

MODULES ON PALLIATIVE CARE

Submission by the WHO Collaborating Centre on training and policy on opioid availability and WHO Collaborating Centre for community participation in palliative care and long term care

*To the Indian Nursing Council
for consideration to be included in the
Undergraduate Nursing education curriculum*

To

22nd October 2013

The Chairperson and Members of the Education Committee
Indian Nursing Council
New Delhi

Respected Madam/Sir,

Sub: Submission of palliative care modules for consideration of incorporation into Undergraduate Nursing Curriculum

Ref: 1. National strategy for palliative care declared by Ministry of Health & FW of Government of India

2. Public Interest Litigation (PIL) WP (C) 76/2007 pending before Supreme Court of India

We are writing this on behalf of the WHO Collaborating Centre Trivandrum. With participation of the Indian Nursing Council, the Ministry of Health & FW participated in development of National Strategy for Palliative Care for the current five year plan. This was declared in 2012. An important part of this strategy is inclusion of palliative care in undergraduate nursing curriculum.

Kerala and Maharashtra have already declared State Palliative Care Policy with a few other states poised to follow suit, reflecting the relevance of this field within the community. Thus, this endeavour by the INC would surely be fulfilling a felt need within our healthcare sector. As internationally agreed, palliative care skills need to be integrated into regular nursing practice and hence it is possible and necessary to include these subjects as part of existing subjects in the undergraduate nursing curriculum.

The WHO Collaborating Centres at Trivandrum and Calicut, and other palliative care organisations of the country have collaborated to create a palliative care curriculum for UG Nursing course.

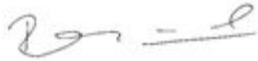
Please find Modules on Principles of Palliative Care, Communication Skills, Symptom Management in nursing care, end of life nursing process, Palliative Care nursing Procedures and facilitator manual, prepared by the nursing faculty from different centres in India.

Requesting you to kindly accommodate the above modules under appropriate subjects and during appropriate periods of training with due consideration of the existing syllabus.

We hope that the initiative taken by the INC would result in palliative care being incorporated into the nursing curriculum which would eventually impact the care component of healthcare delivery in our country.

Sincerely,

On behalf of the Editorial team



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1. PRINCIPLES OF PALLIATIVE CARE



From inability to let alone,

From too much zeal for the new and contempt for what is old,

*From putting knowledge before wisdom, and science before art, and cleverness
before common sense,*

*From treating patients as cases, and making cure of the disease more grievous than
the endurance of the same,*

Good Lord, deliver us.

Sir Robert Hutchinson

PRINCIPLES OF PALLIATIVE CARE

Introduction



Ravi is a 25 year old man who lives in a semi urban area. Four years ago, he had a fall from the construction site following which he became paraplegic. Post-surgery he has not regained power in his limbs. Doctors have told him that it is no more reversible. He was also told that “nothing can be done and there is no use of coming back”. He has been bedridden since then, has repeated attacks of fever and several bed sores. The wounds have foul smelling discharge and are gradually increasing in size. He cannot lie supine comfortably. He is in severe distress and has nowhere to go for his further medical care.

*What do you feel regarding the remark that
'Nothing can be done' for Ravi?*

Let us try and understand Ravi's condition and reflect a little more on it.

Ravi is a young man with a wife and an infant; he lives close to the city; he was the main breadwinner; and in his present condition, has to depend on his older brother for his family's sustenance.

He is distressed due to his physical disability, pain and repeated febrile illness and is greatly distraught with the medical expenses incurred during these episodes with the local GP. He also has to travel to a distant clinic for changing his urinary catheter. He had visited a Spine Specialty Centre one month ago looking for cure, but they too informed him that nothing more can be done to make him walk. They suggested he use an air bed.

Now, he feels isolated and a burden to everyone; he shuns company and refuses to meet even his old friends. He is also distressed by the foul smell from his ulcers. He is angry, and feels that God has been unjust to him especially when he interacts with others. He finds their sympathizing attitude most distressing. He is desperate to start earning, contribute to family expenses and get back to his role.

He is worried, unable to sleep and often considers suicide as a solution from this misery. Then he worries about what might happen to his family after he is no more.

What are the different dimensions of Ravi's concern?

We can understand that besides his etiological factors that led to paraplegia which are not reversible, there are many more issues at physical, emotional, social and spiritual levels for Ravi. Medical science has made great progress in these areas and we have a lot to offer to patients like Ravi.

All over the world, even in places where there are many healthcare professionals, plenty of drugs and the most modern equipments, there are patients who cannot be totally cured. Aren't these patients also the responsibility of the health care systems? Where can they go with their problems? What can we offer in terms of care for them?

As healthcare professionals, does our responsibility end with being able to cure or not cure? What can we do in terms of care when disease is no longer responsive to available therapy?



Fig 1.1: World Health Organisation defines health as well-being at physical, emotional, social and spiritual dimensions.

Palliative Care may be a new term for many of you, but it is a global movement to emphasize and assure ‘quality of life’ and the ‘care component’ within the healthcare sector.

How did Palliative Care evolve?

Modern medicine has been competent in handling acute medical problems and achieved prominence in the health care sector through analytical research and intense study of etiological and therapeutic factors. It has expanded to include prevention, through public health measures, vaccination programs and health education.

Presently most of our health services are disease centred; specifically designed for acute episodic care.

*The huge need for the ongoing care for those who have long term diseases, progressive diseases or incurable diseases are **unmet** within the current healthcare delivery system.*

Can you list the diseases that we see commonly, for which we can promise definite cure?

Can you list the diseases that we see commonly, which we can control to a large extent?

Can you list the diseases that we see commonly, which would progress despite best medical inputs?

History of palliative care

The word “Palliate” is derived from the Latin word ‘*pallium*’ meaning cloak i.e., an all-encompassing care which “cloaks” or protects the patients from the harshness of the distressful symptoms of the disease, especially when cure is not possible.

It is person focused and seeks to address the issues which are of most concern to the patient at that stage.

Palliative care is not really a new speciality. Care of the sick has been a constant concern of human society throughout history. We have ancient traditions in India, for special care and attention for those who are very old, ailing or dying. The eighteen institutions built in India by King Asoka (273 – 232 BC)¹ had characteristics very similar to modern hospices. We are presently building on these ancient traditions as well as the expertise and wisdom of pioneers in this field to develop palliative care services.

The modern hospice movement is attributed to Dame Cicely Saunders who founded the first modern hospice - St Christopher’s Hospice in London in 1967. Dame Cicely was triple-qualified professional, having practised as a nurse, social worker and doctor. This background influenced and impacted the way she approached her patient’s concerns. This led to the development of modern palliative care with its holistic dimensions.



I once asked a man who knew he was dying what he needed above all from those who were caring for him. He said, “For someone to look as if they are trying to understand me.” Indeed it is impossible to understand fully another person, but I never forgot that he did not ask for success, but only that someone should care enough to try.

Dame Cicely Saunders

¹ Pg 3 Historical development of Hospice and Palliative Care; In Hospice and Palliative Care: Concepts and Practice: edited by Walter B. Forman

As a nurse, you are likely to come into contact with people in a variety of settings who may benefit from palliative care and support. Through the chapters of this module, we shall look at the approach, knowledge and skills required in providing good quality palliative care.

Clarification of terms

Life-limiting illnesses: This term describes illnesses where all activities that make a person feel alive get restricted e.g. paraplegia. The term may also be used for diseases where death is expected as a direct consequence e.g. advanced cancer.

Hospice and hospice Care: This refers to a philosophy of care of the whole person and all that matters to her / him. It is NOT a specific building or service and may encompass a program of care and array of skills delivered in a wide range of settings – hospital, home or hospice.

Holistic approach to care: It is care, upholding all aspects of a person's needs including psychological, physical, social and spiritual needs.

Supportive care is all that helps the patient to maximise the benefits of treatment and to live as best as possible with the effects of the disease. This may be nutritional advice, physical therapy, antibiotics, symptom control, transfusions or counselling. It helps the patients and their families through periods of pre-diagnosis, diagnosis, treatment, cure, death and into bereavement.

Quality of life: WHO defines Quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to their environment².”

Terminal Care: Palliative care is often misinterpreted as terminal care. However, it refers to the management of patients during their last few days or weeks of life when it becomes clear that the patient is in a progressive state of decline. Another term used is ‘End of life care’. Thus terminal care is a part of the spectrum of Palliative Care.

Continuum of care: It is a concept involving an integrated system of care that guides and supports a patient with chronic illnesses, through a comprehensive array of health services. This includes out-patient care (assessment, evaluation, management), patient family education, linking with community based care facilities (GPs, home based care programs, link centres) and also acute episodic needs and care during advanced stages of the disease (in-patient services).

² On the individual level, this includes physical and mental health perceptions and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status.

Caregivers: Refers to the relative or friend, who takes care of the patient. It may also refer to the paramedical professional who is involved in the program.

Multidisciplinary care: Multidisciplinary care occurs when professionals from a range of disciplines with different and complementary skills, knowledge and experience work together to deliver the most appropriate healthcare. Here, physiotherapist, social worker, psychologist, nutritionist etc. have significant roles to play along with doctors & nurses. This approach aims at best possible outcome based on the physical and psychosocial needs of a patient and family. As needs of the patients change with time, the composition of the team may also change to meet these needs.

Suffering: It is the distress associated with events that threaten the wellbeing or wholeness of the person.

Spiritual pain: Spirituality is that special dimension in human beings that gives a purpose to life. It includes searching and finding meaning in life and death, reason for suffering, and the need for love, acceptance and forgiveness. Faith in God, prayers, religious faith and its relevance may be a path chosen by some. A person may be spiritual without being religious. Spiritual pain is when these dimensions get disturbed or questioned leading to suffering. E.g. I did not drink, smoke, was kind and good throughout my life. Why did this happen to me?

Psychosocial pain: It includes anxiety, fear, apprehension, depression, loss of dignity, loneliness, a sense of being a burden on others and no longer being valued as a person.

Dying with dignity: Refers to the humanitarian concept that a terminally ill patient should be allowed to have peaceful, natural and comfortable death, rather than being subjected to aggressive, isolating, distressful, costly and invasive interventions. An example for an undignified death would be a patient with multisystem failure being kept “alive” with long term mechanical ventilation and regular dialysis in an ICU setting.

Bereavement support: When a person dies, we say that their family is bereaved. This means they have lost someone precious and close to them and are grieving. Support given to the family to go through this period and get back to regular productive life is called bereavement support.

“Add life into their days, not just days into their life.”

Nairobi Hospice 1988

What is Palliative Care?

Learning Objectives of this Chapter

By the end of the chapter, the student should be able to:

- *Define Palliative care*
- *Outline the essential principles of palliative care*
- *Describe the concept of holistic approach to care*

Definition of Palliative Care

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

(WHO)

Key points in the WHO Palliative Care approach

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- The palliative approach comes early in the course of an illness, not just as end-of-life care.
- There is an emphasis on impeccable assessment, early identification of problems and implementation of appropriate treatments.
- The care runs in conjunction with disease modifying treatments such as chemotherapy and radiotherapy
- Palliative care can be provided in any setting – in hospital, out- patient or as home based care.
- There is an emphasis on a team approach to care.

What is different about palliative care?

Usually, healthcare professionals tend to focus mainly on physical problems – organs and their diseases. Palliative care recognizes that people are much more than organs put together; their minds, spirits and emotions are all part of who they are. It also recognizes the families and communities to which they belong. So the problems facing a sick person and their family are not just physical in nature; there may be psychological, social and spiritual concern which are just as important. Sometimes problems in one area may worsen others e.g. pain is often worse when people are anxious or depressed. It is only when we address all these areas that we are helping the whole person. It is this holistic approach that distinguishes Palliative care from the conventional medical care.

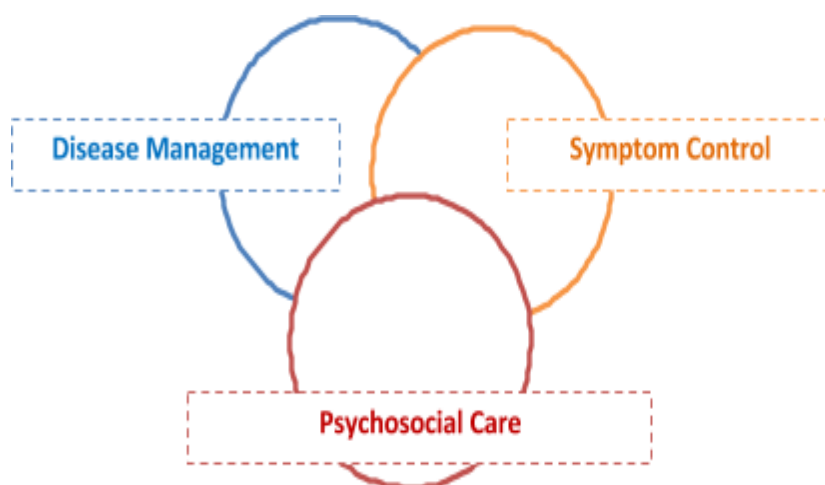


Fig 1.2 – Components of inputs in Palliative Care

No single sphere of care is adequate without considering relationship with the other two. This usually necessitates genuine interdisciplinary collaboration and social interventions.

Table 1.1 – Comparison of conventional bio-medical and palliative care approaches

Conventional approach	Palliative approach
<ul style="list-style-type: none"> ● Disease is the central concern ● Physician is the General ● Intent – Curing ● Disease, a problem to be solved ● “Don’t just be there, do something” ● Goal is to improve quantity of life ● Death: A failure of treatment, to be prevented at all cost ● Valuable approach in caring for acute episodic diseases 	<ul style="list-style-type: none"> ● Human dignity is the central value ● Patient is the Sovereign ● Intent – Healing ● Disease an experience to be lived ● “Don’t just do something... be there..” ● Goal is also to improve quality of living ● Death: An inevitable reality, neither to be hastened nor postponed ● Valuable approach in caring for chronic progressive disease

Palliative care is about ‘Quality of life of the person’ who is chronically ill

The aim of palliative care is not to lengthen – nor shorten – life but to **improve quality of life** so that the time remaining, be it days, or months, or years, can be as comfortable, peaceful and fruitful as possible.

Like Ravi, many patients with life-limiting illnesses have so many problems that doctors can feel overwhelmed and powerless to help. People are often sent home and told not to return because “there is nothing more to do”. This happens mostly because **the care component** of our profession has not been emphasised adequately during professional training. Important beginning is by *focusing on what we can do to care, rather than be discouraged by what we cannot cure.*



*There may be limits to cure,
but care and comfort have no limits.....*

We should try to understand the chief concerns of patients suffering from chronic life limiting illnesses and use our knowledge and caring approach to seek ways of help them. These are perhaps the greatest healing inputs we can give to patients with long term progressive diseases.

A professional who understands the “care” concept would not say, “there is nothing more I can do” instead would seek to find things to do for the patient, so as to relieve suffering and improve the quality of life.

Test your knowledge

1. What is the chief aim of Palliative Care? (Tick one)

- a) to cure illness
- b) to prolong life
- c) to hasten death
- d) to improve quality of life
- e) to treat pain

2. The following are statements regarding Palliative care. State whether true (T) or false (F)

Palliative care

- a. uses a team approach T / F
- b. is synonymous with terminal care T / F
- c. includes family in the care process T / F
- d. focuses on the whole person T / F
- e. cannot be practiced in conjunction with other therapies T / F

Ans: 1- D; 2.a – T; 2.b – F; 2.c – T; 2.d – T; 2.e - F

Why is Palliative Care Training Required?

Learning Objectives

By the end of the chapter, the student should be able to:

- *Explain the need of palliative care in regular clinical practice*

The need for Palliative Care Worldwide³

There is a shift in global burden of disease towards non-communicable disease. Although the **mortality has come down** with average global life expectancy of 70.4 (73.3 Male & 67.5 female) the **morbidity has gone up** with more and more people with chronic diseases living longer with poor quality of life.

- Fifty-two million people die each year; of which about five million people die of cancer each year, to which can be added the numbers of patients dying with AIDS and other chronic progressive diseases. That many of them die with needless suffering has been well documented in many studies and published in scientific papers and reports.
- Palliative Care can improve the quality of life of all these patients.

The World Health Organization [WHO] (1990) and the Barcelona Declarations (1996) both called for palliative care to be included in every country's health services. WHO has recognized palliative care as an integral and essential part of comprehensive care for cancer, HIV, and other diseases⁴.

³ Murtagh F E et al. "How many people need Palliative Care? Palliative Medicine online: 21 May 2013

⁴ World Health Organization (WHO), "National Cancer Control Programmes: Policies and Managerial Guidelines,

“Human Rights Watch” also recommends integration of meaningful palliative care strategies into national programs for chronic diseases⁵.

The modules on Palliative Care; the principles, communication skills, optimisation of care and nursing procedures discuss the general approach in managing patients in advanced disease states, and help orient the student in managing the complex concerns of these patients.

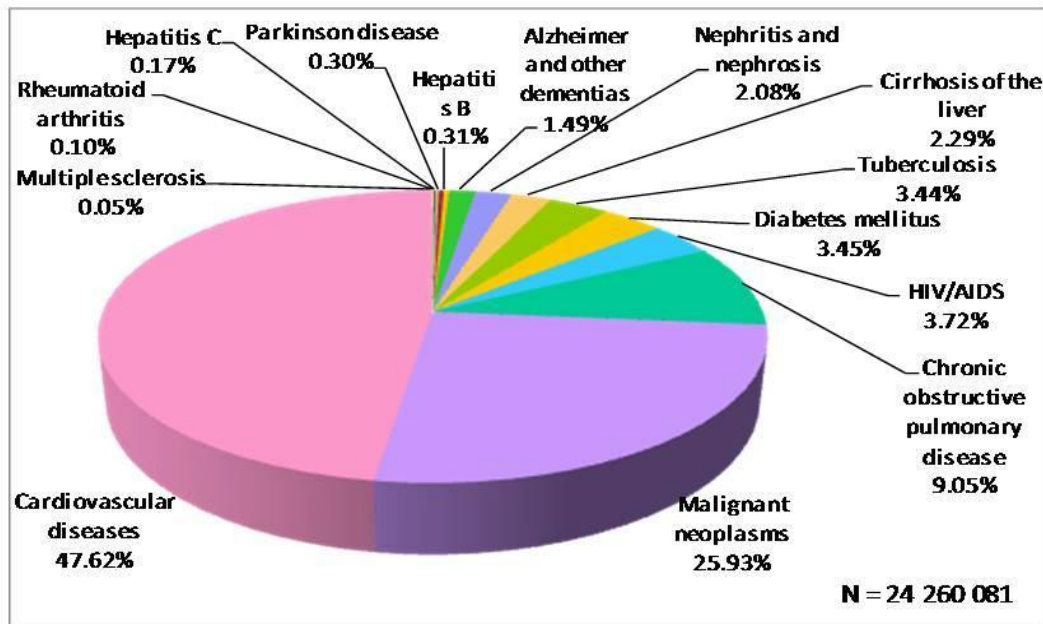
second edition,” 2002, pp. 86-87

5 Unbearable Pain India’s Obligation to Ensure Palliative Care. Human Right Watch: Oct 2009.

ETIOLOGY BASED ANNUAL PALLIATIVE CARE NEED IN INDIA ⁶

Annual Palliative Care needs – India Etiology based

21,95,537.3



Source: WHO estimates based on mortality (GBD 2008) 

- *2.5 million cancer patients in India*
- *80% stage IV at time of diagnosis*
- *Only 0.4% have access to Palliative Care*

These figures have been quoted to emphasise the enormity of the problem and the likelihood of us facing it in our practice, irrespective of our field of specialisation. Specialised knowledge and skill is needed to take care of a person with progressive illness.

Test your knowledge:

Choose the correct answer from following options:

1. Why should Palliative Care be included in the undergraduate medical curriculum?
 - a. So that basic principles of palliative care may be utilised by all professionals for patient care
 - b. So as to make appropriate references to specialists in the field
 - c. To reorient attitude of health care professionals to managing chronic diseases.
 - d. To provide platform for decision making when there is dilemma in outcome regarding quality and quantity of life
 - e. All of the above

Ans: 1 - e

Who needs Palliative Care?

From among the following situations choose those conditions where palliative care inputs may be needed



Patients with
Cancer



Retinoblastoma



Chronic Renal
disease



Diabetic
foot ulcer



Old age /
dementia



Paraplegia

You may note from the earlier discussions that all these patients shown above, would benefit from palliative care inputs

Learning Objectives

By the end of the chapter, the student should be able to:

- *Enumerate who needs palliative care*
- *List the key misconceptions that are prevalent with regard who may be suitable for receiving palliative care*

There is some recognition in India that patients with cancer need palliative care services. There is also improved understanding on the unmet need in patients with other progressive, chronic and incurable diseases.

Common conditions requiring Palliative Care

- Cancer
- HIV / AIDS
- Dementia
- Progressive neurological disorders
 1. Parkinson's disease
 2. Multiple sclerosis
 3. Motor neuron disease
 4. Stroke
- Progressive systemic diseases
 1. COPD, ILD
 2. Heart diseases
 3. Liver and kidney dysfunctions due to various causes
- Old age and other degenerative disorders

*Palliative Care can help patients regardless of age, gender, education
or socio-economic status*

Needs of Family Members of chronically ill patients

- In Life limiting illnesses, the family members are the major care givers. Educating and supporting them would not only enhance care and quality of life of patients but also contribute to longevity.
- Being with the patient, they are also facing stressful situations related to the patient's illness, directly or indirectly.
- The family endures the grief of watching their dear ones suffer. They are burdened with continuous caring of these patients who are worsening over time and also in the terminal phase.

1. CANCER

India has 25 lakh cancer patients at any given time. There are 10 lakh new patients diagnosed with cancer every year. With recent advances, some of the cancers are now having a chronic course. About 75-80% of these are diagnosed at an advanced stage. Patients with “incurable cancer” may now survive longer with palliative oncological interventions. Due to all these reasons, palliative care is ideally required to be incorporated into comprehensive cancer care programs.

2. HIV-AIDS

HIV / AIDS is now a chronic disease. Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS because of the burden of distressing symptoms they can experience – e.g. pain, diarrhoea, cough, shortness of breath, nausea, weakness, fatigue, fever, and confusion. Palliative care is an important means of relieving these symptoms.

In countries with a high burden of HIV infection, palliative care should be part of a comprehensive care and support package, which can be provided in hospitals and clinics or at home by caregivers and relatives.

Developing guidelines and training for palliative care should be specifically included in national guidelines for the clinical management of HIV/AIDS.

World Health Organisation

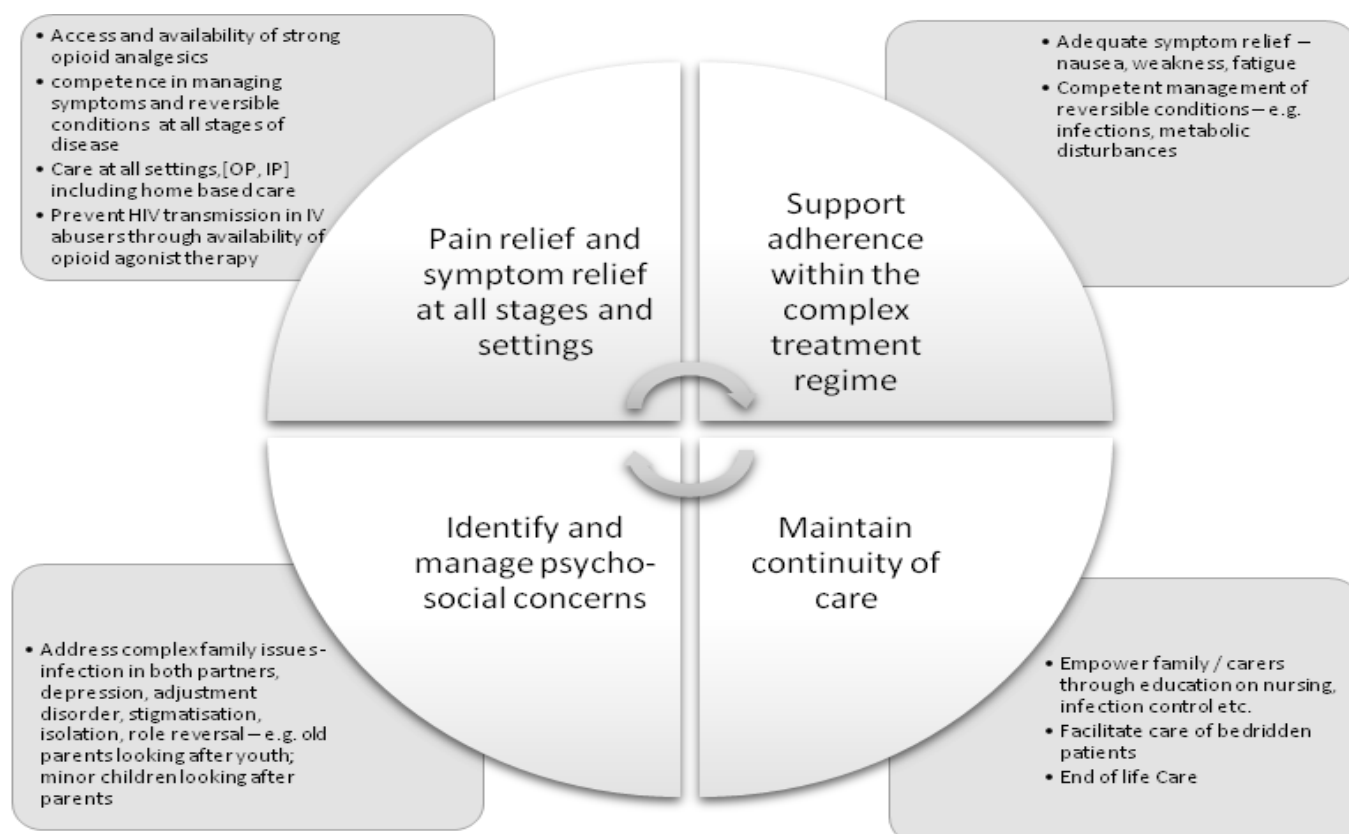


Fig 1.3: Interphase of Palliative Care and HIV Care

3. DEMENTIA:

Dementia is cognitive impairment beyond what might be expected from normal ageing. It is not a single disease, but a non-specific progressive illness in which affected areas of cognition may include memory, attention, language and problem solving. Alzheimer's disease is the most common of all dementias.

Dementia care should include components of PC⁷. Here, the palliative care needs of the carers could be more than that for the patient.

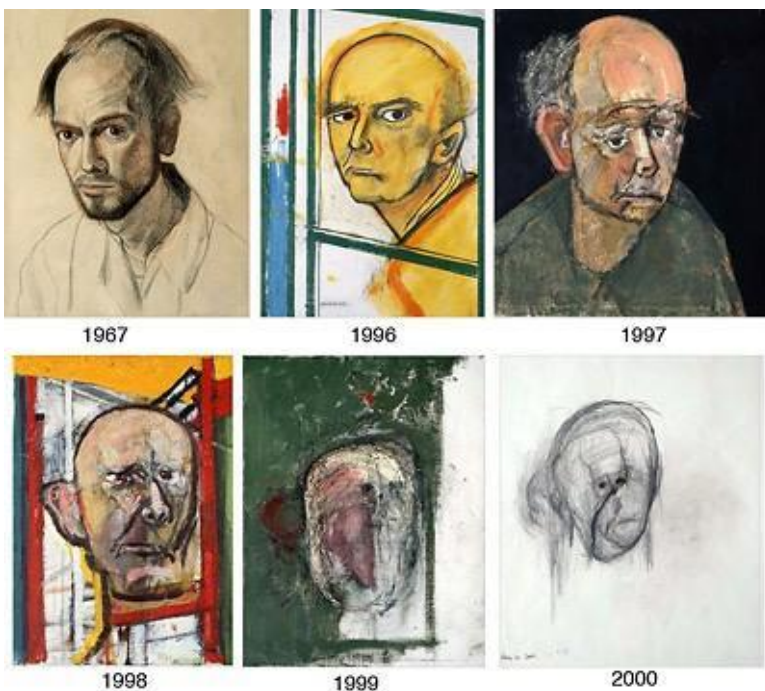


Fig 1.4: This is a series of self-portraits. It expresses the artist William Utermohlen's personal perspective of his descent into Alzheimer's dementia.

This indicates that the awareness of cognitive deterioration is real to the person.

4. Neurological disorders:

Patients with neurological disorders require palliative care services often for their problems due to pain, mobility, communication, cognitive and social issues.

Some common neurological problems obviously requiring palliative care inputs are listed below.

5. Non-communicable diseases

The life span of patients with NCD has increased. Hence we find more patients with chronic heart failure, COPD, or renal / liver dysfunction with distressing symptoms, solely on curative therapy. Their care needs can be met and their quality of life can be improved by incorporating PC within their medical management.

7 Palliative Care

6. Paraplegia, stroke

The discussion on Ravi's case above may have thrown some light on input requirements in this group of patients.

7. Motor Neurone Disease (MND):

These patients need continued best supportive care and their families need education, counselling and support.

Test your knowledge

1. State whether True (T) or False (F)

- Palliative care is only for patients with malignant diseases.
- People with dementia need palliative care
- Palliative care is care given only during terminal stages of the disease
- The skills imparted to doctors and nurses through the current training methods on disease management are sufficient for providing quality palliative care.

2. Why is there a need for Palliative Care in older people?

1. There is higher incidence of injury amongst older people
2. There is high incidence of cancer in geriatric population
3. Older people suffer from chronic illnesses
4. Older people have multiple concerns at physical, emotional and social dimensions
5. All of the above

Ans: 1.a – F; 1.b – T; 1.c – F; 1.d – F; 2 - e

When is Palliative Care Appropriate?

Learning Objectives

By the end of the chapter the student should be able to:

- *Describe how palliative care can be introduced at diagnosis of the disease, continued along with curative treatment and also when the disease becomes incurable.*
- *Explain how palliative care continues even after the death of the patient*

Simultaneous therapy⁸

Palliative care works alongside and within other treatment regime. It does not replace other forms of care. It ought to be integrated into existing comprehensive care of different disease programs and should be seen as a part of a continuum of care given to everyone with a life-limiting illness.

Many hospital programs, such as comprehensive cancer care centres with chemotherapy or radiotherapy services, HIV clinics and super-specialty centres [Spine centre] are competent in providing interventions for diseases but not well trained with helping patients with symptom relief, psychosocial problems such as anxiety, grief, isolation and stigma. This often leaves the patient unsupported and may in turn influence compliance to curative inputs itself.

Palliative care when integrated into such programs can complete the care inputs and also improve compliance to treatments and hence overall outcomes.

Palliative care should accompany curative measures, providing medical management of difficult symptoms and side-effects, and giving social, emotional and spiritual support to the patient and their family.

⁸ Temel J.S., et al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," *N Engl J Med* 2010; 363:733-742, August 19, 2010

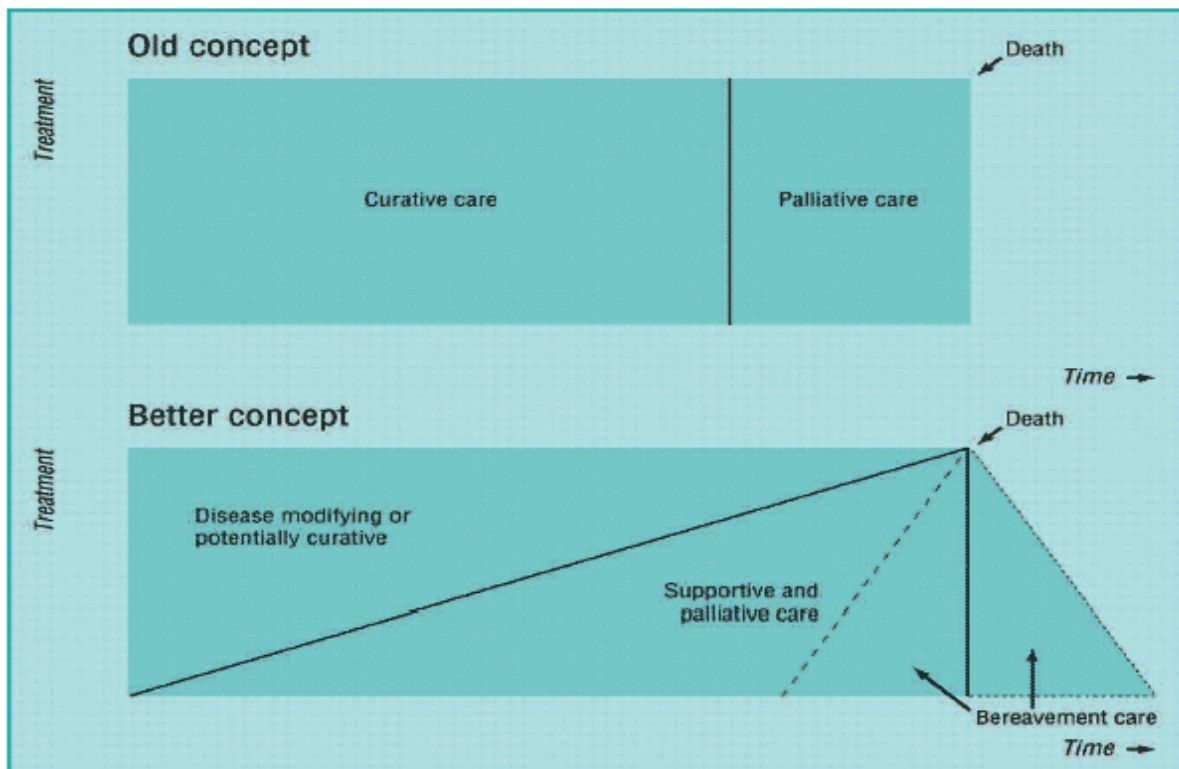


Fig 1.4: Relevance of palliative care during the course of a chronic disease⁹

With progress of the disease, the needs of the person may change and palliative needs may overshadow curative treatment [Fig 1.4].

The requirement for palliative care enhances visibly during critical transition phases in the disease trajectory.

For example, in cancer, as given below, the need for palliative care can be perceived at different stages of the disease and the inputs required may be variable.

At diagnosis

There is an increased need for communications here. E.g. Clarifications on diagnosis of cancer, impact of that particular cancer, available interventions and adverse effects of interventions, expectations of cure, are all to be discussed with patient for decision making. It is important to communicate effectively with patient and family, provide symptom control and maximize support to help complete a curative therapy.

⁹ Living and Dying Well: A national action plan for palliative and end of life care in Scotland- <http://www.scotland.gov.uk/Publications/2008/10/01091608/2>

Post cure phase

This is a phase with heightened anxiety, where the patient needs adequate information to clarify doubts and fears and support for their genuine concerns. Few distressing symptoms due to the curative therapy e.g. lymphedema of arm post mastectomy, shoulder pain syndrome after Radical neck dissection etc. may need competent long term management.

At recurrence or when cancer becomes unresponsive to disease modifying therapies

Here the symptoms and psycho-social concerns keep increasing due to progressive disease. The patient and family are in need of regular medical, nursing and counselling inputs to go through the matrix of complex phase.

Terminal phase

Here the emphasis would be to allow a dignified peaceful and symptom-free dying without undue burden on family resources.



Bereavement support

After the death of a loved one, it may take many months for family members to accept their loss and rebuild their life. Supporting them through this process is important and essential part of comprehensive cancer care.

Test your knowledge

1. Choose the most correct answer from the options given below.

When should palliative care begin?

- After completing curative treatment
- After all treatments have failed
- From the time of diagnosis of chronic illness
- When disease reaches terminal stages

2. The need for Palliative care inputs are the same throughout the disease trajectory True / False

3. Fill in the blanks:

The support provided to the family after the death of the patient is called _____ support.

Ans: 1 – c; 2 – F; 3 - bereavement

Where can Palliative Care be given?

Learning Objectives

By the end of the chapter, the student should be able to:

- *Acquire the knowledge to provide palliative care in various health care settings*
- *Describe the importance of community in delivering Palliative Care*

Models of palliative care provision

Outpatient Services: Addresses the needs of ambulatory patients. In many PC units, as the disease progresses and the patient gets sicker, he continues to access PC services through his carer visiting the OPD thereby reducing the frequency of his own visit.

Hospital based palliative care: Operates with or without dedicated beds, in a secondary or tertiary referral hospital. Here patients are admitted for symptom control and occasionally for end of life care.

Stand-alone In-patient palliative care unit [Hospice]: What makes a hospice different from a hospital is the holistic, personalized approach and treatment plan along with the attitude and focused commitment of the staff.

Day palliative care unit: It is a setting for caring the patients living at home but brought in on a day basis for clinical and social care. These are community based service centres run by Non-Government Organizations.

Home based palliative care services: It is based on the concept of caring the patients at home. This is a continued need-based care for home bound patients. This facility meets the needs of patients to be at home, amongst their family and friends, during a time in life when they are most vulnerable; and continued through their terminal stages.

In home based care model, the strong family set up still observed in India is acknowledged and used as health care resource. Family can care better when empowered with training (wound dressing, catheter care etc.) and also provide emotional and spiritual support. This fulfils cultural needs of patients and carers apart from reassuring a dignified death at their place of preference, which is home.



Community based palliative care services: Home based services can become even more effective when the local community takes ownership and an active role in providing services within their locality¹⁰. This model is being effectively practiced in Kerala through the Neighbourhood Network in Palliative Care [NNPC]¹¹. The training of volunteers can positively influence the overall response of the community to the health care needs and related policies.

10 PUBLIC HEALTH APPROACH IN PALLIATIVE CARE – THE EVOLVING KERALA MODEL -Dr Suresh Kumar, Director, Institute of Palliative Medicine, Kerala, India

11 **Year : 2005 , Volume : 11[1] Page : 6-9;** Neighborhood network in palliative care, Suresh Kumar, Mathews Numpeli



Fig 1.5 – The trained volunteers in Kerala, transporting a person in the appropriate manner across a difficult terrain. This was in response to his expressed wish to watch a football match.

Good quality home care services, with participation of family and trained volunteers can help in reversing the present trend of financially and emotionally expensive institutionalized health care models. In addition, it can free up hospital beds for much needed emergency care.

Models of Care

- There is no one right or wrong model for the provision of palliative care
- The best model is determined by local needs and resources.

Test your knowledge

Choose the correct answer from following Multiple Choice Questions

1. Which of the following healthcare set up can provide palliative care services?
 - Tertiary care hospital
 - Primary health care centre
 - hospice
 - Home based care programs
 - All the above
2. The chief benefit of home based palliative care services is
 - Doctor's precious time within the hospitals do not get wasted
 - All modern facilities of advanced medical care can be reached to patient at home
 - Terminal patients do not need any investigations, treatment or a hospital admission
 - Patient gets appropriate care in the setting that she / he desires
3. What is the aim of rehabilitation in community based palliative care?
 - To make patient attain complete physical fitness
 - To make patient fit enough to attend hospital services
 - To help patients maximize opportunity, control, independence and dignity.
 - To help him achieve his functional capacity pre- disease

Ans: 1 – e; 2 – d; 3 - c

Let us now reflect on what can be done for our patient Ravi.

We can help Ravi live productively and with better quality of life for a long time as at present he has no other systemic co-morbidities.

Where shall we start?

To begin with, we can instil a sense of security in him by being there, conveying our empathy and willingness to listen and care for him throughout his illness.

Holistic Approach: Through effective communications, management of his symptoms and psychosocial inputs, we can allow him to feel supported and help prioritize his needs realistically.

Managing Ravi's physical symptoms: For his bedsore, we could relieve the causative factor; i.e. pressure, though appropriate education on back care and bed making. It can be allowed to heal by the use of antibiotics, which would also eliminate the foul smell. Since he already has an airbed, we can teach the family how to use it appropriately and how to maintain it.

Fig 1.5 – Empowering family through education



We can educate and empower Ravi on bowel and catheter care and thereby give him a sense

of control. If he is motivated, we may teach him Clean Intermittent Self Catheterisation technique [CISC] and eliminate the need for a permanent indwelling catheter itself. This can also prevent repeated febrile episodes due to the urinary tract infections. All these measures can enhance his confidence, quality of life and reduce his financial burden.

Multi-disciplinary team Inputs: His range of movement can be preserved or improved with regular physiotherapy. Functional mobility for activities of daily living may be achieved with the help of an occupational therapist.

The medical social worker [MSW] in the team could link him and his family with rehabilitation programs active in the locality. This can include linking with social entitlement programs [disability pension], income generation training or support for educating his child. For e.g. support groups of paraplegics nurture synergistic relationships leading to better social adjustment and opportunities to improve their earning capacity. This would bring in the crucial dimension of economic self-sufficiency and would greatly enhance the self-esteem and confidence of this young man.

With the new found self-confidence we can expect Ravi to get back to his friend circle.



*Do you think that with all above inputs, this young man Ravi may regain some of his zest to live?
Do you think that these inputs are within the purview of medical practice?*

2. COMMUNICATION SKILLS

“True listening is love in action” – M. Scott Peck



COMMUNICATION SKILLS

“Communication is as vital as basic needs and apt communication is no less than an art”

Scenario I: Smt.Sudha a patient with acute exacerbation of bronchial asthma is brought to OP by her relatives. She is breathless on mild exertion which makes her confined to bed most of the time. She appears worried and tells the Doctor

“I am scared and not able to sleep”

Nurse:“Don’t worry!”

Smt. Sudha: “But I feel anxious, am awake throughout night.

Nurse: I know, I shall ask the doctor to give you medicines to get good sleep. You will be alright then.

The physician prescribes anxiolytics and Sudha leaves the OP deciding not to take the prescribed medicines.

Scenario II. Mr. Gopal is a sixty year old man and has been having loss of appetite, pain in upper abdomen, nausea and fullness of stomach for two months. He approaches a primary care physician. The physician after a quick examination gives him reference letter to Gastroenterologist to get an endoscopy done. Gopal, a farmer living in a rural area is reluctant to go elsewhere and tells the nurse,

“Give me some medicines to make me feel better”

The Nurse: “do as advised, this is best for you”

Gopal: “That seems difficult. We are having the harvesting season and I cannot leave soon “

Nurse is irritated, passes on the letter of reference and Gopal walks away dissatisfied

- What do you feel regarding the above consultation scenarios? Could these situations have been handled differently?

Introduction

What do we remember, when we try to recollect the times when we or one of our loved ones was ill and admitted to a hospital? The recollections would mostly be feelings; those related to interaction with staff, nurses and doctors; how they made us feel. We often recollect gratefully, those professionals and interactions *that brought in clarity to the clinical situation, helped prioritise and supported us in deciding* on the next steps.

On the other hand, we may recollect the deep distress and anguish of uncertainties that we faced due to poor communication and inadequate access to information.

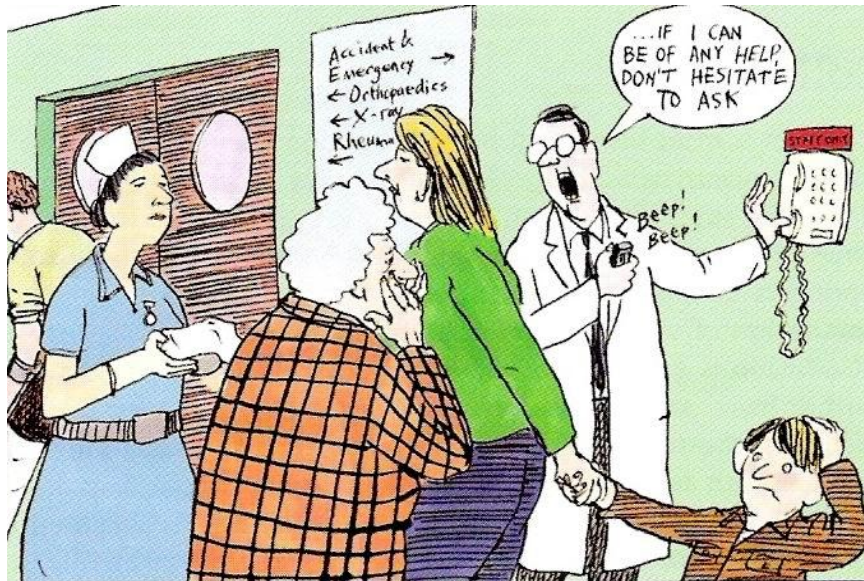
Good communication is a trainable skill. Proper communication is vital for the wellbeing of the patient and the family and for satisfaction from work. Research in health professional – patient communication has consistently shown that there is room for improvement in the way physicians talk with their patients. Studies indicate there is a major unmet communication need for information about the disease, prognosis and treatment options, intent, side effects and complications.

Learning Objectives of this Chapter

At the end of the course, the student is expected to

- a) Describe *why* communication skills are important.
- b) Describe the *barriers* to effective communication.
- c) Recognize the *don't-dos* in communication.
- d) Enumerate the steps of *effective* communication.
- e) Describe the steps of communicating *bad news*.
- f) Describe how to deal with *extremes of emotions* (crying, anger etc)
- g) Describe how to deal with *collusion*.

In regular clinical practice, the crucial aspect of good communication is often by-passed more due to convention and hierarchy of interactions. This leads to misunderstandings, erroneous interpretations, inappropriate decisions, confrontations and sometimes even law suits.



What is the need for communication skills?

Good clinical communication will help the patient to express his needs to the treating team better. It helps clarify doubts and baseless apprehensions. The therapeutic rapport that develops through effective communication supports the patient and family to handle the emotional responses to the illness and deal with the uncertainty.

It helps the nurse to understand the symptoms, their sequences and their impact ***on the patient's quality of life*** and bring in clarity on the clinical condition. It is also helpful in understanding the thought processes and meanings being attached to the situation by the patient. Through good communication, the nurse is able to convey the required supported. Effective communication helps build trust that will sustain a long term clinical relationship. This encourages rational and shared decisions about treatment and the patient is more likely to complete prescribed therapeutic plan and adopt health promoting behaviours. The nurse is the centre of clarity to allow shared and balanced decision to evolve, ***based on patient's values, beliefs and priorities yet supported by clinical evidence and rationale from a caring treating team.***

Common areas where the communication skills become essential

Providing information in a supportive manner

Shared decision making

Recognizing and responding to patient cues for information and emotional support

Soliciting patient consultation agendas

Delivering prognostic information

Responding empathetically to patients

Checking patient understanding

Encouraging the patient to ask questions

Breaking bad news

Handling collusion

Discussing transitions in goals of care from curative to palliative

What if we fail to communicate?

1. It may lead to poor symptom control
2. Patient may not comply with the plan of care as their needs / agendas have not been discussed and supported.
3. The adjustment to the illness and interventions would be poor and this can lead to worsening of distress
4. There can be situations with escalating conflict
5. The team that does not communicate effectively may find an enquiring patient as 'too demanding'. This can impact on therapeutic relationship.
6. Medico-legal problems stem primarily from poor communication and the misperceptions and misunderstandings that ensue.

What are communication skills?

Acknowledging, understanding the concerns of the patient and family and responding in the most appropriate manner to bring in clarity in their current situation.

Core Principles

- **Respect:** Treat the patient and family with respect. This is essential for a healthy relationship, which in turn, promotes good communication.
- **Empathy:** Empathy is the ability to try to understand another person's feelings by placing yourselves in their shoes. It helps to acknowledge the other person's suffering and helps to build a good relationship. It is *very different from sympathy which is a sense of pity that the other person may find offensive.*
- **Trust:** Once the patient loses trust in you, you lose the ability to help him. Truth is essential for maintaining trust. Lies, as for example in an effort to conceal the diagnosis, destroy trust.
- **Unconditional positive regard:** We have no right to be judgmental. Whether the patient is *good* or *bad*, thankful or grumbling, optimistic or pessimistic, we should try to consider him the most important person. *Care is particularly needed to ensure that we do not come to a position of taking sides when there is rift within a family, particularly between a patient and a relative.*

What is NOT communication skill?

Conversation is **NOT** communication skills. This means that talking with the patient on general conversational topics like travel, politics or weather is **NOT** considered communication skills.

Convincing the patient to follow the agenda decided unilaterally by the clinical team is **NOT** communication skills.

Conversing in a soothing and gentle manner and in kind tones alone without empowering him /her with information and clarity is also **NOT** communication skills

Barriers to effective communication

Possible barriers that may hinder the professionals

Too busy to spend time on understanding thoughts and feelings of patient

Worried about **upsetting** the patient & **handling reactions**

Not having the **knowledge and the skill**

Uncomfortable to enter into **unpracticed areas** of interaction

How to say – 'I do not know'!

Familiar and easier to concentrate on **physical concerns**

May not perceive communication as **part of their job**

Worried about **being blamed** or worsening the situation

Not knowing the **language and dialect** can be a barrier

Possible barriers that patients may face

Lack of **time** available with the health care professional

Lack of **privacy** and **unfamiliarity** of the surroundings

Not sure whether the distresses **other than physical** are to be told or not?

They may be afraid themselves of their **fears being confirmed**

Afraid of **treatment being denied** if they raise questions / doubts

Fear of **losing control** over emotions

Stumped by the '**med speech**' [medical terms / Jargon]

Authoritative **hierarchy** of the hospital environment

Complexity of Communication Process

Every communication follows a common process from its inception to completion. A thought is conceived by the speaker → gets processed based on the various mental processes, impressions and memories within → this is put into words based on the language, mood, culture and intent and the tone of the voice and body language aligns with it → information conveyed.

The listener hears the words and perceives the non-verbal cues as well → these are processed based on the various mental processes, impressions and memories within the listener.

The “information heard” by the listener is unique to that person and could be very different from the “intended information” conveyed by the speaker.

The original thought of the speaker will reach the receiver in its correct form only when the speaker ensures clarity at each step in the communication process. In other words, clarity is of prime importance throughout the communication cycle for effective transfer of information.

During consultation, nurse should observe and process patient’s nonverbal and verbal behaviour. This process allows them to acknowledge unstated or inexplicit needs and agendas the patient may have¹².

Example 1 – *“I don’t know much about the different treatments”* – here patient may be lacking confidence in directly asking for more information on pros and cons of each.

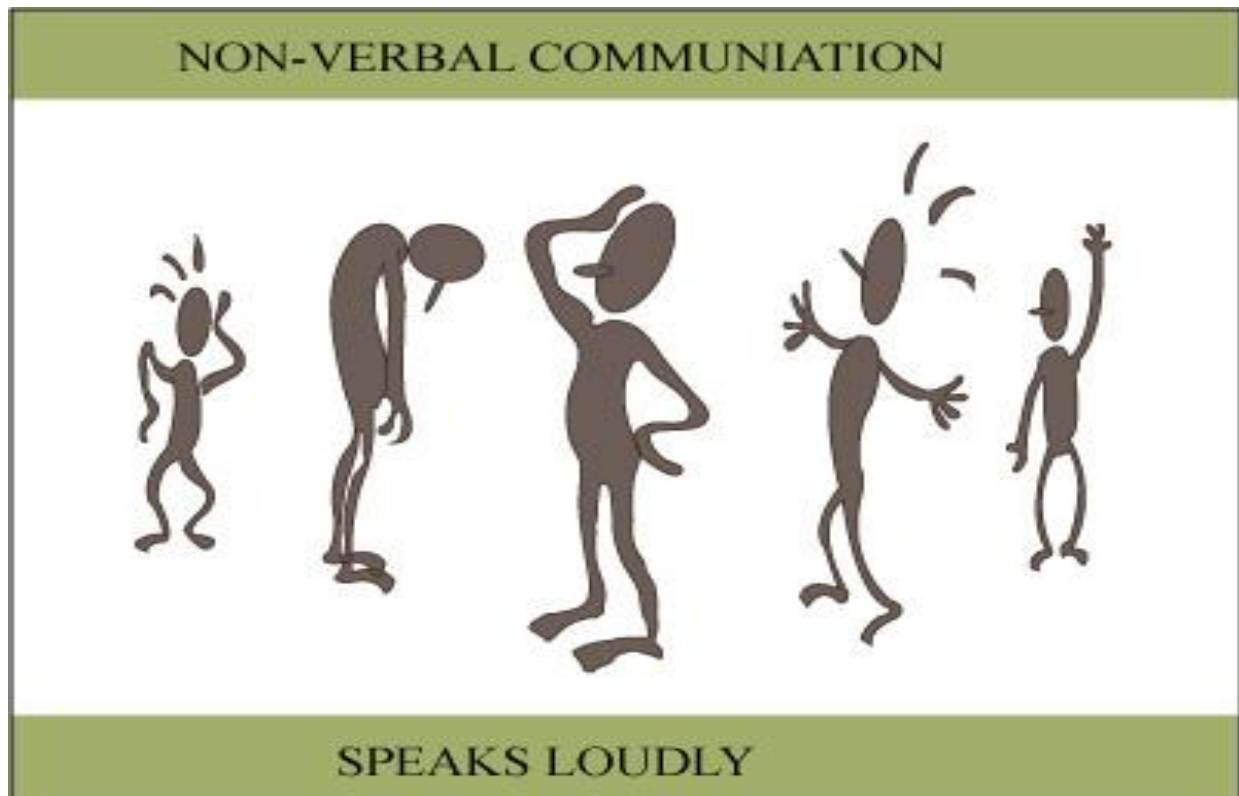
Example 2 – *“at times, I just can’t think clearly; wonder why?”* – Although not a direct request, this may be a cue for help to cope emotionally.

Example 3 – whenever discussions on treatment options begin, the patient may keep introducing blocks and avoid coming to decisions– this may be related to previous experiences with someone known or may be due to denial of reality. This behaviour needs to be noted and understood by the nurse and uncovered empathetically if the cues are recognised.

12

Non-verbal Communication

We all know that communication occurs verbally and non-verbally. But we are unaware that non-verbal communication accounts for about ninety percent of our daily communication process. It is also the sole means of communication in *children, people who are differently abled, when emotionally laden and in semiconscious and terminally ill patients.*



Frequently used strategies for effective clinical consultation

Beginning interactions

After the greetings and introductions, **begin with open questions** e.g. “So, *how are you feeling today* or *what brings you here today?* OR “*How have you been doing lately?*” Such questions are not restrictive and do not pin down the discussion to a pre-decided agenda. This beginning would allow the consultation based on patient agenda and can then proceed with information sharing and setting priorities.

In case of *an important perceived need*, nurse may **declare an agenda** “today, let us discuss the various treatment options for your current condition”.

Closing consultation

Here it is important to **check patient understanding** e.g. *“why don't you tell me what you have understood so far? “ OR “what questions do you have?”*

It is also useful to summarise to **reinforce joint decision making** e.g. *“I just want to go over what we've been talking about .This will make sure that we are on the same page.”*

Arranging a follow up **emphasizes ongoing therapeutic relationship** and a sense of partnership in the journey. Emphasise support *“if you think of anything else later, please write it down and we can discuss them next time we meet on”*

Response strategies

Responding to information cues

This can begin with clarification on the statement that gave the cue as in **Example 1** above. Once the patient expresses need for information, we may give preview of information and proceed empathetically based on patient responses.

E.g. *“Do you have some specific questions about the treatment? OR “When you mentioned complications of this treatment, was there anything particular that you were worried about?”*

More examples are discussed below under the section on communication in advanced disease.

It is important to avoid overload of information and medical jargon. Patient should be encouraged to ask questions and an attempt is made to address each of them. Here again checking patient's understanding is an important aspect of effectiveness of communication.

Summarizing statements like *“so, in a nut shell, we will start this medication today and then after you complete 3 weeks of physiotherapy we can review how you feel.”* is useful to convey that we have listened and understood their concerns and this helps in building trust.

Responding to emotion cues

Acknowledge and validate the emotion that came across as in **example 2** above. We can do this by *naming it* to convey our understanding.

E.g. *“I can see that you are **feeling very distressed**” OR “it seems like this has been **very tough** for you to cope...”* It is useful to state it as normal under the circumstances and praise the patient efforts in coping through the situation.

E.g. *“it not uncommon to feel this way under the circumstances” OR “it is natural to feel tired and unable to focus at work. It would be very reasonable to take some leave from work after this cycle of chemotherapy”*

Silences: It is very important that silences are allowed through the conversation. This allows the person to gather her / his thoughts through the emotional turmoil and bring out the most significant concerns. We as professionals often feel compelled to fill in the silences with some extra information. This is unwarranted, our talk is often unheard and it may disturb their flow of thoughts. Also, one should avoid interruptions during the communication process, as much as practical. ***You may feel overwhelmed with a need to reassure the patient with statements like “don’t worry; everything will become alright” but this could be meaningless and premature.***

Responding to patient barriers (E.g. 3 – mentioned above)

Here a “take stock” approach can help to begin the discussion followed by clarification regarding the thoughts behind them.

E.g. “so far we have talked about*There are some more aspects that need consideration for us to reach a decision; would you like to discuss those today?*” Then the dialogue can proceed with **open questions and partnership statements**.

E.g. “*let us work together to figure out how to solve this problem.*”OR “*these are difficult decisions to make. If there is anything I can do to help you with these decisions, please let me know*”

Examples of Good and Poor Communication Skills

Principle	Poor communication	Good communication
Ask open questions	Is your pain better today? <i>This is a closed question and restricts and forces the patient's response.</i>	How are you feeling? <i>This is an open questions and allows the patient to talk about what is most important issue for her / him</i>
Be empathetic E.g. Pt: I feel very scared when I am short of breath	Ns: take these tablets and your breathing will improve	Ns: breathlessness can be very frightening; what sort of fears do you feel when you are breathless?
Balancing hope and truth	Ns: There is nothing more we can do, your disease is incurable and there is no point in continuing in staying in the hospital. <i>Here the nurse may be destroying hope irrevocably</i>	Ns: I am afraid there is no more treatment available to cure your disease. But we can definitely keep you comfortable with regular evaluation and medications. We are with you.
Respectful confidentiality and avoiding unhealthy curiosity E.g. Pt: I feel distressed by the fact that this cancer is the direct consequence of the abortion that I had when I was 17 years. I have not disclosed this to anyone.	Ns: Were you not married then?	Ns: I think we need to discuss this more as it is obviously a very significant reason for your distress. Be assured that everything that we discuss will be kept confidential.
Therapeutic relationship	Ns: You have not taken the medicine for your pain as advised. Don't waste my time. <i>Here, the nurse is not interested in understanding reasons why the medicines were not taken and correcting them.</i>	Ns: Tell me why were you unable to take the medicines? I would like to understand further. Did you have any trouble when you started them? Do you have any questions or clarifications?

Now, let us re-look at the scenarios discussed at the beginning of this module and see how to handle them differently.

Scenario I. Here Smt. Sudha appears really apprehensive and is not able to sleep. **The nurse has not taken a detailed history to explore reasons behind her apprehension.**

Is it because she had a relative who died from breathlessness?

Is she worried that how long her illness would continue?

Is she upset because she continues to be burden to her family?

Eliciting and addressing these are the most important aspects of treating her insomnia. Prescribing anxiolytics without exploring her concerns would shut the door for self-expression and definitely will not settle her symptoms

Scenario II

Why does Gopal walk away in frustration?

Here the nurse insists that the patient has to do as advised and meet Gastroenterologist.

Her suggestion is professional and with good intension. **But Gopal has his own genuine reasons to deny that.** Here the nurse could have spent little more time with Gopal, explained the problem to the doctor and supported him with medicines for acid peptic disease and arranged for review . The nurse can also talk to the family about the doctor's doubts, need for evaluation and discuss possibility of alternate arrangements to relieve him through his harvest commitments. Then Gopal may be more receptive to the team's suggestion as he would feel understood and cared for. The relatives would also know the real concerns and help Gopal understand the need for evaluation.

Learning to communicate with patients with advanced and progressive diseases

Effective communication with patients facing progressive disease, with complex problems and an uncertain future is a challenge and it needs more skills and practice. Patients with advanced and progressive diseases have issues other than physical and they require compassionate listening and empathetic responses.



25 year old Mrs. Gita has come to the hospital. She has been diagnosed to have advanced cancer of the stomach. She has not been eating much for the last 5 days. She has not been interacting with her family and has been mostly confined to her room. She has even stopped telling stories, one of her favourite pastimes to her little niece to whom she used to be very close.

She wishes to speak to the nurse alone and says, “Chemotherapy is not helping me. I cannot stand it. Sister, please help me. I want to die.”

How will you respond to Mrs. Gita’s statement – “Sister, please help me. I want to die”

Do you think one of the following responses would be appropriate?

- “You should not say such things. God gave you life. Trust him.”
- You must chant regularly for strength to endure this.

- “Look at that man over there. He has no family; he is alone and in pain. At least be thankful that you have a loving family.”
- “Oh you poor thing; it is so sad you have to go through this terrible disease”.
- “There is nothing to be afraid of. Be brave! We shall look after you. Don’t worry!”
- “It is a squamous cell carcinoma. It is quite radiosensitive. You have a good chance of remission”.
- “Oh, so you are waiting for your final Visa?! Ha, ha”
- "When your general health improves, we shall try more chemotherapy. That will cure you.'

Do you think any of these responses would be caring enough to the expressed distress by Gita ?

If not, why?

There are evidences to suggest that certain responses are to be avoided while communicating with sick patients.

***What is not recommended during clinical communication?*¹³**

1. **Do not immediately reply** to the patient’s words. It is useful to enquire for feelings or real questions behind what the patient words.
E.g. For Gita’s statement; it may be more appropriate to respond with another question – *I can see that you are deeply distressed; would you like to share your thoughts with me?*
E.g.- When a patient asks... “**Sister, how long do I have?**” the implicit question usually is “**Sister...now that I have very little time left, what can I expect, how can you help me?**”
2. **Do not philosophise or moralise.**
e.g. “You should not say such things. God gave you life. Trust in God.” *They may hurt the patient’s feelings conversation stoppers.*
3. **Avoid comparisons.** It is insensitive to say that someone else’s grief is greater and therefore, the patient has no right to grieve.
e.g. “Look at that man over there. He has no family; he is alone and in pain. At least be thankful that you have a loving family.”

13 Dr MR Rajagopal – personal communications

4. **Avoid meaningless words** like “*There is nothing to be afraid of.*”
5. **Avoid medical words.** They are jargon from patient’s point of view. Technical language tends to overwhelm patients.
6. **Avoid false reassurance.** E.g. "When your general health improves, we shall try more chemotherapy. That will cure you.' It really doesn't provide reassurance and it destroys trust. Reassurance is essential to maintain hope after due interactions and explanations **but it must be based on truth.**
7. **Do not make assumptions.** Check the patient’s insight about the diagnosis and prognosis, and what it means to her. E.g. *What made you ask that question?*
8. **Avoid patronising or condescending attitude.** The patient will open up to you only if you deal with her / him with respect.
9. **Do not force your beliefs or convictions** on the patient.
e.g. “You must chant ----- regularly for strength to endure this” is imposing your own beliefs on patient.
10. **Avoid sympathy,** which is hard to bear.
E.g. Oh you poor thing; it is so sad you have to go through this terrible disease’. Instead convey empathy – an attempt to put ourselves in the patient’s shoes and to try to understand what he is going through. For e.g. “*I can see that you are going through a lot...*”
11. **Avoid inappropriate humour.**
E.g. . Oh, so you are waiting for your final Visa?! Ha, ha
The patient himself may use humour as a coping strategy, but coming from us it may seem insensitive.
12. **Avoid both lies and thoughtless honesty.** Lies may not be believed, and even if believed, will destroy trust later. Also, truth should not be disclosed like a bombshell. “**Truth is a powerful therapeutic tool, but must be applied in the right doses at the right time**”.



One of your colleagues appears dejected. You would like to help.

How would you go about being with her / him?

What location would you choose?

How would you open the communication?

Steps for effective communication¹⁴

1. Build a relationship
2. Open the discussion
3. Gather information
4. Understand the patient's perspective
5. Share information
6. Reach agreement on problems and plans
7. Close discussion sensitively

1. Build a relationship:

- Set the scene. For dealing with a request like Gita's, you *need the time and privacy*
- Preferably, you could be sitting down at eye level, not too close to invade private space, but close enough to lean forward and touch the patient *if need arises*.
- Convey empathy with your expression and with a statement like, "*I see that you are very much worried.*" The important thing is to *convey that you care*.

2. Open the discussion

- Acknowledge feelings like pain or loss. In the case of Gita it would be appropriate to say, "*it looks like life is a burden for you right now*". Acknowledgement of suffering makes the patient feel that she is understood.
- Listen actively. Active listening involves *eye contact, appropriate facial expression (empathy), body language (leaning forward) and verbal responses like "Yes, I see...", "and?", "hmmm", oh... etc. It also involves encouraging the patient by repeating her last few words and paraphrasing.*

¹⁴ Kalamazoo consensus statement

- Listening not only to what is said, but also to what is not said – to the facial expression, body language of the patient, indicating suffering, avoiding eye contact indicating, she is uncomfortable to continue etc.

3. **Gather information**

- Explore and find the patient's level (What does she know? How much does she want to know?)
- Use open questions or statements which invite responses like,
 - “*What do you think might be the problem?*”
 - “*What worries you most?*”
 - “*That must have come as a shock to you*”.

4. **Understand the patient's perspective**

- What does she feel about it all? What questions does she have?
- Be prepared for emotions and behaviours (sobbing, anger ,silence , despair)
- It may be necessary to facilitate sharing with words like, “*could you tell me your thoughts and how you are feeling?*”

5. **Share information**

- The patient decides the agenda for further discussion. In other words, what she considers important must be discussed at this stage.
- If she wants to postpone discussion about further treatment, that should be allowed within the reasonable time frame
- The patient has a *right to know everything; but not a duty to know*. Confirm what the patient really wants to know.
- Use common conversational language
- Check understanding at every stage.

6. **Reach agreement on problems and plans**

- Summarise the problems brought out by the patient.
- Suggest a course of action.
- Answer any questions the patient has.
- Arrive at a course of action acceptable to the patient, making it clear that this is *not an iron-clad contract and that the plans are renegotiable*.

7. **Close discussion sensitively**

- Avoid abruptness
- Review and summarise discussion before finishing.
- Leave the door open to talk again.

At the end of discussion, Gita is likely to have brought out her important concerns. She would have felt that someone cares and she is not alone. We may have found some way of encouraging communication between her and her family members. She would now have clarity about her treatment plans and might feel more in control of her life. Her prioritised physical concerns would be managed. Her unrealistic fears would have been elicited and removed and some realistic hopes of achievable targets (like relief from pain and other symptoms, regular sleep, improved functionality and of-course Gita spending quality time with her dear niece) might have been possible.

With all these inputs, do you think we would have responded adequately to her distressed request for death? Wasn't it actually a plea for help and support!?

Communicating Bad News

The desired outcome of consultation while breaking bad news would be “to convey threatening information in a way which promotes understanding, recall and support for the patients’ emotional response and a sense of ongoing support”

When the news is really bad (like the disclosure of diagnosis of cancer), the seven steps described above are still relevant. However well communicated, bad news is still bad. It is important to understand how the patient may respond to the bad news. The aim is to minimise the impact, to remove needless fears, to instil realistic hope and to make the person cared for.

Some examples on helpful and non-helpful nurse-patient-communication styles

Hit & Run approach

Nurse: "You have stomach-cancer and it is important to start treatment immediately, say next Monday."

Patient may feel **shattered**

Straight answer to straight questions

Patient: "How much more time do I have?"

Nurse: "Can not say precisely. But we have seen people living up to one year!"

Patient may feel **worried & depressed**

Talking to the relative only

Patient: "Sister, please tell me about my condition!"

Nurse: "Don't worry. I have explained everything to your son. He will tell you".

Patient may feel **suspicious & worried**

Blunt & unfeeling

Patient: "I have severe pain and it kills me!"

Nurse: "Your disease and its treatment procedures will be painful. Do understand that and cooperate with us. Otherwise it is going to be difficult.

Patient may feel **upset, lonely and abandoned.**

Breaking bad news as a painful duty to be accomplished

Nurse: "It is sad, but it is my duty to speak to you. You have an advanced illness which has gone beyond the stage of cure. I can't help you further. I am sorry!"

Patient may feel **hopeless**

Sad, feeling inadequate and occupied only with himself

Nurse feels very sad to have to speak to the mother of an ill child, who will die. Here she avoids or postpones speaking to the mother or gives the responsibility to somebody else.

Patient/Mother may feel **alone / desperate**

Sad, feeling inadequate, but emphasizing and sharing with patient/relatives

Nurse: "It is sad that your child has limited time in this world. It is very painful for all of us. But we will do our best to care and give comfort to him; we are all with you."

Mother/Patient may feel **consoled, reassured and supported**

Flexible, based on feedback with reassurance

Nurse: "What do you know already about your disease?"

Patient: "I have a severe form of cancer"

Nurse: "Yes, and unfortunately it is progressing. There are some treatment options, you can choose from. Some useful treatment will always be available for you, even if there is no cure!"

Patient may feel **concerned but reassured**

Elizabeth Kubler Ross has described different possible reactions to a bad situation. They are:

- a) **Denial.** ("This cannot be true. This cannot be happening to me.") This is usually a passing phase; but once in a way, someone may continue in denial. In a way, this is a beneficial coping strategy; but eventually when the person is unable to deny any more, he may get devastated.
- b) **Anger.** Anger at the situation may get re-directed in the form of "shooting the messenger" - anger at the doctor or nurse. Or often, the anger may be directed at whoever is close to the patient, like the spouse.
- c) **Bargaining.** Bargaining may be with God, and may accompany offers to "go straight" hereafter. It may also take the form of "doctor-shopping" or "system-hopping" trying different systems of medicine one after another.
- d) **Depression.** It is normal to grieve when there is a bad situation, and may need help and support. Sometimes the patient may go into clinical depression which needs to be identified and treated.
- e) **Acceptance.** This state, when the patient says to himself, "Well, this has happened, I cannot undo it; let us see what we can do about it", is the healthiest of all.

Kubler-Ross herself was the first to admit, that not everyone goes through the same stages and not in the same sequence. Our job is to find out the person's feelings, react appropriately and help the person to come to the state of acceptance.

Collusion

Collusion usually occurs when the family conspires among themselves or with professionals to withhold information or lie to the patient.

It is often well intentioned, acting in what is believed to be the best interests of the patient. Usually the family members of the patient collude, to protect the patient from emotional harm; which they expect would happen if the bad news is broken to the patient. However, this inevitably creates tension because the patient has the right to information.

Collusion is addressed when it is

- **hindering good quality care**
- **leading to futile interventions**
- **becoming harmful to the patient**

Steps to manage collusion

1. **Convey to the relative that you are on their side.** Do not start by persuading the relative. The message should be, “You want the best for your mother (patient). I too want the best for her. Let us talk about it and make plans.”

2. Explore the family’s understanding/insight about the illness and reasoning

- Establish whether they are trying to protect themselves or the patient
- Recognize that they may have valid concerns about the patient’s capabilities and past behaviour patterns
- Do they have a correct understanding of their situation?

3. Reassure and explain

- Reassure that you will not walk in and impose information
- Find out if the family already has felt adverse effects of the patient not knowing the diagnosis. Has he been anxious? Has he been in the "bargaining" phase making unrealistic demands about treatment?
- Explore how much this (withholding information) has affected the communication and interaction within their family
- Explain the consequences of keeping the diagnosis from the patient.
- Mention that you recognize the patient's right to information, if requested.
- Offer to facilitate the conversation between the family and patient, if they find it too difficult to handle.
- If they are still unwilling, get conditional permission for finding out what the patient already knows.

4. Share information as and when required

- Explore the patient’s understanding, and assess their desire for further information
- Inform the family about patient’s desire.
- Share information in digestible chunks.
- Inform family members what has been discussed with the patient.
- Encourage open communication between the family and patient.
- If situation demands clarifications or explanations, pitch in.

Occasionally patients collude with professionals to withhold information from their family. This is more difficult as the patient has to give permission for disclosure of information, but the principles are the same as above – sensitive handling, exploration of reasoning, and explanation about consequences, reassurance and offer of facilitation.

Managing Anger

Anger is a response to feelings of helplessness, distress and fears. It may also be a negative result of an ineffective communication between health care professionals and the patient/carer/ family members.

Anger is often unleashed on a person who is perceived as close (like spouse, close friends, close family members) or non - threatening (usually security staff, reception staff, attenders, junior nurses and junior doctors).

Anger is the source of medico – legal suits. Direct simple and empathetic approach helps. **Acknowledge and name the emotion.** Then address the need of the patient to be understood.

e.g. “I can see that you are angry; can we sit down and talk....tell me what you thought went wrong.....I may be able to help you”

How to handle anger?

- The patient may direct anger at you irrespective of whether you are the source of distress or not.
- Be calm, empathetic and use positive non-verbals throughout the conversation.
- Give the patient time to express himself
- Allow the patient to express his emotions/feelings
- Observe the nonverbal cues of the patient
- Acknowledge the reasons for anger
- Arrive at a consensus through ‘participatory decision making’.
- Summarize the conversation
- Ask if the patient would like to add something or need any clarification
- Assure your continued support & follow up after a stipulated time

What can worsen anger?

Defensive responses

Indifference / dismissive attitude

Blaming the patient’s behaviour for what had happened

Blocking the patient’s questions and leaving them feeling inadequately understood. This includes premature assurance.

Passing the task on to a junior or unrelated personnel

Managing Denial

Denial is the patient's refusal to take on board the bad news. It is avoiding thoughts and feelings that are painful or that you cannot deal with. It occurs to some degree in everyone who has a serious illness. It is a shock absorber that helps you bear an overwhelming situation and cope with it.

However, for some patients, denial of the illness or of its severity can cause delayed diagnosis or compromised compliance with treatment. In that event, patient and sustained efforts may be required to convey at least one part of the truth to permit treatment.

Denial can be a problem if the patient

- does not accept the diagnosis and /or prognosis and avoids/delays treatment
- minimizes the symptoms and implications of the illness
- insists on continuing with curative treatments and other measures which have been proven futile / ineffective.

Denial appears to be a common defence mechanism in majority of palliative care patients. It varies in its severity and pervasiveness. It has varying effects in the process of adaptation. In some cases denial reduces anxiety, where as in some others it results in excessive delay in seeking help and poor compliance to treatment.

Questions, like the following, can help in getting an idea about the nature of denial.

- *What do you think about your illness?*
- *What is your understanding about the seriousness about your illness?*
- *What are your future plans?*
- *Do you have another plan (Plan B) if the former is found to be not working?*

Assessment of Denial

- A cognitive evaluation is essential to rule out the possibilities of any psychiatric disorders.
- Check patient's insight – establish what he/she knows. This should include his/her understanding on the diagnosis, prognosis and current treatment regime.
- Listen to the words used and observe the non-verbals of communication when the patient narrates. This will tell you how much the patient knows or how he feels about the illness.

How do we manage denial?

1. Ensure that the patient's denial is not due to lack of information, lack of understanding or lack of agreement with medical recommendations

2. Distinguish between a fact being denied (e.g. diagnosis of cancer) and implications of the fact denied (e.g. cancer will not return).
3. Assess how and when denial is used by the patient.
4. Assess the benefits and risks of denial to the patient's psychological condition and compliance to treatment.
5. If denial is expressed by minimization of illness, or lack of emotional response, it signals that the patient is frightened. Provide emotional support and discuss their issues/concerns.
6. Adopt a non-confrontational approach. If denial is causing significant problems, direct confrontation may only increase the use of denial.
7. Last but not least, emphasise to patients that they will not be abandoned. They will be supported and cared for.

Conclusion

The Nurse is the centre of clarity to allow shared and balanced decision to evolve, based on patient's value beliefs and priorities along with clinical evidence and rationale.

A good clinical communication will help the patient to understand her /his perceptions better, remove baseless apprehensions and find support to handle the emotional aspect of illness, deal with uncertainty and build trust that will sustain long term clinical relationship. This encourages rational, shared decisions about treatment and the patient is more likely to complete prescribed therapeutic plan and adopt health promoting behaviours.

The challenge of “**lack of time**” invariably comes up. We should remember that good communication is more of an attitude of genuine caring or approach with readiness to support the patient, irrespective of time. Also most patients do not fall in the advanced disease category and do not require time for interactions to complete. The important starting point for the treating unit is acknowledging the fundamental role of communications on therapeutic outcomes. Then, it is always possible to create systems to assure it's regular practice through modifications in the intake forms and involving appropriately trained team members for this important task, within the unit. The Multidisciplinary Team approach is thus crucial for complete caring systems to evolve.

My friend I care

Don't tell me that you understand; don't tell me that you know,

Don't tell me that I will survive; how I will surely grow.

Don't come at me with answers; that can only come from me,

Don't tell me how my grief will pass; that I will soon be free.

Don't stand in pious judgement of the bonds I must untie

Don't tell me how to suffer and don't tell me how to cry.

My life is filled with selfishness; my pain is all I see,

But I need you; I need your love unconditionally.

Accept me in my ups and downs, I need someone to share

.....Just hold my hand and let me cry; and say... “my friend, I care”

Test your knowledge

Multiple Choice Question

1. What is a must in communication?

- α. Active listening
- β. Giving medical advice
- γ. Normalizing
- δ. Reassuring

2. Which is the most apt way to overcome denial?

- ଦେଖି Be short and precise
- ଦିଅନ୍ତୁ Involve colleagues as testimonial
- ନିଅନ୍ତୁ Non- confrontational approach
- ଠାଏନ୍ତୁ Rational and assertive explanation

True or false questions

1. Collusion makes the work for doctors easy and quick.
2. Sensitive truth telling is harmful for the patients.
3. Nurses can show emotions even at the clinic, it is helpful for patients.
4. Nursing students need to be trained in good communication skills

Ans: 1 – a; 2 – c;

True / False – 1 – F; 2 – F; 3 – T; 4 - T

Suggested Reading

1. J. Randall Curtis and Douglas B. White; Practical Guidance for Evidence-Based ICU family conferences-*Chest* 2008;134;835-843
2. Buckman.R1992: How to Break Bad News – Pan Books
3. Buckman R1998: ‘I Don’t Know What to Say – Pan Books
4. Falcon. M Neil B 2000: ABC of Palliative Care - BMJ Books
5. Faulkner A et al.1994: Breaking bad news - a flow diagram in *Palliative Medicine* 8:2:145-151.

3. NURSING CARE FOR CONTROLLING SYMPTOMS IN PALLIATIVE CARE PATIENTS



If love can't heal it..... nurse can

NURSING CARE IN CONTROLLING SYMPTOMS

Dyspnoea



“Air! I need Air I can’t breath...”- A Patient

Mr. Kumar 55 year old beedi worker, father of three children was diagnosed with lung cancer. His disease was in an advanced stage spread locally and his general condition was very poor to tolerate chemotherapy. He had a course of palliative radiotherapy to his chest. He presented with complaints of severe dyspnoea before treatment, which has worsened after the treatment. The patient had been bedbound and anxious to move since any kind of exertion, worsened his breathlessness.

He was taught breathing techniques, energy conserving techniques and activity pacing by the Care Nurse. The patient was prescribed two weeks course of steroids to reduce the inflammatory response within the lung tissue due to radiation and due to the extensive disease. He was started on oral morphine and benzodiazepines for his troublesome cough and breathlessness.

The steroid, morphine and other medications gave the patient a good symptomatic relief. Mr. Kumar was able to get out and move about and had regained a good quality of life that he thought was no longer possible.

What are the non-pharmacologic interventions used for patients with dyspnoea?

What made Mr. Kumar feel frightened to move from the bed?

Dyspnoea is defined as distressing shortness of breath. The experience of dyspnoea can be extremely frightening.

Nursing Diagnosis - Impaired breathing pattern/dyspnoea:

Related factors:

- Primary lung tumor
- Lung metastases
- Pleural effusion
- Restrictive lung disease
- Decreased energy and fatigue
- Tracheobronchial obstruction
- Anxiety
- Cardiovascular disease
- Pulmonary edema
- Thromboembolism
- Pneumonia
- Aspiration etc

Defining Characteristics:

- + Dyspnoea
- + Tachypnoea
- + Fremitus
- + Cyanosis
- + Cough

- ✚ Nasal flaring
- ✚ Respiratory depth changes
- ✚ Altered chest exertion
- ✚ Use of accessory muscles

Tachypnea is not dyspnea

Expected Outcome of care

Normal breathing pattern is maintained as evidenced by normal skin color, and regular respiratory rate/pattern.

Actions/Interventions	Rationales
Assess respiratory rate and depth by listening to lung sounds.	Respiratory rate and rhythm changes are early warning signs of impending respiratory difficulties.
Monitor breathing patterns such as, bradypnoea, tachypnoea, and hyperventilation.	Specific breathing patterns may indicate an underlying disease process or dysfunction.
Assess the position that the patient assumes for normal or easy breathing.	Orthopnea is associated with severe breathing difficulty.
Assess for use of accessory muscles.	As moving air in and out of the lungs becomes more and more difficult the breathing pattern alters to include use of accessory muscles increasing chest exertion to facilitate effective breathing.
Assess skin color and temperature.	Pale or cyanotic color indicates increased concentration of de-oxygenated blood and indicates that the breathing pattern is no longer effective to maintain adequate oxygenation of

	tissues.
Assess level of anxiety	Hypoxia and the sensation of “not being able to breath” is frightening and the anxiety may cause worsening hypoxia.
Use pulse oximetry to monitor oxygen saturation and pulse rate.	It is a useful tool to detect changes in oxygenation
Monitor for changes in level of consciousness	Restlessness, confusion and irritability can be early indicators of less oxygen to brain.
Position patient with proper body alignment for optimal breathing pattern.	Sitting position allows for good lung & chest expansion
Maintain oxygen saturation of 90% or greater.	This provides for adequate oxygenation.
Encourage deep breathing and coughing exercises	This promotes deep inspiration.
Plan activity and rest to maximize the patient’s energy.	Fatigue is common with the increased work of breathing. Activity increases metabolic rate and oxygen requirements. Rest helps mobilize energy for more effective breathing.
Provide reassurance and allay anxiety by staying with patient.	Simpler technique promotes deep inspiration and adequate gas exchange.
Use pain management as appropriate.	Pain relief enhances the ability to deep breath and cough.
Administer prescribed respiratory medications as indicated.	Beta-adrenergic agonist medications relax airway smooth muscles and cause bronchodilation to open air passages. Steroids are effective anti-inflammatory drugs for treatment of reversible airflow obstruction.

Homecare Education:

1. Positioning - the most comfortable position is usually sitting upright with support.
2. Minimize the exacerbation as much as possible by pacing the activity.
3. Before any activity encourage the patient to perform few deep breathing exercises.
4. Advise the caregiver of the patient to keep the room of the patient cool.
5. Avoid doing any activity in a hurry; encourage the patient to do slowly.

6. Promote adaptation of lifestyle in reducing nonessential activities while maintaining independence and mobility of the patient.
7. Encourage the patient to avoid provoking factors for breathlessness.
8. If the patient is mouth breathing, it can dry up the oral mucosa and oxygen inspired will be dry, which in turn aggravates the condition So oral hygiene should be encouraged to humidify oxygen inspired.
9. Dietary modifications with small and frequent feeds are well tolerated for the patients with dyspnoea. Patients with end stage respiratory disease are usually cachexic and advice from a dietician will be helpful.
10. Educate the patient and the family about medications to be taken at the time of acute episode of breathlessness. (Eg.) Inhalers (or) Nebulizer (or)
Inj.Dexamethasone (or) T. Lorazepam

Chronic Pain

Description

Unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage (International Association for the study of pain IASP)

Pain which is of sudden or slow onset of any intensity from mild to severe, constant or recurring without an anticipated or predictable end and lasting for a duration of more than 6 months is described as chronic pain.

Chronic pain may be classified as chronic malignant pain and chronic non-malignant pain. In the former, the pain is associated with a specific cause such as cancer. With chronic non-malignant pain, the original tissue injury present but not progressive or has been healed. Identifying an organic cause for this type of chronic pain is more difficult.

Chronic pain differs, from acute pain in that it is harder for the patient to provide specific information about the location and the intensity of the pain. Over time it becomes more difficult for the patient to differentiate the exact location of the pain and clearly identify the intensity of the pain. The patient with chronic pain often does not present with behaviors and physiological changes associated with acute pain.



Mr. Raju is a 60 year old driver diagnosed to have metastatic pancreatic cancer. During his OPD visit the nurse assessed his pain. He started crying, few minutes later he said that he has severe pain in the abdomen, which is radiating to the back. He lives with his wife and two children. He does not want to interrupt other's sleep so he is sleeping outside the house. His wife conveyed that for the last two weeks he is very much irritable and getting angry for simple issues. Children are afraid to talk to him. He is not showing any interest in activities of daily living. (e.g bathing, eating, grooming).

How will you describe the concept of “total pain”?

How will you assess Mr. Raju's pain?

What are the nursing measures which will improve Mr. Raju's QOL?

Pain is whatever the patient says hurts and occurs when they say it does.

Nursing Diagnosis: Impaired comfort - Pain

Related Factor

Chronic physical or psychosocial disability

Defining characteristics

Patient reports pain

Guarding behavior protecting body part

Self-focused

Irritability, restlessness

Weight changes

Anorexia

Changes in sleep pattern

Fatigue

Fear of re-injury

Reduced interaction with people

Depression

Altered ability to continue previous activities

Atrophy of involved muscle group

Sympathetic mediated responses (e.g., temperature, cold, changes of body position, hypersensitivity)

Expected Outcomes to care

Patient reports pain at level less than 3 to 4 on a 0 to 10 rating scale.

Patient uses pharmacological and non-pharmacological pain relief strategies.

Patient engages in desired activities without an increase in pain level.

Actions/Interventions	Rationales
<p>Assess pain characteristics:</p> <ul style="list-style-type: none"> • Quality (e.g. sharp, burning) • Severity - scale of 0 (no pain) to 10 (most severe pain) • Location (anatomical description) • Onset (gradual or sudden) • Duration (e.g., continuous, intermittent) • Precipitating factors • Relieving factors 	<p>The most reliable source of information about the chronic pain experience is the patient's self-report. Systematic assessment and documentation of the chronic pain experience provides direction for a pain management plan.</p>
<p>Assess for signs and symptoms associated with chronic pain such as fatigue, decreased appetite, weight loss, changes in body posture, sleep pattern disturbance, anxiety, irritability, restlessness, or depression.</p>	<p>Patients with chronic pain may not exhibit the physiological changes and behaviors associated with acute pain. Pulse and blood pressure are usually within normal ranges. The guarding behavior of acute pain may become a persistent change in body posture for the patient with chronic pain. Coping with chronic pain can deplete the patient's energy for other activities. The patient often looks tired with a drawn facial expression that lacks animation.</p>
<p>Assess the patient's perception of the effectiveness of methods used for pain relief in the past.</p>	<p>Patients with chronic pain have a long history of using many pharmacological and nonpharmacological methods to control their pain. An effective pain management plan will be</p>

	based on the patient's previous experience with pain relief measures.
Evaluate gender, cultural, societal and religious factors that may influence the patient's pain experience and response to pain relief.	Understanding the variables that affect the patient's pain experience can be useful in developing a care plan that is acceptable to the patient. The patient's heritage will influence the meaning of pain, expressions of suffering associated with pain and selection of pain management strategies.
Assess the patient's expectations about pain relief.	The patient with chronic pain may not expect complete absence of pain but may be satisfied with decreasing the severity of the pain and increasing activity level.
Assess the patient's attitudes toward pharmacological and nonpharmacological methods of pain management.	Patients may question the effectiveness of nonpharmacological interventions and see medications as the only treatment for pain. Patients may have misconceptions regarding alternative and complementary therapies for pain relief.
For patients taking opioid analgesics, assess for side effects, dependency and tolerance.	Drug dependence and tolerance to opioid analgesics are concerns in the long terms management of chronic pain. The patient and family may have misconceptions and fears about drug tolerance, dependence and addiction.
Assess the patient's ability to accomplish activities of daily living, instrumental activities of daily living, and demands of daily living.	Fatigue, anxiety, and depression associated with chronic pain can limit the person's ability to complete self-care activities and fulfill role responsibilities.
Encourage the patient to keep a pain diary to help in identifying aggravating and relieving factors of chronic pain.	Knowledge about factors that influence the pain experience can guide the patient in making decisions about lifestyle modifications that promote more effective pain management.
Acknowledge and convey acceptance of the patient's pain experience.	The patient may have had negative experiences in the past with attitudes of health care providers

	towards the patient's pain experience. Conveying acceptance of the patient's pain promotes a more cooperative nurse- patient relationship.
Provide the patient and family with information about chronic pain and options available for pain management.	Lack of knowledge about the characteristics of chronic pain and pain management strategies can add to the burden of pain in the patient's life.
Assist the patient in making decisions about selecting a particular pain management strategy.	Guidance and support from the nurse can increase the patient's willingness to choose new interventions to promote pain relief. A combination of nonpharmacological therapies and analgesic medications may be most effective. Non-opioid medications are preferred medications because of their low side-effect profile, especially among older patients. Medications should be given around the clock to achieve a consistent level of pain relief and comfort. The oral route is preferred.
Refer the patient to a physical therapist for evaluation.	The physical therapist can help the patient with exercises to promote muscle strength and joint mobility and therapies to promote relaxation of tense muscles. These interventions can contribute to effective pain management.
Teach the patient and family about using nonpharmacological pain management strategies.	Knowledge about how to implement non-pharmacological pain management strategies can help the patient and family gain maximum benefit from these interventions.
Cold applications	Cold reduces pain, inflammation, and muscle spasticity by decreasing the release of pain-inducing chemicals and slowing conduction of pain impulses. This intervention requires no special equipment and can be cost-effective. Cold applications should last about 20 to 30 min/hr.

Heat applications	Heat reduces pain through improved blood flow to the area and through reduction of pain reflexes. This is a cost-effective intervention that requires no special equipment. Heat applications should last no more than 20 min/hr. Special attention needs to be given to preventing burns with this intervention.
Massage of the painful area.	Massage interrupts pain transmission, increases endorphin levels, and decreases tissue edema. This intervention may require another person to provide the massage. Many health insurance programs will not reimburse for the cost of therapeutic massage.
Progressive relaxation, imagery and music	These centrally acting techniques for pain management work through reducing muscle tension and stress. The patient may feel an increased sense of control over his or her pain. Guided imagery can help the patient explore images about pain, pain relief, and healing. These techniques require practice to be effective.
Distraction	Distraction is a temporary pain management strategy that works by increasing the pain threshold. It should be used for a short duration, usually less than 2 hours at a time. Prolonged use can add to fatigue and increased pain when the distraction is no longer present.
Acupressure	Acupressure involves finger pressure applied to acupressure points on the body. Using the gate control theory, the technique works to interrupt pain transmission by “closing the gate”. This approach requires training and practice.
Transcutaneous electrical nerve stimulation (TENS)	TENS requires the application of two to four skin electrodes. Pain reduction occurs through a mild

	electrical current. The patient is able to regulate the intensity and frequency of the electrical stimulation.
Teach the patient and family about the use of pharmacological interventions for pain management: Nonopioids (acetaminophen; nonselective, nonsteroidal anti-inflammatory drugs (NSAIDS); and selective NSAIDS (COX-2 inhibitors)	These drugs are the first step in an analgesic ladder. They work in peripheral tissues by inhibiting the synthesis of prostaglandins that cause pain, inflammation, and edema. The advantages of these drugs are that they can be taken orally and are not associated with dependency and addiction. They should be given around the clock to provide a consistent level of pain relief.
Opioid analgesics (narcotics)	These drugs act on the central nervous system to reduce pain by binding with opiate receptors throughout the body.
	The side effects associated with this group of drugs tend to be more significant than those with the NSAIDS. Nausea, vomiting, constipation, sedation, respiratory depression, tolerance, and dependency are of concern in patients using these drugs for chronic pain management.
Antidepressants Anticonvulsants	Antidepressants and anticonvulsants may be useful adjuncts in a total program of pain management, especially for those with chronic neuropathic pain. In addition to their effects on the patient's mood, the antidepressants may have analgesic properties apart from their antidepressant actions.

Home care teaching:

- Teach the patient and family how to give pain medications.

- Explain the patient and caregiver about each analgesic's time of intake, duration, route, expected side effects and importance of PRN dose.
- Write out the instructions clearly on the medicine envelope.
- Encourage the patient to use complimentary therapies like distraction, music, imagining a calm scene, as much as possible.
- Explain about the importance of drug compliance in pain management and discourage to stop any self prescribed medications
- Teach family how to give oral Morphine.
- Teach the patient and family about rectal route for Morphine administration in patients who can't take orally.
- Advise family on additional methods for pain control- emotional support, physical method (touch, hot and cold application).
- Give adequate information on managing side effects of Analgesic at home (Eg. Constipation- T. Dulcolax 5mg, dry mouth— ice chips, lemon pieces.)

Nausea and vomiting



Nausea is an unpleasant wave like sensation in the back of the throat epigastrium or throughout the abdomen that may or may not lead to vomiting.

Case Scenario: Miss. Emily Sharada is a 16 years old school going girl who gets high marks in her studies. Four months back she was diagnosed to have osteosarcoma of the right femur and was planned for an amputation after chemotherapy. She has been undergoing high dose of chemotherapy for the treatment of her disease. She wants to continue her school until her exams are done. But she has been having persistent nausea and vomiting. Whatever food she takes she vomits immediately. She lives with her parents and 3 younger brothers. Father an auto driver and Mother is a servant maid. Her persistent vomiting has led to deterioration of general condition and inability to do day-to-day activities.

Nausea and vomiting are symptoms, which can cause patients and their relative's great distress. Of the two, nausea causes the most prolonged misery. Many patients can tolerate one or two episodes of vomiting a day while persistent nausea can be profoundly debilitating.

What are the consequences for not providing adequate relief for nausea and vomiting?

Nursing Diagnosis – Fluid and Electrolyte Imbalance

Relating Factors:

- Anxiety
- Chemotherapy
- Gastritis/ulcers
- Brain metastasis
- Metabolic disturbances
- Indigestion, constipation etc.

Defining characteristics:

- Inability to ingest food due to nausea
- Inability to digest food
- Inability to absorb or metabolize food
- Knowledge deficit
- Unwillingness to eat
- Assess for past history and effectiveness of treatment of nausea and vomiting
- Medication history
- Frequency of episodes of nausea and any correlation with vomiting
- Abdominal evaluation, which includes assessment for bowel sounds and rectal vault.
- Sight of food makes patient nauseated.
- History on consistency, frequency and volume of emesis, emesis associated with position changes, presence of contributing factors i.e vertigo, blood sugar levels and medications.
- Documented inadequate food intake
- Aversion to food
- Frequent vomiting

Expected Outcome to care

Patient reports diminished or no nausea and vomiting.

Nursing interventions

Interventions	Rationale
<ul style="list-style-type: none"> Obtain nutritional history include family or caregiver 	The patient's perception of intake may differ.
<ul style="list-style-type: none"> Monitor attitudes toward eating and food 	With that will be able to assess the reason for minimal consumption of food.
<ul style="list-style-type: none"> Monitor laboratory values such as serum albumin, serum electrolytes and RBC's. 	So that replacement can be done.
<ul style="list-style-type: none"> Check to see if something unpleasant that contributes to nausea and vomiting 	Offensive sensory data can stimulate the vomiting center in the brain
<ul style="list-style-type: none"> Temporarily limit the patients food intake 	Episodes of vomiting can be reduced by decreasing the food intake
<ul style="list-style-type: none"> Help the patient to take deep breaths 	Distraction can overcome nausea but changing the conscious focus from an unpleasant sensation will reduce nausea.
<ul style="list-style-type: none"> Limit the patient's movements and activities 	Movements stimulates the vomiting centre
<ul style="list-style-type: none"> Help the patient to rinse the mouth soon after vomiting 	Emesis usually produces an unpleasant aftertaste
<ul style="list-style-type: none"> Avoid making negative comments about the food 	Negative comments usually stimulate the vomiting centre
<ul style="list-style-type: none"> Adjust light, sound, ventilation and temperature to comfortable level 	Minimizing sensory stimulation may reduce the desire to vomit
<ul style="list-style-type: none"> Remove the container of emesis from the bedside as soon as possible 	The appearance and odor of the emesis may stimulate more vomiting
<ul style="list-style-type: none"> Provide oral care after each emesis 	Oral hygiene will help promote comfort.
<ul style="list-style-type: none"> Offer frequent, small amounts of foods that appeal to the patient provides bland, simple foods like soups, rice, bananas. 	This approach will maintain nutritional status for some patients, an empty stomach exacerbates the nausea.

<ul style="list-style-type: none"> • Avoid greasy or fried foods 	Fats are difficult to digest and may exacerbate the nausea.
<ul style="list-style-type: none"> • Administer antiemetic as ordered. 	Most antiemetic act by raising the threshold of the chemoreceptor trigger zone to stimulation.

Home Care Education

- Encourage small and frequent feeds.
- Encourage the patient to choose the menu.
- Avoid taking high protein diet when patient has nausea and vomiting.
- Make sure patient is taking adequate salt –Normal salt intake 10-12mg/day.
- Explain the patient and family about the signs and symptoms of dehydration and hyponatremia.
- Avoid sitting near the kitchen while cooking this smell may aggravate the nausea.
- Environmental modification – eliminates strong smells and sights.
- Maintain good oral hygiene, especially after episodes of vomiting.
- Use complimentary therapy to manage nausea and vomiting eg: distraction.
- Rule out the cause- if it is due to constipation consider laxative or enemas as necessary.
- Educate the patient and family about taking the medication at correct time
(Eg: T Omeprazole on empty stomach; T. Metoclopramide [Perinorm] 10mg half an hour before food)

Constipation

Mr. Ravi is a 75-year-old gentleman with a history of adenocarcinoma of the bowel. He lives with his wife and has two grown children who do not live with him. They survive on government pension. He is on T. Tramadol 50mg q6h, and T. Paracetamol 500mg q6h for his abdominal pain. His recent CT abdomen shows disease recurrence in the mesenteric lymph nodes. Now he has come to OPD with the complaints of not passing stools for past 9 days and presented with colic abdominal pain, and vomiting since 2 days.

What are the causes for constipation?

What measures can be taken to relieve his constipation?

List the different types of laxatives?



Constipation is decrease in normal frequency of defecation accompanied by difficult or incomplete passage of stool and or passage of excessively hard, dry stool.

Nursing diagnosis - Constipation

Relating Factors

- Malignant Bowel obstruction
- Hypercalcemia

- Inadequate fluid intake - dehydration
- Low fiber diet
- Inactivity/ immobility
- Medications e.g: Morphine
- Lack of privacy
- Fear of pain with defecation – fissures/fistula
- Stress or depression
- Neurogenic disorders – cord compression.

Defining Characteristics:

- Bowel history includes the characteristics such as appearance and consistency, frequency of stool
- History of use of bowel medications
- Presence of concurrent medical conditions
- Constipation problems prior to disease
- Perform an abdominal assessment to rule out obstruction which includes examination for bloating, tenderness, bowel sounds and rectal assessment for impaction
- Abdominal x-ray may be necessary to rule out bowel obstruction
- Digital rectal examination should be initiated.
- Visual inspection should be accomplished examining for hemorrhoids, ulceration or rectal fissures



Expected Outcome to care

Patient passes soft-formed stool at a frequency perceived as “normal” by the patient.

Nursing interventions

Interventions	Rationale
<ul style="list-style-type: none">Assess usual pattern of elimination; compare with present pattern. Include size, frequency, color and quality of stool.	“Normal” frequency of passing stool varies from twice daily to once every third or fourth day. It is important to ascertain what is “normal” for each individual.
<ul style="list-style-type: none">Evaluate reliance on enemas for elimination	Abuse or overuse of cathartics and enemas can result in dependence on them for evacuation.
<ul style="list-style-type: none">Evaluate usual dietary habits, eating habits, eating schedule and liquid intake.	Change in mealtime, type of food, and disruption of usual schedule can lead to constipation.
<ul style="list-style-type: none">Assess activity level	Prolonged bed rest, lack of exercise, and inactivity contribute to constipation.
<ul style="list-style-type: none">Evaluate current medication usage that may contribute to constipation.	Drugs that can cause constipation include the following: narcotics, antacids with calcium or aluminium base, antidepressants, and anti-cholinergic drugs.
<ul style="list-style-type: none">Maintenance of an adequate bowel protocol usually requires a prophylactic stool softener and stimulant	This helps to soften the stool and for easy expulsion
<ul style="list-style-type: none">Encourage patients to drink plenty of fluids as tolerated while increasing their activity as appropriate	Oral fluid promotes hydration and avoids dry stool
<ul style="list-style-type: none">Teach on active and passive exercises	To improve GI motility
<ul style="list-style-type: none">High fiber food (e.g., raw fruits, fresh vegetables, whole grains) to be taken with adequate fluids	Intestinal fiber adds bulk to and pulls water into stool. A bulky soft stool distends the rectum and promotes the urge to defecate
<ul style="list-style-type: none">Consider enema and suppositories if	Suppositories and enema help the patient to

patient is no longer able to tolerate oral medications or they have become ineffective	defecate easily without much effort
<ul style="list-style-type: none"> Digitally removal fecal impaction as ordered 	Stool that remains in the rectum for long periods becomes dry and hard; debilitated patients may not be able to pass these stools without manual assistance.

Home care education:

1. Explain about laxative protocol necessary to the patient
2. Explain to the patient that even though the patient is on liquid diet, they are expected to pass stools (at least small volume)
3. Seek for medical help when patient has more than 2 to 3 days of constipation
4. Explain about spurious diarrhoea¹⁵

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This is leaking of foul smelling loose stools due to sever constipation. Here the loaded feces is acted on by anaerobic bacteria and liquefies and may be mistaken for diarrhoea. Treatment is relieving the constipation.

Diarrhoea

Mr. Paul Varghese a 40 years old man recently diagnosed with carcinoma hypopharynx. He is on nasogastric tube for dysphagia. He is dehydrated with coated tongue, very fatigue and bed ridden. His caregiver verbalized regarding his burden in frequent changing of bed sheets and cloths because of continuous loose stool.

What will be the immediate management?



Diarrhoea is the frequent passage of loose non-formed stool.

Nursing Diagnosis – Impaired bowel movements - Diarrhoea

Relating factors

- Excessive dietary fiber intake,
- Radiation therapy to pelvis
- Drugs
- Herbal remedies
- Infection
- Over the counter medications

Defining Characteristics:

- Bowel history
- Nature of diarrhea
- Medication history including use of laxatives
- Assessment of nature and frequency of stools
- Presence of dehydration

Expected outcome to Nursing interventions

Interventions	Rationale
<ul style="list-style-type: none"> • Assess the patients normal bowel elimination pattern 	To obtain the baseline data
<ul style="list-style-type: none"> • Determine the cause for incontinence 	To provide appropriate intervention
<ul style="list-style-type: none"> • Perform manual check for fecal impaction 	When the patient has a fecal impaction (hard, dry stool that cannot be expelled normally), liquid stool may leak past the impaction.
<ul style="list-style-type: none"> • Assess the use of diapers and underpads 	Patient or caregivers may substitute familiar products.
<ul style="list-style-type: none"> • Assess perineal skin integrity 	Stool can cause chemical irritation to the skin, which may be exacerbated by the use of diapers and under pads.
<ul style="list-style-type: none"> • Correct any obvious factors related to assessment 	Decreasing nutritional supplements changing fiber intake, holding or substituting medications associated with diarrhea
<ul style="list-style-type: none"> • Notify physician if it is of bacterial cause 	For clostridium difficile is most common
<ul style="list-style-type: none"> • Educate patient and family about cleaning the perineum carefully and gently after defecation 	To prevent skin breakdown
<ul style="list-style-type: none"> • Instruct patient and family on any untoward signs and symptoms including dizziness, excessive thirst, fever etc 	Immediate treatment can prevent complication such as dehydration.

<ul style="list-style-type: none"> • Provide support to patient and family. 	Recognize negative effects of diarrhea on quality of life.
<ul style="list-style-type: none"> • Advice to eat small frequent bland meals. Low residue diet – potassium rich 	
<ul style="list-style-type: none"> • Avoid intake of hyper osmotic supplements 	This will increase the frequency of stool.
<ul style="list-style-type: none"> • Increase fluids in diet atleast 3 litres/day which includes electrolyte drinks 	To prevent fluid and electrolyte imbalance.
<ul style="list-style-type: none"> • Wash the perineal areas after each evacuation with soap and water, dry thoroughly. 	Any fecal material left on the skin can cause skin excoriation and pain.
<ul style="list-style-type: none"> • Treat any perineal irritation with moisture barrier ointment. 	Perineal or Perianal pain from irritation may result in fear of defecating and cause the patient to deny the urge to defecate.
<ul style="list-style-type: none"> • Discourage the use of pads, diapers, or collection devices as soon as possible. 	Fecal containment devices can be useful in the short term to prevent soiling.

Home care education

1. Explain to the patient about the signs and symptoms of dehydration.
2. Explain about ORS preparation
3. Acknowledge the carer's burden and sharing the work will minimize the burden
4. Explain about importance of maintaining skin integrity

Nutrition



Mr. Anand 44 year old gentle man diagnosed with carcinoma of the esophagus who has persistent pain reports feeling anxious and tearful and had trouble having a sleep. He thinks the sickness is a sign that his cancer is taking over his body that he won't be able to eat any more. He knows that if he does not eat he will get weaker until he dies and his body image distresses him greatly.

The home care nurse, visited him and assessed. He and his family members were taught about methods of overcoming anorexia. List of different high calorie blenderized menu was provided to them. They were also advised to offer him small quantity, frequent feeds. After 3 weeks, he was found to be doing better. The patient was comfortable as he had stopped losing weight, and had gained half kilograms.

What balanced diet chart will you prepare for Mr. Anand?

Anorexia is defined as a loss of desire to eat or a loss of appetite associated with a decrease in food intake (Grant, 1986).

Cachexia is a general lack of nutrition and wasting occurring in the course of a chronic disease.

Related factors:

- Inability to ingest food
- Inability to digest food
- Inability to absorb or metabolize food
- Loss of taste
- Dry mouth, Mucositis

- Knowledge deficit
- Unwillingness to eat
- Increased metabolic needs caused by disease process or therapy.
- Anorexia/cachexia
- Oral or systemic infection
- Disease progression and obstruction of GI tract

Defining Characteristics:

- Review the dietary pattern
- Check weight
- Watch for edema- Anasarca
- Watch for symptoms of anemia, dehydration, electrolyte imbalance, loss of appetite
- Assess for oral thrush, oral mucositis
- Assess for nausea, vomiting and constipation
- Laboratory evaluation- Hb Level, Serum sodium, potassium, albumin

Nursing Diagnosis – Imbalanced nutrition intake less than body requirements

Expected Outcome to nursing interventions

Patient or caregiver verbalizes and demonstrates interest in selection of food or meals that will achieve the optimal requirements.

Intervention	Rationale
<ul style="list-style-type: none"> ● Monitor nutritional status 	By weighing and reviewing what patient is eating
<ul style="list-style-type: none"> ● Monitor for sore throat that progress to dysphagia and odynophagia 	Suggestive of esophageal candidiasis
<ul style="list-style-type: none"> ● Consult with a dietician 	To develop strategies for nutrition care
<ul style="list-style-type: none"> ● Include patient in decision making regarding nutrition care 	It promotes QOL (Quality Of Life)
<ul style="list-style-type: none"> ● Encourage mouth wash every two hours 	It prevents dryness of mouth.

<ul style="list-style-type: none"> • Encourage small and frequent feeds with high energy e.g.: honey, chocolates, desserts... 	Easy for digestion and prevent early satiety
<ul style="list-style-type: none"> • Avoid highly seasoned and spicy food 	It increases anorexia
<ul style="list-style-type: none"> • Offers blenderized home food and avoid giving commercially available ready mix food. 	To minimize chewing and ease swallowing and it encourages family participation. Homemade food is cost effective and promote satisfaction
<ul style="list-style-type: none"> • Provide odour free environment 	Cooking smell or odour aggravates anorexia
<ul style="list-style-type: none"> • Administer appetite stimulants (magentrol), steroids (Dexamethasone) 	Increases appetite
<ul style="list-style-type: none"> • Administer medication for associated symptoms 	Relieves symptoms associated with anorexia
<ul style="list-style-type: none"> • Daily requirement of 8-10gm of salt should be added to the diet. 	To prevent hyponatremia
<ul style="list-style-type: none"> • Appropriate electrolyte replacement (Na⁺, K⁺, Mg⁺) is done with Parenteral fluids 	In some cases Parenteral or enteral nutrition may prove useful in patients who cannot swallow but continue to have an appetite, such as in esophageal cancer.
<ul style="list-style-type: none"> • Enteral feeds such as gastrostomy, jejunostomy, NG/NJ feeds are given where needed 	Intestinal obstructions are managed with enteral feeds and stent placement

Home care education:

1. Explain to the relatives NOT to force.
2. Small quantity with high calories and protein will help in meeting required calories.
3. Routine pattern of meal to be avoided.
4. Serve each in a small quantity, which the patient could finish

Anxiety

Anxiety is a subjective feeling of apprehension, tension, insecurity, and uneasiness, usually without a known specific cause.



Mrs. Suchita forty-five year old woman is diagnosed with carcinoma breast. Seven months back mastectomy had been performed and she received her course of chemotherapy after her surgical recovery. She was readmitted four months later with nausea and vomiting. On admission she was told about possible recurrence and advancement of her disease and that cancer was incurable. Mrs. Suchita and her husband were extremely anxious and they had many plans thinking that her initial surgery had been successful. Her only daughter got engaged recently and her marriage date was falling after three months.

The primary nurse ensured that her husband was included in planning her care. Most of her subsequent care continued at home within the surrounding where she lived. Mrs. Suchita and her husband knew that time together was the only valuable thing during the difficult journey towards death. Arrangements were made to prepone her daughter's marriage. Many nursing measures were taught to both of them to reduce the anxiety level.

In his next outpatient visit Suchita's husband verbalized that her anxiety level has come down and she was able to make some planning about her life and was able to participate in family decision-making process.

Nursing Diagnosis - Anxiety

Related factors:

Changes in or threats to

- role function or status of a person
- health status
- environment
- economic status
- interpersonal relationship
- unmet needs

Defining Characteristics:

- Apprehension
- Worry
- Inability to relax
- Fear of death
- Feeling of worthlessness and hopelessness
- Irritability
- Tension
- Difficulty in concentrating
- Difficulty in falling and staying asleep
- Physical symptoms can include perspiring for no reason, tearful
- Tachycardia, restlessness, agitation, trembling, chest pain, hyperventilation.

Expected Outcome to nursing intervention

Patient uses effective coping mechanism and describes a reduction in the level of anxiety experienced.

Intervention	Rationale
<ul style="list-style-type: none">• Assess causes for anxiety	To get the base line information.
<ul style="list-style-type: none">• Develop an honest non - judgmental relationship with the patient.	Nurse patient relationship allows appropriate discussion of concerns.
<ul style="list-style-type: none">• Stay with the patient	Physical presence relieves fear and enables trust relationship with the patient.
<ul style="list-style-type: none">• Acknowledge patient fears, using open-	Helps the patient to identify effective coping

ended questions, reflecting, clarifying, and use of empathetic listening and remarks	strategies they have used in the past and to learn new coping skills.
<ul style="list-style-type: none"> • Provide concrete and relevant information pertaining to their anxiety 	Eliminates fear of the unknown, and in appropriate situations, provide stressful event warning.
<ul style="list-style-type: none"> • Assess family / caregiver reactions and concerns to the patient's condition. 	Relieves unknown fear and it enables compliance with the patient care
<ul style="list-style-type: none"> • Increase patient and family participation in care activities 	Patient and family are considered as single unit
<ul style="list-style-type: none"> • Control symptoms with appropriate measures. 	Maximizing symptom management to decrease physical stressors that can exacerbate depression and anxiety symptoms.
<ul style="list-style-type: none"> • Teach anxiety reduction strategies such as focusing in deep breathing, massaging, relaxation and imagery techniques 	Relaxation therapies is the one of the first step in stress management it can be used to reduce anxiety
<ul style="list-style-type: none"> • Administer anxiolytics as prescribed 	Benzodiazepines, tricyclic anti depressants relieves anxiety
<ul style="list-style-type: none"> • Repeat realistic reassurances 	Promotes hope
<ul style="list-style-type: none"> • Refer to psychiatric experts 	It may be needed for those experiencing significant inability to cope with the experience of their medical illness

Homecare Education:

1. Never leave the patient alone. Presence of the family members will reduce the anxiety.
2. Encourage the patient to avoid sleeping in the daytime, So that patient will have good sleep at night.

Social isolation



Mr. Roshan, 35 years old gentle man from a middle class family was diagnosed one year ago with carcinoma of right buccal mucosa, which is inoperable. He underwent local radiation therapy but unable to afford for the full course of chemotherapy. Two months back he developed a fungating wound over the cheek with foul smelling and continuous discharge from the wound. After developing cutaneous fistula he separated his personal things like utensils like plate, glass and started to restrict himself from mingling with family members and neighbours. He found that the dressing materials were expensive so he was not able to dress his wound daily. He didn't allow his family members to clean his wound because he thought that it was contagious and the disease will spread to them. During the nurse visit, patient and his caregiver were explained that it is not a communicable disease. She demonstrated the cost effective dressing material and solution preparation at home setting. Metronidazole was used to minimize the bad odor. This enabled him to easily mingle with the family members and neighbours. It also improved his body image. Adequate explanation was given by the community nurse to clear their doubts.

Nursing Diagnosis – Social isolation

Related factors:

- Social stigma about the malignancy
- Misconception about contagiousness
- Care giver's burden

- Body image disturbances
- Being neglected from family member, relatives, and neighborhood.
- Self-withdrawal from the family and the social activities.
- Financial constraints.
- Body image disturbances.

Defining Characteristics:

- Loneliness
- Sleeplessness
- Visual grimaces
- Limited speech
- Poor eye contact
- Expressing sadness
- Difficulty to Communicate

Expected Outcome to care

Patient demonstrates positive coping strategies, use of available resources and decreased number of self-deprecating remarks.

Intervention	Rationale
<ul style="list-style-type: none"> • Assess the reason for social isolation 	There is a stigma that cancer is due to curse/sin.
<ul style="list-style-type: none"> • Educate the patient and family that cancer is not contagious 	Cancer is a non-communicable disease.
<ul style="list-style-type: none"> • Introduce other patients and family with the same diagnosis 	Peer group clarifies their doubts from each other.
<ul style="list-style-type: none"> • Encourage the patient and family to get involved in the social events. 	It will improve the self-esteem
<ul style="list-style-type: none"> • Identify the level of financial constraints and help them out with appropriate resources. 	Nurses can refer them to other available resources

<ul style="list-style-type: none"> • Get help from counselors or refer them during the time of family crisis and relationship problems. 	Nurses need to be a license between the patient and other interdisciplinary team.
<ul style="list-style-type: none"> • Help them to resolve the body image disturbances by appropriate interventions and devices (prosthesis). 	Able to cope with the current situation.
<ul style="list-style-type: none"> ▪ Spend time with the client 	Social interaction make the patient to feel as worthwhile person
<ul style="list-style-type: none"> ▪ During the interaction sit within three feet of the client 	Sitting closely provides evidence that closeness is a not problem
<ul style="list-style-type: none"> ▪ Acknowledge verbally that smell from the ostomy, wound, fistula is difficult to accept. 	Verbalizing what the client is implying non-verbally and actively demonstrating shows empathy.

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Death and dying: End of life Care Inputs

Dying is an inevitable aspect of life. It is an active process, but it is often difficult to note when it begins. Health professionals who understand the inevitability of a patient's death may seek to provide patients with an opportunity for a "good death", or a positive dying experience. A care plan guide addresses the emotional aspect of death and dying.

Commonest emotional and physical concerns faced during end of life are:

1. Fear
2. Dyspnoea
3. Pain
4. Grief
5. Fatigue and powerlessness
6. Spiritual distress
7. Care giver role strain
8. Impaired physical mobility
9. Self care deficit
10. Knowledge deficit

Fear:

Common related factors

- Threat of death
- Pain and anticipation of pain
- Anticipation or perceived threat of danger
- Unfamiliar environment
- Environmental stressors
- Separation from support system
- Treatment and invasive procedure
- Sensory impairment
- Phobias and anxieties
- Concern about future, ability of survivors to manage
- Dependence on others

Defining characteristics

- Expressions of fear and mixed emotions
- Rapid respirations and heart rate
- Gaunt appearance
- Tension, jitteriness and irritability
- Impulsive behavior

Expected outcomes to care

- Help patient to
 - identify source of fear related to dying.
 - implement a positive coping mechanism.
 - verbalize reduction and absence of fear.

Actions/Interventions

Rationales

Help the patient express his or her fears by careful, thoughtful questioning and active listening.

Do not assume that because a patient is dying that his or her fears are limited to death.
Fears are patient-specific.
Being present and being silent are powerful communication techniques.

	It is important for the nurse to acknowledge his or her own fears.
Assess the nature of the patient's fear and the methods that the patient uses to cope with the fear.	<p>Fear ranges from paralyzing, overwhelming feeling to mild nagging concern.</p> <p>Some fears can be resolved by providing the patient with information.</p> <p>Fears can be managed through talking and sharing.</p> <p>Patient philosophy about death may influence his or her ability to cope.</p>
Document verbal and non verbal expressions of fear	Documenting expressions of fear gives care providers the information they need to provide support to the patient.
Confirm your awareness of the patient's fear. Validate the feelings of the patient and communicate an acceptance of those feelings.	Loved ones may think that the patient who is dying should be protected from the knowledge that his or her condition is terminal, or the patient may maintain denial until the end, which can lead to distressful death.
Spend time with the patient	The simple act of being present can have profound significance. This presence may involve talking or touching, ministering to a physical need, or simply sitting near to the bedside.
Reframe hope to alleviate fear.	Patients may fear impending hopelessness or abandonment and need reassurance and validation that comfort (palliation) is obtainable.
Encourage reminiscing	Reminiscing provides reassurance that one's life has meaning and eases the intensity of the present reality.

Actions/Interventions	Rationales
<p>While interacting with the patient, maintain a calm and accepting manner that expresses care and concern.</p>	<p>Patients who are talking about real feelings do not want false reassurances.</p> <p>They do need to feel safe in discussing troubling matters. Some of the social isolation that dying patients feel is the result of trying to protect intimate friends and family members from their need to talk about their impending death and what it means to them.</p>
<p>Confirm that fear is a normal and appropriate response to situations when pain, danger, or loss of control is anticipated or experienced.</p>	<p>This reassurance places fear within the scope of normal human experiences.</p>
<p>Assist the patient in identifying, coping and comfort strategies that were helpful in the past.</p>	<p>Identifying the strategies helps the patient to focus on fear as a real and natural part of life that has been and can continue to be dealt with successfully.</p>
<p>Include family members in care activities.</p>	<p>Involvement of family in the care of the dying patient may assist in their sense of worth and decrease their sense of fear and helplessness in the dying process.</p>
<p>Assess sensory stimulation preferences. Remove unnecessary threatening equipment.</p>	<p>Fear may escalate with over stimulation or under stimulation.</p> <p>Although staffs are comfortable around high technology medical equipment, many patients are not.</p>
<p>Encourage rest and relaxation.</p>	<p>Rest builds inner coping resources.</p> <p>The health care team will need to pace activities (especially for older adults) in order to conserve the patient's energy and offset fatigue.</p>
<p>Instruct the patient in the performance of</p>	<p>These measures reduce fear or make it more</p>

<p>self-calming measures:</p> <ul style="list-style-type: none"> • Breathing exercises • Relaxation, meditation or guided imagery exercises • Affirmations and calming self-talk exercises. 	<p>manageable.</p> <ul style="list-style-type: none"> • The exercise reduces the physiological response to fear. (i.e, blood pressure, pulse, respiration) • These exercises promote relaxation and relieve distress. • The exercise enhances the patient’s self-confidence.
<p>Provide continuity of care</p>	<p>An ongoing relationship establishes trust and is a basis for communicating fearful feelings.</p>

Impaired breathing pattern - dyspnoea

Dyspnoea is an uncomfortable awareness of breathing that is common in patients approaching the end of life.

Relating factors:

- Primary lung tumor
- Lung metastases
- Pleural effusion
- Restrictive lung disease
- Decreased energy and fatigue
- Cardio pulmonary compromise
- Consolidated pneumonia
- Pulmonary Edema etc.

Defining Characteristics:

Dyspnoea

Tachypnoea

Fremitus

Cyanosis

Cough

Nasal flaring

Respiratory depth changes

Altered chest excursion

Use of accessory muscles

Expected Outcome to care:

Optimal breathing pattern is obtained as evidenced by comfortable posture and ability to rest and relax.

Actions/Interventions	Rationales
Assess respiratory rate and depth.	Respiratory rate and rhythm changes are early warning signs of impending respiratory difficulties.
Monitor breathing patterns such as bradypnea, tachypnea, hyperventilation.	Specific breathing patterns may indicate an underlying disease process or dysfunction.
Assess the position that the patient assumes for easy breathing.	Orthopnea indicates breathing difficulty.
Assess for use of accessory muscles.	As moving air in and out of the lungs becomes more and more difficult the breathing pattern alters to include use of accessory muscles to increase chest exertion to facilitate effective breathing.
Assess skin color and temperature.	Pale or cyanotic color indicates increased concentration of de-oxygenated blood and indicates that the breathing pattern is no longer effective to maintain adequate oxygenation of tissues.
Assess level of anxiety	Hypoxia and the sensation of “not being able to breath” is frightening and may cause worsening hypoxia.
Use pulse oximetry to monitor oxygen saturation and pulse rate.	It is a useful tool to detect changes in oxygenation
Monitor for changes in level of consciousness	Restlessness, confusion and irritability can be early indicators of less oxygen to brain.
Position patient with proper body alignment for optimal breathing pattern.	Sitting position allows for good lung & chest expansion
Maintain oxygen saturation to the optimum level.	This provides adequate oxygenation and prevents hypoxia.
Plan activity and rest to maximize the patient’s energy.	Fatigue is common with the increased work of breathing. Activity increases metabolic rate and oxygen requirements. Rest helps mobilize

	energy for more effective breathing.
Provide reassurance and allay anxiety by staying with patient and administer prescribed anxiolytic medications.	This relieves anxiety and thereby reduces hypoxia.
Use pain management as appropriate.	Pain relief enhances the ability to deep breath and cough.
Administer prescribed respiratory medications as indicated.	Beta-adrenergic agonist medications relax airway smooth muscles and cause bronchodilation to open air passages. Steroids are effective anti-inflammatory drugs for treatment of reversible airflow obstruction.

Risk for Aspiration

Patient is at risk for entry of gastrointestinal secretions, oropharyngeal secretions, solids or fluids into tracheobronchial passage.

Relating Factors

- Reduced level of consciousness
- Depressed cough and gag reflexes
- Presence of tracheostomy
- Increased secretions
- Presence of gastrointestinal tubes
- Inappropriate Nasogastric tube feeding
- Sedative medication
- Decreased gastrointestinal motility
- Impaired swallowing

Expected outcome to care

Patients maintain patent airway and to decrease the risk of aspiration by frequent assessment and early intervention.

Actions/Interventions	Rationales
Monitor level of consciousness	Decreased level of consciousness is a prime risk factor for aspiration.
Assess cough, noisy breathing (death rattle) and gag reflexes.	Diminished reflexes increases the risk of aspiration
Position the patient with head end elevation and turned to one side.	This protects the airway. Semi-conscious patients need frequent turning to facilitate drainage of secretions.
Monitor swallowing ability, assess for	Food can be easily aspirated at a later time.

residual food in mouth after eating.	
Explain the family members about current situation.	To minimize their anxiety.
Do gentle suction whenever necessary. Suction should be done only at the level of the mouth, throat and nasal pharynx	Suction rarely needed but can be done when appropriate.
Explain the relatives to feed sips of fluid when the patient is only fully conscious and oriented.	Thick fluids (porridge, honey) minimizes aspirations
Provide oral hygiene every 4 hourly	This removes residuals of food that can be later aspirated
Administer inj. Hyoscine Butylbromide as needed	Anticholinergic action reduces secretion.
Maintain upright position for 30-45 min. after feeding.	This facilitates the gravitational flow of food or fluid through the GI tract.

Grief

Common related factors

Impending death

Defining Characteristics

Expression of guilt, anger, sorrow, or anxiety.

Expression of feelings regarding potential loss of own life.

Suppression of feelings – withdrawn

Change in sleep, eating habits and level of activity.

Expected outcome to care

Patient verbalizes feelings regarding impending death.

Patient has functional support systems to aid in his or her grieving process.

Actions/Interventions	Rationales
Identify the patient's grieving process	Patient will express grief in varied and in personal ways.
Consistently reassess the phase of grieving being experienced by the patient or significant others.	This reassessment allows the care provider to place the patient and family's feelings, which are often turbulent and contradictory, within a framework that is sometimes more understandable.
Assess whether the patient and significant others are in different phases of grieving.	When appropriate, share this assessment with patients or family members. This may assist their understanding of conflicts or differences in expectations.
Identify available support systems: Family, peer support, primary physician, consulting physician, nursing staff, social worker, clergy, therapist, counselor, and professional or lay	Multiple options for help broaden the opportunities for patients and families to personalize their methods of problem resolution.

support group.	
Evaluate the need for home based care, social services, referral to hospice or support groups.	Patients prefer to die in their homes while receiving care from the family supported by a care team.
Establish a comfortable rapport with the patient and family. Listen and encourage the patient and family to verbalize feelings.	This rapport opens lines of communication and facilitates successful resolution of grief. The patient and family needs to complete issues within their relationships through open communication and shared feelings.
Provide privacy for the expression of grief	The environment needs to support the patient's expressions of grief (to cry loudly, make wide gestures with their hands and bodies). Expression of feelings is more likely to occur in privacy.

Anticipate strong emotions.	Patients whose emotional responses to life have been fairly predictable in the past may experience turbulent and disrupting grief. The use of a trained team member supporting her / him may prove helpful in working through this phase.
Help family members to understand that a patient's verbalizations of anger should not be perceived as personal attacks.	It is important for the family to understand that the dying patient is processing a large amount of emotional load. Help them understand that anger is part of the process of accepting death.
Provide information about the patient's health status without false reassurance or taking away all hope.	Hope is a basic survival instinct. After being informed of a poor prognosis, many patients and their families experience a defensive retreat from the shock of what they have been told. During this time, patients may engage in denial and wishful thinking. They may become unwilling to participate in self-care or may become indifferent about it.

Encourage the patient and family to engage in meaningful dialogue.	Exploring potential reality issues in a non-threatening manner will lead to informed decision-making and assist the patient and family in verbalization of the anticipated loss.
Encourage family members to talk with the patient who is withdrawn.	Encouraging family members to talk and visit with the patient, instills hope. It has been shown that the patient is well aware of his or her surrounding beyond the point of responsiveness.
Facilitate conversations with the patient and family on “final wishes (funeral, cremation, organ donation, funeral)	A clear understanding of the patient’s and family’s belief systems and cultural differences will help in advocating and facilitating open and honest communication regarding difficult subject matter.
Encourage the patient and family to share their wishes regarding who should be present at the time of death.	Family must think about this but may feel uncomfortable discussing this issue together.
Confirm whether family member/s that not being present at the time of death, does not indicate lack of love and caring.	The moment of death cannot be predicted. It is important to remember that individual needs of the bereaved are different. Yet essential to the process of grieving.

Follow unit policies to identify the patient’s critical status.	This identification informs all staff of the patient’s status and ensures that staff members do not act or respond inappropriately when encountering the patient or family.
Identify need for additional support system (peer support, groups, clergy)	Patients and families often become immersed in their grief and forget to access the resources available to them. Others may require expert help in negotiating grief. In either case, the care provider may be able to offer the observation that additional help is available.

<p>Foster continuity of end-of-life care across settings (Home care, hospice care).</p>	<p>Home based care is culturally suitable to India. The hospice concept offers an interdisciplinary approach and adds a unique dimension to end of life care for both patients and families.</p>
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Fatigue and powerlessness

Common related factors

- Terminal illness
- Irreversible physical decline
- Deconditioning

Defining Characteristics:

- Verbal expression of having lost control or influence over life.
- Reluctance to participate in decision-making
- Diminished patient initiated activities
- Submissiveness, apathy
- Withdrawal, depression
- Aggressive behavior, acting out, irritability
- Decreased interest in activities of daily living

Expected Outcomes to care

- Patient participates in care decisions.
- Patient makes important end of life decisions.

Actions/Interventions	Rationales
Assess the patient’s need for power and control.	Patients can identify those aspects of self-governance that are most important to them. Actively listen so the patient truly feels heard (offer your presence).
Assess for feelings of hopelessness, depression, and apathy	These feelings may be components of grief. There may be a tremendous guilt associated with any loss of control.
Identify situations or interactions that may increase the patient’s feelings of powerlessness.	Many medical routines are superimposed on patients without ever receiving the patient’s permission. This can foster a sense of powerlessness in patients. It is important for

	care providers to recognize the patient's right to refuse procedures.
Assess the patient's decision-making energy level and ability.	Powerlessness is not the same as the inability to make a decision. It is the feeling that one has lost the implicit power for self-governance. Energy conservation will help reduce or relieve fatigue so the patient will be better able to use available energy for appropriate decision making.
Recognize the patient's wishes for information about end-of-life decisions.	The act of providing information may heighten a patient's sense of autonomy. Realistic expectations actually decrease distress and worry, once again enhancing the patient's decision making (i.e., empowerment).
Support the patient's sense of autonomy by involving the patient in decision making, by giving and accepting information, and by assisting the patient with controlling the environment as appropriate.	The ultimate decision making authority lies within the patient. However, the goal of the health care professional is to assist patients in identifying and verbalizing their preferences in making authentic choices.
Assist the patient with developing an advance directive.	An advance directive allows patients to make decisions about their lives even after they are unable to express their own needs and desires.
Implement personalized methods of providing hygiene, intake and sleep. Enhance basic care by offering food, drink, comfort and security.	Allowing or helping the patient decide when and how these things are to be accomplished will increase the patient's sense of autonomy.
Encourage comfortable environment.	Having comfortable surroundings will enhance the patient's sense of autonomy and acknowledge the patient's right to have dominion over controllable aspects of his or her own life. This gives some normalcy to life during the dying process.

<p>Provide the patient with acceptable opportunities for expressing feelings of anger, anxiety, and powerlessness.</p>	<p>Verbalizing these feelings may diminish or diffuse the patient's sense of powerlessness. The care provider may need to make a special effort to maintain a careful sense of timing and compassion to alleviate the patient's feelings of loneliness or abandonment.</p>
<p>Offer continuity of a support network.</p>	<p>Encourage personal control by offering continuity in staffing and sustained involvement of family.</p>

Advance directive:

An advance directive is a legal document that expresses the patient's wishes and desires for his or her health care treatment in case he or she becomes terminally ill and unable to articulate wishes and desires. These directives will act in the place of the patient's verbal requests and serve as assurance that the patient's end-of-life decisions will be honored.

Durable power of attorney for health care:

This document allows the patient to designate another person to make health care decisions on the patient's behalf. The durable power of attorney for health care becomes effective if the patient becomes unable, either temporarily or permanently, to make his or her own health care decisions.

Living will declaration:

This document contains instructions that a patient is allowed to die if he or she becomes terminally ill and unable to communicate to the extent required by law. It recognizes the patient's desire not to be kept alive artificially and sets parameters on the limits to which health care providers may proceed.

Spiritual Distress

Common Related Factors

- Terminal illness
- Separation from loved ones
- Separation from religious and cultural ties
- Challenged belief and value system
- Pain and suffering.

Defining characteristics

- Questions like meaning of life and death and/ belief system seeks spiritual assistance.
- Voices guilt, loss of hope, spiritual emptiness, or feeling of being alone.
- Appears anxious, depressed, discouraged, fearful or angry.

Expected outcome to care

Patient expresses value and comfort in his or her personal belief system.

Actions/Interventions	Rationales
Assess history of religious affiliation.	Information regarding specific religion and importance of rituals or practices may improve understanding of the patient’s needs while dying.
Assess spiritual beliefs.	Individuals may have other important beliefs apart from those from religion that provide strength and inspiration at the end of life.
Assess the spiritual meaning of illness and death. “do you wonder regarding the meaning of your illness?” “How does the current situation affect your relationship with God, your beliefs, or other sources of strength?” “Do your illness and grief interfere with	These questions provide a basis for understanding the patient’s distress. The patient’s process of introspection will assist him or her in the process of comprehending the loss.

expressing your spiritual beliefs?”	
Assess whether patients need help with unfinished business.	Patients may not find peace or acceptance until important affairs are in order. The health care team can provide guidance to patients while assisting in identifying strengths and values pertinent to their system.
Provide understanding and acceptance. Support crying by offering caring touch.	Sharing concerns and understanding of the end-of-life journey the patient and family are experiencing will reveal the integrity and professionalism that the care provider holds in helping them through the dying process.
Encourage verbalization of feelings of anger or loneliness.	Patients need the opportunity to express feelings associated with fear of abandonment.
When requested by the patient, arrange for priest, rituals, music, prayers, scriptures or images.	Patients may derive comfort and relief from these intimate spiritual experiences.
If requested, sit with the patient who wishes to pray, and arrange for priest at time of death as requested by the patient.	Being open to cultural and religious differences will allow the patient’s traditions and rituals to be a part of their care while providing comfort and compassion to both the patient and family.
Do not provide intellectual solutions for spiritual problems.	Spiritual beliefs are based on faith and are independent of logic.

Pain

Definition:

Unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage (International Association for the study of pain IASP)

A patient with chronic pain often does not present with behaviors and physiological changes associated with acute pain.

Common Related Factor:

Chronic physical or psychosocial disability

Defining characteristics:

Patient reports pain

Guarding of a body part

Irritability, restlessness

Anorexia

Changes in sleep pattern

Fatigue

Fear of reinjury

Reduced interaction with people

Depression

Altered ability to continue previous activities

Atrophy of involved muscle group

Occasionally - Sympathetic mediated responses (e.g., temperature, cold, changes of body position, hypersensitivity)

Expected Outcomes to care

Patient reports pain at level less than 3 to 4 on a 0 to 10 rating scale.

Patient uses pharmacological and non-pharmacological pain relief strategies.

Patient engages in desired activities without an increase in pain level.

Actions/Interventions	Rationales
<p>Assess pain characteristics:</p> <ul style="list-style-type: none"> • Quality (e.g. sharp, burning) • Severity – pain scale is to be explained clearly as 0 (no pain) to 10 (the worst imaginable pain) • Location (anatomical description) • Onset (gradual or sudden) • Duration (e.g. continuous, intermittent) • Precipitating factors • Relieving factors 	<p>The most reliable source of information about the chronic pain experience is the patient’s self-report. Systematic assessment and documentation of the pain experience provides direction for a pain management plan.</p> <p>Pain score of 0-3 is mild; 4-7 is moderate and 8-10 is considered severe. Documenting the pain score as the 5th vital sign in the chart and maintaining it to < 3/10 is helpful to assure relief.</p>
<p>Assess for signs and symptoms associated with chronic pain such as fatigue, decreased appetite, changes in body posture, facial grimace, groaning with pain, sleep pattern disturbance, anxiety, irritability, restlessness, or depression.</p>	<p>Patients with chronic pain may not exhibit the physiological changes and behaviors associated with acute pain. Pulse and blood pressure are usually within normal ranges. The guarding behavior of acute pain may become a persistent change in body posture for the patient with chronic pain. Coping with chronic pain can deplete the patient’s energy for other activities. The patient often looks tired with a drawn facial expression that lacks animation.</p>
<p>Assess the patient’s perception of the effectiveness of methods used for pain relief in the past.</p>	<p>Patients with chronic pain have a long history of using many pharmacological and non-pharmacological methods to control their pain. An effective pain management plan will be based on the patient’s previous experience with pain relief measures.</p>
<p>Evaluate gender, cultural, societal and religious factors that may influence the patient’s pain experience and response to pain relief.</p>	<p>Understanding the variables that affect the patient’s pain experience can be useful in developing a care plan that is acceptable to the patient. The patient’s heritage will influence the</p>

	meaning of pain, expressions of suffering associated with pain and selection of pain management strategies.
Assess the patient's expectations about pain relief.	The patient with chronic pain may not expect complete absence of pain but may be satisfied with decreasing the severity of the pain and increasing activity level.
Assess the patient's attitudes toward pharmacological and nonpharmacological methods of pain management.	Patients may question the effectiveness of nonpharmacological interventions and see medications as the only treatment for pain. Patients may have misconceptions regarding alternative and complementary therapies for pain relief.
For patients taking opioid analgesics, assess for side effects dependency and tolerance. Administer alternative routes (Parenteral, transdermal patch, sub lingual) as needed.	Drug dependence and tolerance to opioid analgesics are concerns in the long terms management of chronic pain. The patient and family may have misconceptions and fears about drug tolerance, dependence and addiction.
Review the drug history and remove non-essential drugs.	Administer only the necessary drugs relevant to symptom relief and quality of life. Reassess the need to continue anti-diabetic, anti-cholesterol, multi vitamins etc.
Acknowledge and convey acceptance of the patient's pain experience.	The patient may have had negative experiences in the past with attitudes of health care providers towards the patient's pain experience. Conveying acceptance of the patient's pain promotes a more cooperative nurse- patient relationship.
Provide the patient and family with information about pain and options available for pain management.	Lack of knowledge about the characteristics of pain and pain management strategies can add to the burden of pain in the patient's life.
Assist the patient in making decisions about selecting a particular pain management strategy.	Guidance and support from the nurse can increase the patient's willingness to choose new interventions to promote pain relief. A combination of nonpharmacological therapies

	<p>and analgesic medications may be most effective. Nonopioid medications are preferred medications because of their low side-effect profile, especially among older patients. Medications should be given around the clock to achieve a consistent level of pain relief and comfort. The oral route is preferred.</p>
<p>Refer the patient to a physical therapist for evaluation.</p>	<p>The physical therapist can help the patient with exercises to promote muscle strength and joint mobility and therapies to promote relaxation of tense muscles. These interventions can contribute to effective pain management.</p>
<p>Teach the patient and family about using non-pharmacological pain management strategies.</p>	<p>Knowledge about how to implement non-pharmacological pain management strategies can help the patient and family gain maximum benefit from these interventions.</p>
<p>Allow family members and caregivers to express feelings about the patient's impaired memory and behavior.</p>	<p>The demands of caring for the patient with impaired memory may have a significant impact on the family's lifestyle and interactions. Unresolved stress and frustration may lead to angry verbal or physical outbursts directed toward the patient.</p>
<p>Teach the patient effective timing of the medication dose in relation to potentially uncomfortable activities and prevention of peak pain periods.</p>	<p>Patients need to learn to use pain relief strategies to minimize the pain experience.</p>
<p>For retractable pain terminal sedation may be required after discussing with the family members and as per the decision taken by multidisciplinary team.</p>	<p>Acknowledge the need for terminal sedation after trying all other measures of pain management. It is very important in maintaining the quality of life in end stage.</p>

Impaired Physical Mobility

Definition: Limitation in independent, purposeful physical movement of the body or of one or more extremities.

Common Related Factor:

- Activity limitation
- Perceptual or cognitive impairment
- Musculoskeletal, neuromuscular impairment
- Decreased muscle endurance, strength, control or mass
- Imposed restrictions of movement, including mechanical and medical protocol
- Prolonged bed rest
- Sedentary lifestyle
- Pain or discomfort
- Depression or severe anxiety
- Deconditioning decreased endurance

Defining characteristics:

- Inability to move purposefully within physical environment, including bed mobility, transfers, and ambulation.
- Reluctance to attempt movement
- Limited range of motion (ROM)
- Inability to perform action as instructed.

Expected Outcomes to care

Patients able to

- perform physical activity independently or within limits of disease.
- demonstrate use of adaptive techniques that promote ambulation and transferring.
- live free of complications due to immobility, as evidenced by intact skin, absence of thrombophlebitis, normal bowel pattern and clear breath sounds.

Actions/Interventions	Rationales
Assess for impediments to mobility.	Identifying barriers to mobility (e.g., chronic arthritis versus stroke versus pain) guides design of an optimal treatment plan.
Assess the patient’s ability to perform ADL¹⁶ effectively and safely on a daily basis using an appropriate assessment tool, such as the functional independence measures.	Restricted movement affects the ability to perform most ADL.
Provide positive reinforcement during activity	Patients may be reluctant to move or initiate new activity.
Assist the patient in accepting limitations.	Quality of life is influenced by a variety of factors that can extend beyond only physical function.
Provide a safe environment, bed rails up, bed in down position and keep the necessary items close by.	These measures promote a safe secure environment and may reduce risk for falls.
Institute measures to prevent skin breakdown and thrombophlebitis from prolonged immobility: Clean, dry and moisturize skin as needed Use antiembolic stockings or sequential compression devices if appropriate Use pressure-relieving devices as indicated (gel mattress)	These measures reduce skin breakdown, and the compression devices promote increased venous return to prevent venous stasis and possible thrombophlebitis in the legs.
Turn and position the patient every 2 hours or as needed. Maintain limbs in functional alignment (e.g., with pillows, sandbags, wedges, or prefabricated splints). Support feet in dorsiflexed position. Use bed cradle.	Position changes optimize circulation to all tissues and relieve pressure. Maintaining correct alignment of extremities reduces strain in joints and prevents contractures. Supporting heavy bed linens can reduce improper alignment of feet.

16 Activities of Daily Living

<p>Provide recommendations for nutritional intake for adequate energy resources and metabolic requirements</p>	<p>The patient will need adequate, properly balanced intake of carbohydrates, fats, protein, vitamins and minerals to provide energy resources.</p>
<p>Encourage coughing and deep-breathing exercises. Use suction as needed.</p>	<p>Decreased chest excursions and stasis of secretions are associated with immobility. Coughing and deep breathing preventing buildup of secretions.</p>
<p>Explain progressive activity to the patient. Help the patient or caregivers establish reasonable and obtainable goals.</p>	<p>Information promotes awareness of the treatment plan. Setting small, attainable goals helps increase self-confidence and reduces frustration.</p>
<p>Instruct the patient or caregivers regarding hazards of immobility. Emphasize importance of measures such as position change, ROM, coughing and exercises.</p>	<p>Information enables the patient to assume some control over the rehabilitative process.</p>
<p>Reinforce principles of progressive exercise, emphasizing that joints are to be exercised to the point of pain, not beyond.</p>	<p>“No pain, no gain” is not always true! Pain occurs as a result of joint or muscle injury. Continued stress on joints or muscles may lead to more serious damage and limit ability to move.</p>
<p>Instruct the patient and family regarding the need to make the home environment safe.</p>	<p>A safe environment will help prevent injury related to falls.</p>

Caregiver Role Strain

Definition: Difficulty in performing family caregiver role.

The focus of this care plan is on the supportive care rendered by family, significant others, or caregivers responsible for meeting the physical and or emotional needs of the patient. With limited access to health care for many people, most diseases are diagnosed and managed in the outpatient setting. Rapid hospital discharges, for even the most complex health problems result in the care of acute and chronic illnesses being essentially managed in the home environment. Today's health care environment places high expectations on the designated caregiver, whether a family member or someone for hire. For many older patients, the only caregiver is a fragile spouse overwhelmed by his or her own health problems. Even in cultures, in which care of the ill is the anticipated responsibility of family members, the complexities of today's medical regimens, the chronicity of some disease processes, and the burdens of the caregiver's own family or environmental milieu provide an overwhelming challenge. Caregivers have special needs for knowledge and skills in managing the required activities, access to affordable community resources, and recognition that the care they are providing is important and appreciated. Moreover, caregivers can be considered "secondary patients" who are at high risk for injury and adverse events. Nurses can assist caregivers by providing the requisite education and skill training and offering support through homevisits; special clinic sessions; telephone access for questions and comfort; innovative strategies such as telephone or computer support, opportunities for respite care; and guidance in engaging in activities that promote their own health (nutrition, exercise, sleep, yoga, stress management).

Common Related Factors:

Illness severity of care (patient) receiver

Unpredictable illness course

Discharge of family member (patient) with significant home care needs

Caregiver may have health problem.

Caregiver may have limited knowledge regarding management of care.

Social isolation from others

Economic crisis.

Defining Characteristics:

Caregiver expresses difficulty in performing patient care

Caregiver verbalizes anger with responsibility of patient care.
 Caregiver's worry about own health will suffer because of care giving.
 Competition among caregiver's in deciding the primary caregiver.

Expected Outcomes to care inputs

Caregiver

- expresses satisfaction with caregiver role
- demonstrates competence and confidence in performing the caregiver role by meeting care recipient's physical and psychosocial needs.
- demonstrates flexibility in dealing with problem behavior of care recipient.

Actions/Interventions	Rationales
Assess caregiver-care recipient relationship.	Mutually rewarding relationships foster a therapeutic care giving experience. Dysfunctional relationships can result in ineffective, fragmented care or even lead to neglect or abuse.
Assess family communication pattern.	Open communication in the family creates a positive environment, whereas concealing feelings creates problems for caregiver and care recipient.
Assess family resources and support systems.	Family and social support is related positively to coping effectiveness. Some cultures are more accepting of this responsibility. However, factors such as blended family units, aging parents, geographical distances between family members, and limited financial resources may hamper coping effectiveness.
Determine the caregiver's knowledge and ability of provide patient care, including bathing skin care, safety nutrition, medications and ambulation.	Basic instruction may reduce caregiver's anxiety and improve the relationship

<p>Assess the caregiver’s appraisal of the caregiving situation, level of understanding, and willingness to assume caregiver role.</p>	<p>Caregivers need to have a realistic perspective of the situation and the scope of responsibility. Individual responses to caregiving situations are mediated by an appraisal of the personal meaning of the situation. For some, caregiving is viewed as a “duty” for others it may be an act of love.</p>
<p>Assess for neglect and abuse of the care recipient.</p>	<p>Safe and appropriate care is priority in nursing concerns. The nurse must remain a patient advocate to prevent injury to the care recipient and strain on the caregiver.</p>
<p>Encourage the caregiver to identify available family and friends who can assist with caregiving.</p>	<p>Successful caregiving should not be the sole responsibility of one person.</p>
<p>Encourage involvement of other family members to relieve pressure on the primary caregiver.</p>	<p>Caring for a family member can be a mutually rewarding and satisfying family experience.</p>
<p>Suggest that the caregiver use available community resources.</p>	<p>Resources provide opportunity for multiple competent providers and services on a temporary basis for a more extended period.</p>
<p>Encourage the caregiver to set aside time for self.</p>	<p>The caregiver may need reminders to attend to own physical and emotional needs. Having own “respite” time helps conserve physical and emotional energy.</p>
<p>Teach the caregiver stress-reducing techniques.</p>	<p>It is important that the caregiver has the opportunity to relax and reenergize emotionally throughout the day to be able to emotionally and physically assume care responsibilities.</p>
<p>Provide time for the caregiver to discuss problems, concerns and feelings. Ask the</p>	<p>As a caregiver, the nurse is in an excellent position to provide emotional support and</p>

caregiver how he or she is managing.	provide guidance throughout this challenging period.
Inquire about the caregiver's health. Provide suggestions for ways to adjust the daily routines to meet the physical limitations of the caregiver.	The caregiver may have his or her health challenges that can become aggravated during the caregiving process.

Self care deficit

(Self Care activities – grooming, bathing, and toileting)

Relating factors:

Fatigue, disease progression or metastatic disease
Cachectic, impaired mobility, dyspnoea

Defining Characteristics:

Altered sensorium, tachycardia or bradycardia
Irregular pulse
Tachypnea with apnic spell
Mouth breathing
Hypotension

Expected Outcomes to care

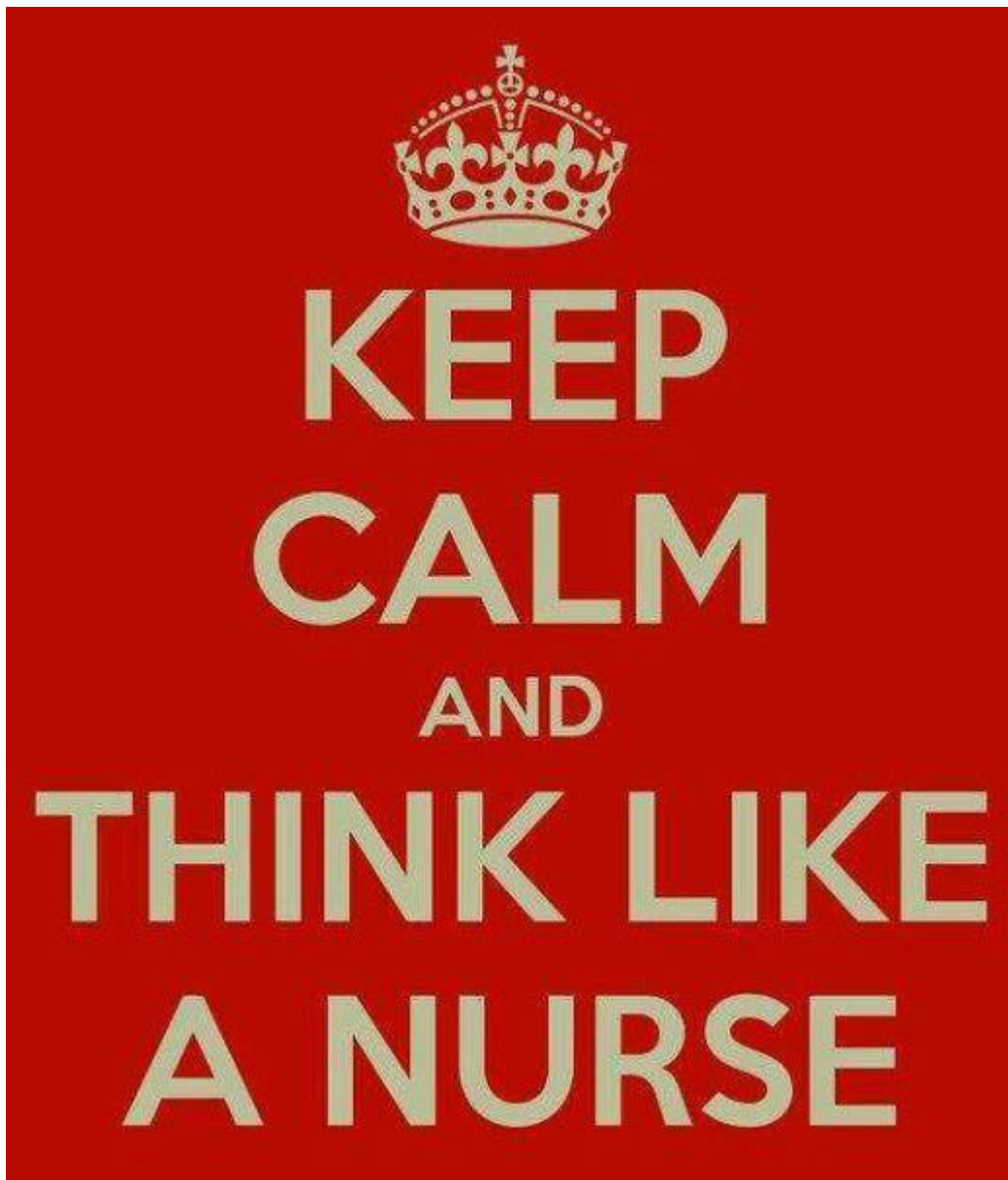
Activities of daily living are helped out by the nursing personnel as well as by the caregiver.

Intervention:

<i>Interventional</i>	Rationale
<i>Assess the ability of the patient to carry out activities.</i>	The patient requires assistance with some self-care measures.
<i>Assess the need for assistive devices (bed-side table, straw, spoon, extra pillows etc)</i>	This increases independence in activities of daily living performance.
<i>Set short range goals</i>	Assisting the patient to set realistic goal will reduce frustration.
<i>Encourage the family members to involve in the care</i>	This promotes good compliance to the care.

<i>Maintain adequate privacy during bathing as appropriate.</i>	The need for privacy is fundamental for most patients
<i>Frequent changing of wet linen when required.</i>	To prevent pressure sores and promote comfort.
<i>Offer bed pan or provide adult diapers</i>	This can lengthen incontinence time intervals, as required.
<i>Frequent oral hygiene is mandatory.</i>	During the end stage, many patients will have dry coated hallutosis and patient will have slurred speech, mouth breathing, and sticky tongue.
<i>Apply moisturizer or coconut oil (4-5 drops) frequently</i>	To prevent coated dry tongue
<i>Clean both eyes frequently with saline</i>	Keratitis can be avoided when eyelids are not closed completely.
<i>Gentle massage of the feet and palm.</i>	This will help the patient to relax
<i>Help and encourage the family members to carry out passive range of movement exercise.</i>	This will help in venous return to prevent edema and DVT.
<i>If patient is conscious ask the patient to change position Q2h with adequate pillows.</i>	To prevent pressure ulcer.
<i>Make sure all the nursing care is carried out with respect and dignity.</i>	To maintain self esteem.
<i>Keep communicating to the patient throughout the care</i>	This minimise the fear. Patient hearing will be intact till the end.
<i>Help keep the patient in hygienic state</i>	The image of the patient at the end will remain with the family even after patient's death.

4. NURSING PROCEDURES IN PALLIATIVE CARE



1. Nursing Assessment

1) History

- Present medical history
- Past medical history
- Family history
- Personal (hygiene, habits)

2) Physical examination

- Head to foot examination
- Inspection
- Palpation

3) Common symptom assessment

- Pain
- Nausea / Vomiting
- Constipation / Diarrhoea
- Diet advice
- Wound / bed sore management
- Tube placement (Ryle's Tube, CBD)
- Tube care (Chest Tube, Tracheotomy Tube, Colostomy/ Urostomy Bags)

4) If patient is ill

- Monitor BP, Pulse, Respiration, Saturation, Temp, If needed GRBS.

Drug explanation

- Explain the drugs in simple language.
- Explain the drug name
 - Dose

- Timing and frequency
 - For what symptom (purpose)
 - How to take (methods of administration)
 - What are the side effects (awareness of possible side effects and preventive measures)
- Explanation about importance of PRN (as required)doses
 - After explanation ask the patient / relative to repeat to assess how much they have understood
 - Ask the patient or relative to bring all remaining medicines at each visit and cross check how they are taking the medicines

2. Chronic Wound Care

Assessment of wounds

- Site of the wound
- Size of the wound
- Any discharge
- The discharge is exudative or transudative,
- Any bleeding
- It was associated with any pain or not
- Any odour
- Are there any maggots
- Any super added Infection present

Common solutions used

- Normal saline
- Metronidazole solution (for foul smelling discharge)
- Dakin's solution (If there is slough)
- Betadine solution (usually not used in malignant wounds)

Wound Cleaning

- Wash the hands with soap and water
- Wet the wound and remove the old dressing gently without further trauma as it may be stuck. This avoids injury to the delicate repair tissue.
- Gently sponge the wound with normal saline inner to outer aspect of the wound
- If irrigation is needed usually with minimal force using smaller syringe (5 CC)
- Debridement if required

Dressing

- Choose appropriate dressing material.
- Use Vaseline gauze to avoid adhesion to the wound.
- If adhesive is not secured safely, bandage can be used.

Managing wound related problems

S.No.	Problems	Management
1	Pain	<ul style="list-style-type: none"> • Round the clock analgesics using WHO ladder. • Local application of Lignocaine jelly. • Analgesic ½ hr before dressing
2	Fungating/necrotic wound	<ul style="list-style-type: none"> • Regular dressing using saline solution • If necrotic tissue is present debridement may required. • Radiation therapy also can be considered.
3	Foul smelling	<ul style="list-style-type: none"> • Metronidazole solution or powder dressing. • One course of oral Metronidazole can be given. (e.g T. Metronidazole 400mg tid x 1 week followed by 200mg once daily) • During dressing consider using stronger incense.
4	Bleeding	<ul style="list-style-type: none"> • Use Vaseline gauze for dressing • Soak with saline before removing the dressing, tranexamic acid can be powdered and used over the wound. • Apply adequate pressure for the wound. • Haemostatic radiation therapy can also be considered.
5	Maggots	<ul style="list-style-type: none"> • Manual removal using turpentine oil. • Repeat removal may require for few days. • Prevention is better by adequate covering of the wound.

Home Care Education

Preparation of clean dressing material at home

- Boil the cup and clamp in a bowl of water then drain and cool it
- Wash the cotton cloth/ gauze
- Steam the cotton cloths [cut pieces of cotton cloth] / cotton balls / gauze in an idly cooker
- Spread and Sun dry

- Store neatly in a plastic box for use

Saline preparation at home

- Add three pinches (using three fingers) of salt to 200ml of water
- Boil for ten minutes and cool it
- Do not keep the solution for the next day

Key Points for a patient with wound

- Daily bath
- Wash the hands before and after procedure
- Advice on complete covering of wound to avoid maggots
- Used dressing materials should be burnt
- Keep the patient surrounding tidy and clean to avoid flies

3. Colostomy Care

Definition

Maintenance of personal hygiene by regularly emptying colostomy bag and cleaning colostomy site.

Purpose of care

- To prevent leakage
- To prevent excoriation of skin around stoma
- To observe stoma and surrounding skin
- To teach patient and relatives about the care of colostomy and collection bag

Equipment

1. A tray containing:

- Towel
- Gloves (one Pair)
- Cotton swabs and gauze pieces
- Big rag pieces
- Soap
- Disposable colostomy bag with clamp
- Zinc oxide ointment Skin Barrier
- K – Basin

2. Other articles

- Mackintosh
- Water in basin
- Bed pan

Procedure

1. Explain the procedure to the patient

2. Collect articles
3. Provide and maintain privacy
4. Position the patient in comfortable position and cover with top sheet
5. Arrange rubber sheet and towel to protect bedding and gown
6. Wash hands and put on clean gloves
7. Change colostomy collection bag as follows
 - If the bag is full, remove clamp and empty contents into bedpan
 - Gently remove the bag, remove the clamp and place in K – basin
 - Place gauze piece over stoma to absorb any drainage
 - Clean and remove fecal material around the stoma with rag pieces
 - Rinse well to remove soap completely, as it can hinder adherence of the bag
 - Pat dry thoroughly with towel
 - Apply a thin layer of skin protectant about 2 inches around the diameter of stoma
 - Remove paper backing of skin barrier, centre hole over the stoma and press down firmly, see to that there are no wrinkles, cut the bag according to the size of stoma
 - Fold bottom end twice and clamp
8. Empty the colostomy collection bag as follows:
 - Remove clamp
 - Unfold the bottom end of the bag
 - Allow contents to drain through the opening into bedpan / K - basin
 - Rinse the bag with water instilled from the bottom opening with syringe
 - Instill deodorant into the bag
 - Clean the bottom of the bag with cotton or gauze pieces
 - Fold the bottom end twice and clamp
9. Place the patient in a comfortable position
10. Ask the patient to inform any discomfort at the stoma site
11. Remove, clean, dry and replace the articles

INSTRUCTIONS FOR THE PATIENT

1. Wash stoma with soap and water during bath
2. Watch for
 - Skin excoriation
 - Prolapse
 - Retraction
 - Inversion
 - Obstruction
 - Constipation
 - Infection
 - Diarrhoea
 - Necroses
 - Bleeding
3. These symptoms to be reported to the Doctor or Nurses.

4. Subcutaneous Injection procedures

Important Information about Subcutaneous Injections for Nursing and Medical Staff

Subcutaneous injection is given in the fatty layer of tissue under the skin. It is a convenient alternative route of parenteral route of drug administration. Family members can also learn to give essential injections at home using this route.

Indications for using this route:

1. Persistent, Nausea and Vomiting
2. Dysphagia.
3. Intestinal obstruction.
4. Coma.
5. Poor absorption of oral drugs.
6. Terminal care.

Symptoms that can be managed through subcutaneous drug administration

1. Pain.
2. Nausea and Vomiting.
3. Confusion
4. Agitation
5. Respiratory secretions
6. Dyspnoea.
7. Seizures

Methods

1. Bolus using 26 g disposable needle.
2. For round the clock use ---- Butterfly needle 20 or 22 g / Insyte 24 g
3. Continuous infusion.

Drugs that can be used

1. Inj. Metoclopramide
2. Inj. Haloperidol
3. Inj. Midazolam
4. Inj. Dexamethasone
5. Inj. Morphine
6. Inj. Fentanyl
7. Inj. Rantac

Advantages

- α. Increased comfort for the patient because there is less need for repeated injections
- β. Control of multiple symptoms with delivery of drugs in sequential or combination
- γ. Compatible drugs can be loaded in the same syringe
- δ. Round the clock administration of drug provides comfort because plasma drug concentrations are maintained without peak and troughs
- ε. Independence and mobility maintained
- φ. Less frequent change of needle site

Common sites

1. Anterior chest wall
2. Antero lateral aspect of upper arm

If needed

1. Anterior abdominal wall
2. Anterior surface of the thigh

Procedure

Insert a 20 G needle or 22 G butterfly needle or 24 G Insyte two fingers below the clavicle bone, at an angle of 30 to 45 degree under the skin into the subcutaneous tissue. (You can hold the needle/ Insyte just as you would to insert intravenously, but instead of trying to find a vein you can easily place it in the subcutaneous plane by pinching up a fold of skin.)

Connect to 3- way with extension tubing.

Secure the tube with micropore adhesive.

There is no need for heparin bolus.

Points to remember

1. Avoid mixing dexamethasone with other drugs in the same syringe
2. Non irritant drugs –injection sites can be used for more than 7 days; if there is recurring problem with inflammation or pain the site should be changed prophylactically every two days.

Procedure

- Wash hands with soap and water
- Clean the vial top with spirit
- Invert bottle of medicine and insert needle through rubber seal at an angle. Tip of needle should touch wall of bottle
- Load medication from ampoule or vial into syringe
- Position and expose appropriate site
- Clean skin with cotton ball moistened with spirit
- Expel air from syringe
- Gently bunch up the skin at the injection site
- Insert the needle in 90 degree straight in to the skin use dart like motion
- Release the skin
- Slowly push the piston and inject medicine
- Quickly remove the needle apply pressure with cotton swab
- Avoid massaging the site to avoid tissue irritation
- Handle syringes and needles using Universal Precautions
- Position the patient comfortably

Site inspection

- Tenderness
- Hardness
- Haematoma
- Leakage from the insertion site
- Swelling
- Erythema
- Displacement of the needle

General Instructions

- Strict aseptic technique to be followed
- Do not aspirate before injecting
- Do not recap the needle discard immediately in to the sharps container
- Do not bend, break or handle needles with hand
- If needle prick occurs, squeeze area and swab with spirit (70%)
- Report immediately

Patient and family education

- Explain the drug action and what for it is administered
- Loading technique
- How much to take for administration
- Ensure that drugs being delivered are safe to use and can be used at home setting
- Thorough patient assessment is important
- Careful inspection of the site every day for signs of inflammation

Precautions for biohazard patient (HIV/AIDS/ HEP B/C)

- Use gloves and disposable syringe and needle
- Replace articles in designated disposable unit after procedure (Separate needle from syringe using artery clamp)
- Do not recap used needle, Discard immediately into I 'sharp' container

5. Diet explanation

- Ask patients preference / choices of food
- Encourage small frequent feeds (6 -7 times)
- Advice frequent mouth washes with salt water/ lime water / drinking water
- Homemade foods are encouraged
- Small quantity with more calories and more protein
- Never force the patient for food
- If patient has nausea – high protein may increase the nausea and vomiting
- Salt intake is mandatory unless patient has any cardiac /renal problems / hypertension
- Explain to relatives that loss of appetite is common and the patient should not be forced to eat more than he can willingly take.

6. Mouth Care/Oral Hygiene

Purpose:

- To remove the food particles that provides a likely medium for bacterial growth
 - ✓ especially in a patient with altered sensorium
- To prevent dental caries.
- To improve nutritional status by enhancing appetite.
- To refresh the mouth of a person who is confined to bed, critically ill or dehydrated
- To stimulate the blood circulation of gums, thus maintaining healthy firmness.
- To reduce incidence of Ventilator associated pneumonia

Equipment

- A sterile mouth toilet tray containing
- Artery clamps (2)
- Cups (2-one with cotton balls, the other to pour dentifrice)
- Other articles
- K-basins (2-one to discard the used cotton balls, the other for the patient to spit after rinsing the mouth)
- Swab sticks
- Small mackintosh
- Face towel

Common antiseptic solutions (dentifrices) used

- Thymol glycerine
- 1% soda bicarbonate
- Potassium permanganate
- 0.9% sodium chloride
- Hydrogen peroxide (avoid for unconscious patients)
- Chlorhexidine

Common lubricants used

- Liquid paraffin
- Coconut oil
- Borax glycerine
- Vaseline

Procedure:

- Explain the procedure to patient.
- Provide privacy
- Bring the patient to the edge of the bed, and preferably in semi-Fowler's if not contraindicated.
- Position pillow according to the comfort of patient.
- Place a small mackintosh with a face towel on the patient's chest.
- Place K-basin close to the chin of the patient
- Raise head of the bed to 45°
- Pour antiseptic solution into a cup
- Soak cotton balls in solution and squeeze out excess solution by using artery clamp
- Use the same clamp to clean the patient's mouth. Use one clamp to pick up cotton balls and the other to clean (avoid interchanging of clamps)
- Clean teeth from incisors to molars using up and down movements, from gums to crown
- Clean oral cavity from proximal to distal, using one cotton ball for each stroke
- Discard used cotton balls into K-basin
- Provide a tumbler of water and instruct the patient to gargle mouth
- Position K-basin so that spillage is avoided
- Clean tongue from inner to outer aspect, folding rag piece in such a way that the tip of clamp is completely protected.
- Provide water to rinse mouth.
- Lubricate lips using swab stick.

- Wipe face with towel
- Rinse used articles and replace equipment

Document time, solution used, condition of the oral cavity, abnormalities noticed and the patient's response.

Home care nursing advice for patients with head and neck cancer

Mouth care education

What is mouth care and why is it needed?

A clean, fresh, comfortable mouth is very important for patients. It helps with comfort, communication and feeding. Many people with head and cancer have problems with their mouth.

This can be related to the disease itself, to the treatments or other problems. Many patients will need help with their mouth care.

Main Problems

Dry mouth (this may affect up to half of all patients and can be very troublesome)

Sore mouth

Infection

Assessment

The mouth (including the lips, gums, tongue, teeth and palate) should be carefully examined every day to look for any problems.

Things to look for

Cracked lips, sores at the corner of the mouth, dry or coated tongue, white curd-like patches on the surface of the tongue or around the gums and palate, ulcers in the mouth, redness and dryness throughout the mouth and bleeding.

Things to ask about

Pain in mouth when trying to swallow. Difficulty in chewing or speaking due to dryness.

Management

- Assist the patient in brushing and cleaning the mouth, tongue and teeth.
- If brushing is difficult then a small gauze or clean cloth can be used.
- For a coated tongue a soft baby's toothbrush or clean cotton cloth can be used. Also helpful is using a solution of soda bicarb to assist cleaning.
- Rinse the mouth before and after food using warm water or saline solution.
- If the mouth is dry, saliva production may be stimulated by sucking a piece of pineapple or sipping fresh lime juice. Be careful with this if there are ulcers or pain.
- Regularly apply a simple vegetable oil, such as coconut, to the lips. A few drops can also be smeared on the tongue. Often it is best to ask the patient to do this himself.
- Frequent sipping of water can also be helpful so ensure cup is nearby.

Preparing saline solution

- Take 500mls of drinking water and add one teaspoon of salt.
- Boil, cool and keep covered till needed.

Preparing soda bicarbonate solution

- Take 500 ml of boiled water and add a quarter teaspoon of soda bicarb. (soda bicarb is the same as idly/appam soda)

Troubleshooting

- If the dry mouth is severe consult with your doctor who may help to adjust any drugs to help.
- If there are white cur-like patches, especially with pain on swallowing, there is likely to be a fungal infection and the doctor will prescribe some specific treatment.
- If pain persists you will need general painkillers which your doctor can prescribe.

If there is an unpleasant smell there may be bacterial infection and your doctor may give antibiotics as tablets or metronidazole solution.

7. Naso-gastric tubes

A naso-gastric tube is a plastic tube passed through the nose into the stomach and left in place. A piece of sticking plaster is usually used to keep the tube attached to the nose. It may be in place for a short time or even for many weeks. It is mainly used to pass food, fluids and drugs directly to the stomach when there is difficulty eating by mouth. It needs to be kept clean and free of blockage.

How to use and care for a naso-gastric tube

Articles needed

Dry towel, 20ml syringe, glass of water, glass of liquid food.

Preparation of liquid food

Simple home foods can be used depending on the patient's choice and what is available. This can include foods such as porridge, rice gruel, soup, juice, milk or curd. More solid foods such as idly, fish, vegetables, dals or meat can be used if cooked well and ground finely. The usual food cooked for the family can also be used. Any food to be given should be ground finely with a mixer or mashed with a large spoon. Liquid is added to make a thin consistency and then filtered through a strainer such as that used for tea. Patients who cannot swallow can still taste a tiny amount which can give pleasure.

Procedure of feeding

- Place the patient in a sitting position. If unable to sit, place 2-3 pillows under the head and shoulders.
- Wash hands well with soap and water.
- Place a dry towel around the neck to catch any spills.
- Fix the syringe to the end of the naso-gastric tube.
- Gently pull back and make sure it fills with stomach contents. This checks the tube is still in the correct place in the stomach.
- Take off the syringe and remove the central piston or inner tube from the syringe.
- Re-fix this outer part of the syringe to the end of the tube.
- Pinch the tube to prevent air going down the tube.
- Hold the end of the tube about 12 inches above the patient's head.

- Slowly pour the prepared liquid food, fluid or drugs into the outer syringe. It should flow slowly and steadily. Do not force fluids to go through.
- Take care not to let air enter as this will cause wind and discomfort for the patient.
- Flush the tube at the end of the feed by pouring enough drinking water to clear the tube. Around half a small cup (50ml)
- Give small amounts of feed regularly. Usually a small cup or 150 mls is enough.
- Remember to add salt to the feeds. Most patients require around 2 teaspoons of salt per day.
- Once every 3-4 days repeat this procedure using only warm saline solution to clean thoroughly and prevent coating of the tube which may lead to blocking.
- Occasionally change the sticking plaster that keeps the tube attached to the nose. This is not needed every time.

Troubleshooting

- If the fluid is not flowing well, then first check it is still in place by looking for stomach contents when you pull back on the syringe. You may also notice that the tube has slipped out and appears much longer.
- If the tube is in the correct place it may be becoming blocked so increase the number of times you flush and clean it with warm saline. Using soda bicarb solution to flush may be more effective.
- If the tube has come out of the stomach or is completely blocked you will need to seek advice from your doctor or nurse.

8. Tracheostomy Care

What is Tracheostomy care and why is Tracheostomy care needed?

A Tracheostomy is an opening made in the front of the wind pipe. A tube is then inserted into the opening to help with breathing. There will be a metal outer tube which stays permanently in place and a metal inner tube regularly removed for cleaning.

Tracheostomy care includes changing and cleaning the inner tube, cleaning around the site and changing dressings. It should be carried out daily or more often if needed and will take around twenty minutes. The inner tube should always be in place except when cleaning.

Articles needed

Clean cotton cloth pieces (cotton balls and gauze may be used if available), two small cups, saline solution, sodium bi-carbonate solution, paper cover to dispose the waste.

Procedure

- Position the patient in a sitting position. If unable to sit place 2-3 pillows under the head and shoulders.
- Wash hands well with soap and water.
- Remove the cloth or gauze from around the tracheostomy.
- Gently remove the inner tube and place in a cup with sodium bi-carbonate solution.
- Clean the tube by passing a cloth or gauze piece through the tube and then remove.
- Rinse the tube thoroughly with water, allowing the water to run freely through the tube.
- Boil the inner tube in water for ten minutes then allow to cool and dry.
- Clean around the tracheostomy area and outer tube with saline solution.
- Place a saline soaked cloth or gauze around the outer tube leaving the opening clear.
- Replace the inner tube by holding the outside edge and gently inserting back into the outer tube.
- Place another saline soaked gauze over the opening. Covering the opening avoids dusts or insects getting into the tube and also helps moisten the air breathed by the patient. Cotton cloth can be used only if it is of a very fine mesh as air needs to pass through.

- Provide some rag pieces and encourage the patient to cough out any secretions through the tracheostomy tube.

Troubleshooting

- If the inner tube is becoming blocked by mucus or blood you may increase the cleaning up to three or four times a day.
- If the tube becomes totally blocked or there are breathing difficulties, then try removing the inner tube or let the air pass through. If it remains blocked consult a doctor or nurse.
- If you are not able to reinsert the inner tube then cover the area with a wet gauze and consult a doctor or nurse.
- If the patient is having fever and increased sticky secretions then consult your doctor

9. Assisting in Thoracocentesis

Purpose:

- To drain fluid / air from pleural cavity for diagnostic or therapeutic purpose.
- To introduce medications.
- To aid in full expansion of lung.
- To obtain specimen for biopsy.

Procedure:

- Explain procedure to patient and relatives.
- Provide privacy.
- Collect all equipment on dressing trolley and keep them ready at bedside. Collect the recent chest X-ray.
- Protect bed with mackintosh.
- Position the patient in fowler's. Bring the patient to one side of bed with feet supported, arms and head leaning forward on a cardiac table with pillows.
- Untie gown and expose the site for aspiration.
- Instruct the patient to avoid coughing and to remain immobile during procedure.
- Explain that a feeling of deep pressure will be experienced while fluid is being aspirated from pleural space.
- Provide sterile gloves to doctor.
- Open sterile set and slide 20cc, 5cc syringes, 20 and 22G needles, and 1.5 inch 18G syringe in aspiration needle into the tray.
- Pour antiseptic solution in the cup to clean site.
- After showing label to the doctor, clean the top of local anesthetic bottle and assist to withdraw medication.
- Reassure the patient and instruct him/her to hold breath during insertion of aspiration needle.
- As the physician does the procedure, assess the patient for increasing respiratory rate,
- Diaphoresis, rapid pulse, cyanosis, complaints of chest pain, chest tightness, uncontrollable

cough and blood tinged, frothy sputum.

- If any untoward reactions are observed, inform the doctor who may halt the procedure temporarily.
- After fluid is withdrawn from pleural space, transfer it to specimen containers.
- Assist in sealing the site with tincture benzoin swab.
- Make the patient comfortable.
- Replace equipment.
- Document the amount, colour and nature of the fluid collected and patient's condition. Send the specimens to respective laboratory.
- Instruct the patient to be on strict bed rest for 6-8 hours

10. Assisting in Indwelling Ascitic Catheter Placement

Definition: Assisting in withdrawal of fluid and placing indwelling catheter in the peritoneal cavity.

Purpose: To remove ascitic fluid when large accumulation causes severe symptoms.

Equipment:

Dressing trolley with

Injection tray with

1. Tincture Benzoin
2. Betadine
3. Lignocaine 2%
4. 5cc syringe – 1
5. 26 G Needle -1
6. 22 G needle -1
7. Sterile Gloves – 2

Arrow needle (single lumen 16 fr)

- Abdominal tapping set or Dressing pack and towel pack
- Sterile Curved Needle and thread
- Scalpel blade no.11
- Betadine ointment
- Adhesive and scissors
- Three way with extension

Procedure:

- Check whether the patient is on anticoagulant therapy
- Explain the procedure to patient and relative
- Provide privacy
- Collect equipment on dressing trolley
- Encourage the patient to empty bladder before procedure

- Place the patient on supine/semi fowlers
- Protect bed with Machintosh
- Cover the patient with top sheet and expose only abdomen.
- Check vital signs (pulse, respiration, BP)
- Wash hands with soap and water
- Provide sterile glove to doctor
- Open abdominal tapping set
- Assist the doctor in cleaning site by pouring antiseptic solution (Betadine) over cotton swabs.
- Open 5 cc syringe, 26 G needle, 20 G needle and place one by one into sterile tray. Assist the doctor in withdrawing and administering local anaesthetic.
- Open arrow catheter (including stillet guide wire and dilator) place it into the sterile tray
- Open sterile scalpel blade and slide it into the tray.
- Wear sterile glove and make multiple holes (4-5) in the arrow catheter in different
- directions using scalpel blade, without counter puncturing opposite side or breaking the

catheter. Then remove gloves.

- As the doctor does the procedure assist the patient's pulse, respiratory rate. Watch for pallor, cyanosis and syncope.
- As the doctor placed the Arrow Catheter after dilatation. Open the three ways with extension and drop it in to the sterile tray.
- Once stay stitches are made to secure the catheter call the relative for demonstration.

Draining

- Dressing (using Betadine ointment)
- Ask the relative to empty minimum amount of fluid to relieve symptoms.
- Once the catheter is placed on the abdomen dry dressing is performed.

Post procedure:

Watch for leakage or bleeding from the site.

Instruct the care giver to do dressing on alternate days and to report if there is fever, pus discharge or if the catheter falls out

11. Lymphoedema management

Lymphoedema is an accumulation of lymph in the interstitial space of subcutaneous tissues.

The Four cornerstones of lymphedema management:

1. Skin care
2. Position and exercise
3. Compression bandage/ stockings
4. Massage

1. Skin care

Aims

- To maintain a healthy tissue condition
- To reduce the risk of infection

Daily care

- Meticulous hygiene
- Inspection of the limb and adjacent trunk
- Moistening of limb and adjacent trunk.

Instruction for skin care

- Wash the affected arm with Luke warm water.
- Do not use too much soap which will dry the skin.
- Dry it using a towel. Do not rub.
- Apply coconut oil from distal to proximal end of the limb
- It's better to avoid jewellery on the affected limb
- To avoid injury to the limb
- Use loose clothing
- Avoid injections in the swollen arm including blood sampling
- Avoid blood pressure measurement on the swollen arm.

- Take care when cutting toe or finger nails using nail cutter.
- Treat cuts scratches insect bites promptly by cleaning well and applying antiseptic cream or solution.
- Seek medical aid if the skin becomes red and inflamed.

2. Position and exercise

- Limb elevation achieved by using pillows (2-3).
- Make sure limb is straight and above the heart level.
- Do not dangle the legs if swollen; Avoid crossed legs.

Assessment before exercise

- Posture
- Joint range
- Muscle power
- Function
- Ease of movement.
- Changes in sensation.

Exercise

It plays an important part in encouraging fluid drain since the muscle help to pump lymph out of the limb.

Exercise to be performed every day morning and evening.

- Active and passive range of movement exercises.
- Slow and rhythmical with rest period has to be followed.
- All joints in the affected quadrants will be moved through pain free range.
- Exercises are done within the ability of the patient.

Arm Exercise

- Slowly and firmly clench and unclench fingers. Repeat 10 times.

- Wrist Flexion and extension X ten times
 - Rotation of the wrist clock wise and anti clock wise. Ten times.
- Slowly and firmly strengthen the arm, and then bend at elbow till it go no further.
- Place hands behind the neck then slowly bring hands forward. Repeat ten times.
- Place hands on top of the head then slowly bring down to touch shoulders.
- Lie flat on bed. Clasp hands together and lift arms straight up as far as they go.

Leg exercises

- These exercises are best done lying on a bed floor with the legs raised on pillows or cushions.
- Slowly and firmly rotate feet making circular movement with pointed toes.
- Slowly and firmly point foot towards floor then bring back as far as it will go.
- Slowly and firmly bring knees up to chest.
- Slowly straighten legs and lower down to pillows.
- Bring knees up to chest slowly and firmly do bicycling movements.

3. Compression bandage/ stockings

Multi Layer Lymphoedema Bandaging (MLLB).

Benefits

- Improved lymph drainage.
- Improve movement and function of the limb.
- Improve distorted limb shape.
- Improve thickened fibrotic skin.
- Reverse lymphorrhoea.

Procedure

- Wash and dry the limb carefully
- Manual lymphatic drainage has to be done before bandaging.
- Moisturize with coconut or moistening cream before bandaging
- Artiflex cotton padding done to bring the limb in to cylindrical shape.

- Using short stretched small width bandages are applied from distal to pommel end of the limb.

Post bandage assessment

- Pain (pins and needles)
- Numbness
- Discoloration of toes and fingers.
- Breathing difficulty.

These symptoms should be reported to doctors and remove the bandage immediately.

4. Massage

LYMPHATIC MASSAGE

Definition:

Lymphatic massage is the procedure used to encourage lymphatic fluid away from swollen, congested areas of the body to areas where it can drain away normally.

Purposes

- Swelling at the root of a limb
- Trunk and midline oema (eg:chest,breast,back,abdomen,genitalia ,head and neck)
- Provides comfort and pain relief when other physical therapies are no longer appropriate.
- Adjunctive treatment to pain management.

Contraindications

- Acute cellulitis /erythema
- Renal failure
- Unstable hypertension
- Severe cardiac insufficiency
- Hepatic cirrhosis with ascites
- Superior vena cava obstruction

- Untreated tuberculosis or malaria
- When patient is on active treatment (eg: chemotherapy or radiotherapy)

Principles

- Treat unaffected Lymph nodes and region of the body first.
- Moves proximally to distally to drain the affected area.
- Movements are slow and rhythmic.
- The session begins and finish with a short breathing exercise which helps to clear the deep lymphatic system.
- Massage using your finger pads.
- If the swelling increases or limb becomes red seek medical aid.
- Use gentle pressure if the pressure is too hard it stimulates blood flow, the skin becomes red, and more fluid is encouraged to move in to the tissues.

Pre procedure care

- Explain the procedure to the patient.
- Provide adequate privacy.
- Remove the ornaments and tight clothing.
- Keep the patient in relaxed and comfortable position(lying/sitting)

Procedure

To improve drainage from arm

- Advise to take deep breath hold it for few seconds and breathe out through the mouth. Repeat the same for 10 times.
- Massage both sides of the neck below the ears. Take the skin back and then circle down towards the shoulder. Repeat the same for 10 times
- Massage both sides of neck between ears and shoulders. Repeat the same for 10 Times
- Massage the area between the collar bone and the shoulder move it towards the neck. Repeat the same for 10 times

- Massage the axilla pushing fluid toward the back. Repeat the same for 10 times
- Massage the upper chest wall. Repeat the same for 10 times
- Massage the back - Repeat the same for 10 times
- Do the deep breathing exercise for 10 times
- Relax.

To improve drainage from the leg

Do all the massages for the arm drainage.

- Massage inner aspect of the upper thigh and repeat the same for 10 times
- Massage top of the thigh and repeat the same for 10 times
- Massage the lower abdomen with direction towards the axilla. and repeat the same for 10 times
- Massage lower back and repeat the same for 10 times
- Complete with breathing exercise.
- Relax.

Use bandages as indicated before massage. Perform massage two times daily

This can be taught to the relatives to follow it at home.

12. Home Care Instructions for Bedridden Patients

Preventing bed sores

- Change your position every 2 hours
- If you are on a wheel chair, lift yourself up every 15 – 20 minutes
- Make the bed without wrinkles
- Do not drag the patient on the sheet
- Do not leave the patient on a wet sheet for a long time
- Gently massage the following areas where bed sores can develop: (Trochandrums, sacrum, ankle and heel)

1. Scapulla
2. Sacrum
3. Ankle
4. Toes
5. Iliac rest
6. Chin
7. Pinna
8. Knees
9. Trochantric region

Everyday examine the skin for redness / blisters.

Treating bed sores

For dressing

- Small artery clamp
- Small cup
- Cotton balls
- Gauze / clean sun dried cotton clothes
- Saline preparation at home

Boil the cup, clamp – leave to cool

Wash and sun dry the cotton cloth then steam it in an idly cooker.

For preparing saline

Add 3 pinches using 3 fingers of salt to 200 ml of water

Boil for 10 minutes

do not keep the solution for the next day

Procedure

- Clean the ulcer with saline, from inner aspect to outer aspect
- Apply the saline soaked gauze
- Cover the wound with dressing pad
- Apply micropore
- Avoid lying on the place where you have a bed sore.

13. Bladder Care

- Every day clean the perineal area well with soap and water
- Drink adequate water to maintain good flow of urine and to flush the catheter
- Clean the urinary catheter with betadine soaked cotton ball from the urethra towards the catheter bag
- Change the urinary catheter every 2 weeks (if it is silicon catheter once in 3 months)
- Urinary catheter should to be striped on the lower abdomen for men, for women on the thigh
- If catheter block it should be changed immediately.
- Remember to drink plenty of fluids.
- If you develop fever, contact your doctor for further management.

14. Care in the Terminal Phase

- Allow the family to voice their concerns. Clarify expectations and prognosis. Involve the Counsellor or Chaplain if needed.
- Ask the family if they wish to take the patient home or continue terminal care in hospital.
- Check if appropriate medicines have been ordered for troublesome symptoms e.g pain ,, breathlessness, dyspnoea according to Unitary policies and relevant to the care setting (home/ hospital.)
- Check if inappropriate interventions need to be tapered or discontinued.
- Encourage the family to support the primary caregiver and allow him/ her respite.
- Check that nursing care for the patient with attention to oral hygiene, skin, bowel and bladder care is continuing.
- Remain sensitive to the changing physical and emotional needs of the patient and family.

Diagnosing and declaring death

Procedures in place for handling dead patients

Death Certification

- Any doctor preferably from the treating unit can certify death.

-He/she should Diagnose and declare the death

- Inform the relatives
- Certify death & fill the necessary forms
- Seek permission & arrange for autopsy, if necessary
- Assist the family in decisions regarding transportation, embalming, mortuary care, etc

Criteria for declaring death.

After failed cardiopulmonary resuscitation or after withdrawing life supports, patient should have (for minimum of 5 minutes)

- Apnoea
- Absence of mechanical cardiac activity (absence of heart sounds on auscultation & absence of central pulses on palpation)

- After 5 minutes check for:
- Absence of pupillary light reflexes (pupils non reactive to light and fixed)
- Absence of corneal reflexes (remove contact lenses)
- Absence of motor response to supraorbital pressure/pain
- If the above features are fulfilled death can be declared. The time of death should be noted as the time when all these criteria are fulfilled. The record should be signed, dated with employment number.

Informing relatives

- The doctor should inform the relatives that the patient has expired and should clarify any doubts the relatives have.
- The relatives should be allowed to see the body as soon as death is declared.
- If trouble is expected from the relatives when informing them the security services can be asked to be present during the time of breaking the news.
- Certifying death and filling the necessary forms

A doctor should write a detailed account of the terminal events in the progress sheet and also fill the following forms:

- Medical certificate of cause of death
- Medical certificate of death international (in duplicate)
- Authorization for release of body

In case of MLC, the detailed death summary should be completed within 24 hours and handed over to the M. S. Office.

Last office/death care

Purpose:

- To maintain normal body alignment before rigor mortis sets in
- To prepare the body for transport to mortuary/residence
- To reduce mental distress of family

Equipments:

- A tray with

- Long artery clamp
- Bandage
- Non-absorbent cotton
- Absorbent cotton
- Mortuary card in transparent plastic cover
- Towel
- Hospital gown or patient's clothes draw sheet
- Long mackintosh
- Equipment needed for bath

Procedure:

- Death is declared by the Doctor. All deaths are to be informed to the concerned unit registrar /consultant as soon as possible. The death certificates should be immediately completed accurately and legibly. To inform the MS about deaths happening within 24 hours after admission into wards.
- In medico legal problems, the CMO should be informed as the body can be released only after the police have been notified
- Provide privacy for grieving family
- Follow all protocols and policies of the hospital
- Allow relatives to see the dead person in a presentable condition.
- Disconnect all tubing gently and seal wounds with clean gauze and adhesive.
- Replace dentures if the patient has been using dentures.
- Give thorough bath and remove secretions, discharge and blood stains.
- Put a clean gown/ patient's dress and comb hair.
- Apply jaw bandage so that the mouth is kept closed.
- Plug orifices (nose, mouth, vagina, and rectum) with absorbent cotton followed by non – absorbent cotton.
- Close eyes with by keeping wet cotton ball on closed lids.

- Pack the nose in such a way that cotton is not visible.
- Fold the hands in praying position and tie the thumbs together. Straighten the legs, bring the feet together and tie the big toes similarly.
- Complete the nurse's record including information from time of imminent death till the placing of the body in mortuary or sending home.
- Doctor will record the patient details.
- The chart is send to the billing section.
- Drugs are sent to pharmacy for refund if any.
- Handover the body directly to relatives after settling bill, within half an hour. If bill settlement takes more than half an hour, keep the body in mortuary. Fill mortuary register with necessary information.

Before releasing the body check medical documents for:

- Copies of death certificate
- Autopsy permit slip
- Mortuary register entries
- Authorization slip to take body to destination
- Embalming procedure if requested by relatives
- Handover the body to relatives after bill has been settled and get them to sign in the mortuary register.
- If Medico Legal Case, the body to be released to police who will accompany for post mortem.
- Inform to After Life Service if required.

Documentation in case of death:

- All documents as stated above.
- Resuscitation measures carried out should be documented.
- The date and time of death should be clearly written in the progress sheet and order sheet.
- Body should be handed over to the relatives or the police (in case of medico-legal cases), after settling the bill. This should be recorded and signed on the order sheet.

- Death certificate should be completed.
- A brief death summary is typed out onto the clinical work-station.

5. OPTIMISATION OF CARE



“You matter because you are you.....you matter to the last moment of your life..... We will do all we can not only to help you die peacefully.....

.....but also to live until you die”

Dame Cicely Saunders

OPTIMISATION OF CARE

62 year old Raj is known case of lung cancer with distant metastasis. He is brought to the hospital with severe respiratory distress, chest pain, cough, fever, delirium and poor urine output. His Arterial Blood Gases [ABG] and hemodynamics being unstable, he is admitted in the ICU, paralysed, intubated, given fluids, diuretics and started on ventilator support. Invasive monitoring is established, IV antibiotics are started after blood and urine culture and on the 3rd day, dialysis is given to tide over the crisis. Once the ABG and kidney parameters are showing some improvement, trials are now on to wean him off ventilator.

Would you consider this line of management as appropriate for Raj?



The primary goal of health care training is to help choose the appropriate line of management based on a clinical situation. This will depend on the general condition of patient, functionality, reversibility of the pathological process which led to the clinical deterioration, co-morbidities and the response to treatment which the patient has received until then.

Let us bring more clarity to this concept with two scenarios for this patient Raj.

Scenario 1

Let us consider that Raj was responding well to chemotherapy. He was leading an active and ambulatory life with normal food intake, sleep and activity level and deteriorated only a few days prior to admission. Here deterioration could be due to reversible conditions like transient neutropenia, lower respiratory tract infection, electrolyte disturbances, dehydration and so on. Under such a circumstance, evaluating for all reversible contributory factors and considering an aggressive line of management is justifiable and must be resorted to. After communicating to the family [including financial considerations] about the possibility of reversibility and fair prognosis and with their informed consent, the above line of management as a shared decision can be considered as appropriate.

Most likely, this Raj would be successfully weaned of the ventilator and recover close to pre-deterioration health status.

Scenario 2

Let us now consider that Raj a retired school teacher had been diagnosed with advanced lung cancer, multiple disseminated metastasis and multiple co-morbidities with organ dysfunction. He is unaware of the diagnosis. The treating team suggested chemotherapy with palliative intent and although financially burdening, the family opted for it, believing this to be curative as they did not understand their medical language with ‘percentages of median survival’. While on chemotherapy, Raj had intolerable side effects, exacerbation of symptoms and his general condition worsened due to disease progression. He was bed bound most of the time with persistent breathlessness, cough, poor intake, sleep and severe fatigue. When his condition gradually deteriorated, as described above, he was brought to the hospital.

As we often see, for this patient, the story would mostly proceed as follows.....after a few days when parameters show some improvement, weaning him off from the ventilator was attempted but was unsuccessful. He is now confined in the ICU, started on tube feeds and isolated from his caring family who were allowed to see him only for a few minutes every day. His wife and son are distressed seeing the pathetic condition of Raj in the ICU, when the paralytic drug influence lightens and he coughs on the endotracheal tube. From the anguish on his face and the tears in his eyes, they can perceive the deep distress that he is experiencing. They are desperate to be with him and express their affection but are restricted even from seeing him. As he is not covered under any insurance, they are also finding it difficult to pay the daily ICU bills and his wife has pawned her

ornaments to tide over the financial crisis. His son, who has exhausted his paid leave is now worried stiff about the uncertainty and also about his own job security.

Let us analyse this situation

Raj's admission to the hospital was consequent to progressive deterioration and irreversible multi system failure. Here it is most likely that he may die in the ICU on the ventilator. Hence in this scenario, the line of management cannot be considered as appropriate.

An intervention that is appropriate at an early stage of the disease may not be appropriate in the same patient at a later stage.

So what is appropriate line of management for patients with advanced disease and multi system dysfunction?

'Curing' or 'not curing' is not the sole responsibility of medical professionals; caring and comforting are our responsibility too.

For caring to happen, we need to understand the priorities and needs of patients like Raj and his family. Evaluating, acknowledging and optimising the total needs of Raj and his family with early, honest and empathetic communications is crucial. Making individualised shared decisions on goals of care emphasising "Quality of Life" [QOL], would be considered appropriate line of management¹⁷

We should take shared decisions based on discussions with the patient and family. The decisions to be taken are regarding goals of care emphasising what is "quality of life" for them and not what we decide based on organ parameters.

"...it almost always takes less time to explain the side effects and schedule of a new treatment than it does to discuss death and dying."

Daugherty CK

Quality of Life

Health has conventionally been measured narrowly, often using measures of morbidity or mortality.

The Health Related QOL - HRQOL is the functional effect of a medical condition and/or its consequent therapy upon a patient. This includes physical and mental health perceptions and their correlates including symptom control, functional status, relationships, socioeconomic support and alignment with meaning and fulfillment for the individual.

Adapted from World Health Organisation HRQOL

The evaluation of QOL¹⁸ is useful to guide health care inputs because it helps the practitioner to take the best decisions regarding patient care. The health care of patients thus becomes more meaningful.

18 http://www.who.int/mental_health/media/68.pdf

What are the QOL issues for this patient?

Let us go back to the point of time, when Raj was brought to hospital in distress and review our line of management from this perspective. He had multiple physical symptoms like cough, breathlessness bordering on panic, and delirium.

Aim of treatment is maximum longevity with best possible Quality of life..... Sacrificing one for the other can only be by patient's informed choice.

Optimisation of physical symptoms: As the disease modifying inputs are no longer applicable, we start him on low dose morphine (2.5 mg Q4H) which is also an antitussive along with dexamethasone(8 mg IV OD), and nebulisation with salbutamol - ipratropium to relieve his dyspnoea. An initial trial of oxygen is given via nasal cannula after explaining to the family that it would be continued only if it is beneficial for his comfort. Raj was uncomfortable with it also since it did not relieve the symptom nor the saturation further, oxygen was discontinued¹⁹.

As Panic reinforces breathlessness and works to maintain the vicious cycle, lorazepam 1mg was given sublingually for quick anxiolytic effect²⁰.

Delirium is acute psychotic behaviour, a common symptom in late stages of progressive diseases. It compromises the fabric of QOL for the patient and family. Reversible contributory factors are electrolyte disturbances, infection and dehydration were looked for and corrected²¹. Symptomatic management of delirium was then initiated using haloperidol (2.5mg SC²² / dose) and was slowly titrated up according to the response. By managing these symptoms Raj's physical distress was brought under control and the family felt supported

Emotional issues: We have already mentioned many of the psychological distresses and anxiety in Raj's case that happened more due to gaps in early and honest communication, failure to tailor the management to Raj's present disease status and the socio economic capacity of the family. The spiritual concerns, which surface intensely during severe illnesses were also left unexplored.

Raj was not told about the diagnosis. He was not consulted about what his wishes were regarding management.

19 Putting the patient under continuous oxygen is a carefully considered decision and not a routine intervention

20 Alternative is Inj. Midazolam 2mg, subcutaneously. For details, refer Introduction to Palliative Care 4th Edition by Robert Twycross.

21 The strange in-patient environment, and lack of exposure to day / night rhythm and inaccessibility to their visual / auditory aids itself can initiate it.

22 Subcutaneous

Often it is the lack of clarity and uncertainty which is more distressing to the patient and family than an empathetic communication of the necessary truth about poor prognosis with continued support and care inputs.

Benefit vs. Effect and Futile care

Effect is a response to an intervention limited to improvement in investigation parameter or function of an organ (eg serum creatinine decreasing from 6mg to 3.7 mg % OR urine output increasing from 100ml to 500ml/day)

Benefit is the response which the patient has the capacity to appreciate (an unconscious ventilated patient becoming oriented and ambulant)

We as health care professionals are more often carried away by the 'effect' whereas we should be concerned more with 'benefit' that the patient values.

Futile Care: Goal of medical care is to achieve a benefit above a certain minimal threshold. Futile care is care that fails to achieve that benefit.

What did we do to help him?

During the admission, we had few meetings with Raj and his family. The poor prognosis was 1st conveyed to the family. They were hesitant initially about including Raj in discussions on future plans regarding his care. I.e. place of care, decision on aggressive interventions in case of a critical event etc. It was made clear to the family that their affection was the basis for such a step. Subsequently they opted for open discussion in Raj's presence. It was then apparent that Raj had already guessed the diagnosis but had hesitated to clarify his doubts because of "silence" on the part of his family and also because he did not want to distress his family. The advanced nature of the disease and futility of aggressive management were thus made clear to both Raj and his family, they were now empowered in participating in the planning of care inputs.

Home based Care

The family opted for home as place of future care and were introduced to the home care team of the hospital so that Raj's day to day problems could be managed by his family with inputs from the Home care Team.

Essential care

Prior to discharge, we reviewed his ongoing medications other than those for symptom relief e.g. anti-hypertensives, hypoglycaemic agents, anti-anginal, anticoagulants and cholesterol lowering agents. With due considerations for his lowered intake, cachexia and poor haemodynamic status we could discontinue many of the medications except the essential ones needed for symptom relief and the anti-anginal drug.

Anticipatory prescription

His family was educated regarding how to manage breathlessness, panic and delirium in case of their recurrence at home and a clear discharge summary with anticipatory usage of medications for each symptom was provided. This was also to assist the local G.P to support the family in case of need.

We also discussed about the "living will". Raj and the family opted against CPR and invasive interventions and this was documented.

Living will (Advance health directive)

When the disease becomes unresponsive to available therapy, it is important to talk about personal choices regarding resuscitation or invasive interventions with the patient and the family in a personalised, culturally acceptable manner. In the current scenario of technologically assisted health care [which is sometimes used without wisdom and discrimination] it allows a sick person the possibility for choosing a natural death process²³.

We must tackle the subject of expected death very sensitively and with empathy. This is because although on everybody's mind, nobody talks about it.

It helps to get the patient and family mentally prepared, close unfinished business like legalities, make arrangements for religious / spiritual inputs as per the wishes and say the final good bye to relatives and close friends. It also allows making of "living will" to avoid undignified hospitalised deaths.

Living will OR Advance directive:

This is a legal document that expresses the patient's wishes and desires for his or her health care treatment in case he or she becomes terminally ill and unable to speak for oneself. These directives will act in the place of the patient's verbal requests and serve as assurance that the patient's end-of-life decisions will be honored. It recognizes the patient's desire not to be kept alive artificially and sets limits to which health care providers may proceed with aggressive and invasive interventions.

23 Indian Journal of Critical Care Medicine by the ISCCM journal Vol 9; issue 2; 2005

Re-Considering Cardiopulmonary Resuscitation

CPR is an efficient intervention for patients in reversible critical care situations such as poisoning, near drowning, trauma etc. However if used indiscriminately and inappropriately it could hinder a dignified death.

Our patients do not want to live for ever...nor do they want to die for ever.....

In conditions such as advanced cancer with multiple organ failure OR persistent vegetative state due to irreversible neurological damage, CPR may be considered inappropriate and honest communications need to be initiated with family to help them with advance directive on resuscitation interventions.



Fig 5.1: Home care team on their way to attend to Raj

What happened to Raj at home?

With empowered caring by his wife and regular visits by the home care team, Raj though bedridden, continued to have satisfactory symptom control for few weeks. However, due to the disease progression, his general condition deteriorated gradually.

The terminal phase

The terminal phase is defined as the period when day to day deterioration particularly of strength, appetite and awareness occurs. Only if we detect this phase, can we ensure the patient's comfort physically, emotionally and spiritually and make the end of life peaceful and dignified. We can also make the memory of the dying process as positive as possible by care and support given to the dying patient and their carers.



Fig 5.2: Raj being evaluated by the home care team

Nutrition in terminal stage: He was soon unable to take solid food. There was a discussion whether tube feeding was to be initiated. The home care team had a discussion with Raj for his opinion. He clearly expressed his preference for continued natural oral intake. His words were, “Doctor, I know that I have very little time ahead. I would rather you don’t insert a tube.”

The home care team counselled the family regarding diminishing needs of the body with onset of terminal stage and the load on the digestive system by force feeding. This allowed them to accept the situation. They continued to feed him in small frequent sips of fluids and soft feeds as much as he was comfortable with.

Raj’s statement also led to a discussion regarding the approaching death. He had accepted the situation and completed the legal issues regarding his assets. He expressed a desire to see his daughter and grandson again to say the final good bye. The family was distraught, but readily made arrangements for this. Raj and family got more closely bonded during these days.

Dying Phase

The last 48 hours is a crucial period in care for the person, family and caring team. There is only one chance to “get it right”, and when things do not go well families and staff can be left with long term guilt and regrets.

Key to “getting it right” is anticipating that this stage has been reached. Carers who are regularly looking after the patient, spending the most time with the patient, intuitively pick up subtle signs of global deterioration. They are often quite accurate at predicting the approaching death than professionals.

Table 5.1: Symptoms and signs of dying phase

Symptoms	Signs
Profound weakness/ bed bound	Gaunt appearance
Needs assistance for basic needs	Drowsiness
Diminished intake of food and fluids	Loss of skin turgor and luster
Disoriented in time, place and person	Dry mouth and conjunctiva
Difficulty in concentrating and cooperating	Cold extremities

A practical way to answer the question on “how long” in the background of a chronic progressive disease trajectory is - if each week is worse than previous, then we may predict that there are just weeks left, if each day is worse than the previous, we may predict that there are days left.....

Can we predict death? ²⁴

We cannot usually accurately predict exactly in how many hours or days or weeks that a person would die. A useful starting point is asking the “surprise question” to ourselves i.e. would I be surprised if this person were to die within the next few ...weeks.....days?

It is useful to understand the situation more as a method to anticipate needs and meet them than predicting the exact time left; so as to ensure right care at right time.

When a patient asks... ***“Doctor, how long do I have?”*** the implicit question usually is ***“Doctor...now that I have very little time left, what can I expect, how can you help me?”***

As days passed, Raj became profoundly weak, gaunt in appearance, totally bed bound and needing assistance for all activities, drowsy, without any intake, difficulty in taking his medications and abnormal patterns of breathing. These being the indicators of impending death, we again communicated with the family to help them get prepared. They informed his close friends and relatives and also arranged for rituals as per their belief. That is to say Raj is being prepared for a dignified death or a good death

What is dignified dying?

Natural death free from avoidable distress and suffering for patients, families and care givers, in accordance with wishes of patients and families and consistent with clinical, cultural and ethical standards.

Withholding Treatment: Considered decision not to institute new treatment or escalate existing treatments for life support *with the understanding that the treatment has a higher potential to cause pain and suffering than resolution of organ failure*

In Raj's case, his death is expected and understood as a natural consequence of the disease progression. It is not taken as failure of medical inputs. He is not chained to the ventilator, isolated within the ICU. He is at home surrounded and cared for by his family and friends. His distressing symptoms are under control and he is reasonably in control of his situation (nothing being forced e.g. tube feeds). His wish to see his daughter and grandson has been fulfilled, he has completed all legal formalities. He has had a chance to express his love, affection and bid good bye to his friends and relatives. His family has had regular support throughout this difficult phase from the palliative care team and have the satisfaction of meaningfully looking after and caring for Raj. They are fully aware of Raj's impending death, understand the futility of hospitalisation.

Thus Raj died peacefully at home amidst those he loved, after meaningful period of bonding with his loved ones.

“.....the pain of loss is still immense, but to feel that everything that could have been done was done, that those who cared did so with knowledge, professionalism, devotion, and even love, and that the person died without pain, comfortably, with those they loved around them, is to feel immense gratitude and a curious humility...”

Statement by a relative after death of a loved one - Julia Neuberger

FACILITATOR'S MANUAL

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1. Aim

The aim of this manual is to help the facilitator to go through and help the student understand the essence of Palliative Care and provide holistic care to their patients and family in hospital as well as in the community.

2. Overview

Palliative Care is practiced in some parts of India but the need for Palliative Care is much more than what is available. On any given day two million people in India are in need of end of life care although the definition of Palliative Care has been expanded to include chronic diseases.

Most students think Palliative Care is only intended for cancer patients but in reality, it is for any type of patients with incurable chronic diseases including but not limited to, HIV, Motor Neuron Diseases and other life limiting diseases. It does not necessarily begin, near the end of a person's life. Appropriately, Palliative care should start much sooner in the chronic disease process, specifically from the point of diagnosis.

Delivering Palliative Care utilizes physical, psychosocial, and spiritual dimensions. It will require the student to utilize previous learning in these areas but expand and apply it to the specialized complex issues associated with Palliative Care.

Nursing excels in the ability to care for the entire person, their family and has always played a major role in the delivery of Palliative Care. Nurses are the ones who are with the patients 24 hours a day in hospital and are the most frequent professional care providers in the community setting.

3. Learning objectives

Upon completion of the modules the facilitator should have the necessary knowledge and skills needed to deliver meaningful quality content to the students.

4. Learning activities

To teach the key components a variety of methods will be used to assist the facilitator in delivering this content including:

Classroom teaching

1. Demonstration of nursing procedures
2. Use Teaching Videos including Life Before Death
3. PowerPoint presentations
4. Role Plays
5. Blackboard/White board as Visual Aids
6. Group discussion
7. Case study analysis

Clinical Teaching

1. Visit to hospice and/ or home visit in the community
2. Care of Palliative Care patients in hospital.
3. Care of Palliative Care patients in community.
4. Education of the family member by the student.

Small Group Work

1. Discussions
2. Role plays
3. Health Education as a group

CONCEPT	CLASSROOM TEACHING	BEDSIDE OR CLINICAL TEACHING	SMALL GROUP WORK
Pain	PowerPoint on Assessment of Pain with Visual Analog Scale, Body Chart and Complete Assessment, Pain Assessment Videos by International Association for Study of Pain (IASP)	Complete assessment of patient experiencing pain	View Life Before Death Video of someone in severe pain with follow up discussion of: 1) What they saw? 2) How do they feel?
	Pharmacologic and Non-		What should be done

	pharmacologic methods		<p>for the patient they saw in the video form Life Before Death</p> <p>Usage of WHO analgesic ladder for cancer patients</p> <p>Group discussion of reasons why patients may or may not be taking their pain medicines</p> <p>Role Play for pain assessment.</p>
	Evaluation of Relief	Appropriate questioning to patient	
CONCEPT	CLASSROOM TEACHING	BEDSIDE OR CLINICAL TEACHING	SMALL GROUP WORK
Nausea and Vomiting	<p>Assessment of nausea and vomiting.</p> <p>Recognition of the various consequences of prolonged nausea and vomiting in Palliative Care patients including dehydration and nutritional problems.</p>		<p>Discussion of consequences of unrelieved nausea and vomiting</p> <p>How do you feel, when someone is vomiting?</p>
	<p>Pharmacologic and Nonpharmacologic interventions –</p> <p>Importance of recognizing the need for</p>	<p>Identify any environmental causes, identify stress/ anxiety</p> <p>cleanliness</p>	

	administering anti-emetic medications on a regular basis and prior to chemotherapy or any other things that might make the patient nauseous. Remove any items in the environment that might induce vomiting (smells, foods)		
CONCEPT	CLASSROOM TEACHING	BEDSIDE OR CLINICAL TEACHING	SMALL GROUP WORK
Constipation	Complete assessment of constipation. Palliative Care patients are often less active, may have inadequate diet, and on medications that have side effects. Some may have a pathology that interferes with bowel habits.		It is often initially difficult for young nurses to ask patients about their bowel habits. This can be overcome by discussion and by having role-plays.
CONCEPT	CLASSROOM TEACHING	BEDSIDE OR CLINICAL TEACHING	SMALL GROUP WORK
Diarrhea	Diarrhea can have a detrimental effect on a patient's condition. Accurate assessment of the cause of diarrhea is mandatory - to identify and to plan the appropriate intervention.	Importance of accurate measurement of diarrhea, skin care and personal hygiene.	What are the implications of a patient at their home with recurring diarrhea? How can patients be kept clean if the house has no running water and if the patient's bed is on the floor? What effect can this have on

			the patient's caregivers as well as the patient?
CONCEPT	CLASSROOM TEACHING	BEDSIDE/CLINICAL TEACHING	SMALL GROUP WORK
Dyspnea	Lecture: Assessment of dyspnea and causes. Recognition of the fact that unable to breath properly, makes people afraid which makes the breathing harder. Impact of dyspnea on patients quality of life	Measures to reduce dyspnea. Positioning of patient in dyspnea. Helping patient relax. Use of opioid in the management of dyspnea. Importance of drug compliance.	What are the impacts of dyspnea in performing Activities of daily living? List the drugs used for the management of dyspnea?
CONCEPT	CLASSROOM TEACHING	BEDSIDE/CLINICAL TEACHING	SMALL GROUP WORK
Nutrition	Lecture: altered nutrition. Recognition of inadequate nutrition due to disease, treatment or financial constraints. Small and frequent feeds are encouraged.	Measures to make the food more palatable. Importance of environmental hygiene.	Identify the causes for anorexia in Palliative Care patients and anti emetics available. Identify the fruits and vegetable that are rich in protein, carbohydrate, vitamins etc.
CONCEPT	CLASSROOM TEACHING	BEDSIDE/CLINICAL TEACHING	SMALL GROUP WORK
Anxiety	Recognize that Palliative Care patients have many reasons for anxiety. Fear of disease, treatment, body image disturbances, potential loss of a variety of body functions,	Have you cared for a Palliative Care patient who was experiencing severe anxiety? What interventions were used to assist the patient?	Divide students into four groups 1) chronic illness such as paraplegic or stroke, 2) one with a cancer diagnosis that can be cured but with a loss of a body part such as a

	<p>hopelessness and the reality of death.</p> <p>Long term pharmacologic interventions / methods to reduce anxiety.</p>		<p>breast or part of your face 3) a rapidly progressing motor neuron disease, 4) a rapidly advancing cancer that will probably end your life in less than six months.</p> <p>What other members of the health care team can provide needed assistance for patients with anxiety problems?</p>
CONCEPT	CLASSROOM TEACHING	BEDSIDE/CLINICAL TEACHING	SMALL GROUP WORK
Social Isolation	<p>Lecture: Conditions that create situations where patients and their families may isolate themselves or be isolated by the community.</p> <p>Educational interventions to help patients and their families to become less isolated.</p> <p>Many people believe cancer is contagious. Appropriate education can greatly improve the patient's quality of life and decrease isolation.</p> <p>Community educational interventions may also be appropriate.</p>	<p>Methods used to avoid the infestation of maggots.</p> <p>Methods for cleansing a bad odor wound and needed frequency to keep it clean.</p> <p>Home sterilization of dressing materials and preparation of homemade saline.</p>	<p>Have you seen a wound that have foul smell and infected with maggots? How did it make you feel?</p> <p>Can you understand why someone might not want to be around family or others with this condition?</p> <p>How important is it to educate and empower patients and families with proper wound care?</p> <p>After removal of maggots and cleansing of wounds how could you help the patient and</p>

			family be less isolated.
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5. Formative assessment questions

Multiple choice questions, True / False, Completion questions, short answer, matching, case studies

MULTIPLE CHOICE QUESTIONS

CHOOSE THE BEST ANSWER AND FILL THE ALPHABETS IN THE SPACE PROVIDED

1. Which one is an example of counterirritant cutaneous stimulation?
 - (a) Imagery
 - (b) Massage
 - (c) Minor surgery
 - (d) Subcutaneous administration of morphine -----

2. Directing one's attention away from the sensations and emotional reactions produced by pain is known as
 - (a) Autogenic relaxation
 - (b) Bio feed back
 - (c) Distraction
 - (d) Hypnosis -----

3. Assessment of behavioral parameters in cancer pain includes an evaluation of
 - (a) Associated psychological problems
 - (b) The quality of the pain
 - (c) The duration of the pain
 - (d) The effect of the pain on the activities of daily living -----

4. Which of the following is the most accurate assessment of dyspnea in the individual with cancer?
 - (a) Arterial blood gas level
 - (b) Oxygen saturation
 - (c) Patient self report
 - (d) Respiratory rate -----

5. Which of the following side effect is associated with Opioid administration?
 - (a) Agitation
 - (b) Constipation
 - (c) Lethargy
 - (d) Nausea -----

6. Which one is the primary aim of palliative care?
 - (a) Mercy killing
 - (b) To delay death

- (c) To make life as comfortable and as meaningful as possible
- (d) To prolong life -----

7. What do you mean by quality of life?

- (a) Good when aspirations of an individual are matched and fulfilled by present experience
- (b) Influenced by all dimensions of personhood (Physical, Psychological, Social and Spiritual)
- (c) Relates to an individual's subjective satisfaction with life
- (d) What a person says it is -----

8. How many steps are there in WHO analgesic ladder for cancer pain?

- (a) 2 Steps
- (b) 3 Steps
- (c) 4 Steps
- (d) 5 Steps -----

9. A nursing diagnosis represents the

- (a) Assessment of patient data
- (b) Actual nursing interventions
- (c) Patient's health problems
- (d) The proposed plan of care -----

10. The effectiveness of nurse patient communication is best validated by which one of the following

- (a) Health team conference
- (b) Patient's feedback
- (c) Patient's psychological adaptation
- (d) Medical assessment -----

COMPLETION QUESTIONS

1. Pain is whatever patient says it -----
2. Pain which is associated with tissue distortion (or) injury is called -----pain
3. Marked weight loss and muscle wasting is called -----
4. The commonest side effect of oral morphine is -----
5. Depression becomes pathological when depression persists more than -----weeks
6. Normal saline is a ----- solution
7. Short acting morphine should be given every six hourly in case of -----failure
8. The concept of ----- pain includes physical, psychological, social, and spiritual aspects of life.
9. When there is a complete bowel obstruction -----is the alternative route for medication administration in palliative care
10. Withholding bad news from the patient (or) their relatives is called ---

EXTENDED MATCHING QUESTIONS
CLASSIFICATION OF ADJUVANT ANALGESICS

ADJUVANT ANALGESICS	EXAMPLES
1. Anti depressant 2. Anti epileptic 3. Anti spasmodic 4. Corticosteroid	a) Hyoscinebutylbromide b) Dexamethasone c) Amitriptyline d) Sodium Valporate e) Lorazepam
CLASSIFICATION OF LAXATIVES	EXAMPLES
1. Bulk forming laxatives 2. Osmotic laxatives 3. Stimulant laxatives 4. Stool softener	a) Soap b) Castor oil c) Fybogel d) Bisacodyl e) Lactulose f) Liquid paraffin

Summative assessment questions and examples

1) Mr. Joseph is a 70-year-old patient who has the diagnosis of squamous cell carcinoma of the larynx. He has undergone surgery and radiation for his disease and the treatment appeared successful. He was left with a permanent tracheostomy and part of his lower jaw and maxilla had to be removed. He has not needed additional treatment until now. He has returned to the clinic in severe pain, with a large wound on his face, which he keeps covering with his hand so you can't see it. As you are talking with him during your initial assessment you observe maggots falling on the floor and a strong odor coming from his face. He is very thin and emaciated his clothes are loose fitting. As you talk with him it is clear that he is having trouble breathing and can only say one short sentence before he must take another breath. His wife has come to the clinic with him and is very concerned about him. His wife appears very depressed and anxious about her husband.

Instructor

1. Identify your priority nursing interventions for this patient and list them in order of priority.
 2. How would you manage his wound and what health education is needed for his wife?
 3. How would you take care of his wife?
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2) Mrs. Geetha is a 60-year-old lady who has breast cancer and a fungating wound where her breast once was. She has come to clinic today for care of the fungating wound but it is clear that she is severely depressed. By talking to her she tells you that her family no longer comes to see her, which causes her great pain, and additionally her grandchildren are not allowed to visit her either. Prior to this the family was very close and one of the great joys of her life was her grandchildren. She keeps herself and her house clean. she has separated her eating utensils from others eating utensils in the house. Mrs. Geetha lives alone because her husband left her after her initial diagnosis and has not had any further communication with her. She has a son who loves her very much, is devoted to her and supports her financially but he will not come to see her. It is difficult for her son to visit because his job is not near where Mrs. Geetha lives.

Instructor

1. What factors are causing the social isolation?
2. As a Nurse how are you going tackle this problem?
3. How important is it to solve this problem for Mrs. Geetha?
4. After your interventions Mrs. Geetha's family has begun to visit her and she is allowed to

see her grandchildren but the only time she leaves her house is to come see the doctor?

5. What interventions would be appropriate for Mrs. Geetha and her family and friends?

3) Arun is a sixteen-year-old boy who has been diagnosed with an Osteogenic Sarcoma of the right femur. He is undergoing Intra Venous Methotrexate therapy and in the near future his right leg will have to be amputated. When you first see him he has been admitted for severe dehydration secondary to vomiting from his most recent chemotherapy. When you walk into his room his back is towards the door and he has the sheet pulled up over his head. As you begin to talk to him he tells you that his life is over, that he has nothing to live for and he will never be able to play football or cricket again. Although you have not known him but a short time he seems very anxious. His leg is very painful and he does not want anyone to touch it and because of the pain he has not slept well for several days. His right femur is much larger than the left and it does not have good color because it is not getting good blood supply because of the tumor. His chemotherapy made him very nauseated and he has decided just to stop eating and drinking in hopes that the nausea will pass. He has not passed stools for over a week.

Instructor

1. Identify your priority nursing interventions for this patient and list them in order of priority.
 2. How would you manage his pain?
 3. What will need to be done for his constipation?
 4. What other members of the health care team can be consulted to help him?
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4) Mr. Albert is a 38-year-old who fell out of a coconut tree, is now paraplegic and suffered a head injury from the fall that has left him unable to speak. He seems aware of his surroundings and attempts to speak but becomes frustrated and at times cries because he cannot effectively communicate. He does not have urinary bladder control but has learned to catheterize himself on a regular basis. His father is deceased and lives with his mother in her home. He is a tall man and his mother is very small. Currently Mr. Albert's friends come every day and bathe him and put him in a wheelchair after they finish their jobs. They also play cards with him, which seems to bring Mr. Albert great happiness. This gives his mother great joy but she wonders how long they will continue to come and help her son. Because he lies in bed most of the day and is currently unable to change his position he has developed a small pressure ulcer over his coccyx.

Instructor

1. Identify your priority nursing interventions for this patient and list them in order of priority?

2. How will you educate the mother regarding the pressure sore management at home?
 3. What are the possible rehabilitation measures for Mr. Albert?
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5) Mrs. Rani a fifty year old woman is diagnosed with esophageal carcinoma seven months ago undergone an oesophagectomy and she received a course of radiotherapy after her surgical recovery. She was readmitted four months later with nausea and vomiting. On admission she was told about possible recurrence and advancement of her disease and that cancer was incurable. Mrs. Rani and her husband were extremely anxious and they had many plans thinking that her initial surgery had been successful. Her only daughter got engaged recently and her marriage date is falling after three months. Now Mrs. Rani is anxious whether she will be able to attend her daughter's wedding. Arrangements were made to have the wedding earlier than planned. Mrs. Rani and her husband knew that time together was the only valuable thing during the difficult journey towards death.

The primary nurse ensured that her husband was an integral part of her care and the care continued at home within the surrounding where she lived more than two decades. Many nursing measures were taught to Mrs. Rani and her husband to reduce the anxiety level.

Next Outpatient visit Rani's husband verbalize that her anxiety level has come down and she is able to make concrete planning in her life and participate in family decision making process

Instructor

1. What are the positive and negative factors associated with moving the wedding?
2. What are the possible problems that will arise as the disease progresses?
3. What anxiety relieving techniques would you teach this family and the patient?
4. What can patients and families be taught to reduce anxiety?

Nausea and vomiting

Miss Emily Sharada is a 16-year-old school going woman who is gets high marks in her studies. She has a known case of Osteogenic sarcoma in her right femur and was planed for an amputation after chemotherapy. She has been undergoing high dose Methotrexate therapy for the treatment of her disease. She has attempted to continue her schoolwork but has had consistent problems with nausea and vomiting secondary to her chemotherapy. She lives with her parents and 3 younger brothers. Both of her parents work, her mother as daily worker and her father as an auto driver.

When you first see her she appears thin and dehydrated.

Instructor

1. Identify the symptoms of dehydration.
2. What part might fear play in Emily's nausea and vomiting?
3. Priorities her needs according to the severity of her disease.
4. How will you meet her nutritional needs?
5. What is the relationship of her dehydration, chemotherapy and nausea/vomiting? If she continues with poorly controlled nausea and vomiting what effect will that have on her ability to continue treatment?
6. How does chemotherapy induce vomiting and what role might her anticipation of the nausea caused by chemotherapy contribute to her problem?
7. How do you treat this vomiting in palliative care?
8. Is she a candidate for palliative care?

Constipation

Ravi is a 75 year old gentleman with a history of adenocarcinoma of the rectum which is thought to be in remission. Normally he would walk 10 km / day but recently had a foot injury which prevents him from walking. He lives with his wife in their home and has two grown children who do not live with him. They receive money from the government every month. Recently he has been experiencing episodes of constipation and is having tests to determine what the cause might be. It has been determined that he has had a recurrence of his cancer and this news is not shared with him. A surgical consultation has been sent.

What will be your plan about communicating the recurrence to Mr. Ravi?

What measures can be taken to relieve his constipation?

Instructor

1. How will the fact that Mr. Ravi does not know his diagnosis affect your ability to communicate with him?
2. What if the students ask you what they should say if Mr. Ravi asks why he's having such constipation?
3. How is constipation related to the age, disease process and the side effect of the morphine?

4. If medical management fails what will be the next step of his treatment likely be?

Pain

Mr. Raju is a 60 year old gentleman with buccal mucosa cancer who is experiencing severe pain in his face from a large tumor which he rates as a 10/10 on a visual analog scale. The pain is preventing him from sleeping, eating and he has no joy in his life. He lives in his home with his wife and two children. Prior to his illness he was a bus driver, an occupation that he enjoyed. He currently sleeps outside of his house so he does not interrupt the rest of his family. When you approach him for the first time he puts his hand over his face and cries “please help me.” What would it be like to have such a disfigurement and have no relief of the severe pain?

Instructor

The purpose of the exercise with Mr. Raju is to help the student see that his pain is severely limiting the quality of his life. Prior to his illness he was a productive person and will never be able to return to that position. Pain adversely affects many aspects of this patient’s life and until it is relieved he will have no quality.

Questions:

1. What would be the main cause of his suffering?
2. What interventions would help Mr. Raju feel less isolated?
3. What are the most likely causes to have Mr. Raju say “ Please help me?”

Diarrhea

Mrs. Paulin Varghese an 80-year-old bed ridden post stroke person who was left hemipalegic, now has a sacral pressure ulcer, and an indwelling urinary catheter. Her bed bound state has her lying 24 hours a day on the floor because of her financial constraints. Caretaker reports infrequent small quantities of foul smelling loose stools.

Instructor

1. What would be your diagnosis?
2. What will be immediate management?
3. What other information would you need to collect about her diarrhea?
4. What are the likely consequences of her bed bound state?

5. What could be the reason for the current foul smelling stools?
6. What are the simple measures to be taught to the caretakers regarding loose stools and fluid replacement?
7. What is the role of nutrition in this patient with diarrhea?

Breathlessness

Mr. Kumar 55 year old beedi worker, father of three children was diagnosed with lung cancer. His disease was in an advanced stage spread locally and his general condition was very poor to tolerate chemotherapy. He had a course of palliative radiotherapy to his chest. He presented with complaints of severe dyspnoea before treatment, which has worsened after the treatment. The patient had been bedbound and anxious to move since any kind of exertion, worsened his breathlessness.

He was taught breathing techniques, energy saving techniques - spacing activity by the Palliative Care Nurse. The patient was prescribed two weeks course of steroids to reduce the inflammatory response within the lung tissue due to radiation and due to the extensive disease. He was started on oral morphine and benzodiazepines for his troublesome cough and breathlessness.

The steroid, morphine and other medications gave the patient a good symptomatic relief. Mr. Kumar was able to get out and move about and had regained a good quality of life that he thought was no longer possible

Instructors

1. What is going to be the likely consequence when he finishes this course of steroids?
2. What must be the likely problems that made Mr. Kumar think he would be unable to get out of bed?
3. What emergency measures can be taken to assist Mr. Kumar?
4. What physiological response would fear create that would contribute to his breathlessness?
5. How can you help the family understand how the disease process will progress so that they can be supportive of Mr. Kumar?

Nutrition

Mr. Anand 64 year's old gentle man diagnosed with carcinoma of the esophagus who has persistent pain reports feeling anxious, tearful and has had insomnia. He thinks the sickness is sign that his

cancer is taking over his body that he won't be able to eat any more. He knows that if he does not eat he will get thinner and thinner until he dies and he has a picture in his mind of his body looking like a skeleton with skin hanging off it.

Patient is visited by the community palliative care nurse, at his home. He was assessed for imbalanced nutrition. He and his family members were taught about methods of overcoming anorexia. Different kinds of high calorie blenderized menu were enlisted to them. After one month, reassessment was done and he was found to be taking sufficient calories and protein in the diet. The patient had gained two kilograms of weight.

Instructors

1. How could you manage his fear and anorexia by health education?
2. How is anxiety going to affect his health and what could be your management?
3. What guidance will be necessary to provide to the family as his disease progresses?
4. What could be the unseen problems that will arise in this patient?
5. What type of diet would you recommend for this patient, which is easily swallowed and digestible?
6. What methods of overcoming anorexia will you teach to the patient and family members?
7. What balanced diet chart will you prepare for Mr. Anand?

Additional teaching resources

- I. Web sites that focus on palliative care, journals, PubMed (search engine of journals and texts) Textbook references,
- II. Video of Dr. Biju on giving bad news.
- III. Symptom management in advanced cancer, 3rd Edition, Robert Twycross and Andrew Wilcock- 2001, Radcliff Medical press. Oxon
- IV. Palliative Nursing Improving end of life care, Shawn Kinghorn, Sandra Raines, 2nd edition, Bailliere, Tindall, Elseiver, 2007, Churchill Livingstone
- V. Oxford textbook of Palliative nursing 3rd Edition, By Betty R. Ferrel, Nessa Coyle, Oxford University Press, 2010
- VI. Hospice and Palliative formulary US by palliative drugs. Com ltd