settings. *Psychological medicine*, **17**(2): 461–70.

Goodwin L., **Lee W.**, **Price A.**, et al. (2011). Predictors of non-remission of depression in a palliative care population. *Palliative medicine*, **26**(5): 683–95.

Hall S., **Chochinov H.**, **Harding R.**, **Murray S.**, **Richardson A.**, and **Higginson I.J.** (2009). A Phase II randomised controlled trial assessing the feasibility, acceptability and potential effectiveness of dignity therapy for older people in care homes: study protocol. *BMC geriatrics*, **9**: 9.

Hamilton M. (1960). A rating scale for depression. *Journal of Neurology Neurosurgery and Psychiatry*, **23**: 56–62.

Hatch S.L., **Frissa S.**, **Verdecchia M.**, et al. (2012). Identifying socio-demographic and socioeconomic determinants of health inequalities in a diverse London community: the South East London Community Health (SELCoH) study. *BMC public health*, **11**: 861.

Hayes R.D., **Lee W.**, **Rayner L.**, et al. (2011). Gender differences in prevalence of depression among patients receiving palliative care: the role of dependency. *Palliative medicine*, **26**(5): 696–702.

Hotopf M. and **McCracken L.** (2014). Physical health and mental illness. In: Mehta N, (ed.), *Annual Report of the Chief Medical Officer 2013*. London: Department of Health.

Hotopf M., **Chidgey J.**, **Addington-Hall J.**, and **Ly K.L.** (2002). Depression in advanced disease: a systematic review Part 1. Prevalence and case finding. *Palliative medicine*, **16**(2): 81–97.

Katon W.J., **Lin E.H.B.**, **Von Korff M.**, et al. (2010). Collaborative Care for Patients with Depression and Chronic Illnesses. *New England Journal of Medicine*, **363**(27): 2611–20.

Kessler R.C., **Amminger G.P.**, **Aguilar-Gaxiola S.**, **Alonso J.**, **Lee S.**, **Ustun T.B.** (2007). Age of onset of mental disorders: a review of recent literature. *Current opinion in psychiatry*, **20**(4): 359–64.

Kroenke K., **Spitzer R.L.**, and **Williams J.B.W.** (2001). The PHQ-9 The validity of a brief depression severity measure. *Journal of general internal medicine*,**16**: 606–13.

Lewis G., **Pelosi A.J.**, **Araya R.**, and **Dunn G.** (1992). Measuring psychiatric disorder in the community: a standardised assessment for lay interviewers. *Psychological medicine*, **22**(2): 465–86.

Lloyd-Williams M., **Friedman T.**, and **Rudd N.** (1999). A survey of antidepressant prescribing in the terminally ill. *Palliative medicin*, **13**(3): 243–8.

Matcham M.F., **Rayner L.**, **Hutton J.**, **Monk A.**, **Steel C.**, and **Hotopf M.** (2014). Self-help interventions for symptoms of depression, anxiety and psychological distress in patients with physical illnesses: a systematic review and meta-analysis. *Clinical psychology review*, **34**(2): 141–57.

Minton O., **Richardson A.**, **Sharpe M.**, **Hotopf M.**, and **Stone P.** (2008). A systematic review and meta-analysis of the pharmacological treatment of cancer-related fatigue. *JNatlCancer Inst*, **100**(16): 1155–66.

Mitchell A.J., **Chan M.**, **Bhatti H.**, et al. (2017). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *The Lancet Oncology*, **12**(2): 160–74.

Mitchell A.J., **Vahabzadeh A.**, and **Magruder K.** (2011). Screening for distress and depression in cancer settings: 10 lessons from 40 years of primary-care research. *Psycho-oncology*, **20**(6): 572–84.

Montgomery S.A. and **Asberg M.A.** (1979). A new depression scale designed to be sensitive to change. *British Journal of Psychiatry*, **134**(4): 382–9.

Moorey S., **Cort E.**, **Kapari M.**, et al. (2009). A cluster randomized controlled trial of cognitive behaviour therapy for common mental disorders in patients with advanced cancer. *Psychological medicine*, **39**(5): 713–23.

Owen G.S., **Richardson G.**, **David A.S.**, **Szmukler G.**, **Hayward P.**, and **Hotopf M.** (2008). Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study. *Bmj*, **30**(337): a448.

Pariante C.M., **Orru M.G.**, **Baita A.**, **Farci M.G.**, and **Carpiniello B.** *(*1999). Treatment with interferon-alpha in patients with chronic hepatitis and mood or anxiety disorders. *Lancet*, **354**(9173): 131–2.

Powers P.M.B., **Zum Vorde Sive Vording M.B.**, and **Emmelkamp P.M.** (2009). Acceptance and commitment therapy: a meta-analytic review. *Psychotherapy and psychosomatics*, **78**(2): 73–80.

Price A., **Lee W.**, **Goodwin L.**, et al. (2011). Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study. *BMJ supportive & palliative care*, **1**(2): 140–8.

Rayner L., **Higginson I.J.**, **Price A.**, and **Hotopf M.** (2010). *The Management of Depression in Palliative Care: European Clinical Guidelines*. Department of Palliative Care, Policy and Rehabilitation, London: King's College London and European Palliative Care Research Collaborative.

Rayner L.M.F., **Hutton J.**, **Stringer C.**, **Dobson J.**, **Steer S.**, and **Hotopf M.** (2014). Embedding integrated mental health assessment and management in general hospital settings: feasibility, acceptability and the prevalence of common mental disorder. *General hospital psychiatry*, **36**(3): 318–24.

Rayner L., **Lee W.**, **Price A.**, et al. (2005). The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: cross-sectional survey with four-week follow-up. *Palliative medicine*, **25**(3): 229–41.

Rayner L., **Price A.**, **Evans A.**, **Valsraj K.**, **Higginson I.J.**, and **Hotopf M.** Antidepressants for depression in physically ill people. *The Cochrane database of systematic reviews*, (3): CD007503.

Rayner L., **Price A.**, **Evans A.**, **Valsraj K.**, **Hotopf M.**, and **Higginson I.J.** Antidepressants for the treatment of depression in palliative care: systematic review and meta-analysis. *Palliative medicine*, **25**(1): 36–51.

Rayner L., **Price A.**, **Hotopf M.**, and **Higginson I.J.** (2009). The development of evidence-based European guidelines on the management of depression in palliative cancer care. *European journal of cancer*, **47**(5): 702–12.

Rayner L., **Price A.**, **Hotopf M.**, and **Higginson I.J.** (2011). Expert opinion on detecting and treating depression in palliative care: A Delphi study. *BMC palliative care*, **10**(1): 10.

Rush A.J., **Giles D.E.**, **Schlesser M.A.**, **Fulton C.L.**, **Weissenburger J.**, and **Burns C.** (1986). The Inventory for Depressive Symptomatology (IDS): preliminary findings. *Psychiatry research*, **18**(1): 65–87.

Rush A.J,, **Trivedi M.H.**, **Wisniewski S.R.**, et al. (2006). Acute and longer-term outcomes in depressed outpatients requiring one or several treatment steps: a STAR*D report. *The American journal of psychiatry*, **163**(11): 1905–17.

Rush AJ, **Warden D**, **Wisniewski SR**, et al. (2009). STAR*D: revising conventional wisdom. *CNS drugs*, **23**(8): 627–47.

Seedat S. and **Scott K.M.**, **Angermeyer M.C.**, et al. (2009). Cross-national associations between gender and mental disorders in the World Health Organization World Mental Health Surveys. *Archives of general psychiatry*, **66**(7): 785–95.

Spitzer R.L., **Williams J.B.**, **Gibbon M.**, and **First M.B.** (1992). The Structured Clinical Interview for DSM-III-R (SCID) 1: History, rationale, and description. *Archives of general psychiatry*, **49**(8): 624–9.

Strong V., **Waters R.**, **Hibberd C.**, et al. 2008). Management of depression for people with cancer (SMaRT oncology 1): a randomised trial. *Lancet*, **372**(9632): 40–8.

Sullivan P.F., **Neale M.C.**, **Kendler K.S.** (2000). Genetic epidemiology of major depression: review and meta-analysis. *American Journal of Psychiatry*, **157**(10): 1552–62.

Sullivan S.D.R., **Mongoue-Tchokote S.**, **Mori M.**, **Goy E.**, and **Ganzini L.** (2016). 18 Randomized, double-blind, placebo-controlled study of methylphenidate for the treatment of depression in SSRI-treated cancer patients receiving palliative care. *Psycho-oncology*, doi: 10.1002/pon.4220.

Uitterhoeve R.J., **Vernooy M.**, **Litjens M.**, et al. (2004). Psychosocial interventions for patients with advanced cancer—a systematic review of the literature. *British journal of cancer*, **91**(6): 1050–62.

Walker J., **Cassidy J.**, **Sharpe M.**, and **Trialists SMO-**. (2009). The third symptom management research trial in oncology (SMaRT oncology-3): a randomised trial to determine the efficacy of adding a complex intervention for major depressive disorder (depression care for people with lung cancer) to usual care, compared to usual care alone in patients with lung cancer. *Trials*, **10**(92).

Walker J, **Cassidy J**, **Sharpe M**, and **Trialists SMO-**. (2009). The second Symptom Management Research Trial in Oncology (SMaRT Oncology-2): a randomised trial to determine the effectiveness and cost-effectiveness of adding a complex intervention for major depressive disorder to usual care for cancer patients. *Trials* **10**: 18.

Wasteson E., **Brenne E.**, **Higginson I.J.**, et al. (2009). Depression assessment and classification in palliative cancer patients: a systematic literature review. *Palliative medicine*, **23**(8): 739–53.

Weich S. and **Lewis G.** (1998). Poverty, unemployment, and common mental disorders: population based cohort study. *British Medical Journal*, **317**(7151): 115–9.

Zhang Z.M.F., **Wen Y.S.**, **Liu W.Y.**, **Peng L.F.**, **Wu X.D.**, and **Liu Q.W.** (2015). Effectiveness of Mindfulness-based Therapy for Reducing Anxiety and Depression in Patients With Cancer: A Meta-analysis. *Medicine*, **94**(45): e0897–0.

Zigmond A.S. and **Snaith R.P.** (1983). The Hospital Anxiety and Depression Scale. *Acta psychiatrica Scandinavica*, **67**(6): 361–70.

Chapter 10

Psychotherapeutic interventions

Luigi Grassi, Maria Giulia Nanni,
and Rosangela Caruso

Introduction

A person-centered approach and treatment of patients in advanced phases of illness and at the end of life is a requirement that the multidisciplinary team should provide in palliative care settings. Whereas the pillars of this approach, as underlined by pioneers of palliative care, such as Saunders (2006) and Kübler-Ross (1969) (i.e.: compassion, empathy, responsiveness to needs, values, and expressed preferences; emotional support, relieving fear and anxiety; involvement of family and friends, physical comfort), should be part of any health-care professional armamentarium in the relationship with the patient and their families, psychotherapy is a more specific form of intervention and has become an extremely important ingredient of palliative care (Breitbart and Alici, 2014).

It is a fact that end of life presents a series of challenges for the patient and the family and that their needs within the interpersonal, psychological, and spiritual domains are frequently unmet (Sanson-Fisher et al., 2000). Overcoming fears; finding hope and meaning in life; exploring spiritual resources; concerns not to be a burden to others; feelings of not making a meaningful and/or lasting contribution in one's own life; not feeling worthwhile or valued, are amongst the most frequent psychosocial and existential issues activated at the end of life (Moadel et al., 1999).

A number of studies have also indicated that these problems are often intertwined with clinically significant psychosocial conditions, (Fava et al., 2001) that have been reported to affect medically ill patients in an advanced stage of illness, including terminally ill patients (Robinson et al., 2014). Among these demoralization (i.e.: hopelessness, loss of meaning, and existential distress, cognitive attitudes of pessimism, helplessness, sense of being trapped, personal failure, or lacking a worthwhile future; absence of drive or motivation to cope differently, a sense of social alienation or isolation and lack of support) is one of the most studied and registered conditions in palliative care settings. Its symptoms/dimensions can have a significant impact on the patient and can cause damage to quality of life (Kissane et al., 2001). Finally, more specific psychiatric disorders, including depressive spectrum and stress-related disorders (post-traumatic stress and maladjustment reactions), and anxiety disorders can be diagnosed in at least 25% of the patients in palliative care (Mitchell et al., 2011).

Therefore, careful assessment and integrated treatment of all these disorders and psycho-existential suffering (e.g. the spiritual pain caused by extinction of being and meaning of self through loss of relationships with others, loss of autonomy, or loss of a future) (Murata, 2003; Kissane, 2000) is mandatory, since they are associated with poorer quality of life, desire for a hastened death, hopelessness, and suicidal ideation (Chochinov, 2000; Chochinov et al., 2012; Grassi et al., 2016).

Family members also are part of comprehensive care and their needs should be taken into careful consideration within a family- (and not just patient) centered approach. The series of emotional events related to the impending death of a loved one and the expectations of emotional pain and the life changes that the loss will cause, are part of the trajectory of palliative care and are usually described as anticipatory grief (or similar terms, such as forewarning of loss, anticipatory loss, family emotional responses to terminal illness, 'pre-mourning' phase, and preparatory grief) (Cohelo and Barbosa, 2016; Nielsen et al., 2016). The psychological reactions of the family in this phase are an intensification of attachment, a strong tendency to stay close to their loved one, and overprotection accompanied by fears of abandonment, anxiety, hopelessness, and helplessness (Carolan et al., 2015). Several studies have also indicated that 25–35% of family members experience and present in fact a range of psychological complications, including clinical depression, anxiety, and phobic reaction, (Grassi, 2007), as well as complicated grief (Guldin et al., 2012; Nanni et al. 2014). Since several sources of caregiver stress and psychosocial problems have been shown to be related to negative family relationships, sense of abandonment, outside demands related to work, and levels of symptom distress in patients, careful attention to becoming a family burden and proper intervention are extremely important in palliative care (Northouse et al., 2012).

For all these reasons psychotherapeutic interventions have become part of standard care in palliative medicine, with a series of theoretical and clinical models available (Watson and Kissane, 2011) for which many reviews and metanalysis are available (Block, 2001; LeMay and Wilson, 2008; Applebaum and Breitbart, 2013).

In this chapter we will describe the most significant approaches which have been developed and demonstrated to be effective in improving psychological, social, and spiritual wellbeing in palliative care patients and their families.

Psychotherapeutic interventions

Patient-centered psychotherapy

There are several models of psychotherapeutic intervention in palliative care which are based on different theoretical backgrounds or are structured in different formats, such as individual or group intervention, and short- or medium-term intervention (according to the phase of illness they are delivered). However, they all have to deal with common existential themes, including death and dying; freedom, isolation, meaning and purpose, dignity and spirituality, (Thompson and Chochinov, 2008; Chochinov, 2002; 2006), as summarized by Yalom (1980) within his existential psychotherapy framework as the ultimate concerns of life (death, freedom, existential isolation, and meaninglessness) (see Box 10.1). Also psychotherapy has common aims and goals, namely providing a supportive presence; encouraging a life review to help the patient recognize purpose, value, and meaning; exploring guilt, remorse, forgiveness, and reconciliation; facilitating religious expression, and focusing on meditative practices (see Box 10.2). We will summarize these approaches.

Supportive-expressive group psychotherapy

Supportive-expressive group psychotherapy (SEGT) is amongst the early interventions that have developed for patients in advanced phases of illness (Spiegel and Yalom, 1978). A main component of the intervention is its focus

Box 10.1 Existential issues as focus of psychotherapy in palliative care

- Isolation (loneliness): the existential conflict is between our awareness of absolute isolation and our wish for contacts, protection and to be part of a larger whole.
- Meaning (meaninglessness): the existential conflict stems from the dilemma of being a meaning-seeking creature who is thrown into a universe that has no meaning (Why me? Why not me?).
- Freedom: the existential conflict is between freedom to choose how to live, to 'create' our own world and life (confrontation with groundlessness) and the need for a structure and a ground.
- Death and dying: the existential conflict is determined by the wish to live forever and the reality of death as an unavoidable fact.

Box 10.2 Main purposes of psychotherapy in palliative care

- Reducing anxiety, demoralization, fears
    - Not to be alone with terrifying phantasies of death and nothingness
    - Breaking threatening subjects into smaller, more manegeable pieces
    - Making fears more tolerable (it's impossible to delete them)
- Redefining life priorities
    - Define and refine life projects
    - Consider time (later may be too late)
- Improving coping skills
    - From passive to active coping styles
    - Increasing the sense of meaning (finding hope in opening up about the meaning of life and important events of life; improving communication
    - Getting one's own needs met
    - Openness in therapy as a model for openness outside therapy

on social and interpersonal relationships within the group as an experience to build bonds and mutually support each other, both as a way to reproduce this style of support out of the group and as an instrumental assistance and coping strategy against social isolation as a harbinger of death. Facilitation of expressing emotions is the second main component of SEGT (Spiegel and Classen, 2000) and it is based on the importance that the powerful feelings elicited by life-threatening disease as a meaningless tragedy should be expressed (rather than repressed) in order to relief and facilitate confrontation with one's own fragility and mortality. The SEGT model, as a semi-structured intervention, has the main goals of: building bonds; expressing emotions; 'detoxifying' death and dying; redefining life's priorities; fortifying families and friends, enhancing doctor–patient relationships and improving coping. The role of the therapist is to create a high level of group cohesion and a supportive environment where participants are encouraged to confront their problems, strengthen their relationships, and find enhanced meaning in their lives.

Preliminary data reported by Spiegel et al. (1981) showed that SEGT for metastatic cancer patients had a positive impact in improving the profile of mood states, improving coping, as well as helping with physical symptoms (e.g. pain). Subsequent research confirmed that SEGT can be extremely helpful for patients with depressive spectrum disorders as well as patients in non-advanced phases of illness (Classen et al., 2001; Butler et al., 2009). In a study by Kissane et al. (2007) on stage IV breast cancer patients SEGT reduced hopeless-helplessness and trauma symptoms; improved social functioning and, for a minority of patients with a DSM-IV depressive disorder, it ameliorated and prevented new episodes of depression. Similar results were reported in a study by Grassi et al. (2010) who showed that among breast cancer patients with a diagnosis of depressive disorders, SEGT determined a reduction of psychological stress symoptms, hopelessness, anxious preoccupation, and cancer-related worries and favoured an increase of communication and openness within the family.

Meaning-Centered Psychotherapy

Meaning-Centered Psychotherapy (MCT) is a more recent intervention that has been developed both for groups or individuals by Breitbart and Poppito (2014a; 2014b) and is based on Victor Frankl's logotherapy (Frankl, 1969). The main aims of MCT are to improve psychological and spiritual well-being by focusing on issues of meaning and purpose in life in the face of a limited prognosis, which are part also of existentially oriented psychotherapies (Breitbart, 2002; Breitbart et al., 2004). MCT is a seven-week programme that can be delivered both in group and individual formats and utilizes a mixture of didactics, discussion, and experiential exercises that focus on particular themes related to meaning and advanced cancer in order to increase the acceptance of the awareness of death and implement practitioners' search for meaning and promotion of personal agency and responsibility as patients face life-and-death issues. Each session addresses specific themes related to an exploration of the concepts and sources of meaning, the relationship and impact of cancer on one's sense of meaning and identity, the encounter with life's limitations; placing one's life in a historical and personal context (i.e. understanding one's 'legacy'). This is obtained by reflecting on some stimuli (e.g. 'List one or two experiences or moments when life has felt particularly meaningful to you'; 'Write down four answers to the question, "Who am I?' "). Other considerations could be raised on what emerges by answering some different questions (e.g.: 'When you look back on your life and upbringing, what are the most significant memories, relationships, traditions, etc., that have had the greatest impact on who you are today?') A shorter version of MCT has been devised to address the needs of palliative care patients in the final weeks or months of life (Rosenfled et al., 2017). A number of studies and randomized clinical trials have proved the efficacy of MCT in improving spiritual well-being and a sense of meaning and reducing symptom burden and symptom-related distress (Breitbart et al., 2010; Breitbart et al., 2012; Breitbart et al., 2015).

Dignity Therapy

Dignity Therapy (DT) (Chochinov, 2012) is a further approach based on the conceptualization of dignity developed by Chochinov (2002; 2006) and Chochinov et al. (2002; 2006a) consisting of the sum of three main dimensions:

1. Illness-related concerns (i.e. concerns related to symptoms of physical and psychological distress, functional capacity, cognitive acuity) that threaten or impinge on the individual sense of dignity.
2. The dignity-conserving perspectives and practices (i.e. continuity of the self; role preservation; maintenance of pride; hopefulness, autonomy/control, acceptance, resilience, living in the moment, seeking spiritual help, maintaining normality).
3. The social aspects of dignity (i.e. privacy boundaries, social support, not being a burden to others, aftermath concerns).

Poor dignity has been associated with both physical (e.g., lack of energy, pain, shortness of breath) and psychological symptoms (e.g., anxiety, sadness, irritability), with psychological distress correlating with all dignity dimensions (Oechsle et al., 2014).

This conceptualization represents the therapeutic map that guides clinicians to find interventional strategies or insights based on each of the themes and subthemes subsumed within the dignity model. DT is based on a dialogue concerning dignity-oriented questions that offer an opportunity to patients at the end of life to explore aspects of their existence that they feel are a source of meaning and pride. Issues of patients' personal history that they most want remembered and things that need to be said are a part of the DT dialogue. Transcription of the tape-recorded sessions (1–2 sessions in total), are edited and returned to the patient, as a tangible product (generativity document) to be discussed and approved by the patient and for the family. Data from randomized trials indicate that DT is a valuable intervention in palliative care, heightening the patients' sense of dignity, increasing their sense of purpose, lessening their sense of suffering, and helping them to prepare for death and the family members for grief (Chochinov et al., 2005; Chochinov et al., 2011; Houmann et al., 2014). The generativity document, as a specific process of legacy creation, has been shown to positively affect the sense of self, meaning, and acceptance near end of life in patients who underwent DT (Vuksanovic et al., 2017). Data are available about the feasibility of DT in palliative care patients with different physical illnesses (Aoun et al., 2015) with the potential to be an intervention exerting an impact at a spiritual level and/or as a life-completion task and having an effect on the illness experience within the context of not only the patient, but also the family and community (Fitchett et al., 2015; Martínez et al., 2017).

Managing Cancer and Living Meaningfully (CALM)

Managing Cancer and Living Meaningfully (CALM) is a more recent psychological intervention developed by Hales et al. (2010) based on Rodin and Zimmerman (2008) psychoanalytic theory on the psychological impact of advanced and terminal cancer. Besides the Yalom existential theoretical background which also characterizes CALM, other theories inform this approach, including relational theory, interpersonal psychoanalysis, the British school of object-relations theories, and self psychology. In this way, the dialectical nature of the therapeutic situation wherein patient and therapist co-create meaning and understanding of the patient's experience is beneficial (Mitchell, 1988). Also, attachment theory has a specific role in CALM, by stressing that early experiences with caregivers form enduring cognitive schemas or internal working models that are stable, and persistent patterns of cognition, emotion, and behaviour are important to relationships throughout life. For this reason, attachment security, (that is the tendency of individuals to believe they are worthy of care and that others are trustworthy to provide it), which may be threatened by the illness experience is part of the CALM intervention. It is a short (three to six sessions) individual treatment aimed at relieving psychosocial distress and promoting psychological growth. During CALM sessions four broad domains are covered:

1. Symptom management and communication with health-care providers.
2. Changes in the self and relations with close others.
3. Spiritual well-being or sense of meaning and purpose.
4. Issues related to advance care planning and to end of life (thinking of the future, hope, and mortality) (Nissim et al., 2012).

There are data accumulating on CALM as a feasible intervention to benefit patients with advanced cancer, (Lo et al., 2014; Lo et al., 2016) showing the role of conversation about death and dying as an important part of CALM therapy (Shaw et al., 2017).

Other approaches

Other approaches, often integrating different techniques of different models have been tested to help palliative care patients deal with existential issues. Miler et al. (2005) developed a group intervention entitled Life-Threatening Illness Supportive-Affective Group Experience (LTI-SAGE) for reducing patients' spiritual, emotional, and death-related distress. They showed that intervention patients had significantly fewer depression symptoms and death-related feelings of meaninglessness and significantly better spiritual well-being than did control patients.

Narrative approaches, which also have a role in palliative care, are based on the exploration of the meaning of the physical illness in the context of the patient's life trajectory, with the patients encouraged to tell their story and reflect on their perspectives on their sense of 'meaning' when discussing suffering and psychological, physical, social, and spiritual well being. This type of intervention has been shown to improve anxiety and depression among cancer patients admitted to hospice, in randomized controlled trials (Lloyd-Williams et al., 2013).

In a similar way, Ando et al. (2010; 2012) found that a one-week Short-Term Life Review, which is essentially a form of dignity therapy, for the enhancement of spiritual well-being, was effective in improving the spiritual well-being of terminally ill cancer patients, and alleviating psychosocial distress and promoting good death.

Cognitive-behavioural intervention (CBT) has also been applied as a form of intervention to both augment somatic palliative care therapy (e.g. pain control, fatigue) and deal with psychological symptoms affecting the medical condition (e.g. fear and anxiety, symptom preoccupation) (Turk and Fledman, 2009). Literature indicates that the benefits of CBT are often integrated with different techniques, including relaxation, imagery, mindfulness, meditation hypnosis, and distraction (Ball and Vernon, 2015; Beng et al., 2015; Chi et al., 2016; Jaffray et al., 2016). Other studies have incorporated cognitive-behavioural approaches to existentially oriented intervention showing the efficacy of this model in improving the existential and psychological quality of life (Gagnon et al., 2015).

Family-centered psychotherapy

There are several forms of psychosocial approaches for the family of cancer patients in advanced phases of illness (Northouse et al., 2012; Northouse et al., 2010). However, specific family-oriented psychotherapeutic intervention in palliative care are not frequently applied, (Zaider and Kissane, 2009), except for some forms such as Family Focused Grief Therapy (FFGT) and Grief Therpy.

Family Focused Grief Therapy

Family Focused Grief Therapy (FFGT) is a manualized specific form of family-centred preventive intervention that begins during palliative care and continues during bereavement (Kissane and Bloch, 2002). The aims of FFGT are to optimize family functioning and facilitate the sharing of grief, in order to minimize psychosocial morbidity from bereavement. Brief, focused, and time-limited, usually extending flexibly across six to 18 months (Masterson et al., 2013), the intervention aims to enhance the functioning of the family through the exploration of the family's cohesiveness, communication of thoughts and feelings, and resolution of conflict. As the story of illness and related grief is shared, its impact on family functioning is observed. Each session lasts 90 minutes, and the whole course of FFGT can be divided into three sequential phases:

1. Assessment (two weekly sessions), involving identification of issues or concerns relevant to the family and negotiation of a therapeutic plan to work on these concerns.
2. Intervention (typically four to six fortnightly to monthly sessions), focusing on agreed concerns.
3. Termination (one to two three-monthly sessions), incorporating consolidation and termination of therapy.

The frequency and total number of sessions are adapted to each family's context and needs. Key themes, namely family communication, cohesiveness, conflict resolution, and shared grief have been demonstrated in FFGT (Kissane et al., 1998; Chan et al., 2004). Data form randomized clinical trials are available and show the efficacy of FFGT, especially when delivered to high-risk families during palliative care and continued into bereavement, in reducing the severity of complicated grief and the risk of the development of prolonged grief disorder (Kissane et al., 2006; Kissane et al., 2016).

Grief therapy

Besides grief counselling, usually aimed at facilitating the tasks of mourning and adjustment to loss (Waller et al., 2016), grief therapy has the more specific objective to help family members solve the psychological problems secondary to loss and the symptoms of complicated grief (Worden, 2009). Although the definition of complicated grief (and its several forms, including traumatic grief, complicated bereavement, prolonged grief disorder, pathologic grief, abnormal bereavement—and its phenomenological presentations) is still debated (Shear et al., 2011; Maercker and Lalor, 2012), data indicate that it causes significant social and occupational impairment and is associated with suicidality, substance abuse, poorer health-related quality, and higher morbidity and mortality (Shear et al., 2013). Thus, prevention and proper treatment are essential components of palliative care (Wittouck et al., 2001; Simon, 2013; Doering and Eisma, 2016).

Interpersonal Therapy (IPT) has been adapted for complicated grief (CGT) (Wetherell, 2012), by using both attachment theory based on the fact that human beings are biologically programmed to seek, form, and maintain close relationships and that the disruption of proximity, support, and reassurance determined by separation cause grief rections and possible complications (Shear and Shair, 2005; Shear, 2010). IPT is a 16-session treatment which has indicated its efficacy in complicated grief in several situations including adults (Shear et al., 2005), elderly bereaved people (Shear et al., 2014; 2016), and patients receiving antidepressants for complicated grief (Shear et al., 2016).

Specific cognitive-behavioral interventions have been also proposed for prolonged grief (PG-CBT). The therapy consists of a series of sessions aimed at stabilizing and motivating the patient to explore the grief situation. Relaxation thechniques, confrontation and reinterpretation of the cognitions and perceptions related to patients themselves, their loved ones, and the circumstances of death are part of the intervention. This is followed by focussing on future prospects while maintaining a healthy bond to the deceased. PG-CBT has shown to have positive effects in both the short- and long-term (Rosner et al., 2014; 2015). When delivered in a group format, CBT integrates several techniques such as

1. education regarding grief (e.g. management of avoidance, and excessively negative appraisals),
2. teaching specific cognitive restructuring strategies to reframe common maladaptive grief-related appraisals (e.g. hopelessness and guilt),
3. rumination management (e.g. identification of the merits and costs of repetitive thinking and learning distraction techniques);
4. writing a letter on unresolved issues, facilitation of positive memories, and identification of future goals, and including exposure.

These have been found to promote emotional processing of memories of the death and reductions in PGD severity both after treatment and two years later (Bryant et al., 2014; 2017).

Cross-cultural considerations

Cross-cultural issues also deserve to be examined given the implications of cultural diversity in clinical settings, particularly for racial and ethnic minorities for whom health disparities are related to socioeconomic disadvantage or the difficulty of integrating their cultural model into the dominant model (Kagawa-Singer et al., 2010; Surbone, 2012). Since palliative care settings are gradually becoming multiethnic and multicultural, the need for clear policies of screening and assessment which take into account the implications determined by cultural diversity, is nowadays mandatory (Grassi and Riba, 2012). Language, ethnicity, race, and religion have important roles in affecting the patients' and families' perception of illness at the end of life, in influencing communication and doctor–patient relationships and patients' and families' coping mechanisms, including the awareness and knowledge of treatment options, and their acceptance of psychological intervention. All these phenomena should be taken into consideration when training physicians and multidisciplinary oncology and palliative care teams (Grassi et al., 2013). Although it is said that research on the impact of cultural issues in medicine is not well-developed, data has accumulated regarding the importance of cultural variables in palliative care and the specific role of cultural competence in providing care (Seelman et al., 2009). Cultural (and linguistic) competence as a set of congruent behaviours, attitudes, and policies enabling effective work in cross-cultural situations, has thus a specific role in palliative care when dealing with patients belonging to other cultural backgrounds with their own rituals, but at the same time needing psychological intervention and psychotherapy (Teal and Street, 2009). In culturally sensitive patient/family-centered care, the clinical encounter is grounded in communication whereby cultural cues (i.e. values and beliefs) of the patient and the clinician are incorporated within the therapeutic relationship and mutually shared (Kumagai et al., 2009). Data is progressively accumulating about the application and efficacy of managing patients' problems, including psychosocial disorders, by using psychotherapy intervention among patients belonging to different cultural contexts, including Asia and southern Europe. Several reports and randomized clinical trials have been conducted in this respect by using Supportive-Expressive Group Psychotherapy (Grassi et al., 2010), Meaning-Centered Psychotherapy (Leng et al., 2017), Dignity Therapy (Akechi et al., 2012; Houmann et al., 2010; Julião et al., 2017; Rudilla et al., 2010; Grassi et al., 2017), CALM (Scheffold et al., 2015; Caruso et al., 2017), Family-Focused Grief Therapy (Del Gaudio et al., 2013; Mondia et al., 2012).

Conclusion

As Rodin reports (2009), end of life is accompanied by an increased help-seeking and reflective functioning, with a heightened need for authenticity and the poignancy of the therapeutic encounter; and an increased motivation and sense of urgency to address existing interpersonal and existential issues. Person-centered care for patients at the end of life is thus critically important and should be provided with evidence-based techniques. There are important needs of patients, families, friends, and care providers that need to be integrated into a summative process for patients, who are at the centre of this care (Grassi et al., 2016). What has emerged over the last years in palliative care psycho-social intervention has been extremely helpful in giving the field the sense of a person-centered approach according to the philosophy of personalized medicine. Existential issues and existentially-oriented psychotherapy have particularly contributed to this approach by showing the importance for patients to explore their past, present, and future in terms of meaningful opportunities and experiences during their lifetime (Russo-Netzer et al., 2016).

Psychotherapy is thus a significant component of care and has been demonstrated to be, in its several and different approaches, essential in favoring patients' quality of life; their physical well-being and functioning; their psychosocial well-being and functioning; their spiritual well-being; and their family's well-being and functioning (Box 10.3). As underlined in metanalysis of studies, however, at least for certain disorders, such as depression, more specific and higher-quality studies are necessary to better implement the psychotherapeutic strategies in palliative medicine (Okuyama et al., 2017). Furthermore, it

Box 10.3 Common areas and domains covered by psychotherapy in palliative care

Symptom management and communication with health-care providers
- analysis of the patient's experience of symptoms, general functioning, and the relationships with health-care team members
- support of the patient's involvement in their medical care

Changes in self and relations with close others
- exploration of the patient's experience in relationships with close friends and family
- facilitation of the expression of emotions
- exploration of anxieties and conflicts about dependency and caregiving and barriers to accepting support

Spirituality or sense of meaning and purpose
- exploration the patient's spiritual beliefs and/or sense of meaning and purpose in life
- evaluation of priorities and goals

Sustaining hope, facing the future and mortality
- anticipation and preparation for the future (including needs of children and family members)
- exploration of the personal meaning of one's own death and dying
- encouragement of double awareness or the balance of living while facing mortality
- support of advance care planning

Adapted from: Hales S., Lo C., and Rodin G., *Managing Cancer and Living Meaningfully (CALM) Treatment Manual: An Individual Psychotherapy for Patients with Advanced Cancer*. Department of Supportive Care, Princess Margaret Cancer Centre, University Health Network, Toronto, Canada, © 2015. Copyright#: 1124205.Canadian Intellectual Property Office. Date of issue: 2015-09-04.

is important that proper assessment can be planned early in palliative care in order to maximize the effects of treatment both for the patients and the families (Sealey et al., 2015). In fact, early psychotherapy avoids the problems that the patient can be too debilitated, unable to communicate, or cognitively impaired because of the disease progression. Also, family members would benefit from early intervention both in terms of the desirable resolution of family conflicts and preparation towards the loss of their loved ones, and of being accompanied through the process of grief after loss.

According to Breitbart (2017), there has been a remarkable evolution in the nature and scope of psychological intervention and counselling in palliative care. Principles of support and non-abandonment have been significantly implemented by more specific frameworks that have made psychotherapy more ambitious, with more evident aims to help patients come to an acceptance of their life lived, thus the acceptance of death, through the practice of compassion. By providing hospitality (e.g. creating the setting for community and communication), presence (e.g. give the patient full presence), and listening (e.g. empathy and understanding) psychosocial health professionals may help their patients and families to pursue a sense of coherence, meaning, and completion of the trajectory of life and its challenges both for the person who will die and those who will continue their journey.

References

Akechi T., **Akazawa T.**, **Komori Y.**, **Morita T.**, **Otani H.**, **Shinjo T.**, **Okuyama T.**, and **Kobayashi M.** (2012). Dignity therapy: Preliminary cross-cultural findings regarding implementation among Japanese advanced cancer patients. *Palliat Med*, **26**(5): 768–9.

Ando M., **Morita T.**, **Akechi T.**, and **Okamoto T.** (2010). Japanese Task Force for Spiritual Care. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *J Pain Symptom Manage*, **39**(6): 993–1002.

Ando M., **Morita T.**, **Akechi T.**, and **Takashi K.** (2012). Factors in narratives to questions in the Short-Term Life Review interviews of terminally ill cancer patients and utility of the questions. *Palliat Support Care*, **10**(2): 83–90.

Aoun S.M., **Chochinov H.M.**, **Kristjanson L.J.** (2015). Dignity therapy for people with motor neuron disease and their family caregivers: a feasibility study. *J Palliat Med*, **18**(1): 31–7.

Applebaum A.J. and **Breitbart W.** (2013). Care for the cancer caregiver: a systematic review. *Palliat Support Care*, **11**(3): 231–52.

Ball M.S. and **Vernon B.** (2015). A review on how meditation could be used to comfort the terminally ill. *Palliat Support Care*, **13**(5): 1469–72.

Beng T.S., **Chin L.E.**, **Guan N.C.**, **Yee A.**, **Wu C.**, **Jane L.E.**, and **Meng C.B.** (2015). Mindfulness-based supportive therapy (MBST): proposing a palliative psychotherapy from a conceptual perspective to address suffering in palliative care. *Am J Hosp Palliat Care*, **32**(2): 144–60.

Block S.D. (2001). Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *JAMA*, **285**: 2898–905.

Breitbart W., **Gibson C.**, **Poppito S.R.**, and **Berg A.** (2004). Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry*, **49**: 366–72.

Breitbart W., **Poppito S.**, **Rosenfeld B.**, **Vickers A.J.**, **Li Y.**, **Abbey J.**, **Olden M.**, **Pessin H.**, **Lichtenthal W.**, **Sjoberg D.**, and **Cassileth B.R.** (2012). Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol*, **30**(12): 1304–9.

Breitbart W., **Rosenfeld B.**, **Gibson C.**, **Pessin H.**, **Poppito S.**, **Nelson C.**, **Tomarken A.**, **Timm A.K.**, **Berg A.**, **Jacobson C.**, **Sorger B.**, **Abbey J.**, and **Olden M.** (2010). Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. Psychooncology, **19**(1): 21–8.

Breitbart W., **Rosenfeld B.**, **Pessin H.**, **Applebaum A.**, **Kulikowski J.**, and **Lichtenthal W.G.** (2015). Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol*, **33**(7): 749–54.

Breitbart W. (2017). *Meaning-Centered Psychotherapy in the Cancer Setting: Finding Meaning and hope in face of suffering*. New York: Oxford University Press.

Breitbart W. (2002). Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer*, **10**: 272–80

Breitbart W.S. and **Alici Y.** (2014). *Psychosocial palliative care*. New York: Oxford University Press .

Breitbart W.S. and **Poppito S.R.** (2014a). *Individual Meaning-Centered Psychotherapy for Patients with Advanced Cancer: A Treatment Manual*. New York, NY, USA: Oxford University Press.

Breitbart W.S. and **Poppito S.R.** (2014b) *Meaning-Centered Group Psychotherapy for Patients with Advanced Cancer: A Treatment Manual*. New York, NY, USA: Oxford University Press.

Bryant R.A., **Kenny L.**, **Joscelyne A.**, **Rawson N.**, **Maccallum F.**, **Cahill C.**, **Hopwood S.**, and **Nickerson A.** (2017). Treating Prolonged Grief Disorder: A 2-Year Follow-Up of a Randomized Controlled Trial. *J Clin Psychiatry*, Apr 25. doi: 10.4088/JCP.16m10729. [Epub ahead of print.]

Bryant R.A., **Kenny L.**, **Joscelyne A.**, **Rawson N.**, **Maccallum F.**, **Cahill C.**, **Hopwood S.**, **Aderka I.**, and **Nickerson A.** (2014). Treating prolonged grief disorder: a randomized clinical trial. *JAMA Psychiatry*, **71**(12): 1332–9.

Butler L.D, **Koopman C.**, **Neri E.**, **Giese-Davis J.**, **Palesh O.**, **Thorne-Yocam K.A.**, **Dimiceli S.**, **Chen X.H.**, **Fobair P.**, **Kraemer H.C.**, and **Spiegel D.** (2009). Effects of supportive-expressive group therapy on pain in women with metastatic breast cancer. *Health Psychol*, **28**(5): 579–87.

Carolan C.M., **Smith A.**, and **Forbat L.** (2015). Conceptualising psychological distress in families in palliative care: Findings from a systematic review. *Palliat Med*, **29**(7): 605–32.

Caruso R., **Nanni MG.**, **Rodin G.**, **Lo C.**, **Sabato S.**, and **Grassi L.** (2017). Efficacy of a brief manualized intervention Managing Cancer and Living Meaningfully (CALM) adapted to Italian cancer care setting. Study protocol for a randomized controlled trial (submitted).

Chan E.K., **O'Neill I.**, **McKenzie M.**, **Love A.**, and **Kissane D.W.** (2004). What works for therapists conducting family meetings: treatment integrity in family-focused grief therapy during palliative care and bereavement. *J Pain Symptom Manage*, **27**(6): 502–12.

Chi N.C., **Demiris G.**, **Lewis F.M.**, **Walker A.J.**, and **Langer S.L.** (2016). Behavioral and Educational Interventions to Support Family Caregivers in End-of-Life Care: A Systematic Review. *Am J Hosp Palliat Care*, **33**(9): 894–908.

Chochinov H.M. (2012). *Dignity Therapy Final Words for Final Day*. New York: Oxford Univerosty Press.

Chochinov H.M. (2006). Dying, dignity, and new horizons in Palliative End-of-Life Care. *CA Cancer J Clin*, **56**: 84–103.

Chochinov H.M. and **Cann B.J.** (2005). Interventions to enhance the spiritual aspects of dying. *J Palliat Med*, **8** Suppl 1: S103–15.

Chochinov H.M., **Hack T.**, **Hassard T.**, **Kristjanson L.J.**, **McClement S.**, and **Harlos M.** (2005). Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol*, **23**(24): 5520–5.

Chochinov HM, **Hack T**, **McClement S**, **Kristjanson L**, **Harlos M.** (2002). Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*, **54**(3): 433–43.

Chochinov H.M., **Kristjanson L.J.**, **Hack T.F.**, **Hassard T.**, **McClement**., and **Harlos M.** (2006a). Dignity in the terminally ill: revisited. *J Palliat Med*, **9**(3): 666–72.

Chochinov H,.M., **Kristjanson L.J.**, **Breitbart W.**, **McClement S.**, **Hack T.F.**, **Hassard T.**, and **Harlos M.** (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*, **12**(8): 753–62.

Chochinov H.M. (2002). Dignity-conserving care--a new model for palliative care: helping the patient feel valued. *JAMA*, **287**(17): 2253–60.

Chochinov H.M. (2000). Psychiatry and terminal illness. *Can J Psychiatry*, **45**(2): 143–50.

Classen C., **Butler L.D.**, **Koopman C.**, **Miller E.**, **DiMiceli S.**, **Giese-Davis J.**, **Fobair P.**, **Carlson R.W.**, **Kraemer H.C.**, and **Spiegel D.** (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer: a randomized clinical intervention trial. *Arch Gen Psychiatry*, **58**(5): 494–501

Coelho A. and **Barbosa A.** (2017). Family Anticipatory Grief. *Am J Hosp Palliat Care*, **34**: 774–785.

Del Gaudio F., **Hichenberg S.**, **Eisenberg M.**, **Kerr E.**, **Zaider T.I.**, and **Kissane D.W.** (2013). Latino values in the context of palliative care: illustrative cases from the Family Focused Grief Therapy trial. *Am J Hosp Palliat Care*, **30**(3): 271–8.

Doering B.K. and **Eisma M.C.** (2015). Treatment for complicated grief: state of the science and ways forward. *Curr Opin Psychiatry*, **29**(5): 286–9.

Fava G.A., **Mangelli L.**, and **Ruini C.** (2001). Assessment of psychological distress in the setting of medical disease. *Psychother Psychosom*, **70**(4): 171–5.

Fitchett G., **Emanuel L.**, **Handzo G.**, **Boyken L.**, and **Wilkie D.J.** (2015). Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research. *BMC Palliat Care*, **14**: 8. doi: 10.1186/s12904-015-0007-1. eCollection 2015.

Frankl V. (1969). *The Will to Meaning: Foundations and Applications of Logotherapy*. World Publishing Co, USA.

Gagnon P., **Fillion L.**, **Robitaille M.A.**, **Girard M.**, **Tardif F.**, **Cochrane J.P.**, **Le Moignan Moreau J.**, and **Breitbart W.** (2015). A cognitive-existential intervention to improve existential and global quality of life in cancer patients: A pilot study. *Palliat Support Care*, **13**(4): 981–90.

Grassi L., **Costantini A.**, **Caruso R.**, **Brunetti S.**, **Marchetti P.**, **Sabato S.**, and **Nanni M.G.** (2017). Dignity and Psychosocial-Related Variables in Advanced and Nonadvanced Cancer Patients by Using the Patient Dignity Inventory-Italian Version. *J Pain Symptom Manage*, **53**(2): 279–87.

Grassi L., **Sabato S.**, **Rossi E.**, **Marmai L.**, and **Biancosino B.** (2010). Effects of supportive-expressive group therapy in breast cancer patients with affective disorders: a pilot study. *Psychother Psychosom*, **79**(1): 39–47.

Grassi L. (2007). Bereavement in families with relatives dying of cancer. *Curr Opin Support Palliat Care*, **1**(1): 43–9.

Grassi L., **Caruso R.**, **Nanni M.G.** (2013). Psycho-oncology and optimal standards of cancer care: developments, multidisciplinary team approach and international guidelines. In Wise T.N., Biondi M., Costantini A. (eds), *Psycho-Oncology*. American Psychiatric Publishing Press, Arlington, VA, , pp. 315–39.

Grassi L., **Riba M.**, **Bras M.**, and **Glare P.** (2016). Person-centered palliative care. In Mezzich J., Botbol M., Christodoulou G., Cloninger C.R., Salloum I.M., (eds) *Person-Centered Psychiatry*, New York: Springe, pp. 487–500.

Grassi L. and **Riba M.** (2012). Introducing multicultural perspectives in psycho-oncology. In Grassi L., Riba M. (eds.), *Clinical Psycho-Oncology: An International Perspective*. Chichester: Wiley, pp. 1–9.

Guldin M.B., **Vedsted P.**, **Zachariae R.**, **Olesen F.**, and **Jensen A.B.** (2012). Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Support Care Cancer*, **20**(8): 1679–85.

Hales S., **Lo C.**, and **Rodin G.** (2010). *Managing Cancer and Living MeaningFully (CaLM). Treatment Manual: an Individual psychotherapy for patients with advanced cancer*. Toronto, Psychosocial Oncology and Palliative Care, Princess Margaret Hospital, Univerisity Health network.

Houmann L.J., **Chochinov H.M.**, **Kristjanson L.J.**, **Petersen M.A.**, and **Groenvold M.A.** (2014). prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care. *Palliat Med*, **28**(5): 448–58.

Houmann L.J., **Rydahl-Hansen S.**, **Chochinov H.M.**, **Kristjanson L.J.**, and **Groenvold M.** (2010). Testing the feasibility of the Dignity Therapy interview: adaptation for the Danish culture. *BMC Palliat Care*, **9**: 21. doi: 10.1186/1472-684X-9-2.

Jaffray L., **Bridgman H.**, **Stephens M.**, and **Skinner T.** (2016). Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review. *Palliat Med*, **30**(2): 117–31.

Julião M., **Oliveira F.**, **Nunes B.**, **Carneiro A.V.**, and **Barbosa A.** (2017). Effect of dignity therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial. *Palliat Support Care*, **7**: 1–10.

Kagawa-Singer M., **Valdez A.**, **Yu M.C.**, and **Surbone A.** (2010). Cancer, culture and health disparities: time to chart a new course? *CA: Cancer Clin J*, **60**: 12–39.

Kissane D.W. and **Bloch S.**, **McKenzie M.**, **McDowall C.**, **Nitzan R.** (1998). Family grief therapy: a preliminary account of a new model to promote healthy family functioning during palliative care and bereavement. *Psycho-Oncology*, **7**: 14–25.

Kissane D.W. and **Bloch S.** (2002). *Family Focused Grief Therapy: A Model of Family- Centred Care during Palliative Care and Bereavement*. Buckingham and Philadelphia: Open University Press.

Kissane D.W., **Clarke D.M.**, and **Street A.F.** (2001). Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. *J Palliat Care*, **17**(1): 12–21.

Kissane D.W., **Grabsch B.**, **Clarke D.M.**, **Smith G.C.**, **Love A.W.**, **Bloch S.**, **Snyder R.D.**, and **Li Y.** (2007). Supportive- expressive group therapy for women with metastatic breast cancer: survival and psychosocial outcome from a randomized controlled trial. *Psychooncology*, **16**: 277–86.

Kissane D.W., **McKenzie M.**, **Bloch S.**, **Moskowitz C.**, **McKenzie D.P.**, and **O'Neill I.** (2006). Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement. *Am J Psychiatry*, **163**(7): 1208–18.

Kissane D.W., **Zaider T.I.**, **Li Y.**, **Hichenberg S.**, **Schuler T.**, **Lederberg M.**, **Lavelle L.**, **Loeb R.**, and **Del Gaudio F.** (2016). Randomized Controlled Trial of Family Therapy in Advanced Cancer Continued Into Bereavement. *J Clin Oncol*, **34**(16): 1921–7.

Kissane D.W. (2000). Psychospiritual and existential distress. The challenge for palliative care. *Aust Fam Physician*, **29**(11): 1022–5.

Kübler-Ross, E. (1969). *On death and dying*. New York Simon and Schuster.

Kumagai A.K. and **Lypson M.L.** (2009). Beyond cultural competence: critical consciousness, social justice, and multicultural education. *Acad Med*, **84**: 782–7.

LeMay K. and **Wilson K.G.** (2008). Treatment of existential distress in life threatening illness: a review of manualized interventions. *Clin Psychol Rev*, **28**(3).

Leng J., **Lui F.**, **Chen A.**, **Huang X.**, **Breitbart W.**, and **Gany F.** (2017). Adapting Meaning-Centered Psychotherapy in Advanced Cancer for the Chinese Immigrant Population. *J Immigr Minor Health*, doi: 10.1007/s10903-017-0591-7. [Epub ahead of print.]

Lloyd-Williams M., **Cobb M.**, **O'Connor C.**, **Dunn L.**, and **Shiels C.** (2013). A pilot randomised controlled trial to reduce suffering and emotional distress in patients with advanced cancer. *J Affect Disord*, **15**(148): 14–15.

Lo C., **Hales S.**, **Chiu A.**, **Panday T.**, **Malfitano C.**, **Jung J.**, **Rydall A.**, **Li M.**, **Nissim R.**, **Zimmermann C.**, and **Rodin G.** (2016). Managing Cancer And Living Meaningfully (CALM): randomised feasibility trial in patients with advanced cancer. *BMJ Support Palliat Care*, pii: bmjspcare-2015-000866.

Lo C., **Hales S.**, **Jung J.**, **Chiu A.**, **Panday T.**, **Rydall A.**, **Nissim R.**, **Malfitano C.**, **Petricone-Westwood D.**, and **Zimmermann C.**, **Rodin G.** (2014). Managing Cancer And Living Meaningfully (CALM): phase 2 trial of a brief individual psychotherapy for patients with advanced cancer. *Palliat Med*, **28**(3): 234–42.

Maercker A. and **Lalor J.** (2012). Diagnostic and clinical considerations in prolonged grief disorder. *Dialogues Clin Neurosci*, **14**(2): 167–76.

Martínez M., **Arantzamendi M.**, **Belar A.**, **Carrasco J.M.**, **Carvajal A.**, **Rullán M.**, and **Centeno C.** (2017). 'Dignity therapy', a promising intervention in palliative care: A comprehensive systematic literature review. *Palliat Med*, **31**(6): 492–509.

Masterson M.P., **Schuler T.A.**, and **Kissane D.W.** Family focused grief therapy: a versatile intervention in palliative care and bereavement. Bereavement Care, 2013, **32**: 117–23.

Miller D.K., **Chibnall J.T.**, **Videen S.D.**, and **Duckro P.N.** (2005). Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *J Palliat Med*, **8**(2): 333–43.

Mitchell A.J., **Chan M.**, **Bhatti H.**, **Halton M.**, **Grassi L.**, **Johansen C.**, and **Meader N.** (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies *Lancet Oncol*, **12**(2): 160–7.

Mitchell, S.A. (1988). *Relational Concepts in Psychoanalysis*. Cambridge: Harvard university Press.

Moadel A., **Morgan C.**, **Fatone A.**, **Grennan J.**, **Carter J.**, **Laruffa G.**, **Skummy A.**, and **Dutcher J.** (1999). Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psychooncology*, **8**(5): 378–85.

Mondia S., **Hichenberg S.**, **Kerr E.**, **Eisenberg M.**, and **Kissane D.W. P.** (2012). The impact of Asian American value systems on palliative care: illustrative cases from the family-focused grief therapy trial. *Am J Hosp Palliat Care*, **29**(6): 443–8.

Murata H. (2003). Spiritual pain and its care in patients with terminal cancer: Construction of a conceptual framework by philosophical approach. *Pall Supp Care*, **1**: 15–21.

Nanni M.G., **Biancosino B.**, and **Grassi L.** (2014). Pre-loss symptoms related to risk of complicated grief in caregivers of terminally ill cancer patients. *J Affect Disord*, **160**: 87–9.

Nielsen M.K., **Neergaard M.A.**, **Jensen A.B.**, **Bro F.**, and **Guldin M.B.** (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clin Psychol Rev*, **44**: 75–93. doi: 10.1016/j.cpr.2016.01.002. Epub 2016 Jan 8.

Nissim R., **Freeman E.**, **Lo C.**, **Zimmermann C.**, **Gagliese L.**, **Rydall A.**, **Hales S.**, and **Rodin G.** (2012). Managing Cancer and Living Meaningfully (CALM): a qualitative study of a brief individual psychotherapy for individuals with advanced cancer. *Palliat Med*, **26**(5): 713–21.

Northouse LL, **Katapodi MC**, **Schafenacker AM**, and **Weiss D.** (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin Oncol Nurs*, **28**(4): 236–45.

Northouse L.L., **Katapodi M.C.**, **Song L.**, et al. (2010). Interventions with caregivers of cancer patients: Meta-analysis of randomized trials. *CA Cancer J Clin*, **60**: 317–39.

Northouse L.L., **Williams A.**, **Given B.**, and **McCorkle R.** (2012). Psychosocial Care for Family Caregivers of Patients With Cancer. *J Clin Oncol*, **30**:1227–34.

Oechsle K., **Wais M.C.**, **Vehling S.**, **Bokemeyer C.**, and **Mehnert A.** (2014). Relationship between symptom burden, distress, and sense of dignity in terminally ill cancer patients. *J Pain Symptom Manage*, **48**: 313e321.

Okuyama T., **Akechi T.**, **Mackenzie L.**, and **Furukawa T.A.** (2017). Psychotherapy for depression among advanced, incurable cancer patients: A systematic review and meta-analysis. *Cancer Treat Rev*, **6**: 16–27.

Robinson S., **Kissane D.W.**, **Brooker J.**, and **Burney S.** (2014). A Review of the Construct of Demoralization: History, Definitions, and Future Directions for Palliative Care. *Am J Hosp Palliat Care*, pii: 1049909114553461. [Epub ahead of print.]

Rodin G, Zimmermann C. (2008). Psychoanalytic reflections on mortality: a reconsideration. *J Am Acad Psychoanal Dyn Psychiatry*, **36**: 181–96.

Rodin G. (2009). Individual psychotherapy for the patient with advanced disease. In Chochinov H.M. and Breitbart W. (eds) *Psychiatry in palliative Medicine*. New York: Oxford University Press, 2nd edition, pp. 443–53.

Rosenfeld B., **Saracino R.**, **Tobias K.**, **Masterson M.**, **Pessin H.**, **Applebaum A.**, **Brescia R.**, and **Breitbart W.** (2017). Adapting Meaning-Centered Psychotherapy for the palliative care setting: Results of a pilot study. *Palliat Med*, **31**(2): 140–6.

Rosner R., **Bartl H.**, **Pfoh G.**, **Kotoučová M.**, and **Hagl M.** (2015). Efficacy of an integrative CBT for prolonged grief disorder: A long-term follow-up. *J Affect Disord*, **183**: 106–12.

Rosner R., **Pfoh G.**, **Kotoučová M.**, and **Hagl M.** (2014). Efficacy of an outpatient treatment for prolonged grief disorder: a randomized controlled clinical trial. *J Affect Disord*, **167**: 56–63.

Rudilla D., **Galiana L.**, **Oliver A.**, and **Barreto P.** (2016). Comparing counseling and dignity therapies in home care patients: A pilot study. *Palliat Support Care*, **14**(4): 321–9.

Russo-Netzer P., Schulenberg S.E., and Batthyany A. (eds) (2016). *Clinical Perspectives on Meaning: Positive and Existential Psychotherapy*. Switzerland: Springer Cham.

Sanson-Fisher R., **Girgis A.**, **Boyes A.**, **Bonevski B.**, **Burton L.**, and **Cook P.** (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*, **88**(1): 226–37.

Saunders C. and **Clark D.** (2006). *Cicely Saunders: Selected writings 1958–2004*. Oxford: Oxford Univeristy Press.

Scheffold K., **Philipp R.**, **Engelmann D.**, **Schulz-Kindermann F.**, **Rosenberger C.**, **Oechsle K.**, **Härter M.**, **Wegscheider K.**, **Lordick F.**, **Lo C.**, **Hales S.**, **Rodin G.**, and **Mehnert A.** (2015). Efficacy of a brief manualized intervention Managing Cancer and Living Meaningfully (CALM) adapted to German cancer care settings: study protocol for a randomized controlled trial. *BMC Cancer*, **19**(15): 592.

Sealey M., **Breen L.J.**, **O'Connor M.**, and **Aoun S.M.** (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliat Med*, **29**(7): 577–89.

Seeleman C., **Suurmond J.**, and **Stronks K.** (2009). Cultural competence: a conceptual framework for teaching and learning. *Med Educ*, **43**: 229–37.

Shaw C., **Chrysikou V.**, **Davis S.**, **Gessler S.**, **Rodin G.**, and **Lanceley A.** (2017). Inviting end-of-life talk in initial CALM therapy sessions: A conversation analytic study. *Patient Educ Couns*, **100**(2): 259–66.

Shear K., **Frank E.**, **Houck P.R.**, and **Reynolds C.F.** (2005). Treatment of complicated grief: a randomized controlled trial. *JAMA*, **293**(21): 2601–8.

Shear K. and **Shair H.** (2005). Attachment, loss, and complicated grief. *Dev Psychobiol*, **47**(3): 253–67.

Shear M.K (2010). Complicated grief treatment: the theory, practice and outcomes. *Bereave Care*, **29**(3): 10–14.

Shear M.K., **Ghesquiere A.**, and **Glickman K.** (2013). Bereavement and complicated grief. *Curr Psychiatry Rep*, **15**(11): 406.

Shear M.K., **Reynolds C.F.** 3rd, **Simon N.M.**, **Zisook S.**, **Wang Y.**, **Mauro C.**, **Duan N.**, **Lebowitz B**, and **Skritskaya N.** (2016). Optimizing Treatment of Complicated Grief: A Randomized Clinical Trial. *JAMA Psychiatry*, **73**(7): 685–94.

Shear MK, **Simon N**, **Wall M**, **Zisook S**, **Neimeyer R**, **Duan N**, **Reynolds C**, et al. (2011). Complicated grief and related bereavement issues for DSM-5. *Depress Anxiety*, **28**(2): 103–17.

Shear M.K., **Wang Y.**, **Skritskaya N.**, **Duan N.**, **Mauro C.**, and **Ghesquiere A.** (2014). Treatment of complicated grief in elderly persons: a randomized clinical trial. *JAMA Psychiatry*, **71**(11): 1287–95.

Shear MK, **Reynolds CF** 3rd, **Simon NM**, **Zisook S**, **Wang Y**, **Mauro C**, **Duan N**, **Lebowitz B**, **Skritskaya N.** (2016). Optimizing Treatment of Complicated Grief: A Randomized Clinical Trial. *JAMA Psychiatry* **73**(7): 685–94.

Simon N.M. (2013). Treating complicated grief. *JAMA*, **310**(4): 416–23.

Spiegel D., **Bloom J.R.**, and **Yalom I.** (1981). Group support for patients with metastatic cancer. A randomized outcome study. *Arch Gen Psychiatry*, **38**(5): 527–33.

Spiegel D. and **Yalom I.D.** (1978). A support group for dying patients. *Int J Group Psychothe*, **28**(2): 233–45.

Spiegel D. and **Classen C.** (2000). *Group Therapy for Cancer Patients: A Research-Based Handbook of Psychosocial Care*. New York: Basic Books .

Surbone A. (2012). Bioethical challenges: understanding cultural differences and reducing health disparities. In: L. Grassi and M. Riba (eds), *Clinical Psycho-Oncology: An International Perspective*. Chichester: Wiley, pp. 199–210.

Teal C.R. and **Street R.L.** (2009). Critical elements of culturally competent communication in the medical encounter: a review and model. *Soc Sci Med*, **68**: 533–43.

Thompson G.N, Chochinov H.M. (2008). Dignity-based approaches in the care of terminally ill patients. *Curr Opin Support Palliat Care*, **2**(1): 49–53.

Turk D.C. and **Feldman C.S.** (2009). Cogntive behavioural approach to symptom management in palliative care: Augmenting somatic intervention. In Chochinov H.M. and Breitbart W. (eds) *Psychiatry in palliative Medicine*. New York: Oxford University Press, 2nd edition, pp. 470–89.

Vuksanovic D., **Green H.J.**, **Dyck M.**, and **Morrissey S.A.** (2017). Dignity Therapy and Life Review for Palliative Care Patients: A Randomized Controlled Trial. *J Pain Symptom Managel*, **53**(2): 162–170.e1.

Waller A., **Turon H.**, **Mansfield E.**, **Clark K.**, **Hobden B.**, and **Sanson-Fisher R.** (2016). Assisting the bereaved: A systematic review of the evidence for grief counselling. *Palliat Med*, **30**(2): 132–48.

Watson M. and **Kissane D.** (2011). *Handbook of Psychotherapy in Cancer Care*. Chichester: Wiley.

Wetherell J.L. (2012). Complicated grief therapy as a new treatment approach. *Dialogues Clin Neurosci*, **14**(2): 159–66.

Wilson K.G., **Chochinov H.M.**, **Skirko M.G.**, **Allard P.**, **Chary S.**, **Gagnon P.R.**, **Macmillan K.**, **De Luca M.**, **O'Shea F.**, **Kuhl D.**, **Fainsinger R.L.**, and **Clinch J.J.** (2007). Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage*, **133**: 118–29.

Wittouck C., **Van Autreve S.**, **De Jaegere E.**, et al. (2011). The prevention and treatment of complicated grief: a meta-analysis. *Clin Psychol Rev*, **31**: 69–78.

Worden J.W. (2009). *Grief Counseling and Grief Therapy, Fourth Edition A Handbook for the Mental Health Practitioner*. New York: Springer.

Yalom I. (1980). *Existential Psychotherapy*. New York: Basic books.

Zaider T. and **Kissane D.** (2009). The assessment and management of family distress during palliative care. *Curr Opin Support Palliat Care*, **3**(1): 67–71.

Chapter 11

Spiritual care

Mark Cobb

Introduction to spiritual care

Palliative care is constantly guided and challenged by the question of what it means to die well. In attempting to answer the question palliative care has come to view the needs of the whole person and not be limited by to the physical body and its ailments. This is the embodied life of a person whose intelligibility far exceeds the grasp of the biological sciences and requires a wider perspective that is sensitive to social, psychological, and spiritual aspects of being human. Medicine and other health-related disciplines are necessary to address the range of medical and health-related problems, but palliative care has learnt that we need other forms of understanding, explanation, and practice to attend more fully to the breadth and depth of human living and dying.

The spiritual aspects of being human relate to the ways in which people make sense of life and find meaning and purpose in it beyond its practical and mundane realities. Spirituality concerns the ways in which people are orientated to and experience the sacred in their lives expressed through normative beliefs, values, practices, artefacts, and places. Religions provide many of the organized and structured forms of spirituality that people associate with and practice, but people also identify with and invoke other forms of spirituality that take more secular forms. A terminal illness is a reminder of the finite nature of human existence and raises profound questions about how to live life when death is no longer remote, how to make sense of suffering, and ultimately what death signifies; all of which can be spaces in which to engage with the spiritual aspects of living and dying. This dimension of being human is a constituent component of the palliative care approach that seeks to promote spiritual wellbeing and address spiritual needs as part of its aim of achieving the best quality of life.

Spiritual issues in palliative care

The care of the dying established in the modern hospice movement and developed through the speciality of palliative care recognizes and aims to address the spiritual issues that can be manifest in the holistic needs of people living with a terminal condition (Rumbold, 2002; Puchalski and Ferrell, 2010). The salience of spirituality to palliative care is evident in the wide range of studies that explore this phenomenon and its role in the care of patients and those who are important to them (Edwards et al., 2010; Cobb et al., 2012a). Spirituality is a broad domain that finds expression in the particular worldviews, values and behaviours of persons in relation to their identity and sense of self, to their social situation, and the context of their illness and care. It is important to recognize therefore that spiritual expressions and experiences of people are both age related (Barry, 2014; Nelson-Becker, 2017) and culturally based (Ortiz et al., 2000). We will consider four aspects of spirituality that have a particular relevance to the context of palliative care: faith and beliefs, practice, suffering, and death.

Faith and beliefs

There are a variety of stances that people take towards illness and death that depend upon the way they make sense of their lives and the worldview they inhabit, or to put it another way, their beliefs. In dialogue with the social and cultural context, life history and the way reality is conceived, beliefs provide people with a dependable framework of meaning within which to understand and respond to experiences and events. When this meaning extends beyond a materialistic account and includes a transcendent reality then we are dealing with matters of faith (Cobb et al., 2012b). The language of faith refers to that which is fundamentally important or real to people, and transcendent reality is traditionally associated in the western context with terms such as God, the Holy, and the Eternal. The major religious traditions have their own descriptions of ultimate reality and these provide the basis for beliefs around which people can structure and direct their lives (Sorajjakool et al., 2017). However, a person who does not hold to any particular faith tradition may still adopt a spiritual orientation and inhabit a worldview that includes the transcendent. Spirituality is therefore not simply an intellectual proposition but consists of cognitive, emotional, and behavioural components that contribute to defining the person and to the way life is experienced (Argyle, 2000).

When people have to contemplate their own death, they have to contemplate the end of themselves and their non-existence in the world as they know it. A diagnosis of terminal illness signals that life is not inviolable and that the frail and fragile body through which we experience and live in the world will fail us. Mortality is a challenge to life and it is a challenge to the beliefs we hold about life. From the questions of ‘why me?’ to those about life beyond death, beliefs will shape the way people respond to their ailing health and eventually to their death. Beliefs can develop over a lifetime but significant foundations are laid in our childhood when we form our worldview. Children seem to be naturally sensitive to the spiritual dimension of life (Hay and Nye, 2006), and it has been reported for example that children aged six to 17 years of age, with advanced cancer, discuss their spiritual beliefs and concerns when it is meaningful to them (Kamper et al., 2010). When adults are trying to make sense of their situation facing a life-limiting condition latent or childhood beliefs that have not been developed further may be re-engaged. For this reason, it can be helpful to explore the spiritual autobiography or history of a person who may be struggling with an incongruity between early beliefs and current experience, and there are a range of tools available to support obtaining a spiritual history (Lucchetti et al., 2013).

Spiritual beliefs can be a source of meaning and provide a framework for making sense of and interpreting illness, dying, and death (Park, 2007). These may play a positive role in the ways in which some patients understand and adapt to their situation, for others their spiritual beliefs may be ineffective or even problematic. Stressful life-events challenge a person's worldview and they can put a strain on beliefs. Negative aspects of coping may result when there is a disintegration of beliefs evident in doubts, confusion, conflict, and distress. However, it should be noted that what may be interpreted as problematic to a clinician may to a patient be an opportunity to wrestle with beliefs and to reappraise them (Pargament et al., 1998). What this suggests is that learning what it means to be dying may involve spiritual growth and enrichment.

Spiritual beliefs can give meaning to experience, but more practically they can provide the basis upon which patients respond to care: choose treatment options; face their death, and determine their concerns following death. For example, a study of patients with end-stage renal disease that focussed on religious beliefs and practices, reported on how beliefs impacted on ethical and end of life care decisions (Elliott et al., 2012). When the patient is a child it is the parent's faith that may be a key factor in decision making. Situations do arise when beliefs that impinge directly on decisions affecting care and treatment, issues concerning quality of life, the nature and meaning of pain, the need to fulfil end of life tasks, and the nature of death, may not be in accord with accepted palliative care practice or the best interest of the patient as considered by the care team. Ideally these differences need carefully exploring and understanding with the aim of finding some accommodation or resolution within relevant ethical and legal framework (Ranton, 2013). Further, discrepancy in views, and particularly negative or uncertain attitudes, may signal to a patient not only a disinterest by health-care professionals but more negatively discrimination against such beliefs.

Practices

Beliefs and faith are seldom just philosophical concepts for they relate to being human and living meaningfully. Spirituality has practical, social, and material expressions and manifestations (Smart, 1996). The practical aspects of spirituality may involve activities such as rituals, prayer, meditation, the reading of sacred texts, sacramental rites, and pilgrimage. Spirituality also exists in social forms, most notably through religious communities and in the values, beliefs, and ethics that they express. Spirituality is therefore embodied in people's lives and actions as well as in concrete material forms. Chapels, temples, mosques, icons, rosaries, holy books, and art can all be considered material expressions of the spiritual. It is therefore important when approaching spiritual issues that we consider their form as well as their content and the implications this has for the resources we may need to support people.

Patients may have practices and rituals that they wish to maintain and observe because of their faith and beliefs. Illness and its consequences can interfere with the routines of life and the habits through which people sustain meaning and identity. Faith practices can be interrupted by health-care commitments and patients can be easily dislocated from their faith communities and the people who support them in their religious beliefs and customs. In particular people from minority faith traditions may find it difficult to access the support they need. The obligations of being a patient or the limitations of illness can also restrict the access of patients who currently have no connection to a faith community but want to return to a former community or explore new connections.

People who observe faith practices, rituals, festivals, and ceremonies do so for a range of reasons, but they may find them affirming and sustaining, particularly in the face of change and uncertainty, and they may be a resource in coping (Kaliampos and Roussi, 2017). Faith practices may help to maintain a sense of personal identity as well as connectedness to a faith community. For this reason beliefs and practices cannot be separated from the social dynamic of culture. Faith practices are not generic and a lack of knowledge by health-care professionals; stereotyped assumptions or the rigid categorization of practices can obscure the actual needs of individuals. However, people of nominal or no expressed religious commitment may still employ faith practices, such as prayer or meditation, and they may wish to participate in ritual of a religious or spiritual nature. Patients involved with a faith community may also want and benefit from the ongoing social support and care of that community.

Finally, in considering rituals and faith practices in the context of palliative care we have to take account of those that concern the dead. Rituals around death underscore the transition from life to death and place the event of an individual within a wider collective context. Many faith traditions have a span of ritual practice that begins when a person is approaching death and continues through to acts of remembrance and calendrical memorialization. Rituals following death serve a very functional purpose of last offices and the disposal of the corpse, but they also provide a framework of meaning, beliefs, and behaviour that can enable the bereaved to make sense of their loss (Davies, 2002). The faith traditions provide a rich source of ritual practice that people can draw upon, and often those who have no connection with a faith community may still seek ritual expression for their grief patterned upon faith practices.

Suffering

Terminal illness is an assault on the integrity of the person which may result in expressions of suffering. In addition to the bodily burdens resulting from symptoms of the disease a patient can suffer through the many dimensions of personhood (Carel, 2008; Ellis et al., 2015). This is because a terminal illness is a threat to a person's existence in the world and to the individual's life-course affecting such things as social roles and identity, relatedness to self and others, and a sense of well being and purpose. People can suffer therefore when the integrity of their personhood is damaged or where there is some form of irrecoverable loss. When people cannot make sense of what is happening to them, and particularly when they can find no place for it within their framework of meaning, then suffering may be related to the spiritual dimension (Best et al., 2014). It is important therefore that we can differentiate the spiritual factors that contribute to suffering and pain from the physical and psychological factors (Boston et al., 2011).

Suffering has the potential to diminish people but many also find the resilience to respond to suffering. This enforced challenge may result in striving for a new sense of wholeness in which the self that emerges incorporates or transcends the illness. Transcendence enables connectedness and removes the isolation of suffering by setting it within a larger horizon and through bringing people close to sources of ultimate meaning and hope (Fanos et al., 2008). The religious traditions of the world have their own interpretations of suffering and many have practices that enable people to transcend their immediate selves through prayer, meditation, and ritual. Whilst they acknowledge the reality of suffering, they point towards an ultimate goodness of the universe and the fulfilment of the human soul beyond suffering.

Existential doubt or spiritual disorientation may be unfathomable for some people to the extent that it can overwhelm them. In these circumstance people speak of injustice, hopelessness, darkness, and despair. Any faith a patient may have had can become shattered, they can feel abandoned and the idea of hell can seem a very present reality. Spiritual suffering can be related at this level to depression and a psychiatric assessment may help in determining whether the patient has a mood disorder that may benefit from treatment or if the patient is at risk of suicide. This degree of suffering can be difficult to endure for carers and there are no quick remedies to lighten the troubled spirit. Patients may literally give up, become withdrawn and become disconnected from people. The spiritual challenge for carers is to be able to contain this sense of dereliction and maintain a consistent presence that may bear witness to the possibility of relatedness and love.

Death

It can be difficult to grasp the fact of death from a personal perspective and people with a terminal illness may avoid anticipating the end of their lives. But for those who do contemplate it there can be significant spiritual issues that follow from reflecting on one's mortality. Some people hold that the result of death is simply nothing, or to be more accurate the permanent absence of the dead person from the world with its resultant losses for the bereaved. Many people with a religious commitment place death within the transcendent possibilities of the eternal and attempt to live their life in preparation for this reality. But what all these accounts have in common is the question of human destiny and how we can live in the face of death:

> We can shun death as an annihilation, or greet it as a transition. We can see it as a loss of something precious, or as the gain of another way of being. It is, in a sense, up to us. When we live in full awareness and acceptance of our mortality, we see the world as making a place for us. We open ourselves to death, and accept death as our completion. (Scruton, 2014: p. 197)

In a detailed study of the last months of nine terminally ill people, researchers reported that participants, regardless of their spiritual or religious orientation, searched for 'some tangible evidence of continuity with ongoing life after their own death' (Staton et al., 2001). Transcending physical death for these people was in part about finding a connection with something that endured and this seemed to be related to accepting the finality of their existence. This was expressed both through a notion of a tangible legacy, such as passing on valued objects or property, and an intangible spiritual connection with others, creation, and the transcendent. Death can therefore be seen as something of a spiritual boundary that marks both the cessation of life and a re-integration of the self with the natural world or the infinite.

Exploring what death means to people can often betray their deepest fears and hopes, but paradoxically the anticipation of decay and death can also hold the expectation of liberation. Symbolic images and stories are often the means for contemplating death and many can be found in the religious traditions. However, contemporary culture also supplies plentiful examples that express ideas of death and destiny through fiction, songs and films. These attempts to make sense of death and to find meaning in it can provide the starting point for a patient and this is where the creative arts can provide a language and means of personal exploration. In contrast, attempts to explore death by a patient can be overlooked or unintentionally blocked by health-care professionals who have not considered their own mortality or are fearful of it. The result can be that patients are obstructed from engaging with a meaningful part of their dying.

Providing spiritual care

The philosophy of palliative care is premised on an understanding of personhood that includes the spiritual dimension. But this philosophy requires putting into action if it is to mean anything in terms of the care that is offered, and this raises questions about how we understand and respond to the spiritual needs of patients. It is clear that we will need to take a broad approach that allows for a wide spectrum of spiritual orientations: from those that can be highly differentiated as religious to those that have no reference to faith traditions and are clearly humanistic. The benefit of this approach is that it is an attempt at being inclusive of the range of spiritualties that are found among patients. However, this should not be a fudge of the very real differences that exist between distinctive spiritual orientations, nor an attempt at reaching the lowest common denominator, but a means of accommodating and respecting the breadth of spirituality that people present.

The variety of spiritual beliefs, experiences, and practices that coexist in the population served will be depend on local demographic, cultural, and social factors. The most routinely measured are religious categories through questions that ask respondents whether or not they identify with a religion. For example, in 2011 the Census for England and Wales recorded that 59% of the population declared themselves to be Christian and 5% of the population Muslims (the second largest group) (Office for National Statistics, 2012). However, whilst people may hold beliefs associated with a particular religion they may not belong actively to a faith community, or they may only turn to it when faced with major life-events. Most health-care services make some attempt to record the ‘religion’ of a patient, but beyond this cursory question there may be no further steps taken to enquire about the patient’s spirituality particularly if a person responds that they have none. People respond with ‘none’ for a variety of reasons, they may be unwilling to be associated with a religion or religious category, but they may take part in some form of spiritual or religious practice, and they may not necessarily be atheists (Woodhead, 2016). A study of 13 to 17 year olds who had identified as religious 'nones' found some were clearly not religious, others were, and there was a middle ground of different and changing beliefs and practices (Madge and Hemming, 2016).

Results of research among patients suggest that spiritual issues may be more prevalent and meaningful than professionals sometimes accept (Murray et al., 2004). There are patients who will disclose their spirituality directly to health-care professionals or indirectly through their faith practices, rituals, and symbols. Other patients will not, and professionals may lack the interest, confidence, understanding or skills to explore this area or identify concerns. Patients may also withhold their concerns in order to appear that they are coping or if they perceive staff would not cope (Heaven and Maguire, 1997). The spiritual domain is one that can be subject to prejudice, presumption, and neglect and consequently patients may feel isolated and unsupported. What this suggests is that a consistent approach should be taken by palliative care services to ensure patients are given the opportunity to express their spiritual beliefs and practices, and for health-care professionals to understand their needs and provide support where required. We shall consider three aspects of the care process: patient assessment, modes of spiritual care, and resources.

Assessment

Palliative care services should provide routine opportunities for the assessment of the spiritual needs of patients along the patient pathway (National Cancer Action Team, 2011) as part of a holistic approach to patient care (National Palliative and End of Life Care Partnership, 2015). This requires that there are professionals within a service who can recognize, explore, understand, and are able to assess spiritual requirements and concerns. Spirituality touches on profound and sacred aspects of people's lives and it is important that any form of assessment is approached within a robust ethical framework of trust, understanding, and respect. In addition, if an assessment is to be reliable and sensitive it must be informed, responsive to the particular patient, and mindful of the potential for the subject area to be problematic. Proceeding with these cautions it is important that a palliative care service has a properly considered approach to assessing spirituality with a clear rationale. In addition to fulfilling the ethos of palliative care to pursue quality of life and address suffering, these may include:

- To ensure compliance with professional ethics codes
- To respect clients' basic human rights
- To honour client autonomy
- To identify and operationalize spiritual strengths

- To provide culturally relevant services
- To adhere to professional standards of good practice. (Hodge, 2015, p. 13)

There has been a wide range of tools developed to measure spirituality as part of research studies but far fewer tools or frameworks have been developed for clinical practice. A systematic review reported 55 tools validated in palliative care/advanced cancer/HIV populations which could be clustered into three types: (1) general multidimensional measures (typically of quality of life) that included spiritual items, (2) functional measures of spirituality/religiosity, and (3) substantive measures of spirituality/religiosity (Selman et al., 2011). There are also measures of spiritual wellbeing such as the stand-alone measure for palliative care patients with cancer being developed by the European Organisation for Research and Treatment of Cancer (Vivat et al., 2012). From these there maybe spiritual outcome measures that have clinical utility and there are assessment tools that have been developed in other populations that may be sensitive to the needs of palliative care patients but have yet to be tested, for example the Spiritual Distress Assessment Tool (Monod et al., 2010).

An assessment process for spirituality should begin by addressing the question of whether or not spirituality is important to a patient at the time of enquiry. Even this most basic stage in the process cannot proceed without good communication skills and an informed approach. Consideration should be given to the wording of questions and what may be known already about the patient. The patient's previous notes may contain relevant information that may provide a starting point: 'I see from your notes that you describe your religion as Jewish, can you tell me about this?'. If there is no information prior to meeting the patient then a broader and more open-ended type of question might be useful, such as: 'Do you have any spiritual or religious beliefs that it might be helpful for us to know about?'. These questions are the first stage of the assessment process and demonstrate to patients a positive awareness and sensitivity to spirituality, that spirituality is routinely assessed as part of a holistic approach, and that spiritual concerns will be taken seriously.

Providing that the patient has indicated that this is a meaningful aspect of their life that they are prepared to discuss the assessment can move onto eliciting something of the nature and significance of the patient's spirituality. Spirituality may have obvious form and content, or it may be more abstract, in which case the professional carrying out the assessment must ensure that the patient's narrative has been correctly understood, and where there is doubt, clarification sought. Patients are often prepared to explain their spiritual orientation and what it means to them, and where it is clearly communicated that a service is interested holistic needs, then patients are unlikely to be surprised or find this intrusive.

Once an outline of a patient's spiritual orientation has been gained the next stage in the assessment is to ascertain how important and helpful it is. A simple question is often sufficient: 'Is your faith/spirituality/religion helpful to you?' or 'How important would you say this is to you?' Patients may indicate that whilst they hold certain beliefs they are not something, at this time, which concerns them, and the assessment can be concluded with reassurance that if the patient wants to talk about their spirituality a member of the team will be happy to do so. If a patient indicates that their spiritual orientation is more significant then the assessment needs to continue to establish how the patient may be supported in this. Questions can be open: 'Are they ways in which we can support you in your faith/spirituality/religion?' and practical: 'Can we help provide you with anything or any facilities to support you in your faith/spirituality/religion?' Equally it is important for a palliative care service to know about aspects of a patient's spiritual orientation which may prohibit certain clinical practices or treatments, or which may be an important determinant in decision making and care planning: 'Are there things we need to know about your faith/spirituality/religion that would help us in caring for you?'

Finally, in an initial form of assessment, where the person enquiring is not a spiritual-care specialist, the patient should be given the opportunity to explore their spiritual needs further: 'Would you like to talk with someone about these matters?' or 'We have a chaplain who is part of the team, would you like see him/her?' It may be, depending upon previous answers, that the patient is already involved with a faith community, and the more appropriate question might be: 'Would you like us to arrange a member of your faith community to visit you?'

This simple overview assessment process is person-focussed, sensitive to the responses of the individual, and should proceed at their pace. A more objective and systematic approach may be gained by using some form of patient-completed questionnaire which may provide the basis for a more personal follow-up discussion. Whatever form is taken the assessment should provide basic information to enable a palliative care team to support a patient's spiritual orientation and ensure the care plan is consistent with a patient's beliefs and practices. It should be recognized that an assessment interview may be therapeutically beneficent for a patient, in part because of the cathartic opportunity that it may present someone. As with other forms of assessment it is not a single event, but needs to be an ongoing process. Professionals should be alert to the patient who has initially declined any discussion of spirituality but who may seek some form of spiritual care in the future.

Any form of assessment needs to be incorporated into care planning and it must be properly documented. Information gained about a patient's spiritual beliefs and practices should be evaluated alongside other aspects of the person within the multidisciplinary team and used to inform decisions about care and interventions. However, there is a limitation in this exercise in that the spiritual can never be captured adequately by words and that the fullest understanding of a person's spirituality is usually only gained by sharing in some of their spiritual journey where metaphors, symbols, and silence may be the preferred language of the spirit (Stanworth, 2004).

Modes of spiritual care

The form and type of any specific spiritual care is best determined by the patient in consultation with a member of the care team. In their routine tasks and interactions, the care team can promote the personhood of patients and with it show respect and support for the spiritual aspects of life. This was illustrated in a study of exploring the meaning of spiritual care from the perspectives of patients living with moderate to severe dementia, where small but intentional caring processes such as attentiveness and listening, helped to connect people with what was sacred to them: 'When done within this relational context, the little things can serve to nurture the soul of both the one caring and the cared for and can represent every day, yet sacred encounters' (Carr et al., 2011).

There will be patients who will have their spiritual care needs met by people from their own faith community or belief group external to the team. In this case, with the permission of the patient, supportive arrangements need to be put in place to allow access and provide necessary facilities. For patients who are not involved or do not wish to be referred to any external agency, or for those with access difficulties, then the team will need to facilitate spiritual care.

One of the principle modes of spiritual care is that provided by health-care chaplains who are trained and experienced practitioners working within a professional code of ethics, and typically in palliative care as members of the multidisciplinary team providing care to patients and those important to them as well as staff. Chaplaincy has been defined as: 'a practice of care involving the intentional recognition and articulation of the sacred by nominated individuals authorized for this task in secular situations' (Swift et al., 2015: p 2).

Patients whose spirituality is not orientated around any particular faith tradition or related to any particular faith community may still benefit from a pastoral care approach. It will be important for both parties to have mutual respect and to maintain their own integrity. Beyond this mode spiritual care may operate within a more general therapeutic framework. This humanistic mode will be located in a patient's worldview and their understanding. This is a supportive mode of spiritual care that aims at fostering positive coping and the enhancement of well-being. A humanistic approach to spiritual care will provide opportunities for patients to explore their spiritual beliefs and experience: to address concerns and to empower them in their own spiritual journey. This mode will draw upon counselling skills and the relational context, but it is not just problem focussed and will involve sustaining positive aspects of spirituality.

Resources

The patient

It is not with the intention of objectifying the patient that we should consider him or her as a primary resource. It is in valuing the person's spiritual history, beliefs, and experiences that the resources within someone may emerge and be encouraged to develop. A patient may have much to teach the care team about his or her spiritual beliefs and practices. But the patient may require assistance in making use of his or her own resources. For example, a patient may have a developed a daily habit of prayer that seems difficult to sustain. Without regular prayer, the person may feel spiritually isolated and alone. Prayer requires attention and focus and with appropriate support, encouragement, and some practical rearrangements, the patient may be enabled to draw upon this deeply personal and transcendent aspect of their spirituality.

The patient's own resources may include spiritual practices and beliefs, and they may involve significant people. It may be helpful for palliative care teams to have in mind some form of spiritual genogram for those patients whose spirituality has transpersonal and social aspects. The involvement of other people may correspond to significant personal relationships, such as those of a partner or family; it may relate to people who have died but are still active in the person's worldview; or it may involve members of a faith community. This will need to be carefully and sensitively explored with the patient and could form part of an ongoing assessment.

The palliative care team

It is probable that the only member of the team with a specified responsibility will be that of the chaplain, but many team members have an expectation of being able to provide some level of spiritual care. Doctors may be attentive to the spiritual dimension as part of their overall concern for the wellbeing of patients and compassionate medical care (Brown et al., 2006). Nurses in particular consider this to be an aspect of their role. In a study of nurses almost half of them responded that they provided spiritual help and support for the terminally ill primarily by taking them to spiritual events on the ward: facilitating participation in rituals, entering discussions about the meaning of life and God, and consulting with a chaplain. However, almost half of the nurses felt they had poor skills and knowledge in this area and over one-third of the nurses were not willing to provide spiritual support (Kuuppelomäki, 2001).

If a team is functioning well then it will appreciate the complementary skills and knowledge of its members (Speck, 2006). A chaplain who is properly integrated into a team should be an important resource to a team not only for direct patient care but also for advice and consultation. As part of the care planning a decision should be taken with the patient on who should be the lead person in facilitating and providing spiritual care. In this way spiritual care does not dissolve into some generic but marginal team function, nor does it exclude others members of the team from contributing.

Facilities

Palliative care services in the form of day care and outpatient and inpatient care are hostages to architecture and the facilities may include dedicated space for spiritual reflection and prayer, and for inpatient services there may be appropriate room for culturally-sensitive rituals particularly around death. Community based services will need to be more resourceful and make use of both patient dwellings and the facilities available in the neighbourhood provided by faith communities and sacred sites. To facilitate this palliative care services need to develop good working relationships with their local communities and the various networks and groups that may exist already. In addition to sites and building spiritual care can be supported by scared objects and items such as copies of sacred texts, prayer mats, and rosaries, however care needs to be taken not to cause offence in handling such items inappropriately. The patient, as an expert by experience, a chaplain or a faith leader, should be consulted before initiating the use of such items.

Faith communities

Local communities and networks are important resources and are likely be involved to some level in public services. In matters of spiritual care there is much that can be learnt from local faith communities and services need to develop effective mechanisms to allow this to happen. People are often very willing to be involved and it is important that hard to reach or minority groups are encouraged and supported in this. The involvement of faith communities may be strengthened by establishing some form of local Faith Forum or Network if something similar is not already in existence to facilitate consultation and participation in the provision of spiritual care. The Faith Forum may also be an effective route through which to establish associate chaplains from minority faith groups.

Education, training, and professional development

Spirituality is a complex domain and one that requires different levels of skill, knowledge, and practice. If spirituality is an important dimension of palliative care then training programmes should be provided to resource staff with an adequate knowledge base and clinical skills. At present, there are wide variations among disciplines and organization as to what is available, and a more systematic approach would suggest including spiritual care within the educational strategy of a service (Balboni et al., 2013) and teaching from a common syllabus which includes a consistent evaluation of the knowledge, skills, behaviours, and practice of learners (Marr et al., 2007).

Spiritual care also requires more than the application of theory or knowledge because spirituality is necessarily a reflective and contemplative practice. Professionals who work in this domain need to be resourced with some form of supervision to enable them to explore the impact of intimate personal encounters upon their own spirituality; to develop skills, and to face their own doubts, distress, prejudices, and defences (Leach and Paterson, 2015).

Conclusion

If we are to treat patients as whole persons then spiritual care will not be something extraneous to palliative care. If we are to listen to patients and pay attention to their spiritual beliefs, experiences, and practices then professionals have a responsibility to integrate spiritual care into clinical practice. This can be a challenging aspect of care but it is one that can reveal the inspiring nature of the human spirit even in the face of death. Throughout this chapter we have been reminded that spirituality is not homogenous category but manifest and experienced in a rich variety of ways. But whatever form it takes, spiritual care must be purposeful, properly resourced, and undertaken within a clear ethical framework. Inevitably professionals who develop skills and knowledge in this domain will need to address their own spirituality and mortality. In doing so they may deepen their own humanity and be more able to respond to the spiritual depths of others.

References

Argyle, M. (2000). *Psychology and Religion: an Introduction*. London: Routledge.

Balboni, M.J., **Sullivan, A.**, **Amobi, A.**, **Phelps, A.C.**, **Gorman, D.P.**, **Zollfrank, A.**, **Peteet, J.R.**, **Prigerson, H.G.**, **Vanderweele, T.J.** and **Balboni, T.A.** (2013). Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. *Journal of Clinical Oncology*, **31**: 461–7.

Barry, C.M. (2014). *Emerging Adults' Religiousness and Spirituality: Meaning-Making in an Age of Transition*. Oxford: Oxford University Press.

Best, M., **Aldridge, L.**, **Butow, P.**, **Olver, I.**, **Price, M.** and **Webster, F.** (2014). Assessment of spiritual suffering in the cancer context: A systematic literature review. *Palliative and Supportive Care*, **13**: 1335–61.

Boston, P., **Bruce, A.** and **Schreiber, R.** (2011). Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management*, **41**: 604–18.

Brown, A.E., **Whitney, S.N.** and **Duffy, J.D.** (2006). The physician's role in the assessment and treatment of spiritual distress at the end of life. *Palliat Support Care*, **4**: 81–6.

Carel, H. 2008. *Illness: the Cry of the Flesh*. Stocksfield: Acumen.

Carr, T.J., **Hicks-Moore, S.** and **Montgommery, P.** (2011). What's so big about the 'little things': A phenomological inquiry into the meaning of spiritual care in dementia. *Dementia*, **10**: 399–414.

Cobb, M., **Dowrick, C.** and **Lloyd-Williams, M.** (2012a). What can we learn about the spiritual needs of palliative care patients from the research literature? *J Pain Symptom Manage*, **43**: 1105–19.

Cobb, M., **Puchalski, C.M.** and **Rumbold, B.D.** (2012b). *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press.

Davies, D.J. (2002). *Death, Ritual and Belief: the Rhetoric of Funerary Rites*. London: Continuum.

Edwards, A., **Pang, N.**, **Shiu, V.** and **Chan, C.** (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliat Med*, **24**: 753–70.

Elliott, B.A., **Gessert, C.E.**, **Larson, P.** and **Russ, T.E.** (2012). Religious beliefs and practices in end-stage renal disease: Implications for clinicians. *Journal of Pain and Symptom Management*, **44**: 400–9.

Ellis, J., **Cobb, M.**, **O'connor, T.**, **Dunn, L.**, **Irving, G.** and **Lloyd-Williams, M.** (2015). The meaning of suffering in patients with advanced progressive cancer. *Chronic Illness*, **11**(3) 198–209.

Fanos, J.H., **Gelinas, D.F.**, **Foster, R.S.**, **Postone, N.** and **Miller, R.G.** (2008). Hope in palliative care: from narcissism to self-transcendence in amyotrophic lateral sclerosis. *J Palliat Med*, **11**: 470–5.

Hay, D. and **Nye, R.** (2006). *The Spirit of the Child*. London; Philadelphia: Jessica Kingsley Publishers.

Heaven, C.M. and **Maguire, P.** (1997). Disclosure of concerns by hospice patients and their identification by nurses. *Palliat Med*, **11**: 283–90.

Hodge, D.R. (2015). *Spiritual Assessment in Social Work and Mental Health Practice*. New York: Columbia University Press.

Kaliampos, A. and **Roussi, P.** (2017). Religious beliefs, coping, and psychological well-being among Greek cancer patients. *Journal of Health Psychology*, **22**: 754–64.

Kamper, R., **Van Cleve, L.** and **Savedra, M.** (2010). Children with advanced cancer: responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, **15**: 301–6.

Kuuppelomäki, M. (2001). Spiritual support for terminally ill patients: nursing staff assessments. *Journal of Clinical Nursing*, **10**: 660–70.

Leach, J.A. and **Paterson, M.A.** (2015). *Pastoral Supervision: a Handbook*. London: SCM.

Lucchetti, G., **Bassi, R.M.** and **Lucchetti, A.L.G.** (2013). Taking spiritual history in clinical practice: a systematic review of instruments. *EXPLORE: The Journal of Science and Healing*, **9**: 159–70.

Madge, N. and **Hemming, P.J.** (2016). Young British religious 'nones': findings from the Youth On Religion study. *Journal of Youth Studies*, 1–17.

Marr, L., **Billings, J.A.** and **Weissman, D.E.** (2007). Spirituality training for palliative care fellows. *Journal of Palliative Medicine*, **10**: 169–77.

Monod, S.M., **Rochat, E.**, **Büla, C.J.**, **Jobin, G.**, **Martin, E.** and **Spencer, B.** (2010). The spiritual distress assessment tool: an instrument to assess spiritual distress in hospitalised elderly persons. *BMC Geriatrics*, **10**: 88.

Murray, S.A., **Kendall, M.**, **Boyd, K.**, **Worth, A.** and **Benton, T.F.** (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative medicine*, **18**: 39–45.

National Cancer Action Team (2011). *Holistic Needs Assessment for people with cancer*. London: National Cancer Action Team.

National Palliative and End of Life Care Partnership (2015). *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*.

Nelson-Becker, H. (2017). *Spirituality, Religion, and Aging: Illuminations for Therapeutic Practice*. Los Angeles: SAGE.

Ortiz, L., **Villereal, S.** and **Engel, M.** (2000). Culture and spirituality: A review of literature. *Social Thought*, **19**: 21–36.

Pargament, K.I., **Zinnbauer, B.J.**, **Scott, A.B.**, **Butter, E.M.**, **Zerowin, J.** and **Stanik, P.** (1998). Red flags and religious coping: Identifying some religious warning signs among people in crisis. *Journal of Clinical Psychology*, **54**: 77–89.

Park, C. (2007). Religiousness/spirituality and health: a meaning systems perspective. *Journal of Behavioral Medicine*, **30**: 319–28.

Puchalski, C.M. and **Ferrell, B.** (2010). *Making Health Care Whole: Integrating Spirituality into Health Care*. West Conshohocken, PA: Templeton Press.

Ranton, D. (2013). Parental religious beliefs when making decisions for terminally ill children. *Family Law,* **43**: 684–92.

Rumbold, B.D. (2002). *Spirituality and Palliative Care: Social and Pastoral perspectives*.South Melbourne, Vic.; Oxford Oxford University Press.

Scruton, R. (2014). *The Soul Of The World.* : Princeton: Princeton University Press.

Selman, L., **Harding, R.**, **Gysels, M.**, **Speck, P.** and **Higginson, I.J.** (2011). The measurement of spirituality in palliative care and the content of tools validated cross-culturally: a systematic review. *Journal of Pain and Symptom Management*, **41**: 728–53.

Smart, N. (1996). *Dimensions of the Sacred: An Anatomy of the World's Beliefs*. London: HarperCollins.

Sorajjakool, S E., **Carr, M F.E.** and **Bursey, E.J.E.** (2017). *World Religions for HealthcarePprofessionals*. Abingdon, Oxon: Routledge.

Speck, P.W. (2006). *Teamwork in Palliative Care: Fulfilling or Frustrating?* Oxford: Oxford University Press.

Stanworth, R. (2004). *Recognizing Spiritual Needs in People Who Are Dying*. Oxford: Oxford University Press.

Staton, J., **Shuy, R.W.** and **Byock, I.** (2001). *A Few Months to Live: Different Paths to Life's End*. Washington, D.C: Georgetown University Press.

Swift, C., **Cobb, M.** and **Todd, A.** (2015). *A Handbook of Chaplaincy Studies: Understanding Spiritual Care in Public Places*. Abingdon, Oxon: Routledge.

Vivat, B., **Young, T.**, **Efficace, F.**, **Sigurđadóttir, V.**, **Arraras, J.I.**, **Åsgeirsdóttir, G.H.**, **Brédart, A.**, **Costantini, A.**, **Kobayashi, K.**, **Singer, S.** and **Group, O. B. O. T. E. Q. O. L.** (2012). Cross-cultural development of the EORTC QLQ-SWB36: A stand-alone measure of spiritual wellbeing for palliative care patients with cancer. *Palliative medi*cine, **27**(5): 457–69. doi: 10.1177/0269216312451950.

Woodhead, L. (2016). The rise of 'no religion' in Britain: The emergence of a new cultural majority. *Journal of the British Academy*, **4**: 245–61.

Chapter 12

Diagnosis of prolonged grief disorder (PGD)

Allison M. Marziliano, Wendy G. Lichtenthal, and Holly G. Prigerson

Introduction to prolonged grief disorder

Whereas most individuals who experience loss are resilient, requiring no more than modest support from their family and friends, a significant minority experience abnormally persistent and disabling responses to bereavement (Prigerson et al., 1995a, Prigerson et al., 2009). Initially, the term used to describe this response was complicated grief (CG), an informal term referring to debilitating non-normative grief (Horowitz et al., 1997, Prigerson et al., 1995b). With the advent of DSM-5, the term persistent complex bereavement disorder (PCBD) has been utilized, and the term prolonged grief disorder (PGD) is proposed for inclusion in the International Classification of Diseases, ICD-11 (Prigerson et al., 2009; Maercker et al., 2013a; Maercker et al., 2013b). PCBD was introduced as a provisional term to be used temporarily until further empirical support provided more evidence to support PGD (Friedman, 2016). Data from the Yale Bereavement Study demonstrated that the difference between PCBD and PGD is semantic; the two diagnoses do not differ in content and are therefore not distinct entities (Maciejewski et al., 2016). Thus, given its prominence as the subject of much empirical research and empirical support, the term PGD will be used in this chapter.

PGD is defined as ‘a severe and enduring symptom pattern of yearning or longing for the deceased or a persistent preoccupation with the deceased’ (Prigerson et al., 1995a, Maercker et al., 2013b; Prigerson et al., 1999a). Symptoms include difficulty accepting the reality of the death: feeling as if part of oneself is lost or has died; anger or bitterness over the death, guilt or blame regarding the death, or difficulty with new social situations. For a diagnosis of PGD, symptoms must remain apparent beyond a period considered normal within an individual’s culture, often six months or greater post-death.

In addition, these symptoms must be far beyond what is expected based on social/cultural norms and must interfere with functioning (Prigerson et al., 2009).

Rates of PGD

A great deal of empirical research has been devoted to estimating the rates of PGD as it is defined here. The first systematic review and meta-analysis of PGD included 14 studies with non-psychiatric adult populations experiencing non-violent bereavement. Results demonstrated that one out of ten bereaved adults is at risk for PGD, as the pooled prevalence of PGD was 9.8% (Lundorff et al., 2017). This prevalence rate is consistent with earlier research indicating that, in a sample of individuals confronted with stressful life events, 50–60% will not express complaints, 30–40% will express some complaints but will recover within a year, and 10% will report problematic and persistent complaints (Bonanno, 2004, Bonanno et al., 2011).

Individual empirical studies demonstrate a broader range of the prevalence of PGD in different countries with different populations. Data collected as part of the Yale Bereavement Study, the first study of PGD in a community based sample using the PGD diagnostic criteria, suggest rates ranging from 7–10% (Prigerson et al., 2009). The prevalence of PGD is higher in studies of populations undergoing war or violent bereavement. For example, in a study of psychiatric clinic patients in Karachi, Pakistan, an area with periodic violence, 34% of the sample met criteria for what was termed CG at the time (Prigerson et al., 2002). A similarly high rate of 34.6% was found in a study of bereaved young adults who had lost their father ten years earlier as a result of war-related violence in Kosovo (Morina et al., 2011). In a sample of 40 women who were widowed by the 1994 Rwandan genocide, 12.5% met criteria for PGD (Schaal et al., 2009). In a study of 775 Cambodians who lost at least one family member during the Khmer Rouge regime, the prevalence of PGD was estimated to be 14.3% (Stammel et al., 2013). The prevalence of PGD is also elevated in samples of patients bereaved by natural disasters. The rate of PGD in a sample of 643 survivors of a tsunami in India was 14.2%; further, in survivors bereaved by this natural disaster, the prevalence rate increased to 25.9% (Rajkumar et al., 2015).

High rates of PGD have also been found in a sample of bereaved Portuguese family members, 28.8% of whom experienced PGD six months post-loss and 15.1% of whom warranted a PGD diagnosis 12 months post-loss (Coelho et al., 2015), and bereaved Chinese adults, 13.9% of whom reported PGD (Li and Prigerson, 2016). In addition; increased rates of PGD have been demonstrated in bereaved caregivers of patients in minimally conscious states, ranging from 27.6% (Leonardi et al., 2012) to 60% (Elvira de la Morena and Cruzado, 2013) and parents bereaved by cancer, 12% of whom warranted a probable PGD diagnosis based on self-report assessments (Lichtenthal et al., 2015).

Although high levels of PGD are present in specific populations, studies of general populations report minimal PGD, as is the case in a study of the general population of China in which PGD is estimated at 1.8% (He et al., 2014). Low rates of PGD have also been found in general samples of the bereaved from Germany, 3.7% (Kersting et al., 2011) and the Netherlands, 4.8% (Boelen, 2016; Newson et al., 2011).

Disparities in rates of PGD

Minimal research has focused on racial/ethnic disparities in PGD rates. The findings suggest that African Americans experience significantly higher rates of PGD compared to Caucasians, 21% compared to 12%, respectively (Goldsmith et al., 2008). In other research examining how African Americans and Caucasians differ in their experience of loss, the authors found that African Americans reported higher levels of grief symptoms than Caucasians, particularly when they did not speak with others about their loss (Laurie and Neimeyer, 2008). Furthermore, African Americans compared to Caucasians were more often bereaved by homicide, maintained a stronger bond with the deceased, spoke less with others about their grief, and less often sought out formal support services. This is a critically important area that warrants additional research.

Risk factors for PGD

Studies have demonstrated several sets of risk factors for the development of PGD (Roberts et al., 2017). One such set of risk factors is the cause of death, as deaths that are violent and sudden are more likely to spur emotional difficulties than non-violent expected deaths (Boelen, 2016; Kristensen et al., 2012). A study comparing bereaved relatives of missing individuals and individuals dead due to homicide suggested higher rates of PGD in the latter sample (Lenferink et al., 2017). Similarly, death by suicide and accidents left more bereaved caregivers with PGD than illness losses (Boelen, 2015). Nevertheless, even within the context of illness loss, higher perceived unexpectedness was positively correlated with PGD symptom severity (Boelen, 2015). Other studies demonstrate that perceived deterioration and disfigurement of the patient (Coelho et al., 2016) and damage to homes in the context of deaths due to natural disasters (Rajkumar et al., 2015) are related to higher levels of PGD. Even within the samples entrenched in a violent mass shooting, those who reported greater exposure to media coverage of the event experienced higher PGD levels

(Kristensen et al., 2016). Also, partners of survivors with high exposure to trauma events in post-conflict Timor–Leste had more elevated grief symptoms compared to partners of survivors with less exposure to trauma (Silove et al., 2017). Thus, it is clear that violent and sudden deaths are more likely to leave the bereaved at risk of PGD (Lichtenthal et al., 2013).

In addition to the cause of death, another set of risk factors that impacts the rate of PGD is the bereaved individual's relationships, both with the deceased and with others (Bowlby, 1982). A study of 192 widows in the Yale Bereavement Study demonstrated that when the bereaved perceived high levels of parental control during their childhood, they are more likely to have demonstrated dependency on their spouse during adulthood and more likely to experience symptoms of PGD during bereavement (Johnson et al., 2007). In a study of caregivers of terminally ill spouses, results demonstrated that security-increasing marriages and insecure attachment styles increase the risk of the bereaved partner developing PGD (van Doorn et al., 1998). In another study examining predictors of anxiety among elderly spouses of terminally ill patients, the results indicated that excessively dependent attachment styles increase the risk for developing an anxiety disorder (Prigerson et al., 1996).

Recent literature suggests that close relationships (Heeke et al., 2017, Schaal et al., 2014; Mitchell et al., 2004) and insecure dependent relationships (Coelho et al., 2016) present a significant risk factor for PGD. With regard to relationship type, the loss of a parent, child, or partner presents greater risk of developing PGD in the bereaved compared to the loss of a sibling or non-immediate family member (Boelen, 2016; Stammel et al., 2013). In another study, however, findings were more specific and indicated that parents, and more specifically mothers, widowers, and sisters of the deceased were more strongly affected by the loss than adult children, brothers, and widows (Cleiren et al., 1994).

Beyond cause of death and the relationship with the deceased, certain characteristics of the bereaved individual contribute to an increase in the prevalence and severity of PGD. Demographic factors associated with a higher rate of PGD include older age (Lundorff et al., 2017), fragile current or prior mental health, low socioeconomic status, poor education (Boelen, 2016), less years of education (Rajkumar et al., 2015), high levels of depression, female gender (Lai et al., 2015), and high levels of religiosity (Schaal et al., 2014). Cognitive factors such as worry (Eisma et al., 2017); negative thoughts about one's grief (Boelen et al., 2016a); intolerance of uncertainty (Boelen et al., 2016b); lack of acceptance and denial or self-blame (Elvira de la Morena and Cruzado, 2013); are also related to higher levels of PGD. In addition, in a sample of bereaved parents, the authors found that nearly half (45%) of the sample reported difficulty with making sense of their loss, which was more common when the loss resulted from violence than non-violence (Lichtenthal et al., 2013), and nearly a quarter (21%) could not identify benefits associated with their loss experience. Both difficulty with making sense of the loss and finding benefit were positively related to more severe grief symptoms (Lichtenthal et al., 2010).

Factors associated with the post-loss experience also increase the risk of developing PGD. For example: following the homicide of a partner or child, a missing or disfigured body, and a missing or insufficiently punished perpetrator create circumstances that may also contribute to PGD (Boelen, 2016). Some research suggests that the ways in which the bereaved individual processes the loss may increase his or her risk of developing PGD, such that those experiencing feelings of regret, guilt, shame, or self-blame are at greater risk (Akiyama et al., 2010; Rozenzweig et al., 1997; Kelly et al., 1999). Some research has demonstrated that higher levels of PGD pre-loss are a risk factor related to higher levels of PGD post-loss (Lichtenthal et al., 2011; Givens et al., 2011). Given this association, and that the bereaved underutilize psychosocial services, one pathway to increasing the use of bereavement services is to identify those at greatest risk pre-bereavement (Roberts et al., 2017).

Outcomes associated with PGD

Just as certain variables have been found to be related to the development of PGD, other variables have been studied as outcomes associated with this disorder. Negative physical health outcomes associated with PGD include high blood pressure, elevated rates of cardiovascular events or conditions, and cancer (Prigerson et al., 1997), and negative mental health outcomes associated with PGD include changes in eating habits, substance abuse, harmful health behaviours, increased depression severity, enduring functional impairment, increased risk of suicidal ideation, and increased risk of suicide (Boelen and Prigerson, 2007; Dell'osso et al., 2011; Stroebe et al., 2007; Prigerson et al., 1997; Prigerson et al., 1999b; Latham and Prigerson, 2004; Mitchell et al., 2005; Szanto et al., 1997; Prigerson et al., 1995b). The negative outcomes associated with PGD are not confined to the individual, however. One study showed that, in parents whose child died, maternal symptoms of PGD were directly positively associated with surviving sibling outcomes such as surviving siblings' post-traumatic stress disorder (PTSD), depression, and PGD (Morris et al., 2016). Thus, PGD has serious implications for the physical and mental health of both the individual with the diagnosis and his or her family members.

PGD and comorbid disorders

Several studies have assessed the presence of PGD and comorbid mental disorders. Research shows high rates of comorbidity between PGD and depression, PTSD, substance abuse, and anxiety (Schaal et al., 2012; Schaal et al., 2014; Stammel et al., 2013). In a study conducted in China, rates of comorbidity with PGD were estimated at 75% for PTSD, 87.5% for depression, and 75% for anxiety (He et al., 2014).

Some have argued that the line between PTSD and PGD is blurry in cases of traumatic loss (Heeke et al., 2017). A review of the evidence suggests that both PTSD and PGD are defined by a potentially traumatizing experience and occur as the result of insufficient integration of the experience into one's autobiographical knowledge base (Boelen et al., 2006; Ehlers, 2006). However, although they share similarities, there are critical differences between the two disorders. Whereas PTSD is characterized by symptoms such as intrusion, avoidance, and increased arousal, the main component of PGD is separation distress related to the death, and missing and longing for the person who died (Lichtenthal et al. 2004). In addition, the negative appraisals associated with PTSD are directed toward the potential for a recurrence of danger; by contrast, the negative appraisals associated with PGD are related to the impact of the loss on oneself and one's future (Heeke et al., 2017), as well as an increased sense of vulnerability (Horowitz et al., 1997). In one study, the emergence of a PTSD-diagnosed group and a predominantly PGD-diagnosed group suggests that the two diagnoses, although comorbid, are distinguishable and can occur independently (Heeke et al., 2017).

Measurement/assessment of PGD

Few measures have been developed to assess PGD. Initially, the Inventory of Complicated Grief was the most widely used measure to assess dysfunctional grief (Prigerson et al., 1995a). Validations of the measure occurred in Chinese (Li and Prigerson, 2016) and Italian (Carmassi et al., 2014). A revised version of this measure was created, the Inventory of Complicated Grief-Revised (Prigerson et al., 2002), which incorporated additional items developed through a consensus conference (Prigerson et al., 1999a). In 2009, Prigerson and colleagues utilized data from the Yale Bereavement Study to assess these diagnostic criteria proposed by the consensus conference. These analyses resulted in 12 informative, unbiased symptoms with strong internal consistency, one of which, yearning, was deemed as most common and informative and, as a result, is a required symptom for a PGD diagnosis (Prigerson et al., 2009). Thus, yearning plus the remaining 11 items were evaluated using combinatorics, which examine different ways of arranging sets to determine alternative symptom combinations and possible diagnostic algorithms. Evaluation of the candidate algorithms revealed that the most promising one included yearning as a mandatory symptom and then at least five of the nine following symptoms: avoidance of reminders of the deceased; disbelief or trouble accepting the death; a perception that life is empty or meaningless without the deceased; bitterness or anger related to the loss; emotional numbness; feeling stunned, dazed, or shocked; feeling part of oneself had died along with the deceased; difficulty trusting others; and difficulty moving on with life. The Prolonged Grief Disorder-13 was constructed based on this diagnostic algorithm (Prigerson et al., 2009).

Since their development, the Prolonged Grief Disorder-12 (PG-12) and the PG-13 have been widely utilized to assess pre-loss risk for maladjustment and post-loss grief, respectively. Both the PG-12 and the PG-13 have been validated in a sample of Portuguese patients (Coelho et al., 2017; Delalibera et al., 2011), and the PG-12 has been validated in a sample of Italian patients (Chiambretto et al., 2008). In addition, the PG-13 has been translated into several languages including Chinese, Danish, English, German, Hebrew, Italian, Japanese, Korean, Lithuanian, Portuguese, Slovenian, Spanish, Swedish, Thai, Hungarian, and Arabic. Other less used measures of PGD include the Inventory of Prolonged Grief for Children and the Inventory of Prolonged Grief for Adolescents, both of which showed adequate internal consistency, temporal stability, and concurrent and construct validity (Spuij et al., 2012a).

Prevention of PGD

Some research has been devoted to understanding how the development of PGD may be prevented, particularly in at-risk populations. In a randomized controlled trial of family-focused grief therapy (FFGT), a manualized intervention that begins pre-death and continues into bereavement for families of advanced cancer patients that are at risk for family dysfunction, Kissane et al. (2016) found that 15.5% of the bereaved in the standard care arm, compared to 3.3% of the bereaved who received ten sessions of FFGT, developed PGD. Variations of CBT have also been used to successfully prevent PGD (Kersting et al., 2013). One such variation, referred to as healthy experiences after loss, or HEAL, is an internet-based therapist-assisted cognitive behavioural prevention intervention for PGD. In a randomized controlled trial of 84 bereaved individuals at risk for PGD comparing HEAL to a waitlist control, the authors found that HEAL was associated with larger reductions in PGD and fewer people meeting the criteria for a PGD diagnosis post-intervention (Litz et al., 2014). On the other hand, a separate pilot study found a CBT-based preventive psychoeducational intervention to be ineffective in preventing the development of PGD (Wittouck et al., 2014).

Interventions for PGD

Several efforts to develop and evaluate psychological interventions designed to reduce PGD symptom severity have been made. The intervention with the most demonstrated success is cognitive-behavioural therapy (CBT), with at least ten randomized controlled trials demonstrating that it results in considerable improvement in PGD symptom severity (Boelen et al., 2007). Researchers have examined data from both study completers and intent-to-treat analyses (Papa et al., 2013; Rosner et al., 2014; Shear et al., 2005), describing short-term as well as longer-term treatment effects (Rosner et al., 2015). Some studies have compared CBT alone to CBT plus exposure therapy; evidence from these suggest CBT plus exposure is the superior treatment, leading to greater reductions in PGD and fewer individuals meeting criteria for PGD post-intervention than CBT alone (Bryant et al., 2014).

The CBT interventions used for reducing PGD symptom severity are focused on cognitive behavioural conceptualizations of disturbed grief borrowed from PTSD models. These conceptualizations assume that recovery from a loss is hindered when the bereaved is not able to accept that the loss is irreversible, it leads the bereaved to think negatively about themselves, their world, and their future, and the bereaved person avoids reminders of his/her loss because s/he believes s/he cannot confront reality (Boelen et al., 2006). Thus, CBT for PGD focuses on acceptance of the loss, promoting confidence in the bereaved, their lives and their futures, and engaging in meaningful and fulfilling activities (Boelen et al., 2006).

Although CBT interventions have the largest evidence base, other approaches have also been explored. Meaning-centered grief therapy (MCGT) (Lichtenthal and Breitbart, 2015; Lichtenthal et al., 2017) is an individual cognitive-existential intervention adapted from meaning-centered psychotherapy (MCP) (Breitbart et al., 2012; Breitbart et al., 2010; Breitbart et al., 2015) and designed to reduce PGD symptoms by addressing the challenges bereaved individuals often face in making meaning of their loss and lives following the death of someone significant. MCGT focuses on assisting the bereaved with connecting to sources of meaning; highlighting the choices they have despite the profound pain they experience, and helping them to maintain a connection to the person they lost as a way of learning to co-exist with their grief. Efforts to develop and evaluate this approach to date have focused on parents who have lost a child to cancer (Lichtenthal and Breitbart, 2015; Lichtenthal et al., 2017), but future research will adapt MCGT for other bereaved populations.

Writing interventions have also demonstrated promise in reducing PGD symptoms. In a sample of 68 bereaved undergraduates, directed writing focused on either sense-making or benefit-finding were both associated with better adjustment to loss at three months post-intervention than two other groups: non-directed emotional disclosure and a control arm (Lichtenthal and Cruess, 2010). Similarly, in a case study of a woman suffering from PGD following the death of her father, narrative reconstruction was successful in reducing symptoms of PGD (Peri et al., 2016). Narrative writing interventions for PGD assume that the inability to integrate the loss memory gives rise to PGD in the bereaved. Similar to CBT interventions, this treatment has been borrowed from the PTSD literature. It is based on the rationale that emphasizing exposure to loss memory, detailed written reconstruction of loss memory narrative, and an elaboration of the personal significance of the memory of the bereaved will aid in integrating the memory, thereby reducing the severity of PGD symptoms (Peri et al., 2016).

New interventions to treat PGD continue to be developed and assessed, including metacognitive therapy, which uses detached mindfulness to help individuals understand the way they think about their own unhelpful thoughts, in an effort to change dysfunctional thinking styles (Wenn et al., 2015).

Adapting interventions for PGD for notable subgroups

Some populations require specific modifications to PGD interventions in order to enhance their efficacy (Rosner et al., 2015). Bereaved parents and those bereaved by suicide are two groups with higher likelihood of dropping out of treatment; suggesting that their interventions should incorporate components to retain study participants (Boelen et al., 2011; Rosner et al., 2015; Shear et al., 2005). Bereaved elderly patients with PGD are also more likely than other bereaved patients to suffer from loneliness as a result of multiple losses; suggesting that including social contact and behavioural activation into treatment for PGD in the elderly may lead to a more effective treatment (Rosner et al., 2015). Lastly, several studies have demonstrated the need for an intervention adapted for bereaved caregivers of patients who died in the intensive care unit or the hospital (Downar et al., 2014; Wright et al., 2010), with the incidence of PGD a year post-death of a family member in the ICU estimated at 10.3% (Rodriguez Villar et al., 2012).

The majority of research on PGD has utilized Western samples; however, adaptations of interventions should consider the needs of different non-Western cultural groups (Li and Prigerson, 2016). Studies on bereaved parents from Switzerland show they exhibit high levels of grief-related preoccupation, whereas bereaved parents from China endorse higher levels of functional impairment. The two groups also had different sets of PGD predictors. Whereas the primary predictors of PGD in the Chinese sample were general health and overall world view, primary predictors of PGD in the Swiss sample include female gender and a sense of coherence (Xiu et al., 2016). Therefore, interventions for each of these groups may be more effective if tailored to meet these unique needs and address their unique risk factors.

Addressing concerns about PGD

Concerns about establishing PGD as a mental disorder in diagnostic manuals center around the potential of pathologizing normal grief responses (Stroebe et al., 2000; Stroebe et al., 2017). However, careful attention has been paid to minimizing over-diagnosis; that is, the rates of false positive diagnoses. We have empirically examined the clinical utility of PGD to create a common dialogue among professionals. In doing so, we found that mental health providers who received a brief tutorial on PGD were over four times more likely to correctly diagnose video vignettes portraying PGD than those who did not receive the tutorial and no more likely to diagnose vignettes depicting normative grief as pathological. Furthermore, only a minority of bereaved samples, less than 10%, warrant diagnosis, and those who express symptoms even after six months only warrant diagnosis if their condition is persistent and debilitating (Maercker et al., 2013b). The criteria for PGD have been validated across a wide range of cultures and non-Western samples, and at different stages along the life trajectory from children to the elderly lend further support for including PGD as a formal diagnosis. In addition, those with PGD demonstrate cognitive patterns distinct from those with other disorders (O'Connor et al., 2008).

As discussed earlier, there is overwhelming evidence that PGD is distinct from established mental disorders and not adequately captured by existing diagnoses like major depressive disorder (MDD) or PTSD (Maercker et al., 2013b). For example, in a non-Western, violent, post-natural disaster context during the Great East Japan Earthquake and Tsunami, PGD emerged as qualitatively different than PTSD and MDD (Tsutsui et al., 2014). This finding was based on an exploratory factor analysis including items from three assessment instruments, the ICG for PGD, the Impact of Events Scale-Revised (IES-R) for PTSD and the Center for Epidemiological Studies-Depression (CES-D) for depression. Based on these analyses, the depression and PTSD items loaded on different factors than the ICG items. Other studies corroborate these findings in PTSD and MDD (Prigerson et al., 1995b; Boelen and Prigerson, 2007; Golden and Dalgleish, 2010; Spuij et al., 2012b), as well as support the distinction between PGD and anxiety (Boelen et al., 2007; Golden and Dalgleish, 2010).

Conclusion

Although the majority of individuals adjust, a substantial minority experience abnormal, persistent, and disabling responses to loss. The rates of PGD vary widely in different populations, but studies consistently indicate a prevalence rate of approximately 10% of the bereaved develop PGD. Rates have been shown to be higher among bereaved individuals who are members of ethnic/racial minority groups. Literature shows that risk factors for developing PGD include experiencing a loss due to a violent or sudden death; having had an insecure, dependent, or close relationship with the deceased; having lost a parent, child, or partner, or being older in age or female. PGD is a public health concern, as it is associated with both negative physical and mental health outcomes, and often presents alongside depression, anxiety and PTSD. CBT has been demonstrated as an effective treatment for PGD, and has also been used to prevent PGD in some cases, with more focused efforts on adapting interventions such as CBT for different sub-populations of the bereaved. Caution has been exercised to address concerns regarding the PGD diagnosis pathologizing normal grief, and emphasize its role in creating a common dialogue for mental health professionals. In conclusion, this niche of research has made great strides, as we now have reliable, valid, and clinically useful criteria for diagnosing PGD, and understand well-identified risk factors for the disorder. Still, there is much to be learned about PGD, particularly in the area of racial/ethnic disparities in diagnosis, and intervention adaptation for specific bereaved groups, both of which will expand this critically important literature.

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References

Akiyama A., **Numata K.**, and **Mikami H.** (2010). Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement. *Arch Gerontol Geriatr*, **50**: 175–8.

Boelen P.A. (2015). Peritraumatic distress and dissociation in prolonged grief and posttraumatic stress following violent and unexpected deaths. *J Trauma Dissociation*, **16**: 541–50.

Boelen P.A. (2016). Improving the understanding and treatment of complex grief: an important issue for psychotraumatology. *Eur J Psychotraumatol*, **7**: 32609.

Boelen P.A., **De Keijser J.**, **Van Den Hout M.A.**, and **Van Den Bout J.** (2007). Treatment of complicated grief: a comparison between cognitive-behavioral therapy and supportive counseling. *J Consult Clin Psychol*, **75**: 277–84.

Boelen P.A., **De Keijser J.**, **Van Den Hout M. A.**, and **Van Den Bout J.** (2011). Factors associated with outcome of cognitive-behavioural therapy for complicated grief: a preliminary study. *Clin Psychol Psychother*, **18**: 284–91.

Boelen P.A. and **Prigerson H.G.** (2007). The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults: a prospective study. *Eur Arch Psychiatry Clin Neurosci*, **257**: 444–52.

Boelen P.A., **Reijntjes A.**, **Djelantik J.**, and **Smid G. E.** (2016a). Prolonged grief and depression after unnatural loss: latent class analyses and cognitive correlates. *Psychiatry Res*, **240**: 358–63.

Boelen P.A., **Reijntjes A.**, and **Smid G. E.** (2016b). Concurrent and prospective associations of intolerance of uncertainty with symptoms of prolonged grief, posttraumatic stress, and depression after bereavement. *J Anxiety Disord*, **41**: 65–72.

Boelen P.A., **Van Den Bout J.**, and **Van Den Hout M.A.** (2006). Negative cognitions and avoidance in emotional problems after bereavement: a prospective study. *Behav Res Ther*, **44**: 1657–72.

Bonanno G.A. (2004). Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? *Am Psychol*, **59**: 20–8.

Bonanno G.A., **Westphal M.**, and **Mancini A D.** (2011). Resilience to loss and potential trauma. *Annu Rev Clin Psychol*, **7**: 511–35.

Bowlby J. (1982). Attachment and loss: retrospect and prospect. *Am J Orthopsychiatry*, **52**: 664–78.

Breitbart W., et al. (2012). Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol*, **30**: 1304–9.

Breitbart W., et al. (2010). Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychooncology*, **19**: 21–8.

Breitbart W., **Rosenfeld B.**, **Pessin H.**, **Applebaum A.**, **Kulikowski J.**, and **Lichtenthal W.G.** (2015). Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol*. **33**: 749–54.

Bryan, R.A., et al. (2014). Treating prolonged grief disorder: a randomized clinical trial. *Jama Psychiatry*, **71**: 1332–9.

Carmass, C., et al. (2014). Validation of the Italian version inventory of complicated grief (Icg): A study comparing cg patients versus bipolar disorder, ptsd and healthy controls. *Compr Psychiatry*, **55**: 1322–9.

Chiambretto P., **Moroni L.**, **Guarnerio C.**, and **Bertolotti G.** (2008). Italian validation of the prolonged grief disorder questionnaire (PG-12). *G Ital Med Lav Ergon*, **30**: A10–10.

Cleiren M., **Diekstra R.F.**, **Kerkhof A.J.**, and **Van Der Wal J.** (1994). Mode of death and kinship in bereavement: focusing on 'who' rather than 'how'. *Crisis*, **15**: 22–36.

Coelho A., **Delalibera M.**, **Barbosa A.**, and **Lawlor P.** (2015). Prolonged grief in palliative family caregivers: a pilot study in a Portuguese sample. *Omega (Westport)*, **72**: 151–64.

Coelho A., **Silva C.**, and **Barbosa A.** (2017). Portuguese validation of the prolonged grief disorder questionnaire-predeath (pg-12): psychometric properties and correlates. *Palliat Support Care*, 1–10.

Coelho A., **Delalibera M.M.A.**, and **Barbosa A.** (2016). Palliative care caregivers' grief mediators: a prospective study. *Am J Hosp Palliat Care*, **33**: 346–53.

Delalibera M., **Coelho A.**, and **Barbosa A.** (2011). Validation of prolonged grief disorder instrument for Portuguese population. *Acta Med Port*, **24**: 935–42.

Dell'osso L., **Carmassi C.**, **Rucci P.**, **Ciapparelli A.**, **Conversano C.**, and **Marazziti D.** (2011). Complicated grief and suicidality: the impact of subthreshold mood symptoms. *Cns Spectr*, **16**: 1–6.

Downar J., **Barua R.**, and **Sinuff T.** (2014). The desirability of an intensive care unit (ICU) clinician-led bereavement screening and support program for family members of icu decedents (Icu Bereave). *J Crit Care*, **29**: 311. E9–16.

Ehlers A. (2006). Understanding and treating complicated grief: what can we learn from posttraumatic stress disorder? *Clin Psychol (New York)*, **13**: 135–40.

Eisma M.C., **Boelen P.A.**, **Schut H.A.**, and **Stroebe M.S.** (2017). Does worry affect adjustment to bereavement? a longitudinal investigation. *Anxiety Stress Coping*, **30**: 243–52.

Elvira De La Morena M.J. and **Cruzado J.A.** (2013). Caregivers of patients with disorders of consciousness: coping and prolonged grief. *Acta Neurol Scand*, **127**: 413–8.

Friedman M.J. (2016). Seeking the best bereavement-related diagnostic criteria. *Am J Psychiatry*, **173**: 864–5.

Givens J.L., **Prigerson H G.**, **Kiely D.K.**, **Shaffer M.L.**, and **Mitchell S. L.** (2011). Grief among family members of nursing home residents with advanced dementia. *Am J Geriatr Psychiatry*, **19**: 543–50.

Golden A.M. and **Dalgleish T.** (2010). Is prolonged grief distinct from bereavement-related posttraumatic stress? *Psychiatry Res*, **178**: 336–41.

Goldsmith B., **Morrison R.S.**, **Vanderwerker L.C.**, and **Prigerson H.G.** (2008). Elevated rates of prolonged grief disorder in African Americans. *Death Stud*, **32**: 352–65.

He L., **Tang S.**, **Yu W.**, **Xu W.**, **Xie Q.**, and **Wang J.** (2014). The prevalence, comorbidity and risks of prolonged grief disorder among bereaved Chinese adults. *Psychiatry Res*, **219**: 347–52.

Heeke C., **Stammel N.**, **Heinrich M.**, and **Knaevelsrud C.** (2017). Conflict-related trauma and bereavement: exploring differential symptom profiles of prolonged grief and posttraumatic stress disorder. *Bmc Psychiatry*, **17**: 118.

Horowitz M J., **Siege B.**, **Holen I.A.**, **Bonanno G.A.**, **Milbrath C.**, and **Stinson C.H.** (1997). Diagnostic criteria for complicated grief disorder. *Am J Psychiatry*, **154**: 904–10.

Johnson J.G., **Zhang B.**, **Greer J.A.**, and **Prigerson H.G.** (2007). Parental control, partner dependency, and complicated grief among widowed adults in the community. *J Nerv Ment Dis*, **195**: 26–30.

Kelly B., **Edwards P.**, **Synott R.**, **Neil C.**, **Baillie R.**, and **Battistutta D.** (1999). Predictors of bereavement outcome for family carers of cancer patients. *Psychooncology*, **8**: 237–49.

Kersting A., **Brahler E.**, **Glaesmer H.**, and **Wagner B.** (2011). Prevalence of complicated grief in a representative population-based sample. *J Affect Disord*, **131**: 339–43.

Kersting A., et al. (2013). Bief internet-based intervention reduces posttraumatic stress and prolonged grief in parents after the loss of a child during pregnancy: a randomized controlled trial. *Psychother Psychosom*, **82**: 372–81.

Kissane D.W., et al. (2016). Randomized controlled trial of family therapy in advanced cancer continued into bereavement. *J Clin Oncol*, **34**: 1921–7.

Kristensen P., **Dyregrov K.**, **Dyregrov A.**, and **Heir T.** (2016). Media exposure and prolonged grief: a study of bereaved parents and siblings after the 2011 utoya island terror attack. *Psychol Trauma*, **8**: 661–7.

Kristensen, P., **Weisaeth L.**, and **Heir T.** (2012). Bereavement and mental health after sudden and violent losses: a review. *Psychiatry*, **75**: 76–97.

Lai C., et al. (2015). Attachment style dimensions can affect prolonged grief risk in caregivers of terminally ill patients with cancer. *Am J Hosp Palliat Care*, **32**: 855–60.

Latham A.E. and **Prigerson H.G.** (2004). Suicidality and bereavement: complicated grief as psychiatric disorder presenting greatest risk for suicidality. *Suicide Life Threat Behav*, **34**: 350–62.

Laurie A. and **Neimeyer R.A.** (2008). African Americans in bereavement: grief as a function of ethnicity. *Omega (Westport)*, **57**: 173–93.

Lenferink, L.I., **Van Denderen M.Y.**, **De Keijser J.**, **Wessel I.**, and **Boelen P.A.** (2017). prolonged grief and post-traumatic stress among relatives of missing persons and homicidally bereaved individuals: a comparative study. *J Affect Disord*, **209**: 1–2.

Leonardi M., **Giovannetti A.M.**, **Pagani M.**, **Raggi A.**, and **Sattin D.** (2012). Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: results from a national Study. *Brain Inj*, **26**: 1201–10.

Li J. and **Prigerson H.G.** (2016). Assessment and associated features of prolonged grief disorder among chinese bereaved individuals. *Compr Psychiatry*, **66**: 9–16.

Lichtenthal W.G. and **Breitbart W.** (2015). The central role of meaning in adjustment to the loss of a child to cancer: implications for the development of meaning-centered grief therapy. *Curr Opin Support Palliat Care*, **9**: 46–51.

Lichtenthal W.G., et al. (2015). Mental health services for parents who lost a child to cancer: if we build them, will they come? *J Clinical Oncology*, **33**: 2246–2253.

Lichtenthal W.G. and **Cruess D.G.** (2010). Effects of directed written disclosure on grief and distress symptoms among bereaved individuals. *Death Stud*, **34**: 475–99.

Lichtenthal W.G., **Cruess D.G.**, and **Prigerson H.G.** (2004). A case for establishing complicated grief as a distinct mental disorder in Dsm-V. *Clin Psychol Rev*, **24**: 637–62.

Lichtenthal W.G., **Currier J.M.**, **Neimeyer R.A.**, and **Keesee N.J.** (2010). Sense and significance: a mixed methods examination of meaning making after the loss of one's child. *J Clin Psychol*, **66**: 791–812.

Lichtenthal W.G., **Lacey S.**, **Roberts K.**, **Sweeney C.**, and **Slivjak E.** (2017). Meaning-Centered Grief Therapy. In: Breitbart, W. (ed.) *Meaning-Centered Psychotherapy In The Cancer Setting: Finding Meaning And Hope In The Face Of Suffering*. New York, NY: Oxford University Press, pp. 88–99.

Lichtenthal W.G., **Neimeyer R.A.**, **Currier J.M.**, **Roberts K.**, and **Jordan N.** (2013). Cause of death and the quest for meaning after the loss of a child. *Death Stud*, **37**: 311–42.

Lichtenthal W.G., et al. (2011). Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatr Serv*, **62**: 1225–9.

Litz B.T., et al. (2014). A randomized controlled trial of an internet-based therapist-assisted indicated preventive intervention for prolonged grief disorder. *Behav Res Ther*, **61**: 23–34.

Lundorff M., **Holmgren H.**, **Zachariae R.**, **Farver-Vestergaard I.**, and **O'Connor M.** (2017). Prevalence of prolonged grief disorder in adult bereavement: a systematic review and meta-analysis. *J Affect Disord*, **212**: 138–49.

Maciejewski P.K., **Maercker A.**, **Boelen P.A.**, and **Prigerson H.G.** (2016). 'Prolonged grief disorder' and 'persistent complex bereavement disorder', but not 'complicated grief', are one and the same diagnostic entity: an analysis of data from the Yale Bereavement Study. *World Psychiatry*, **15**: 266–75.

Maercker A., et al. (2013a). Proposals for mental disorders specifically associated with stress in the international classification of diseases-11. *Lancet*, **381**: 1683–5.

Maercker A., et al. (2013b.) Diagnosis and claification of disorders specifically associated with stress: proposals for Icd-11. *World Psychiatry*, **12**: 198–206.

Mitchell A.M., **Kim Y.**, **Prigerson H.G.**, and **Mortimer-Stephens M.** (2004). Complicated grief in survivors of suicide. *Crisis*, **25**: 12–8.

Mitchell A.M., **Kim Y.**, **Prigerson H.G.**, and **Mortimer M.K.** (2005). Complicated grief and suicidal ideation in adult survivors of suicide. *Suicide Life Threat Behav*, **35**: 498–506.

Morina N., **Von Lersner U.**, and **Prigerson H.G.** (2011). War and bereavement: consequences for mental and physical distress. *Plos One*, **6**: E22140.

Morris A.T., **Gabert-Quillen C.**, **Friebert S.**, **Carst N.**, and **Delahanty D.L.** (2016). The indirect effect of positive parenting on the relationship between parent and sibling bereavement outcomes after the death of a child. *J Pain Symptom Manage*, **51**: 60–70.

Newson R.S., **Boelen P.A.**, **Hek K.**, **Hofman A.**, and **Tiemeier H.** (2011). The prevalence and characteristics of complicated grief in older adults. *J Affect Disord*, **132**: 231–8.

O'Connor M.F., **Wellisch D.K.**, **Stanton A.L.**, **Eisenberger N.I.**, **Irwin M.R.**, and **Lieberman M.D.** (2008). Craving love? enduring grief activates brain's reward center. *Neuroimage*, **42**: 969–72.

Papa A., **Sewell M.T.**, **Garrison-Diehn C.**, and **Rummel C.** (2013). A randomized open trial assessing the feasibility of behavioral activation for pathological grief responding. *Behav Ther*, **44**: 639–50.

Peri T., **Hasson-Ohayon I.**, **Garber S.**, **Tuval-Mashiach R.**, and **Boelen P.A.** (2016). Narrative reconstruction therapy for prolonged grief disorder-rationale and case study. *Eur J Psychotraumatol*, **7**: 30687.

Prigerson H.G., et al. (2002). Rates and risks of complicated grief among psychiatric clinic patients in Karachi, Pakistan. *Death Stud*, **26**: 781–92.

Prigerson H.G., et al., (1997). Traumatic grief as a risk factor for mental and physical morbidity. *Am J Psychiatry*, **154**: 616–23.

Prigerson H.G., et al. (1999a). Consensus criteria for traumatic grief. a preliminary empirical test. *Br J Psychiatry*, **174**: 67–73.

Prigerson H.G., et al. (1999b). Influence of traumatic grief on suicidal ideation among young adults. *Am J Psychiatry*, **156**: 1994–5.

Prigerson H.G., et al. (2009). Prolonged grief disorder: psychometric validation of criteria proposed for Dsm-V And Icd-11. *Plos Med*, **6**: E1000121.

Prigerson H.G., et al. (1995a). Inventory of complicated grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Res*, **59**: 65–79.

Prigerson H.G., et al. (1995b). Complicated grief and bereavement-related depression as distinct disorders: preliminary empirical validation in elderly bereaved spouses. *Am J Psychiatry*, **152**: 22–30.

Prigerson H.G., **Shear M.K.**, **Bierhals A.J.**, **Zonarich D.L.**, and **Reynolds C.F.** 3rd. (1996). Childhood adversity, attachment and personality styles as predictors of anxiety among elderly caregivers. *Anxiety*, **2**: 234–41.

Rajkumar A.P., **Mohan T.S.**, and **Tharyan P.** (2015). Lessons from the 2004 Asian Tsunami: nature, prevalence and determinants of prolonged grief disorder among tsunami survivors in South Indian Coastal Villages. *Int J Soc Psychiatry*, **61**: 645–52.

Roberts K., et al. (2017). Development of the Bereavement Risk Inventory And Screening Questionnaire (Brisq): Item generation and expert panel feedback. *Palliat Support Care*, **15**: 57–66.

Rodriguez Villar S., et al. (2012). Incidence of prolonged grief disorder in relatives of patients who die during or after admission in Intensive Care Unit. *Rev Esp Anestesiol Reanim*, **59**: 535–41.

Rosner R., **Bartl H.**, **Pfoh G.**, **Kotoucova M.**, and **Hagl M.** (2015). Efficacy of an integrative cbt for prolonged grief disorder: a long-term follow-up. *J Affect Disord*, **183**: 106–12.

Rosner R., **Pfoh G.**, **Kotoucova M.**, and **Hagl M.** (2014). Efficacy of an outpatient treatment for prolonged grief disorder: a randomized controlled clinical trial. *J Affect Disord*, **167**: 56–63.

Rozenzweig A., **Prigerson H.**, **Miller M.D.**, and **Reynolds C.F.** 3rd. (1997). Bereavement and late-life depression: grief and its complications in the elderly. *Annu Rev Med*, **48**: 421–8.

Schaal S., **Dusingizemungu J.P.**, **Jacob N.**, **Neuner F.**, and **Elbert T.** (2012). Associations between prolonged grief disorder, depression, posttraumatic stress disorder, and anxiety in Rwandan Genocide survivors. *Death Stud*, **36**: 97–117.

Schaal S., **Elbert T.**, and **Neuner F.** (2009). Prolonged grief disorder and depression in widows due to the Rwandan Genocide. *Omega (Westport)*, **59**: 203–19.

Schaal S., **Richter A.**, and **Elbert T.** (2014). Prolonged grief disorder and depression in a german community sample. *Death Stud*, **38**: 476–81.

Shear K., **Frank E.**, **Houck P.R.**, and **Reynolds C.F.** 3rd. (2005). Treatment of complicated grief: a randomized controlled trial. *JAMA*, **293**: 2601–8.

Silove D.M., et al. (2017). Symptoms of post-traumatic stress disorder, severe psychological distress, explosive anger and grief amongst partners of survivors of high levels of trauma in post-conflict Timor-Leste. *Psychol Med*, **47**: 149–59.

Spuij M., et al. (2012a). Psychometric properties of the Dutch inventories of prolonged grief for children and adolescents. *Clin Psychol Psychother*, **19**: 540–51.

Spuij M., **Reitz E.**, **Prinzie P.**, **Stikkelbroek Y.**, **De Roos C.**, and **Boelen P.A.** (2012b). Distinctiveness of symptoms of prolonged grief, depression, and post-traumatic stress in bereaved children and adolescents. *Eur Child Adolesc Psychiatry*, **21**: 673–9.

Stammel N., et al. (2013). Prolonged grief disorder three decades post loss in survivors of the Khmer Rouge Regime In Cambodia. *J Affect Disord*, **144**: 87–93.

Stroebe M., **Schut H.**, and **Stroebe W.** (2007). Health outcomes of bereavement. *Lancet*, **370**: 1960–73.

Stroebe M., **Stroebe W.**, **Schut H.**, and **Boerner K.** (2017). Grief is not a disease but bereavement merits medical awareness. *Lancet*, **389**: 347–9.

Stroebe M., **Van Son M.**, **Stroebe W.**, **Kleber R.**, **Schut H.**, and **Van Den Bout J.** (2000). On the classification and diagnosis of pathological grief. *Clin Psychol Rev*, **20**: 57–75.

Szanto K., **Prigerson H.G.**, **Houck P.**, **Ehrenpreis L.**, and **Reynolds C.F.** 3rd. (1997). Suicidal ideation in elderly bereaved: the role of complicated grief. *Suicide Life Threat Behav*, **27**: 194–207.

Tsutsui T., **Hasegawa Y.**, **Hiraga M.**, **Ishiki M.**, and **Asukai N.** (2014). Distinctiveness of prolonged grief disorder symptoms among survivors of the Great East Japan earthquake and tsunami. *Psychiatry Res*, **217**: 67–71.

Van Doorn C., **Kasl S.V.**, **Beery L.C.**, **Jacobs**, and **Prigerson H.G.** (1998). The influence of marital quality and attachment styles on traumatic grief and depressive symptoms. *J Nerv Ment Dis*, **186**: 566–73.

Wenn J., **O'Connor M.**, **Breen L.J.**, **Kane R.T.**, and **Rees C.S.** (2015). Efficacy of metacognitive therapy for prolonged grief disorder: protocol for a randomised controlled trial. *Bmj Open*, **5**: E007221.

Wittouck C., **Van Autreve S.**, **Portzky G.**, and **Van Heeringen K.** (2014). A CBT-Based psychoeducational intervention for suicide survivors: a cluster randomized controlled study. *Crisis*, **35**: 193–201.

Wright A.A., **Keating N.L.**, **Balboni T.A.**, **Matulonis U.A.**, **Block S.D.**, and **Prigerson H. G.** (2010). Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol*, **28**: 4457–64.

Xiu D., **Maercker A.**, **Woynar S.**, **Geirhofer B.**, **Yang Y.**, and **Jia X.** (2016). Features Of prolonged grief symptoms in Chinese and Swiss bereaved parents. *J Nerv Ment Dis*, **204**: 693–701.

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Note: b denotes *box, f* is *figure* and *t* is *table*