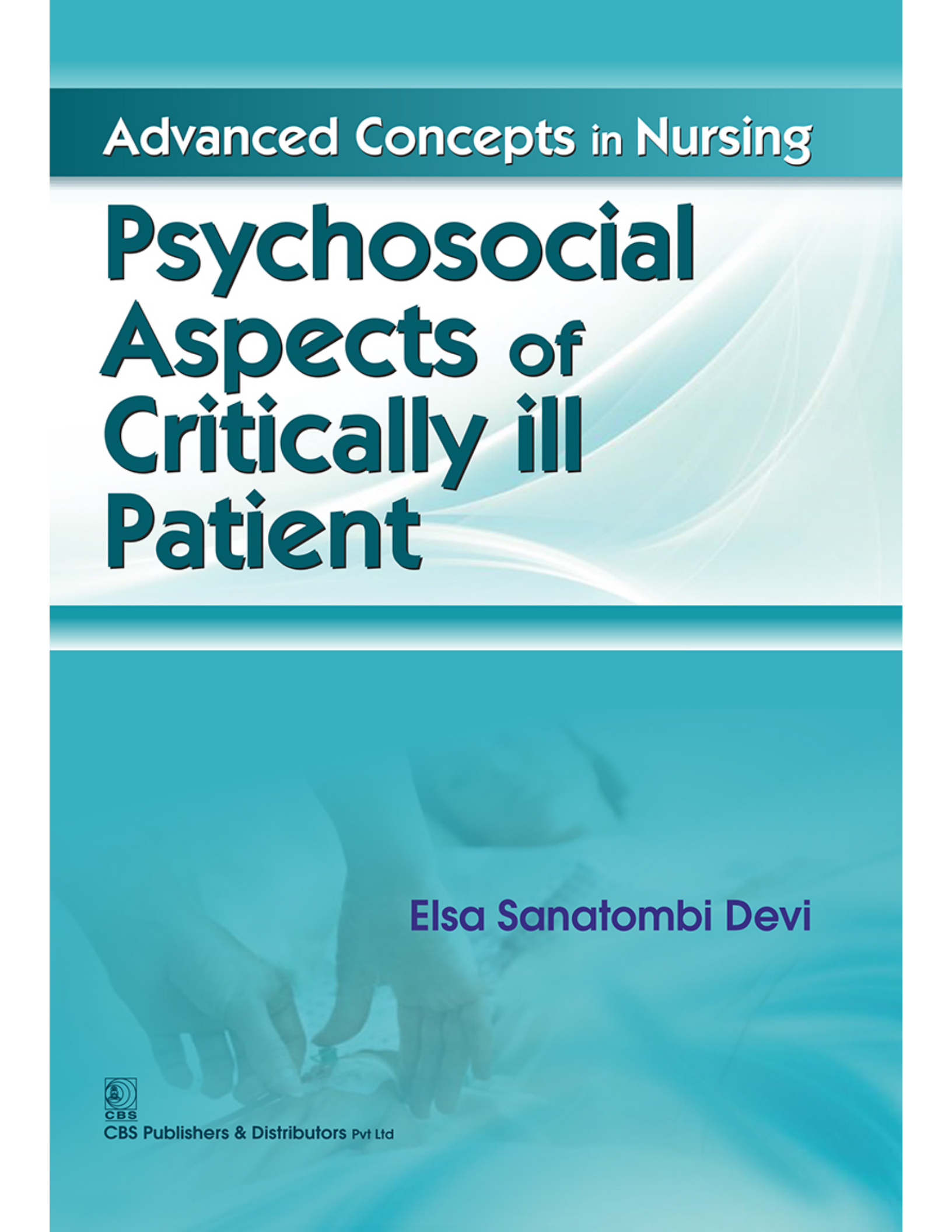
Advanced Concepts in Nursing

Psychosocial Aspects of Critically ill Patient



Elsa Sanatombi Devi

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Foreword

Psychosocial Aspects of Critically ill Patient by Dr. Elsa Sanatombi Devi offers an amazing insight into the heart of a critically ill patient who is battling for life, who has become, so to say, helpless, vulnerable, unstable and totally dependent on a doctor and a nurse. She/he is longing for companionship, reassurance and words of comfort and healing at this critical life-threatening juncture of their life.

The book delves in depth about the plight of critically ill patients who rely on others for everything, particularly their caregivers. The entire health care team must be sensitive, therefore, to the feelings of the patients. They need to take on their patient's pain and agony as if it was their own. They should be able to give confidence and hope to them and even build relationship of a father, mother, brother, sister, son or daughter as the case may be.

Dr. Sanatombi says, "Every patient is unique and his/her problems are specific and no single yardstick can determine each one's feelings." It is, therefore, vital to understand the patients, communicate with them through verbal and non-verbal gestures and even let them know they are important and precious.

The concept of aging and other pertinent issues of critical nature are put forth beautifully by the author and how a nurse or a doctor can deal with people of various age groups and also how they can help patients go through their difficult moments in life.

It is indeed gratifying that my student and good friend, Dr. Elsa Sanatombi has made such a marvellous effort at a time when it is needed the most. The painstaking manner in which she has pieced together the contents and structured its chapters is indeed praiseworthy. This book is not just a testimony of academic knowledge but the evidence of her rich clinical experience as a nurse.

While there are several books on how to deal with critically ill patients, this book Psychosocial Aspects of Critically ill Patient is bound to prove to be an invaluable resource and a repository of inspiration for all those who are in the caring and healing profession. The book will definitely trigger a spark of 'care' inside you for the critically ill patients!

Dr PD John SDB
Principal
Don Bosco College
and
Director
DBCTE, Tura
Meghalaya, India

Preface

The most forgotten aspect of care in a critical care unit is the psychosocial. Every individual admitted to the ICU faces some sort of fear and anxiety. When the diagnosis is not promising, the individual definitely gets into depression which is not easily identified by the health care professionals. Having a holistic approach to looking at how a patient feels, will make us cognizant of the care needs of an individual. Neither nursing curriculum nor the medical curriculum focuses enough on the psychosocial aspects of a critically ill patient. Diseases have specific protocol to treat but feelings and thoughts of an individual cannot be X-rayed and treated with medication alone. It needs empathetic approach to get diagnosed. If the psychosocial issues are addressed at the right time, patient's recovery can be quicker and length of hospital stay can be minimized.

Understanding and communicating the right matter to the patient and his family means a lot to them. In this arena, time is the most crucial resource which no one seems to have for another person. Just a few moments shared with the patient and his family mambers may make them feel at ease.

After glancing through this book, one can realize how an individual with health problems experiences through. Diagnosis becomes very painful to an individual when you know the disease is incurable or needs lifelong treatment. Treatment side effects seem hard to tolerate and tackling with the ill effects of medication is another journey in the lives of many patients. Having a positive attitude towards patient care and dealing with patients patiently shows how much concern one possesses while we nurse them. Helping patient to cope with his illness experience may make his life events and processes even better.

Elsa Sanatombi Devi

Acknowledgements

Constant attention by a good nurse may be just as important as a major operation by a surgeon.

— Dag Hammarskjold

As rightly mentioned, I have the honour to salute my nursing profession that gave me ample amount of opportunities to reflect. Every patient is a history and every pain is unique, from the personal pain to the pain experienced by every patient. If I can sense the painful experience, then the job is done. As I gather through this piece of work, I had needled the experience of many individuals who had something to say about their feelings as they go through the illness experience or having to look after their loved ones going through terrible pain and agony in their last moments. In many instances I have been a keen witness to the situation and a few I was involved in the care aspect. I owe my loving memories to my dear parents who instilled in me the instinct to feel for others' pain and develop a nature that can sense and help them to feel from their ends. Being with them in their older age and understanding their needs made me feel proud to realize that the days are also meant for all of us someday. Making them happy and cheering them up in their times of need makes every parent proud for having had children of such kind.

My gratitude to my uncle P Biren Singh, the man who made me feel that "I am not alone". My aunt's motherly words and affection made me feel all the more loved and being a special child to them. Their words of wisdom and thoughts formed the basis for my interest in the psychosocial field. My love and gratitude to all my friends, relatives, teachers, mentors, and my very patients who motivated me in this field of writing.

My heartfelt admiration for Manipal University, the mission that makes all of us thrive to be unique in all aspects. Appreciation given to all who succeed drives and makes each one of us look for something new in

our ways and dealings. Humanity is something that I learnt from Manipal and that makes a health care professional a big human in the face of pain and anguish.

My appreciation to my spiritual leaders from the Prajapita Brahma Kumari Ishwariya Vishwavidyalaya, Manipal, who taught me the way of life and also who instilled in me to complete my guidance, counselling and psychology to understand others and illness that shaped my thinking. My soul belongs to the creator, and my being, my thinking, my relation and my feelings belong to Him, the almighty.

We would like to thank Mr S.K. Jain (CMD), Mr. Varun Jain (Director), Mr. YN Arjuna (Senior Vice President – Publishing and Editorial), and Mr. Ashish Dixit (Business Head – Digital Publishing, Marketing & Sales) and his team at CBS Publishers & Distributors Pvt. Ltd. for their skill, enthusiasm, support, patience and excellent professional approach in producing and publishing this eBook.

Elsa Sanatombi Devi

About the Book

Advanced Concepts in Nursing: Psychosocial Aspects of Critically ill Patient offers an amazing insight into the mind of a critically ill patient who is battling for life, has become helpless, vulnerable, unstable and totally dependent on a doctor and a nurse, and is longing for companionship, reassurance and words of comfort and healing.

The book delves in depth about the plight of critically ill patients who rely on others for everything, particularly their caregivers. The entire health care team must be sensitive to the feelings of the patients, should be able to give them confidence and hope and even build relationship of a father, mother, brother, sister, son or daughter, as the case may be.

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"Every patient is unique and his/her problems are specific and no single yardstick can determine each one's feelings."

"It is, therefore, vital to understand the patients, communicate with them through verbal and nonverbal gestures and even let them know they are important and precious."

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About the Author

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is Professor and Head, Department of Medical Surgical Nursing, Manipal College of Nursing, Manipal University, Manipal. She completed her GNM from Rapsbun School of Nursing, Shillong, Meghalaya, in 1996; PCBSc from MAHE, Manipal, in 2001; MSc in nursing from MAHE, Manipal, in 2003; and PhD in nursing from Manipal University in 2012. She completed her MBA in health care management from Sikkim Manipal University in 2007, 'diabetes educator' through World Federation project HOPE in 2010, and PGD in guidance, counselling and psychology from Royal Institute, Pondicherry, in 2014. She is author of *Manipal Manual of Nursing Education* and *Surgery for Nurses*.

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Psychosocial Aspects of Critically ill Patient: Introduction

Outline

- Introduction to psychosocial health
- Dimensions of psychosocial health
- Strategies to improve emotional health
- How to build up relationship

INTRODUCTION TO PSYCHOSOCIAL HEALTH

In today's complex world, communication with people within the workplace or within health care becomes very significant for the fact that people are aware of their rights. As a human being, we have the right to be respected with dignity and cared for. When one is faced with being cared mechanically, then only the value of communication, sympathy and empathy is felt as a need. Patient in the ICU or in a critical state of health care need goes through isolation from the rest of his family and that's the point of time when the nurses and doctors need to focus on individualized care understanding the patient's preferences, beliefs and practices. Obtaining the three desired components of any learning that is knowledge, attitude and skills in handling patient care will prove forward safe, supportive and enjoyable learning experiences as a health care student.

DIMENSIONS OF PSYCHOSOCIAL HEALTH

One's thinking, being, feeling and relating to other matters to the psychosocial upbringing of an individual and more importantly to a

patient's wellbeing (Fig. 1.1).

Being mentally, emotionally, socially, and spiritually well means one is psychosocially healthy. Life's ups and downs, challenges while being hospitalized, disappointments, frustrations, pain, complex treatments and diagnostics may pose imbalance in one's mental state of mind. Enhancing the intellectual health, such as ability to reason, interpret, remember, sense, evaluate, solve problems of life is purely developed through healthy attitudes, beliefs and practices, family support, positive relationships and the ability to appreciate the differences of individuals. Resiliency to one's psychosocial health means that the person is able to feel good, feel comfortable, control tensions and stress, meeting demands of life, curbing the guilt feelings, looking at life positively, valuing their sickness and health and appreciating their life's happenings. Therefore, how one handles one's situation depends on the strengths and weaknesses of the four dimensions as one or the other could be stronger or weaker depending on the situation and state of mind. Strengthening the weak areas and balancing the four aspects will contribute to good mental health. Balancing them wisely will help us communicate better, express sensibly and think effectively.

Fig. 1.1: Dimensions of psychosocial health

My Emotional Health: My Feelings how does it Matter

Emotional health refers to our overall wellbeing and overall health. How each of us think, feel, and cope with the challenges in life with the best abilities to manage one's own emotions and relate appropriately with others contribute to the emotional wellbeing.

STRATEGIES TO IMPROVE EMOTIONAL HEALTH

- Listen carefully to one's own health and stay fit
- Take good care of oneself even in busy times
- Relaxation, the best technique to stay mentally alert. Learn yoga, meditation, etc.
- At least 6–8 hours of quality sleep to rejuvenate one's body and mind.
- Balanced diet and work out sessions to keep the physical health. Faulty diet causes diseases and disorders.

My Social Health: How do I Relate with People Around Me

Social health of an individual involves one's ability to make a fulfilling relationships with others around him. No environment can be familiar but the ability to adapt and be comfortable in any given situation and environment means to socially sound individual. The level of comfort one feels will depend on the type of communication, IPR, empathy one possesses and the sense of accountability. When a patient is admitted to your unit, the patient can feel comforted only if the nurse or the doctor greets them with affection and concern. This feeling shown to the patient can help find patients adjust as quickly as possible to the unit and treatment that they will receive. Stress within the workplace, unwelcoming health care professionals can create stress in the patient that may in turn cause

threat to healthy relationship. Therefore, stress need to be managed so that healthy relationship can be built in the clinical care as well as in the classroom scene where the impact could be towards the student when a teacher is stressed.

HOW TO BUILD UP RELATIONSHIPS

To build any relationship, one needs to give time for the individual. In today's world, no one has a single minute for anyone and then we expect relationships and understanding. Give a hand and we receive a hand. In any good relationship, one's self-esteem and emotional status helps strengthen healthy relationship. On the other hand, establishing a sense of identity that is staying with our own true-self will help us stay in healthy relationship. A healthy relationship can be experimented through development of the following features, such as trust, compassion, respect, acceptance, reciprocity and empathy. Few of the challenges one may face while building a good relationship are: Jealousy, lack of honesty, no openness, unrealistic expectations, materialistic, and selfish. Undue rewards need to be given to any deserving friend or near ones. We consider a woman at home to be doing all the household work and no appreciation is rendered. In few days' time, conflict can build up and relationship status can be strained. Don'ts of good relation among team members are—do not criticize; never show your self-protective nature, avoid too many questions, do not disregard, never over lean too much, etc. While dealing with patient, follow a few tips to win your patient's confidence.

- **Emotions:** Show that you can feel from their ends by appropriate expressions and behaviour. Empathetic communications will help build trusting therapeutic relationship.
- **Minimize distractions:** Hospital setting is full of distractions whether we like it or not. When a patient enters the unit, if the nurse or doctor is on mobile phones chit chatting, patient can sense their unwelcome attitude. It is wise to keep mobile or phone to minimum noise or silent mode so that patients feel comfortable and that attention is paid. On the other hand, patient too needs to follow the same rule. It applies to both parties.
- **Active listening:** Pay attention and ask right question when patient tells you their health problems. Take very problem as unique because

illness is actually experienced by the patient not by the nurse or the doctor. Value patient's rights to information. Listen more than talking all the time. Listen with empathy and patient's half problem can be solved.

- **Understanding non-verbal communication:** According to Kramer, "94% of our communication is non-verbal. But today we have lots of over the mobile talks and orders. Technology has taken health care to another level altogether. But when face to face interaction and care is delivered, both verbal and non-verbal communication congruency is essential. Our body language, that is how we node our head, shruck our shoulder, tap your feet, flick your fingers, plays a major role in patient's perception. Our facial expressions, that is the way we look, our eye contacts can easily tell the patient our emotions like anger or happiness and also how bored one person is. Posture is not only to align anatomically to prevent bone deformity but also shows how we carry ourselves with confidence. India is rich in its tradition. Common gestures, like shaking hands, are common but restricted to some extent between a male and a female. Then we fold the hands and wish 'Namaste'. This beautiful gesture makes people feel wanted and courtesy is maintained. Various culturally accepted gestures may be utilized. In public appearance, it's hard to manage our hands. Many a times either you poke your nose, scratch the head or put them in the pocket. These gestures though infrequently and unconsciously used can be rationalized from situation to situation.

My Intellectual Health: My Thoughts and Understanding

Intellectual health refers to our cognitive level. Handling situation depends on how well we are able to think critically, clinically reason and taking the right decision. Intellectual abilities as well as our affective and psychomotor skills interweave. Being positive has greater role as nurses in the real scenario in handling critically ill patients. When one is positive, she or he is able to think clearly and appropriate attention to details. We need to be open to ideas, new learning so that we are updated with current information to

solve greater problems patient may face with. Having good physical and mental health is important because when one is physically or mentally under stress, one may not be able to think and act reasonably. Our emotional states can be challenging to ourselves because of our disordered thinking. If we are healthy intellectually, we need to:

- Think critically for every concern patient comes with.
- Possess good sense of humour so that depressed moments can be made lighter.
- Lifelong learners to keep abreast to current changes.
- Have a fulfilling or satisfying work life balance so that we find meaning in our lives.
- Have confidence and high morale to boost your self-esteem.
- Take up challenges and face them wisely.
- Be curious and be helpful to others in times of need.
- Motivate yourself to enjoy one's hobbies to keep oneself lively.
- Exercise to stay healthy.
- Stay with social groups to get mental strength and vigour.

My Spiritual Health: My Being

Utmost wellness can be made through our spiritual wellbeing. Our thoughtful silence is not a state of nothingness but a state of inner peace and deep comfort one experiences after being relived from the pains and aches of life or poor health. Spiritual wellness in the inner peace which everyone seeks when one is unwell physically, emotionally or mentally. Our thoughts are very important. They are nucleus of every action of ours. Thought shapes our world and thoughts are made through knowledge. A person with good knowledge of the problems makes meaningful thoughts that give meaning to the health problems and how to solve them. In the beginning, world seemed round, later science proved it is spherical in shape. Likewise,

our belief system would have developed through many of our thoughts. Cultural differences and religious practices would have had great influence on health care. Understanding oneself understands true self. Human beings are mostly body conscious whereas we are expected to be soul conscious. Meaning and purpose in life is one thing you and I run for every nook and corner. But have I ever thought of stopping a moment and think 'how important I am'. Or how important that person is to this world. Each one need to feel special. It's like a beautiful costly car you purchased but if one of the wheel which cost you thousands of rupees doesn't function, you probably cannot run the car. This example helps us understand that we need to have harmony and peace within our self. Although spirituality is a personal business, yet a health care professional can help patient find solace in the midst of troubled feelings of sickness. Living everyday with values will add life to years. When we introspect the beauty within oneself, one tends to recognize the real being, the real existence and will also be able to find meaning in living. This awareness will create confidence in the individual and live a meaningful life. This very peaceful meaningful existence will create awareness for others too without any efforts. The capacity to love, forgive and live with fulfillment makes you feel your spiritual health. Our faith in God, our values, beliefs, principles in life, and moral values defines our spirituality. Learning to meditate, relax and reducing our stress will help us find our comfort.

"The greatest disease in the West today is not TB or leprosy; it is being unwanted, unloved, and uncared for. We can cure physical diseases with medicine, but the only cure for loneliness, despair, and hopelessness is love. There are many in the world who are dying for a piece of bread but there are many more dying for a little love. The poverty in the West is a different kind of poverty—it is not only a poverty of loneliness but also of spirituality. There's a hunger for love, as there is a hunger for God."

Mother Teresa

2

Factors Influencing Patient's Psychosocial Health

Outline

- Factors influencing patient's psychosocial health
- External and internal factors
  - ♦ External factors: role of family and friends
  - ♦ Internal factors
- Non-medical and medical factors
  - ♦ Non-medical factors
  - ♦ Medical factors

FACTORS INFLUENCING PATIENT'S PSYCHOSOCIAL HEALTH

When an individual is ill, he is faced with multiple factors that interplay with his illness experience. Recently, Mr. X was newly diagnosed to have type 2 diabetes and also hypertension on his first medical check-up. Mr. X looks normal, healthy, slim and trim although both his parents were hypertensive and diabetic. With no habits, and having eaten diabetic diet almost to suit to parents' meal pattern, yet developed at very young age diabetes and hypertension. He asked 'why sweet people have diabetes'. The doctor's answer was 'It's a gift from parents'. The answer sounds ridiculous but we know that genetic factors play a major role. Although unable to accept the fact through evidence of blood and urine report, he had various questions to ask, such as why I only got it, why so early, I even never ate high calorie diet, never went out to party, etc. Patient tends to reason every

bit of his past experience with oneself and finds oneself at the end of depressive expressions. Any newly diagnosed patient feels between two ends. Added to his health problems, he now has to take lifelong medications and practice all life maintaining health habits. It is not too hard but tough to handle and comply. Therefore, understanding the psychosocial factors that disturb the individual during illness experiences are explained below.

- Type 1: External and internal factors
- Type 2: Non-medical and medical factors

TYPE 1: EXTERNAL AND INTERNAL FACTORS

External Factors: Role of Family and Friends

Family members undergo a strange feeling of losing their loved ones when their loved ones get diagnosed with life-threatening illnesses. Then how much a patient who actually is facing the reality will feel about his disease, death and dying. Psychosocial support at this juncture becomes a paramount to the patient as well to the family. Relationship to the patient matters in relation to the amount of stress and psychosocial problems individual has. If the patient is a child, then mother gets most affected. If the only earing member is diseased, then the entire family gets affected. Care and concern shown by family members become one of the most important factors in treatment and recovery. Unwanted behaviours shown by family members either during visit or lack of support of their loved ones during illness experience can have low level of confidence and neglect by the patient. In today's world where nuclear family is the style of every family, caregivers are a concern. In the past when any member of the family is sick, family members come together to share their responsibilities in taking care of their family member. But today everyone staying away from each other and being busy with their own job, people have very little time to pay their attention towards the ill person's welfare. In many circumstances, untrained personnel are placed at home to take care of the sick or are put up in the day care or a nursing home with a paid attender to look after. This definitely adds to the feelings of neglect. Family and friends support is best counted by any individual in illness experience. Clinical experience speaks "Mrs. X 19 years old was diagnosed with end stage renal disease (ESRD). She was advised renal transplant or haemodialysis for her sustenance. She hails from

a poor family with her father being only a driver merely earning enough to manage their living. Mother promised to give one kidney and renal transplant was done but rejected in a few months and once again back to haemodialysis. Haemoglobin became an issue and there was no one to replace blood to the blood bank. She at last reconnected all her classmates and to my surprise 9 of her classmates would alternate and donate blood for her". This is what friends mean to her in her last days. Therefore, high level of mental disturbance or stress among the friends and family may also hamper the care support especially emotional aspects and their adaptation is a must through counselling.

Internal Factors

- **Heredity:** Depending on the type of personality that one carry with, anger, denial and depression may set in with any patient who is diagnosed with either a chronic incurable disease or a fatal disease that needs a prolong treatment that may lead to disappointment and low self-esteem in life. People who are not able to cope up with the challenges in sickness and treatment may cope up using unhealthy behaviours and also living with negative environment eventually contribute to poor quality of life and morbidity. Stress response is important for individuals to protect oneself but excessive stress due to illness and treatment is harmful to the individual as catecholamine is linked to cardiovascular disorders, like hypertension, myocardial infarction and stroke, cortisol to cardiovascular disease, type 2 diabetes, reduced immune function and cognitive impairment. Therefore, adequate balance between catabolic and anabolic processes is essential for healthy survival.
- **Hormonal function:** When any patient undergoing stressful moments due to diagnosis or treatment sets off neuron in the hypothalamus and releases corticotropin releasing hormone (CRH). It is then transported to the pituitary gland and helps secret adrenocorticotropic hormone (ACTH) which stimulates the adrenal cortex producing cortisol. To keep our system in balance, a negative feedback system helps. That is high level of cortisol triggers the hypothalamus to reduce its output of CRH which in turn lowers the level of ACTH and cortisol. Long-term rise of cortisol may lead to morbidity (Fig. 2.1).

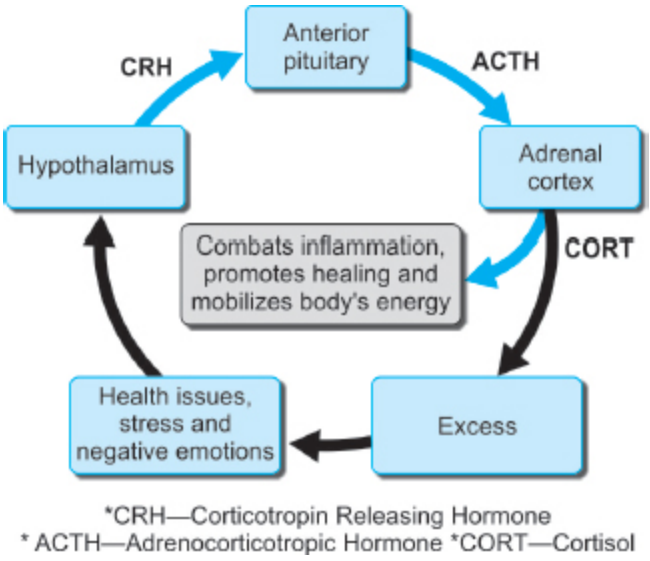


Fig. 2.1: PNI and health issues—a cyclic process

- **Physical fitness:** Exercise keeps our physic fit and also keeps away from cardiovascular risks, stroke and protects an individual from cancers, osteoporosis and promotes psychosocial wellbeing. When an individual is anxious we know it is due to distress caused by their health concerns and if one land up with depression, you can identify the patient being very aloof with less ADL. Exercise can bring forth better mood state, better self-esteem and wellbeing during an illness. As health care professionals, one needs to make correct assessment of the state of mind as depressed mood, anxiety, stress and low self-esteem could be due to medications, social stigma, isolation, lack of family support, etc. Correct identification is a must for better treatment and outcome. Therefore, one needs to occupy the patient with regular ADL and also some form of exercise to strengthen and tone up the physical health to improve quality of life.

TYPE 2: NON-MEDICAL AND MEDICAL FACTORS

Non-Medical Factors

- **Access:** Access to physician in times of need and also nurse patient ratio for the care required based on progressive patient care.
- **Waiting area:** A good waiting area for the patient's party will solve hassles related to information to be given on progress of the patient

from time to time and also a time for them to relax as they wait for the patient.

- **Information:** Information related to various procedures and care aspects to be conveyed to the patient as well as party by a well-trained personnel or by a counsellor who can be a mediator to make the patient convinced and also make the work of the physician more at ease.
- **Family members' presence/visit:** Experience of being a patient and being a patient party is different from different perspectives. Wanting to see a loved one by the side of the patient in critical condition and family members wanting to see the patient are two different sides of a coin. Patient may experience a sense of fear related to ICU experience and wanting loved ones to care for him and be with him or her. On the other side, the loved ones may feel a sense of losing someone close to them and also could feel the difficulties faced by the patient with all modern technologies which they hardly understand. Restricted time for visiting the patient makes the patient party feel all the more anxious so as to what is happening and also feeling that they aren't able to care for him or her. Hospital need to crucially look into the matter to see if there could be a better protocol to allow patient party to partake in the care of the patient when they are critically ill or needing loved ones by their side.
- **Administration:** Administrative protocols related to admission and discharge should be made people friendly. Long hours of waiting in the billing areas as well as discharge planning need to be made patient friendly and waiting time to be reduced.
- **Communication and IPR:** Every patient and patient party needs interaction with their nurse or physician to get answers to their queries. Counselling room adjacent to the ICU or the care area to be made possible so that once the physician has evaluated the patient and made his treatment plan, points of concerns can be discussed with the patient party so that they are clear of their expectations and prognosis.
- **Ancillary services:** Ancillary services, such as basic needs, need to be provided to both patient and patient party as they may come from far distance and timings may not suit them to go around hunting for food or shelter and also with required calories and selected pattern of diet

for the patient. In this regard, a good pantry and a dormitory will help patient party to be at ease.

Medical Factors

- **Qualified health care professionals:** Qualified physician and nurses make a difference in the critical care aspects. Nurses, doctors and allied health personnel with specific training have to be made available to carry out specific skills through CME or CNE. Recruitment process need to focus on specialized nurses trained for the right job. Standardization of training with standard curriculum is a must for all nurses across the country to provide standard care through evidence based.
- **Equipment/technologies:** Equipment used in the critical care areas need to be monitored for its functioning through stock checking on every duty shift. Keeping all instruments in working condition can save the lives of patients in emergency. Calibration of instruments to be carried out from time to time and replacing of nonfunctioning instruments or equipment to done on regular schedule through appropriate systems within the hospital.
- **Quality assurance system:** Care standards to follow strict adherence to quality system check on regular basis. Certification by standard qualifying body is a must for health care sector to focus on patient safety and satisfaction.
- **Medication:** Medications of affordable cost is necessary as many of our patients falls below the poverty line and they cannot afford high cost drugs but equally effective in the treatment of their conditions. Dangerous drugs and narcotics need to be under strict custody of the nurse and check for expiry date and drug inventory to be carried out daily. Maintaining rights of patients to be emphasized to minimize errors in medication.
- **Quality protocols and procedures:** All procedures carried out for the patient should follow strict protocols which are evidence based. Right from the admission till discharge, patient and their family members expect a process that would be easy and convenient. When laid down protocols exist in an emergency or critical care unit, it is easy for any health care professionals follow the instructions. It also saves time

from waiting for orders and implement them. Strong protocols help develop good standing orders for nurses to function in times of emergency and work with ease and perfection.

Summary

Literature clearly depicts that patient's psychosocial is shaped by multiple factors that makes him/her feel safe and secured when he/she is under the care of the health care professional. His/her internal factors, external factors, medical and non-medical factors play a significant role.

3

Patient Satisfaction

Outline

- Introduction to patient satisfaction
- Principles for customer satisfaction
- 10 pillars of patient satisfaction
- Advantages of patient satisfaction
  - Why patient needs to be satisfied
  - Standards for patient satisfaction
- Patient satisfaction questions
- Health care professionals' attitude towards patient satisfaction

INTRODUCTION TO PATIENT SATISFACTION

Patient care is the core of every health care professional. Satisfying the health needs is the mission of every health care organization. Creating a culture that provides holistic care understanding their body, mind and spirit will help satisfy an individual's need especially when they are ill and going through difficult times in life. Therefore, providing client centred culture will help patients accept for what they are during their hospital stay. Without patient we don't exist either as health care professional or as an organization. They must be satisfied while they leave the hospital either with regained health or to the worse with death. Challenges that may pose us while we care for the patients are:

- Long-term interaction
- Unstable emotional level, such as anxiety, fear and pain

- Clinical competency of the health care professionals and patient's understanding or demand
- Wide demarcation between professionals and patients
- Lack of high tech equipment to support
- Long hours of work for professionals that may hamper communication bonds, etc.

PRINCIPLES FOR CUSTOMER SATISFACTION

The principles that every organization stand for customer satisfaction are:

- Quality care
- Managing patient's anxiety and fear
- Good therapeutic communications
- Personal attention or individualized care
- Accountability
- Work culture to enhance quality in life of patient

10 PILLARS OF PATIENT SATISFACTION

According to Wendy Leeboy (1984), 10 pillars are:

- Leadership vision and commitment
- Continuous improvement through process designing
- Employee empowerment and engagement
- Accountability by all staff
- Monitoring and feedback
- Vertical and horizontal communication
- Staff development and training based on need assessment
- Service recovery dissatisfaction to satisfaction
- Patient focus
- Sustainability

In today's modern health care delivery system, patient has turned customer and health care professionals as provider of care unlike the past when physicians were considered God. Today without the patients, neither

the physician/nurse nor the organization exists and henceforth patient becomes the core of focus. In reality, the health care professionals are the internal customers and patients, their relatives and others as the external customers. Therefore, treating customer with satisfaction will help develop total quality management system.

ADVANTAGES OF PATIENT SATISFACTION

Advantages of patient being very satisfied are:

- Revisit to the hospital/physician with trust
- Higher expectation in subsequent visit through prior experience
- Better fame and name for the organization
- Better perception by customers
- Attainment of goals or vision of the organization, etc.

Sham was just 8 years when he was diagnosed with Ewing's sarcoma. After he had fallen in school during the games, his parents took him to the hospital feeling that he had a fracture. Instead his diagnosis was cancer. He hardly knows any medical terms and his 12-year-old brother took care to communicate. He had couple of surgeries that is one to remove the tumour and one to amputate the leg. Today after a couple of years later he is fine running with his prosthesis. He was so grateful to his doctors and nurses who accompanied him throughout his illness experiences. Therefore, staying positive during illness can help overcome life's uneventful moments. We earnestly request health care professionals to keep oneself cheerful with the patients to lighten their every troubled moments and patients too need to focus on one's wellness and be happy with care given through trustful relationships by their physician and nurses. Smile of positive attitude can solve all ailments.

Why Patient Need to be Satisfied

- Our primary focus is patient
- Being satisfied with care given seems to be the strongest determinant for a well-functioned hospital
- Today's expectation to quality service is to satisfy our customers

- To coordinate with family members and friends for social support and care maintenance thereafter
- To update and train workers for their motivation and to rebuild their work life balance for better job satisfaction which in turn can bring about patient satisfaction.

Standards for Patient Satisfaction

- **Punctuality/time sense:** This morning I interacted with Mr. X an American who is in India and who is to undergo a knee surgery for meniscus injury. I just knew him the morning when a friend of mine needed my help to reach him and also to locate where is the Unit where he was posted. Over the short conversation just before his surgery, I could sense his anxious state as his surgery was getting delayed. He was hungry, dehydrated as he could not have his usual coffee. I kept explaining to him regarding the present case that's going on and some delays would have caused his delay although he was informed of his time for OT which was at 11 am. His wife kept on consoling him and she being with him was a great moral support. Punctuality was my principle and I had to break it with lots of Yoga as waiting beyond time causes me restlessness. Finally he was taken to OT at 12 noon and we wished him all the best. He was indeed happy that his surgery will begin and that he can go home the same day. To his surprise, the surgery took place only at 3 pm and he expressed that no one spoke to him in the pre-medication room. He expressed his wish for someone to converse with him although he never received. It will be very nice if at least someone who is administering the pre-medication informs him of his proceedings and also what is happening to him. Though we presume we shouldn't be disturbing a patient, he or she may always want someone to talk to them to clarify their concerns. When talking about the amount of stretch time he spent inside the ICU and preoperative room, he expressed that, 'now that I got used to waiting beyond time because in Indian system waiting becomes almost inevitable' and that took off my patience sometime back. Therefore, punctuality or time sense has to be kept up as patient can become more anxious and worried. We as health care professionals feel 'let them wait' when one case is going on and other's time is out. Patient cannot understand what's going on inside

the OT and each patient waiting for his turn has the right to receive the right information even if the case is delayed. Explaining the reason for delay may help him tolerate and be patient.

- **Quality care:** Quality is designed to follow a cascade of standard protocols and procedures. Every hospital approved by NABH expects. Audits either internal or external need to be conducted on regular basis for continual improvement.
- **Managing patient's fear, apprehension and discomfort:** Health problems and anxiety related to disease or treatment outcome creates fear in the individual. Even to do a test, the patient seems to be restless till the test results are delivered. Patient may even breakdown during diagnosis disclosure. When anxious no patient can take a right decision and, therefore, the nurse need to be well trained to counsel the patient to handle prediagnosis stress and post-test counselling.
- **Therapeutic communication and personalized care approach:** A good therapeutic communication can solve half of patient's problem. Explain to patient based on his level of understanding. No jargon to be used. Communicate to show you really are concerned for the patient and give time till they understand what you mean to them.
- **Individualized attention:** In today's corporate world, care too is privatized and every patient wants personalized care and pay good for health care facilities. It may be hard for the poor to afford but with the existing health care insurance facilities even the not so affordable group of the society are going in for privatized care. People have realized the health care facilities and opportunities. Though the facilities and population are reverse in the urban and rural sector, yet many health care organizations are reaching out to the rural community. Not only the patient but the family members need comfort and right informative care for their patient. This shift of health care concept and costs are burning issues in our society. Therefore, it is our utmost need to train the nurses to get well equipped with the changing scenario and be able to handle patients of various natures.
- **Accountability and commitment:** Nursing in the 21st century has taken a gigantic leap to the standards of care. ICN code of ethics, INC code of conduct and also super specialization has taught us to be accountable. Nursing being the largest health care workforce, the need

arises as to how we can focus and shape the nursing care pathways. It is high time that we set equal standards of care be it in the private or the government sector by lifting our assertive efforts and raising the current issues at the political and economic level. Roles and responsibilities to be well defined for nursing jobs. Nurses to be paid for the quantum of work assigned according to her performance. Performance appraisal though causes misunderstanding and pain to same level workers, serves the right purpose. People need to be paid and rewarded for the accountability and earnest efforts put forth. Need arises for 360 degrees feedback from the customers and superiors and also peer to our performance. Any misconduct to be handled legally. Today covering up the mistakes done in the hospital outnumbered due to ill-trained health care professionals. In an institution where students are posted for their training needs close supervision to avoid undue errors and complication of incomplete treatment. Accountability from the part of very novice and trained nurses need to be documented and consequences need to be dispensed.

- **Work culture of the organization:** Talk about quality, the back bone is quality assurance certification. Sustainable health care sector holds on to the current changes through certification. Certification need and demands training from time to time. Work orientation to any newly appointed staff and students so that understanding improves quality. In this arena, a hospital or educational institute cannot sustain with continual improvements. People are very much aware of quality process and services and our duty demands right work culture. Being controlled by a system that suits to continuous monitoring, training and action plans, organization is bound to be successful. Having a good vision, mission and quality objectives, one can render care as per expectation. Complying with the values and standards will help us do our job with 100% determination.
- **Values and objectives of the organization:** Every institution or organization holds on to some values they wish to comply with, such as transparency, accountability, loyalty, humane touch, integrity, etc., which are essential to satisfy our customers. Well set values and healthy adapted workers will find their work satisfying. We all cling to our principles and values in life that makes our lives as well as other's lives meaningful.

- **Respect:** Addressing and carrying out patient centred approach. Respect includes involving the patient in his treatment decisions, and his priority given utmost importance. Cultural differences to be respect as well as staff need to be culturally sensitive. Patient's wishes need to be considered.
- **Health care professionals' attitude:** Special attention to attitude building is a must for health care professionals. Being trained although for science and evidence the humane aspects may slip off from an individual. The science of humanity can take us along way. Understanding our good attitude and the attitude for high moral practice will keep us away from legal issues.

"Seven Deadly Sins"

- *Wealth without work*
- *Pleasure without conscience*
- *Science without humanity*
- *Knowledge without character*
- *Politics without principle*
- *Commerce without morality*
- *Worship without sacrifice."*

– Mahatma Gandhi

- **Behaviour of caregivers:** Every organization gives minimum guidelines for code of conduct. International Council for Nurses (ICN) speaks about code of ethics in patient care. *Nurses and people:* Where nurses are responsible for the people under their care. Their environment, individual differences, confidentiality, cultural differences, society, and when to advocate for patients during their care. *Nurses and practice:* It is the nurses' utmost responsibility to be accountable for the care provided. They need to maintain the standards of care and promote continual improvements in their practice. *Nurses and professions:* It is not only care but the nurse has her/his major responsibility to implement standard clinical practice through evidence research, managerial skills, and also education. The nurse expertise herself on the evidence-based care to keep to the professional code of conduct which is the core of care. Therefore, to

have a sound behaviour, a sound personality and a sound organization upholding the code of conduct is an essential component. *Nurses and coworkers:* It speaks about our work in collaboration with others. Healthy relationship in the workplace creates added advantage on the patient where specialized care is rendered. Any good communication among the health care team will impact personalized care. Our behaviour of good intentions is important matter to patient and the society at large.

- **Dignity and privacy:** Dignity is a matter of how people feel, think and behave according to the value one possesses and how others relate. We need to treat patients with respect. Privacy is one area of concern. Every patient is conscious of when he or she is under the care of the health care professionals. When a doctor or a nurse wants to carry out a procedure, they are so used to as they have been repeatedly doing the procedure but for the patient it may be his or her first time being exposed in front of someone. Having a screen or closing the door may help patient gain confidence. When Mr. X was about to be taken to the OT, the ward boy came to shave the right leg for the knee surgery. He was given a gown which was quite transparent and while wearing it, he felt he was exposed. Diaper was provided as he would undergo a spinal anaesthesia. When covered with the diaper he was very comfortable even to shave the entire right leg. Having to consider the patient's privacy, one may be able to gain his or her confidence. Training or orientation of newly appointed staff to focus on:
  - Confidentiality
  - Issues of privacy and dignity
  - Record access only by designated staff
  - Sensitive issues to be handled with dignity
  - Consent to be obtained for any procedure and also to get into any personal space
  - Respect patient's personal conversation and documents

PATIENT SATISFACTION QUESTIONS

With the advent of technology, assessing patient's satisfaction is easily obtained. Mobile communication, e-mail and also feedback questionnaire

dropped in any corner of the hospital helps management so as what level care has been rendered. Personal expressions of satisfactions are being asked for, such as:

- How often does your consultant visits you during your stay in the hospital?
- Do the doctors and nurses treat you with respect?
- Did the team explained to you of your treatment or test ordered?
- Are the services comfortable to you?
- Did they explain to you in your understandable terms for the medications you receive?

HEALTH CARE PROFESSIONALS' ATTITUDE TOWARDS PATIENT'S SATISFACTION

- Professionalism
- Multidisciplinary approach
- Clinical experience
- IPR
- Clinical outcomes
- Good clinical facilities
- Well-coordinated team

Happiness comes when you believe in what you are doing, know what you are doing and love what you are doing.

Ally

4

Multidisciplinary Approach to Patient Care

Outline

- Introduction to multidisciplinary approach to patient care
- Health care professionals' role:
  - Nurse
  - Physician
  - Nutritionist
  - Physical/respiratory/occupational/speech therapists
  - Spiritual counsellor
- Benefits of multidisciplinary approach to patient care

INTRODUCTION TO MULTIDISCIPLINARY APPROACH TO PATIENT CARE

The process of taking care of any terminally ill or critically ill patient requires multidisciplinary team members in the health care to benefit the patient, their family, community and significant others. No one team member will be able to function in all level as all of us are trained for specific aspects of care. Nursing being the team coordinator of care is due to the constant care provided, yet other team members play also role for its perfect management. As per assessment and re-assessment, either specific test and treatments are applied for the patient so that best therapeutic goal is achieved. Treatment or care is continued till the care benefits the patient and if no longer, then services may be terminated (Fig. 4.1).

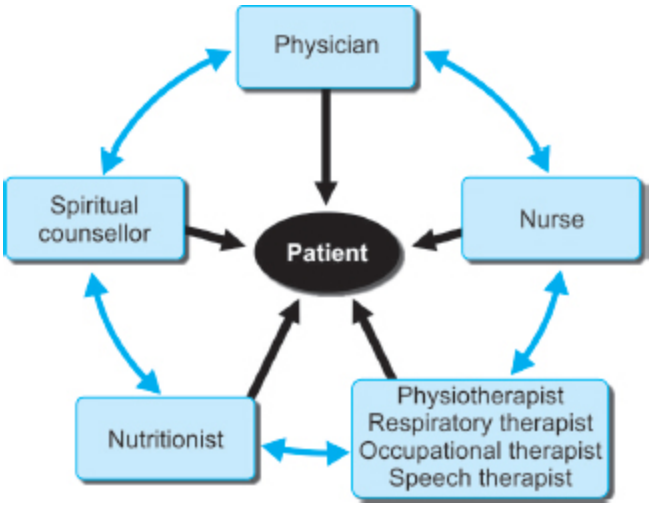


Fig. 4.1: Multidisciplinary approach to patient care

HEALTH CARE PROFESSIONALS' ROLE

Nurse

The patient is under 24 hours observation by the nurse to note their self-care and need for care based on the nursing assessment. Using nursing process approach, the nurse assesses the patient, sets their target therapeutic objectives, plans care with rationale, implements and also evaluates their care provided. They report their assessment findings and management effectiveness to the physician. It is nurses' specific role to teach the patient or family about their self-care abilities to be carried out while they are back home so that continuity of care is provided with confidence.

Physician

The physician diagnoses the patient based on the assessment made and also the specific findings in the tests provided. They prescribe medications appropriate for the diagnosis made and authorize other health care team members to carry out their respective roles and functions.

Nutritionist

Nutrition or diet becomes a major factor in caring for patient who is critically ill and unable to take food themselves or people with specific diet recommendation based on disease or disorder, e.g. diabetes, CAD, renal failure. Therefore, the nutritionist's role to understand patients' nutritional

status, their eating patterns and body's requirements to manage their therapeutic blood or physical level is a major concern in today's treatment modalities.

Physical/Respiratory/Occupational/Speech Therapists

The critically ill patient needs multidimensional needs rendered by health care professionals. When they are on either ventilator or speech and physical conditions are not permitted for one's normal functioning, the role to enhance health status lies in the exercises that can bring about muscle strengths and cardiovascular status, the respiratory care to keep one free from aspirations and normal respiratory status.

Communication becomes a major hurdle in dealing with the critically ill patients. Communication boards are developed for use in ICU where patient is bound to ventilator but effective speech expressions can only be fulfilled with the expert skills of speech therapy to enhance their communication skills and abilities.

Chronic disease may cause disability or inability to function in the way the individual had been prior to his or health problems. If any disability or decreased ability to function normally, then the role of occupational therapy becomes very significant in performing one's activities of daily living, prescribe exercise to improve their flexibility and also adaptive ways to managing their job with or without device.

Spiritual Counsellor

In India, religious and cultural factors play a pivotal role in patient care. Beliefs, practices and preferences of individuals differ depending on to which religion they belong to. Major religions across India are Hindu, Muslim, Christianity, Sikh, Jainism, Buddhism, etc. Each of the mentioned religion practices their faith related to illness and health in different ways. When patients are admitted in the hospital, the nurse counsellor/professional counsellor on arrival of the patient needs to collect appropriate history to understand their beliefs, practices and preferences based on their religion or faith to help us fulfil patient's desires related to care aspects (Fig. 4.2).

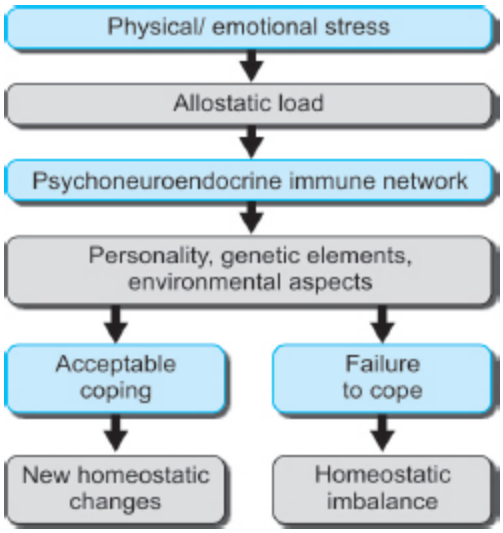


Fig. 4.2: Psychoneuro-immunological response to psychosocial health problems

BENEFITS OF MULTIDISCIPLINARY TEAM APPROACH CARE

- Allows nurses to make multiple nursing diagnoses with ideal assessment.
- Investigations can be minimized and not duplicated or repeated.
- Initiation of early treatment based on relevant test.
- Multiple management approach to care.
- Individualized care plan formulation.
- Well-coordinated care.
- Improves patient satisfaction through improved health status within time frame.
- Well-informed care by all team members
- Continuity of care assured.
- Evidence-based care based on new findings and added technology.
- Creates optimism towards patient's recovery.
- Shorter hospital stay.
- Economical.
- Knowledge sharing is possible in team approach.

- Opportunity for discussion and clinical conferencing.
- Improves work culture.
- Reduces conflicts among health care professionals as roles and responsibilities are well assigned.
- Improves job satisfaction among health care professionals.
- Interdisciplinary research is made possible through coordinated care approach.

5

Quality of Life of Critically ill Patient: Holistic Considerations to Patient's Psychosocial Health

Outline

- Introduction
- Distress: A threat to life and holistic approach
- Psychosocial health determinants
- How to win over patient's satisfaction and change his behaviour
- Psychological disturbances and their management

INTRODUCTION

Our biological and psychosocial factors in one's experience are many a times interwoven in the process of illness. The varying degree of experiences accounts to the total quality of life of an individual with health problems and expresses their unique experience as a patient when they get hospitalized or being cared at home.

DISTRESS: A THREAT TO LIFE AND HOLISTIC APPROACH (Fig. 5.1)

Actual assessment and planning nursing care based on identified concerns of patients individually will help reduce distress and improve quality of life. Areas of concerns are:

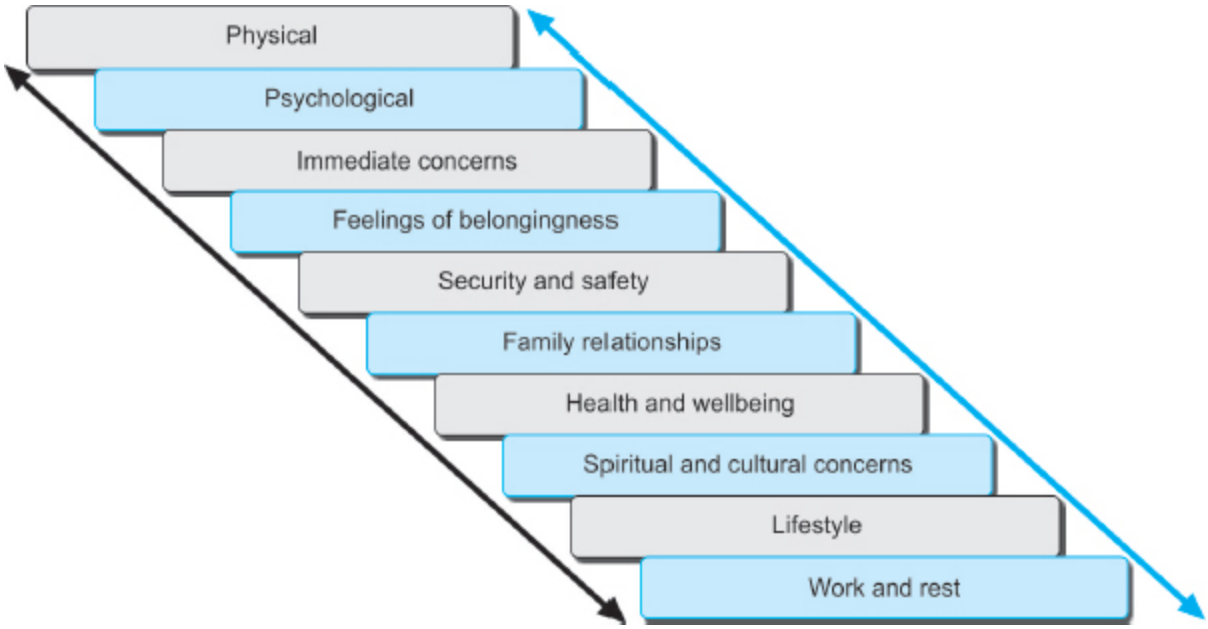


Fig. 5.1: Holistic approach to quality of life of patient

When one is diagnosed with a chronic disease which may not be promising, then the patient starts looking at prolonging life and improving quality of life. Prospective, longitudinal cohort study among 396 advance cancer patients shows rank order in their concerns that is ICU stay in final days, hospital death, religious prayers and meditation, site of cancer, feeding tube in place during last days, care at the hospital and palliative chemotherapy in the final week. Patients who refused hospitalization were found to be less worried. Patients who were visited by a religious pastor, prays in hospital and who feels therapeutically aliant with their physicians had better quality of life. *(Zhang B, Nilsson ME, Prigerson HG. Factors important to patients' quality of life at the end of life. Arch Intern Med. 2012 Aug 13;172(15):1133–42.)*

PSYCHOSOCIAL HEALTH DETERMINANTS

Healthy psychosocial health is determined by the following factors given below which is influenced by access to quality health care facilities and also the standard care aspects provided by a hospital based on policies and protocols (Fig. 5.2).

- Patient's behaviour
- Biological factors

- Social environment
- Physical environment

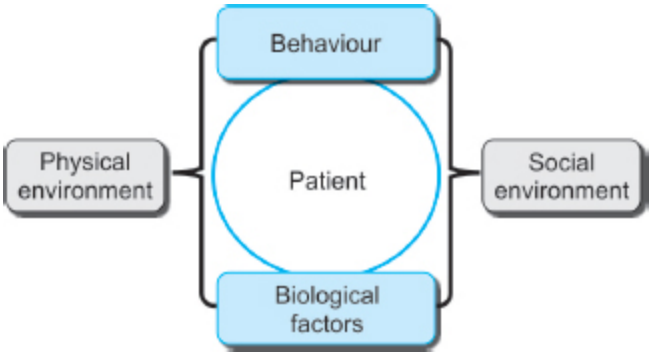


Fig. 5.2: Psychosocial health determinants

Patient's Behaviour

Patients behaviour is greatly shaped by the diagnosis made on him and also the type of treatment they undergo either lifelong or temporary. We generally understand that patient undergoes a stage of depression when chronic diseases are being tagged to them. This depression could be because of imbalance in the biochemical, physiological, and neurological changes due to the disease process and advancement in the health issue. All the above adds to the potential development of depression. When one is depressed, the behavioural signs and symptoms would be helplessness, hopelessness, low appetite, sleep disturbances, low weight, low energy, irritability and anger. Therefore, patient's behaviour may be shaped by his own problem as well as his immediate environment and also the social environment that is the interaction shares with his family, friends and spouse.

Biological Factors

SIGMA (Slim Initiative in Genomic Medicine for the Americas), as reported by Haley Bridger on 20th Dec 2013, describes that people who carry the higher risk version of gene are 25% more likely to have type 2 diabetes. The higher risk form of the gene has been found in up to half of people who have recent Native American ancestry, including Latin Americans. The variant is found in about 20% of East Asians and is rare in populations from Europe and Africa. We understand that diabetes is a

disorder that involves the hormone insulin. Lack of physical activity, obesity, over weight, etc. are some of the forms with which one may develop diabetes. Hence our biological make up and also our lifestyle shape our health. Low level of health and treatment patterns may disturb our psychological health in varying degrees. So is the case with any disease or disorder.

Social Environment

No one can live like an island. Social support means the physical and emotional comforts that one receives from family members, friends, spouse, co-workers, etc. Indian family and friend circles are closed knit and hence visiting a sick person, bringing them what they may need to eat and even waiting for them patiently in the hospital waiting areas are common scene to show our concern for the person. This very act is because we value our social system, and respect for the love and concern. We all need someone to share our emotions, our feelings, likes and dislikes, happiness and sorrows. Man is a social being and more social support is needed when one is ill and helpless. We count our social support when in trouble. With the changing demographics in this century and the behavioural attitude of the present generation, it is imperative that we induce social system, norms and values. One child norm and nuclear family brings in isolation just to only the close family members and we tend to forget our neighbours and friends. Mr. X, father of a professor in a campus, was brought for his investigations for having had a mild stroke at his place. He was kept under observation for a few days where the daughter in-law was looking after. One afternoon Mr. X was not responsive and the daughter in-law knew no driving. Called the husband to his office and mobile was not reachable. The only thing she did was to call a neighbour who was an American couple who were visiting professors. They just happen to be there at their home opposite to this neighbour. The couple took Mr. X in their car and was brought to emergency unit and thereafter he was taken care in the hospital. Mr. X expresses “if they were not there, that was my last day”. It doesn’t matter who they are, but the need and help rendered mattered to the patient at the right time.

Physical Environment

Patient who occupies as close as to the duty counter is more at rest and peaceful than those who are placed at the end of the unit. Access and proximity helps induce sense of security. In an ICU, where patients are kept under strict observation by health care professionals but patient party are restricted. This very environment can become very stressful and uncomfortable for the patient.

Patient's room: Our set up does not facilitate love ones' presence which in fact will ease the patient. Having a loved one nearby to care can induce a conducive and healing environment for the patient. Ambience of the room matters to the healing or positive outcome of the patient. When Mr. X was brought out of the OT, he asked his wife for a kiss. The wife closed their face with the bed sheet and gave him a welcome back kiss. Feeling embarrassed she said, we Americans show our love and affection through kiss and this is allowed in the hospital. Patient's expectations of affection and care may be expressed differently by different nationals, culture and traditions. Therefore, understanding cultural differences and practice will help a nurse to identify patient's wishes and concerns, so that right type of approach can be incorporated.

Waiting room/ dormitory: Having a rest room or a place for patient party may help people more at ease and comfortable to face the challenges of having a sick person inside an ICU or ward where their presence throughout is not appreciated. Having a rest room close to the unit will help better communication for the nurses and doctors with the patient party. Having a rest room close to the unit is best preferred or with life facilities if on different floors.

Prayer facilities: Most people like to pray and spent time praying for their loved ones better outcome. Irrespective of which religion, prayer place may help find peace and harmony while on wait in the hospital. In some Christian hospitals, the priest distributes sacrament for all the sick people of their religion. Receiving a sacrament from a priest means a lot to them. Faith helps heal one's soul. Happy soul can make a difference in bodily health and feelings.

Garden or place of natural scenario: Hospital within cities finds it hard to find another space for garden unless created a lounge on the terrace. In

hospitals where garden and seating arrangements are made, people find it nice to relax for few moments Irom their stressful events.

HOW TO WIN OVER PATIENT'S SATISFACTION AND CHANGE HIS BEHAVIOUR

- Improve therapeutic relationships with good IPR.
- Answer to queries by patient and his party. More understanding, more positive in approach.
- Use current technologies and tools which are patient friendly for communication and also get reports of the investigations.
- Involve family members in care process so that patient is comfortable and also family members feel good in giving care to their loved one.
- Empower the patient by involving him in his care and also helping him find ways to manage his problems while he goes back home.

In spite of all efforts, patient may still feel different and he may not be very happy and have psychological disturbances.

PSYCHOLOGICAL DISTURBANCES AND THEIR MANAGEMENT

As a patient suffering from any disease or disorder either curable or deadly, disease matters to the psychosocial disturbances or developing a psychiatric disorder which is very common among our critically ill patient. Depression is very common among chronically ill patient as they go through their illness experience and also due to long-term treatment which may cause long-term ill effects. Recognizing the psychiatric disorder or the psychological symptoms at the earliest is the key solution to morbidity and mortality.

- Diabetes and depression
- Cancer and depression
- Suicidal ideation

Psychosocial aspects or factors affecting patients are important components in management of patients. It is observed that 41% of the diabetic patients have poor psychological wellbeing and only 10% received

psychological care *(Young M. Diabetes Education: Behaviour change and motivational interviewing in the patient with diabetes. JEMDSA. 2010;15(1):45–7).* Psychosocial problems are different among Indian and western patients due to difference in the economic status, cultural and religious factors *(Sridhar GR, Madhu K. Psychosocial and cultural issues in diabetes mellitus. Curr Sci. 2002; 83(12):1556–64; Sridhar GR. Containing the diabetes epidemic. Natl Med J India. 2003; 16(2): 57–60).*

Cognitive behavioural therapy is strongly advised in diabetes, such as:

- Motivational therapy
- Problem-solving therapy
- Coping and counselling therapy
- Family therapy

Psychological management strategies, such as yoga, meditation, folk dance therapy, sexual counselling and eating habits in diabetes, are major concerns.

On the other hand, cancer and depression are crucial point to be noted in every stage of patient management. Of the many types and sites of cancer, QOL of patients with head and neck have difficulties in speaking, eating, breathing, and most of all appearance plays a vital role in self-image. Other than pain and palliation, psychosocial factors play a major hurdle in dealing with these patients. Educating the patient alone will not allay the anxiety and describe the depressive feelings. Research has brought about wonderful innovations in the treatment modalities yet research need to focus on psychosocial aspects which greatly affect patients' quality of life.

QOL is a construct, concept or hypothesis that may be different from person to person depending on their perceptions and expectations in life. Neither health care personnel nor family nor loved ones can satisfy 100% of anyone's wishes. Yet we wish to satisfy the patient to his best expectations through appropriate treatment and communication and most of all by being with them in their difficult moments. WHO defines quality of life as 'Individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' *(WHO Measuring Quality Of Life, 2007).* As nurses, we need to look into the gap between standards of care and patient's

actual expectations to affirm quality of life. Research trends show that health care professionals are interested in finding out factors that affect patients with various cancers thus helping health care professionals to understand patients from their perspectives that helps in improving their quality of life.

6

Psychosocial Factors to be Considered in Patient Care

Outline

- Introduction to psychosocial factors
- Cultural factors
- Spiritual factors
- Beliefs and practices
- Preferences

INTRODUCTION TO PSYCHOSOCIAL FACTORS

Holistic care includes care for the physical, physiological, cultural, beliefs and practices, preferences and spiritual aspects of an individual. All these factors contribute to the health and wellbeing of individuals or a community. The aim of holistic approach is to enhance QOL which is inbuilt in the trust that is being developed between the health care personnel and the patient considering their cultural, spiritual, beliefs, practices and preferences. Let's follow through the points given below to understand and provide care to patients undergoing illness experience.

- Cultural factors
- Spiritual factors
- Beliefs and practices
- Preferences

CULTURAL FACTORS

India being a country with various groups of people with varied religion, cultural differences, beliefs and practices. The nurse who works in critical care areas need to focus on the cultural factor which the patient strongly holds on to and that could lead us to legal concerns. Major cultural differences exist among the varied ethnic groups in India. But we share a common humanity and that our needs need to be respected by health care professionals at the background of our beliefs and culture. So when a patient is under our care we need to explore their cultural needs through good interpersonal relationship (IPR).

SPIRITUAL FACTORS

Spirituality refers to our human experience of being connected to a larger meaning and experience. It is beyond religion and everyone longs for the soul connection to the creator especially when one is distressed, ill, in loss and bereavement. The 21st century technology has made phenomenal advances focusing on cure rather than caring. Today it is also seen that health care professionals are trying their best to recognize the need for spirituality in their care aspects. Compassionate care that involves serving the patient considering his or her physical, emotional, social and spiritual aspects are to be considered. Therefore, the health care professionals need to understand their values, beliefs and relationships established between family members and friends and initiate the ability to find hope and meaning in life. Spiritual health contributes to the emotional health of the individual through motivation to positive health behaviours.

"Cancer didn't bring me to my knees, it brought me to my feet."

Michael Douglas

BELIEFS AND PRACTICES

Person's health beliefs and practices will definitely influence their health status. Beliefs are ideas and attitudes that a person believes to be true even if there are no scientific evidences. Belief system plays a vital role in the health and lifestyle choices. Beliefs and practices related to activities of daily living (ADL), taking medicines, visiting the doctor or getting admitted on certain days of the week. In few communities, cutting hair on Tuesday is forbidden. In another community, getting out of home on Thursday is not auspicious and hence even in critical situation; the patient may not be

brought to the hospital for needed care. Dying in the hospital that is outside of one's home means the person's body cannot be brought inside the house and the funeral preparation/process is done outside the house which is not the wish of everyone who wants to die inside their homes and be cared by their loved ones. The belief behind this could be translated differently in different community. In case of infectious diseases, the dead body is sealed and explained to the family members not to open again before the funeral but death bath is a ceremonial process in many Indian communities. Using turmeric, oil, etc. during death bath is positive practice. I personally have observed that, people in their dying process are given water in their mouth irrespective of their conscious state. The belief behind is that the person's soul should not be thirsty on their way to heaven or the supreme power's home. Therefore, it is challenging for nurses to understand each community's beliefs and practices which may influence their heavenly satisfaction.

Internal Factors Influencing Person's Beliefs

These are:

- Developmental stage
- Intellectual background
- Emotional factors
- Spiritual factors

Growth and developmental stage makes every individual perceive the right reason for one's health and illness. Knowledge in addition adds to the knowledge of health and illness experience. A very small child may not be very much disturbed by a bad diagnosis as he or she may not understand. The child will understand the care and concern shown by parents in times of physical concerns and also being with the child throughout the illness experience. Most preferred person for a child is mother when they are ill. Intellectual background and past experiences help an individual to develop the cognitive ability to comprehend health, illness and the best practices. An individual who is calm and poise during an illness diagnosis and treatment copes better than a person who is emotionally disturbed. Emotionally disturbed person may or may not comply to the treatment. Fluctuation in treatment choices may be observed as the person is irritable and restless. A

person who introspects and believes in some form of spirituality follows some values and beliefs for oneself and may be able to find meaning in life. He or she may be able to relate well with friends, family and health care professionals and may be able to take up positive health practices.

External Factors Influencing Beliefs

These are:

- Family practices
- Economic status of the family
- Cultural background

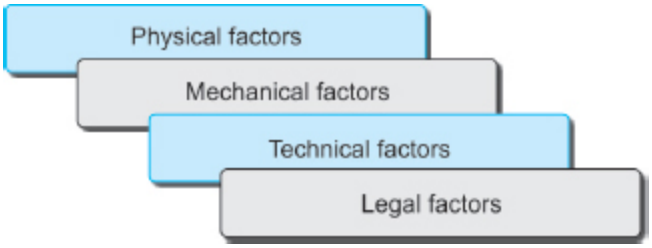
Family's health care values and beliefs totally shape the practices of members of the family. In India, health decisions are either made by parents or grandparents. In some families, main earning member of the family may be the decision maker. When a family routinely follows health checks yearly, definitely the younger generation takes it as a health habits to follow through their health routinely. Today's health care cost makes poor people to take poor health care decisions and, therefore, it may influence them to take up decisions that actually may not help the person's illness symptoms and cure. Instead of right medical management, they may go in for rituals. Therefore, economic status directly influences the practices. On the other hand, cultural background plays a major role in health care decisions depending on their beliefs and practices.

PREFERENCES

Preferences are defined as sense of likes and dislikes. Likes and dislikes of care aspects may pose to change depending on the impact on the individual by people who showed concern. Therefore, preference may change over time and decision may be taken accordingly. But when an elderly is admitted with a chronic disease which may not be promising to him, he may express few things which he prefers to be treated with when he is no longer able to take decision for himself in a dignified manner. There are communities where the elderly prefers to keep materials for their funeral process to be kept ready well ahead of time. They buy white clothes to be used which are washed and kept which signifies clean and pure to be used for a soul that has departed. Whereas few express how they would like to be

dressed when they are no more and be presented prior funeral. In India, there are so many religious groups, practising different customs and formalities but as a health care personnel, one needs to emphasize on the patient's preference. Therefore, preferences are made by every individual irrespective of his status in his or her family and we as health care professionals need to assess and activate our senses to understand its importance in the psychosocial aspects of care to improve their wellbeing and satisfaction even life after death.

Other Factors to be Considered in Patient care



Physical Factors

Physical factors of patient and his environment incude the unit where he is being physically placed with the instruments, machines and health care professionals. Every visit to the hospital is a stressful situation for every individual. In many occasions, the patient is kept under restraints and experience of uneasiness and lack of movement poses risk to patients and develop pressure ulcers. The patient is physically bound to the bed and no freedom to walk around and loses his emotional security what is happening around him. He is kept away from family members and friends and their presence is not appreciated in an ICU. Therefore, accessibility to his needs is never like home care environment. Although accessibility to new information is available yet patients are never completely told of his prognosis and treatment modalities so as to take the right decision. In Indian scenario, patients are expected to follow the instructions of the health care personnel without having to ask or clarify all their doubts. On doing so, the patient in many cases is labelled as a talkative patient who asks too many questions. The noise of the monitors, ventilators, infusion pumps, suction apparatus, X-ray machines being pulled to and fro, loud noises of health care team and the trolleys place great deal of sleep disturbance to one's sleep and rest leading to fatigue and discomfort. Noise level needs to be

kept within the frame of patient's tolerance and his rest pattern. Traffic during the rounds in the ICU greatly disturbs the patient's wellbeing. During the medical and nursing rounds, good amount of teaching takes place at the bedside, if it is a teaching institute. The number of people and the type of discussion plays a major hurdle in patient's level of understanding and stress built up due to discussion that may frighten the patient. This very discussions and crosstalks among the health care personnel may look normal to us but not to the patient. Therefore, teaching at the bedside needs to be in a calm and positive mode with the consent of the patient. It is imperative to educate the patient but not at the cost of his sleep and rest.

Mechanical Factors

Cannulation, suctioning, BP monitoring, Ryle's tube feeding are few among the common procedures that wakes up the patient from time to time. Frequent handling of the patient loses the patient's routine sleep throughout the 24 hours care. Care needs to be provided considering the needs of patients and their status. When patient is fast asleep, routine procedure to be kept minimal to avoid disturbance. Pushing and pulling the patient while shifting and also position change to consider level of patient's concerns.

Technical Factors

Technical factors that need to be considered in patient care are the medical device, equipment which is used in the diagnostic and treatment process. When you are asked to have an MRI done, the patient if not explained properly, he may face claustrophobia. Getting the shrill sound and also the irritating sound that may get registered in the brain. There are times patient runs away from the MRI table and totally refuses future MRI. Ventilator, defibrillators, cardiac monitors, altogether may be new to the patient and he or she may be stressed out in the ICU related to these machines which are used for them. Therefore, it is a must to explain for what the machine is being used for them in their own understandable terms.

Legal Factors

Better a thousand times careful than once dead. Patient safety should be mastered by all. Medication errors, falls, trauma and unsuccessful events during procedures are common. The health care professionals especially the

novices should be trained on specific skill areas with rationale so that errors are minimized.

It is the highest form of selfrespect to admit our errors and mistakes and make amends for them. To make a mistake is only an error in judgment, but to adhere to it when it is discovered shows infirmity of character.

Dale Turner

7

Therapeutic Communication and Transactions

Outline

- Introduction
- Meaning
- Principles
- Process
- Levels
  - ♦ Intrapersonal communication
  - ♦ Interpersonal communication
  - ♦ Small group communication
  - ♦ Transpersonal communication
  - ♦ Public communication
- Techniques of communication
- Barriers to assertive communication
- Patients' experience that hinders therapeutic communication
- Essential elements of effective nursing care
- Non-verbal communication in workplace

INTRODUCTION

If we are humane, communication makes the transference of meaning between individuals and the means of reaching, of the individual

understanding and influencing others. Skills in communication depend on the capacity of the individual to express feelings and expressions to the patients for a right response from the patient in relation to his care aspects. Every therapeutic communication has an intention to bring about desired outcome. Good interpersonal relation (IPR) intends to bring about collaborative actions from the health care professionals for a desired outcome on the patient to improve his quality of life. IPR calls for mutual understanding among health care professionals and the patient for a common understanding through accountability and proficient use of technology and human nature merged with beliefs and cultural differences. Nursing is a science and art and the outcome of patient is based on the foundation of caring relationship with humane dignity, unity and holistic approach to care. The caring relationship between the health care professional and the patient is fundamental.

In this regard, it is necessary for health care professionals to use simple words instead of jargon and medical terminologies which patients can misunderstand and worry all time. A good coordination between verbal and non-verbal signals is important. India is known for its number of languages. Our right understanding of terms, our posture, facial expression and body language should be in right sequence. Mistaken words may create havoc in patient's understanding and hence content and context need its clarity. One needs to use concrete words which are brief and precise. Reframe if necessary as patients may be from different background or on medical ground they may have missed to understand. One needs to have patience with patients and never be in a hurry which we see on daily basis while dealing with patient. Our ear lent for an extra second may mean a concern to the patient. It is interesting but the physician or nurse who takes care of the patient when arrived at the patient's side with a good gait, posture and happy expressions makes a moment lighter to the patient. Our body movement and a therapeutic touch with a personal space respect may heal patient's psychological distress.

WHAT IS THERAPEUTIC COMMUNICATION

Accepting someone under your care as who they are is the basis for a good therapeutic communication. As nurses, every patient expects that we understand their emotions (empathy), more authentic in our therapeutic

approach and to show our positive regards for whatever he is going through. We are expected to be honest in our communication and being sensitive to their concerns. Therapeutic communication differs from social interaction for the fact that the nurse or the doctor communicates with the patient for a purpose with a vision to treat his health problems. The communication is nonjudgemental and confidentiality is maintained. Hence therapeutic communication is a process in which the doctor or the nurse purposefully influences the patient for his better outcome.

PRINCIPLES OF THERAPEUTIC COMMUNICATION

- **Appropriate time:** Being aware of the right time to converse with the patient may help convey information in right wavelength. For example, when a patient is undergoing haemodialysis, once the excess fluid and waste products are removed, one feels very comfortable and may go off to sleep. If we wake them up and ask questions, the patient may get irritated. Therefore, understand when best one can ask questions to patients. Or when in pain if we raise more questions to the patient, it may not be appropriate.
- **Physical environment:** Confidential matters to be spoken to the patient in person. When a procedure is to be done, privacy is to be considered especially for a woman. Even in OT, head count and consent is taken before the patient is put on to anaesthesia. No one other than consented person is allowed to view the surgery or draping. Privacy is one concern which patient always has an issue with it.
- **Objective/purpose of the communication:** The nurse must be very clear with the objective with which she is going to interact with the patient. Patient may drift away from the topic but the nurse needs to be focused. Make the patient feel that the conversation is going to help her. When it is concern to their cause, they will definitely listen to what you say.
- **Broadmindedness in communication/ being non-judgemental:** The nurse must accept what the patient says as it is and no comments will be made to others not in concern. No personal judgement will be passed on the patient so as to gain their confidence and avoid our personal bias against the patient.

- **Correct understanding, interpretation and confirmation:** Medical terminologies or jargon used by the nurse may confuse or frighten the patient. Therefore, always used simple language that is understandable to the patient and if possible repeat what you say and confirm their complete understanding. Rather be a good listener.

PROCESS OF COMMUNICATION

Figure 7.1 describes process of communication.

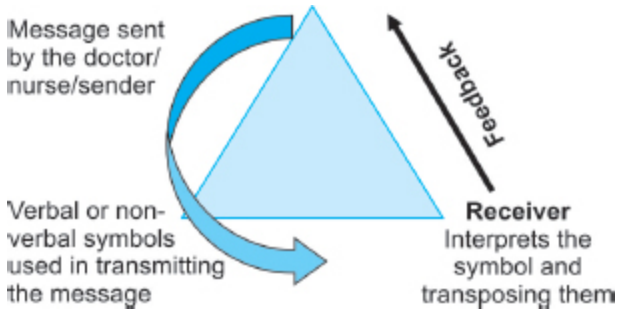


Fig. 7.1: Process of communication

LEVELS OF COMMUNICATION

Levels of communication will help every health care personnel to give the best interaction while they work with their counterparts and patients. Understanding self and also how the other person will perceive depends on the attentive clues to our own self conversation and also the body language shown while communicating. Levels of communication include:

- Intrapersonal
- Interpersonal
- Small group
- Transpersonal
- Public

Intrapersonal Communication

This reveals the talk that one has within one's own thoughts. For example, you have a microteaching or a seminar the next day. One may lose the day night sleep preparing oneself rehearsing for the best performance. Every

thought that one wants to deliver is sequentially well thought. This very thought is delivered in the best way possible. Likewise, when we counsel our patients, intrapersonal thought conversation becomes important. Today, we experience unhappy patients while they go to seek care for their health problems. Unexpectedly, one experiences scolding and harsh talk from their health care professionals. This very hostile experience will not help in the healing process. Therefore, one need to communicate internally within oneself so as to converse with our patients in a level that is best suited for better patient satisfaction.

Interpersonal Communication

Communication face to face with one or more person for a desired objective is termed as interpersonal. Every conversation between a health care personnel and a patient is always on patient's objective for better treatment, care and compliance. With low literacy and multiple comorbidities, patient may have to take multiple drug regimens which make them frustrated and land up with noncompliance to their therapies. Having wrong dosage becomes one of the most occurring errors in medication. It is not surprising even for a well-educated individual to noncompliance. Mr. M, a bank manager, once upon a time my class teacher, met me in the hospital while he came for his routine blood sugar check. After having met after 23 years, he was very excited to tell me that he has diabetes and that he is not taking his medication regularly but no other health problems so far. His wife expresses that he has great habit of drinking every day. Now that he has leg pain, dark rashes or spots all over his leg and also less sensation. Although he is highly qualified and literate, his treatment knowledge seemed very risky. I did explain to him the risk of drinking, smoking and tobacco chewing with his present illness. Understanding through conversation about his health literacy helped me to give an instant teaching on the health habits, medication compliance and foot care which is very essential for patients with diabetes. The communication seemed to have served its purpose when a teacher of mine called a few days later that he started following my instructions and changed his lifestyle.

Small Group Communication

Small group discussion becomes very important in a hospital set up when a group of patients suffering from similar illnesses are being instructed and

also in clinical rounds when a group of students learn from their professor or clinical teachers for a common goal. Sharing personal experiences of disease management and lifestyle change happens best when each successful patient narrates their efforts to comply. The less compliant patient hears and get motivated. For any successful small group discussion, the group rules, environment and health care personnel's moderation become very important. Clarifying their doubts and myths about the disease management is a must and very patient should be given an opportunity to express their concerns for a good small group discussion to take place. For students, the clinical teacher or professor on round takes them to every patient and discusses at the bed side giving them a glimpse of every patient with its specific management. Students are allowed to discuss the case and also learn the gaps they needed. This way direct patient care conferences or discussion makes every health care personnel to be well equipped with the knowledge and skill to manage patients and communicate what is expected by the patient in the right sense.

Transpersonal Communication

It is the interaction within one's spiritual domain. Spirituality is one of its highest forms of soul connection with the supreme power. When we are young and healthy, we hardly bother about spirituality. But the moment we are ill and helpless, spirituality counts more than medication. There is longing for peaceful soul that consoles an individual. If you look across each culture in India, pooja and rituals for wellness is practiced widely. The priest praying for the sick, family members visiting temples of gods and goddesses are clear examples for transpersonal communication for inner peace and wellness. Therefore, understand the patient's inner desire that indicates his desire for spiritual needs.

Public Communication

Public health nurses are usually concern with health teaching for the public. Correct knowledge and also good language well understood by the people whom he or she is addressing is prime importance. Eye contact, gestures and humour shared create an enormous impact on the people for their health maintenance. When I was in my second year of nursing, I was expected to give a health education to group of mothers and their toddlers on brushing habits and techniques. The local language I was supposed to use was Khasi,

a dialect used by the natives of Meghalaya. I being a novice, yet learnt and cramped line to line. Few words sound very similar *'sgni' 'snem'. Sgni* means day and snem means year. I was to tell the mothers *"shut yak e biniat arsin shisngi"* brush your teeth twice a day. Instead I said *"shut yak e biniat arsin shi snem"* that is brush twice a year. My teacher rose from her seat and corrected my wrong teaching although I did not actually realise. Therefore, language plays a major role in influencing the people. Wrong words spoken came have negative impact on people.

TECHNIQUES OF COMMUNICATION

- **Relevant questions:** One should ask relevant question to the patient. Start from simple to complex questions while communicating and one at a time. Have background information prior to conversing if you have to talk to a patient so that you have complete knowledge about his condition and you can be mentally prepared to provide facts.
- **Relevant information:** Today, patient wants relevant information about his investigations and treatment plan. It is the right of the patient to be communicated about his tests and treatment at any given point of time while he is under the care of the health care professionals.
- **Repeating the statement/paraphrasing:** Best understanding is signalled by paraphrasing what the other person has expressed. When a patient's spoken words are being paraphrased or repeated to note that the nurse completely understood. This helps the patient confirm that his or her needs are understood through active listening.
- **Clarification of communication:** The nurse needs to evaluate whether her instructions are well understood by the patient. Many a times, the nurse tells the patient on discharge all that he should take including timings of his medication and also the health habits. Ignoring to listen to the patient for further queries or understanding of the patient leads to medication errors by the patient. Medication errors are common phenomenon in hospital as well as at home. Mr. M who is diabetic for 5 years, says that, the night he goes to eat more, he takes extra hypoglycaemic agents that are being prescribed for him so that blood sugar is adjusted. Non-compliance by patient is due to lack of understanding regarding his treatment process and rationale. Therefore, every patient needs to be explained about is treatment

continuation through a language that is best understood by him so that clarification is through and patient can comply.

- **Summarize the conversation:** After all the explanations are over, summarize whatever is instructed once more to the patient so that he or she is acquainted with the information given. A nutshell review of all that you say helps patient confirm what he actually understood.
- **Focusing on the topic:** Patient usually gets distracted when something serious is to be talked about out of either their anxiety or distress. The nurse needs to keep focusing on the main topic or the concern and bring back the patient's attention towards the important matter to be discussed. Foci=using on the concern help patient understand and submit to his management strategies.
- **Antagonize with the patient:** Direct talk or confrontation with the patient helps the nurse to understand how the patient feels. Inconsistent feelings, beliefs, practices, preferences and attitudes can be understood when we confront directly with the patient.

BARRIERS TO ASSERTIVE COMMUNICATION

Figure 7.2 describes the barriers to assertive communication.

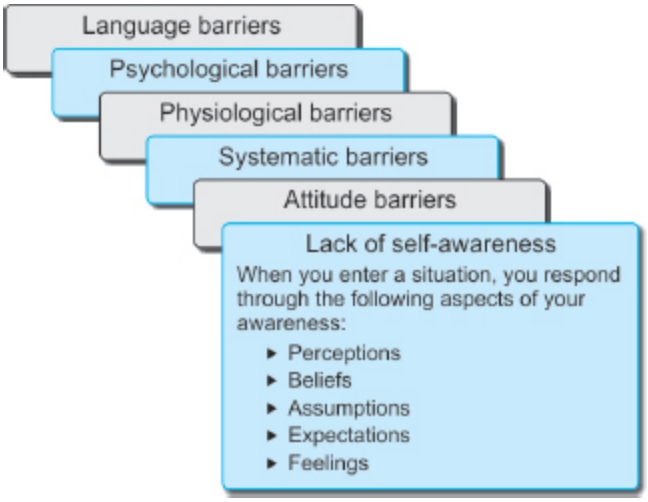


Fig. 7.2: Barriers to assertive communication

PATIENTS' EXPERIENCE THAT HINDERS THERAPEUTIC COMMUNICATION

- Treatment aims and objectives of the health care team are not known to the patient and his expectation and management sometimes mismatch.
- Blame attitude and being judge by the health care team, family and friends makes them feel inferior.
- Patient's anger, denial, depression that set in during disclosure of his diagnosis or treatment may make him not take a right decision.
- Withdrawn patients who did not come out of the stages of bereavement need counselling and motivation to feel accepted.
- Patient experiences low self-esteem and low self-management with the difficulties due to disease process and treatment outcome.
- Out of denial and anger, the behaviour of the patient may be a concern to non-compliance.
- Not getting adequate access to the right treatment facilities, the patient may feel a sense of lack of effective treatment and unsatisfactory attitude.
- The health care professionals not understanding to his health problems or concerns and not sharing a common understanding.
- Lack of privacy in the care setting.

ESSENTIAL ELEMENTS OF EFFECTIVE NURSING CARE

Essential elements that make nursing care effective are:

- Language
- Empathetic approach
- Pleasant appearance
- Intonation
- Body language/facial expressions
- Body posture during communication
- Gesture and sense of humour
- Therapeutic touch
- Cultural competence

Language

Understanding the patient's language makes conversation and therapeutic communication better. Patients sometimes prefer same caste nurses or doctors or from same community speaking the same language to take care of them. Especially when you are far away from home and get treated in an unknown place, a person who speaks to you even a single word in your language makes a great difference to them. The concern felt by the patient builds trust in the therapeutic process. Therefore, health care professionals are bound to learn the local language and also many languages to understand and treat patient better.

Empathetic Approach

Empathy helps built a trusting relationship in the treatment process. A physician or nurse who could feel and sense the difficulties faced by the patient and acts accordingly to give the best possible care are always appreciated. Physician and nurses are bound to take care of large number of patients who have different expectations. Meeting every patient's needs based on assessment may or may not be feasible to every nurse unless the nurse patient ratio is balanced and facilities are appropriate. In India, 75% of the people live in villages and 75% of the hospitals are in the city. When people from the villages and from poor facilities come to the tertiary care setting, people are lost with the system unawareness and find themselves in difficult situations. This is the very time that nurses and physicians have a greater role to empathize and make them feel wanted, cared and treated for their expectations.

Pleasant Appearance

The way the nurse grooms herself, her selfconfidence and attitude plays a great influence in the minds of the patient. When one is well dressed with dignity and elegance, the patient is sure to feel safe and secured in the hands of the health care professionals.

Intonation

The way we say means a lot to every patient. The tone of voice and the circumstances or happenings to the patient will make patient well understood. Using appropriate language with a comforting tone may mean

concern to the patient. In real scenario, sometimes health care professionals show their power through anger and raise their voice to the patients when repeated questions or concerns are raised by the patient and patient party in an attempt to understand the condition of the sick person, which is not appropriate.

Body Language/ Facial Expressions

Non-verbal communication plays a major role in therapeutic communication. At any given moment in the clinical situation, when a health care professional joins duty, his or her facial expressions symbolize her mental state of mind with which she or he comes. Smile and expressions of eye reveal the nurse's emotions, or her happiness which may make a difference in her care provided. Understanding the cut-off point between professional and personal matters may help appear infornt of patients in an appropriate manner.

Body Posture during Communication

Posture and gait reflects one's energy, attitude, emotions and physical wellness

Gesture and Sense of Humour

A hello! Namaste! on first meeting for the day may brighten patient's emotional state. Sense of humour sometimes lightens the stressful moments and help cope with their concerns.

When a loved one of the family is sick, we forget the little things that help us smile share and be happy. However, serious the condition, our small gestures can mean a lot to the patient and family members and this very little kind act of yours will help them cope in difficult times. Few of the ways by which we can show our concern for the patient are:

- Being available to listen to them and to share their grief and concerns
- Be calm and be confident and not show your surprise look and emotions even if the patient is not doing well to allay his anxiety and fear.
- Show concern even by watching a movie with him as a diversional therapy.

- Encourage and appreciate their attempt to do his ADL and even with the slightest attempt to get up from bed itself.
- Provide safe environment as depression may make him take unwelcome decisions that may be harmful.
- Provide care with dignity and respect at all time.

APPROPRIATE NONVERBAL COMMUNICATIONS IN WORKPLACE

The talk between health care professionals requires professionalism. When we work together for a long time for a common goal, the talk sometimes becomes informal which may be rather misinterpreted by the patient. Our body language to either with the team members or with the patient is an important component to be considered. Body language differs from people to people, place to place and culture to culture. Nodding head forward or sideways may mean yes to some and no to some. Eye contact and its expressions tells more than any spoken words. Therefore, positive approved body language to be used while dealing with patient. The nurse listening to patient may respond 'yes' from her mouth but may shrug her shoulder. Shrugging shoulder means no to some people. This contrasting approval vs disapproval may cause anxiety and stress to the patient about his care aspects. Few of the body expressions are:

Eyes and Facial Expression

Direct eye contact during conversation shows your assertive listening. Lethargic eyes or rolling eyes or eyes that wander during conversation show boredom or not interested attitude towards the conversation. Therefore, active listening involves good eye contact and nodding the head to show you really are listening and understanding what the patient is trying to say.

Hand Gestures

Shaking hand is internationally accepted way of saying hello or showing your good gestures. But in Indian culture, a man shaking hand with a woman becomes controversial sometimes especially if the woman is married. Conservative spouse may not appreciate and so they usually use folded hands to say 'NAMASTE'. Adapting to the Indian culture becomes culturally most accepted by patients. Though the young professionals are

informal yet the patients may come from a very traditional family and hence making feel comfortable with our hand gestures to be individual specific. Using appropriate hand movement may convey lots of understanding.

General Body Language and Body Positioning

Body posture tells what you are and what emotional status one is in. When a patient enters your unit, if the nurse or doctor sits crossed leg and gives a blunt look, the patient can never feel accepted or welcomed. While talking to the patient if one keeps fiddling the hand or playing with the available instruments on his table, the patient will sense that the doctor is not interested in his concern. Keep a good posture, facing the patient while you converse and maintain quite attention/ listen actively while the patient narrates his concerns. When a person whom you are concern about his welfare enters your chamber, you in fact rise from your seat, wish and make him sit comfortably. But when a person whom you don't like enters your room, your body positioning, such as leaning away from the chair or looking away from him or concentrating on something else rather than facing the person sitting in front of you happens to show your disagreement. These very body positioning need be repositioned when a patient comes to you for his concern. Every patient has the right to be treated decently and fairly for his visit to your unit.

Touch

Touch with positive energy helps patient heal from their illness. Touching a patient appropriable can solve issues of battery which is an intentional and wrongful physical contact with a person that entails an injury or offensive touching. When a female patient is cared by a male physician or a male nurse, either another female nurse or the relative be informed and witnessed unless in an emergency. In India, female privacy is to be respected. Physical examination of a female patient demands privacy. Privacy and touch to be appropriate while handling patient. Touching the shoulder of a patient in distress may mean a whole lot of concern and acceptance and patient may show up satisfaction and fulfilment. During our standard care process, maintaining our professional boundaries and protecting patient from physical and psychological abuse are important.

Recently I visited a home for the abandoned orphan children whose parents are no more with HIV/AIDS. Few of the children are positive for HIV infection and majority are not. Children are not aware of their status. They are normally brought up by the religious nuns who sacrificed themselves to look after these children with love and affection. It was a wonder struck for me when I saw them caring like their own children. Hugging them, cooking for them protein rich diet, praying together, playing together and sharing the same meals and place of rest. The happiness they share through their pure lovable soul makes me feel they are the real happy people on earth. Each child runs back to hug their caregivers and with no hesitation, arms wide open receives each child in their arms. This is real service to human kind. Health care professionals need to find job satisfaction through caring their patients in the like manner. At times we lack humanity and treat people mechanically. Conscientious efforts are a need of the hour to provide care with no expectation from the patients.

"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language that goes to his heart."

Nelson Mandela

8

Understanding Transaction Analysis for Effective Therapeutic Communication

Outline

- Introduction
- Essence of therapeutic communication
- Ego states of an individual
- Clinical importance of ego side transaction
- Types of ego side transaction
- Symbiosis and nurse-patient interaction
- Therapeutic compliance—contamination in transaction and medication issues
- Patient's issues in clinical areas that need understanding of ego states
- Understanding of Johari window to illness experience
- Therapeutic compliance
- Divine self-existence and clinical impact

INTRODUCTION

Ms. Y was to be operated for an abscess on her thigh. Since she has undergone too may surgeries in the past she requested neither spinal nor general anaesthesia. Her surgeon promised to give anaesthesia through mask for the 20 minutes of surgery planned. On the day of surgery, she was shifted to the premedication room. On arrival, the anaesthetist PG asked her to get up from the trolley. She rose and sat up. The PG immediately searched for the lumbar area. Ms Y asked the PG doctor what she is

searching for? The doctor replied looking for any issues around the lumbar region to give you spinal anaesthesia. She told the doctor that she is not going for spinal anaesthesia. The doctor replied, then you have to go for general anaesthesia. The patient replied 'no' I am not going for that too. My surgeon told me that I will have to take anaesthesia though mask. The doctor replied "who said that". The patient out of anxiety so as what they would do inside the theatre after she is being taken to OT responded. "Please do not take me to the OT till my surgeon arrives". The situation becomes intense when the anaesthetist' sperception and patient's level of decision and understanding and also the decision taken by the surgeon is being questioned. Every patient sometime or the other feels what would be their outcome when they are under the care of too many levels of instructions and practices. The anaesthetist would have looked at the surgeon's preoperative orders and with an understanding if she would have spoken to the patient, the situation would have been much better for allaying the anxiety of the patient who is to undergo a surgery. A ritualistic practice which is not individualized in nature creates confusion and low satisfaction among patients in the health care arena.

ESSENCE OF THERAPEUTIC COMMUNICATION

Illness is experienced by a patient as a strange interference in one's life process that disturbs not only physically but also mental capacity of an individual to function normally. When anyone is seriously ill, the person feels powerlessness and self-autonomy seems to lose. So whenever one feels ill, they will always respond from the child's ego state and views nurses and doctors acting from their parental or adult ego states. For example, when a patient is brought to emergency in a non-responsive state and nurses doing CPR resuscitate the patient. In his once again conscious state, he feels that the nurse saved him which his people could not do. On the other hand the patient party feels the act as something which only a trained personnel is able to save his loved one and, therefore, both patient and family feel they are dependent on the health care professionals and hence they are in their dependent child position mode and that their adult and parent ego states were not functioning at that point of time. Normally, the three ego states according to Eric Berne depict the parent, adult and child.

EGO STATES OF AN INDIVIDUAL

Figure 8.1 shows the ego states of an individual.

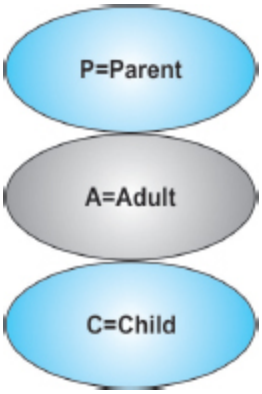


Fig. 8.1: Ego states of an individual

Parent ego	What is learnt from outside of oneself. Generally t hey are critical, precarious, parental, directorial, do minant, controlling and at the same time nurturing
Adult ego	Assumed or thoughtful 'new or novel' learning. Th ey are non-emotional, realistic, evidence gathering or information giving
Child ego	Within originated influence. They are unique, inqui sitive, imaginative, playful, innocent, playful and e xpressive

Parent egoWhat is learnt from outside of oneself. Generally they are critical, precarious, parental, directorial, dominant, controlling and at the same time nurturingAdult egoAssumed or thoughtful 'new or novel' learning. They are non-emotional, realistic, evidence gathering or information givingChild egoWithin originated influence. They are unique, inquisitive, imaginative, playful, innocent, playful and expressive The way we speak and the way our words are said, help us understand from which mode one speaks. Parent modes are always with values. Words spoken from adult mode will be clearly defined with scientific reasons and child words are direct and very spontaneous without any inhibition. We are taught positive attitude, values, feelings, etc. which attribute to parental mode which are inheritted or copied from our parents. Therefore, sometimes this

mode makes conversation either judgemental, critical, patronizing and nurturing at the same time and one could be biased towards the patient's decision making as we tend to project how we have been brought up and we expect others to follow the same.

When we deal with people we must consider the two aspects of being in the parental mode that is either nurturing or structuring. It can be either positively nurturing vs negativley nurturing and positively structuring vs negatively structuring. When we positively nurture a patient or a child, the performance is much better than negativley nurturing as we may spoil the child. Positively structuring will help a child grow with positve nature whereas structuring negativley will bring about critical behaviours in later life.

Adult mode is the matured level where we are able to see as it is or as they are. It is always a direct healthy response without any influence of the past. It is based on evidence in the clinical scenario. Telling patients of their test finding having to tell lies in a mutured way could be a sign of adult conversation mode.

Child ego states are interesting features often seen with our patients whom you treat. Patient asks the physician about his test results and he answers saying why you want to know. Even if I tell you will not be able to understand". Here the patient may respond saying, I am not knowledgeable enough to understand. How useless I am for myself not to understand. I never get what I want to know". In the same way, our internal parent ego may push down the individual to child ego state and may respond irrelevantly when one is sick and may not be able to respond from an adult state.

Internal adult dialogue is important in moments of difficulties so that one is able to balance between the child and parent ego states. All three states exist interchangeably and one needs to understand that each mode helps us build interesting lives in day-to-day living. If one is to live only in parent mode, the person can never smile and be happy. If only adult ego states, then only rationalized, facts and figures will always be a question for response and if only in child ego, life becomes a question with less responsibilities. Examine a child ego states with an example. Father calls his son who went out with his frieds just for an evening. The son trembles thinking what his father would tell. He tries to remember if he has done any

blunders. Coming back home, he asks his dad the reason for his call. Father says, son lets go outing this weekend as we have not been on vacation for long. Although this situation is negaivley perciecved by the child ego state, all child ego states are not negative. We see in work place that if people are in child ego state, they escape serious matters which need problem solving and they are seen as nuisance in many situation. Matured state is a must in dealing with workforce but all three states are important part of one's dealing for a healthy living.

CLINICAL IMPORTANCE OF EGO SIDE TRANSACTION

When a health care professional who is to make most of the decisions related to care aspects may show up a parental ego states by displaying improper gestures, pointing finger which is not the right way in any conversation, and showing anger towards patient's preferences may pose insecure feeling among patients. In India, we need to focus on the body language and the cultural differences. On the other hand, patient being in the child ego state may pose with sadness over his diagnosis and treatment, pain and anguish, temper tantrum, shrugging shoulder, raising voice, or using inappropriate language. The nurse or the physician needs to identify and understand the patient and his anxiety and related stress and be decisive about the situation and management. To be decisive means the nurse or the physician is in an adult ego state trying to listen carefully in a nonthreatening environment with appropriate body language to make sure he is showing acceptance and approval for the issues and problems raised by the patient and at the same time taking a rationale decision for his care based on scientific background. Using why, how, when, where, who, what, and reasoned statement will be able to convince the patient and build therapeutic action plans. Therefore, it is well said that only 7% are spoken words, 38% are paralinguistic and 55% of the communication is through our facial expressions or body language (Albert Mehrabian). People may ask so as to what is ideal and only way to communicate. There is no 100% yardstick to judge the only right way or a balanced approach to therapeutic communication and life adjustment to various treatment transactions. Sometimes some children best respond to authoritative parents and not reasoning parents to improve their academic performance. There are times when the child throws temper tantrum and gets his or her things done. Progressive parenting and good natured children as a by-product is the

expectation of very parent. But does it happen in all situations in our parenting. Today we have children who are left in the hands of caretaker and attachment between parents and children becomes a wider pole with intolerance as a feature of multifaceted experience of life. These same children one day become a nurse or a physician with very little attitude towards their patients due to their personality shaped in the early years of their life. Unconsciously, the nurse or the physician may exhibit his or her child ego nature which supposed to be in an adult state causing conflicts in health care settings. Therefore, clinical training needs its focus on good therapeutic communication and patient-nurse interaction as a MUST KNOW and experience area for better IPR and care outcomes.

TYPES OF EGO SIDE TRANSACTIONS

Complementary Transaction (Fig. 8.2)

The below diagram shows how a nurse in parent ego states communicates with a patient who is in a child ego states. Patient asked the nurse for a glass of water, the nurse understanding that the patient has fever and may be dehydrated and is thirsty so she offers him a glass of water. This patient's transactional stimulus matches the nurse's transactional response (complementary).

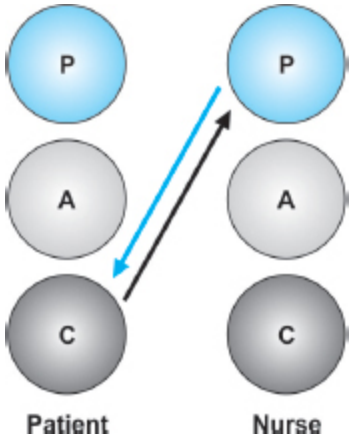


Fig. 8.2: Complementary transaction

Case 1: Analysis of Complementary Transaction

Mrs X brings her son who is unconscious to the emergency. On entry to the emergency triage, the doctor finds the child not responding and

immediately he started on compression and then intubated the child. The anxious mother in tears asked the doctor whether her son is going to be alright. The doctor understanding that the mother is speaking from her child state and hence answered her from his nurturing parent ego state saying "he is still ill but I feel he is much better". I know how you are feeling and going through. We will inform you all that are being done for his welfare. Would you like to sit next to him and be comforted? Such consoling words with empathetic approach will keep every mother at ease even when her child is sick. Clear cut explanation of the process and standard of care will help cope in any critical or crisis situation.

Crossed Transaction

In a crossed transaction, an ego state different than the ego state which received the stimuli is the one that responds.

Husband asks his wife 'can you offer me a glass of chilled water' wife responds 'you ask the lady you roamed with you last night' and you are never happy with whatever I do but negatively comment always. Husband expecting that the wife would respond from an adult ego state but instead she responded from an ego state different than expected (Fig. 8.3). In clinical experience too, there may be a time when the health care personnel is annoyed and may respond similarly. Example, Mr A the patient party asked for an extra pillow for his father who is unconscious and needs position change from left to right. The nurse responds 'don't you see that we are busy with rounds'. Here the party expected a complementary answer but received what was against their concern (crossed transaction). Although the nurse is busy, she can very well tell the patient party to wait for just a moment and would give the patient pillow soon after the rounds or send another person to give the pillow. This type of transactions which are negative and not congruent can interfere with therapeutic progress and future interaction into nursing practice. Therefore, one needs to analyse and think for a moment before any word is delivered to the patient or patient party or with one's colleague.

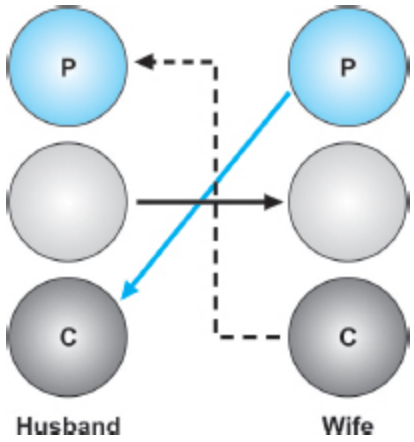


Fig. 8.3a: Crossed transaction

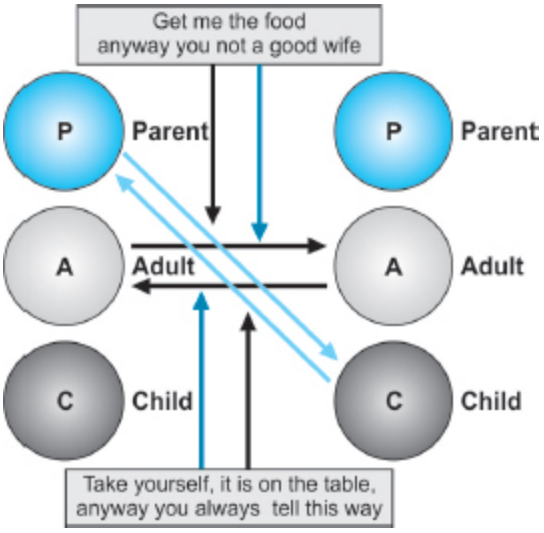


Fig. 8.3b: Crossed transaction

Ulterior/Hidden/Mysterious Transaction

Ulterior transaction is one of the most complex forms of transaction between two individuals in the working relationship. When an obvious social conversation is going on, parallel unspoken psychological transaction happens. For instance:

(a) "We need to go back home by my bike this evening after the class hour". (Adult words) body language indicates sensual intent (playful child).

(b) "Oh yes." (Adult response to adult statement), nods the head (accepts the hidden drive).

Therefore, when people converse, we need to understand the hidden motive to keep yourself away from the wrong but sense the goodwill, if reasonable.

From the above statement, we understand that transactional analysis brings about our wellbeing. TA helps us understand our own personality and helps us change ourselves and improves our ability to deal with the demands of life in the current arena. When we work in an organization and also with patients who are suffering, it is important to understand how others behave and empower them so that health teachings become more receptive when trust is built between the patient and the nurse. Knowing the mental strength and abilities towards their health care autonomy will optimize their psychological health and wellbeing.

In today's modern world, people are time bound with its productivity. High productivity can only happen when same strategy works for all employees. Building a functional relationship with common goals can help eliminate dysfunctional attitudes and behaviours among the employees. Understanding from which ego state one is interacting will help us identify their motive and will be able to maintain good IPR and relationship in the workplace. Health care professionals find their job satisfaction only when their patients get well. Harmonious working relationship in workplace and coordinated care will help enhance patient satisfaction.

SYMBIOSIS AND NURSE-PATIENT INTERACTION

According to David Zigmond, symbiosis is a state of mutual dependence where one individual provides certain things that the other does not have but needs. It is observed from our experience that in the health care sector, the physician or nurse is always in a parent and adult state as we treat the patient and the patient in a child mode at least while in the hospital. As I have already indicated, doctors tend to function in parent and adult ego states, and patients, at least within the medical consultation, are often functioning in their child ego states.

Figure 8.4 shows a patient who obeys the health care team's status of being a parent or adult treating the patient who is in the child state. The nurse's task is mainly controlling, nurturing and problem solving based on the assessment made and also the physician's orders. The nurse's duty is to show compassion to patient in the midst of suffering keeping in mind the

various facets of patient's preferences and understanding. To carry out this task, the nurse or health care personnel always works from adult and parental level of ego states. For a child, the concept expressed by Eric is "Felt concept of life" which involves our reactions and feelings to external dealings. The fear and stress a patient go through puts him to speak from his child ego state, means the actual reasoning capacity may be weakened by his illness and treatment effects and decision taken by him or her is an immature and hence doctors and nurses feel and act strongly from their parent and adult ego level assuming to be taking the right decision for the patient who is in a child ego state. Therefore, according to Eric, the following are analytical concepts where anyone of us may be put to various situations.

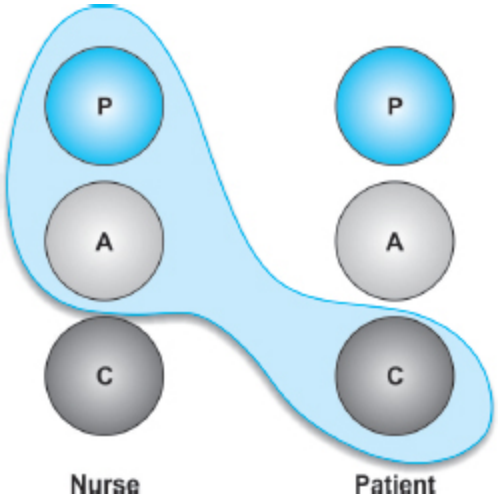


Fig. 8.4: Analysis of nurse and patient's relationship/ interaction

- Parent ego is our *'Taught'* notion of life.
- Adult ego is our *'Thought'notion* of life.
- Child ego is our *'Felt'notion* of life.

Complementary transaction is what the health care professionals expect with every encounter with a patient to get the best therapeutic benefit through good IPR.

But this state may not be the same for all situation when you have a patient who is dominant, aggressive and who had been stuck to his parental ego state and that he has to be in a child state. He also may be preoccupied with his taught concept of life and finding a very young health care

professional who commands on him for his management may pose conflict. Here you will face a problem of resistance or rebellious patient who may not listen to your instructions. This very situation is termed as symbiosis according to David Zigmond. Hence man is a mixture of personality, communication and sets of accepted behaviours within the context of care environment and hence every individual either the patient or the health care professional is influenced by his personality and upbringing in his present situation. Understanding the ego states and interacting appropriately with the sick patient will help us carry out the nursing care with ease and perfection and thus improve the quality of life and enhance their care satisfaction.

THERAPEUTIC COMPLIANCE—CONTAMINATION IN TRANSACTION AND MEDICATION ISSUES

In our traditional Indian culture and traditional practices, mothers are responsible for the health of their children and also the entire family. Medications as understood are usually taken after meals and basically they are monitored by the mother. When the patient gets admitted in the hospital, the traditional concept of giving medication after food remains a constant practice. If the nurse administers a proton pump inhibitor which is to be given prior to meals that is before food, the patient may refuse saying that he has been taking all medications only after meals. This explains the contamination from the mother to the child or the patient who is refusing to take the medication in empty stomach. This is contamination prejudice (Fig. 8.5). On the other hand contamination delusion is best explained through this example. The only child of parents Mr Ryan, 18 years old, who lives in a hostel calls his mother and says “Mom I have fever and this fever will not come down unless you buy me a bike by tomorrow”. This is contamination delusion made by the child to the parent or to the adult figure, the mother. This situation happens very frequently in the health care arena when a child is to be given medication, the mother tries many tactics to give the medication and sometimes the child may condition the mother who is in an adult state or a parent state. This contamination is termed as contamination delusion. Hence understanding the general practices of the patients and explaining to them the rationale why particular drug is to be given in empty stomach need emphasis. Correct explanation or reason provided can change

the mind-set of the patient and thus comply with medication timing concepts.

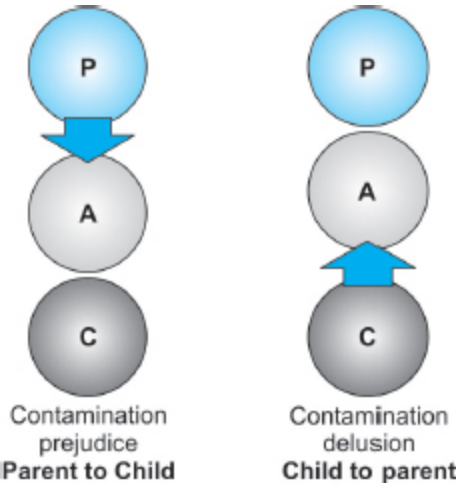


Fig. 8.5: Contamination perjudice and contamination delusion

Double Contamination

Double contamination means the adult as well as the child contaminates the adult ego (Fig. 8.6).

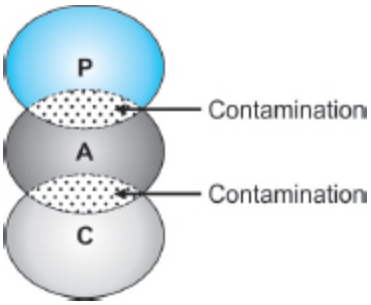


Fig. 8.6: Double contamination in transaction

Published work of Anita Mountain and Chris Davidson about "Working Together: Organizational Transactional Analysis and Business Performance July 2011 showed that while working together we relate to peoples' behavioural responses and make correct diagnosis of the ego state. Understanding their complexities can help function an organization better than ever as one will be responding based on their current ego states. They have described behavioural, social, historical and phenomenological diagnoses (Table 8.1).

Table 8.1: Psychosocial diagnoses	
• Behavioural diagnoses	Behavioural diagnosis is made from the ton e of voice; the tempo of our speech, facial e xpressions, the body postures made, gesture s and breathing patterns denotes our ego sta tes. For example, when a student is caught f or malpractice in the examination, the breat hing pattern, facial expressions and emotio ns are not going to be normal. The child ma y breakdown or even show aggression. A ne wly diagnosed HIV positive status individu al may exhibit fear and anxiety, tearful eye s, clenching fist to how he got it, stoop dow n his face unable to face the reality, may bu st to tears so on and so forth. Counselling b ased on the behaviours exhibited and assess ed would serve as a diagnostic tool to prove better coping mechanism for the individual in crisis.
• Social diagnoses	Our observation during interaction, such as 'Namaste' (folded hands) in bended positio n, is indicative of being in parent mode. Sh aking hands with body posture upright sho ws the person is in adult mode. Cultural diff erences, upbringing differences can be obse rved and in fact we can diagnosed from whi ch family or from which country one belon gs to.
• Historical diagnoses	Patient's history serves as an important tool to diagnose one's ego state. If the patient sp eaks the way his parents speak and behaves the way his parents do presently of the past, then we can say that he is in parent ego stat e.
• Phenomenological diag noses	This usually is experienced by the person hi mself or herself. One introspects to examin

	e oneself.

PATIENT'S ISSUES IN CLINICAL AREAS THAT NEED UNDERSTANDING OF EGO STATE

- Number of tablets
- Tablets vs injection
- How medicine works for me?
- How long to take the drugs?
- Is there one drug for all problems?
- Drug to instant fitness Side effects
- What about continuing other treatments side by side?
- Can I be my own doctor?
- Fear of rejection by physician
- Will they do the needed investigation?
- Will they diagnose me correctly?
- Is the right doctor specialized in the area treating me?
- What if I had to change my physician?

Student's Issues

- Big pharma terms are a jargon
- Cramming for no understanding
- Lack of practical orientation of learnt theory
- Not my business attitude
- Laziness, apathy/lack of concern
- Pharma a devil in my career just can't remember all the drug names
- What if I make a mistake in drug administration?

Perception of Health Care Personnel

- Routineness of ritual
- Failure to look beyond the need
- Clearing competitive exams and neglecting bound duty

- Poor bonding and no team feeling
- Why teach patient attitude
- No time and less staff

UNDERSTANDING OF JOHARI WINDOW TO ILLNESS EXPERIENCE

Johari window is developed by American psychologists Joseph Luft and Harry Ingham in the 1950s, calling it 'Johari' after combining their first names, Joe and Harry. The significance of Johari window in this chapter describes the importance of soft skills nurses possess, the empathetic approach one can apply to patient care, the group coordination in team and to improve IPR. This is a model of self-awareness, personal development and building relationships. Here the relationships link to therapeutic relationship for better health outcome of the patient. Understanding this model will enable every nurse to understand one's feelings, attitude, skills and intentions so that we are able to successfully relate to patients feelings and wellbeing. The model depicts its information, whether it is known or unknown to the person as well as the team. Team functions well when each one of us is aware. The four quadrants/regions are (Fig. 8.7):

- Open area/open self/free area/free self: Area that is known to oneself and others.

Fig. 8.7: The four quadrants in Johari window

- Blind area/blind self/blind spot: Unknown to the person but known to others.
- Hidden area/hidden self: Known to self but not known to others.

- Unknown area/unknown self: Unknown by person as well as others.

Open Area

This is the open self-quadrant where all the team members know each others' attitude, behaviour, like and dislikes, feelings, emotions, knowledge, skills, etc. When you know each other's views then the communication and flow of work is finer and perfect in nature. In our work place, we aim at having open area for common goals and objectives to be achieved. When we know each other, we know what to do at the right moments, our strengths and weaknesses to combat the bitter illness experience by the patient. When we know and understand each other conflicts and confusions can be minimized in patient care.

Table 8.2: Personality profiles and reactions to illness

Personality	*Patients who …*	*Often feel …*	*Are helped by …*
Dependent	Ask lots of questions make it hard for you to end the conversation or leave the room	Afraid that you won't find them worthy. Afraid you won't want to care for them	Offering regular, brief sessions setting tactful limits that reassure the patient and do not annoy staff offering detailed explanations
Obsessive	Are insistent, detail oriented	Are angry when they can't control their illness, the staff, and the schedule	Providing choices whenever possible trying to use patient input collaboratively avoiding confrontation, but emphasizing they deserve the best care we can provide
Narcissistic	Are self-centred, criticize others, believe no one is	Are fearful, threatened, and vulnerable	Keeping them informed (same message from all staff)
Suffering victim	Always have symptoms and request much attention Might not follow recommendations Do not trust, refuse to participate in plans	Suffering is their role; illness punishes them (and sometimes physician) but hopes doctor will keep trying	Regular visits, no matter how varying the complaints, encouraging them to "suffer" through treatments, staying calm not arguing
Paranoid	Threaten to sign out of the hospital against medical advice	They are being taken advantage of by others or purposefully neglected or harmed	Offering understanding of their position, making clear recommendations Encouraging the patien to verbalize concerns
Histrionic	Are flirtatious want to call the doctor by his or her first name	They want to be special in the eyes of the physician. Illness will invalidate them or make them unattractive	Setting boundaries for the courteous and objective relationship, remaining courteous and objective
Schizoid	Are very lonely. Tend to avoid medical care	Doctors are invading their privacy	Engaging them in helping to make medical decisions

Each team member needs to focus on wider open area. When a new faculty or students joins a new team, initially they may not open up to open communication as they are new to the system. Start with relatively small open areas and then gradually the member can be motivated to share his or her views so that open area becomes greater by extending vertically downwards trough their disclosure. This disclosure can happen only if trust is built between the team and the new member.

Expanding the open area and reducing the blind area can happen through feedbacks that the team gives to the new member. Any person who joins the new team may experience novel know-how. Their skills, knowledge, attitude and feelings can be understood through constructive

feedback. Hidden area can be reduced through disclosure as well as through others observation and feedback on the individual. Self-discovery helps to reduce unknown self. Therefore, reducing hidden and unknown areas and widening the open areas are the prime objectives of Johari window model. How important is to the health care professionals. We deal with many patients who comes to you with varying mentality. Some narrate their history to get the best tests and diagnosis for better treatment outcome. Whereas some may not be comfortable to tell the actual problem for which a wrong test and diagnosis may be made. Few people may not even know what they actually are facing and health care professional too may just order for a symptomatic treatment without an ideal test. Understanding the patient, understanding our state of mind and the knowledge of the field remains an important factor for better patient outcome.

Blind Area

The space or the area that is unknown to self and also others. People are ignorant of their feelings, behaviour, attitude, etc. and also group is not aware of the same of this very new person in their group. It so happens in workplace where people are very quiet. This behaviour seems strange but the person himself or herself may not aware of what they possess. Ignorance of self can be dealt by encouraging disclosure through an atmosphere that is conducive and also encouraging them to speak out to create selfawareness in the individual. No judgements to be passed and one needs to give a constructive feedback to help comprehend his or her attitude and behaviours for better modification. It is the responsibility of the team members to guide mutual understanding among team members to convince the individual for self-awareness

Hidden Area

Known to self but unknown to others. Facts that are hidden from others knowing about the person. Information, feelings, personal attributes, behaviours, etc. that are hidden from others for fear of misunderstanding. This very facts need to be brought to the open area where team can help each other understand. Sensitive matter need to be handled cautiously. Working environment and team relationship matters in this regard. Cohesiveness and trust among team members can enhance disclosure. If there is very sensitive issue, it is to be revealed through consent of the

individual. No force to be made. In any circumstances, people want right to privacy in their personal matters. Therefore, sensitive issues to be taken up with utmost care.

Unknown Area

In this area, the person and team members are not aware of his or her feelings, talents, altitudes, and also experiences. Counselling and prompted self-disclosure will serve best to reveal the unknown either to self or others. Repressed feelings and experienced supressed need to be brought up to the surface so that team and self understand their motives in the care aspects. When we are just new to a unit, the person nor the team members know each other prior in some circumstances. Getting to know each other through round table conferences, group discussions and small meetings may help disclose the above mentioned attributes for smooth functioning.

Hence, understanding Johari window makes us relate to our emotional intelligence. Assessing and understanding someone's behaviour, management roles and functions, attitudes, IPR and their potentials need one's emotional quotient. Having large open area means the person's self-awareness is superior. People with high EQ will only to able to put one's foot down and understand from the other person's shoes. Understanding our goals, our intentions, our behaviours and responses helps understand other people's goals, objectives, intentions and behaviour. EQ also speaks about four types of awareness that is self-awareness, social awareness, and relationship management. In any work place, if you have people with high EQ, one can bring about sustainability, less conflict, increased productivity, better understanding, peace and harmony in the work they do.

THERAPEUTIC COMPLIANCE

Therapeutic compliance is following the instructions given by the physician rightly or appropriately. But many of us as patients skip any one or even more that one or two of the following issues:

- Getting a prescription from the physician but not buying and taking it
- Not taking the right dose
- Taking medication at the wrong time
- Manipulating the dose based on feelings and mood

- Stopping treatment by self when one feels better
- Not attending the planned OPD visit or follow-up
- Not seeking help for health problems
- Fails to follow doctor's instructions
- Stops and takes medications whenever one feels like/drug holiday
- Takes medication regularly only prior to visiting the physician for fear of the doctor/white coat compliance

When patients forget or do not comply with any one of the above mentioned issues to medication, the question of drug resistance and treatment challenge creeps in. With many people being literate to medical treatment modalities, the compliance factors are expected to be highlighted. But compliance even with educated and literate people becomes a concern due to lack of motivation, chronicity, memory issues, lifestyle change expected and also the diet restrictions to many of the disease conditions. For example, a patient undergoing haemodialysis due to chronic renal failure (CRF) is restricted to take high protein diet, asked not to take any fruits, and low salt diet. When examined they can eat almost nothing that excites the taste buds. When patient is so used to some of the food items, it is hard to leave them suddenly unless he is highly inclined to the prescription. Therefore, patient may take the diet that is being restricted. Therefore, modified cooking pattern becomes important in the diet counselling. In south India, the practice of taking tender coconut at least once a day is the culture. They also use coconut in cooking. The reality is that tender coconut contains high amount of potassium that may result in hyperkalaemia, if taken by the patient. Hence tender coconut is totally restricted for CRF patients. Reason not to take or use the items in cooking or eating directly is to be emphasized and taught with rationale.

DIVINE SELF-EXISTENCE AND CLINICAL IMPACT

The theoretical concept of self-transcendence addresses an enhanced understanding of well-being in late adulthood (Reed, 2008). The core of self-transcendence is the expansion of the self-boundaries in four ways (Reed, 2008): intrapersonally, interpersonally, transpersonally and temporality.

According to Haugan, 2011, the factors that indicate nurse-patient interaction are:

- The nurse takes me seriously
- Interaction with my nurse makes me feel good
- My nurse understands me
- She treats me with respect
- She listens interestingly
- The nurse's interaction gives meaning to my life
- I am satisfied with the interaction I had with my nurse.

(Haugan et al. The Self-Transcendence Scale. An investigation of the factor structure among nursing home patients. Journal of holistic nursing, Vol XX, number X, month 2011, 1–6.)

The interaction between patient and nurse becomes very prominent because, nurse is the one the patient trusts and look up to for what they wish to know and get care concerns. Therefore, the role of nurse is quite demanding and standard training to equip one's knowledge, attitude and skills in handling these patients' needs fine tuning. Today, people are looking for correct information and attitude towards their health care needs. On the other hand, people are aware of the legal issues and consumer forum. Health care personnel need to be more alert with the current knowledge and build a correct attitude towards patient care. It's simple to say that you need to follow my home rules but people also pay and come to get their desired needs in regard to their health. The little mistake one does has major impact on patient's later life and this is the major flaw in the health care. We treat 100 patients and mortality and morbidity as per statistics is expected but if the one per cent error falls on my loved one, it is hard to digest. Utmost care needs to be taken before we conduct. Therefore, according to Haugan, our interpersonal self-existence as health care personnel need to focus on selfwellbeing through:

- Having hobbies that one enjoys
- Socializing with people around us
- Sharing one's experiences with others to lighten one's feelings
- Helping people in need without having any expectation in return

- Being a lifelong learner to update with current information
- Able to prioritize activities
- Accepting the changing trends in one's life and situation
- Accepting the declining physical abilities in life
- Ability to live with one's health problems
- Finding meaningful life and living for every moment

With the advance technology and health care, people are able to live healthy long. Health problems have no definite age but once people turn 40, life seems to turn a little to make us realize that we need to take care of our health. The food habits, lifestyle play a more important issue because in the Indian scenario, most of the health problems are related to lifestyle. Fast life, fast food and corporate culture have brought in lots of chronic diseases with which one needs to tolerate long-term medications. Having to swallow medication whole life with specific time and diet makes anyone depressed. Limits set on our lifestyle become almost a curse for every one of us at very early age. This is the right time where the nurse plays a very important role in educating the patients and people around them to be more aware of healthy lifestyle.

Summary

The core of patient care success lies in good IPR and understanding the ego side transaction and also having open area wider in the concepts explained in Johari window. Understanding oneself in the context of patient care becomes prime importance as our attitude makes a lot of difference in dealing with sick and suffering.

"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language that goes to his heart."

Nelson Mandela

9

Patients' Experiences as They Go through Difficult Moment: Role of Nurse Counsellor

Outline

- Patients' experiences of illnesses
- Narrations
- Patient counselling
- Factors that influence counselling outcome
- Approaches to counselling
- Phases/Steps
- Steps in problem solving
- How to handle a slick individual

PATIENTS' EXPERIENCES OF ILLNESSES

For any dreadful disease, like cancer, anxiety is common experience. It is not only the final diagnosis but also the tests itself can cause anxiety among patients. The pain one undergoes while fine needle aspiration and cytology (FNAC). The stress that one experiences during mammography although it sounds to be only an image captured but the compression caused by the device during X-ray creates pain and discomfort to patients especially young woman. The time the patient waits for the test result is something very stressful. The patient always fears so as to what the test result would

be. If the physician who does the test has skills of counselling, then the patient may be comforted otherwise patient may take up negative coping patterns even before the diagnosis is made. Anxiety of patient is different from time to time. The thought of chemotherapy or radiation or surgery causes fear and anxiety. On the other hand, understanding that the cancer has spread to other organs, anxiety in a big way disturbs the patient. The health care personnel may ask the following questions to elicit anxiety and fear of the patient right through the diagnosis and treatment phases:

- Are you nervous?
- Are you afraid or tensed with the test to be carried out?
- Are you getting fast heart beat?
- Do you tremble?
- Are you feeling like being choked or a lump in the throat
- Do you have problem falling off to sleep?
- Do you worry about the next test?
- Are you afraid to lose control?
- Do you fear dying?
- Do you worry about the worst pain that you may experience?
- Do you worry about the medication continuity?
- Do you feel that they will not provide you bedtime pain medication?

NARRATIONS

Mrs. Y was travelling in the flight Indigo. We happen to sit on the opposite side of the aisle. She tapped my shoulder and asked me whether I belong to the same state where she comes from. I said 'yes'. Then she asked me if I could ask a glass of water to the air hostess as she could speak neither English nor Hindi. She narrates "I am extra thirsty because I am so tense with what is happening to my back". I asked her what happen to your back? She replied that she had two LSCS under spinal anaesthesia. After the second LSCS, she experienced lots of back pain that kept bothering her. She now has radiating pain and numbness in her lower limbs. So she finally decided to go outside state to get the best treatment. She explains further and says that "now that I long for nothing in life—just good health. When I

am not feeling well I want no wealth, no gold, and no good house and not even husband at my side". I just want to get alright. She says 'It's better to dig the ground and earn than living with such pain and sleepless nights'. This is how mother of two feels with back pain that may regain or not. I kept conversing with her regarding to which hospital, which doctor that she was looking for. When I gave her few good doctors' names for reference she was indeed very glad as she was new to the place where she was travelling and also the hospital where she would go thereafter. People in pain and anguish even travel to find their doctors who could ease their pain and heal them. Neither language nor innocence can be barriers when such situation arises. This is the time we as health care professionals need to talk and get to understand their feelings and concerns they wish to get rid of. To some health is a problem and to some money may be the primary concern. Illness with poverty is one that hinders treatment access to many of our countrymen. Financial problems need to be tackled and health insurance should provide every citizen a chance to live with good health.

Mr. X, a father of two children, who are 12 and 8 years old, was recently diagnosed to have blood cancer. Unusually, he assured to cook a good meal for his wife and children. After the dinner, when all children and his wife were fast asleep, he commits suicide by creating a short circuit in his room. The suicide note reads "instead of wasting money on my treatment, my kids can have better education. I am really sorry for the incident". This very narration would have caused you goose bumps. Or you may even criticize why he took his life. Today euthanasia is not in practice in our country. There is very little hope given to such a patient on the other hand. Treatment in many states is not protocol based. Good doctors treating such patients are rare in many health care setting. Comprehensive care becomes a dream to many patients although quality assurance speaks of standard value based care. Why he took his life becomes a story to many and misery to his loved ones. We are not very sure what he would have thought and to what extent he would have been mentally upset. This very incident would have been prevented if counselling was provided before the test, during and after when he was to choose his treatment options and also counsel the family members of the hope that medical science could give.

PATIENT COUNSELLING

Meaning

The application of science of understanding patient's emotional, social, spiritual and intellectual health. Understanding someone's feelings, involvement, thinking and being is a strategic challenge in the health care. Counselling is like doing a postmortem on individual's psychosocial distress. Counselling in a way will help the individual identify his own problems, find appropriate strategies and solve his own problems. In a health care sector, the patient who is sick may not be able to solve all his problems but at least make his choices based on the best available services.

Objectives of Counselling

The goals of counselling are to:

- Bring about desired psychosocial changes in the patient.
- Convey the best possible behaviour changes made with counselling.
- Bring about changes in the self-realization for the need for treatment compliance.
- Provide assistance during change process through good therapeutic communication and understanding his ego states.
- Assist in the change process and being with the patient for support required.
- Assisting the patient sketch their own plans and to solve the problems.
- Draw up their own plans and find solutions to the problem.
- Comprehend his abilities to impact the society at large with his changed behaviours
- Provide counselling sessions for nurses to understand their patients' problems.

Principles of Counselling Critically ill Patient

Counselling is an intentional interaction to find solution between a counsellor and the patient in view to solve patient's problem by himself through the insight obtained from the counsellor. Few basic principles to be kept in mind are:

- Counselling is individual based and problems are unique to the patient.
- Counselling is comprehensive in nature, dealing with patient's total dimensions of care aspects.
- It is goal oriented.
- It is provided by only professionals in totality.
- Counselling is based complete understanding of the patients' needs and concerns.
- It is a continuous process till the therapeutic objective is met (termination phase).
- Counselling is given based on objective data obtained from the patient after assessment and observation.
- Counselling patient needs flexibility depending on the capabilities of the patient as he might be ill sometime or the other.
- Conducive environment is best considered.

Significance of Counselling

- Each individual has different disease condition, some curable, some life long and some dreadful.
- Medication issues are complex in nature that need individual attention for compliance.
- Complex nature of family pattern, caregivers need to be stressed upon. Sometime it is the old spouse who might be illiterate to look after the medication back at home. Compliance becomes a concern.
- Access to health care and cost of medication are prone to non-compliance.
- Cultural practices and traditions hampering medication administration. Rituals of fasting on occasions become a danger to diabetes patients as they might land up with hypoglycaemia.
- Distinct differences between individuals and their personality and medication issues.
- Critically ill patients with working children and care attention. Many families are going in for caretakers at home well paid as children have

no time to spend with their loved one's sickness. Children don't mind spending money but care is given an authority in the hands of untrained person. Care satisfaction by loving children has a different impact on a sick individual. Life is not all about having to just satisfy basic needs but also love and belonging needs from their children in older age. This situation has become a second nature today with the corporate jobs and their demands. In the current scenario, the counsellor has a harder job of counselling the critically ill and their family members.

- Changing lifestyle and economic position.
- Therapy to heal psychosocial aspects (Complementary therapy). Patient can be given the choices of utilizing complementary therapies to ease their pain and anguish.
- Patient can be given sessions on health tips and strategies for compliance to lead a meaningful end of life.

FACTORS THAT INFLUENCE COUNSELLING OUTCOME

(a) Contextual factors

(b) Process factors

(c) Qualities of the patient

(d) Qualities of the nurse counsellor

Contextual Factors

The place or environment in which the counselling takes place has an important impact on the patient and counsellor. Comfortable room with chairs and table well placed. Personal space for each of them may give positive feeling to the patient. Environment must be non-threatening, calm, quite, free of noise and people walking around and also not a peculiar place as it may induce fear in the patient.

In any work place, the physical environment helps increase productivity. Likewise, in counselling also, the unit ambience, privacy maintained, confidentiality assured by the counsellor, calm and quite environment impact the counselling process and outcome. If counselling is given in an open ward, patient definitely will feel embarrassed and will be conscious of the surrounding and may not speak out what he really wanted

to. Having good chairs to sit, a room well ventilated will add to the comfort of the patient.

Process Factors

- Understand each other's roles
- The bond that is developed over time with the patient
- Attentive listening
- Absolute acceptance of the patient
- Elicits the problems faced by the patient
- Awareness about the issues to be dealt
- Allowing emotional outburst if any
- Exploring new areas of handling the patient
- Judiciously sensitising sensitive issues
- Ability to evaluate the outcome of counselling
- Capability to follow-up

Qualities of the Patient

Patients during counselling are expected to be:

- Positive towards their therapy
- Honest to treatment received and compliance to follow up
- Open-minded in discussing about their concerns and change process
- Assertive in handling one's life challenges
- Asking questions so as to understand that he is receiving
- Enquiring the duration of the therapy and their goals to be achieved
- Relating to his medical treatment so as to how it work on him
- Asking specific drug issues to be clarified during the counselling
- Understanding the specific adverse effects of medications and if so how to handle the interactions and side effects.

Qualities of the Nurse Counsellor

Health care professional counsellors have unique role to play. They have to understand that every health problem is unique to the patient. Illness experience is different from person to person. Even though migraine and its treatment are almost the same, experience differs. To understand each patient's experience, counsellor should adopt a democratic approach to counselling relationships. Based on the mutually made goals, therapy needs to be initiated. Whatever said and done, selfawareness of one's being is important in meeting the patient's set goals. In any situation, patient should not influenced by the counsellor's negative motives, if any. Therefore, the following characteristics will help function as a counsellor.

- **B**eing precise and specific
- **U**pholds integrity and honest
- **M**aintains professional distance
- **A**vailability towards the patients
- **C**onserves confidentiality
- **E**mpathetic and warm in nature
- **T**rustworthy and being genuine
- **S**elf-transformation
- **Being precise and specific:** When a test result is to be revealed and treatment is to be planned, being clear cut with the definitive result and treatment outcome being explained to the patient will allay their anxiety rather than withholding information from them. Patients are inquisitive about their test result. Accurate information, timely given is being precise in our dealings with patient.
- **Upholds integrity and honesty:** Honesty or integrity towards the patient, his treatment and information to be kept only for the purpose meant for. What we planned with the patient be given with 100% in faith. When we cheat a patient with low standard treatment options, we are failing with our honesty.
- **Maintains professional distance:** Maintaining personal and professional cut off point is very essential. From the entry of patient to the hospital, care and treatment process takes it sequence to wind up. Termination phase makes it clear that we need to maintain our professional distance from patients whom we care.

- **Availability towards the patients:** Availability of the counsellor to the patient when in need is paramount. Many unwanted events occur in a fraction of second when we failed to sense the signal the person is going through. Being available in correct time for counselling can prevent most of these undesirable events in life. Chronically ill patients require counselling from time to time. Planned counselling sessions for patients for inpatients will help patient to comply with their therapy.
- **Conserves confidentiality:** Confidentiality is to be maintained strictly. The first principle to be followed by a counsellor is confidentiality. When the patient knows that the counsellor can keep up with the information that he gives, he will be comfortable in revealing his concerns that may even seem stigmatized so that we are able to strengthen him with confidence.
- **Empathetic and warm nature:** Empathy is putting you into the shoe of the one patient who is suffering and feeling from his point of view. It is feeling in. Once a woman fell into the drain. A friend of her saw and jumped into the drain to save her and both were unable to come out anyway. Another friend passed by, saw these two women in the drain. She looked around, saw a plank of wood, brought it and placed it slanting and helped them come out of the drain without any injury. The later is empathy and the former is sympathy. Empathy and sympathy are two different terms. Empathy is what a patient requires from a health care professional.
- **Trustworthy and being genuine:** The faith patient has on physician needs to be strengthened. An elective surgery was planned. During the surgery, the postgraduate and the junior doctor performed the surgery instead of the professor who promised to do. Surgery posted needed maximum 1.5 to 2 hours and the surgery lasted 5 hours with suspected complications. On day three, the surgeon visits the patient postoperatively. Forgetting that the patient understands English, asked the PG student what they did during the surgery. Patient was astonished to hear that and related with the consequences that she suffered. Patient had lost her trust on the surgeon completely. Trust is to be upheld and embraced as a successful tool to success in one's professional practice.

- **Culturally competent:** India is a land of many tongues and health practices. Although one explains the correct phenomenon of drug compliance, culturally it may not be accepted. Understanding individual differences, beliefs, norms, standards and practices among various communities will enable the counsellor to put his best efforts.

In a nutshell, the counsellor should possess positive outlook about the treatment and also the outcome for the patient. Warmth and empathetic with positive regard for the patient can win any patient for their counselling compliance and success is determined by being non-judgemental and helping them to accept the approach. Counselling is an art and science and having an expertise in the field is a must for a professional counsellor.

APPROACHES TO COUNSELLING

Counselling is a progressive and person-specific built in relationship for a specific purpose. It is the counsellor who ignites the patient to express his concerns but assesses and analyses the concerns and strategies that the patient lacks and builds upon trust so that patient is able to come out with his own decision to follow his health maintenance process after a systematic analysis. Commonly used approaches are (Fig. 9.1):

- Directive
- Non-directive
- Eclectic

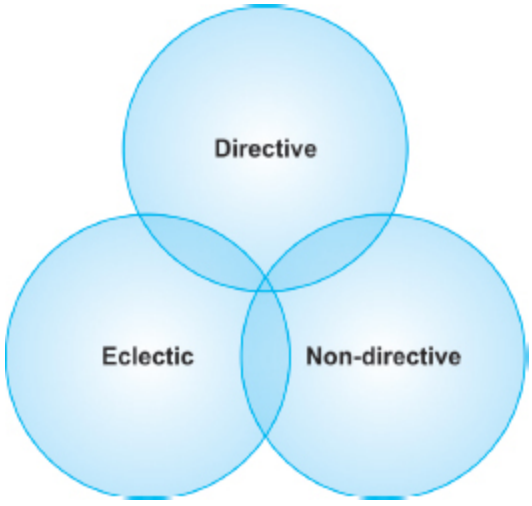


Fig. 9.1: Approaches to counselling

Directive Counselling: Explanation with Example

Directive counselling is counsellor addressed. Most of the time, this approach works in clinical scenario when the physician/nurse explains to the patient what they ought to take while they are in the hospital or when they go home. Health care personnel usually advices the patient on his treatment that he or she is giving without having to note the patient's choices and understanding regarding his management. The counsellor may explain, inform and interpret his test result to solve his health problems but patient's decision is secondary in this approach.

Advantages

- Time saving
- Counsellor initiates with active involvement
- Economical
- More organized

Disadvantages

- Patient is dormant and counsellor lacks understanding
- Patient may not be motivated to comply as wises are not considered/confused
- Interaction is limited
- Patient is dependent on the physician for all decision

Non-Directive Counselling

This method allows patient's maximum decision. It is patient-centred approach. Many-of the patients want to express but they are unable to openly express for the fear that the health care person may disregard their problems. They also feel ashamed especially when they want to discuss about their sexual problems either during treatment or after treatment. I remember a lady expressing to one of the nurse. She says, I am undergoing my chemotherapy and worried if I become pregnant. My husband cannot understand my problem nor can I discuss with my doctor. How to address to him my problems, its disgusting sometimes. Sexual issues are not talked about openly in the Indian context. Therefore, the counsellor needs to have

a standard protocol for patients in all areas of concern through assessment, and then he can work on the needed areas as per the patient in precedence. Hence the counsellor is passive in his counselling process and the patient tries his or her best to come out with solution. This approach helps patient to become more accountable towards his care aspects and how to lead a normal near normal life with the best treatment options provided to him.

Advantages

- Patient takes the lead and becomes more independent in his care concerns.
- Patient is given the freedom to choose his treatment options given as per his comfortable level.
- In deciding to take self-responsibility, the patient ultimately gains insight or knowledge about his condition and management from the health care personnel.

Disadvantages

- It is time consuming because one has to wait until the patient is comfortable to express his concerns. Patient might have inhibitions to tell. So one needs to give enough time to patient to open up their feelings or express their distresses.
- The counsellor needs certification especially in areas of health care counselling because, problems may be unique unlike in school or academic counselling.
- Since the patient takes the decision, he might come out with no solution. The counsellor needs to reinforce and provide more time for the patient which makes the process non-economical.

Eclectic/Mixed Method of Counselling

In this approach, the counsellor uses either of the above method mentioned or evens both. The method that suits best to the ego state of the individual within the process of counselling based on the observation and assessment of the present and the past.

Advantages

- It is flexible in nature.
- Counsellor and patient interact well through their active participation.
- Adjustments are made and approaches are either shifted or mixed.

Disadvantages

- Difficulty of going through only a single approach
- Maximum co-operation is required form the patient

Effective Characteristics in Counselling

(a) Having a well-defined purpose
(b) Providing flexibility for both patient and counsellor
(c) Respecting the patient and his values and beliefs
(d) Two-way communication with understanding of the patient's own language, gestures and non-verbal cues

PHASES/STEPS

(a) Establishing rapport
(b) Assessment and eliciting problems
(c) Preparing for the counselling and setting goals
(d) Implementing the counselling/intervention
(e) Termination and follow-up

Establishing Rapport

In any encounter between a counsellor and the patient, building up trusting relationship is very essential. Unless trust is built up no counselling can be successful. Through initial interaction, the patient as well as the counsellor gets to know each other and plans for the sessions that are being planned for the patient. Communication skills in this phase are very essential.

Assessment and Eliciting Problems

Quality of answer from the patient depends on what the counsellor asks the patient. Probing questions, such as asking why, how, when, where, what, will help the counsellor elicit patients' problems. Ask for any clarification.

If trivial, they may hide some information which may be important for diagnosis. Therefore, concentrate on patient's attitude and emotions while you elicit his issues and problems. When assessing the patient, use more of open-ended question rather than closed ended so that patient will be able to express oneself and his problems. For example: How is counselling helping you? Closed ended question gives you only two options 'Yes' or 'No'. In this you really cannot elicit inner problems that are troubling the person. Example: Have you followed the technique? The only way is to say yes or no for the questions you posed. If the patient requires further explanation, the counsellor needs to paraphrase or restate so that patient understand the right instructions. Keep in mind also the emotions and non-verbal languages the patient expresses. Once you elicit, summarize the feelings and problems expressed by the patient so that the counsellor's understanding is congruent to the one expressed by the patient. Although you observe emotions and body languages of the patient we have no right to evaluate rather we need to acknowledge his or her non-verbal behaviours.

Preparing for the Counselling and Setting Goals

Setting workable goals for the patient helps the patient to keep tract and limits wandering away from the topic of discussion. Goals usually are mutually set by the patient and the counsellor in common understanding. Goals need to be:

- **S**pecific and understandable
- **M**easurable and observable
- **A**chievable/realistic
- **R**elevant to the behaviour exhibited
- **T**ime bound and success oriented

Implementation/Intervention

In this phase, the implementation of the goal takes place. All the options were listed and analysed for its merits and demerits. Best option is selected and implemented to solve the issue.

Termination

There is no one answer when termination is to take place. Questions you may wish to ask yourself concerning termination include: Have clients achieved behavioural, cognitive, or affective goals? Can clients concretely show where they have made progress in what they wanted to accomplish? Is the counselling relationship helpful? Has the context of the initial counselling arrangements changed?

Resistance to termination: Clients and counsellors may not want counselling to end. In many cases, this may be the result of feelings about the loss and grief or insecurities of losing the relationship. For clients, this is something to process. For counsellors, this is an issue for supervision.

Premature termination: How one can handle such a situation when the patient is lost to follow-up before the goal is achieved. It is true that the patient is unable to come for the appointments or not wanting to continue but feel bad to tell the counsellor. Compliance factors play major role in this aspect. At this point of time, the patient may be referred to another counsellor after scheduling a closure session and termination. The counsellor with good intention need to make the referral with specific issues addressed and also reasons so as to why he wishes to be transferred or referred. Note the changes in the behaviour during referral process and also list a few counsellors for the referral.

Follow-up

Follow-up too is scheduled for the patient for checking their behaviour change and also performance in terms of compliance to their instructions.

STEPS IN PROBLEM SOLVING

If patient wishes to solve problems, these few steps can help them through:

1. Identify the problem
2. Gather information
3. Develop criteria
4. Generate possible solution
5. Analyse possible solution
6. Compare possible solution
7. Implementing the decision

8. Follow-up for behaviour change

CRISIS COUNSELLING

When the pressure out, the individual is more than his capacity to take it, the person experiences psychological, emotional, physical and behavioural distress. In distress, the person may take any drastic step to one's life. This is the time the person needs emotional first aid to understand his situation and be pout of the trouble through counselling. His distress or crisis state can be temporary but immediate active support to be provided least we may lose the person. Crises happen to everyone in minor or major form. Identifying and counselling him or her is to help cope with the problems to reduce its impact on his physical, psychological and behavioural effects of the stress or crisis. In times of diagnostic revelation, the patient may undergo a severe form of distress due to the nature of the disease. This is the time the person needs counselling and also support from his loved ones in way by being in his difficult time. This empathy shown by friends and family will help him cope. When faced with chronic distress and poor support system, the person may land up with mental disorders. Jeffrey H. Mitchell speaks about few principles that follow a crisis counselling or intervention (Table 9.1).

Table 9.1: Principles in crisis counselling

Principle	***Explanation***
Simplicity/ease	People respond to simple not complex proc ess in a crisis
Brevity/conciseness	Minutes up to 1 hour in most cases (3–5 co ntacts typical)
Innovation/novelty	Providers must be creative to manage new s ituations
Pragmatism/practicality	Suggestions must be practical if they are to work
Proximity/nearness	Most effective contacts are closer to operati onal zones
Immediacy	A state of crisis demands rapid intervention

Principle	*Explanation*
Expectancy/anticipation	The crisis intervener works to set up expect ations of a reasonable positive outcome

On every day basis, we see OP poisoning, hanged cases, running on tract and attempting or committing suicide. I would rather ask "Is it so easy to take one's life"? It is not. It takes lots of inner courage from an individual. When the crisis situation sees no solution, the person feels life is worthless to be lived. During examinations and result announcements, the youth in their pursuit for higher expectation in their performance may lead to stress if the result is not of their expectation and they may end up with an attempt to take their own lives. Trend is changing slowly towards our elderly population. Older people either living alone or only with their old spouse undergoes depression in many instances and tries to commit suicide as they feel they are no more productive as well as they have become a burden to their family. A neighbourhood, an old man who has his two children settled abroad was not seen for two days outside his house. When peeped through the window, he was found dead and decayed. Can you now put yourself into the shoe of this man and feel how he would have gone through his last moments. What would be his last wishes? What if he was hungry and dead? Did he call out for his children? To imagine becomes a mystery almost. No one can trace the feelings that went through the mind of this old man who died without having anyone at his side during his last breath. Referring to ourselves, the same situation cannot be scrapped from all of us someday. Learning to live to the best of our expectation and also living for yourself and the close one is necessary to prevent ourselves from psychological distress and psychiatric disorders.

HOW TO HANDLE A SICK INDIVIDUAL

For any mother, it is hard to experience child getting ill and being hospitalized. Even the slightest of cold or fever worries any mother. They would do anything to make their child feel alright. In this context, the mother may raise many questions probably repeatedly from a nurse. The nurse even in her busy schedule, should be able to allay the mother's anxiety while the treatment for the child is going on. More than dozens of medication, the mother may feel very comfortable if the nurse would utter

at least a consoling words that the child is being nursed with utmost care. Therefore, few of the tips the nurse need to keep in mind when any patient is sick and is under your direct care are: MATCAM:

- **M**ake them comfortable
- **A**lert the physician in times of need/ concerns
- **T**reat the cause aptly
- **C**ommunicate efficiently
- **A**llow them to visit frequently, if in ICU
- **M**eet their nutritional needs

Make them Comfortable

It is not the medication that puts a child to rest. It is the comfort and reassuring presence of a mother that makes a child most comfortable. The ambience of the room, machines, clean bed with appropriate play items based on child's likes and dislikes will help child cope. Any hospitalization is an apprehensive moment for every individual. Making them feel like home in the hospital and mother or loved one being with the person is going to make treatment at ease. Never leave a child alone unattended. Fear induced may play a major role in late recovery.

Alert the Physician in Times of Need/ Concerns

Whatever may be the time of the day, the physician needs to be well informed of the changes in the child for prompt treatment. There is a difference in the treatment approach for an adult and a child. Change in temperature for little child may lead to irreversible damage, if left unattended at the right moment. Although continuous nursing interventions are given, yet the physician be informed of the series of events taking place in the child for right treatment at the right time.

Treat the Cause Aptly

A child may not be able to explain what he is feeling like. But from the signs and symptoms and also the cry, every mother is able to understand the trouble the child is going through. This sensibility of the mother is an instinct human make up. Depending upon the history given by the mother or the child and also through the nurse's objective data through assessment

should be able to direct the physician for a correct diagnosis and right treatment. Right treatment heals a person fast, stay less time in the hospital and cost incurred is less. Patient will be able to go home at the earliest to live comfortably in his own environment and with loved ones.

Communicate Efficiently

Effective communication with the care aspects, progress, treatment rendered has to be explained to the mother, relatives and also the child if he or she is able to understand. Half of patient's anxiety can be allayed with good communication skills.

Allow them to Visit Frequently, if in ICU

Visiting hours become an issue to the loved ones in the ICU. Even mother of the child is not allowed in some instances to be with the child. Psychological distress and support deprivation make every mother feel to the core. It is easy for health care professionals to tell the mother or the relatives to wait till the next visiting hours but how the loved one feels is tremendous. If an ideal ICU is to be created for this century, closed person to the patient should be allowed at the bedside unless it does not endanger the person. Loved one being near serves two souls. The patient even in unconscious state can sense the voice and touch of the loved one which makes them feel cared and loved even in sickness. On the other hand, the caretaker feels he or she is able to do something for the sick person. Satisfaction of having cared for is a domain we forget in the critical care areas. Nurses and other health care professionals are so used to with one's duty bound activities. Yet the psychosocial aspects of critical patient should be considered. It is not worth living without having to see and feel their loved ones and dying process becomes a painful moment for the sick individual. Except for the few stories of near death experience narrated, death is only once and it is the right of the person to have his loved ones at the bedside. Death to be taken as a normal process. If all of us are asked so as to where we prefer to die, either hospital or home? Each of us will prefer home. But how many of our parents are allowed to have a peaceful death at home. Even at the point of death and when no medical aid can help and sick person even not willing to go to hospital, people still shift their sick person to the hospital. This is how many of us deal with our ill person who is at the

mercy of the family members. It is time for us to reflect and be thoughtful of the actions because that can happen to anyone of us someday.

Meet Their Nutritional Needs

Critically ill patient may be managed with IV fluids, if oral fluids and food are not allowed. But maintaining their calories as per body's requirement is a must and also nutrients required protecting from the ill effects of large dosages of medication. Getting treated for one condition, the patient may land up with complications to other system. Therefore, nutritional aspects are important aspect to be considered. Medication with or without food to be well monitored and tailored to meet the therapeutic needs. Modified diet based on condition to be considered and also serving them attractively to improve the patient's appetite. Hydration through calculate fluid intake to be monitored 24 × 7.

10

Pain and Palliation

Outline

- Pain experiences
- Emotional aspects of pain
- Impact of pain on family
- Impact of psychological factors in pain experience
- Pain assessment
- Types of pain
- Researches in the area of pain control
- Effects of pain
- Myths about pain
- Effective pain management

INTRODUCTION

Pain is personal and it can only be understood by the person who experiences it. Pain is accompanied by profound suffering. Empathetic nurse in some way is able to analyse patient's experiences. Although standard pain management protocols exist, yet adequate pain management is not received by the patient as pain is perceived philosophically as natural process like aging. Pain is differently felt by all individuals in one's life cycle from birth to death very differently. Pain may be either acute or chronic depending on the cause. Pain may not only be physiological but it may be spiritual, emotional and psychosocial pain. Pain management may

be greatly influenced by myths, rumours, fear and cultural practices. Therefore, it is imperative to understand:

- How patients demonstrate pain?
- Assess pain and how it is being managed at the health care level
- Note the difference between psychological dependence and physical dependence
- Will aggressive use of opioids cause addiction?
- How pain and its expressions are culturally being influenced.

Therefore, primary goal of palliative care is relief from suffering and the enhancement of quality of life through effective symptom management and palliative care components include symptom management, effective pain management, psychological management and spiritual management as the philosophy as palliation:

- Affirms life and makes dying a normal process.
- Neither to hasten nor postpones death.
- Provides relief from pain and other symptoms
- Takes a holistic approach to care-integrates the clinical with the psychological and spiritual
- Provides support to both the patient and family

Palliative stems from the word "pall" meaning mantle or shield; meaning to protect the patient from the onslaught of raging disease (John Finn, 2001).

Palliative care is the active total care of patients whose disease is not responsive to curative treatment (WHO).

PAIN EXPERIENCES

Pain is a complex process.

If you put your finger on the flame, you know very well that it hurts and immediate response is pulling away your finger from it. This pain response helps us prevent from injuries. Three systems interact usually to produce pain:

- Sensory—discriminative
- Motivational—affective
- Cognitive—evaluative

Sensory

Discriminative system processes information about the strength, intensity, quality and temporal and spatial aspects of pain (e.g. headache).

Motivational

Affective system determines the individual's approach-avoidance behaviours.

Cognitive

Evaluative system overlies the individuals learned behaviour concerning the experience of pain. It may block, modulate, or enhance the perception of pain.

INDIVIDUAL DIFFERENCES IN PAIN EXPERIENCE

No individual is similar in their features and pain too is perceived differently by every patient. Headache to a medical physician is headache as a diagnosis but experience of every individual with headache differs. Someone cannot tolerate noise, another person get nauseated with

headache, while some eat normally even with headache. Some take a short nap and eases one's pain, while some takes analgesic immediately. Feelings and levels of tolerance are different from person to person. Pain cannot be measured objectively. Pain is subjective feelings and hence we have to believe the patient. Sensory experiences have great importance in our clinical practice because they are felt differently by individuals. Rating scales or picture denoting pain aspects are captured to serve correct diagnosis and treatment of pain. Pain has to be assessed with care for very sensitive patient because they may sometime express severe pain for a procedure that may not cause profound pain to avoid unnecessary medication as they may be dramatic, hereditary, environmental.

Psychological and intellectual variables can shape individual differences in pain experience. Very anxious patients tend to exaggerate pain to greater level and hence pain need assessment with multiple scales to avoid over medication. A counselling in fact with medication and alleviate his pain and his anxiety. In my clinical experience, a child who is just 10 years old was undergoing haemodialysis twice a week. Initially, the child screams and would not allow any nurse or technician to prick even with their highest expertise in pricking abilities. Child had fear of needle. During the initial month of treatment, it was hard time for the child and health care team to manage the child even with sedations. Later, with familiarity and friendly atmosphere of the unit, child with little explanation allowed for cannulation and the child tolerated well with successive settings. Although she had physical pain, yet psychological management could allay her anxiety and could improve her threshold level as she needs therapy lifelong unless a renal transplant is possible.

EMOTIONAL ASPECTS OF PAIN (Fig. 10.1)

Emotional impact of pain has been discussed by Maris Pasquale through the proceeding on "The emotional impact of the pain experience" from the presentation at the SLE Workshop at Hospital for Special Surgery on December 18, 2008. Many factors influence the experience of pain, which are different for everyone. They include age, gender, culture, ethnicity, spiritual beliefs, socioeconomic status, emotional response, support systems, life before pain onset and the learned responses that are projected by our family members towards the person. If one faces chronic pain for a

longer duration, anxiety and depression may set in and the cycle of pain and emotions keeps a constant aftereffect.

Pain and emotions are interrelated. When one is in pain, showing happy face may not look appropriate or when one is anxious and tensed it is natural that one's muscles may tighten that even may aggravate pain experience. For example, when a nurse is about to give injections, seeing the needle itself the patient may already experience tight muscles and pain is already felt. This is because of anxiety related to pricking pain perceived as well as from past experience. If you are an adult patient, then thinking that your life and situation is under your control to some extent, then the person may be able to bring down the anxiety level or the depression to lower level. Counselling patient in areas of treatment and the procedure becomes paramount. Pain and disability may also put an individual on identity crisis. How you project yourself to others makes a big difference in your life. But due to chronic pain that may not leave you, one might be disabled to do the things that once upon a time you used to do with perfection which may put you to demoralization. Culturally, one may develop one's identity through gender, socioeconomic conditions, ethnicity, caste, the type of job you take up, etc. and if the individual is unable to perform his or her role to the expected level then the individual may have identity issues. For example, Mr. X, man of the family, used to plough the field every year for a good harvest. Because of pain he is unable to do the same this year. The wife and children will feel the impact of helplessness as he could not function the way it used to be.

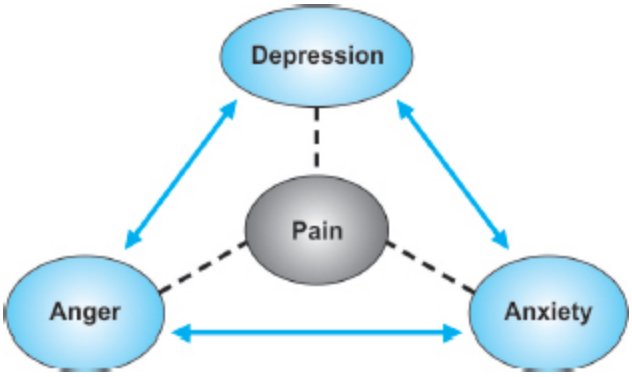


Fig. 10.1: Pain and emotional cycle

IMPACT OF PAIN ON FAMILY

When the mother of the family is in pain and unable to function as a mother anymore, the pain and anguish is being felt by all family members. The pain of the affected may hamper the communication pattern and feelings of the family members although they try their best to adapt to near normal that is bothering them. Other factors that may impact the family members are their level of stress based on relationship, financial issues, resentment, and sexuality issues. When mother's role functions are hampered, nutritional needs of the family, children's punctuality to school, love and care and home activities all gets still. If the only earning member of the family is sick, then the economic source is expurgated. Financial burden begins to set in and family's living becomes burdensome and his or her treatment itself becomes uncertain. Way back in 2009, April 26th, the only son of a couple lost him due to blood cancer. The long one year treatment in the hospital could not save him. The child had ALL (acute lymphocytic leukaemia) with M7 positive, a rare case. The mother was the sole caretaker. Father used to manage both hospital and home. The sick child also had an elder sister 6 years old. At times when both parents used to be in the hospital due to his severe conditions for almost a month at a stretch, the elder child used to get totally deprived. Although cared by a grandmother, parents mean everything to a child. Her school, her performance, her love and affection needs were all neglected. Pacifying and explaining about her brother's illness could not be realised by the child as she was too young to understand. One day the little girl told her father "If you do not come by this December home, I will stop eating and going to school". Parent weren't able to go home either in December. Finally the little boy died in April the very same year. The elder sister's reaction to seeing her brother's homecoming but with no response and everyone crying made her feel uneasy and was wondering what is happening. When explained to her, she responded saying "The hospital killed by brother". Parents losing their only son and also having neglected their little daughter pinched them inch by inch. Even after these many years, parents could recall the difficulties they faced when one of their loved ones was ill and being admitted.

IMPACT OF PSYCHOLOGICAL FACTORS IN PAIN EXPERIENCE

According to *(Steven J. Linton, William S. Shaw. Impact of Psychological Factors in the Experience of Pain. PhYS ThER. 2011; vol 91 (5):700–711)* the above research findings, the recommendations are given in Table 10.1.

Table 10.1: Factors affecting pain

Factor	*Description*	*Possible effects on pain and disability*	*Management strategy*
Attention	Pain demands our attention	Vigilance may increase pain intensity Distraction may decrease its pain intensity	Distraction techniques Interceptive exposure
Cognitions	How we think about our pain may influence it.	Pain and disability Catastrophizing may increase pain Negative thoughts and beliefs may increase pain and disability Expectations may influence pain and disability Cognitive sets may reduce flexibility in dealing with pain and disability	Cognitive restructuring Behavioural experiments designed, for example, to disconfirm unrealistic expectations and catastrophizing
Emotions and emotion regulation	Pain often generates negative feelings. These negative feelings may influence the pain as well as fuel cognitions, attention, and overt behaviours.	Fear may increase avoidance behaviour and disability Anxiety may increase pain disability Depression may increase pain disability Distress, in general, fuels negative cognitions and pain disability Positive emotions might decrease pain	Cognitive-behavioural therapy programmes for anxiety and depression Activation (to increase positive emotion) Relaxation Positive psychology techniques that promote wellbeing and positive emotions
Overt behaviour	What we do to cope with our pain influences our perception	Avoidance behaviour may increase disability Unlimited activity (over activity) may provoke pain Pain behaviours communicate pain	Operant, graded activity training Coping strategies training

ELDERLY AND PAIN

Pain experienced by elderly is neglected for many reasons. Their discomforts are often taken for granted as elderly will experience them sometime in lifetime. Quality of life definitely is laden due to pain experiences and also the lowering activities of daily living (ADL). Pain in many ways disturbs the sleep pattern among elderly and medication seems insufficient to handle their pain. Many of the elderly are today left to themselves or left with caretakers or put in the geriatric homes with or without a trained personnel. Comorbidities face by elderly adds to the

complex care aspects. Existing research review reports 506 million elderly above 65 years by 2008 and 1.3 billion by 2040 worldwide. The United States Census Bureau reports that there are 12.8% (38.9 million) elderly above 65 years and 5.7 million elderly above 85 years.

According to National census 1991, 2001, 2011, the elderly population 60+ is 6.8%, 7.4% and 8.8%, respectively. With the advancement in medical facilities and increased earning capacity, the elderly population is on the rise in all the countries across the globe. Adding years to life may not add life to years. Living with quality life becomes an issue even though we live for more years. Most of the elderly with their declining health status, experience various pains, such as joint pains and neuralgias. They have pains but most of the time they are left untreated.

PAIN ASSESSMENT

Every treatment begins with an assessment. Assessment seems easy but otherwise not. Pain is subjective and factors that contribute to pain are multifactorial. Pain perceived differs from person to person. This further is complicated by patient's loss of memory, illness severity, comorbidities, and medication effects. Therefore, best information could be accessed from the main caretaker. Pain management requires team approach. Elderly may also have depression and hence a psychiatrist would be best person to be consulted. Physical therapy may be a help to the elderly for his ADL. Investigations and medical management by the medical team and laboratory experts. Nurse as the main coordinator of care needs to coordinate with every team member and provide care to best of our conscious abilities. Few of the pain scales that describe pain of an individual are—VAS (Visual Analogue Scale), Verbal descriptor scale and rating scales. VAS although used frequently in clinical are to assess pain, yet the elderly may not be able to comprehend correctly and hence, McGill pain questionnaires which have validity, reliability and discriminative abilities are used to assess sensory, affective, evaluative and miscellaneous components of pain. Areas to be focused in assessment according to Alan et al (2010) are:

- Comprehensive history and physical examination on the main pain issues
- Location of pain, intensity, exacerbating or alleviating factors that have impact on the mood of the patient.

- Mini-mental examination to screen for cognitive level
- Screening individual for depressive feelings or depression
- ALD assessment that is bathing, dressing, toileting, transfer, feeding and continence
- Checking for gait and balance
- Assess for visual and auditory functions

Pain may be expressed differently, so one needs to assess with different pain patterns, such as throbbing, stabbing, sharp pain, dull aching pain, etc. and also look for if it persists, recurs, and it really affects the person's quality of life.

Principles of Assessment

(a) Ask
(b) Dispel myths/misunderstandings
(c) Believe the patient
(d) Assess and reassess
(e) Use methods appropriate to cognitive status and context.
(f) Assess intensity, relief, mood, and side effects
(g) Include the family

PQRST Method to Assess Pain

Dolly Curley, from CKHS home care described 'PQRST' method of pain assessment as most applicable and valuable tool in describing patient's pain, appropriate selection of pain medications, eliciting their responses and evaluating the treatment outcome. The pain committee feels that this method is the gold standard due to the reasons given below:

P : Provocation/palliation
Q : Quality/quantity
R : Region/radiation
S : Severity
T : Timing

Provocation/Palliation

Few of the questions that can be raised to provoke the patient are:

- Was the patient doing anything when pain started?
- What caused the pain?
- What makes the pain worse?
- What triggers pain for the patient?
- Is stress aggravating pain?
- Is doing ADL causing pain or any other activities?
- What makes the pain better or relieves pain?
- Did medication help reduce pain?
- Did the change of body position help reduce pain either?
- Did being active, walking around and standing relieve pain?

Quality/Quantity

How do you describe your pain—throbbing, stabbing, burning, crushing, nauseating, shooting, twisting, stretching, and nagging?

Region/Radiation

- Location of your pain?
- Where does the pain radiate as you experience it?
- Where all you feel it is radiating?
- Does it generalized for onetime or located in an area alone by now?
- Does the pain move around?

Severity

- How severe is your pain on a scale of 0–10, zero being no pain and 10 as worst pain ever?
- Does it hamper your ADL?
- How bad is your pain when it is worst?
- Did you have to sit, lie down or slow down once the pain starts?
- How long the pain last once it begins for an episode?

Timing

- When did the pain start?
- How long the pain lasted?
- How often you experience pain
- Is it a gradual or sudden onset?
- What time of the day you experience pain mostly?
- What did you do when you experienced pain for the first time?
- Did pain kept you awake the whole night?
- Is the pain aggravated by eating or being in empty stomach?
- Does it occur seasonally?

Documentation

- Did you record the pain assessment findings?
- Did the patient understand the pain scale scoring pattern?
- How satisfied is the pain with the present pain medication?
- Did you record the patient's response to treatment?
- Did you report pain findings to the physician?
- Did you educate the patient about pain management and his ability to understand and record them?

PATHOPHYSIOLOGICAL CHANGES IN THE ELDERLY

Pain is an indicator for its protection against a health problem. Pain is a normal response of every individual to some injury or the pathology that takes place as normal physiological changes within the nociceptive system. Pain may be perceived differently due to our genetic makeup and also the environmental factors. Other symptoms, such as hyperalgesia, which is an exaggerated response to a noxious stimulus, and allodynia, the perception of pain from normally innocuous stimuli may occur. These two effects are the result of changes either in the peripheral or CNS referred to as peripheral or central sensitization.

The nociceptive response within us not only senses acute pain due to injury or pathology but also if sensitizes chronically, it may lead to chronic

pathological pain disorder from the previous disease or disorder.

Chronic pain is also characterized by abnormal state and function of the spinal cord neurons which become hyperactive. This hyperactivity is the result of increased transmitter release by spontaneously active primary afferent neurons and an increased responsiveness of postsynaptic receptors (in part due to phosphorylation of glutamate-activated NMDA receptors). A hyper-excitable state of synaptic transmission at the dorsal horn is further maintained by release of biologically active factors from activated glia. The state of hyperexcitability is aggrava-ted by the loss of inhibitory interneurons involved in the modulation of pain.

In the normal circumstances, the nociceptive sensory system returns to a normal functional state as soon as healing takes place. But many features of sensitization persist and are manifested as chronic pain and hyperalgesia, especially when the nervous system itself is injured leading to chronic neuropathic pain. Imaging studies have shown that chronic pain is accompanied by permanent structural alterations in specific brain areas that play a crucial role in nociception.

(Alan DK, Amir B, Jared TS. Pain management in the elderly population: A review. The Ochsner Journal, 2010; Vol 10 (3): 179–187)

Our organs and our homeostasis function decline with age. Few of the organs that are most affected with aging and problems faced are:

- **CNS:** Today the most common CNS problems are transient ischaemic attacks (TIA), stroke, dementia and movement disorders. Sometimes our assessment may be misguided by few of these disorders also. After age of 50 years, our CNS and peripheral nervous system cease to function as the nerve cells or the neurons damaged are not regenerated or rejuvenated. Alzheimer's, neoplastic diseases, CNS infections, metabolic disorders, Parkinson's disease are common pathologies in elderly that cause pain experience.
- **Hepatic:** All that we ingest are being metabolized in the liver. Liver in elderly may prolong its clearance. The changes could be due to prehepatic, intrahepatic, or posthepatic causes. Pathology within the liver may be the cause for lowered liver function and test may sometime show normal in elderly despite the changes (Table 10.2). *(Alan DK, Amir B, Jared TS. Pain management in the elderly*

population: A review. The Ochsner Journal, 2010; Vol 10(3): 179–187)

Table 10.2: Hepatic changes in elderly

Parameters	***Hepatic changes in elderly***
Size	Liver mass decreases by 1% per year aft er 50 years
Blood flow and velocity	Blood flow decreases by 33% in inflow and portal velocity decrease by 25% ov er 65 years
Liver function	No significant changes
Conjugation	No significant changes
Microsomal hydroxylation/oxida tion	No significant changes
No microsomal oxidation	No significant changes
Demethylation	Decreased with age and caution with be nzodiazepine use
Protein synthesis	Serum albumin level slightly reduces, re duced quality of albumin, increased free fraction of protein bound drugs
Serum and biliary cholesterol	Increased change of cholelithiasis and a therosclerosis
Liver regeneration and capacity	Decline in regeneration rate.

Renal Changes in the Elderly

Kidney is human sieve. Main function is forming and eliminating urine, maintaining blood volume with proper balance of water, electrolytes, and pH, retaining key compounds such as glucose, while excreting wastes such as urea, controlling arterial blood pressure and regulating erythrocyte development. According to Alan DK, Amir B, and Jared TS, decline in the renal among elderly signifies:

- Kidney decrease in the size by 20–30% by 70 years
- Decreased in the length, number and thickness of renal tubules
- Increased interstitial tissues and tubular diverticula of renal tubules

- Decreased renal blood flow by 10% per decade after 20 years
- GFR decreases by 10 ml/min per decade
- Decreased free water absorption by 5% per decade after 50 years
- Accelerated decline by comorbid conditions, such as hypertension, heart failure, etc.

Chronic Geriatric Pain Syndromes

Pain syndromes among elderly are due to the multiple organ deterioration with advancing age. Signs and symptoms of degeneration in the body tissues are shown up with multiple effects on vital organs. Few of the pain syndromes explained by Alan et al are:

- Rheumatic diseases, such as osteoarthritis and rheumatoid arthritis.
- Cancer pain
- Angina
- Atherosclerotic and diabetic peripheral neuropathy
- Trigeminal neuralgia
- Malnutrition
- Peripheral vascular diseases
- Ischaemic pain, etc.

TYPES OF PAIN

- **Cutaneous pain:** This type of pain originates in the skin.
- **Somatic pain:** Pain that is being generated form deeper connective tissues, such as muscles, tendons and joints.
- **Visceral pain:** Pain that arises from internal organs which might be injured or ailing.
- **Neuropathic pain:** Pain that may be atypical, such as phantom limb pain.
- **Acute pain:** Pain that lasts for seconds to 6 months. It is of sudden onset. It might be due to tissue trauma, surgical cut injury. Its gradual healing and lowered pain helps patient cope better.

- **Chronic pain:** Pain that lasts for more than six months or even lifelong. It causes physical and emotional distress and may induce the patient to depression which is commonly seen in cancer. Coping with pain becomes a concern as gradual increase in the disease severity will cause tremendous pain increased.

Pain Classification

Figure 10.2 and Table 10.3 depict pain classification.

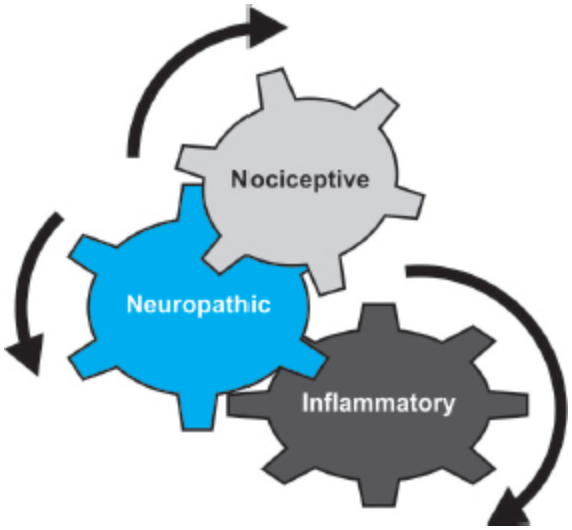


Fig. 10.2: Pain classification

Table 10.3: Types of pain

Classification	*Description*	*Examples*
Nociceptive	Represents the normal response to noxious insult or injury of tis sues, such as skin, muscles, visc eral organs, joints, tendons, or b ones	Somatic: Musculoskeleta l (joint pain, myofascial pain), cutaneous; often well localized Visceral: Hollow organs and smooth muscle; usua lly referred
Neuropathic	Pain initiated or caused by a pri mary lesion or disease in the so matosensory nervous system Se nsory abnormalities range from deficits perceived as numbness t	Examples include, but ar e not limited to, diabetic neuropathy, postherpetic neuralgia, spinal cord inj ury pain, phantom limb

Classification	*Description*	*Examples*
	o hypersensitivity (hyperalgesia or allodynia), and to paraesthesi a, such as tingling	(post-amputation) pain, a nd post-stroke central pa in
Inflammatory	A result of activation and sensiti zation of the nociceptive pain p athway by a variety of mediator s released at a site of tissue infla mmation The mediators that have been i mplicated as key players are pro inflammatory cytokines, such I L-1-alpha, IL-1-beta, IL-6 and TNF-alpha, chemokine, reactive oxygen species, vasoactive ami nes, lipids, ATP, acid, and other factors released by infiltrating l eukocytes, vascular endothelial cells, or tissue resident mast cell s	Examples include appen dicitis, rheumatoid arthri tis, inflammatory bowel disease, and herpes zoste r.

Reference: Steven J. Linton and William S. Shaw. Impact of Psychological Factors in the Experience of Phys Ther. 2011; 91:700–711.

Pain Intensity

Pain is subjective and hence it can be broadly categorized as mild, moderate and severe. For an adult, numeric scale is usually the choice of scale with a scale ranging from 0 to 10. Ten being the worst pain and zero the least pain or no pain:

- Mild: ≤4/10
- Moderate: 5/10 to 6/10
- Severe: ≥7/10

On the other hand, a pictorial form of pain assessment scales available for assessing pain especially for children who cannot comprehend numerical scale.

Quality Pain Assessment

Although pain is assessed using scales, selfrated questionnaires published by Galer, Jensen and Gammaitoni (2003) described the following questions can probe pain felt by an individual holistically.

1. No pain to worst pain in a scale of 0–10.
2. Not sharp to sharp pain in a scale of 0–10.
3. Pain over the last one week on a scale of not hot to burning type of pain felt.
4. Pain that is not dull to most dull on a scale of 0–10.
5. Not cold to very cold pain like “like ice” and “freezing” on a scale of 0–10.
6. Not sensitive to touch and most sensitive to touch on a scale of 0–10.
7. Tender on pressure to most tender sensation imaginable (0–10).
8. Not itchy to most itchy sensation (0–10).
9. Not shooting to most shooting pain (0–10).
10. Not numb to most numbed sensation (0–10).
11. Not electrical type of pain to most electrical sensation type of pain (0–10).
12. Not tingling to most tingling type of pain—needling pain (0–10).
13. Not cramping pain to most cramping pain (0–10).
14. Not radiating pain to most radiating pain—spreading type (0–10).
15. Not throbbing to most throbbing pain (0–10).
16. Not aching to most aching sensation, like toothache (0–10).
17. Not heavy pain to most heavy sensational pain (0–10).
18. Not unpleasant to most unpleasant sensation or intolerable (0–10).
19. No deep pain to most intense deep pain (0–10).
20. No surface pain to most intense deep pain sensation (0–10).
21. Pain can also have different time qualities. For some people, the pain comes and goes and so they have some moments that are completely without pain; in other words, the pain “comes and goes”. This is called intermittent pain. Others are never pain free, but their pain types and pain severity can vary from one moment to the next. This is called

variable pain. For these people, the increases can be severe, so that they feel they have moments of very intense pain ("breakthrough" pain), but at other times they can feel lower levels of pain ("background" pain). Still, they are never pain free. Other people have pain that really does not change that much from one moment to another. This is called stable pain. Which of these best describes the time pattern of your pain (please select only one):

( ) I have intermittent pain (I feel pain sometimes but I am pain-free at other times).

( ) I have variable pain ("background" pain all the time, but also moments of more pain, or even severe "breakthrough pain or varying types of pain).

( ) I have stable pain (constant pain that does not change very much from one moment to another, and no pain-free periods).

Reference: (Copyright © Galer, Jensen and Gammaitoni, 2003, All Rights Reserved. Jensen, M.P. (in press). Pain assessment in clinical trials. In D. Carr and H. Wittink (Eds.), Evidence, outcomes, and quality of life in pain treatment. Amsterdam: Elsevier.)

Pain Pathway and its 4 Phases (Fig. 10.3)

(a) Transduction

(b) Transmission

(c) Perception

(d) Modulation

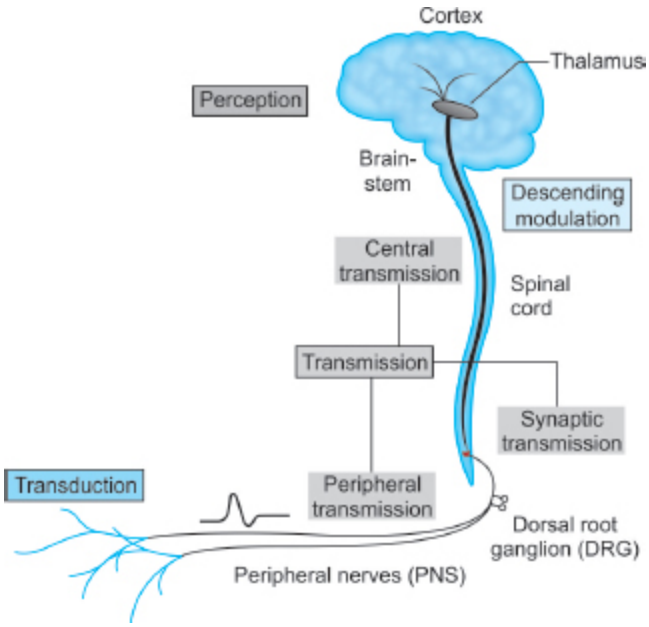


Fig. 10.3: Pain pathway and its 4 phases

Transduction: Transduction refers to the conversion of chemical information at the cellular level into electrical impulses that move toward the spinal cord. Begins when injured cells release chemicals (i.e. substance P). Chemical excite nociceptors. Nociceptors are sensory nerve receptors activated by stimuli.

Transmission: It is the phase during which stimuli move from the peripheral nervous system toward the brain. A-delta fibres carry impulses rapidly. C-fibres carry impulses slower. In the thalamus, within the brain, transmits the message to the cortex, notifies nociceptors that message was received. To discontinue the transmission.

Perception: The conscious experience of discomfort when the pain threshold is reached.

Pain threshold: The point at which sufficient pain-transmitting stimuli has reached the brain.

Pain tolerance: The amount of pain a person endures. Each person tolerates pain differently:

- Pain is influenced by genetic

- Learned behaviour
- Culture

Modulation: Modulation is the last phase of the pain impulse. The brain interacts with the spinal nerves to alter the pain experience releasing pain inhibiting neurochemicals.

PAIN THEORIES

(a) **Endogenous opioids:** Naturally produced morphine-like chemicals.

- Endorphins
- Dynorphins
- Enkephalins

The release is stimulated by serotonin and norepinephrine. They bind to the sites of the nerve membrane that block the transmission of pain.

(b) **Gate control theory:** In 1965, Ronald Melzack and Charles Patrick (Pat) Wall (Melzack and Wall, 1965) proposed a theory that would revolutionize pain research: the Gate Control Theory of Pain. The Gate Control Theory recognized the experimental evidence that supported the Specificity and Pattern Theories and provided a model that could explain these seemingly opposed findings. In a landmark paper, Melzack and Wall (1965) carefully discussed the shortcomings of the Specificity and Pattern Theories—the two dominant theories of the era—and attempted to bridge the gap between these theories with a framework based on the aspects of each theory that had been corroborated by physiological data. Specifically, Melzack and Wall accepted that there are nociceptors (pain fibers) and touch fibers and proposed that these fibers synapse in two different regions within the dorsal horn of the spinal cord: cells in the substantia gelatinosa and the "transmission" cells. The model proposed that signals produced in primary afferents from stimulation of the skin were transmitted to three regions within the spinal cord: (1) the substantia gelatinosa, (2) the dorsal column, and (3) a group of cells that they called transmission cells. They proposed that the gate in the spinal cord is the substantia gelatinosa in the dorsal horn, which modulates the transmission of sensory information from the primary afferent neurons

to transmission cells in the spinal cord. This gating mechanism is controlled by the activity in the large and small fibers. Large-fiber activity inhibits (or closes) the gate, whereas small-fibre activity facilitates (or opens) the gate. Activity from descending fibers that originate in supraspinal regions and project to the dorsal horn could also modulate this gate. When nociceptive information reaches a threshold that exceeds the inhibition elicited, it "opens the gate" and activates pathways that lead to the experience of pain and its related behaviours. Therefore, the Gate Control Theory of Pain provided a neural basis for the findings that supported and in fact helped to reconcile the apparent differences between the Pattern and Specificity Theories of Pain.

RESEARCHES IN THE AREA OF PAIN CONTROL

- Glucose and pain reduction during heel prick for neonates (Santy Jose)
- Foot massage and cancer pain (Moly)
- Effectiveness of ice application for post-ECT headache among mentally ill patients in selected hospitals of Kerala State. (Alphonsa Mary Jeseph-2010)
- A study to determine the effectiveness of acupressure on stress among high school students in selected schools of Udupi District, Karnataka State. (Rachana Das-2010)

EFFECTS OF PAIN

Physiological Effects of Pain

- Increased catabolic demands—weakness, muscle breakdown.
- Decreased limb movement—increased risk of DVT/PE.
- Respiratory effects—shallow breathing, tachypnoea, cough suppression increasing risk of pneumonia and atelectasis.
- Increased sodium and water retention (renal)
- Decreased gastrointestinal mobility
- Tachycardia and elevated blood pressure

Psychological Effects of Pain

- Negative emotions—anxiety, depression
- Sleep deprivation
- Existential suffering

Immunological Effects of Pain

- Decreased natural killer cell counts

MYTHS ABOUT PAIN

- Pain is a normal process and expected sometime
- Pain medication creates addiction
- Pain should be treated when felt by the patient and not prevented
- Pain is always reported to the nurse or physician treating the patient
- Patients always show their pain in their behaviours and expressions
- Level of pain is exaggerated by the patient
- Pain cannot be relived altogether
- Newborn babies do not have pain
- Some pain is good so that patient's indicators are not masked
- Elderly always has some pain
- Men and women both express their pain equally

EFFECTIVE PAIN MANAGEMENT

Due to multiple advances in the field of pain management (i.e. pain assessment, pharmacological and non-pharmacological interventions), licensed nurses may have incomplete or inaccurate information about the following variables which contribute to ineffective pain management:

- What is pain and how do patients demonstrate their pain?
- How is pain assessed and managed?
- Is there a difference between psychological dependence, addiction and physical dependence?
- Does aggressive use of opioids cause addiction?
- How does the patient's cultural background affect pain expression and management?

The WHO Method of Pain Management

Evaluating pain: When dealing with cancer pain, it is important to take a holistic approach to evaluate the pain. The main steps to evaluate pain are listed below (adapted from WHO guidelines).

- Believe the patient's report of pain—it forms the basis of the rest of evaluation.
- Initiate discussions about the pain—as well as direct questioning; take account of nonverbal indications of pain and reports from other team members.

- Take a detailed pain history.
- Evaluate the psychological state of the patient—depression is common in cancer patients, and treating it can have an impact on pain.
- Perform a careful physical examination—a detailed history and examination may reveal all needed to be known to start treating pain effectively.
- Perform any necessary investigations—only if there is doubt of the cause of pain, and if the results will affect management.
- Monitor results of treatment—evaluation of pain is an ongoing process, and changes to the treatment may be needed as the disease or the pain progresses.

Pain history: There are many methods of taking a pain history, and as long as history is thorough and systematic, it does not matter which you use. One common method, the PQRST method for assessing pain.

Causes of pain: Pain in patients with cancer can be from many sources, and establishing the cause will help make managing it easier. Pain may be:

- Caused by the cancer itself (this is the most common cause)
- Related to the cancer (e.g. muscle spasm, lymphoedema, constipation)
- Related to anticancer treatment (e.g. chemotherapy induced mucositis, chronic postsurgical scar pain)
- Caused by concurrent disease (e.g. osteoarthritis, spondylosis)

Many patients have multiple pains from one or more causes. The cancer itself can cause pain through:

- Extension into soft tissues
- Visceral involvement
- Bone involvement
- Nerve injury or compression
- Raising intracranial pressure

Once the cause of the pain is identified, we can establish the type of pain, and better focus the treatment.

Types of Pain

There are many ways to classify pain, we will look at one of the simpler ones: classification according to neural mechanism.

Causes of pain can be classified into two main types—nociceptive and neuropathic (Table 10.4). Nociceptive pain is caused by stimulation of nerve endings, neuropathic pain by nerve injury. Patients will often have more than one type of pain, and may have a mixture of the two types. Table 10.4 gives examples of each type, and typical characteristics of each pain type.

Table 10.4: Pain types and their characteristics

Pain type	***Example***	***Characteristics/description***
Nociceptive Visceral Somatic Muscle spasm	 Liver capsule pain Bone pain Cramp	 Sharp/stabbing/ache Deep/aching/"like toothache"/ "gnawing" cramp, spasm, achey, intermittent
Neuropathic *Nerve injury*		
Peripheral Central Mixed Sympathetically maintained	Neuroma, brachial plexus infiltration Spinal cord compression Postherpetic neuralgia Chronic post-surgical pain	Burning/stabbing/"pins and needles" Numbness/weakness/tight chest pain Cutting/stabbing/shooting/burning Burning (superficial), arterial distribution

Principles of Pain Management

Patients presenting with pain should be assessed and then placed on suitable treatment. The WHO approach to pain management has been shown to be effective in relieving pain in 90% of patients with cancer and 75% of

terminally ill cancer patients. There are five principles of cancer pain management. Drug therapy should be administered:

1. **By the mouth:** Oral administration is convenient, non-invasive, cost-effective and well tolerated in most patients.
2. **By the clock:** Regular analgesia (4–6 hourly) with breakthrough doses when needed provide a more constant level of drug in the body and reduce pain recurrence.
3. **By the ladder:** Patients should move up the ladder as necessary, but may also move down the ladder, if pain decreases.
4. **For the individual:** Patients presenting with moderate to severe pain can be started on a higher step in the ladder. Some patients will not be able to tolerate oral medication and may need other preparations. Patients may need non-drug therapies. There is no standard dose of opioid-morphine requirements can vary from 5 to 1000 mg every four hours.
5. **With attention to detail:** Total analgesia usage should be monitored every 24 hours, and the maintenance dose adjusted accordingly. Breakthrough doses should be adjusted in line with changes to regular medication. New pain should be assessed promptly to ascertain the cause and to allow treatment. Patients should be informed of possible adverse drug effects.

The Pain Ladder

Figure 10.4 represents the different steps of the pain ladder. Patients can be started on any stage of the ladder and moved up until they are free from pain. If pain decreases or becomes steady, drug dosages may be reduced and patients may be moved down a step. We will look at each step in depth later on.

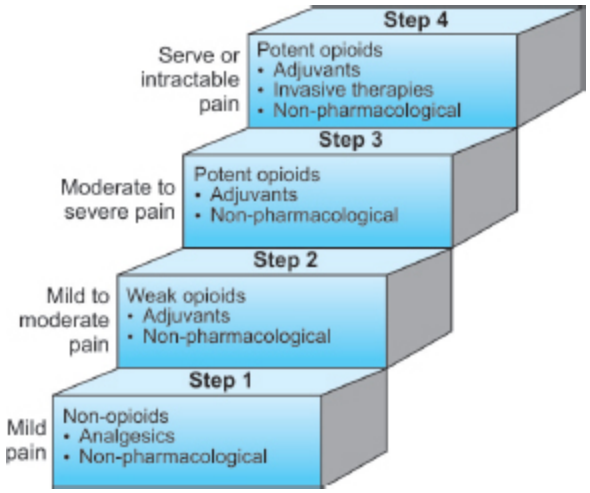


Fig. 10.4: WHO pain ladder (Adapted from WHO pain relief ladder)

The Pain Ladder: Drug Classes

Here are some examples of drugs in each class.

- **Non-opioids:** These include simple analgesics, such as **paracetamol** and **aspirin**, as well as non-steroidal anti-inflammatory drugs (NSAIDs), such as **ibuprofen, keto-profen** and **diclofenac**.
- **Opioids:** The opioids are a large group of drugs that include **codeine**, **tramadol**, **morphine** and **methadone**. They play an important role in the management of pain in a large proportion of cancer patients.
- **Adjuvants:** These include analgesics for specific types of pain, drugs that enhance the effect of other analgesics, and drugs that help treat concurrent symptoms that exacerbate pain. They include **gabapentin** (neuropathic pain), **midazolam** (agitation, anxiety), **baclofen** (muscle spasm), **zoledronic acid** (bone pain), and dexamethasone (nerve root compression). Adjuvants can be added in at any step of the ladder as the need arises. Often more than one adjuvant may be needed.

WHO ladder: Step 1 (non-opioids +/- adjuvant + non-pharmacological): A useful firstline of treatment is often the use of simple analgesics and NSAIDs.

When prescribing NSAIDs, it is important to check for any history of asthma (can be exacerbated by NSAIDs), previous hypersensitivity reaction to any NSAID (class effect contraindicates use of any other NSAID), and

active bleeding/ulceration. In all cases, when NSAIDs will be used for a prolonged period, a gastroprotective drug should be prescribed, e.g. lansoprazole 15 mg od.

So a patient on step 1 may be on a drug regime like this:

- Paracetamol 1g four times a day
- Diclofenac 50 mg three times a day
- Lansoprazole 15 mg a day

WHO ladder step-2 (weak opioid for mild to moderate pain +/- non-opioid +/- adjuvant + non-pharmacological): If pain persists or increases, patients move up from step 1 to step 2. They will typically continue on any NSAID/adjuvants already prescribed, but should also be commenced on a weak opioid, such as **codeine**, **dihydrocodeine** or **tramadol**. If they were also on **paracetamol**, a combined preparation can be prescribed, being careful not to exceed the maximum recommended dose of paracetamol of 4 g in 24 hours.

So a patient on step 2 may be on a drug regime like this:

- Cocodamol (30/500) 2 tabs four times a day
- Diclofenac 50 mg three times a day
- Lansoprazole 15mg once a day
- +/- any adjuvants as needed.

WHO ladder step-3 (potent opioid for moderate to severe pain + adjuvant + nonpharmacological): If pain persists or increases, patients move up from step 2 to step 3. The opioid drugs used in this stage will be more potent drugs, such as **morphine**, **fentanyl** and methadone. Morphine is the most commonly used firstline drug in this step.

To calculate a suitable starting dose, patients should have an oral morphine preparation prescribed as needed, usually oral morphine solution, 10 mg as needed. The total opiate used in 24 hours will give an indication of the best starting dose. So if a patient uses a total of 60 mg of morphine, they can be started on either 10 mg every four hours, or preferably, 30mg twice daily of a modified release preparation.

The PRN (as needed) dose of oral morphine should be increased such that the PRN dose is 50 to 100% of the calculated regular four hourly dose.

So a patient on step 3 may be on a drug regime like this:

- Morphine sulphate modified release 30 mg twice a day
- Diclofenac 50 mg three times a day
- Lansoprazole 15 mg once a day
- +/- any adjuvants as needed.

OPIOIDS AND COMPLEX PAIN MANAGEMENT

- **Opioid analgesia:** There is a huge range of opioid analgesics available for use in cancer pain management, most working in slightly different ways. Opioid analgesics can lead to physical and psychological dependence and tolerance.
- **Dependence** is characterized by withdrawal symptoms, if the drug is withdrawn abruptly, or if an antagonist is administered.
- **Tolerance** is characterized by decreased efficacy and duration of action with prolonged repeated use of the drug (leading to the need for higher doses to maintain the same level of analgesia).
- These are a normal pharmacological response to the use of these drugs and do not normally prevent their safe use in cancer pain management. Patients with stable pain often remain on the same dose for many weeks.
- **Psychological dependence** is characterized by craving for the drug and a preoccupation with obtaining it. Wide clinical experience has shown that psychological dependence rarely occurs in cancer patients taking opioids for pain relief.

Morphine

- Morphine is the most widely used strong opioid used in cancer pain management and usually the drug of choice. Wherever possible, the preferred route is oral, and it is available as a liquid, tablets or as capsules. There are both normal release (4 hourly) and slow release preparations (12 hourly or 24 hourly).
- Morphine is metabolized in the liver, but liver disease does not contraindicate its use. Morphine 6 glucuronide (M6G), an active

metabolite of morphine, is excreted by the kidney, so renal dysfunction can increase accumulation of M6G. This can lead to central depression (sedation/respiratory depression) and may require the use of lower doses or changing to another opioid in some cases.

- Morphine can also be administered subcutaneously, intramuscularly or intravenously.
- Morphine is the standard against which other opioids are measured for potency, and the equivalent morphine dose is used for calculating conversions between opioids.

Side Effects of Opioids

- **Constipation:** This is the most common side effect. To reduce this, all patients started on opioids should be started on a laxative.
- **Nausea and vomiting:** This occurs in up to 50% of patients on opioids for moderate to severe pain.
- **Drowsiness and confusion:** This is particularly common in elderly patients. All patients should be warned about initial drowsiness (which often improves after 3–5 days on the drug). Concurrent psychotropic drugs can make this worse, and sometimes changing to a less sedating drug can help (e.g. from chlorpromazine to haloperidol). Patients with continuing marked sedation may improve when changed to a different opioid (e.g. from morphine to oxycodone or hydromorphone).
- **Respiratory depression:** This is a less common side effect in cancer patients with pain as the pain acts as a physiological respiratory stimulant, balancing the depressive effect of the opioids. However, it can still occur (especially in heavily sedated patients), and can be counteracted by administering naloxone at a dose of 0.2 – 0.4 mg. This may not be appropriate in all patients.
- **Rare side effects:** These include opioid-induced psychosis, or symptoms related to histamine release (pruritis, bronchospasm). These patients may need to be changed to another strong opioid.

Changing Opioids

- The reasons for switching between strong opioids, if patients have poor renal function, experience heavy sedation or develop some of the

less common side effects.

- Another common reason to change is if patients are unable to comply with the medication, because they are too frail, confused, or if they are unable to swallow. In these cases, patients may benefit from changing the route of administration. Analgesia can be given by continuous subcutaneous infusion via a syringe driver, or transdermally via a patch.
- Whatever the route or opioid used, it is important to consider the correct conversion to ensure adequate pain relief continues.

Transdermal fentanyl preparations are sometimes used for patients having problems taking oral morphine. The patches come in fixed sizes, and the equivalent oral morphine doses.

Adjuvant Medications

Adjuvant medications may be used for several reasons. These include (Table 10.5):

- To treat the adverse effects of opioid analgesics (e.g. antiemetics, laxatives)
- To enhance pain relief (e.g. corticosteroids in nerve compression pain)
- To treat psychological disturbances, such as depression, insomnia or anxiety (e.g. antidepressants, night sedation, anxiolytics).

Table 10.5: Adjuvants

Drug	***Uses***	***Dose (example)***
Corticosteroids	Analgesia (nerve compression), improve appetite, antiemetic	Dexamethasone 2–16 mg daily. (higher end for nerve compression)
Diazepam	Analgesia (muscle spasm), anxiolytic	2–5 mg up to TDS
Haloperidol	Anxiolytic, antiemetic	0.5–3 mg up to TDS
Prochlorperazine	Anxiolytic, antiemetic	5 mg TDS
Amitriptylline	Analgesia (neuropathic pain), antidepressant, anxiolytic	25–75 mg od

Drug	*Uses*	*Dose (example)*
Zoledronic acid	Bone pain (prophylaxis with metastases)	4 mg infusion IV, every four weeks

This is a very small list of the many adjuvants available.

The Syringe Driver

There are many situations when a syringe driver provides an effective means of delivering one or more drugs effectively to the patient with cancer pain. The main reason for commencing a syringe driver is when the patient is unable to take medication orally. This may be because the patient:

- Has severe dysphagia (e.g. in head and neck tumours, severe weakness)
- Has severe vomiting
- Has decreased conscious level (e.g. cerebral metastases)

It is important to discuss the use of a syringe driver with the patient and family/carers. This may help to allay some of the fear and stigma associated with its use. Some patients may need a syringe driver for only a short time to help deal with a specific problem.

Some of the advantages of using a syringe driver include the continuous administration of medication—avoiding the peak and trough effect of oral analgesics. It also allows a mixture of drugs to be given through one site (where drugs are compatible), allowing multiple symptoms to be controlled effectively.

Some of the problems with using syringe drivers include the need for medical staff to change the syringe driver every 24 hours (or sooner if a change is indicated), and the possibility of a local skin reaction to the needle or infusion.

Drugs to Avoid with Syringe Drivers

Chlorpromazine, prochlorperazine and diazepam are all contraindicated via syringe driver as they cause skin reactions at the injection site.

ROLE OF NURSE IN PAIN MANAGEMENT FOR CHRONIC DISEASES

The licensed nurse is solely responsible for effective pain management which is evidence based. Understanding the key areas is essential (Pain Management Nursing Roles/Core Competency: A Guide for Nurses. Board of Nursing)

(a) Knowledge of pain management by the health care professional

(b) Knowledge about pain and its characteristics

(c) Understanding the standard of care through evidence-based clinical guidelines

Understand

- All people with cancer have a right to optimal pain relief that includes culturally relevant and sensitive pain education, assessment, and management.
- The public, people with cancer, and significant others must be educated about the right to relief from cancer pain.
- Regulatory, legislative, economic, and other barriers to effective cancer pain management must be eliminated.
- Cancer pain prevention and treatment are essential elements of quality cancer care throughout all phases of the cancer care continuum.
- Health care professionals, particularly nurses, pharmacists, and physicians, are accountable to manage cancer pain effectively.
- All professionals caring for patients with cancer have an ethical responsibility to acquire and use current knowledge and skills and to implement evidence-based pain management guidelines.
- Comprehensive cancer pain management is a multidisciplinary and collaborative effort that must include ongoing individual assessment, planning, intervention, and evaluation of pain and pain relief. Comprehensive pain management addresses physical, psychological, spiritual, and sociocultural effects of unrelieved pain.
- Professional and postgraduate cancer care curricula for nurses and other health care providers must include didactic information and clinical experiences related to cancer pain and its management.
- Ongoing continuing education regarding cancer pain and its management is essential for all oncology nurses.

- The conduct of pain research and the evidence-based findings in education and practice are priorities for nurses.
- All people with pain must be recognized, with special emphasis placed on the populations known to be at high risk for suboptimal pain management (i.e. children; the elderly; minority populations; women; people with a history of previous or active substance abuse; those with limited financial resources, social support systems, or access to health care; individuals with cognitive or psychosocial impairment; and those with previous histories of analgesic allergies or metabolic alterations).
- Health care systems and clinicians providing care to patients with cancer are responsible for adopting and monitoring institutional and clinical guidelines for cancer pain management and symptoms related to its treatment. Health care systems must establish mechanisms for continuous evaluation of pain outcomes in patients at risk for cancer pain.
- Oncology nurses have a professional obligation to ensure that institutional and clinical standards for cancer pain management are adopted.
- Health care providers must adopt and prioritize pain as the "fifth vital sign" and standardize pain assessment throughout their workplaces.
- Oncology nurses must actively involve all patients, as well as their family caregivers and significant others, in the development of a pain management plan of care and encourage open communication for the reporting of pain at all times.
- Healthcare facilities must establish minimum standards for clinician's pain assessment and technical skills (e.g. epidural and patient-controlled analgesia pump management). Organizations and health care facilities must adopt and support the use of evidence-based pharmacologic and non-pharmacologic interventions and establish minimum standards for competency in their use.
- Oncology nurses must adopt pain management as a priority in continuous quality improvement initiatives.
- Provide physical comfort to patients through effective symptom and pain management.

- Educate caregivers about symptom management, standard safety precautions, nutritional needs and basic physical care.
- Identify and mobilise support resources in your community.
- Provide both emotional and spiritual support.
- Pain medication should be given on a regular basis.
- Complementary pain control measures, such as massage, back rubs, cool cloths, touch to be initiated.
- Keep room quiet and well ventilated.
- Address any emotional and spiritual concerns that may impact pain and discomfort.
- Comfortable bed and peaceful atmosphere.

CHALLENGES FACED BY NURSES IN MANAGING PAIN FOR PATIENT

- Stigma
- Fear
- Care often left to family/friend who is untrained
- High physical and emotional burden.
- Access to pain clinic.
- Family members' support.
- Culture and traditional practices.
- Hiring home-based care providers is very expensive.
- Financial constraints.
- Standard protocols and procedures.
- Attitude of health care professionals.

11

Successful Aging

Outline

- Introduction to aging
- Case reports
- Life stages and their impact on psychosexual and psychosocial health
- Human needs
- Physiology and significance of aging
- Human longevity
- Screening for health concerns
- Theories of aging
- Aging and diseases
- End of life issues
- Home/institutional care for elderly
- Role of nurse researchers/counsellors
- Successful stories

INTRODUCTION TO AGING

Of the 1.2 billion populations in India, elderly above 60 years constitute 7.4% (2011 Census of India). The increase in the elderly population contribute to pressure in terms of finance, pensions, outlays, health care costs, fiscal discipline, and savings. Again this segment of population faces multiple medical and psychological problems. There is an emerging need to

pay greater attention to ageing-related issues and to promote holistic policies and programmes for dealing with the ageing society (Central Statistics Office Ministry of Statistics and Programme Implementation Government of India. Situation Analysis of The Elderly in India, 2011). The following facts and figures about elderly are:

- The elderly population (aged 60 years or above) account for 7.4% of total population in 2001. For males, it was marginally lower at 7.1%, while for females it was 7.8%. Among states, the proportion vary from around 4% in small states, like Dadra and Nagar Haveli, Nagaland Arunachal Pradesh, Meghalaya, to more than 10.5% in Kerala.
- Both the share and size of elderly population are increasing over time. From 5.6% in 1961, it is projected to rise to 12.4% of population by the year 2026.
- The sex ratio among elderly people was as high as 1028 in 1951 but subsequently-dropped to about 938 in 1971 and finally reached 972 in 2001.
- The life expectancy at birth during 2002–06 was 64.2 for females as against 62.6 years for males. At age 60, average remaining length of life was found to be about 18 years (16.7 for males, 18.9 for females) and that at age 70 was less than 12 years (10.9 for males and 12.4 for females).
- There is sharp rise in age-specific death rate with age from 20 (per thousand) for persons in age group 60–64 years to 80 among those aged 75–79 years and 200 for persons aged more than 85 years.
- The old-age dependency ratio climbed from 10.9% in 1961 to 13.1% in 2001 for India as a whole. For females and males, the value of the ratio was 13.8% and 12.5% in 2001.
- About 65% of the aged had to depend on others for their day-to-day maintenance. Less than 20% of elderly women but majority of elderly men were economically independent.
- Among economically dependent elderly men, 6–7% were financially supported by their spouses, almost 85% by their own children, 2% by grandchildren and 6% by others. Of elderly women, less than 20% depended on their spouses, more than 70% on their children, 3% on grandchildren and 6% or more on others including the non relations.

Aging is defined as a genetic physiological process associated with morphological and functional changes in cellular and extracellular components aggravated by injury throughout life and resulting in a progressive imbalance of the control regulatory systems of the organism, including hormonal, neuroendocrine and immune homeostatic mechanisms (King, 1988). The Economic Times enlightened the elderly population in India as:

- 100 million elderly at present and expected to increase to 323 million, constituting 20% of the total population, by 2050.
- One-fifth elderly live alone or with spouses only.
- 70% elderly population are illiterate and depend upon some productive labour work outside home.
- >80 years is presently 9,249, will increase to 44,218 by 2050 (women have more life expectancy).
- By 2050, India and China will have about 80% of the world's elderly living there.

There is no explicit definition of successful aging. It is different to all of us facing it on daily basis. Research has proved that advancement in medical science has improved the longevity but the experience of successful aging is yet to be experimented. The 21st century has brought unimaginable technological innovations and medical science has grown unthinkable. With the increase in employment and earning abilities, many elderly are able to afford medical need without having to bother their children and relatives. This period of aging before 70s may be lovesome if spouse is healthy and alive and one is able to do normal activities of living without any comorbidity. Once age advances further and if no family support and relatives, life becomes difficult. Yester year's joint family culture breaks into nuclear today which is well accepted by even by elderly. Life is good when we are young and healthy and live the way you want. But the moment you grow older and sick, the need for family and relatives come into picture. If unclaimed by anyone, then the elderly faces difficulties of selfmaintenance.

Most of these elderly who are being taken care of by the health care professionals are unable to provide reliable medical history related to either the degenerative changes or inability to comprehend the facts and figures.

In this case, we depend on the information given by the relatives/caregiver, friends or even neighbours. History is important for many reasons—medication history so as to understand right dosage taken by the patient as prescribed. History of any drug reactions or omission or any non-compliance, alcoholism, falls, incontinence, altered dietary patterns, sexual problems, anxiety, depressive feelings and medical device or catheters being used for elimination or feeding tubes that meets the nutritional requirement. This history collective serves as a tool for us to educate the patient so that they comply to the regimen prescribed as near ideal practice at home.

CASE REPORTS

Case 1

Mr. X 80-year-old was diagnosed with Parkinson's disease since 3 years, hypertension and type 2 diabetes for 20 years, BPH for 8–10 years and presently diagnosed in 4th stage. He also had sodium fluctuation which leads to an episode of irresponsiveness and was treated in ICU. He is on treatment for all the health problems. A year back, he also had a fall and had femur fracture and fixation was done. Blood pressure and sugar levels were completely under control but his Parkinson's took him to difficult time. After the fall, fracture and surgery, he lost all his confidence in his ADL. Slowly he also lost his speaking ability and writing was the means to communicate. In a year time that too was lost and finger signals and head nodding was the only way of communication. It was really tough time for him and also the family members trying to understand what he says. After 3 years, he was totally in bed and also developed UTI. He was on condom catheter. During his last 8 months, Ryles tube feeding was introduced as he could not swallow his food. Every member of the family was trained to look after in all aspects. Physical exercise to elimination was carefully monitored. Home environment took change as he needs to be turned every two hourly and hygiene to be taken care off. Health care aspects were brought in at home. Family members and friends were totally devoted to his care aspects till his last. But the feelings that went on in the mind of this elderly is a mystery as he could not really express his feelings at last moments. Communication board is being introduced in ICU but if the patient is not conscious, this places a limitation. Death is certain but the last

few years' quality of life matters to every individual. Role of spouse, children, friends and relatives play major role.

Case 2

I remember a grandmother looking after her granddaughter who is 1H-year-old. Daughter and son-in-law go to work and she takes care of the entire need of the child. The grandma in her late 60s found it hard when the child started running around at that age. Frustrated and tired, one find day she left the house and went back to her home. The daughter was amazed to see her own mother leaving daughter's house and also not willing to attend her granddaughter anymore. When situation was analyzed, the grandmother's health care was taken care of by the daughter and in turn grandma was taking care of the granddaughter. It so happen that after a year the grandma felt ill and was hospitalized. The daughter went to visit her and was unable to even spend a day with her in the hospital. The grandma was looked after by an untrained person kept by his son. The daughter explained to her inability to stay with her and the mother made no response to her explanation. Can anyone of us analyze this situation so as to how that grandma would have felt. Life put on a crossroad and you don't know whom to express to for your needs. Many of us some day may be posed with such situation and we need to analyze mindfully so as to what makes a successful aging and what ways can enhance them.

Life is hard to imagine and the end is never sure how it would be. Studies proved that physical wellness and functional attributes mostly focuses on successful aging. Few qualitative studies focuses on their psychological traits, such as optimism, sense of purpose in life, socialization, etc. Therefore, successful aging definitely looks upon multidimensional and multiple domains, such as physical, cognitive, emotional, spiritual and social functioning, which are essential ingredients of human being.

LIFE STAGES AND THEIR IMPACT ON PSYCHOSEXUAL AND PSYCHOSOCIAL HEALTH

Freud's stages of psychosexual development speaks about personality that is mostly established by the age of five. Early experiences play a large role in personality development and continue to influence behaviour later in life.

If these psychosexual stages are completed successfully, the result is a healthy personality. Stages are (Table 11.1):

- **Oral stage (birth to 1 year):** The infant primarily interacts with her world through mouth. Anything you give to this infant goes to his mouth. It derives its pleasure from oral stimulation, such as sucking. If this very need is deprived, we see fixation in later years and developing habits, like smoking, biting nails and over eating.
- **Anal stage (1 to 3 years):** Freud believed that the primary focus of the libido was on controlling bladder and bowel movements. Toilet training is a primary issue with children and parents. Too much pressure can result in an excessive need for order or cleanliness later in life, while too little pressure from parents can lead to messy or destructive behaviour later in life.
- **Phallic stage (3 to 6 years):** Freud suggested that the primary focus of the id's energy is on the genitals. According to freud, boys experience an Oedipal complex and girls experience an Electra complex, or an attraction to the opposite sex parent. To cope with this conflict, children adopt the values and characteristics of the same-sex parent, thus forming the superego.
- **Latent stage (6 to 11 years):** During this stage, the superego continues to develop while the id's energies are suppressed. Children develop social skills, values and relationships with peers and adults outside of the family.
- **Genital stage (11 to 18 years):** The onset of puberty causes the libido to become active once again. During this stage, people develop a strong interest in the opposite. If development has been successful to this point, the individual will continue to develop into a well-balanced person.

On the other hand, Erik Erikson described the psychosocial development that occurs throughout the lifespan.

Table 11.1: Psychosocial stages

Stages	*Basic conflict*	*Important issues*	*Outcome*
Infancy (birth to 18 months)	Trust vs. mistrust	Feeding	Children develop a sense of trust when mother feeds him when he cries for milk and given all love and affection. Lack of this will lead to mistrust.
Early childhood (2 to 3 years)	Autonomy vs. shame and doubt	Toilet training	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy, failure results in feelings of shame and doubt.
Preschool (3 to 5 years)	Initiative vs. guilt	Exploration	Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.
School age (6 to 11 years)	Industry vs. inferiority	School	Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority.
Adolescence (12 to 18 years)	Identity vs. role confusion		Social relationships: Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self.
Early adulthood	Intimacy vs. isolation	Building lives	Strong sense of personal identity is important for developing intimate relationships. Poor sense of self tends to have less committed relationships and are more likely to suffer emotional isolation, loneliness, and depression.
Adulthood	Generativity vs. stagnation	Career development	Build one's lives, focuses on our career and family. Failure leads to regrets.
Old age	Integrity vs. despair reflection	Accomplishm-ents in life	Feels proud of their accomplishments will feel a sense of integrity. Failure leads to bitterness.

Psychosexual and psychosocial health of very individual is deep-rooted in childhood. Any individual going through with successful growth and development makes a difference in life even after 60s. Life stages from birth to death have its significant role in one's life. Having to develop satisfying social interactions, behaviour and a sense of accomplishment gives a greater feel of satisfying life lived at the end. If not the person may go through a feeling of despair. I came across a couple who lived all their life abroad earning for their son who was in India studying his degree. He got into a technical programme and was left alone to manage his day-to-day happening. The child became very independent and took his own decision to live the way he wished. Day by day he was going bad to worse in his academic performance. Parents knew little of his welfare but kept sending

lots of money. He would forged and sign his reports and that's how no one ever thought this boy was misled. After two years, when the parent came for vacation, they understood their child was not in a state to study and was into a wrong world altogether. Crying bitterly, the parents recalled. Have I taken my son abroad he would have not been in this state or I as a mother would have stayed with him, he wouldn't be in this condition. Now that it's too late to trace the truth lost. The priest counselled the parents and parents with little hope went into take their son for a good treatment and stay back. Father says, whatever we earned is for him and now that I cannot buy his health and behaviour back with my money. If he is in this state who will look after us in our old age?

Fear of not having anyone to be looked after in old age also sends a message of fear in all of us although the path to old age experience is not sure. From the above child's life, every parent need to address and understand one's responsibilities to fulfill love and affection a child needs in his or her life stages. If we have not looked after our children we in fact have no right to ask for it in our old age. Today with both parents working, most of our children are kept in the kid's centre or day care centre and when we are old we are placed in the old age home since they too are busy. This is almost a give and take relationship. In India, most of us are from a joint family but today successfully broken down to nuclear with little thought for our old age management.

Findings of a cross-sectional study among 1,281 elderly Chinese living in Singapore proved that the determinant of successful aging proved to be their demographic status, psychosocial support, spirituality, and nutrition. (Ref: *Ng TP1, Broekman BF, Niti M, Gwee X, Kua EH. Determinants of successful aging using a multidimensional definition among Chinese elderly in Singapore. Am J Geriatr Psychiatry 2009 May; 17(5): 407–16.)* This means that when aging the basic needs again becomes very significant. The need described in Maslow's hierarchy (Fig. 11.1) shows that each one of us try to achieve the highest level that is the level of transcendence a place where we are able to help others to achieve their life goals and self-actualization. Practically, we need to analyze case to case basis today. The road mapped and functioned by each one of us needs to prove integrity instead of despair according to Erikson's psychosocial theory. It is therefore imperative to think and bring a change in our way of social associations and relation-ships so that we are not faced by storms of aging.

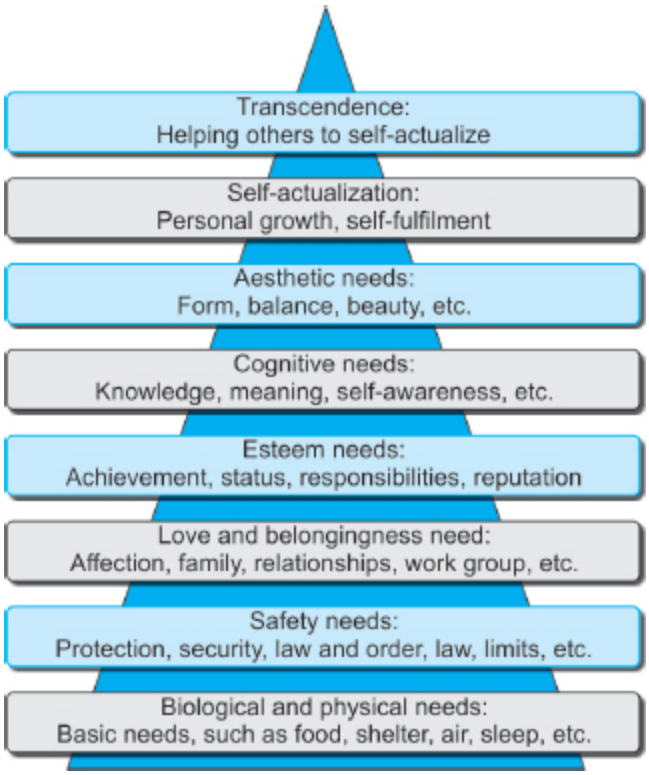


Fig. 11.1: Maslow's hierarchy of needs

HUMAN NEEDS

Maslow's hierarchy of needs reminds every nurse that the basic needs of the patient or elderly to be met first. When under care, the elderly may lose his ability to eat by self so he may be with Ryles tube and urinary catheter, oxygen therapy, nutritional needs, rest and safety needs, dressing for colostomy accounts for his other basic needs which serves to be the basic needs. Not meeting these needs may endanger the life of the elderly under care. Meeting the basic needs will help the elderly to look forward to higher needs of high selfesteem and self-actualization and also helping other elderly members to experience the same. On the other hand, psychological needs, such as love and affection, and belongings are basic emotional needs of the elderly. Nurse's compassionate care and empathetic approach can help meet the emotional needs of the patient. Remembering the days I spent in the palliative care centre where all the health care professionals and counsellors stay under the same roof and also eat the same meals as that of the patients. Nurses frequently meeting them from room-to-room, door-to-door. Praying together and doing yoga and meditation in common place

both for nurses and patients made them feel like in a family. This family feel makes them bring closure and feel wanted, loved and cared for. Although the patients knew their stage and disease progression, they were well prepared for their last moments with pride and happiness. Thus meeting the patients' physiological, psychological and emotional needs is vital for elderly.

PHYSIOLOGY AND SIGNIFICANCE OF AGING

Aging is a normal process with or without any disease. Elderly due to low immunity and hormonal changes are more prone to diseases. Aging onset is unidentifiable and progress never the same from individual to individual that could be influenced by genetic and environmental factors. Gender differences, lifestyle and diseases create disturbances in the homeostasis which is the basis for ageing. Theories try to explain from different point of view but the fact remains the same. Today most of the diseases have their solution and lifestyle being the change agent thereby aging is delayed.

HUMAN LONGEVITY

The 21st century has brought in advances not only in technology but also its medical science the hub of human health reliance. Today, the life expectancy has increased due to lowered mortality and morbidity related to lifestyle change, improved economic conditions, medical care facilities, insurance system and the social environment. Demographic evidence suggests that longevity can be achieved by different combinations of genes, environment, and chance, in a pattern that may be quantitatively and qualitatively different in different geographic areas, and that population-specific genetic factors play a role in the longevity phenotype.[1–5] Longevity is likely to be lowered for women for many of the women's health issues especially the preventable maternal health issues and their access to health care facilities. People with good social and family support especially daughters being with them have better health and lowered mortality when compared to elderly who live alone or are being put up in geriatric homes.

SCREENING FOR HEALTH CONCERNS

Screening for health concerns among elderly includes:

- Blood pressure monitoring
- Clinical breast examination after 40 years
- Mammogram
- Pelvic examination/Pap smear
- Cholesterol examination regularly
- Rectal examination
- Fecal occult blood
- Sigmoidoscopy
- Prostate examination/PSA
- ECG, blood glucose, glaucoma, heart, lungs, nodes, testes, skin, mouth
- Weight and postural blood pressure
- Vision and hearing: If hearing is impaired, the most common cause may be excess cerumen.
- Denture fitness
- Oral cavity is inspected with the dentures removed.
- Thyroid disease becomes more common with age
- Assess ADL which includes:
  - Bathing, dressing
  - Toileting
  - Feeding
  - Getting in and out of chairs and bed
  - Walking
  - Shopping
  - Cooking
  - Financial management
  - Housework
  - Travelling
  - Attending social gathering
  - Going to worship places

THEORIES OF AGING

Biologic Theory

Table 11.2: Biologic theory of aging

Theories	***Concepts***
Programmed theory	Genetic perspective: All living organisms ar e limited with their lifespan. It has biologic clock. Predetermined number of cell divisio n.
Molecular theory	Aging is controlled by genetic materials. En coded for both growth and decline. Reliabil ity of gene appearance declines with age, re sulting in increased portion of abnormal pro teins. Aging caused by changes in gene exp ression regulating both aging and developm ent
Error and repair theory	Error in synthesis leading to error in cells a nd causing progressive decline in function. The making of proteins and the reproductio n of DNA sometimes is not carried out accu rately. This means to say that the system is i ncapable of making perfect repairs on these molecules every time, therefore, the accum ulation of these flawed molecules can cause diseases and other age changes to occur.
Somatic mutation theory	DNA is natural repair processor kick leadin g to loss of kick then nonfunctioning of cel l.
Cellular theory	Due to cell damage, there is reduction in fu nction of tissue thereby lowering the functi on of vital organs.
Free radical theory	Introduced by R Gerschman 1954. Require d for energy production, immunity, transmit nerve impulses, hormone synthesis, etc. Att acks on structure of cell membrane create

Theories	*Concepts*
	metabolic waste product – "lipofuscins". Li pofuscins disturb protein, DNA and RNA s ynthesis, reduce energy levels, muscle build ing, destroy enzyme, etc.
Cross-link or connective tiss ue theory	Johan Bjorksten (1942) recognized the cell molecule, DNA and connective tissue intera ction leading to cross-linking then increase d cross-linking and then shrinking and hard ening.
Wear and tear theory	Dr. August Weismann, a German biologist, first introduced this theory in 1882. He assu med that the body and its cells are damaged by overuse and abuse. Organs, such as live r, stomach, kidneys, skin, etc., are worn do wn by toxins in our diet and in the environ ment; by the excessive consumption of fat, sugar, caffeine, alcohol and nicotine; by the ultraviolet rays of the sun and by the many other physical and emotional stresses to wh ich we subject our bodies. Wear and tear is not confined to our organs, however; it also takes place on the cellular level.
Neuroendocrine theory	Vladimir Dilman proposed this theory. Acc ording to him, hormone works together to r egulate our body function and drop in the p roduction of any one hormone affects feedb ack system leading to improper regulation.
Immunologic theory	Weakening of immune system makes indivi dual susceptible for disease.

Psychosocial Theory

Table 11.3: Psychosocial theory of aging

Theories	*Concepts*
Disengagement theory	Older people are systematically separated, e xcluded or disengaged from society becaus e they are not perceived to be of benefit to t he society. Disengagement is mutual benefi cial.
Activity theory	Activities improve the function and improv e self-esteem of individual.
Erikson's theory	Integrity vs despair: Feels proud of their ac complishments and feels a sense of integrit y. Failure leads to bitterness and causes pro blems in life.
Havighurst's theory	Adjusting to decreased physical strength an d health, retirement, decreased income, adj usting to loss of a spouse, establishing a rel ationship with one's age group, adapting to social roles in flexible way and establishing satisfactory living arrangements in one's lif e.
Newman's theory	Coping with the physical changes of aging. Redirecting energy to new activities and rol es. Accepting one's own life and developin g a point of view about death.

AGING AND DISEASES

When we age, our body fat increases and total water content decreases. Few of the age associated health problems are:

- **Vision:** As we age, the lens of the eye may show opacification, decreased visual acuity leading to lack of accommodation, glare increases and increased need for illumination. Losing eye sight is one of the most feared problems of elderly as it induces insecurity feeling. Common problems identified in India are cataracts which are treated effectively.
- **Endocrine:** Change in hormonal balance may pose health issues, such as impairment of glucose homeostasis, decreased testosterone,

decreased vitamin D absorption and osteopenia is generally seen making elderly prone to fracture with falls and twist.

- **Cardiovascular changes:** The heart pumps sufficient to circulate the entire body. Inefficient circulation with advanced age may be related to drugs, comorbidities, physical exertion, infections and emotional stress that affects the CVS. With advance in age, one is prone to develop angina with low circulation, anemia, atherosclerosis, coronary artery disease (CAD), aortic stenosis and ischaemic heart attacks. Regular exercise, balance diet with low fat and salt, complementary therapies may help elderly stay healthy.
- **Pulmonary system:** Lung function is greatly influenced by age and in spite of aging, the lung tries to supply adequate oxygenation and ventilation during our entire life. Chest wall compliance decreases with age. There is change in the forced expiratory volume in one second (FEV1). After the age of 70, there may increase in the air space size leading to loss of supporting tissues and strength of the respiratory muscle decreases with age. With an advance in age, the respiratory system reserve is lowered so with any episode of hypoxia and hypercapnia, the person is prone to ventilatory failure during high demand states, such as pneumonia, heart failure, etc. Deep breathing exercises and pranayama help elderly maintain their lung capacity to a better stand.
- **Renal and genitourinary systems:** The normal GFR of an adult is approximately 10 ml/minute/1.7 m^2 per decade after the age of 30 years. Consistent with anatomic observation of number of glomeruli decline in normal human kidney with age. In sixth and seventh decades, the number is less than one-half the number present in young adults. Therefore, total number of nephron decreases and thereby decreasing the filtration rate and increasing the waste products accumulation. Decreases in kidney mass, blood flow, GFR (10% decrement/decade after age 30). Decreased drug clearance. On the other hand, bladder and urethra also change with age. Reduced bladder elasticity, muscle tone and capacity are a major concern leading to increased post-void residual and nocturnal urine production. The elastic tissue of the bladder walls becomes tough and bladder wall elasticity toughens and also weakens the bladder muscle walls making

elderly people difficult to hold urine for longer period as usual. Due to weakened muscles, the urethra can also be blocked related to prolapse. In men, BPH is a common factor for blocked urethra. Therefore, role of nurse is to monitor the nephrotoxic and renally cleared drug levels, if the elderly is on treatment, maintaining fluid and electrolyte balance, educating on evening fluid restrictions and preventing falls due to urgent voiding urge.

- **Oropharyngeal and gastrointestinal systems:** Normal BMI of a healthy adult is 18.5–24.9 kg/m^2; overweight: 25–29.9 kg/m^2; obesity, 30 kg/m^2 or greater. When we age, our muscles for mastication decrease, taste alters and notable changes in gastric motility with delayed emptying. Our protective mucosa atrophies. Carbohydrate absorption, vitamins and D, folic acid and calcium malabsorption take place leading to deficiency related health problems. Intestinal changes may lead to delayed bowel emptying due to delayed sensation and constipation may become major challenge. Due to comorbidities, the elderly may be consuming lots of medication that may lead to liver toxicity due to lowered hepatic reserve. On the other hand, they may experience gastric irritation due to drugs consumed. Loss of teeth may pose poor chewing and poor digestion. Assessing bowel pattern, LFT monitored regularly, lifestyle change, diet appropriate for age are important topics to be talked about with elderly for better health maintenance.
- **Musculoskeletal system:** Decline in the muscle mass and also muscle strength is associated with aging (sarcopenia) related to poor exercise tolerance, increased weakness. Bone loss after 30–35 years, loss of strength of ligaments and tendons, degeneration of intervertebral disc, articular cartilage erosion, kyphosis and height reduction are few changes that we see as age advances. All these changes place the elderly to disability, falls, unstable gait, risk of osteopenia, osteoporosis, limited range of motion, and osteoarthritis. With varying degree of exercise (individual based), home environment modification to prevent falls, calcium and vitamin D supplement, diet rich in calcium and pain management to increase ADL becomes important features for musculoskeletal changes management at older age. The elderly are advised to do regular bone density test to add to information for right management.

- **Immune system:** Lowered immunity poses to increased susceptibility to infections. Following the guidelines for preventive management will help improve their health status. Signs and symptoms include decreased appetite, incontinence, urgency, dribbling of urine, burning micturition in case of UTI, raised body temperature, malnourished, etc. Role of the nurse ranges to following through the baseline data, assessing for fever, ruling out any other lung infections, such as tuberculosis, pneumonia and GI problems and also UTI.
- **Nervous system and cognition:** The predominant causes of intellectual impairment in older patients are delirium, dementia, and depression. In older patients, they frequently coexist. With Alzheimer's, many elderly get into dangerous behaviour, such as leaving the gas stove on, wandering behaviour and getting lost at times. The diagnosis is made when there is presence of a depressed mood for at least two consecutive weeks plus at least four of the following eight symptoms, such as sleep disturbance, lack of interest, feelings of guilt, decreased energy, decreased concentration, decreased appetite, psychomotor agitation/retardation, and suicidal ideation. Aging physiologically causes weakness of entire nervous system lowering the motor and sensory feel of the individual. Comorbidities add to the existing health problems of elderly, such as diabetes, hypertension, Parkinson's, etc. Many a times due to lack of drug and lifestyle compliance the elderly experiences stroke, myocardial infarction, etc. leaving the individual at greater chance of mortality.

For elderly to experience successful aging, the nurse needs to reduce the impact of the diseases/comorbidities on the individual. Lifestyle changes and practices, health education on the normal changes in aging to be communicated to the elderly for better adaptation. Following through the effectiveness of the interventions that the health care personnel prescribes to and also their quality of life will help us identify further interventions and strategies for future generation.

END OF LIFE ISSUES

- Rituals
- Practices
- Who owns

- Being alone
- Hospitalization
- Nutritional issues
- Medical care issues
- Abuses among elderly
- Financial issues in hospital
- Untrained personnel's care issues
- Family members unwilling to take care
- Connectivity and technology in current aging
- Change of rituals due to religious differences of offspring

Rituals and Practices

Rituals and practices of elderly or any member of the family depend on their religious practices, beliefs and faith. There are times, the children and parents are of different religion. So when the parent's die sometimes the rituals of children are followed and not what the parents were following. This very last wish may not be fulfilled by the children.

Elderly Being Alone with Loneliness

When children are grown, married and settled in a place of work away from parents, the parents hardly can assure themselves of being loved and care by their children. Today we all look forward to good job anywhere even away from home. The danger is who will own and care for our parents. If we have many siblings, the responsibility is usually shouldered on the sibling with close proximity. Feelings of being at one's own old home where you have grown and nested gives a sense of my belongingness to the home itself. Children usually grumble saying "my parents are not willing to come to our homes and stay in city or town". This demand can be understood only when we face the reality someday. If possible, care for the elderly in their own preferred home and not shift them wherever you wish to. Parents being rotated among children for either days or months or years seem low accountability towards elderly. Holidaying with children when they can travel means different than sharing without responsibilities. Since majority are from patriarchal families, parents staying with their daughters who lives

with their in-laws and extended family may not feel very comfortable with the arrangement. Hence, her own old parents will opt out the idea. Decision becomes rather difficult and question arises 'who should own old parents'. Staying alone with no one to converse may lead elderly to loneliness and depression.

Hospitalization/Medical Care Issues/ Nutritional Aspects

Elderly with chronic diseases are left in the hospital with a caretaker or a paid individual who are less trained. Everyone in family seems to be too busy to look after and don't mind spending money but lacks time. Almost 50% of the caretakers of elderly in the hospital are non-relatives but paid for it. The average amount earned by a paid bystander is Rs. 500/- per day excluding food. People are ready to pay even their mobile recharges. Response of sick elderly looks inexpressive because feelings can be shared only with loved ones and not with anyone and everyone. Violence among patient may be sometimes due to such situation too. When it comes to home-cooked food, rarely it happens because they prefer hotel or hospital food as they do not want to visit twice or thrice a day. Hygiene as well as home-cooked food and mindful eating seems to be missing. Simple home diet fed with love and affection heals a patient physically and emotionally.

Abuses Among Elderly

Scolding, screaming, shouting and demanding from the elderly happens frequently in many homes. Killing the confidence happens when their ADL is being questioned and disability is made to be felt by the elderly. Screaming at them to get up and have the food, makes elderly shiver with fright and uncaring attitude. Mother-in-law and daughter-in-law effects in India are never ending stories. Both find many differences, making life confusing and irritating to live with. Verbal or physical abuses are common among elderly.

Connectivity and Technology

Today the mobile facility has brought all people well connected. Information and wellbeing is assessed through phones that all elderly even at 80s are able to do so. Simple models are best for elderly as they may not be able to visualize the small writings and also handling the features of mobile. What they need is just to call, receive and send few messages.

Children's wellbeing and friends who are prime importance can be connected adequately.

HOME/INSTITUTIONAL CARE FOR ELDERLY

Home, home sweet home, there is no place like home. Elderly love their homes and never would like to live and die elsewhere. Everyone longed to own a palace and live like a king. Even though my home may not be posh, yet that's the place you long to be because of your emotional attachment. In your home, you are free to what you wish to but in someone's home, however, friendly they are, you hesitate to behave originally the way you are. This is same feeling when an elderly is displaced to someone's care setting especially an old age home. Although we have end number of old age homes, the quality, expertise among the caregivers and attitude becomes a concern. Few of the rights of elderly are:

- **Autonomy:** Duty to respect the right of the patient for self-determination. Patient takes decision after a discussion with the treating physician about the risks and benefits of treatment, alternatives and consequence of refusal.
- **Informed refusal:** Ethically and legally permitting the competent patient to refuse medical interventions.
- **Confidentiality:** Maintain of confidentiality (do not disclose even to family members). Exceptions: Communicable disease, conditions injurious to the patient himself or to the society.
- **Advance directives:** 'Living wills' for treatment preferences for future when capacity of the person has lapsed. No consent is required for life saving measures in India.
- **Surrogate decision making:** A surrogate (spouse, an adult child, a close friend, a clergy member or even a distant and uninvolved relative) can direct the care when a person in incapacitated.
- **Do not resuscitate order:** In case of DNR, do not perform CPR, but does not mean 'do not treat'.
- **With holding food and fluid:** Artificial administration of food and fluid is part of medical treatment in India. But in some countries, a competent patient has the right for withholding food and fluid.

- **Euthanasia:** Assisted suicide and palliation—illegal in India.
- **Discharge and long-term care of the patient:** Right to decide on living arrangements. Issues included are financial, practical and quality of life.
- **End of life issues:** Facilities are less in India. Avoid ineffective medical practices (discontinuing life support systems, because of non-payment). Forced?? DAMA to be stopped.
- **National policy on older persons (13th Feb, 1999):** "Wellbeing of older person" Aim strengthen legitimate place in society and help elderly to live their last phase of life with purpose, dignity and peace. State support for financial security, health care, shelter, welfare and other needs of elderly.
- **Article 4l of Indian Constitution:** Wellbeing of older persons has been mandated in the Constitution of India. Securing the right work, education, public assistance in case of unemployment, old age, sickness and disablement are the responsibility of the state.
- **Section 125 of Criminal Procedure Code:** Older children to make a payment of monthly allowance as maintenance to their parents.
- **The Hindu Adoptions and Maintenance Act and Domestic Violence Act:** dependent parents are entitled for maintenance.
- **Maintenance and Welfare of Parents and Senior Citizens Act 2007:** Provide for the maintenance and welfare of parents and senior citizens. State government has constituted tribunals in each subdivision for adjudicating the issues of maintenance of senior citizens. Tribunal can order the children/relatives of senior citizens to provide monthly allowance for maintenance. Noncompliance is punishable. If no relatives, taken care by old age homes.

ROLE OF NURSE RESEARCHERS AND COUNSELLORS

(a) Complementary therapy:

- Laughing therapy
- Yoga and general health
- Spirituality
- Social gatherings

(b) Home visits by:

- Volunteers
- Nurses and home care team
- Friends and relatives

(c) Geriatric counselling:

- Institutional/old age homes
- At home setting
- During hospital visits

(d) Counselling caregivers about patient's:

- Nutrition
- Hydration
- Elimination
- Drugs
- Expected complications
- Psychological support and to remain connected
- They should also be advised to take their time out especially if they are taking care of patients with chronic diseases, like Alzheimer's.
- Caregivers are often elderly and/or ill, or adult children with family and work responsibilities.
- Caregiving may affect physical, emotional, social, intellectual, and spiritual ways of life of caregivers.

(e) Counselling family members:

- Provision of informal care is essential for an elderly person to live in the community and is associated with delayed entry to nursing homes.
- In the care of seniors, the usual two person (dyadic) doctor-patient encounter frequently expands into a three-person (triadic) interaction that also incorporates an informal caregiver, who most often is a family member.
- In dealing with varying medical problems in clinical settings, physicians may not respond to caregiver needs.

- Reasons include limitations within health care systems, interprofessional communication problems, and interpersonal conflict amongst members of the health care triad.

(f) Caregiver's temperament/symptoms (for caregiver):

- Mood swings
- Fatigue
- Headaches
- Joint and muscle pains
- Irritable bowel syndrome
- Marital and family conflicts
- Financial problems
- Depression, etc., may reflect caregiver's stress and a need for physicians to interpret the symptoms and, if appropriate, provide counselling and anticipatory guidance about caregiving.

SUCCESS STORIES

Mr. and Mrs. P Biren Singh express aging as the most valuable time of all ages. In 60s when I retired, I had all the time for myself and my spouse. I just had a son who settled successfully in his career and placed in a good job. Retired as a general manager, I had my entire pension and also my spouse earns herself. We had nothing to depend on someone. We spent good days looking after 4–5 grandchildren as we are in joint family. Taking morning classes at home when their mothers were cooking and getting ready to get to work. Receiving grandchildren from schools, making them have evening snacks. Getting to sit along with good neighbours and locality friends on productive discussions on self-employment for the youth and guiding them to become big business men. Helping local religious people to build community hall for all functions. I never had such an opportunity when I was working. This is the best time that I have ever spent in my decades gone by. By night I water all my plants in the garden and see that all things are right in their space. Meal times at home are lovely events every day. Entire family sits together for meals and ventilating all that each one had for the day and making sure family talks productive moments for future. Four brothers sometime would sit together and talk over things that

would build children's betterment. Respect and discipline is first priority in home. Every child or adult that goes out to work or go to school takes the blessings of elders then only walks out of the house. This culture is something I enjoy every day in my life as a grandparent. This very custom is followed from ancestor's time and that goes every day in my home. I feel that life actually begins in retirement. Having planned my retired life to be useful to my family and community made my life much occupied and happy indeed. Having a spouse who loves to take care of me and my needs are another added flavour in my life. Understanding, respect and her unconditional love makes my life so meaningful than ever. There were days during my home away assignment, I live months away from home and we remained apart. Our attachment, our longings were ever greater day after day. Today, in retired life we have all the time for us to talk to, bend on to and care for each other. Life is worth living and it's great to have lived more that 70 years without health problems. Health is wealth and hard work, exercise and being occupied with healthy living kept me away from illnesses. Great moments can only be shared and each of us have to experience for oneself someday.

Mr. X, 75 years, explains his life as something very strange. Married at the age of 30 and blessed with 3 children. Like any parents dreams for, my daughter and sons completed their education and are placed in good jobs. From my young days, I am blessed with many health problems that I lived with it my entire life. Even at 75, I have not retired as I am the most sort after teacher in the school. My wife left me early and I have to live all by myself sometime and hence I went for second marriage. At this age, I feel a new life has sprung forth altogether. Although I loved and lived with my previous wife, her absence made me feel miserable. Having someone new in my life to take care of me meant building a gap in my insecurity feeling. Although my children doesn't seem to be so happy with my decision, yet my life is taken care of better and I don't have to depend on others for my daily needs. I am now happily married to a woman who is very young and who can take care of me for my entire life. A blessing indeed! "Separation in life did not hinder my being for a long time because of my second life giver".

Mr. Muan expressed "Successful aging means marrying, having children, feeding them well, looking after their welfare, training them to

take care of themselves before we leave to manage themselves when we are no more".

There is no yardstick to measure what successful aging is to every individual. Each person views it differently.

We are all amateurs; we don't live long enough to become anything else."

Charlie Chaplin

12

Dealing with Chronic illness Experiences and Challenges

Outline

- Acute and chronic illness experience
- Coping process
- Coping with critical diagnosis
- Success stories

ACUTE AND CHRONIC ILLNESS EXPERIENCE

Illness can be experienced either for a short period and getting over it (acute) and on the other hand one can experience health problems either lifelong or for a long term with prolong treatment (chronic).

Chronic disease can be either life-threatening, such as cancer or AIDS and on the other hand few of the chronic diseases, such as diabetes, which may not be life-threatening but have to live with it whole life. Stress and concern over both is quite a different one. Chronic diseases, however, cause depression, helplessness, hopelessness, fear and a sense of restricted living. Hence it not only affects physically but emotionally, socially, financially and mentally to great extent. Highly actualized patient with greater age and fulfillment may be able to accept death that may be knocking at his door but a young and vibrant personality, just booming up in life may not be able to accept the diagnosis and treatment that follows. It takes time to console and get adjusted living with the disease. Good counselling should be provided at this point of time to help cope with the above said issues and problems in living with chronic conditions.

COPING PROCESS

One has to cope either positively or negatively in any situation. The mental status of the individual with health problems and also his social support greatly supports his capacity to handle any difficult diagnosis. Coping either early or delayed takes place. If positively looked at the possibilities of treatment and cure, the individual may initiate treatment protocols at the earliest possible but if there is prolong denial and anger phase of the individual, he may either go for medical shopping, testing and testing through various physicians to confirm his diagnosis. By the time he is confirmed, the treatment may be initiated late which may pose an outcome that may not be so promising. Mr. X, 60 years old, was suspected to have cancer of the tongue was brought to a referral hospital in south. He has had two biopsies already before the third time when he did at the referral centre. He stated 'the doctor has scooped my tongue too much and am unable to eat properly and also it pains'. I can't just belief that doctor in my hometown and I guess he is not diagnosing me correctly. I have never smoked, never chewed tobacco or drink even tea in my entire 60 years. No habits at all in my life. When asked further, he said the only possibility is that it must have been due to mobile radiation. Since I am a police officer, I do get lots of calls and frequently I use them. This is the only possibility. In this regard, the coping can be viewed through the following steps.

Step 1. Feelings: Mixed feeling when diagnosed with chronic disease is a normal phenomenon. One may feel he is vulnerable, another may get confused with the treatment options, and one may feel what is going to happen in future. Taking too many drugs, too many tests, and trying to cope with the specific regiment makes them feel disastrous and frustrated. They may show anger and denial towards the tests and also diagnosis. Noncompliance to treatment becomes a common issue among these patients. All these expressions are totally a normal process when one is diagnosed with a critical chronic disease that requires lifelong medications, lifestyle change and dietary restrictions.

Step 2. Understanding: Patients in this arena are very knowledgeable about their illness. Internet facilities have greatly facilitated understanding of one's health conditions. For example, a patient who is undergoing haemodialysis is well verse with renal failure, diet and fluid management.

Since he is suffering from only one disease, he knows in and out of the illness and treatment experience. But a novice staff, just joined a month back to the unit may not be very familiar with terminologies and also the treatment process. Therefore, every patient is very curious about his health conditions and tries every possibilities to know what best is done for their health problems. Knowledge is power and hence more control over his health management.

Step 3. Normalization: In this stage, people feel comfortable and start to live normally. Some people cope fast and some people little later. Lots of emotions are seen during the initial finger prick but life gets adjusted at the earliest. Working with their doctors, nurses and family members helps them understand better about their disease management and monitoring. It's almost second nature to the diabetes patient.

Step 4. Taking control over the diagnosis: People living with chronic illnesses often find that following the treatment schedules and carrying out their normal ADL give them a sense of control over their diagnosis.

Step 5. Acknowledge feelings: Emotions may not be easy to identify. For example, sleeping or crying a lot or resentment may be signs of sadness or depression. It's also very common for teens with chronic illnesses to feel stress as they balance the realities of dealing with a health condition and coping with school work, social events, and other aspects of everyday life. Way back in 2005, I had cared for a student who was diagnosed with SLE with class IV nephritis. She was put on chemotherapy with steroids for long term. I would schedule her therapy on weekends so that she has at least one day of rest after the treatment side effects, such as nausea, vomiting and puffiness. She being a good singer, she would participate in singing competitions, creative writing and took part in every student events in the college. It was rather difficult to identify her emotions as she had a strong determination to get well. She not only completes her four years programme successfully but works abroad as nurse manager and lovingly married to an understanding husband who knows every nook and corner of her health problems. This is positive coping with a positive outlook at life altogether. Many people living with chronic illnesses find that it helps to line up sources of support to deal with the stress and emotions. Some choose to talk to a therapist or join a support group specifically for people with their condition. It's also important to confide in those you trust, like

close friends and family members. Therefore, having to get support from a close person who knows you make sense. You may one day feel frustrated, if treatment doesn't work or get depressed with things that are bothering you. You need someone who can listen to all these concerns willingly and with a meaning. Knowing how you feel, understanding and expressing your concerns is a way of letting out your blue moments can help you feel better.

Step 6. Understanding other people's reactions: I may not only be the person under emotional struggle when I am diagnosed. My mother, my children, husband, brother or sister, loved ones and friends too may be affected. No parents wish their child to undergo any suffering. Any mother on this earth will be alert to make their child have the best comfort. When a child gets sick mother indeed becomes very much affected by the seriousness of the disease and also the prognosis. When a child cries with pain and complaints to his or her mother, her reaction may show you how she feels even though she is unable to express. She might console you with very little possibilities under her jurisdiction. When a child with cancer attains his school, he might want to keep it secret but his look may pose queries from his friend and they may misunderstand. Infect explaining to them the reality will help him feel better understood by his friends and teachers. Therefore, every sick individual needs to be told about the facts of life with the chronic illness but living a near normal life with the rest of the age group and see you as a unique individual or student like any other with greater concerns for him or her.

Step 8. Taking active part in one's treatment: The best way to know one's condition is by asking. Physician and nurses are so used to treating and caring for many chronic diseases. Unintentionally they may think you know about your condition and they may not tell you in simple terms. Instead of burying your doubts, its rather better for us to ask even though it may sound silly to them. The physician and nurse should be ready to explain again, if patient needs information time and again. Being in a depressed mood or sadness may hinder clear thought process. You have every right to ask about the treatment imitated, how it would feel like, side effects it may have on you, number of days you need to visit the hospital, academic hindrances, ability to join for sports, etc. Physicians and nurses who react positively to the patient and respond with positive attitude may help you build stronger in your emotional and psychological properties. Every diagnosis and treatment is way we understand ourselves better. It is

not all about disease, but our emotions, challenges and success that may lead us mentally, physically and emotionally strong enough to face the reality of life.

Step 9. Living with the diagnosis/health problem: How would any children living with type 1 diabetes on insulin for life long feel about their normality of their own lives? It's hard to explain because they only can tell their success stories or otherwise. It's normal for a child to feel the need to play and fit among their friends. Children with cancer with neutropenia are prone to develop infections. Playing and being with friends in dusty or dirty environment may pose infection that is difficult to treat in concurrence with the chemotherapy. Because of the disease, the person may even have body image disturbance. Example, a child with AV fistula for haemodialysis may not feel the same like his friends because he has a fistula created which looks not the normal arm he had due to fistula creation. He on the other hand may not be able to play as usual due to medical restrictions for the arm with fistula. But having known the facts, one adjusts with the life restrictions and lives with the disease and treatment. It's hard to live with restrictions whole life. Having to diet at early age, daily medications make any individual depressed at some point of time. Speaking out the way you feel and experience may lighten you emotionally. One needs to take care of one's body with utmost care and appreciate the capabilities one has with their body and also to accept the limitation in life. Patience, time and tolerance can build success in dealing with chronic illness experience and dealing with challenges and social support the best remedy to counsel oneself from day-to-day health concerns.

COPING WITH CRITICAL DIAGNOSIS

Any diagnostic test makes any patient feel stressed so as to what would be the diagnosis. The time you wait for the result makes you all the more stressful. The emotions and feelings that you undergo cannot be expressed or understood by others. When Ms. Y was ordered for a mammography and also a USG, the picture that appeared in the computerized screen made her feel all out because it had traces of breast mass. The USG showed not only a mass alone but multiple. Later she was asked to have an FNAC. The first FNAC result was inconclusive after all the pain and struggle of being done by an inexpert hand. Later after 5 days FNAC was repeated that showed

benign breast disease. For the diagnostic labs, it might have been just tests and diagnosis but the patient undergoes enormous amount of stress untold. It is imperative to have a nurse counsellor before any specific test that is to be done for diagnosis that doubted for chronic disease, like cancer. The below given six steps may help a patient cope with the diagnostic tests and take a virtuous decision and get on to life.

Step 1. Take time for decision making: Health decisions are to be taken decisively. One needs to sort out important issues and concerns and prioritize and take the best options first. This decision can best be taken in consultation with the physician, family and yourself. Physician will tell you the options and their values and family for their financial and emotional support and yourself to gain the best benefit.

Step 2. Organize and gather your support system: In chronic and dangerous disease, diagnosis and treatment gather your family and friends who can be of great value to you. Who would stand by you in all your difficult moments. They will help you cope better although you are going through rough and tough time in your treatment and take a joint decision.

Step 3. Communicate to your right physician: Today the concept of health care is customer focused. Patient has every right to seek right physician even for a second opinion when the treatment is being decided by a physician. There are instances where the first physician reacted negatively towards the patient because he has gone for consultation with another physician. This is illegal. Therefore, the patient is going to pay for the treatment as well as experience the whole lot of effects from the treatment. Hence he has to voice with the doctor whom he trusts so that he feels consoled and assured of the best treatment rendered and gain confidence. Confidence, satisfaction and happiness help treatment outcome positive.

Step 4. Get right knowledge through evidence based: Best information about disease management are available online through systematic reviews and metaanalysis. If patient is wanting and asking for the right information, sites of the above mentioned scientific data can be reviewed. Seeing in believing and knowing the facts and figures will help assure any patient. Patient to be explained of no miracle cure either to avoid frustration, if the treatment fails at some point of time.

Step 5. Decision on treatment preferences: Work out with your physician and decide on the treatment options that are available so that no

time is lost to act on the right stage of the disease to get the right effects of the treatment. Emphasize on the treatment compliance and other factors that may contribute to therapy compliance by the patient.

Step 6. Reviews: At each step of the treatment process, outcome to be assessed. If standardized treatment, use standard assessment scales related to the diagnosis and management otherwise review with the clinical and physical assessment findings. Any side effects to be neutralized through careful therapy and monitoring.

SUCCESS STORIES

Mrs. X, 45 years old, expressed her success of her son being treated for ALL (acute lymphoblastic leukaemia) six years back. She serves as a security guard in an institute earning for her family's livelihood. She narrates "I noticed bruises over his legs after play and my son who was 2 years that time would show lethargy and cries every now and then. He developed fever and so I took him to the local hospital and they referred me to the hospital for further management. He was diagnosed to have ALL. I was shocked by the diagnosis but I had no other go but treat him. I had lots of financial problems. But I managed to gather 12 lakh rupees for his entire treatment. Food, no food I used to look after him. I had only a son and I needed him above everything else. I spent almost all my days looking after him. After all the chemo cycles, now he is free of cancer. Yearly checkup and investigations are repeated. I have struggled but succeeded to save my child from this horrible disease. It was a nightmare for me and I as a single mother took all that came my way. It's hard but possible". Initially she brought the photo of her son and showed me and later she brought him for us to believe. Son lives with grandma and mother works to earn for the family living away from home to meet all ends.

Mrs. Y, now 58 years old, recalls her lost son due to hydrocephalus. Working as an officer in the agriculture department in the mid-80s. She narrates "I was 24 years old when I got married and at the age of 26, I had a son. My son was normal at birth but after few days his head became bigger and bigger. I knew nothing of what was happening. My in-laws had an opinion that it's due to my horoscope and past life that child is abnormal. They kept blaming me. Finally I and my husband took the child to the hospital and was diagnosed with hydrocephalus. My son was referred to

Dribugard medical College and Hospital. VP shunt was done and I came back home. As soon as I reached home I was divorced by my in-law and the entire family. With broken heart, I returned home with my child. Lived with my parents for so many months with my ailing child. My parents and siblings help me take care of him day and night. Day by day his head was becoming bigger and bigger. I used to hold him day and night in my arms and my arms used to be numbed at times. Till today I have lingering pain in my hands. I could never forgive and control my tears either. I cried every moment. Repeated hospitalization did not save him either and I lost him at 8th month. I can never forget the two pains that pricked my heart. One losing my son, second the divorce. Life after the incident is never the same. Today I realize the injustice done to me but I cannot rewind my life but live another life for my 3 children whom I got from my second marriage. They are grown and settled in life but never can I forget my lost son".

Success is not final, failure is not fatal: it is the courage to continue that counts

Winston Churchill

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Stigma Associated with Chronic Diseases and Role of Nurse

Outline

- Stigma associated with HIV/AIDS
- Stigma associated with Tuberculosis
- Stigma associated with diabetes
- Stigma associated with cancer
- Challenges or consequences of stigma
- Family conferencing
- Role of nurse

INTRODUCTION

Stigma and discrimination exist worldwide with varying degrees of their manifestations. Diseases do not discriminate but people do. Stigma related to chronic and infectious diseases are very common sight even among the health care professionals. When a patient with H1N1 or a patient with tuberculosis is admitted, they are usually isolated with tags around their environment. Stigma not only makes an individual feel inferior but also makes them difficult to manage their disease and life itself. This needs to be addressed to everyone so that care is given irrespective of what disease they have and which religion of caste they belong to.

STIGMA ASSOCIATED WITH HIV/AIDS

In the recent years, HIV/AIDS was the most feared disease by everyone. People who contacted the disease are believed to be morally blemished. They were not taken care of inside the house and were thrown from society once upon a time. But with the advance in technologies, medical science and also people's awareness, they are able to live healthy for a long period of time. But stigma is never completely wiped off. Although illegal, files of patients had tags of 'Biohazard' 'Retro +ve' or even red tags were tagged on the files and were separately kept in a corner of the unit. Those were the days patient had to feel being treated indifferently. But the fact remains that using standard precautions can save all incidents. With the global funds for HIV, prevention strategies have brought down the incidence of HIV drastically in India. Antiretroviral therapy (ART) has brought health to many. Credit to science advancement in this century. An HIV positive woman attending her husband with AIDS syndrome in a medical unit recounts 'The moment my husband dies, I am going to be thrown away from his house with my two daughters. I am here today just because I have to take care of him but they have no concern for me. They don't even bring food for me because they feel that the utensils will get contaminated'. In another incident, a lady with three daughters of 8 years, 6 years and 3 years were left behind by her husband due to HIV infection. On the day of funeral, the in-laws asked her to vacate the house. They removed the lights inside the room so that she gets scared and intends to send her off. But the lady requested at least till the 13th day after the last rite is done. This lady was sent off and three daughters were shared among the three uncles of theirs. They were treated like servants in their homes with no education and no proper facilities. These children were often segregated from their own children thinking they will infect them. After few years, the three children ran away from their paternal home and settled with their mother in an isolated house where she was living. This tells us that women with no fault of theirs, suffers from stigma and severe discriminations even from family members. The reasons for HIV/AIDS stigma are:

- It is life-threatening and highly infectious.
- Once contacted it is lifelong.
- It is associated with behaviour, such as multiple partners, drug abuse, etc.
- Sex is main route of transmission in India.

- People lack correct information regarding HIV infection.
- Poor moral behaviours and that is punishment for the affected individual.

Nurses being the largest workforce in the health care sector and dealing with invasive procedures are prone to get needle prick injuries, body fluid exposure that may pose risk to nurses. Standard precaution greatly helps maintain oneself free from unnecessary transmission of HIV or STIs while we work.

- **Stigma and discrimination:** Stigma prevents people affected to speak out and learn more about their condition and management and also understand their status for right approach to care. Right information rendered can impact the people to reduce stigma against them.
- **Care and treatment compliance for PLHIV:** Stigma prevents people affected to come forward and take their treatment. Good care and treatment will help reduce non-compliance.
- **Stigma reduction:** Stigma reduces access to investigation and treatment. Good counselling will help motivate them to test and get the right treatment. Clear understanding and managing their emotional states will help prevent further transmission.

STIGMA ASSOCIATED WITH TUBERCULOSIS

Tuberculosis (TB) although is the king of all diseases yet right from its origin it has stigma. One-third of the TB burden is contributed by India. Stigma related to TB causes multidrug resistance. People perceive that TB drugs do not cure TB but harms more than ever and they stop treatment in between.

Considerable geographic variability exists in the perceived prevalence of TB stigma, with 27 to 80% of at-risk individuals reporting that TB is stigmatized in their communities. Myths about TB make treatment compliance the biggest threat. The patients usually hide their symptoms because of stigma. Affected people are usually isolated, rejected and socialization becomes a taboo. Patient suffers psychological and psychosocial impact. Focus of TB management should include the same that is tackling not only bacterial treatment but also psychological and

psychosocial aspects of the individual. Health education on myths and stigma to be addressed so that compliance to treatment efficiency increases.

Themes that emerged through the study findings are: *(Andrew Court wright, Abigail Norris Turner, Public Health Reports/2010 Supplement 4/Volume 125).*

- Fear of infection as the most common cause of TB stigma.
- TB stigma has serious socioeconomic consequences, particularly for women.
- Qualitative approaches to measuring TB stigma are more commonly utilized than quantitative surveys.
- TB stigma is perceived to increase TB diagnostic delay and treatment noncompliance

Tuberculosis and HIV co-infection is very common among HIV infected individuals due to immunity issues in both the diseases. People who have HIV infection are prone to develop TB as an opportunistic infection and hence HIV-infected patients admitted are usually screened for TB infection. Owing to its large number existence, people feel that TB infected people are also HIV affected and that stigma exist to avoid them not only for TB issues but also for HIV as it creates a sense of immorality and being with them may pose risk of HIV. It is observed that the most common cause for TB transmission is being with them without any measures to prevent them: Poverty, hygiene, low socioeconomic status, living conditions, malnutrition augment to the transmission. TB stigma has more impact on women who are from the low socioeconomic status with less education. Although treatment is given free of cost by the government access and travel makes it difficult to follow the regime. Their understanding to compliance is an issue leading to MDR TB. Therefore, TB stigma may worsen by virtue of its existing gender and also class disparity in the present scenario.

India being the second most populated country in the world with largest number of TB cases in the world and it is interesting fact that half of the indigenous people of the entire world which is about 84, 326, 240 is living in India as per 2001 census. Most of them reside around 15–30 km away from the district health care facilities. Most of them come to subcentres for their medical help for their health problems when their

traditional medicine or health practices do not favour the health problems. They speak different dialect and strictly follow their cultural practices, moral values, traditions and also food habits. Most of the men and women are agriculturist, construction workers, petty shop owners and labourers. Owing to the isolation, low literacy level, health practices and lack of accessibility, educational background, extreme poverty, and living away from the cities and town make them live isolated. Therefore, ATT treatment for its active phase and continuation phase, if not understood well, can have its reveres effects of resistance. Hence people living the rural areas with less health care facilities to be focused so that TB control program can be best expressed in facts and figures.

STIGMA ASSOCIATED WITH DIABETES

Paper Published by Alexander Wolf and Nancy Liu *(The Numbers of Shame and Blame: How Stigma Affects Patients and Diabetes Management. Diatribe Research and Product News for People with Diabetes, august 7, 2014)* shows that type 1 diabetes patients felt being more stigmatised by people. People with type 2 diabetes with insulin therapy feel more being stigmatised then oral medications. They felt so because visibility of the treatment is more among the intensive therapy by having equipment for monitoring their blood sugar, syringes to inject insulin, structured therapy time to time, pumps if regulated dosages, and many finger pricks. All these are the reasons many patients with insulin therapy feel the reason for stigmatisation.

Schabert J, Browne JL, Mosely K, Speight J's paper on social stigma in diabetes found that people with diabetes have more of selfstigma rather than others who do not have diabetes. The main reasons described in the review were feelings of self-blame, fear of needles, loss of self-control because of repeated hypoglycaemia effects and societal pressure demands for social norms related to behaviour. *(Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic. Patient. 2013; 6(1): 1–10.*

http://www.thediabeteself.net/publication-types/systematic-review-publication-types/review-experiences-of-stigma-associated-with-diabetes/#sthash.k3qDDxMk.dpuf)

Leonard E. Egede and Charles Ellis in their systematic review presents that diabetes and depression exist as a global perspective. It also highlights that a number of appropriate selfcare behaviours are critical to good diabetes management and thereby has a long-term positive outcome. Having clinical guidelines and protocols are of great importance on medication adherence, self-blood glucose monitoring, diet and physical activities.

(L.E. Egede, Effect of depression on selfmanagement behaviors and health outcomes in adults with type 2 diabetes. Curr. Diabetes Rev. 1 (2005) 235–243.)

Recently diagnosed with type 2 diabetes patient expressed the sense of difficulty in early morning 45 minutes' walk which his physician strictly prescribed. In the initial 2 months, he faithfully did all that was instructed and brought down his blood sugar level to near normal from 250mg/dl against the normal range and his haemoglobin A1c was 12% (means 298 mg/dl). Later haemoglobin A1c was brought down to 7% and fasting blood sugar to 119 mg/dl. But with the decline in the values he stopped his exercise but diet remained the same. Later after 4 months, the values again were raised further. When enquired about the issues of exercise he expressed that it was so difficult to get up in the morning and lose all my sleep and evening I come home late. This was the excuse given. Therefore, re-enforcement from time to time and motivation to dietary, medication and exercise remain very vital to diabetes management.

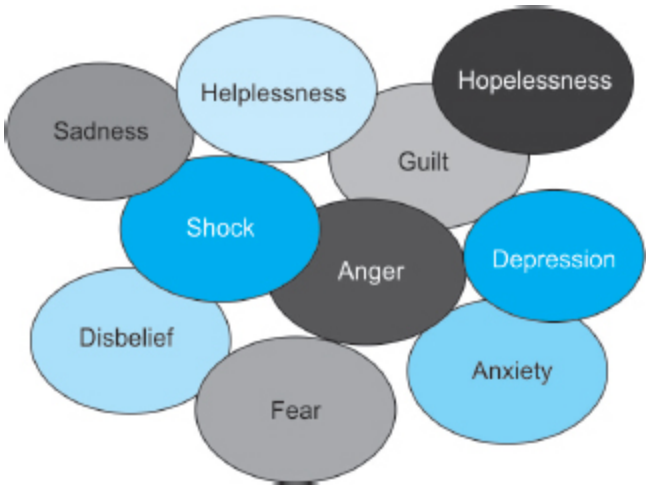
STIGMA ASSOCIATED WITH CANCER

For every disease, people try to look back and see if it has any relation with their habits and lifestyle. Stigma is also associated with cancer. When a person has cancer of stomach, they say 'he must be eating too much spicy food or he is jealous and gets lots of gastritis'. Liver cancer is usually associated with alcoholism. Any individual irrespective of their drinking habits, one may label them as alcoholic which led to his disease condition. It is well described in the study done by Chapple, Ziebland, McPherson

published in BMJ in 2004, stating that cancer of the lungs have strong association with smoking. For this very reason, people who developed cancer of the lungs are stigmatised as having bad habit of smoking. If the person had the habit of smoking and he develops the disease and is being stigmatised, then he develops a sense of guilt, shame and also loses his identity. This will add to his psychological morbidity. Today advertisement on television shows people having oral cancer for having been an addict of tobacco. This very dreadful scene in the advertisement also adds to the fear and anxiety among the patients. Fear and anxiety can lower their immunity.

(Chapple, Ziebland, McPherson. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. BMJ 2004; 328:1470)

Feelings of Cancer Patients



Myths of Cancer Patient

Myths usually cancer patient has are:

- Death
- Fear
- Pain and suffering
- Loss of control and independence
- Helplessness
- Isolation

Every individual fears about cancer as something very dreadful because of the pain one goes through. It is a kind of death sentence. Today we have very good pain management protocols as per WHO. Hence one should not experience pain, rather pain management is to be given on regular basis. If the cancer is detected at the early stage, cure is highly expected.

(M. Daher. Cultural beliefs and values in cancer patients. Annals of Oncology 23 (Supplement 3): iii66-iii69, 2012.)

The fears associated with cancer can be removed only through effective cancer control programmes and also good pain management techniques. Media coverage on cancer survivors can be projected so that patient understands they got out of the condition. Their endurance, confidence and perseverance to be strengthened. Open discussions on current modalities of treatment, clinical trial positive outlook to be shared so that patient understands the latest techniques and success percentage. Our country's celebrities who survived through cancer could be best ambassadors to launch positive programmes and allay the patients' anxiety and reinforce courage. Availability of quality drugs in low cost will greatly help patients' survival rates and it may help patient feel they have options to get the right treatment. In India, many patients forego treatment or loss to follow up because they cannot afford the treatment.

CHALLENGES OF STIGMA ON HEALTH BEHAVIOURS

Treatment Non-Adherence

Treatment adherence is a common crisis with any long-term illness. When it comes to TB or HIV treatment, timings of medication are of great importance. Owing to follow the treatment regimen strictly implies that the outcome is always positive and health maintenance is assured. When co-infection arises treatment planning has greater thought for drug interactions. Conscientious drug regime is to be sought in case of co-infection. Treatment nonadherence is common when an individual has the habit of long journeying, long hours of work away from home or with habits. Clinical outcome depends on adherence. Concerning to diabetes, poor glycaemic control are factors that display non-adherence to oral

hypoglycaemic or insulin. Complications are best delayed with good drug adherence.

Access to Medical Treatment

Access to treatment and consultation becomes significant when the person is totally dependent. If the individual is healthy enough, he himself getting the medication is not a big difficulty but when someone has to get it each time, that individual's time and availability becomes a matter. Being away from health care setting and poor transport system make availability of medication and adherence an issue. Medical stores and hospital proximity might improve adherence. In older age, the access to medical facility greatly depends on sibling's willingness to tackle their parents' health concerns. In a family where both the son and daughter-in-law works away from home, compliance to medical check-up might be a concern because either of them have to take leave every time the elderly wish to visit his or her doctor.

Lifestyle Change

Restrictions to what I have been doing and liking is like a curse to patient. Lifestyle change is expected from a person who is diabetic. He is asked to eat more of vegetables and low calorie food, well measured throughout 24 hours x lifetime. If that individual has been a lover of fast food, non-vegetarian, it is hard to comply. Depression sets in when you restrict one to follow a path you never wished for. Catching up with the dietary restrictions for one's health itself becomes a great challenge. Even though one knows the consequences of complications, still people non-adhere to the lifestyle change till they face dreadful impacts on their health.

Cost of Treatment and Transportation

Initially, there were only few ART centres across each state. Patients would come from different district or state to get their drugs (ART). The reason being stigma. They wanted their HIV status to be concealed from their community. But with the advent of excessive education and communication regarding how to curb stigma, people have come out openly to access their ART from their respective district centres. Having said this, the distance to be travelled every month, and the cost of their other treatment related to comorbidities and complication cost. Frequently, patient with HIV or TB

come with respiratory complications where ICU cost would burden them. For diseases, like diabetes, hypertension, cancer, and other chronic diseases, the expenses are enormous. Cancer not only drains the person's wellbeing but also wealth of the family too. Treatment becomes very costly and most of the patients are lost to follow-up because of this very single financial issue. Hospitalization, cancer treatment at day care centres on specific schedules not only tires the patient but also the family member who accompanies each time. Treatment side effects are depressing with outcome which is quite uncertain. I remember a man who had cancer of the throat and was taking his regular radiation therapy in a regional medical institute which was about 35 km from his place. He had no children and he also had only one leg due to amputation related to past injury. His wife who was in 50s used to accompany him every time he goes for his radiation. After he gets down from the bus, he needed to walk almost a kilometre to his house. He would sit after every 10 steps due to his weakness. As a child I watched him do this every time and thought what was disturbing him. After a few months I did not see him walk again. Weakness one of the most common fact of cancer and its treatment.

Safety and Efficacy

Safety related to medication. When an individual is on insulin, dosage prescribed and taken may vary. There are times patient gets confused with the type of insulin syringe and wrong dosage may be self-administered. Although we teach the patient prior to discharge, safety still remains a concern. Sometimes patient comes with hypoglycaemic attacks and is brought unresponsive to the emergency unit for further management. Repeated hypoglycaemia affects quality of health and may jeopardise the person's health.

Information, Education and Communication

Information is not hidden form anybody today. Just search any content on google, it is right here. But this doesn't mean the person understands what exactly he meant to. When a patient comes to you with certain health problem, one needs to be educated with right information of how and why. Correct information and communicating to them rightly can influence compliance. When we educate patients about diet, for example, everyone has their own way of cooking and pattern of consumption. Educate people

on locally available food items with correct calories and cooking pattern. When a renal failure patient with diabetes and also hypotension comes to you, diet education is a complex phenomenon. Low salt, low calorie, low protein, etc.

Financial Issues and Programmes Initiated

On an average, a renal failure patient pays about Rs. 15000–20000 per month for his dialysis. Expenses increase with hospitalization. A man with no income of his own or low family income hardly can afford treatment. Chemotherapy treatment in no way affordable to common man. Drug therapy and hospital expenses add up to the loss to follow-up. Unconsciously we blame the patient for omitting his visit for treatment but the truth is issues related to expenses and no one to attend them.

Challenges are different for different individuals with the health problems. Few of them have been discussed above. The writings above are purely on how I view from my end. Express needs of patients need to be assessing in every area of health with varying chronic conditions so that standard protocols and programmes can be initiated. With the advancement in science and technology, treatment options for chronic disease is taking a different shape. Literacy regarding the disease and its management needs to be reinforced to the victims so that they can live with quality.

Preventive Aspects

- Positive change through awareness, public education, and resource campaigns.
- To provide right communication to avoid myths.
- Effective media campaigns and follow-up.
- School education to include contents related to some of these problems so that children maintain their diet, exercise and avoid habits in later life.
- Advocate for the patient.
- Services to be available.
- Risks to be widely acknowledged so that people can manage their lifestyles.

How to Curb Stigma and Improve Quality of Life

Figure 13.1 describes how to curb stigma and improve quality of life.

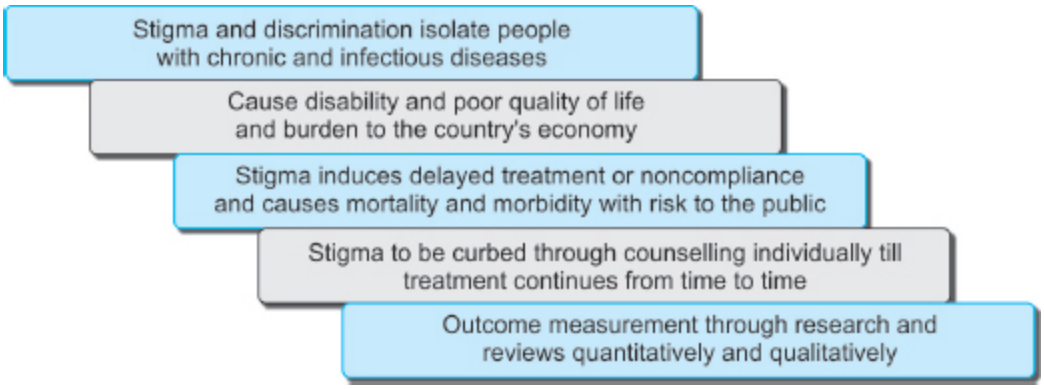


Fig. 13.1: Curbing of stigma for improved quality of life

The trouble with always trying to preserve the health of the body is that it is so difficult to do without destroying the health of the mind.

GK Chesterton

Role of Team Approach Care and Role of Nurse as Coordinator of Care

"In the gradual division of labour, by which civilization has emerged from barbarism, the doctor and nurse have been evolved"

Sir William Osler (1891)

Team care approach is only the one that looks at patient care as holistic. Holistic approach to care is the demand of the hour in the health care sector. We may lots of issues related to communication among the team members. If done properly, it is the patient who benefits most. With the advent of many therapist specialized in various aspects of patient care, care seems to be provided with utmost care in the tertiary and corporate sector but it

remains as a dream in the peripheral health care sectors. Team members include: The nurse, physician, pharmacist, respiratory/ physiotherapy/ speech and hearing therapist, occupational therapist, dietician, social worker, counsellor, spiritual leader and ancillary servicemen. Therefore, patient care team is the group of members mentioned above who communicates and follows standard protocols to provide holistic care to the patient.

Edward H Wagner describes the role of patient care team in managing chronic diseases. Points noted in his publication are:

- Effective patient management emerged from team approach care generally multidisciplinary.
- Team members include doctors, nurses, physiotherapist, respiratory therapist, speech and hearing, occupational therapist. Dietician, counsellor, spiritual leader, social workers, ancillary staff whom possess specific training.
- Standard protocols make care systematic and care is not neglected. Patient care aspects include home-based care plan, follow-up and medication management at home.
- Consultants or specialized nurses available to community level helps clear patient's doubts, myths and fears.

(Edward H Wagner. The role of patient care teams in chronic disease. Management. BMJ 2000; 320:569–72.)

IMPACT OF FAMILY CONFERENCING

When a patient is critically ill in the ICU, the decision is mainly left with the family members. To determine patient's wishes for end of life, formations are traced from the spouse with consent or from the closest family member who may not be right all the time. Major decisions are made with family and health care professionals in India. However, patient's relatives may not know patient's own preferences unless expressed prior. Values and norms of the relatives may be induced while taking the decisions which remain a big challenge for the health care professionals. When the patient loses his or her cognitive power, the only people we can seek for decision is the family members and hence family conferencing becomes very important. Eliciting right information from family members

will help doctors and nurses to take right decision that is satisfying them. Areas of discussion ideas include:

Communication with Family Members

Communication remains the most important concern to ICU patients. A clinical trial on communication strategies using family conference had less post-traumatic stress disorder, low anxiety and depression when compared to controls. *(Lautrette A et al. A communication strategy and brochure for relatives of patients dying in the IC. Engl J Med. 2007 Feb 1;356(5):469–78.)*

Shared Decision Making

Patient lacks the decision making capacity due to his or her acute illness. While caring for a very sick family member in the ICU, the family members always feel that a joint decision is taken by the family members as well as the health care professionals in regard to life sustaining treatment modalities and sustenance itself. Mr. V, who was 82 years old, managed in the ICU for his chronic chest condition and was critically ill. He improved a few days later and was weaned off from the ventilator. After two days his condition worsened and the son was asked for consent to be put back to ventilator. The physician called them and discussed in his conference room and ask if they would put the patient back to ventilator. The son replied "What is better for my father? Please go ahead and decide the best as per your medical knowledge" The medical team gave them all information related to ventilator management and after an hour of thought the family members decided that they would not put him back to ventilator so that he doesn't suffer more. Decision becomes very critical at this point of time but team efforts are a must.

Treatment Plan and Prognosis

Family members have an important role in understanding the causes, signs and symptoms, treatment modalities, side effects and prognosis. Every chronic or acute illness that threatens life has a depression expression accompanied with it. When a loved one is sick and depressed family members cannot help but feel the same. When the ill person suffers day by day, the family members who are unable to do anything to relieve his pain and anguish feel depressed, rejected, irritated and later get into depressive

feelings. The physician and nurse counsellor can greatly help the family members to plan their dying person's distress so that they are able to find satisfaction in what they do. Randal J Curtis *(Randal J Curtis. Practice guidance for evidence-Based ICU family conference. Chest. October 2008; 134 (4): 835–843.)* states the five-step approach to family centred decision through shared decision made keeping family preference in fore front. The five approaces are VALUE:

V = value statements made by family members
A = Acknowledge the emotions of the family members
L = Listen to family members' issues
U = Understand the patient as an individual
E = Elicit questions raised by family members

Multidisciplinary Approach

Best efforts are put by every team which cannot be magically given by just a family member. Team for critically ill patient could be his physician, critical care nurse, therapist, psychiatrist/counsellor for psychological support, dietician, religious person, etc. The role includes medication, oxygenation, diet, activities, health education, psychological support and also his rest and sleep in the critical phase.

Standard Protocols for Care

Standard protocols placed in ICU for patient care and also for family members, help the loved ones assuring them of care. ICU protocols and procedures speak of the discipline that is best followed for patient positive outcome.

Billing and Reimbursement/Financial Issues

Leave against medical advice (LAMA) is common scene in critical care units. Legal issue is maintained but when family members say "I wish to take my patient home" might pose us with difficult decision to be made. Nurses and physician know the patient's condition, in spite of best explanations, family has the right to express decision to take home. The

very reason could be for financial issues. On day of discharge, every family member waits eagerly to pay the bills of the hospital and get back home with the discharge summary. But unless it has a protocol to maintain its flow of process, people wait long hours to get back home in time. On the other hand, reimbursement may be sought by family members for the expenses that are incurred. Having a system that processes reimbursement formalities will make every family member hassle free process.

Follow-up

When any treatment is given follow-up tells us the progress and outcome. Every patient is asked for follow-up and immediate return if any adverse event takes place during the home stay after hospitalization. Family conferencing becomes very important because, medication that nurses were giving is now going to be continued by the patient or to be monitored by the family member. A member of the family who is going to be constantly accompanying the patient is the right one to be educated on discharge so that compliance is assured. Errors in medication or mistakes made during any procedure carried out at home may pose danger to the patient. Errors and ADEs to be monitored and reported. Conferencing with the family, therefore, is vital.

NURSES' ROLE

Nurses can make a difference ultimately!

Nurses play pivotal role in healing of patients. It is the nurse who serves round the clock unlike other profession. Although structured in its nature, benefit belongs to our patients. Functions of nurse changes based on the type of patient she handles. In critical care areas, the nurse is expert clinician who understands patient with skills of humanity and technology. Experts in any field concentrate on their specific areas but the nurse is bound to automate their care based on changing technology and evidences in patient care aspects. This makes nursing roles very unique. Role of nurse handling critically ill patient are:

Care Provider

When a person is sick, the first thing he or she looks for is comfort. To be free from pain and anguish, no pain inflicted by unskilled personnel, no

painful procedures, no frightening investigations and treatment modalities. The care provider looks at the basic needs of the patient as well as the expert personnel who can perform hi-tech clinical manoeuvre. She might be a clinical specialist, practitioner, and a good advocate for the patient. A novice nurse's job seems to be basic care, such as checking vital signs, bathing the patient, caring the back, keeping them clean, turning them from side to side and giving oral medication. More than medication, the patient needs care through touch that makes them recover faster than ever. It is time for us to ponder and see how many baths we do for a patient. Successful and satisfied nurse is one who could communicate and provide basic comforts to the patient. I remember a head injury patient in coma and was lying in bed for more than a month. I was supervising the unit. On the first day of encounter, I saw the patient very fragile and helpless. His wife was looking tired and worn out due to lack of sleep and rest. I took my two students at the bedside and was giving bath, back care and foot massage. Later crape bandage application was also taught to the students as well as to the patient's wife. The very next day, as I visited the unit I looked for the same patient so as to how he is? To my surprise, another patient was in his bed. Astonishingly I looked at my students; they smiled at me and said 'mam he died at 5 pm last night'. I took one step hind and thought what went wrong and I was silent for a while. But in the meantime my students responded 'he would have died in peace with the comfort he had last evening'. This makes me think that life is short and we can make a difference.

Nurse Educator

The liaison between theory and knowledge greatly lies in the hands of a nurse educator. What is learnt and what is practice has gaps in any setting. The views of clinical nurses and educators have wide variance. The opinion could be different but the reality speaks of coerced learning rather than self-interest put forth. Any continuing education programme becomes a formality if not under performance appraisal through an analysis or examination. Having certification and re-certification of practice like in any western countries will enable the nurses in the developing countries to keep abreast with their current knowledge. In many states, registration is either lifetime or 5 years. Credit system yearly may make an individual skilful and updated although the procedure to do so becomes tedious. Having

compulsory credit hours of learning in areas of concern needs mandate. Dual role in any clinical setting makes a difference in nurses' attitude, knowledge and skills of managing patients.

Guidance and Counsellor

Nurse is a born counsellor. Nurse helps the patient to cope with his most distressing diagnosis and prognosis. Helping them build good IPR so that they will be able to express themselves and approach for better health care. Any chronic illness causes depressive feelings. Counselling can help ease emotional and psychosocial issues. Better attitude towards one's health progress and change in behaviour can bring about changes in alternative approach which if made can help develop a sense of control over his health issues and can focus on his positive lifestyle.

Change Mediator

If a person who smokes is asked to stop smoking, he may take double the packs. Having to leave one's habit is rather not too easy. But, when we talk to the patient, and if concern is focused to his wellbeing he might show interest in it. Consistency and followup in counselling is crucial. Example of a little girl of 8th standard started smoking, abusing drugs and chewing pan in such young age. Influence from friends and mother made her chew pan. Her young male friends drink because they see their parents drinking. All habits in 3 years caused cirrhosis of liver. On admission to hospital, the nurse is able to council the ill impacts, habits have on her health. Initially, she was resistant to even listen but as the disease progressed and symptoms were prominent she did change her attitude and gave up her old habits.

Patient's Advocate

The nurse has to speak for their patient. In Indian scenario, the patient is submissive because of the fact that they understand less than their doctor or nurse. The nurse needs to do a good assessment of the patient and motivate him to express his concerns, desires and expectations for his treatment or investigations. Choices can be best made when the patient knows about his condition or investigations. Patient safety and rights to be maintained as per code of conduct and support patient to make his decision. Decisiveness arises only when one can critically think and clinically reason.

Nurse Manager/Administrator

Nurse manager makes decision related to consensus activities that is evidence based. She has the authority with ability to coordinate, evaluate process of care and individuals who provided the care and also allocate resources for the same. CNE should be able to provide directions for practice develop staff on current knowledge, skills and attitude, and monitor the ongoing process of change. She is the right person to advocate for the nurses for best practice with adequate nurse patient ratio. Today, performance appraisal provides a forum for opportunities to improve and hence all nurses should look forward to continual improvement.

Researcher

Nurse research aptly identifies based on the clinical experience and expertise, the areas for change and needed improvement. Clinical practice change happens through research and research is possible only when care needs a change based on outcome of any treatment, procedure, or care aspects. Being a qualified nurse serves as a good standpoint for clinical research. Awareness of research process and having knowledge of scientific language helps a nurse to relate information rightly to the other readers. Right understanding of biostatistics helps nurses to report findings meaningfully. Being sensitive to the ethical issues and concerns serves as a major role today in research. Today the aging population is increasing in India too with multiple health problems thereby requiring not only critical care but long-term care in almost a home-like setting to suit the natural home environment. This very challenge makes us feel a sense of responsibility towards standard geriatric care settings.

Summary

With the advent of many therapy courses across the country, nursing too is posed to high competition in terms of skills and certification. Since we are bound by council and also code of conduct, legal and ethical considerations are a must to be monitored. Educational requirements have to be carefully framed so that at least we start nursing from a baseline. Too many categories make nursing career on the disadvantage. In many countries, only PhD qualified people are on to educational institute with certain credit hours of clinical practice every year. But in India, the quality of training

nurses at every level varies widely but they are all employed in the hospital for the same job. Higher educational qualification and extra skill training must make a difference.

A good laugh and a long sleep are the best cures in the doctor's book.

Irish proverb

14

Care of Death and Dying

Outline

- Introduction
- Signs and symptoms of failing body
- Psychological, spiritual, physical, emotional and social needs of the dying person
- Dying person's bill of rights
- Assessment of signs of death
- Stages of loss, grief and grieving process and social support
- Grief and bereavement support for the family members
- Fears and challenges
- Organ donation and counselling
- Cultural practices among different cultures, regions and rites
- Role of nurse: Law, ethics and moral issues

INTRODUCTION

Losing someone whom you love so much is hard to part. Even the smallest treasure missed has an impact in one's psyche and emotions due to

attachment. Pain as a reaction to loss is a normal process. Getting back to normal is an experience of rewinding painful memories and trying to live to nearest normal human range. Crying, weeping and grieving are expected when near and dear ones part away and there is nothing right and wrong in it.

Death is inevitable in life. The nurse in her best sophisticated care too faces death. Death in the ICUs is common scene every day. Mortality increases due to hospitalization delay or poor health seeking behaviours. Self-medication is one of the most prominent causes for late diagnosis. Symptoms are managed with over the counter drugs and even educated professionals land up in multiple organ failure which is due to selftreatment that may not have rationale for the same. Death cannot be hastened or postponed but the difference it makes is the way we care for the individual with utmost care and with good intentions.

When a person is nearing his death, two very important processes evolve. One the body changes that is fading away and other, emotional changes of departure. In venturing, one's death fear and anxiety are common phenomenon. Reality seems amazing. Even though perception of heaven exists for every individual, yet no one wants to die indeed and leave their loved ones. The transition from life to death is the time patient may need support constantly to ease his or her fears. Death process should be a normal process which is emotionally, mentally and spiritually attached but to let go one's soul from the body.

SIGNS AND SYMPTOMS OF FAILING BODY

When a body starts failing, the typical signs and symptoms are:

- Oliguria
- Coldness
- Confused
- Withdrawal
- Congestions
- Restlessness
- Incontinence
- Unresponsive

- Giving permission
- Vision-like experience
- Unusual communication
- Breathing pattern changes
- Decreased nutritional intake
- Saying good bye to all near ones

Oliguria

Vital organs start failing. Kidney impact is seen through oliguria. This is common when less circulation to the kidney and kidney no longer filters urine. Body will look edematous and it is our responsibility to handle with care. Indwelling catheter may help the dying person for comfort.

Coldness

Lower extremities are the first to become cold as circulation ceases. Vital organs are the last to lose circulation. Nurse's responsibility is to keep the patient warm and observe constantly and carefully.

Confused

Circulation to brain decreases and altered mental status is a sign.

Withdrawal

During the last phase of life, the person may be in a comatose state, withdrawn and irresponsive. Showing signs of detachment from the family, surroundings. Speaking with love to the dying person with name being addressed and holding their hand is a good sign of supporting.

Congestion

Gurgling sound can be heard due to decreased fluid intake and unable to cough out secretions. Gently allow the person to lie on side and drain rather than suctioning. Suctioning may cause more discomfort and hypoxia.

Restlessness

Restlessness begins due to less oxygen supply to the brain and altered metabolism. Calm down the patient by talking gently and rubbing head and

hands for concern shown.

Incontinence

Sphincter muscles get relaxed and person is no longer able to hold bowel and bladder. Having a diaper put and also changing linen as and when necessary may provide good comfort to the patient.

Unresponsive

When person is in coma, his senses may still be felt and touch therapy and constant support by being with him will provide comforting moments at end of life. Person may not be oriented to time, place and person.

Giving Permission

Dying person always long to hold the hands of the loved one and be touched by them. It's a sign that his love ones after his death will be fine. Giving a word of appreciation for what he has done will encourage him to accept his achievement and die in peace. Assurance is what one is expected to reveal during the communication.

Vision-like Experience

This is the most amazing fact that I have ever heard and known. When my mother was in her sick bed and was going through this process she asked my sister "When I die who will come to take me"? We had no answer to her question. Few hours later when all signs of death were approaching she said "see your daddy is coming to take me and he is flying around the roof". We were all in a state of surprise. She kept on telling the same for a while till she breathes her last. This incident made me think what death is all about and who takes you to the concept of heaven. Is it the Almighty or the loved one? Just be with the person and respond normally as the person goes through.

Unusual Communication

Unexpected questions may be raised by the person which may not be even relevant. My mom's last question raised as she looked around all relatives, children and her only sister around her was "You all are looking at me and I can't even die" were the last words. This means that the dying person is in

full consciousness and is aware of her surrounding too unless it is greatly affected by disease process. Showing your love and affection is appropriate to make her feel she is dear to you all and you all are there with her although.

Breathing Pattern Changes

Low circulation and altered metabolism causes change in breathing pattern. Cheyne-Stokes respiration may be common phenomenon where a shallow breathing followed by a pause for few seconds up to a full minute. Sometimes panting for breath may also be seen. Helping him to raised his head or putting the person in semi-fowlers, or holding him up, and comforting him will make him feel better.

Decreased Nutritional Intake

Obviously, the person ceases to have food and drink as the system starts failing. Loss of appetite and thirst be sign of declining body functions. No force to be made. Soft diet is recommended as long as they can have. If unable to swallow then Ryles tube feeding may be the option for the person to sustain his livelihood.

Saying Good Bye

Finally, one bids good bye either holding the person, making final release of your loved one from this world. I happen to witness the last moments shared by a sister whose brother was very critical in the ICU. At midnight, the sister called me from outside the ICU saying that she wishes to see her brother. I knew his condition was not good so I came back to the hospital. Since permission was not granted to her in odd time, I took special permission and took her inside. She had no idea that his heart beats were failing, respirations were no more and the ECG patterns showing flat waves. Lower extremities were beginning to be blue. She held her brother's hands and was kissing it with full tears in her eyes. She rubbed his hands, body which was nonreactive anymore and was whispering to him. She said "get well soon am with you". I left the ICU at around 12.30 am. Next morning when I called to ask her, they already brought him home. Death at 23 years accidentally was never expected by parents and the only sister. It was a tragic moment and family took long time to come out from their bereavement.

NEEDS OF THE DYING INDIVIDUAL

Needs of the individual undergoing dying process may want to express many concerns. Expressing it can happen only by under-standing to whom he wishes to. The closest person that is the spouse or children or parents. Even friends may be an important person. Besides the success expressed as a matter of fact, he might want to confess his wrong deeds that might have hurt someone else. These needs commonly expressed by human are:

- To receive love and affection
- To be respected as an important member in the family/society
- To be accepted as he is
- To be forgiven and to forgive others
- His wishes and desires to be met by family members.

Sick person may need different things at different times and hence needs need to be assessed and prioritized. For a cancer patient, pain may be first priority. With changes taking place physically and psychologically, caring them becomes very challenging. Caretakers' health and status is also vital to quality care.

PSYCHOLOGICAL, SPIRITUAL, PHYSICAL, SOCIAL, EMOTIONAL NEEDS OF THE DYING PERSON

Psychological Needs

Psychological needs are needs of all and more so by patients who are critically ill. Active listening with empathy will help build trust in the dying person and be comforted. The psychological needs of an individual are understanding, freedom, acceptance, respect and love. Sometime patient shy away when they see their relatives entering their sick room. Why this happen? It's the past experiences shared between the two. Trust and faith and relationships are strained between them. Since they were old friends or relatives, societal expectation demands family visit, he would have come but the sick patient showed least interest. Here understanding, the degree of comfortability and respect between the two may pose irritability to the person and may affect healing. Mood of the patient may vary from time to

time and person to person. Our empathetic approach can make a difference in patient care outcome.

Spiritual Need

The moment we age, our inclination towards spirituality increases. Either very religious, atheist, humanist or skeptical, despite its principles in life people incline towards spirituality. Happiness after death is always longed for by human. In every religion, life after death is expected. But spiritual needs in the critical care areas don't exist in particular or being neglected by family friends and health care professionals. This neglected needs need emphasis. Although religion is one of the important demographic data we obtain, its significance is not well improvised.

Do individuals become more religious as they die? This question has often been debated among academics who study death. Such debate avoids the central issue that the dying process raises profound spiritual concerns of meaning and connection for individuals. Whether those who are dying reconnect, review, or renew prior religious beliefs – or are even open to new religious experiences – they are likely to engage in some form of spiritual searching. Hindu religion believes that the dying person be given water in the mouth so that they are not thirsty as they walk the path to reach heaven. Medical science disapproves oral water when the patient is unconscious or on ventilator for fear of aspiration. Situational decision making based on well-informed consent could prove possibility for the dying person.

There are times the patient requests for discharge in spite of his worse condition. His homely environment, love ones caring for him and wishing to die at his own home may pressurize him to ask for. Among the Hindu Manipuri, if a man dies outside his home either in the hospital or elsewhere, his body is never brought inside the house which is not honored by religious practices and customs. Home is home to all of us and every one of us want to die in our own home and be respected. Therefore, when people become ill, many ask for LAMA because of this very fact. Funeral rites and slogan are different even for different sex and marital status. Thus a person who is well oriented to such religious practices may wish for their highest respect even after death as a sign of their spirituality. Is the present clinical scenario prepared for this challenge? Or the curriculum made for health care professionals equipped with this knowledge?

Social, Emotional and Physical Needs of the Dying

The ill person may be helpless, dependent, lost his physical abilities, disfigured or having lots of pain. When a person is totally dependent, all basic needs to be carried out. Avoiding pressure ulcers, nutritional needs, passive exercises in bed, bathing, oral hygiene, etc., all family members and relatives must take equal responsibility to care collaboratively for the patient. Visits by friends may help renew his feelings of social life of the past. Social—separation from family, leaving behind unfinished business is going to be the main social concern of every individual. Mrs. B had an X-ray done for slight protrusion of the right temporal bone. X-ray showed bone thinning and doubted for malignancy in first place and all blood investigations were carried out including CT head. She broke down and bitterly cried. When consoled she expressed that when my mother who is 80 years and hoping only on me is alive and if I become chronic what will be her fate? Emotional expressions are common in a diagnostic test room. A good counsellor should take active role in this aspect.

DYING PERSON'S BILL OF RIGHTS

Our fundamental rights are same irrespective of who we are. In India, we belong to different caste, religion and also region. We practice very different cultural norms across the breath and length of the country. In this diversity, human rights are the same. But how we are treated by our care centres vary greatly depending upon my position, financial background, and also who you are. Like any individual, the sick person has the following rights as a patient when he is treated by the team under certain care institute for the chronic depressive conditions (Thulile Msane, 1st Feb '14):

- Right to treatment till death
- Right to be cared by positive hopeful people
- Right to express my emotions
- Right to take decision for myself at end of life
- Right to receive all comfort measures till death
- Right to have my loved one beside me during my last moments Right to pain medication to relive it Right not to be cheated for the treatment that I receive

- Right to dignified and peaceful death My beliefs and practices will be respected Right for respect towards my body after death
- Patient has to be informed of the treatment in his understandable language
- Exercise his rights as patient in a care centre
- Rights and belongings to be respected
- Right to be informed of current decisions taken for his treatment
- Right to refuse or participate in the clinical trials or any research
- Right to communicate and get across one's needs being met
- Not to be subjected to stigma and discrimination
- Right to choose physician for his management
- Right to receive treatment appropriate for the signs and symptoms assessed

ASSESSMENT OF SIGNS OF DEATH

Facial expressions: Facial muscles relax, cheeks may become sagging moving in and out with each breath, facial structure may change; lips pucker and sink in and glazy eyes are seen.

Changes in sight, speech and hearing: Sight gradually fails. The pupils fail to react to the light on examination. Eyes may be sunken and half closed. A thin film may appear over the eyes. Patient may be confused, cognitively impaired and loss of speech. Whereas hearing may be retained till last.

Changes in respiratory system: Respirations become irregular, Cheyne-Stokes respiration may be observed or low stertorous sounds may be heared due to pooling of secretions.

Changes in circulatory system: Alteration in respiration, pulse and temperature happens when circulatory changes take place. Radial pulse fades, and apical pulse is last to be felt even after complete cessation of respiration.

Changes in gastrointestinal system: Inability to swallow, vomiting, abdominal distension, and hiccoughs may arise and gag reflex diminishes.

Changes in genitourinary system: Distended bladder due to retention and later incontinence of urine and feces due to loss of sphincter control.

Changes in skin and musculoskeletal system: Pallor, skin cold to touch and cold sweats may be observed. Mottled skin is seen due to circulatory failure.

Changes in central nervous system: Nervous system failure causes loss of reflexes and pain. Restlessness may be seen due to diminished oxygen.

Signs and Symptoms of Clinical Death

- Absence of pulse, respiration, heart rate
- Fixed pupils and non-reactive to light
- All reflexes are lost
- Rigor mortis appears within few hours (stiffen body due to muscle fixation after death)
- Arms and legs are hard to bent
- No response of the eyes to caloric (warm or cold) stimulation
- Absent jaw reflex
- Absent gag reflex
- Absent pain response
- No blood circulating to the brain, as demonstrated by angiography
- Autolysis
- Putrefaction

STAGES OF LOSS, GRIEF AND GRIEVING PROCESS AND SOCIAL SUPPORT

Grief is a natural process to loss especially the loved one. Length of grief matters. How close one is to the dying person makes the difference in one's feelings and grieving process. Someday the person has to adjust and go on. During the period of sadness and grief, the person may neglect food,

comfort, and sleep and may develop weakness, headache, pains and aches in the body. If the period of grief lengthens, it may turn to be pathological. I remember a mother who lost his son who just wrote his final MBBS exams. With his friends, he went for picnic and way back he developed fever and disorientation. He was investigated for many queries but died without having made any diagnosis even from the referral hospital. He was the first son of three. He was the child who was very obedient, well mannered, studious, and on whom parents had all their hopes. Even after 20 years, his mother would cry as if he died yesterday and not eat the food items that he used to like and would sit alone for hours together and cry infornt of his photo. Death of a child to mother is very painful but prolonged period of grief may endanger the person's, health and psychosocial wellbeing.

Stages of Grief

Stages of grief according to elisabeth Kubler-Ross are:

- Denial – 'not me'
- Anger – 'why me'
- Bargaining—'yes, but....'
- Depression – oh 'it's me'
- Acceptance – 'it's part of my life I have to get my life in order."

Denial

On being told that one is dying, there is an initial reaction of shock. The patient may appear confused at first and may then refuse to believe the fact. Some patients never pass beyond this stage and may go from doctor to doctor until they find one who supports their position.

Anger

Patients become frustrated, irritable and angry that they are sick. A common response is, "Why me?" They may become angry at God, their fate, a friend, or a family member. The anger may be displaced on to the hospital staff or the doctors who are blamed for the illness.

Bargaining

The patient may attempt to negotiate with physicians, friends or even God, that in return for a cure, the person will fulfill one or many promises, such as giving to charity or reaffirm an earlier faith in God.

Depression

The patient shows clinical signs of depression—withdrawal, psychomotor retardation, sleep disturbances, hopelessness and possibly suicidal ideation. The depression may be a reaction to the effects of the illness on his or her life or it may be in anticipation of the approaching death.

Acceptance

The patient realizes that death is inevitable and accepts the universality of the experience. Under ideal circumstances, the patient is courageous and is able to talk about his or her death as he or she faces the unknown. People with strong religious beliefs and those who are convinced of a life after death can find comfort in these beliefs.

GRIEF AND BEREAVEMENT SUPPORT FOR THE FAMILY MEMBERS

John Bowlby, father of attachment theory, describes grief as a response to actual or potential loss of person who is emotionally attached. It may be projected physically, emotionally, somatically, cognitively, and in a spiritual way. Few of the ways grief is exhibited are numbness, shock, anger, anxiety, loneliness, fatigue, yearning and relief at the end. Physically one may feel tightness in chest, shortness of breath, lack of energy and panic attacks. Cognitively, the person may show disbelief, confusion and lack of concentration. When all the above symptoms are exhibited the person may express behaviours, such as sleep disturbance, loss of appetite, being isolated, absent mindedness and dreaming of people who are dead and gone. Therefore, we begin to counsel for grieving, we need to understand the relation of the individual in grief, ways of attachment, type of death, previous background and also personality of the person in grief and also society's nature. I remember a teacher who uses to bring only refill in the class to note the attendance. His pocket used to be stained with ink almost every time. One day we presented him a parker pen on teachers' day. The very next day he again came only with the refill of the parker. Then we

thought, what is disturbing him. When explored, the teacher lost his beloved family members in an accident few years back and he seems to have lost his way with the very incident. Therefore, we need to understand the relationship he had with the deceased person. Today, a phone call came to the class for a girl who was doing her masters. Her parents and only brother were travelling by car when a Tatavehicke hit them. Brother died on the spot and mother was seriously injured and underwent surgery. Nature of the incident and death makes a difference in the grief response. Now the girl is shocked to hear her only brother's death and on the other hand the mother is serious and undergone a surgery and yet to come back to normal conscious stage. She shows apathy and no reactions with the incident. Therefore, grief and bereavement support must be given in the areas mentioned below:

- Their feelings
- Their hopes after losing their loved one
- Religious formalities and help
- Support group best suited for the family
- Physical care of all members especially the affected person closest to the victim
- Diet maintenance by someone concern to help them
- Patience—time will heal
- Getting back to normal—a leading change by close associates

Fears and Challenges

All of us have fears related to certain things. One may fear darkness, some fear for pain, death, etc. One needs to identify specific fears and solutions for the same. Sharing how you feel and is afraid of to someone who is more experienced or knowledgeable may be able to help you out. Most of the time we share with family members, nurses, doctors, religious persons, support group and counsellor. Most of the time fears of critically ill are death and dying and pain.

- **Fear of the unknown:** Fear associated with unknown destiny is normal for all of us. However, religious we are, some fear exists in different degrees. Spirituality may play a major role in managing fear, especially related to dying process. Spirituality may bring in some

form of peace within the soul. Visit by a spiritual leader at bedside to console may make a dying person find some solace.

- **Fear of pain and suffering:** Few close friends of mine repeatedly remind me that, they have to be given cyanide if they are to be chronically crippled with disease. This may sound illegal and funny but after having seen people suffering and no one to care for, aging becomes a mental burden at this very young age itself. Euthanasia is illegal in India. Fear of pain with multiple pricks the health care professionals make, and the number of invasive investigations one go through, pain is definitely to be experienced. It is not only patient who suffers from pain but also love ones feels for it. When a mother sees her child being pricked by needle and restraint to maintain the patency, mother definitely feels the pain of it. This very psychological pain makes quality of life of patient and mother poor. Pain gate theory has brought in various measures to reduce pain especially while invasive procedures are to be done. Pain relieving research will be well appreciated.
- **Sin, punishment and faith:** All races, all nations, all religions to some extent believe in sin and punishment. Many people believe cancer or any deadly disease is due to past sins. Among the Christians, last sacrament is given during the last moments in life. Dying person is even given a chance to confess his sins. Forgiveness and happiness go hand in hand and the dying person feels hopeful after having disclosed his wrong deeds or those moments that are disturbing his feelings untold.
- **Unfinished worries:** When a mother has to leave behind her little one and die, the times are hard. Mother's heart breaks to sense that her little one has to grow up without a mother's love. Every mother can sacrifice all her live for her children. When a mother of two had to die leaving her son and daughter who were less than 10 years, she made every word clear "how my children will do without me". At the funeral, the two children could not sense that the mother is dead and they were playing and running around the neighbour's house. Of course sensing that something is wrong and why many people are gathered. Knowing her saturation was falling; she kissed and hugged her children time and again till her last breathe. She made her request

to her own mother, sisters and close friend to see to the welfare of the children. Therefore, having to entrust someone whom one trust is very important preparation for a peaceful death.

- **Fear of having to die alone without family members around:** Today, many people say "She didn't wake up this morning". He had gone to sleep with no issues last night but when we called he never replied. These are stories or history we receive every day in emergency. Reflections should be able to tell us what went through the minds of that dying person who was left alone. If I am in that position someday, then what will be my reactions? During crisis and times of need, family, dear and near ones matter to the dying person rather than wealth and luxury. In a joint family, this issue rarely happens as someone is always there to view and take care of it. Attachment, empathy and affection of dying person need to be emphasized to the younger generation health care professionals so that they are equipped to transfer this information to the family members who may so less concern towards their ill person. People have faith and trust in health care professionals and this may go a long way in caring for last moments of life.
- **Feeling of isolation:** When one is sick for a long period of time, neglect creeps in. Having to care for long time also becomes a burden to the family, if children are employed and working. Nuclear family is the choice of the day but when we are old, joint family works out better because elderly will be always cared for by any member who is at home. Their care concerns are better taken care of. Feelings of isolation are more when only few members are there in their living environment. Therefore, acknowledging specific fear is an important part of nurses' assessment and communicating with family members for the needful. Few aspects to be taken care of while we communicate with patient are:
  - Talk to the grieving person as needed
  - Avoid answers, such as "it's God's will"
  - Call for spiritual person's help
  - Arrange religious person's help in the process of rituals

- H Never lose sight of the dying and bereaved family till they are stable with the loss
- H Identify support system
- H Stay with them till they pick up reasonably.

ORGAN DONATION AND COUNSELLING

Indian population approximately on 19th Nov 2014 is 1,266,373,883. Twenty-nine people die every minute (Indian population clock). Pavithra N explains that 6000 people die every day waiting for an organ transplant and 17 people dies every day while waiting for transplant. Every 13 minutes a member is added to the waiting list.

Organ transplants include kidney, pancreas, liver, heart, lung, and intestine. Sometimes, "double" transplants are done, such as kidney/pancreas or heart/lung.

Depending on the organ needed, organs are matched using several characteristics, including blood type and size of the organ needed. Also taken into account is how long someone has been on the waiting list, how sick they are, and the distance between the donor and the potential recipient.

Donating our organ at end of life or singing into donate in times of sudden = unexpected death will save many lives. There is as well a huge need for organ donation and almost every organ in the body could be donated. We need to remember that every single donor can save up to 50 lives.

Prerequisites and Criteria for Donation

- Any person of all ages
- Willing individuals
- Infectious diseases to be rule out
- Prefer relatives/siblings
- Donors to be tested through transplant centre
- Blood test
- Psychological counselling

Donor's characteristics

- Suitable/matching
- Good general health status
- Death time is noted
- Patient is declared brain death for organ donation

Brain Death vs Cardiac Death

- People who die of cardiac arrest are fit to donate tissues and in some instances kidneys and liver.
- Brain death patients can donate organs. You can observe cessation of brain activity in the brainstem. Not breathing without the help of ventilator. No reflex responses elicited, such as gag reflex, blinking and pain indication.

Obtaining Consent

- Prior to obtaining consent, counselling the donor is vital. Informed consent is to be taken with full understanding of the patient prior while he was conscious and if not family members to be counselled for the same.
- Clear information to be given regarding organ and tissue donation and open discussion is appreciated.
- As it is during the transition phase or soon after death, grief counselling to be given.
- Post-transplant compliance to be taught to the recipient and family that is to avoid rejection.
- Medical cost for the donor to be borne by the organization.
- Test to be determined for the matching recipient and donor.
- Preoperation procedure and postoperative care for the recipient and also the donor to be ready.

In the published work of Linda M Tamburri, the role of critical care nurses in the organ donation breakthrough Collaborativ Crit Care Nurse April 2006 26: 20–23 describes the role of critical care nurse towards organ donation as:

- Referring potential donors from critically ill patient who have consented prior for donation based on the hospital policy to be identified and referred.
- Relate with the organ procurement organization (OPO) coordinators so that they will be able to evaluate the patient for donation and forming them as team member.
- Donor winner: To become a donor winner is important motivational feelings. One donation can save many lives. Help your colleagues understand the benefits of organ donation so that they are able to support the patient to take right decision keeping in mind family members' bereavement support.
- Donor registry: Help donors sign registry after consenting and also family members' full awareness.
- Participate in community activities to create organ donation awareness. Advocate for your patients and family and also respect their opinions regarding last wishes.
- Therapeutic communication with compassionate attitude to be emphasized at all times during the last moments.
- Educate oneself and colleagues about organ donation at all times with the current issues and challenges and also legal concerns.
- Research to be promoted in areas of organ donation awareness.

ROLE OF NURSE: LAW, ETHICS AND MORAL ISSUES

Major advances in medical technology, increased expectations, and changing moral attitudes have combined to generate many complex ethical and legal problems in the fields related to cancer nursing. Individuals who care for patients with life-threatening illnesses can face particularly pressing and difficult moral choices. Ethics are more formal term, refers to the systematic study of those standards and values. Ethics is a method of inquiry that helps us answer questions about what is right or good, what ought to be done in specific situations, and what kind of people—and what kind of nurses—we ought to be, and why. Nurse oath to understand and apply the concept of bioethics which is a form of normative applied ethics, that is, it is the study of ethical issues and ethical judgments made within the biomedical sciences, including care of patients, the delivery of health

care, and biomedical research. Bioethics takes into account the difficult and practical realities found in the clinical care of people with every day or unusual health problems and illnesses.

Critical care nurses need to recognize its responsibility to provide services according to its mission and the obligation to do so in a manner that is ethically sound. All individuals providing services within care unit are required to live by the organization's stated values, as well as commit to the following in any decision making process:

- Compassion and respect for human dignity
- Professional competence
- The spirit of service
- Honesty
- Confidentiality of information
- Careful administration of resources
- Recognize and deal with conflicts of interest
- Positive environment
- Safe workplace
- Safeguard property
- Compliance with the law
- Informed consent

Handling Medicolegal Cases (MLC)

The nurse is equipped and trained to handle MLC cases that are being brought to the hospital. One needs to follow hospital or institution protocol. Protocol related to donation, consent and surgical procedures to be taken by the transplant team. The nurse in the emergency, if any, is being reported to the police as per protocol. If brought dead, some hospital policy does not encourage intervention. But if examined, the body is sent for postmortem as a rule to safeguard the policy. Organ donation, or dying person's wishes and desires to be considered important above everything else. If the patient is a registered donor, formalities according to hospital protocol to be done with consultation with the team. Time is crucial for donation and transplant.

Ethics for Nurses

Ethics nurses should abide by are:

- **Non-maleficence:** An obligation to never deliberately harm another. Not to harm others bears more weight than the duty to benefit others.
- **Beneficence:** An obligation to promote the welfare of others, to maximize benefits and minimize harms. Beneficence involves taking deliberate steps to benefit another person.
- **Respect for autonomy:** An obligation to respect, and not to interfere with, the choices and actions of autonomous individuals (i.e. those capable of self-determination). Respect for autonomy involves respecting the capacity of an individual to be self-determining; that is, the capacity to deliberate about actions and life choices, and to act on those deliberations without interference from others.
- Informed consent is an application of the principle of respect for autonomy in the health care setting. Helping the patient make important decisions.
- **Justice:** Justice is a principle of fairness. Fairness means that decisions about the distribution of health care should be based on morally significant characteristics. Therefore, for example, health care distribution should not be based on factors, such as race, ethnicity, gender, social standing, or religious beliefs.
- **Veracity:** An obligation to tell the truth. Veracity is important while taking informed consent because patient needs to be aware of all potential risks of and benefits to derived from specific treatments or their alternatives. Veracity must guide the nurse in all areas of practice, i.e. in colleague relationship, employee relationship, as well as in the nurse-patient relationship.
- **Fidelity:** An obligation to keep promises and fulfill commitments. It forms the bond between individuals and is the basis of all relationships.

Care of Body after Death

This is the most sensitive moments for family members who are witnessing their loved one dying. Proper cleaning, dressing and packing makes sense to the family members. If the body is presentable, the family members feel

cared for even after death and people find it easy to accept when they take home. Few of the roles of health care personnel are:

- The physician declares death and certifies through assessment.
- Death certificate is issued by the physician.
- The nurse prepares the body to make it most appropriate and presentable. All orifices are taken care of and jaw and limbs are placed appropriately as per cultural expectations if no postmortem is to be done. If postmortem is expected, the nurse sends the body to the mortuary/forensic department for further management (accident/poisoning/hanging/homicide/ snake bite, etc.) Consent to be signed by the relatives. If it is medicolegal case, autopsy is a must as documented earlier during the admissions. Legal authorities to be informed. MLC note to be filled during death or discharge from the unit. Original copy is sent to the police, other copies that is one to the medical record section and one is kept in the unit for future reference.
- If the dying person had infectious disease dangerous for people handling them, e.g. HIV infection, dead body is plugged with cotton and sent home with an instruction not to open the seal again. This sometimes becomes an issue for family member because, in India among the Hindus, bath is given prior to death preparation. This ritual compels the body to opened at home. Therefore, counselling family members can help reduce contamination.
- The nurse keeps the body in position immediately which the family members desires and practice before the rigor mortis develops. In some cultures, lower limbs are folded, in some culture body is kept in certain direction and in particular place of the courtyard or inside the house. Nurse needs to be culture sensitive and competent.
- All equipment used for the patient to be removed. Ryles tube, oxygen catheters, IV cannula, catheter, etc. to be all removed.
- Jewelleries to be removed and handed over to the party.
- Management of soiled linen to be instructed to the concern person in case of infectious diseases.
- Records to be completed with accuracy.

Ethical Decision Making

Ethical decisions made in the health care context should take into consideration the interests of the patient, the professional and personal values of health care professionals, institutional values, personal feelings, moral principles, and legal issues.

Steps

1. Identify the health problems
2. Define ethical issues
3. Gather additional information
4. Delineate/define the decision maker
5. Examine ethical and moral principles
6. Explore alternative options
7. Implement decision
8. Evaluate and modify actions

The first step is to identify information needed to understand the situation fully. What are the medical facts (i.e. diagnoses, prognoses, treatment alternatives)?

- Who are the principal agents involved?
- Who are the decision makers and the stakeholders?
- Are the values and goals for treatment and care of the patient clear?
- How do the values, interests, and relationships of others involved affect the problem?
- Are cultural, religious, or other aspects relevant to the case?

It is important to understand the various contexts of the situation, including the physiological, psychosocial, and legal dimensions.

Identify the Problem

The next step is to identify the ethical problem or problems. Is this truly a problem involving a question about or conflict between ethical principles or values, or is the problem primarily a legal or organizational issue or a communication problem? Communication problems and legal restrictions

are often part of an ethical problem; however, some problems can be resolved simply through better communication or legal counsel without ethical analysis.

Analyze the Problem Using Ethical Principles and Results

It is essential to identify the person or people who have the responsibility and authority to make a decision. Is the patient competent, fully informed, and free to make a choice (consistent with application of the principle of respect for autonomy)? Is there a family member able to speak to the best interests of a comatose patient (beneficence)? How is the family involved? Are there vested interests to consider? Consider ethical principles. There may also be conflicts between principles and legal or institutional requirements. These should be clearly articulated.

Analyze Alternatives and Act

Identify all the possible and reasonable alternatives, and evaluate each of them on their conformity to principles and rules and their compatibility with care and compassion for the patient. Which option most promotes respect for the autonomy of the patient? How will each proposed action and its outcome benefit or harm those involved? Which of the possible alternatives seems fairest in terms of process, outcome, or both? After reflection and careful reasoning, nurses and other health care professionals should choose and act on the option that is most consistent with sound ethical analysis and personal/moral convictions. The nurse may not be the primary decision maker. However, because the nurse is an integral member of the health care team, it is important that she or he contribute to the dialogue, facilitate communication, articulate relevant personal views and values, and cooperate in implementation of the course of action.

Evaluate and Reflect

After the action has been taken, the ethical problem, the process of resolution, and the outcome must be further analyzed. The outcome should be compared with what was hoped for or intended. How can a similar situation be handled with greater sensitivity or wisdom in the future? Evaluation is especially helpful if it is undertaken in a nonjudgmental and non-threatening atmosphere conducive to reflection and constructive change. Consider patient’s bill of rights.

Patients Right

Patients have the right to:

- Be informed of your patient rights in advance of receiving or discontinuing care when possible.
- Have impartial access to care and visitation. No one is denied access to treatment or visitation because of disability, national origin, culture, age, colour, race, religion, gender identity, or sexual orientation. No one is denied examination or treatment of an emergency medical condition because of their source of payment.
- Give informed consent for all treatment and procedures and receive an explanation in Layman terms of recommendations, risk, benefit, alternatives, recovery period expected, etc.
- Participate in all areas of your care plan, treatment, care decisions, and discharge plan.
- Have appropriate assessment and management of your pain.
- Be informed of your health status/prognosis.
- Be treated with respect and dignity.
- Personal privacy, comfort and security to the extent possible during your stay.
- Have access to pastoral/spiritual care.
- Receive care in a safe setting.
- Be free from all forms of abuse or harassment.
- Have access to protective services (e.g. guardianship, advocacy services, and child/ adult protective services).
- Request medically necessary and appropriate care and treatment.
- Refuse any drug, test, procedure, or treatment and be informed of the medical consequences of such a decision.
- Consent to or refuse to participate in teaching programmes, research, experimental programmes, and/or clinical trials.
- Participate in decision-making regarding ethical issues, personal values or beliefs.

- Know the names, professional status and experience of your caregivers.
- Have access to your clinical records within a reasonable timeframe.
- Be examined, treated, and if necessary, transferred to another facility, if you have an emergency medical condition or are in labour, regardless of your ability to pay.
- Be informed of the hospital's complaint and grievance procedure and whom to contact to file a concern, complaint or grievance.
- Confidentiality of all communication and clinical records related to your care.
- Have access to interpreter services at no cost to you or your companion when you do not speak or understand the language, as well as communication aides, at no cost, for the deaf, blind, speech impaired, etc., as appropriate.

Legal Issues Involved in Life Support Measures

- Do not resuscitate
- Refusal of treatment for religious reasons
- Advance directives: Living wills and powers of attorney/lawyer
- Patient self-determination act.
- Withdrawal of life-support measures.
- Brain death
- Organ donation

Need for model application/problem solving approach: Ethical decision-making models given above provide a process for systematically and thoughtfully examining a conflict, ensuring that participants consider all important aspects of a situation before taking action. The steps of ethical analysis and evaluation are much like the steps of the nursing process and, as such, are a skill that can be learned. Both provide an orderly approach to problems. There are usually five steps to resolution of an ethical problem in the clinical setting.

Summary

- Team approach care
- Bereavement support
- Spiritual and cultural care
- We can only support, listen therapeutically
- Support the needs of the family members
- Death is the end, as we know it, for that person
- Build ways to provide excellent care at the end of life.
- Make the person as physically comfortable as possible
- Respect the goals, likes and choices of the dying person.
- Help access to needed health care providers and appropriate care settings.
- Look after the medical, emotional, social and spiritual needs of the dying person.
- We can also use our knowledge and expertise to strengthen and support the family.

Life is pleasant. Death is peaceful. It's the transition that's troublesome

Isaac Asimov

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