MODULES ON PALLIATIVE CARE

Submission to the Medical Council of India
by the WHO Collaborating Centre on training and policy on opioid availability and the WHO Collaborating Centre for community participation in palliative care and long term care
For consideration to be included in the
Undergraduate medical education curriculum

To 22nd October 2013

The Chairman and Members of the Governing Council
Medical Council of India
New Delhi

Respected Sir,

Sub: Submission of palliative care modules for consideration of incorporation into MBBS 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 Medical Council of India, 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 MBBS curriculum. In response to the public interest litigation pending before the Supreme Court of India, MCI had also informed the Honourable court that it was agreeable to such a step.

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 MCI would surely be fulfilling a felt need within our healthcare sector.

As internationally agreed, palliative care skills need to be integrated into regular medical practice and hence it is necessary to include these subjects as part of existing subjects in the MBBS curriculum. *The WHO Collaborating Centres on training and policy on opioid availability* and *WHO Collaborating Centre for community participation in palliative care and long term care* in India and other palliative care organisations of the country have collaborated to create a palliative care curriculum for MBBS course. We are enclosing 5 modules as follows:

Module	**Suggested specialty**
Introduction and Principles Communication Skills	Community Medicine, General Medicine
Management of Pain Symptom assessment and management Optimisation of Care	General Medicine, General Surgery, Obstretics & Gynecology, Pediatrics.

We believe that this would be most effective if incorporated into the teaching hours allotted to the specialities of Community medicine, General Medicine, General Surgery, Obstetrics & Gynaecology, Paediatrics and Anaesthesiology. This could be further modified based on the local setting and inclinations. For proper integration of these concepts into the regular teaching programs, it is advisable for individual universities to conduct facilitator's workshop with the faculty.

Where possible, we also suggest exposing the student for hands on training in palliative care units. The time slot for such posting could be arranged from the teaching hours allotted to Community Medicine in the 6^{th} and 7^{th} semesters.

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

Sincerely,
On behalf of the Editorial team

Prof M R Rajagopal
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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

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 to the hospital again". 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

As a doctor, 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.

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

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 environment[2]."

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

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.

also acute episodic needs and care during advanced stages of the disease (in-patient services).

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.

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.

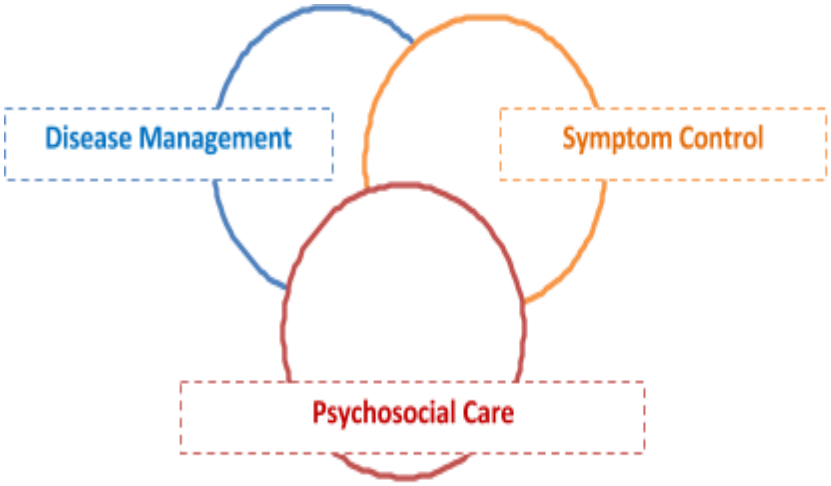


Fig 1.2 – Components of inputs in Palliative Care

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**
• 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	• 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 medical training. Important beginning is by ***focusing on what we can do to care, rather than be discouraged by what we cannot cure***.

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.*

"Add life into their days, not just days into their life."

Nairobi Hospice 1988

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 Worldwide[3]

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 diseases[4].

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

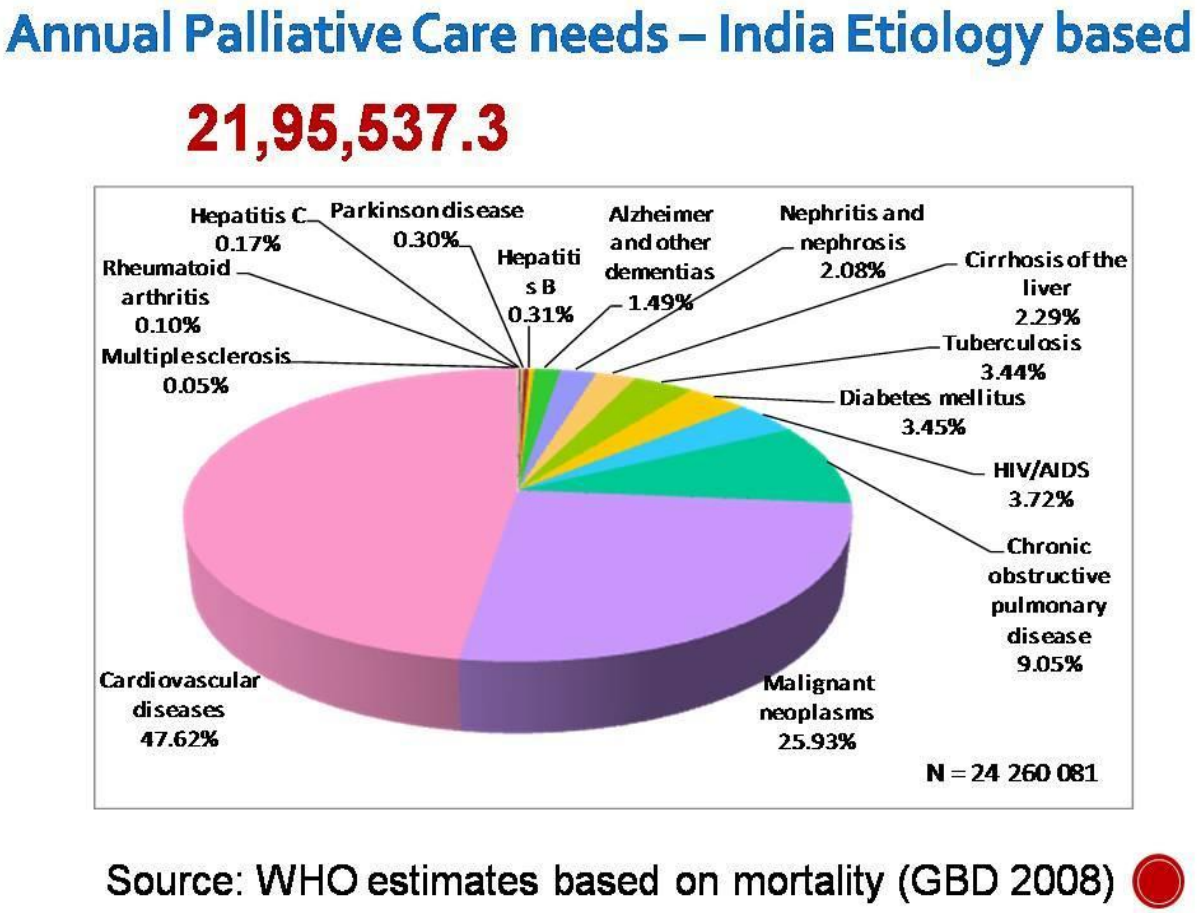
4 World Health Organization (WHO), "National Cancer Control Programmes: Policies and Managerial Guidelines, second edition," 2002, pp. 86-87

"Human Rights Watch" also recommends integration of meaningful palliative care strategies into national programs for chronic diseases[5].

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

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

ETIOLOGY BASED ANNUAL PALLIATIVE CARE NEED IN INDIA [6]



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 clinical practice, irrespective of our field of specialisation. Specialised knowledge and skill is needed to take care of a person with progressive illness.

6 WHO 2008 - Global Burden of Disease

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
    - Parkinson's disease
    - Multiple sclerosis
    - Motor neuron disease
    - Stroke
- Progressive systemic diseases
    - COPD, ILD
    - Heart diseases
    - 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

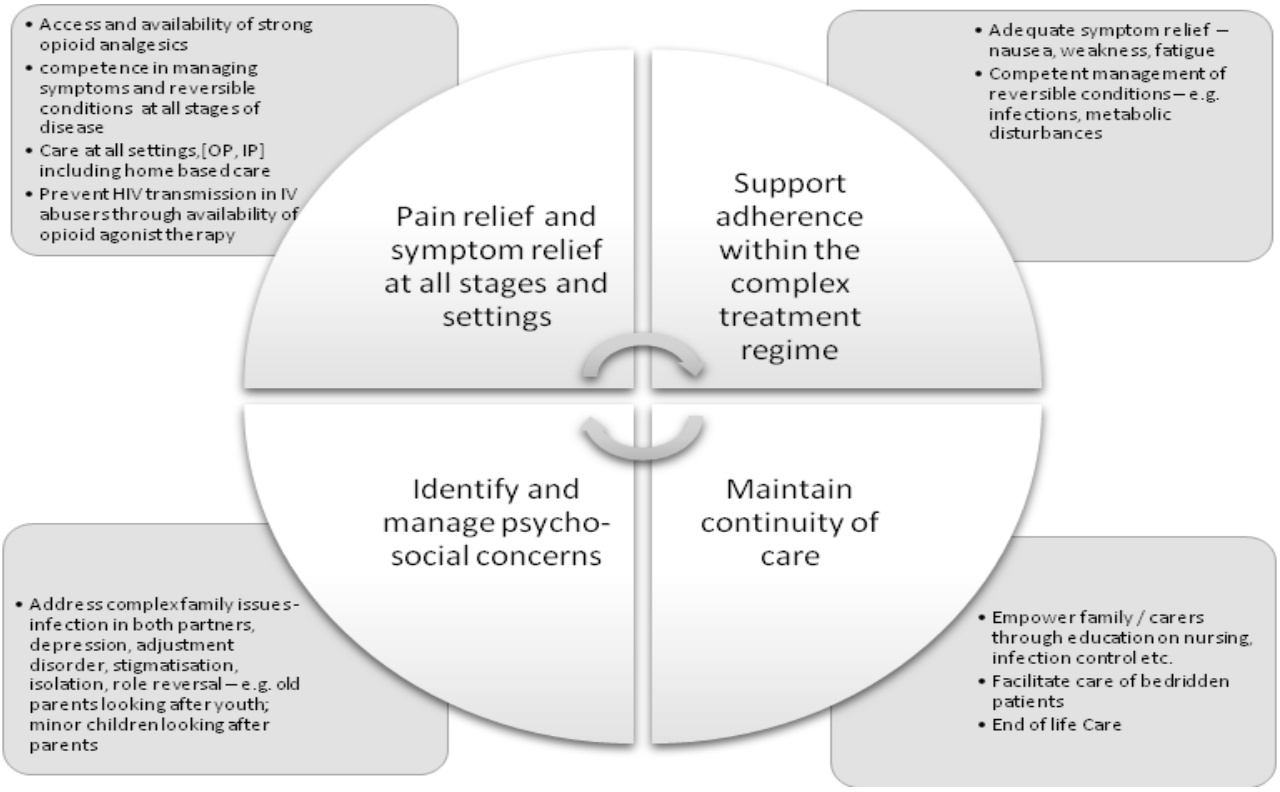
HIV / AIDS is now a chronic disease. Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS because of the burden of distressing symptoms they can experience – e.g. pain, diarrhoea, cough, shortness of breath, nausea, weakness, fatigue, fever, and 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 PC[7]. Here, the palliative care needs of the carers could be more than that for the patient.

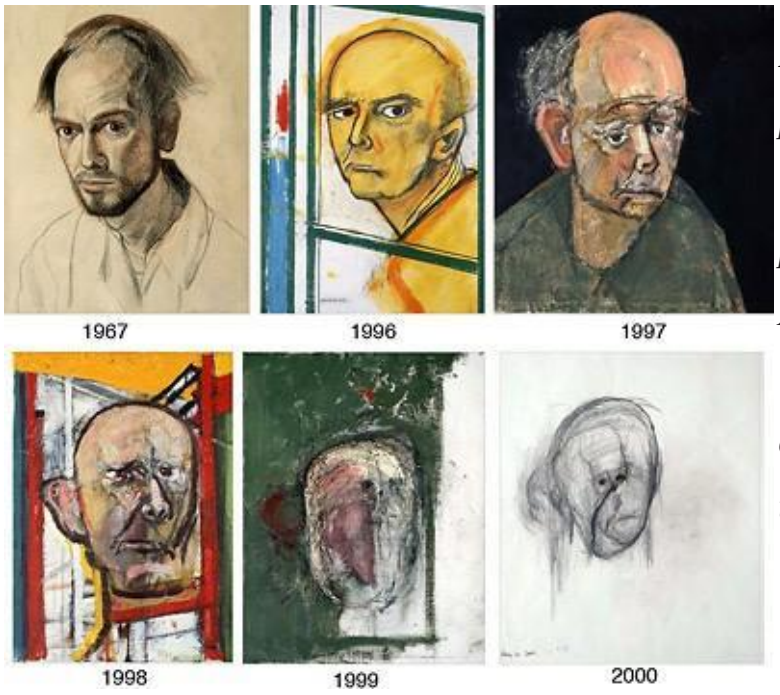


Fig 1.4: This is a series of self-portraits. It expresses the artist William Utermohlen's personal perspective of his descent into Alzheimer's dementia.
This indicates that the awareness of cognitive deterioration is real to the person.

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.

There may be limits to cure,

Yet… care and comfort have no limits…….

Test your knowledge

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

a. Palliative care is only for patients with malignant diseases.

b. People with dementia need palliative care

c. Palliative care is care given only during terminal stages of the disease

d. 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?

a. There is higher incidence of injury amongst older people

b. There is high incidence of cancer in geriatric population

c. Older people suffer from chronic illnesses

d. Older people have multiple concerns at physical, emotional and social dimensions

e. 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 therapy[8]

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

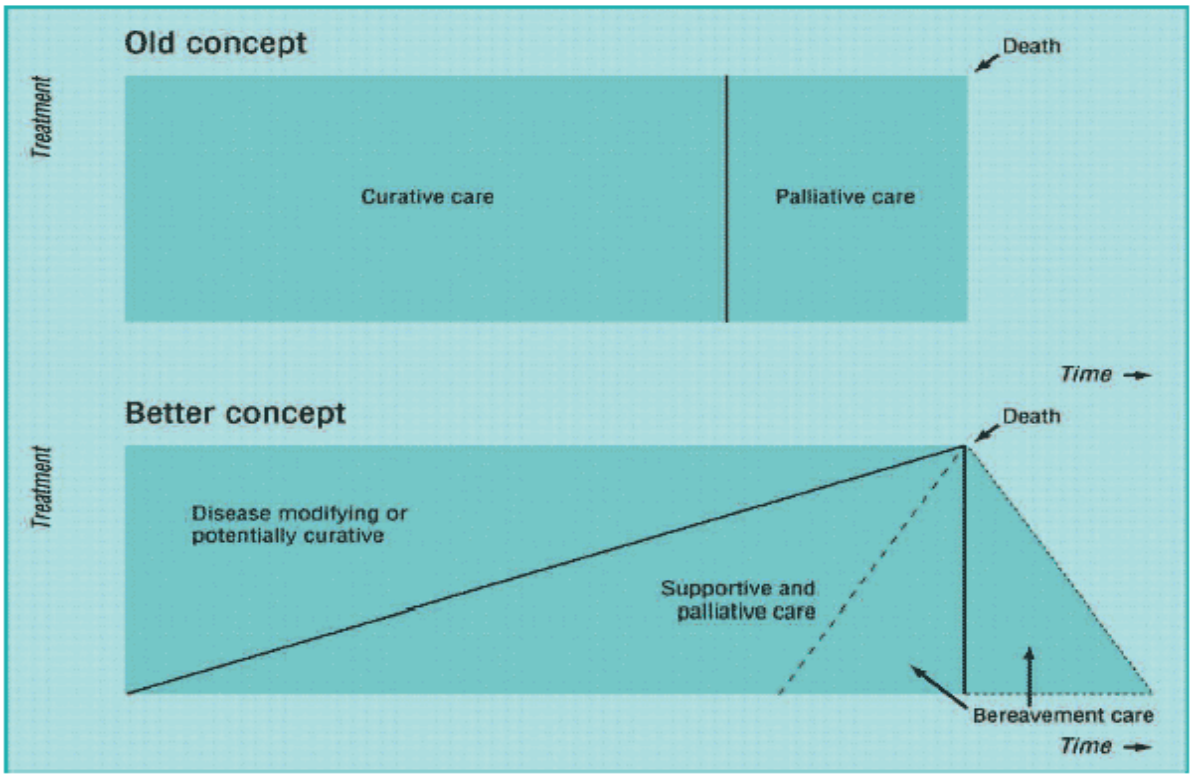


Fig 1.4: Relevance of palliative care during the course of a chronic disease[9]

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.

Post cure phase

This is a phase with heightened anxiety, where the patient needs adequate information to

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

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?

a. After completing curative treatment
b. After all treatments have failed
c. From the time of diagnosis of chronic illness
d. 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 locality[10]. 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?
    a. Tertiary care hospital
    b. Primary health care centre
    c. hospice
    d. Home based care programs
    e. All the above
2. The chief benefit of home based palliative care services is
    a. Doctor's precious time within the hospitals do not get wasted
    b. All modern facilities of advanced medical care can be reached to patient at home
    c. Terminal patients do not need any investigations, treatment or a hospital admission
    d. Patient gets appropriate care in the setting that she / he desires
3. What is the aim of rehabilitation in community based palliative care?
    a. To make patient attain complete physical fitness
    b. To make patient fit enough to attend hospital services
    c. To help patients maximize opportunity, control, independence and dignity.
    d. 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 psycho-social 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 the 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?

Suggested Reading

1. Introduction to Palliative Care by Robert Twycross: 4th edition
2. http://www.who.int/cancer/palliative/definition/en/
3. www.palliativecare.in
4. www.palliumindia.org
5. http://www.instituteofpalliativemedicine.org/

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"

The physician:"Don't worry!"

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

Physician: I know, I shall 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 physician,

"Give me some medicines to make me feel better"

The Physician: "Medicines can be given later; you need to consult a specialist as early as possible"

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

Doctor is irritated, insists and gives the note of reference to the specialist; 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 physician – 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

1. Describe ***why*** communication skills are important.
2. Describe the ***barriers*** to effective communication.
3. Recognize the ***don't-dos*** in communication.
4. Enumerate the steps of ***effective*** communication.
5. Describe the steps of communicating ***bad news.***
6. Describe how to deal with ***extremes of emotions*** (crying, anger etc)
7. Describe how to deal with ***collusion.***

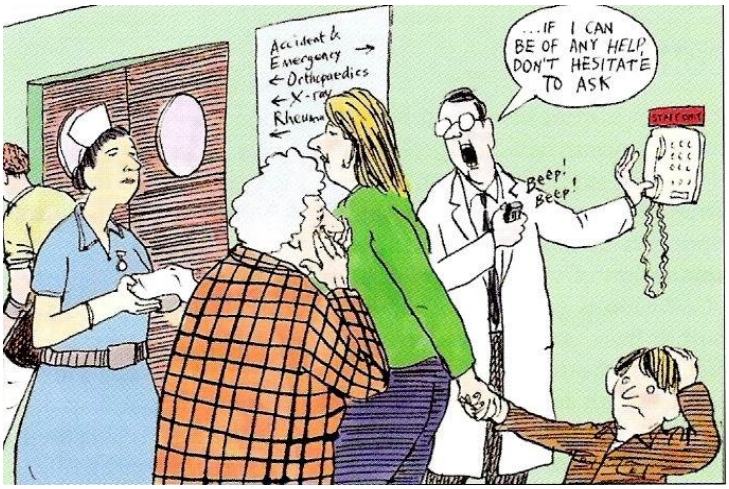
What is the need for communication skills?

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 physician to understand the symptoms, their sequences and their impact ***on the patient's quality of life*** and brings 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 physician is able to convey the required details regarding the disease or plan of care to the patient in a manner that the patient feels supported.

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.

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 physician 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 physician.***



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?

1. Conversation is **NOT** communication skills. This means that ability of talking with the patient on general conversational topics like travel, politics or weather is **NOT** considered communication skills.
2. Convincing the patient to follow the agenda decided unilaterally by the clinical team is **NOT** communication skills.
3. Conversing in a soothing and gentle manner and in kind tones alone, without allowing for their participation 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 physician
- 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 theirs **fears being confirmed**
- Afraid of **treatment being denied** if they raise questions / doubts
- Fear of **losing control** over emotions
- Stumped by the **'med speech'** [technical terms / Jargon]

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, physicians observe and process patient’s nonverbal and verbal behaviour. This process allows the physician to acknowledge unstated or inexplicit needs and agendas the patient may have[12].

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.

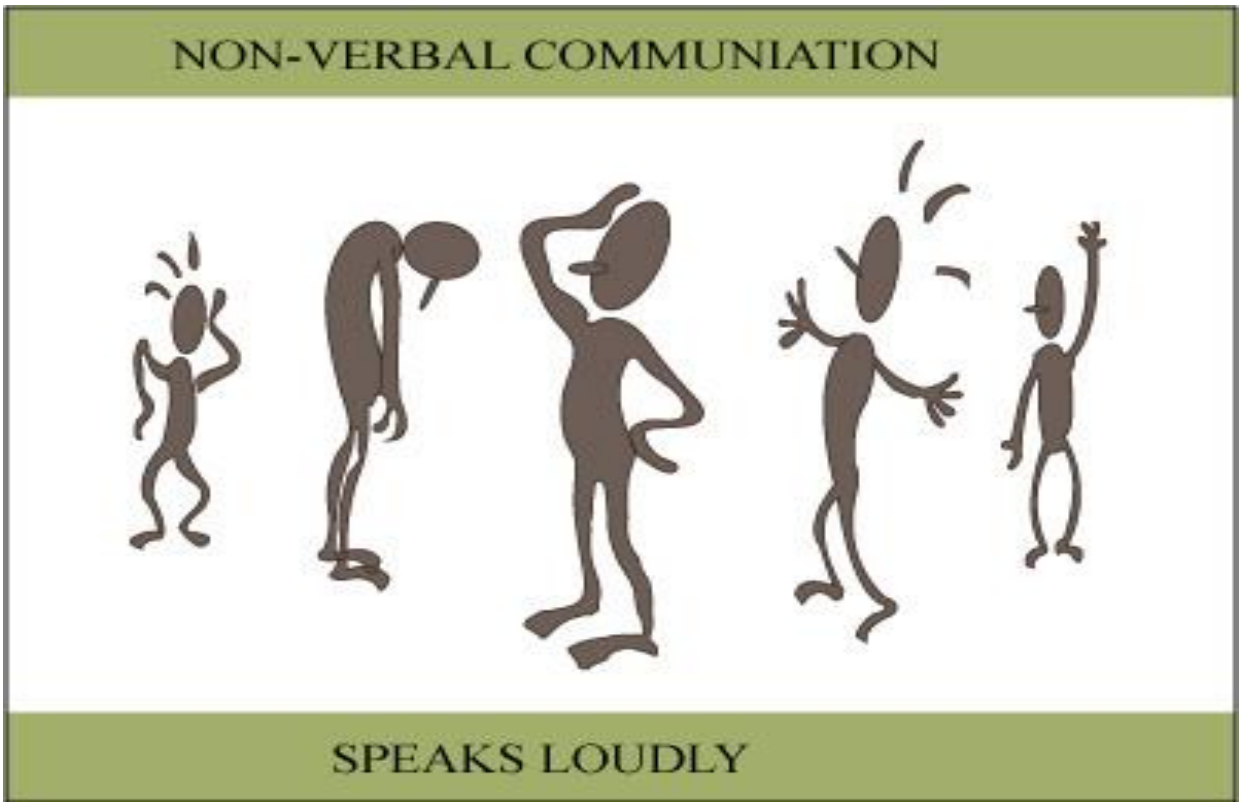
Example 2 – “*at times, I just can’t think clearly; wonder why*?” – Although not a direct request, this may be a cue for help to cope emotionally.

Example 3 – whenever treatment options discussions begin, the patient may keep introducing blocks and avoid discussions to culminate in decisions – this may be related to previous experiences of similar condition with someone known or may be due to denial of reality. This behaviour needs to be noted and understood by the physician and uncovered empathetically by recognising the cues.

12 Richard Brown, Carma Bylund; Comskil laboratory – Memorial Sloan Kettering Cancer centre

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 consultation

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*, physician 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 you the cue as in **Example 1** above[13]. Once we check with the patient and confirms the need for information, we may provide preview of options 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 3 weeks of physiotherapy we shall 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[14]. We can do this by *naming it* to convey our understanding

E.g. "*I note that you are **feeling confused / distressed** due to the ongoing events*" *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*

[13] *"I don't know much about the different treatments*"
[14] "*at times, I just can't think clearly; wonder why*?"

"*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 - *vide supra*)

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? *This is a closed question and restricts and forces the patient's response.*	How are you feeling? *This is an open questions and allows the patient to talk about what is most important issue for her / him*
Be empathetic **E.g. Pt**: I feel very scared when I am short of breath	**Dr**: take these tablets and your breathing will improve	**Dr**: breathlessness can be very frightening; what sort of fears do you feel when you are breathless?
Balancing hope and truth	**Dr**: There is nothing more we can do, your disease is incurable and there is no point in continuing in staying in the hospital. *Here the doctor is destroying hope irrevocably*	**Dr**: 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.	**Dr**: Were you not married then?	**Dr:** 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 **E.g.** Poor compliance with medications	**Dr**: You have not taken the medicine for your pain as I advised. Don't waste my time; sorry, I cannot see you. *Here the doctor is not interested in understanding reasons why the medicines were not taken and correcting them.*	**Dr:** I had given the prescription after due evaluation of your pain. Tell me why were you unable to take it? I would like to understand further. Did you have any trouble when you started the tablets? Do you have any questions or clarifications before using them?

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 physician prescribes anxiolytics so as to make her sleep **. He 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 physician insists that the patient has to meet the Gastroenterologist. His suggestion is professional and with good intension. **But Gopal has his own genuine reasons to deny tha**t. Here the physician could have spent little more time with Gopal, given him Proton pump inhibitors, antibiotics for H Pylori and may be a prokinetic for two weeks and called for review . The physician can also talk to the family about his 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 physician'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 meet the doctor. 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 doctor alone and says, "Chemotherapy is not helping me. I cannot stand it. Doctor, please help me. I want to die."

How will you respond to Mrs. Gita's statement – *"Doctor, 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?[15]

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… ***"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?"***

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."

15 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?*

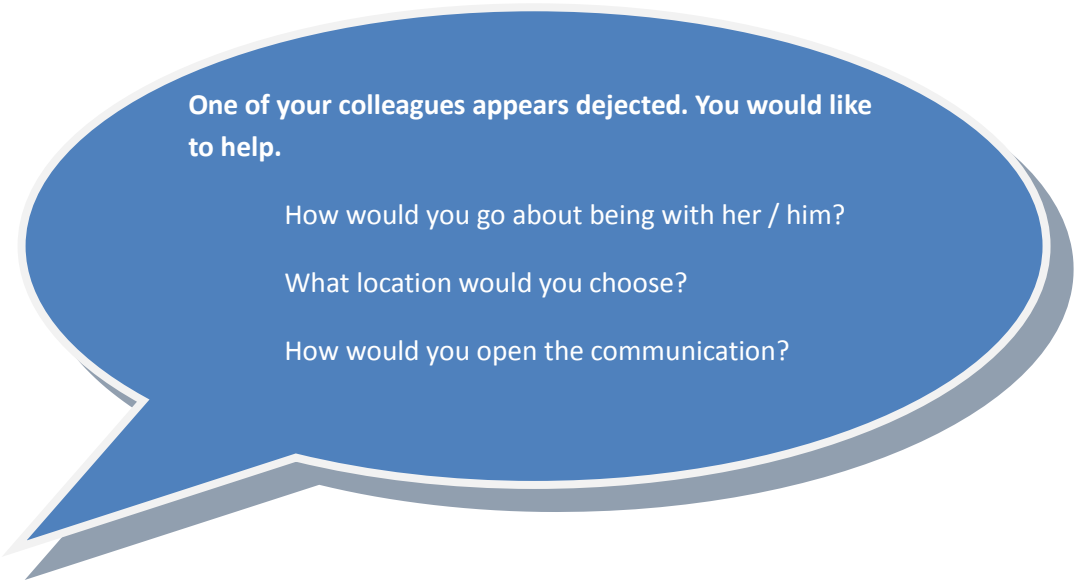
8. **Avoid patronising or condescending attitude**. The patient will open up to you only if you deal with her / him with respect.

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. On the other hand, 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".**



Steps for effective communication[16]

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***

16 Kalamazoo consensus statement

(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.

- Listening is not only to what is said, but also to what is not said – to the facial expression, body language indicating suffering 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 very 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.

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

1. **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.
2. **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.
3. **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.
4. **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.
5. **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.

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

Hit &Run approach

Doctor: "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?"

Doctor: "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: "Doctor, please tell me about my condition!"

Doctor: "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!"

Doctor: "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

Doctor: "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 protective about self

Doctor feels very upset to speak to the mother of an ill child, who will die; feels unprepared. Here doctor may avoids or postpone speaking or gives the responsibility to somebody else.

Patient/Mother may feel alone / desperate

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

Doctor: 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 comfort him and care for him. We are with you."

Mother/Patient may feel consoled, reassured and supported

Flexible, based on feedback with reassurance

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

Patient: I have an advanced form of cancer"

Doctor: "Yes, and unfortunately it is progressing.. *pause… waiting for response and cues to continue.* We are unable to offer cure. *pause… waiting for response and cues to continue.* Here are some possible options, you can choose from. We will always be available for you.

Patient may feel concerned but reassured

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 what 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, 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 paramedical

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 have been proven futile or 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 physician 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 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?

a. Active listening

b. Giving medical advice

c. Normalizing

d. Reassuring

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

e. Be short and precise

f. Involve colleagues as testimonial

g. Non- confrontational approach

h. 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. Doctors can show emotions even at the clinic, it is helpful for patients.
4. Medical 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. ASSESSMENT AND MANAGEMENT OF PAIN

Pain is what the patient says 'hurts'

ASSESSMENT AND MANAGEMENT OF PAIN

Chennayya, 40 year old man diagnosed with Cancer of the buccal mucosa, had attended a busy OP with persistent pain over the jaw which has become severe since few weeks, and not getting relieved by the medications prescribed by the local doctor. He has foul smelling wound over the jaw and has not slept well for several weeks due to pain. He is a carpenter and now unable to work due to illness.

What are the impacts of severe persistent pain on Chennaya's life?

How will you approach the total pain reflected in his eyes?

Learning Objectives of this Chapter

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

- *Differentiate acute and chronic pain*
- *Assess chronic pain*
- *Recognize pain relief as an important aspect of quality of care*
- *Describe pathophysiology, and impact of persistent pain*
- *Describe WHO analgesic ladder*
- *Describe drugs in the WHO analgesic ladder and their effective usage*

What is Pain?

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage

IASP - International Association for Study of Pain

Pain is a common accompaniment of many chronic diseases, for e.g. approximately 30-50% of people with cancer experience pain while undergoing treatment and 70-90% of people with advanced cancer experience pain (Portenoy RK).

Pain is what the patient says hurts; when she / he says it does…

Believe the patient regarding her / his pain.

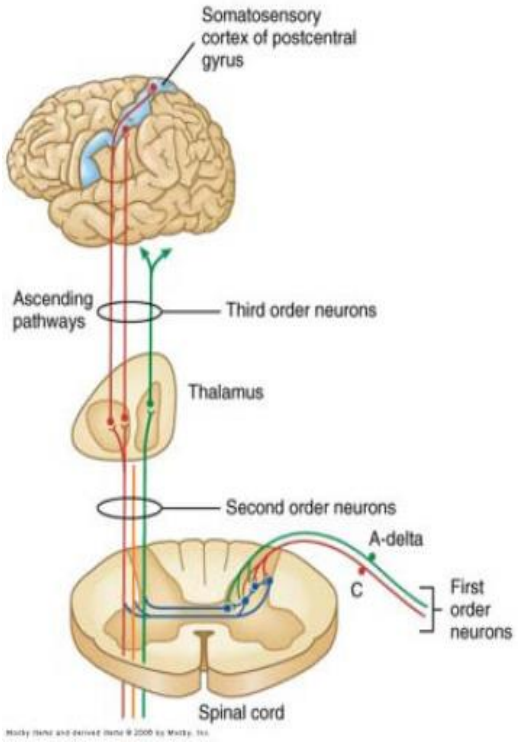


Fig 3.1: Pain Pathway

Fig 3.2 – diagrammatic representation of projection of pain signals to emotional, affective cortex, the limbic system and the brain stem modulatory networks.

Free nerve endings of Aδ and C fibres are stimulated through the release of chemical mediators at the site **of** pathology and the signals travel along the peripheral nerve up to the dorsal horn of the spinal cord. It ascends along the contra lateral spino- thalamic tract to reach the thalamus and eventually the sensory cortex. From Fig 3.2 it is clear that there are projections of pain signals to centres other than sensory appraisal.

Pain is not just a sensation or information appraisal; but an emotional experience.

People do not experience pain in their nerve endings but in their minds where life events and memories combine with physical stimuli to create suffering or resilience. Suffering is very particular to each individual. The anguish of physical pain may be made worse by psychological, social, or spiritual factors (Hayden, 2006).

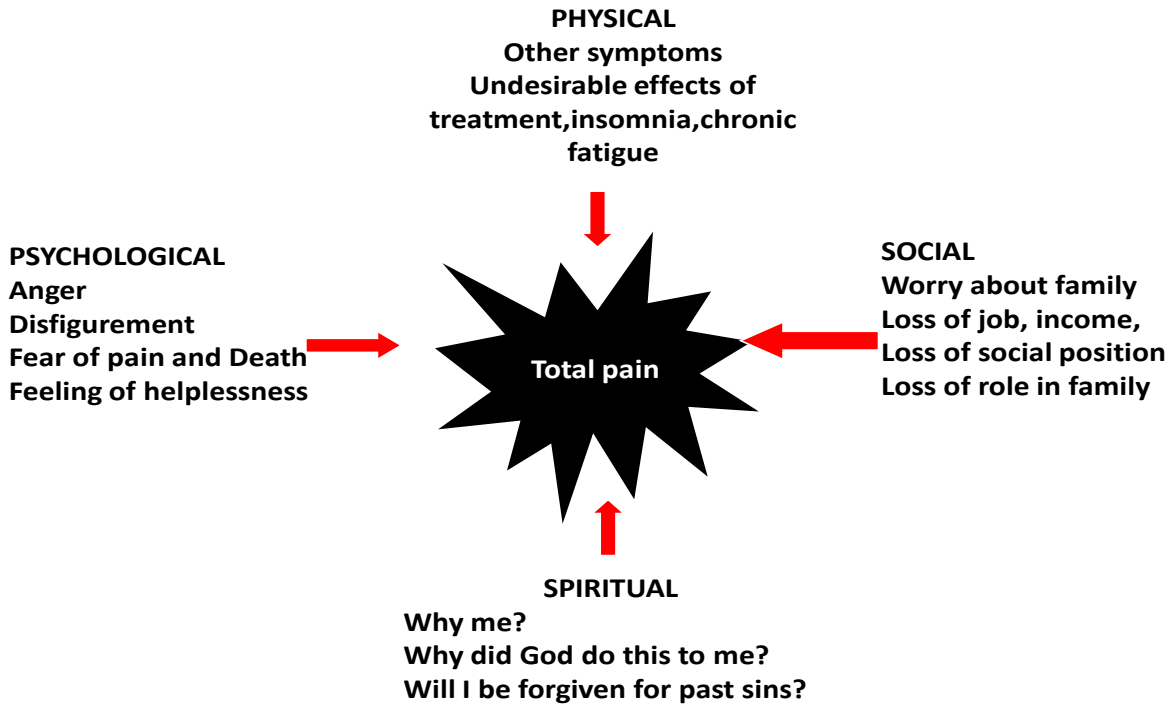
Chennayya has persistent, unremitting pain over his jaw this is the physical component of pain. He is anxious and depressed due to his condition. This would be called the psychological aspect of his pain.

Until recently he was the breadwinner of the house, caring for his family. Now, he is no

longer economically contributory. He is dependant and feels desolate. Moreover because of the foul smell emanating from his wound, he shuns company and friends, avoids stepping out of the house; and keeps to himself. He feels let down. This is the social component of pain.

He is just 40 years, He wonders why God did this to him. He had the habit of betel chewing which he had discontinued after the carcinoma was diagnosed. It is possible that he may be harbouring a guilt that his present illness is the result of his habit. This question of "why me? Or is this a punishment from God!" could be understood as the spiritual component of pain.

Fig 3.3: Total Pain



Total Pain is "the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles".

Evaluation of pain

Why is it that the pain medication has not given him relief to the extent he is unable to sleep for the past several weeks? Has his pain been properly evaluated[17]?

Let us consider Chennayya's pain history.

Is his pain acute or chronic?

What is the severity of pain?

Acute pain	Chronic pain
Indicates tissue injury-potential/actual	Multi-factorial with neuro-chemical changes
Autonomic responses more dominant	Autonomic responses settle and the vegetative responses more dominant
Self-limiting	Unremitting, progressive
Intensity reduces as healing progresses	Constant reminder of a life threatening disease
Acute pain is protective ;it is a symptom	Chronic pain takes on characteristics of a disease

Chennayya is having pain since 2 years, which had led to diagnosis of the carcinoma of buccal mucosa. His pain is chronic and should be acknowledged as such. Often we disregarded chronic pain as mild as the patient does not fit in with the image that we have of painful espressions of crying and shouting in pain or because the haemodynamics are stable.

When pain persists, what happens to the intensity of its experience? Does it stay same or does it increase or decrease over time?

In acute pain situations, the sensation of pain acts as a warning of actual or potential injury. Chronic pain is not just an extension of acute pain over prolonged periods. Changes occur within the pain pathways that augment the frequency and the intensity of impulses reaching the centre.

17 Refer EEMMA in the section on symptom control

What is the pathophysiology of chronic pain?

- Pain receptors do not adapt over time.
- With persistent pain inputs,
  - there is further sensitisation of active nociceptors. Neuro chemicals like prostaglandins, Potassium, Bradykinin etc.accumlate and sensitise the nociceptors.
  - Silent (sleepy) nociceptors are recruited which increases the intensity of pain.
  - The intensity is also amplified by sensitisation of dorsal horn cells- "wind-up" phenomenon via N -methyl D -aspartate receptors [NMDA]
  - Gradually the adjacent spinal segments are also recruited into the firing of signals and this widens the painful area.
  - The inhibitory descending inputs from brainstem get overwhelmed and become ineffective over time.

End Result: Worsening of pain in intensity, severity and extent

In a patient with cancer or other major diagnosis; that per se may not be the only cause for pain. Chronic pain may have several contributors. Let's consider another clinical scenario to understand this better.

35 year old Ramani, with HIV has pain due to the lesions in the facial and neck region.ie **this pain is disease related**.

Subsequently as a result of treatment, she developed neuropathy. This new **pain is treatment related.**

After a few days, she reports with painful dysphagia, found to be having candidiasis and consequent inflammation. This **pain is as a result of debility** and poor immunity due to poor general condition.

A new pain can be added on anytime if she develops infection at any site or develops an aphthous ulcer. This would **pain due to a co-morbidity.**

Table 3.1 – Contributors to pain in chronic disease states

Disease related	Treatment related	Debility related	Co-morbidity
Soft tissue infiltration	Surgery	Constipation	**Spondylitis**
Visceral/nerve compression	Post operative	Deep Vein thrombosis	**Migraine**
Nerve infiltration	Scars	Pressure sores	**Arthritis**
Spread to bone	adhesions	Catheter sepsis	**Infections**
Muscle spasm	Radiotherapy	Bladder spasm	**Angina**
Lymphedema	Fibrosis	Aspiration pneumonitis	**Trauma**
Raised intra cranial pressure	Chemotherapy	Stiff joints	**Acid peptic disease**
Stricture of hollow viscus	Neuropathy	Post herpetic neuralgia	**Glaucoma**

Different types of pain and their temporal relation

1. **Baseline pain – may be continuous or intermittent**
2. **Break through pain**- often extremely painful. It comes on predictably [due weight bearing, movement, change of dressing etc.] OR spontaneously without warning [colics, shooting pain of neuropathy etc.] The breakthrough pain "spikes" usually last between few seconds to half hour.
3. **Incidental pain -**Associated with precipitating factor like movement.
4. **"End of dose" pain-**Occurs prior to the next scheduled dose, gradual onset, lasts longer

What is the pathological type of Chennayya's pain? Why should we differentiate the two types of pain?

We should differentiate the two types of pain because the choice of medications and the management varies**.**

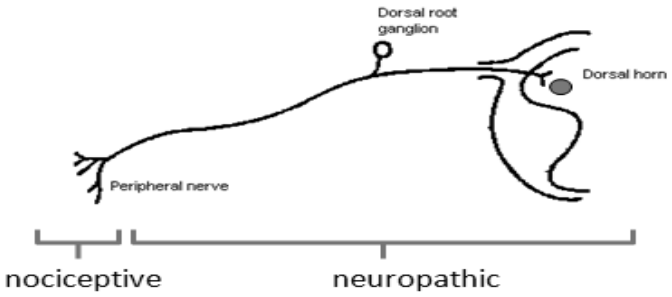


Fig 3.4 - Diagrammatic representation of types of pain

Table 3.2 - Features of Nociceptive and neuropathic pain

Features	Nociceptive pain	Neuropathic pain
Due to	stimulation of nociceptors (free nerve endings) in visceral or somatic structures	**abnormal impulse generation in peripheral nerve, spinal cord and brain**
localisation	Localized in somatic, diffuse in visceral pain	**Neuro dermatomal distribution**
quality	throbbing, aching, gnawing	**burning, lancinating, shooting, stabbing, pricking etc**
Abnormal sensation	Nil	**Eg: Allodynia, hyperalgesia**

Now what is your assessment of Chennayya's pain?

Chennayya has persistent pain over the jaw, which is gripping in character and it is mostly always present. Apart from that, he also has transient shooting pain radiating down from the jaw up to the ear intermittently. He has a burning sensation in the lower part of his jaw. He described the persistent pain as having a score of 6/10 in intensity and the shooting pain as 10/10 i.e. very severe, spontaneously and unpredictable.

Thus he has both types of pain- nociceptive pain i.e. a background continuous pain; and intermittent neuropathic pain with shooting and burning component. There is a breakthrough incident pain component i.e. pain provoked by chewing and swallowing.

All of these components need to be considered when deciding upon the line of management.

Fig 3.5 Allodynia and Hyperalgesia

Fig 4 - Mr. Ramesh, a 40 year old man with healed herpes zoster lesions, is unable to wear his shirt because it produces pain at the site of healed lesions.

Pain caused by a stimulus that does not normally provoke pain **is Allodynia**

Fig 5 - Mr. Subhash, a 50 year old man complains of very severe pain on injection of Insulin which he does not usually experience.

An increased response to normally painful stimulus is known as **Hyperalgesia**

Assessment of Pain

Always listen carefully to the patient regarding his/her pain

The details of pain assessment can be memorised using the mnemonic **"PQRST"**

P-Palliative/ provocative factors

Q-Quality of pain (nature of pain eg: burning, aching)

R-Radiation of pain

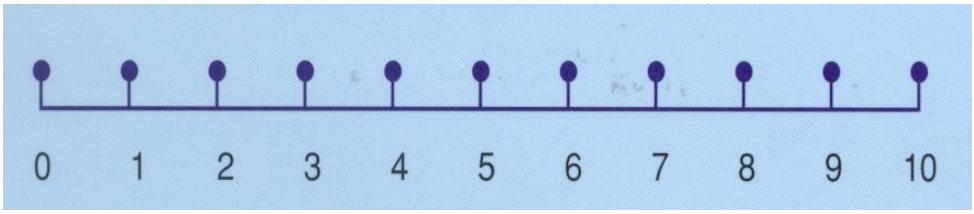
S-Site, Severity

T- Temporal factors (duration, diurnal variation of pain, continuous or intermittent)

Assessment of severity of pain

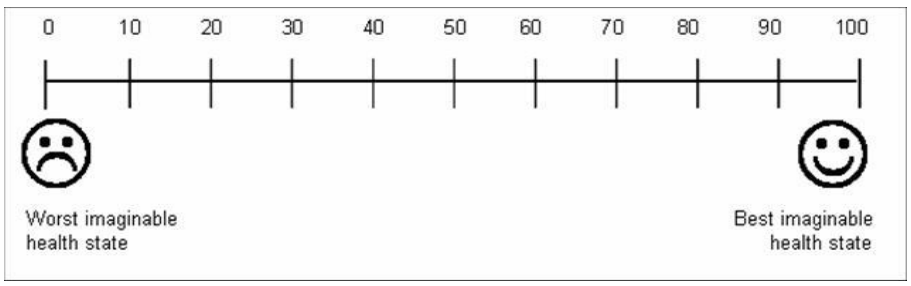
This may be done using various pain scales available. The commonly used ones are

1. **Categorical pain scale**: Patient is asked to grade his pain as having "no pain, mild pain, moderate pain, severe pain and excruciating pain".
2. **Numerical Rating Scale (NRS):**



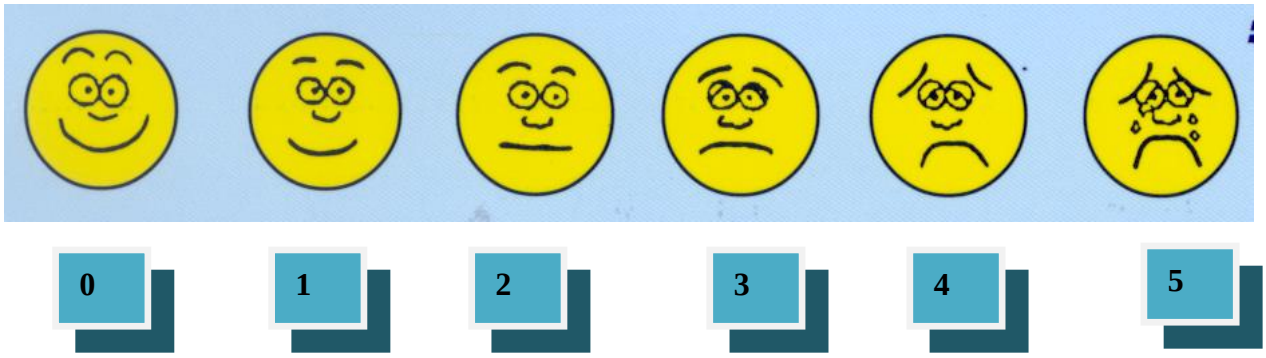
Patient is explained about this scale as zero meaning "no pain" and 10 representing "worst imaginable pain". Then patient is asked to score his pain on this scale according to the severity.

3. **Visual Analogue Scale (VAS):**



VAS is shown to the person who is asked to mark the pain according to the severity. Then the assessor will grade the pain on a **0-10** scale which is given on the reverse side.

4. **Non verbal rating scale (Wong- Baker Faces Scale) -** usually used to assess pain in children



Pain scores of 0-3 is considered MILD PAIN

Pain score of 4-7 is considered MODERATE PAIN

Pain score of 8-10 is considered SEVERE PAIN

The aim of pain management is to keep the pain score < 4 /10

Meaning of the pain – The meaning that the patient may attribute to his suffering is very significant. It is important to know what the patient thinks about the pain experience; his understanding of the cause and reason for his pain. This aspect needs to be acknowledged and addressed within the therapeutic plan.

Patient needs a satisfactory response to his beliefs, …

…….be it rational or irrational.

Test your knowledge

1. Which of the following statements is TRUE regarding chronic pain?

a) Chronic pain is essentially protective

b) Chronic pain is limited to the area of injury.

c) Nociceptors get desensitized with repeated stimuli.

d) There is 'wind up' phenomenon in chronic pain conditions.

2. Which of the following is TRUE about severe cancer pain?

a) It is a part of healing process

b) Majority of cancer pains respond to WHO analgesic ladder

c) Cancer pain is always nociceptive

d) All cancer pains respond to Morphine.

3. Painful response to a non-painful stimulus is called

a) Allodynia

b) Hyperalgesia

c) Hyperaesthesia

d) Akathisia

4. Which of the following is an example of visceral pain?

a) Pain due to skeletal metastasis

b) Pain due to skeletal muscle spasm

c) Pain due to liver capsule stretch

d) Sciatica

Answer Keys:

1 – D; 2 – B; 3 – A; 4 – C

Management of pain

Up to 71-76% of patients with cancer related pains can have satisfactory relief by following the guidelines of the WHO analgesic ladder.

Fig 3.5 - WHO Analgesic ladder

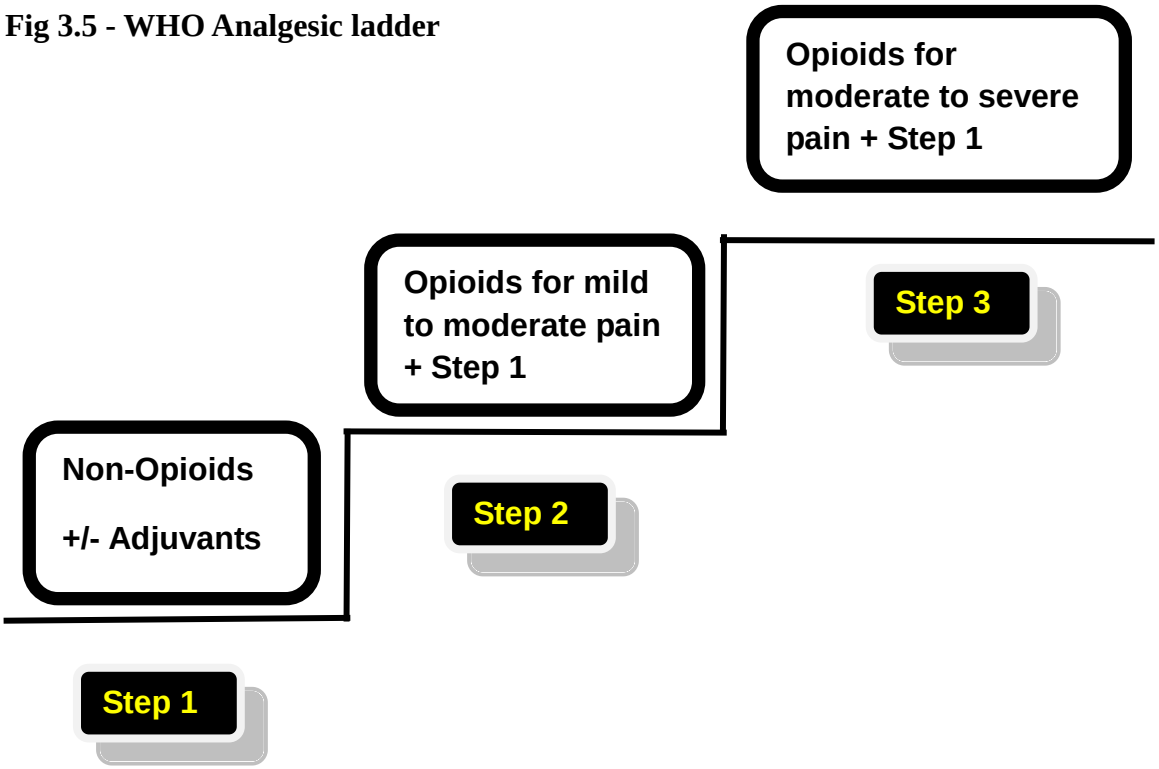


Table 3.3 - Principles of WHO analgesic ladder use:

By the clock	. Continuous pain needs continuous relief. Prescribe drugs according to their pharmacodynamics and duration of action; not arbitrary or as & when needed basis. Continuous pain needs continuous relief
By the mouth	Give medicines orally. This is the simplest route. A well informed patient can use the oral medications by himself.. Injections need professional help, cause additional pains and are hence best avoided.
By the ladder	Choose medications from the ladder steps, according to severity of pain. If pain is already severe, go to step 3.
Individualised approach	Prescription should mention dose for breakthrough pain; this improves the effectiveness, level of control and fine tunes dosage. Choose right drugs, routes and dosages–based on co-morbidities, drug interactions and side effect profile for that patient. In short, each person should be assessed in detail, physically / holistically and managed accordingly. (total pain).

Table 3.4 - Drugs in WHO Analgesic ladder

Non-Opioids	Opioids for mild to moderate pain	Opioids for moderate to severe pain	Adjuvant analgesics
Paracetamol **Ibuprofen** **Diclofenac** **Meloxicam** **Naproxen** **Indomethacin** **Ketorolac** **Aspirin** **Etoricoxib**	Codeine Dextropropoxyphene Tramadol Tapentadol	Morphine Fentanyl Methadone	Tricyclic antidepressants (Amitryptyline, Imipramine) Anticonvulsants (Carbamazepine, Valproate) Gabapentin, Pregabalin Anticholinergic (Hyoscine) Muscle relaxants (Diazepam) NMDA receptor blocker (Ketamine) Bisphosphonates Local Anaesthetics Steroids

Step 1 Drugs from the WHO Analgesic Ladder

This include Paracetamol and a broad class of drugs, the Non-Steroidal Anti -inflammatory Drugs (NSAIDs).

Paracetamol is an analgesic with good safety margin; it is a good analgesic for add on effect. It is usually given 6 hourly to maximum of 2 – 4 g /day in a patient with healthy liver. In the elderly or those with liver dysfunction it is used with caution.

Non-steroidal Anti- inflammatory Drugs [NSAIDs]

NSAID's exert anti-inflammatory action by inhibiting Prostaglandin synthesis through the cyclo-oxygenase (COX) pathways and hence very effective in nociceptive pain. NSAIDS are useful in neuropathic pain also because of the possibility of associated nociceptive component (ie it is mixed pain) and also because they reduce the inflammatory sensitization of nerves.

NSAID's can be divided into following groups.

- Those which act <u>non selectively</u> on both COX 1 &COX 2 receptors and have more gastrointestinal side effects
- Those which <u>selectively inhibit</u> COX 2 pathways only and have less gastro-intestinal side effects. They do not inhibit platelet inhibition and so associated with increased cardio-vascular and cerebro-vascular incidents. Hence has to be used judiciously e.g. Etorocoxib.

Once pain is assessed as mild in severity, start medications with one of the NSAIDs chosen on individual basis. The frequency is adjusted according to duration of action of the chosen drug so as to have round the clock effect.

For e.g. Ibuprofen may be used 6 or 8 hourly to a maximum of 2.4 g / day in a patient without any renal dysfunction.

Renal failure, hypertension and possibility of congestive cardiac failure have to be monitored for all patients on NSAID's, regardless of COX selectivity.

Table 3.5 - Examples of Non-selective COX inhibitors

Drug	Dose	Frequency	Route
Ibuprofen	200-400 mg	TDS or QDS	PO
Naproxen	250-500 mg	BD	PO, Suppository
Ketorolac	10-30 mg	QDS	PO,S/C, IM

Ketorolac (SC, IM, PO): This drug is used minimally for one or 2 doses only due to very high incidence of renal toxicity. Maximum total parenteral dose of ketorolac per person is 60mg. it is best avoided in the elderly.

COX –2 Selective NSAIDs

COX 2 inhibitors have no platelet inhibitory effects. They may be associated with less gastrointestinal side effects. The benefit on gastrointestinal side effects from using COX-2 NSAIDs is lessened by concurrent use of Aspirin.

An increased risk of thrombotic events leading to myocardial ischemia and cerebrovascular events has been found for COX-2-selective inhibitors. The risk of such events increase with higher doses and prolonged treatment.

Table 3.6 - Risk factors for specific toxicity with NSAIDs

Risk factors for GI toxicity	Risk factors for renal toxicity	Risk factors for thrombotic toxicity
High NSAID dose **History of upper GI symptoms** **Advanced age** **Concurrent aspirin or corticosteroid use** **Comorbidities (e.g. rheumatoid arthritis)**	Advanced age Poorly controlled Diabetes Dehydration due to any reason Simultaneous nephrotoxic drugs e.g. radiological studies using dye Poor blood supply to kidney due to any reason	Use of COX 2 drugs Advanced age Hypertension Hyperlipidaemia Diabetes Smoking

Recommendations for safe prescription of NSAIDs

- Drugs are to be given by mouth, by the clock, by the ladder for effective and sustained pain relief
- Use the lowest possible effective dose for the required duration of treatment
- Elderly patients, smokers, alcoholics, those using steroids or aspirin concurrently or those with a past history of peptic ulceration, GI bleeding or gastro duodenal perforation are more at risk from side effects from NSAIDS. A proton pump inhibitor such as omeprazole 20 mg twice a day is recommended to reduce this risk.
- Special caution in patients who have a tendency to get dehydrated to prevent renal side effects e.g. gastroenteritis, diuretics, diabetics, peri-operative state
- Special caution with concurrent use of nephrotoxic drugs – radiological dye, Aminoglycoside antibiotics
- Special caution in patients with history suggestive of coronary artery disease, hypertension, asthma, hyperlipidemia, diabetes, renal dysfunction and smokers
- COX-2 selective inhibitors contraindicated in patients with atherosclerotic disease, history of ischemic heart disease or cerebrovascular disease or in patients with peripheral arterial disease

Long term NSAIDs should be used with caution essential with periodic monitoring of renal function

Test your knowledge

Choose the more appropriate group of Step 1 drug in following situations

1. 66 year old Mr.M was a smoker; is a known to have HT, DM
2. 32 year old Ms K has history of acid peptic disease. No other co-morbidity
3. 50 year old Mr L is a diabetic since last 20 years with a Serum Creatinine of 2.8mg%
4. 57 year old Mr G has bleeding polyps

Ans: 1 – Paracetamol; 2 - COX 2 inhibitor; 3 – Paracetamol; 4 - COX 2 inhibitor

Adjuvant Group of Drugs in Step 1 of the WHO Ladder.

The term adjuvant is used for a drug that has a primary indication other than pain but its specific pharmacological action in certain painful situations impacts positively on pain relief. Adjuvants may be used alone or may be used in combination with a primary analgesic like NSAIDS. or opioids. They may be divided as

-those that improve pain in a specific etiology e.g. Tricyclic antidepressants for neuropathic pain, antispasmodics for intestinal colics etc.

-those improving co-existing conditions thereby contributing to therapeutic response to analgesics e.g. antibiotics when infection is present; bisphosphonates for bone pain

-those countering side effects of analgesic drugs e.g. anti-emetics, laxatives

Table 3.7 – Indications for Adjuvant drugs in pain management

Adjuvant Drug	Situation where it may be used
Corticosteroids	Pain caused by oedema
Antidepressants in low doses and Anticonvulsants	Neuropathic pain
Antidepressants in regular doses	When depressed mood is contributing to the pain
Muscle relaxants	Muscle cramps / trismus
Antibiotics	Infection related pain
Night sedatives	When lack of sleep is lowering pain threshold
Anxiolytic	When anxiety is aggravating the pain
Antispasmodics	For colic from tubular structures

Management of Neuropathic Pain:

This type of pain often requires use of adjuvants from the WHO ladder besides the regular analgesics mentioned as per severity. The following steps may be considered as a general approach to managing neuropathic pain.

Fig 3.6 – Approach to choosing adjuvants that is required in addition to the regular analgesics for managing neuropathic pain.

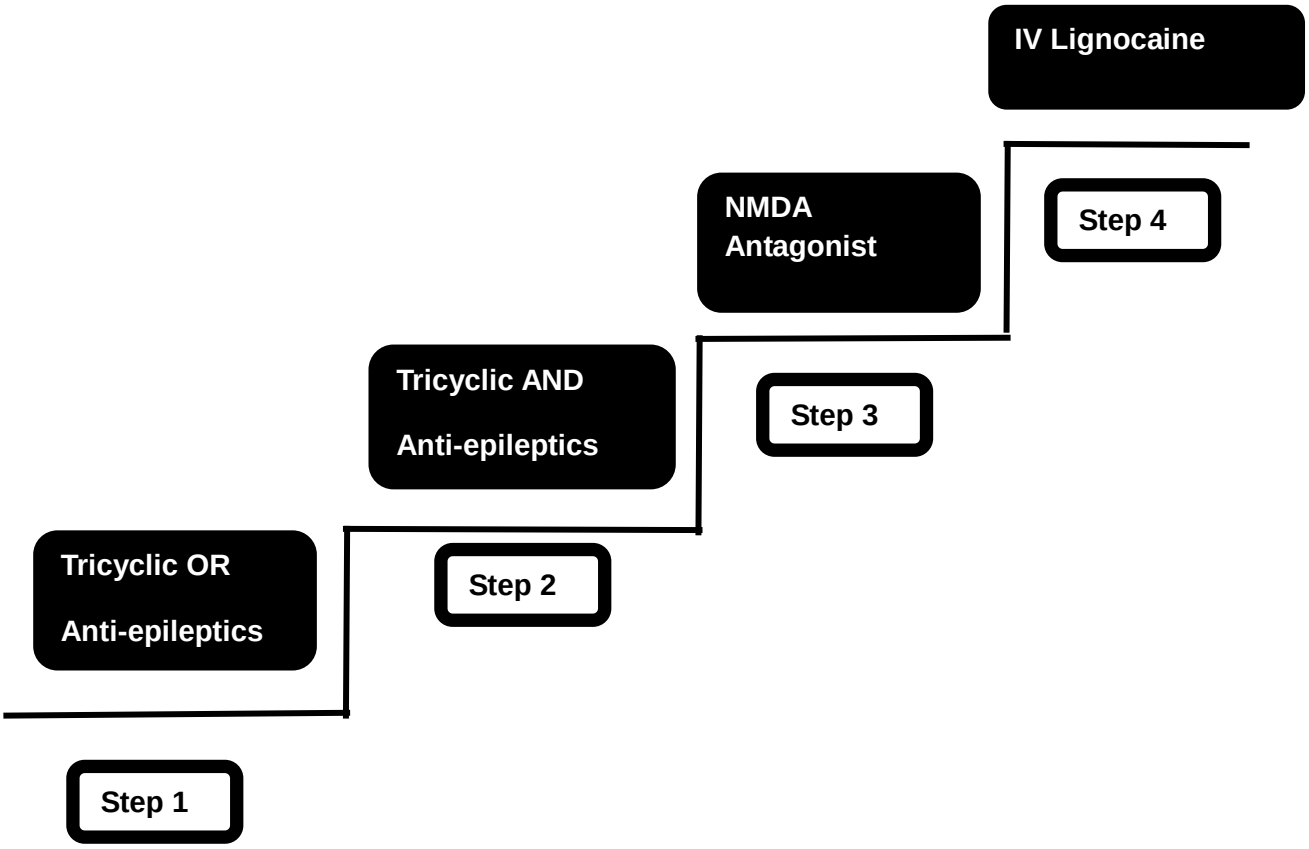


Table 3.8– Common medications used in NeuropathicPain		
Drug	**Dosage**	**S. Effects & Comments**
Anti-Depressant Amitryptiline Imipramine Nortryptiline	Start with 12.5 to 25 mg HS, increase 12.5 to 25 mg every 3-5 days , to a maximum of 100 mg / day	Early morning sedation, anti-muscarinic side effects
Duloxetine	30-60 mg / D	Nausea, dizziness, dry mouth, sleepiness
Anti-epileptics Sodium Valproate	Start with 200mg , titrate upwards 200 mg every 3-5 days , to a maximum of 1000 mg/day	Gastro-intestinal upset, drowsiness, tremor, ataxia
Carbamazepine	Start with 50-100 mg TDS, increase every 2 weeks by 200 mg , to a maximum of 1000 mg/day	Ataxia, diplopia, nystagmus blood dyscrasias
Gabapentin	Start with 100 mg TDS, increase 300 mg TDS every week to a maximum of 1200 mg TDS	Drowsiness, peripheral oedema. Comparable efficacy to the cheaper Tricyclic antidepressants
Pregabalin	Start with 75 mg HS and gradually increase to BD or TDS dosage. Max 600 mg/D	Dizziness, sleep disturbances, ataxia, mood disturbances, dry mouth, constipation
Ketamine	0.25-0.5 mg/kg bodyweight/ dose TDS –QDS S/L, PO (Sub anaesthetic doses). Can be given as continous Subcutaneous infusion as 50-100mg/D; Maximum dose – 200mg / Day	Dysphoria, hallucinations, Nausea and vomiting, dizziness

What are the important non-drug treatments for pain relief?

- Regular empathetic communications, counseling and therapeutic relationship is essential to address the subjective emotional component of the pain experience.
- Physical therapies – heat, , Transcutaneous Electrical Nerve Stimulation, Ultrasound and exercises to improve range of movement.
- Radiation therapy for bone pain, nerve compression pains
- Injection of trigger points with local anaesthetic agents.
- Local anaesthetic and neurolytic blocks (e.g. nerve destruction with alcohol or phenol-in-glycerol)
    - In some centres, nerve blocks are gradually being replaced by epidural or intrathecal analgesia with a continuous infusion of local anaesthetic agents with or without opioid analgesics.
- Modification of the patient's way of life and living environment (for pains exacerbated by weight-bearing or movement)
- Complimentary therapies – there is accumulating evidence for use of yoga inputs, acupuncture, cognitive Behavioural therapies in improving pain related behaviours and perceived self efficacy.
- Involvement in activities that bring in joy to the individual's daily life helps in getting beyond the constant control that pain has over the person's life.

Test your knowledge

1. In WHO Analgesic ladder, Non Opioid analgesics are
    a) Used only in step 1
    b) B. Used in all the 3 steps
    c) C. Not used with strong opioids
    d) D. Avoided with adjuvants

2. Which of the following is NOT an adjuvant?
    a) A. Bisacodyl
    b) B. Codeine
    c) C. Amitryptiline
    d) D. Ondansetron

Answers: 1 – B; 2 - B

Opioids – the Step 2 and Step 3 drugs of the WHO Ladder

Opioids analgesics include naturally occurring, semi-synthetic and synthetic drugs and they combine with opioid receptors, (mu, kappa and delta) in the central as well as peripheral nervous system, to produce analgesic action.

STEP 2 of the WHO Analgesic Ladder

Step 1 drugs ± weak Opioids used in pain of moderate intensity

If step 1 medications are not satisfactory for the pain relief, proceed to step 2 of the analgesic ladder as listed above.

Step 2 medications are not classed as a 'controlled drug' which has some practical prescribing advantages. One may begin directly at step 2 if the pain is **moderate in intensity**. Adjuvants are to be added if indicated for specific reasons, as described below. If step 2 medications are not adequate in 48 hours, proceed to step3

DEXTROPROPOXEPHENE

Dextropropoxephene was available commercially in combination with Paracetamol. The usual daily dose of Dextropropoxephene is one capsule of 65mg six hourly, which comes to a total daily dose of 260mg of Dextropropoxephene. The drug takes up to 72 hours to reach steady state level. Currently it is banned due to concerns regarding side effect causing prolonged Q-T interval in the ECG.

TRAMADOL

Tramadol is a synthetic analogue of codeine. It is rapidly absorbed after oral doses and is metabolized in the liver. Analgesia begins within one hour and starts to peak in two hours. It is usually used in doses up to maximum of 400 mg/ day. It shares all the side effects of the class like, constipation, nausea, neuropsychiatric symptoms, and pruritus. Immediate and slow release formulations are available.

TAPENTADOL

This is a relatively new drug. Besides being a Mu receptor agonist, it also inhibits the reuptake of nor-epinephrine in the ascending pain pathways. It is used for all non-inflammatory nociceptive pain and has some benefit in painful neuropathies. it is available only in oral form and is available as immediate release (50mg, 75mg and 100mg) and as sustained release preparations (50mg ER and 100mg ER). The maximum recommended dose per 24 hours is 600-800mg.

Tapentadol is metabolized in the liver and excreted in the urine and is generally safe in renal failure, although needing dose modification in severe renal failure.

BUPRENORPHINE

Buprenorphine is a partial agonist at Mu receptor and antagonist at Kappa and Delta receptors. Buprenorphine is used for moderate to severe cancer and non- cancer pain, however it is NOT a preferred drug in cancer pain due to ceiling effect (The highest level of analgesia that can be achieved without significant side effects or toxicity) or the analgesia may get reversed. Buprenorphine has poor oral bioavailability and is available as sublingual, transdermal and parenteral preparations.

Step 3 medications of WHO Analgesic Ladder

Step 3 drugs are used when full trial of step 2 drugs do not relieve pain satisfactorily. They are often combined with non-opioids for synergist effect and with adjuvants when indicated. We may start with step 3 drug if pain is severe.

MORPHINE

Oral Morphine is the gold standard treatment for cancer pain.

It is available as injections, tablets, suppositories. In addition to the oral route, Morphine may be used through parenteral, rectal, topical and neuraxial routes[18].

It acts mainly on **μ** receptor. It is metabolized mostly in the liver and converted into two major metabolites namely morphine-3 –glucuronide (M3G) and morphine-6-glucuronide (M6G). M6G is the active component which gives pain relief and M3G is believed to produce CNS adverse effects like Myoclonus.

Morphine will take about 24 -36 hours to get stabilized in the blood. So the titrations are best done with observations of 24 – 36 hours. If a patient is taking two or more PRN doses, the dose can be increased by 50%.

18 IM administration is least preferred due to erratic absorption, difficulty in assessing response and thus possibility of overdose. This is also an additional cause for pain.

Comparison of step 2 opioids with Morphine

- Codeine is 1/10th as potent as Morphine. Codeine is more constipating than Morphine and is a good cough suppressant.

- Tramadol is 1/5th as potent as Morphine if given orally and 1/10th as potent as Morphine if given intravenously[19].It can precipitate seizures in susceptible individuals with brain metastases and when used with drugs which decrease seizure threshold. It is usually given 6-8 hourly. It is useful in chronic pain of malignant or non-malignant origin, especially with neuropathic component. Tramadol appears to produce less constipation and dependence when compared with equianalgesic doses of strong opioids.

- Dextro-propoxyphene is approximately 1/12th as potent as Morphine. Its metabolite nor-propoxyphene has a very long half-life and accumulates in patients with renal failure. So better to avoid in renal failure. Usually given in combination with Paracetamol 6-8 hourly.

- It is important to note that when access is not a problem, Morphine in smaller [equipotent] doses may be used as a Step 2 drug.

Steps for calculating the dose of oral Morphine

1. Assess the severity of pain. Step 3 is considered if the pain is severe [NRS 8, 9 or 10] or when full trial of step 2 does not relieve pain.
2. The usual starting dose for a patient with normal renal function is 5-10 mg 4 hourly. Patient is advised to take extra doses for breakthrough pains between the regular doses.
3. The night dose is usually double that of other doses so as to avoid waking up in the middle of the night for the regular dose that would be due then. Here, the sedation due to the extra dose is often helpful.
4. 1st Review within 2 days – the overall pain relief over that period is noted. It is considered satisfactory, if the NRS stays < 3 most of the time and the patient becomes more functional. The total daily requirements for pain relief is calculated by adding the regular and the extra SOS doses if any. This amount is again divided into 6 doses and continued.

   E.g. Suppose a patient is on 15mg 4th hourly and he also takes 3 rescue doses each of 15 mg, then the total intake during a day is 15 x 6 = 90mg + (15 x 3)= 90 + 45 = 135 mg.

19 Grond S, Clinical pharmacology of tramadol: Clin Pharmacokinet. 2004;43(13):879-923

This is to be divided by 6. Hence his requirement may be calculated as 20mg 4th hourly.

5. 2nd Review in next 2 days - the patient reviewed for stable pain relief.
6. With 2 or 3 reviews over a week the average daily dose may be estimated.
7. Once the daily requirement of regular Morphine for sustained pain relief is estimated, one may also consider converting the format to equipotent slow release preparations based on the 24 hourly requirement of morphine. E.g. If Morphine 20mg every 4 hours gives adequate pain relief round the clock, then the requirement in 24 hours is 120mg. Hence a 12 hour sustained release preparation of 60 mg can be prescribed twice daily if so preferred.
8. The rescue dose for breakthrough pain is generally calculated as equivalent to 1/6th of the patient's current daily opioid dose. i.e. a patient, who is receiving 60 mg of morphine every 24h, should have a rescue dose of 60mg/6 = 10mg of immediate release morphine.

The regulations of step 3 opioids is governed by the Narcotic Drugs and Psychotropic Substances Act – NDPS Act 1985.

Currently the scope of the the NDPS Act 1985 does not address the accessibility and availability issues of these drugs for medical treatment of patients in severe pain.Also, the state NDPS Rules are such that, hospitals have to obtain licences for stocking, import, export, transport etc. each from different departments [Excise, Drugs Control, Health administration] and each with an expiry period. If they don't obtain the next permission in time, stocking would be considered illegal.

Most institutions,including most medical colleges in India solve this problem by not stocking these medicines at all. Hence generations of doctors have passed out, who do not have any experience of seeing or using this useful medicine. Doctors are also not exposed to the pharmacological differences between parenteral and oral morphine. This has led to misconception and mistrust in using oral Morphine.

The overall impact is that, the patients are not able to get access to these medicines for their pain relief and have to go through needless suffering.

NDPS Amendment Bill is currently tabled with the parliament to bring balance in the Act; i.e. have the dimension of medical and scientific use along with prevention of misuse and diversion. This would allow hospitals to store and doctors would be able to dispense opioids meant for medical use.

FENTANYL CITRATE

Fentanyl is a selective **μ** receptor agonist.

In India it is available as injections of 50 ug / cc [2 cc ampoule] and as 72-hour transdermal patch formulation in strengths of 12.5, 25, 50 μg / hour doses and as trans-mucosal preparations [oral / nasal] are available for prevention and quick relief of incident pains.

Fig 3.8: Transmucosal and transdermal preparations of Fentanyl Citrate

Considerations while using fentanyl patch

- Fentanyl is unsuitable for patients with unstable pain.
- Peak plasma concentrations are achieved after 12-24h and a depot remains in the skin for some 24h after the patch is removed.
- Rescue doses of opioid will be necessary during the first 24h of application. It is an expensive drug.
- A reduction of laxative may be necessary when converting from morphine to Fentanyl as the latter may cause less constipation.
- Patches have to be used on dry non-inflamed, non-irradiated, and hairless skin. It should stick well without wrinkles on the skin. The rate of absorption may change in the presence of fever, external heat or a hot water soak
- Conversion ratio for change over to fentanyl patch is as follows. Daily dose of 60 mg of oral morphine is equivalent to 25 mcg / hr transdermal fentanyl patch. In both cases immediate release morphine should be available to manage breakthrough pain
- One in ten patients who have had their pain controlled by Morphine may experience a withdrawal reaction when converted to Fentanyl. They may require oral morphine on a SOS basis to manage the withdrawal symptoms for a day or two.

Patients cannot have their pain medications titrated using patch delivery systems which take up to 36 hours to reach a steady state in the body. Pain control must first be achieved using oral morphine before switching to a Fentanyl patch.

Some specific indications for using Fentanyl Patch

a. Dysphagia
b. Intolerable side effects - nausea, vomiting, constipation, delusions
c. Renal failure
d. Tablet phobia / poor compliance

Ways of improving effectiveness of the WHO Analgesic Ladder

1. Manage the known side effects of the medicines proactively, from the first prescription onwards e.g. proton pump inhibitors or H2 antagonists with NSAIDs; stimulant laxative should always accompany prescription of opioids.
2. While prescribing, educate & provide information on where the drugs are availabile[20]
3. Pharmaco- economics –Many patients may need long term medications for pain relief as the etiology of pain may not resolve. Hence due attention is to be paid in choosing medications that would keep the daily cost of the treatment as low as possible.
4. Communicate with patients and understand phobias that exist regarding certain groups of drugs, especially narcotics. Compliance would be better when questions are answered and doubts are cleared.
5. Review and re- evaluate for general condition, side effects, responsiveness to treatment, or appearance of new pains.

20 Oral Morphine is available in hospitals and centres that are"Recognised Medical Institutions" [RMI] which have been authorised by the State drug controller] in 13 states with modified **NDPS** rules in our country.

Test your knowledge

1. The primary consideration for starting morphine is that,

   a) the disease is incurable

   b) the pain is inadequately controlled on optimal dose of step 2 drugs

   c) the life expectancy is adjudged to be short

   d) the patient does not have a history of drug abuse or addiction

2. A drug that should always should be given when prescribing morphine is

   a) non - opioid

   b) non steroid anti inflammatory drug

   c) laxative

   d) Anti emetic

3. A patient with Pancost tumor is complaining burning type of pain radiating over his left arm. The adjuvant that will benefit him most will be

   a) Amitryptiline

   b) Dicyclomine

   c) Lorazepam

   d) Ondansetron

Answer Key:

1. B
2. C
3. A

Management of opioid side effects

Table 3.9 – common side effects of opioids

Side effects	Incidence	Management
Constipation	95%	Stimulant laxatives (Bisacodyl 10 mg HS) Softeners / lubricant synergistic [liquid Paraffin]
Nausea and vomiting	33 %	Self-limiting within a week. D2 blockers (Haloperidol 1.5-3 mg HS, Metoclopramide 10 mg tds)
Sleepiness and tiredness	33 %	Self limiting within a week. Reduce dose and review if it persists beyond
Dry mouth		Good mouth care
Urinary hesitancy		Alpha blockers (Tamsulosin)
Itching		Skin care 5HT3 blockers (Ondansetron), Antihistamines

A nu nay be used to manage persistent opioid-related side effects:

- Anticipate and treat the side effect with additional drugs e.g. stimulant laxative for constipation
- Use an alternative opioid with lesser side effect – Fentanyl has less constipating side effect than Morphine because of the molecule or the route of administration?
- Use an alternative analgesic or another route, such as spinal opioids, which may cause less systemic or central side effects

Effective pain management would be observed as improved sleep, functionality with adequate pain relief and minimal adverse effects.

Signs of overdose with oral opioids

Overdose should not be confused with side effects seen within the therapeutic range as described above.

The symptoms of overdose are drowsiness, vomiting, confusion, delirium, hallucinations and myoclonus. Patients may have pin point pupils with Morphine overdose.

Respiratory depression is NOT common unless there is a deliberate or accidental over dosage.

If the medicine is titrated to achieve pain relief, along with regular review, overdose easily can be avoided. Adequate hydration is important for managing states of overdose.

Table 3.10 – Signs of overdose with opioids and their management

Signs of overdose	Management
Delirium	Dose reduction and anti-psychotics (Haloperidol)
Myoclonic jerks	Dose reduction and benzodiazepines (Clonazepam)
Extreme drowsiness	Dose reduction
Pin point pupils	Dose reduction
Respiratory Depression	When R.R < 8-9 / minute; O2 SAT < 85% Titrated dose of I V Naloxone, skip next dose

Opioid -induced respiratory depression

This is the common misconception that keeps medical professionals from prescribing this useful drug. Pain antagonises the central depressant effects of narcotic medicines.

Respiratory depression is NOT A SIDE EFFECT, when Narcotic Medication has been initiated and titrated according to the type and severity of pain with regular patient review.

Opioid withdrawal symptoms[21] and pain can rebound back severely if long-term opioids are abruptly stopped and not rescheduled.

21 Withdrawal syndrome is seen when the activity of the particular drug at the receptors is suddenly reduced due to reduction in dose, withholding the drug or using an antagonist. It characterised by Rhinorrhea, lacrimation, Disorientation, hyperthermia, Emesis, myoclonus, anxiety, agitation, delirium, abdominal cramps, diarrhea

Naloxone is indicated only if significant respiratory depression is present. It is important to titrate the dose of Naloxone carefully, to avoid acute opioid withdrawal. Naloxone has a half-life of 20 minutes. As the half-life of most opioids is longer than this, it is important to continue assessment of the patient and give Naloxone at further intervals if necessary.

Clarification on terms

Addiction

It is characterised by behaviours that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

Addiction is a primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations.

Physical Dependence

Physical dependence is a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist. *Physical dependence* develops in most patients who have taken an opioid regularly for more than few days.

Take Home Message in Managing Chronic Pain

- **Acknowledge pain**
- **Evaluate with attention to details**
- **Provide explanation to the patient**
- **Aim for graded pain relief**
- **Respect patient's expectations**
- **Review, review and review**
- **The use of Strong opioids is dictated by therapeutic need and response.**
- **Opioids exists to be given for moderate to severe pains, not merely to be withheld.**

Table 3.11 – Myths and facts about using step 3 drugs like Morphine.

MYTHS	FACTS
Respiratory depression is common with regular use of step 3 drugs	It is rare if the analgesic dose is appropriately titrated as per requirement for pain relief.
All patients on step 3 drugs become addicted to it	The chances of addiction with oral preparations is low
Step 3 drugs are to be used for managing pain only towards terminal stages of a disease	Choosing the drug should be based on severity of pain and not on the stage of the disease.
Step 3 drugs are expensive drugs	Morphine and methadone are not expensive. Fentanyl patch is expensive.
The useful range of dose is narrow, toxic effects can come within therapeutic range.	Oral formulations of step 3 drugs like Morphine, have wide range of therapeutic efficacy and do not have ceiling effect. The dose may be gradually increased and individualised as per relief.

Now let us see how we can manage our patient Chennayya.

The inference was that he has a mixed type of pain with both nociceptive and neuropathic pain. His pain is provoked by chewing movements. He also has a foul smelling wound and has emotional, social and spiritual components to his pain.

For his background persistent pain of moderate severity, we could start him on;

1. Step 2 drug e.g. T. Tramadol 50mg 6^{th} hourly
2. NSAID e.g. T. Meloxicam 15mg once daily after food
3. Cover side effect of NSAID e.g. Cap Omeprazole 20mg early morning on empty stomach
4. Local care for the foul smelling wound with metronidazole gargle [diluted injection metronidazole in saline] with additional powdered tab over it.
5. Antibiotic e.g. Cap Amoxixillin 500mg 8^{th} hourly (If there is infected wound)
6. Amitryptiline 12.5 mg at bed time; in gradually increasing dose upto 37.5 to 50 mg at night - for the neuropathic component

The opioid may be stepped up later to Morphine in case of unsatisfactory pain relief or progressive disease and titrated as described in the text above. Education on mouth care and wound care are important contributors to relief. Once the smell disappears, his social seclusion also could improve.

The non-physical components also need addressing. Building a therapeutic relationship through regular communications, counselling to elicit and help sublimate his suppressed distress are important and relevant inputs without which pain management is incomplete. The family could be involved in his care with due communications and clarifications through a multi-disciplinary team.

Test your knowledge

1. Tolerance develops to all the following adverse effects of oral morphine EXCEPT
   a) Constipation
   b) Nausea and vomiting
   c) Tiredness
   d) Sedation

2. The most unsuitable group of laxatives to relieve morphine induced constipation is
   a) Stimulant
   b) Bulk forming
   c) Osmotic
   d) Stool softener

3. Which of the following is a toxic effect of oral morphine overdose?
   a) Urinary hesitancy/retention
   b) Respiratory depression
   c) Mild Drowsiness
   d) Nausea/ vomiting

Answer Key

1. a
2. a
3. b

Suggested Reading

1. Introduction to Palliative Care by Robert Twycross 4th Edition
2. http://www.who.int/cancer/palliative/painladder/en/
3. http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Pain/Levelsofpaincontrol.aspx

4. SYMPTOM ASSESSMENT AND MANAGEMENT

"Nothing so concentrates experience and clarifies the central conditions of living, as a serious illness" - ***Arthur Kleinman***

ASSESSMENT AND MANAGEMENT OF COMMON SYMPTOMS IN PALLIATIVE CARE

Sukumaran, a 60 year old man diagnosed with chronic renal failure, complains of breathlessness, nausea & vomiting and sleeplessness. He has not passed motion for the past 9 days. He had been a heavy smoker. He lives with his wife and two children. He is a carpenter and now unable to work due to illness.

What are the impacts of illness on Mr.Sukumar's life?

How will you approach these issues in a holistic manner?

The issues of chronically ill patients are complex and professionals have to develop core competencies in order to address these complex issues in diverse settings. To develop skills, one needs to have basic knowledge about symptomatology in chronic illnesses and clinical skills for proper assessment and management.

Learning Objectives of this Chapter

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

- *Enumerate the common symptoms in patients with chronic illness and their implications on quality of life.*
- *demonstrate the key features of holistic assessment of the patient*
- *describe the management plan of the common symptoms*

Relief of suffering is the cardinal goal of medicine….

…….with cure whenever possible.

Principles of symptom Assessment and Management

Symptoms are inherently subjective and hence self-report must be the primary source of information. Thus detailed history taking is important.

The assessment of symptom and related distress is a vital aspect of clinical care, so as to provide comfort and enhanced quality of life. Ideally the management should be guided by a comprehensive assessment of symptoms both subjectively and objectively.

What is holistic approach?

The term holistic means considering the patient as a whole in physical, psychological, social and spiritual domains.

Symptom may be assessed and managed by the following mnemonic "EEMMA[22]"

EEMMA Approach to Symptom Assessment	
Evaluation	**Evaluate details of the symptoms** **Understand the person with symptoms**
Explanation	**Understand all contributing factors** **Explain to the patient as per his / her information needs**
Management	**Manage based on etiological contributors** **Includes management of all symptoms, psycho-social distresses** **Use relevant non-pharmacological interventions**
Monitoring	**Review regularly for relief, side effects and optimize the dose**
Attention to details	**Fine tune the control and individualize the inputs**

[22] Robert Twycross – Introduction to Palliative Care

The key points in managing symptoms are as follows:

1. Centre the care components on patient's idea of Quality of Life
2. Follow the 5 A principles of chronic care – **Assess, Advice, Agree, Assist, Arrange**[23]
3. Correct the correctable contributory factors
4. Involve the multidisciplinary team to address the care inputs for all dimentions – physiotherapist, psychologist, nutritionist, medical social worker, speech and swallow therapist, occupational therapist, yoga therapist etc.
5. Use non-drug as well as drug treatment
6. Prescribe drugs prophylactically for persistent symptoms. Eg: For any continuous pain, analgesia is better achieved with round the clock administration of analgesics rather than giving them p.r.n[24] basis.
7. Keep the treatment regimen as simple and clear to the patient as possible.
8. A formatted prescription with names of drugs, reason for use, dose and timings is more advisable than a verbal advice.
9. Seek a colleague's advice in intractable situations.
10. Avoid false re-assurances yet maintain realistic hope
11. Prioritise concerns from patient's point of view
12. Review and fine tune care inputs

[23] http://www.who.int/hiv/pub/imai/generalprinciples082004.pdf
[24] Only when required

Breathlessness

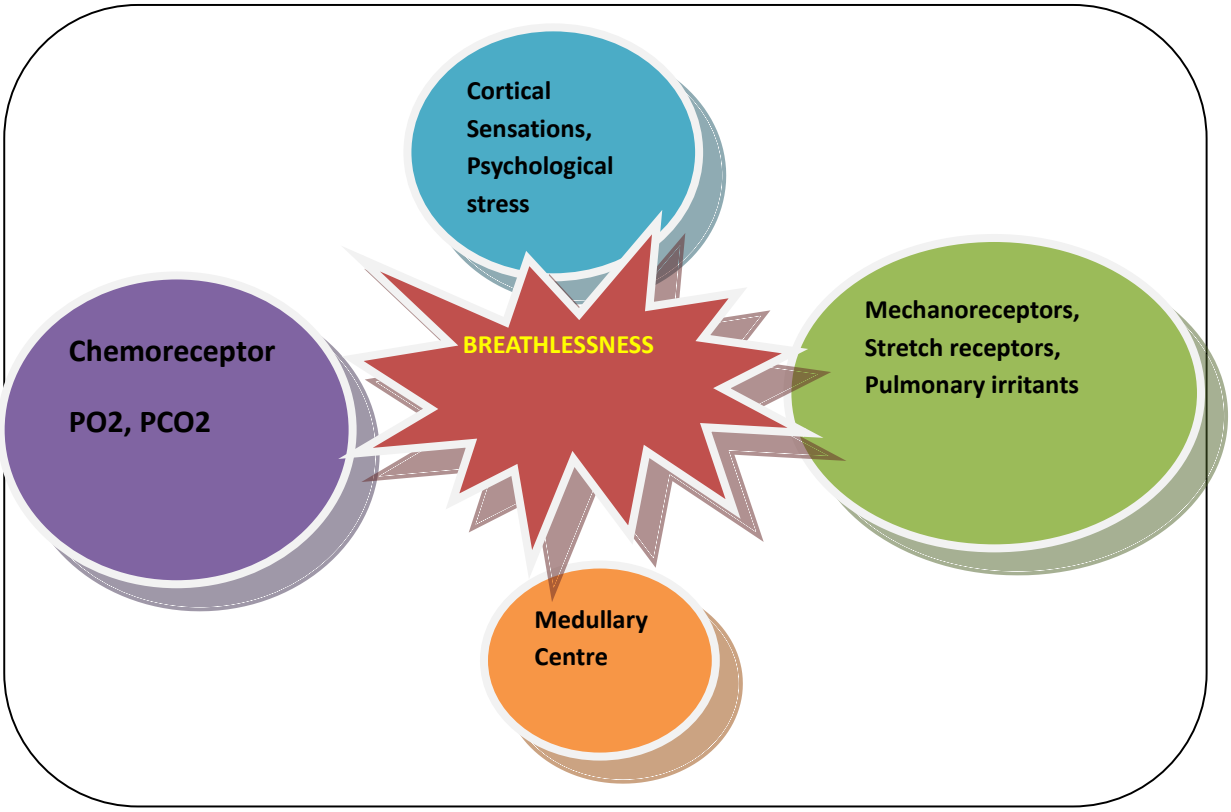
Breathlessness is one of the distressing symptoms and is a conscious and subjective phenomenon. It causes psycho-social distress not only for the patient but also for the family. It is a very difficult symptom for the professionals to manage in situations where the underlying etiology is progressive.

Breathlessness is a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity.

Pathophysiology

Normal breathing is maintained by regular rhythmic activity of the respiratory centre in the brainstem. This is stimulated by the mechanical receptors in the airways, intercostal muscles and the diaphragm, hypoxia and hypercapnoea .When there is a mismatch between the perceived demand and the ventilatory effort, it is experienced as breathlessness by the patient.

Fig 4.1 – Mechanisms of Breathlessness



Breathlessness is a common trigger for panic and a vicious cycle is set up.

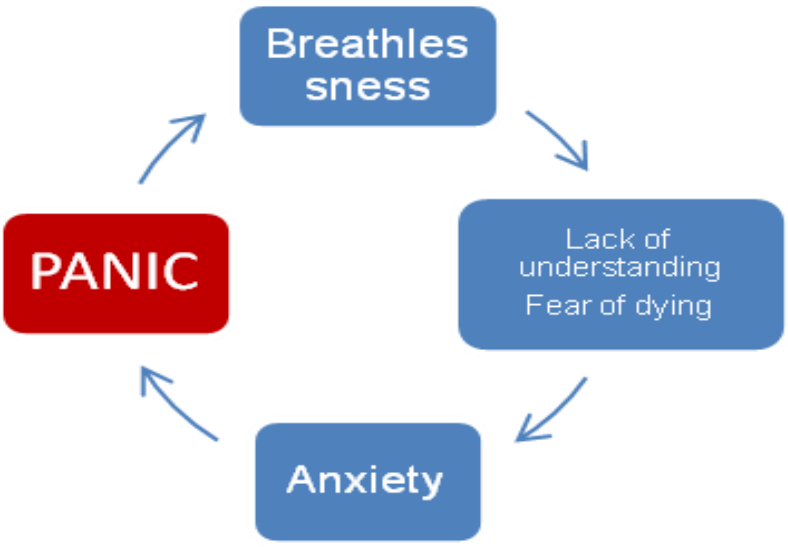


Fig 4.2 - Assessment of severity of chronic breathlessness

Table 4.1 - Modified Medical Research Council (MRC) chronic dyspnoea scale

Category	Dyspnoea	Activity level
0	Nil	
1	Mild	Rapid walking on level OR walking up a slight hill
2	Moderate	walks slower than people of the same age
3	Moderately severe	has to stop because of breathlessness when walking at own pace on the level
4	Severe	stops for breath after walking about 100 yards OR after a few minutes on the level
5	Very severe	too breathless to leave the house or breathless when dressing or undressing

Table 4.2 - History in patient with chronic breathlessness - mnemonic "OPQRSTUV"

Onset		When did breathlessness begin? /What is the duration of an episode? How frequently does it occur?
Palliative/provocative factors		What makes it better? / What makes it worse?
Quality		Whether the person can describe the feeling when he has breathlessness?
Related symptoms		Any other symptoms associated with? (eg:cough, anxiety, isolation etc)
Severity		What is the severity on a scale 0 to 10, 0 representing no breathlessness and 10 worst breathlessness imaginable
Treatment/ Temporal Factors		What medications were used and their effect on the symptom
Understanding		How does the symptom affect the person and the family?
Values		What is the comfortable level which the person expects out of treatment?

Investigations are not very useful in assessing chronic breathlessness due to advanced diseases. X Ray, blood gases etc. can be normal in a patient with moderate to severe breathlessness.

Table 4.3 - Situations where patient can be severely breathless with normal X-ray Chest

- Bronchial asthma
- SVC Obstruction
- Pulmonary Embolism
- Lymphangitis Carcinomatosis
- Resp. Muscle weakness
- Ascites
- Anemia
- Metabolic Acidosis
- Panic attacks
- Early ARDS

Management of Breathlessness

The approach would be to look for and correct the correctable contributors, and utilize non-pharmacological management as well as pharmacological management for control.

Table 4.4 - Controllable causes of Breathlessness

1. Respiratory infections	6. Pleural, Pericardial effusion
2. COPD / Bronchial asthma	7. Ascites
3. Hypoxia	8. Anaemia
4. Superior venacaval obstruction	9. Cardiac failure
5. Lymphangitis Carcinomatosis	10. Pulmonary embolism

Non- pharmacological inputs for controlling breathlessness

- Calm presence of the healthcare team is essential. On the other hand, it would be counter productive to ask patients to "calm down';
- Loosening patient's clothes
- Using fan to maintain air circulation.
- Keeping room windows open for perception of space.
- Comfortable positioning of the patient
- Teaching the patients modified breathing to improves efficiency: pursed lip breathing; diaphragmatic breathing with relaxed abdomen
- Music – as desired

Support coping

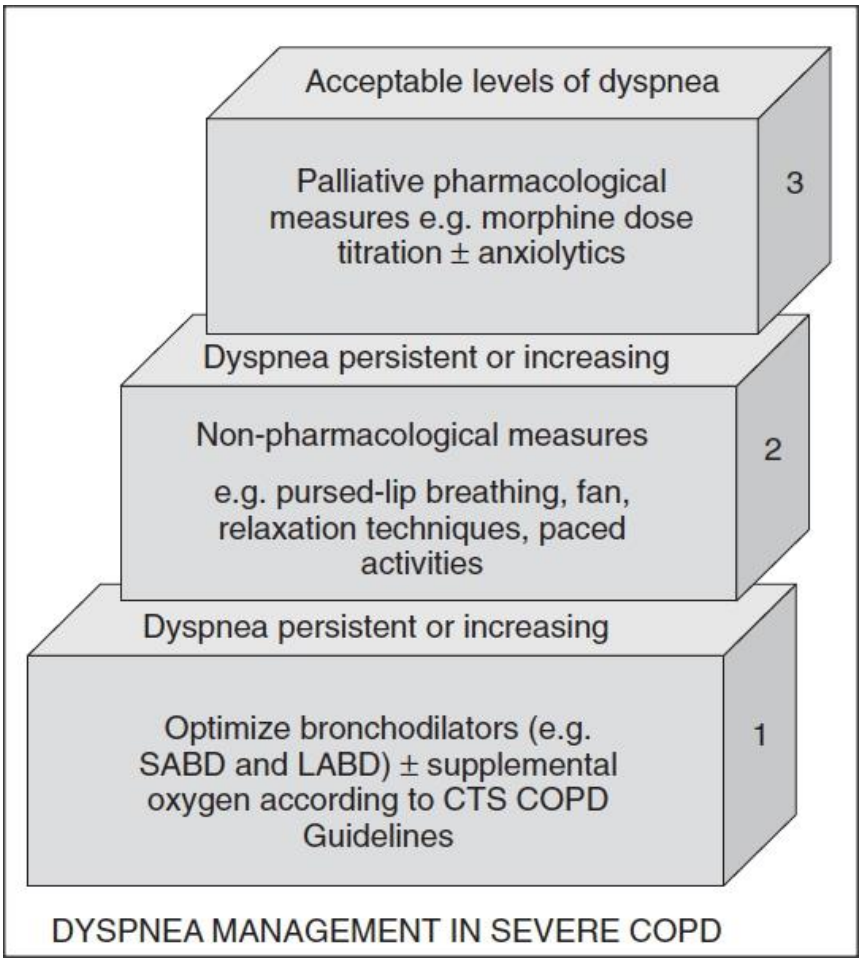
- Addressing patient's fear which is the central element
- Clarifying doubts and exploring about anxiety & meaning of breathlessness to the patient
- Providing inputs to the patient to cope with the current situation
- Instructing carers on using medications to cope with future episodes of breathlessness and panic attacks at home.

Pharmacological management

a) **Bronchodilators** – as shown in the figure above both short acting and long acting bronchodilators have a role and are often helpful even when rhonchi are not detected clinically.

b) **Steroids**: Helps in reducing the oedema of airways which often contribute to wheezing and thereby helps reduce the severity of breathlessness. Dose is variable between 8 mg – 32 mg orally, subcutaneously or intravenously OD. The dose requirement may be high in superior venacaval obstruction and Lymphangitis Carcinomatosis.

Fig 4.3 – Steps of managing Dyspnoea in COPD



c) **Opioids**: Opioids have been the most widely studied agent in the treatment of intractable dyspnea in advanced stages of cancer and have been found to be safe[25]. Morphine reduces inappropriate and excessive respiratory drive and substantially reduces ventilatory response to hypoxia and hypercarbia. By slowing respiration **breathing is made more efficient and the sensation of breathlessness is reduced**.

Short-term administration reduces breathlessness in patients with a variety of conditions, including advanced COPD, interstitial lung disease, cancer and chronic heart failure. In opioid naïve patients, start Morphine 2.5 mg-5 mg QDS and titrate according to breathlessness.

25 A L Jennigs et al - A Systematic Review of the use of opioids in the management of dyspnea; Thorax 2002, 57; 939-944

The Opioid doses required for breathlessness are much less than that required for pain relief.

d) **Benzodiazepines**: If breathlessness is associated with anxiety or panic, benzodiazepines have a role though they are not the first line agent. Lorazepam 0.5 -2 mg sublingual or Midazolam 1-2 mg Subcutaneous can be used.

e) **Trial of oxygen** through nasal cannula (**avoid oxygen masks**). In advanced illnesses, breathlessness occurs not because of non-availability of oxygen but due to inefficiency of body's mechanism to use oxygen. Patients with good oxygen saturation are found to experience breathlessness in advanced stage of illnesses. Oxygen may help in hypoxia as well as panic attacks. Hence we can give a trial with oxygen for 15-30 min. Prior explanation to patient / family is helpful and necessary to avoid misunderstanding. If there is no improvement in symptom during the trial, this fact has to be explained to the family &oxygen is discontinued. The decision to put the patient on ambulatory oxygen therapy should be after due considerations and NOT done lightly as this grounds the patient, increases the cost and could contribute to general panic within the family as focus is on oxygen and its parafernalia.

So how was Sukumaran managed at home by the Home Care Team (HCT)?

HCT first talked to Sukumaran and his family to evaluate his symptoms also to share the family's concerns. They positioned him in the posture which he found most comfortable and demonstrated the effectiveness of non-pharmacological inputs as listed above.

He was started on bronchodialators, low dose morphine, and short course of steroids. (as his renal functions were abnormal, morphine was started 8^{th} hourly)

Constipation

It is very difficult to define constipation as it is a subjective phenomenon and varies from person to person.

Constipation: Constipation can be said to be present when there is infrequent passage, small quantity, hard faeces or passage with difficulty.

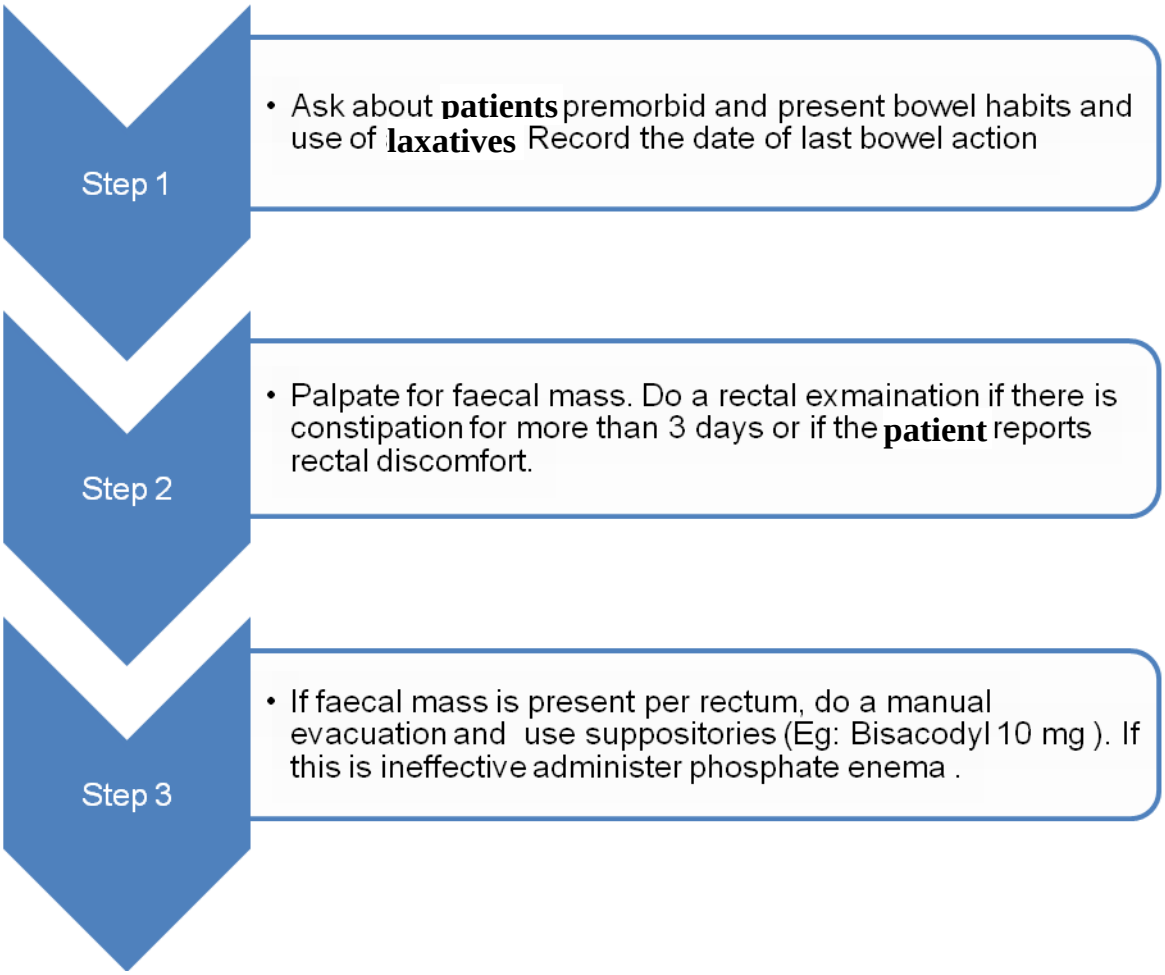
Table 4.5 Causes of Constipation

Medications	Opioids, Tricyclic antidepressants, Anticholinergics, 5 HT3 antagonists, Antacids, Diuretics, Antihypertensives, Chemotherapeutic agents
Metabolic disturbances	Dehydration, Hypothyroidism, Hypercalcemia, Hypokalemia,
Neurological	Cerebral and spinal cord lesions, Parkinsonism, Motor neuron disease
Structural	Pelvic tumours, Anal fissure, Hemorrhoids, Radiation fibrosis
Diet	Poor food intake (particularly fibre and water)
Environmental	Lack of privacy,
Others	Old age, Debility, Inactivity, Depression

Constipation remains as an underestimated symptom which severely affects sense of wellbeing of the patient. Constipation leads to inadequate symptom control through its complications like, loss of appetite, abdominal pain and distension and urinary retention.

Impacted faecal matter often leads to overflow diarrhoea which is manifested as frequent passage of foul smelling soft faeces. This is often misdiagnosed as diarrhea and treated with antidiarrhoeal medications.

Fig 4.4. Practical aspects on management of constipation



Management of constipation

Aims

The aims of management of constipation in palliative care patients are to:

- re-establish comfortable bowel habits to the satisfaction of the patient;
- relieve the pain and discomfort caused by constipation and improve the patient's sense of well being;
- restore a satisfactory level of independence in relation to bowel habits;
- prevent related gastrointestinal symptoms such as nausea, vomiting, abdominal distension and abdominal pain.

Non-pharmacological management:

- Access and ability to get to the toilet may be more important than a supply of laxatives

- Timing and privacy–impatience of patients and carers leads to straining and bracing.
- Taking warm water at a pre-decided time every morning and massaging the left lower abdomen also assists in bowel movement.
- Straining compromises defecation and damages pelvic floor function
- A squatting position facilitates efficient funneling of the pelvic floor ,favouring defecation

Classification of laxatives

Table 4.6 Types of Laxatives

Drug Class	Examples
Bulk forming	Methyl cellulose, Ispagula husk
Lubricants	Liquid paraffin
Surface wetting	Docusate sodium
Osmotic	Lactulose, Poly ethylene glycol, Milk of magnesia
Contact or stimulants	Bisacodyl, Senna, Sodium picosulphate

What was done for Sukumaran's constipation by HCT[26]?

He had not moved his bowel for past 9 days, he was straining a lot which was adding to his breathlessness. He was on hypertensives, antacids and antidepressants all of which contributed to poor bowel motility. Per rectal examination was done which showed hard fecal matter. Phosphate enema was given followed by bowel evacuation and Sukumaran became very much relieved.

Carers were given advice regarding diet modification and Sukumaran was started on Tab Dulcolax 10 mg to be given daily at bed time. Since the toilet was away from his bedroom, HCT also arranged for a chair commode and advised the family regarding responding early to his defecation urge[27] and maintaining privacy during the time of bowel movement**.**

[26] Home Care Team

27 The colonic peristaltic movements supporting for defecation are less frequent – 2- 3 times / day

Diarrhoea

Diarrhoea is less common than constipation in patients requiring palliative care. As with constipation, patients can understand diarrhea in different ways and clarification of the term is required.

Diarrhoea is the passage of more than three unformed stools within a 24 hour period.

Common causes of diarrhoea in palliative care setting:

a) Imbalance in laxative therapy.

b) Drugs (antibiotics, NSAID's)

c) Faecal impaction leading to spurious diarrhoea

d) Radiotherapy to abdomen

e) Bowel fistula

f) Endocrine tumours

g) Odd dietary habits.

Table 4.7 Evaluation of patient with loose stools

Pattern	Diagnosis
Loose stools twice or thrice a day without warning	Anal incontinence
Profuse watery stools	Colonic diarrhoea
Sudden onset of diarrhoea after a period of constipation	Faecal impaction
Alternating diarrhoea and constipation	Poorly regulated laxative therapy Impending bowel obstruction
Pale fatty offensive stools (steatorrhoea)	Malabsorption (pancreatic or ileal disease)

Management of diarrhoea

With the exception of patients with AIDS, diarrhoea is much less common than constipation in patients with advanced disease. Less than 10% of those with cancer admitted to hospital or palliative care units have diarrhoea. Diarrhoea can be highly debilitating in a patient with advanced disease because of loss of fluid and electrolytes, anxiety about soiling, and the effort of repeatedly going to the lavatory.

Symptomatic relief is generally achieved with non-specific antidiarrhoeal agents—loperamide (up to 16 mg daily) or codeine (10-60 mg every 4hours). There are certain specific conditions, which should be treated with specific agents like Ranitidine for Zollinger-Ellison syndrome, metronidazole for pseudomembaraneous colitis, cholestyramine for chologenic as well as radiation induced diarrhoea.

Supportive measures include oral rehydration with home available fluids, ORS (oral rehydration solution). Parenteral rehydration is rarely indicated.

Nausea and vomiting

Nausea and vomiting are common symptoms in patients with advanced cancer. It is important to know the various mechanisms involved in nausea and vomiting for targeted drug therapy rather than prescribing the same antiemetic for various types of vomiting.

Nausea: It is an unpleasant subjective sensation associated with autonomic symptoms like sweating, tachycardia with an imminent need to vomit.

Vomiting: It is the forceful and sustained contraction of abdominal muscles and diaphragm resulting in expulsion of gastric contents.

Assessment:

1. Clarify whether the person is reporting nausea, vomiting, retching or regurgitation.
2. Identify the cause of nausea and vomiting
3. Identify the pathway and receptor involved
4. Document the intensity, frequency, volume and content of vomitus and associated distress
5. Assess nausea and its impact on the daily activities in a **holistic manner.**
6. Evaluate whether the symptom is caused by drugs, radiotherapy, chemotherpy, raised intra-cranial tension, etc.

Retching means spasmodic respiratory movements **against a closed glottis** with contractions of the abdominal musculature **without expulsion of any gastric contents**

Regurgitation means the act by which food is brought back into the mouth **without the abdominal and diaphragmatic muscular activity** that characterizes vomiting

Non-pharmacological management of nausea and vomiting

- Control of malodour from colostomy, fungating tumour, decubitus ulcer etc.
- A calm ,reassuring environment away from the sight and smell of food
- Avoid foods which precipitate nausea for that patient
- Small snacks, e.g. a few mouthfuls given frequently are often more effective than infrequent large meals.

Pharmacological management:

Table 4.8 Management of nausea & vomiting based on etiology		
Aetiology	**Examples**	**Appropriate first line drug**
Chemicals	Drugs - e.g. opioids, digoxin, antibiotics, cytotoxic drugs Toxins - e.g. ischaemic bowel, infection; Metabolic, e.g. Hypercalcemia	Haloperidol, 1.5 mg bd or 5 mg SC over 24 hrs. 5-HT_3 receptor antagonists e.g. Ondansetron 8 mgs tds Neurokinin-1 antagonists e.g. Aprepitant
Delayed gastric emptying	Drugs, e.g. opioids, Tricyclic antidepressants; Ascites Hepatomegaly; autonomic dysfunction	Metoclopramide, 10 mg qds; 40 mg subcutaneously over 24 h OR Domperidone, 10 mg qds
Gastrointestinal	Bowel obstruction	Hyoscine butyl bromide, 60 mg subcut: over 24 hr. Consider adding haloperidol and/or Dexamethasone. If partial obstruction and/or abdominal colic consider Metoclopramide.
	Radiation colitis, post-chemotherapy	Ondansetron, 8 mg bd-tds
CNS causes	Raised intracranial pressure, e.g. from tumour or intracranial bleed; meningeal infiltration	Dexamethasone 16-32 mg Subcutaneous/ oral
Psychological	Anxiety, anticipatory nausea to chemotherapy, pain	Benzodiazepines, e.g. oral lorazepam,0.5 mg as required

Clinical points to consider:

- Nausea and vomiting in cancer is often multifactorial and combinations of anti-emetics which act at different receptors are often needed.
- If more than one anti-emetic is used try to choose one from each class of anti-emetics.
- Always give anti-emetic regularly, not PRN.
- If vomiting is preventing drug absorption , use alternative route (SC or IV)
- Combination of prokinetics (Eg: Metoclopramide) and anti-spasmodic (Eg: Hyoscine Butyl Bromide) is not advised**.**
- Opioids can cause nausea and vomiting through a number of mechanisms. These include stimulation of chemo receptor trigger zone, increased vestibular sensitivity, gastric stasis, impaired intestinal motility and constipation. If nausea and vomiting is not controlled by drugs, try another opioid.

How was Sukumaran's nausea and vomiting managed by the HCT?

He being a patient with chronic kidney disease, uraemia is a very likely cause for his nausea. He also said he did not like the smell emanating from the kitchen. One cause for vomiting could be his constipation.

HCT advised the family to give him small frequent feeds rather than 3-4 meals a day. The wife was requested to keep the kitchen door closed while she cooked. (In fact she was keeping the door wide open to keep an eye on her husband.) He was also started on tab Haloperidol 2.5 mg at bed time as the etiological factor was uraemia stimulating the CTZ[28]

[28] Chemoreceptor Trigger Zone

Nutrition and Hydration

Request for nutrition and hydration is a common issue that has to be faced in palliative care. Understanding the pathophysiology, medical ethics and appropriate treatment are paramount in assessing and managing these requests.

Anorexia is the absence or loss of appetite for food and is common in patients with advanced cancer and other chronic illnesses.

It is important to look for secondary anorexia may be reversible. E.g. dyspepsia, altered taste, malodor, nausea, vomiting, constipation, sore mouth, pain, biochemical abnormalities, treatment induced (drugs, radiotherapy, chemotherapy), anxiety and depression.

Cachexia is a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without fat mass) that cannot be fully reversed by conventional nutritional supports and leads to functional impairment. Pathophysiology of Cachexia is characterized by negative protein and energy balance caused by variable combination of reduced food intake and abnormal metabolism.

Anorexia-cachexia syndrome is often accompanied by asthenia or fatigue. This is described by the patient as unusual tiredness, decreased capacity for work, decreased motivation, mood and energy, decreased concentration and mental agility.

Non-pharmacological management of Anorexia

- Small but frequent meals
- Energy-dense food
- Limit fat intake
- Avoid extremes in smell
- Pleasant environment
- Presentation of food to the patient in a pleasing manner

Pharmacological management of Anorexia

Progestagens (megestrol acetate and medroxyprogesterone acetate) are the first-line therapy for cancer anorexia. They are highly effective in relieving the symptoms of cancer anorexia and thus are widely prescribed. In a recent systematic review of randomized clinical trials, Maltoni and

co-workers showed that high-dose progestagens (up to 800 mg/d of megestrol acetate, and up to 1000 mg/d of medroxy progesterone acetate) improve food intake, and, to a lesser extent, body weight.

Dexamethasone 2-4 mg od may be used as an appetite stimulant and may help in nausea. It's effect is generally short. Side effects limit its use as an appetite stimulant.

Prokinetic drugs, like Metoclopramide is a drug which is helpful in anorexia due to gastric stasis.

Thalidomide, omega-3-fatty acids, melatonin and NSAID's are also considered as emerging drugs in the management of anorexia-cachexia but it needs more research.

Hydration in Terminally ill patients

Artificial hydration should be used judiciously, so as to allow maximum patient comfort. It can be administered intravenously or subcutaneously. Hypodermoclysis (HDC), also known as "clysis," is the infusion of isotonic fluids into the subcutaneous space for rehydration or for the prevention of dehydration.

Subcutaneous infusion[S/C] or Hypodermoclysis

- In ambulatory patients, common sites for S/C injections include the abdomen, upper chest, above the breast, over an intercostal space and the scapular area.
- In bedridden patients, preferred sites are the thighs, the abdomen and the outer aspect of the upper arm.
- Fluid can be delivered subcutaneously by gravity at a rate of 1 mL per minute at one site; thus, about 1.5 L can be delivered at one site and 3 Ls at two separate sites over 24 hours.
- Average duration for which the subcutaneous canula can be retained at a single site is 4-7 days.
- Normal saline, 5 % Dextrose and dextrose normal saline can be administered for rehydration.
- Subcutaneous route is usually used for administration of common medication like morphine, Midazolam, haloperidol, Metoclopramide, Hyoscine butyl bromide and Glycopyrrolate.

Table 4.9 Advantages and Disadvantages of S/C infusion

Advantages	Disadvantages
Low cost, easily taught to lay person	Local Oedema
More comfortable than IV administration, does not cause thrombophlebitis	Local reactions
Less likely to cause fluid overload	Cannot be used when rapid rehydration is needed
Simple insertion, less pain	Not recommended in patients with bleeding disorders
Usually does not cause systemic infections	Limitation to total volume per day

Anxiety and Agitation

Anxiety may be acute or chronic and implications of anxiety could vary from person to person. Anxiety is a common symptom in persons with advanced illness and in the terminally ill for a variety of reasons including the fear of uncontrolled symptoms and of being left alone to die.

Anxiety: A state of apprehension, uncertainty, and fear resulting from the anticipation of a realistic or fantasized threatening event or situation, often impairing physical and psychological functioning.

Assessment of Anxiety

Symptoms like excessive worrying, increased motor or autonomic hyperactivity should trigger further evaluation?

➔ Assessment of the nature of anxiety, acute or chronic

➔ Assessment of any reversible factors such as pain or inappropriate medications.

➔ Assessment of medication history (stimulant drugs or excessive alcohol intake or withdrawal may precipitate or exacerbate anxiety).

➔ Assessment of worries and concerns of the person

Agitation is a state of chronic restlessness and increased psychomotor activity generally observed as an expression of emotional tension and characterized by purposeless, restless activity.

Terminal Agitation

There are many causes for agitation including delirium, dementia, schizophrenia etc. Diagnosis of Terminal agitation is made when reversible conditions are excluded or the symptoms fail to respond to treatment. Some of the common reversible causes to be rules out are given below

Pain Urinary retention Loaded rectum Cerebral irritability	Side effects of medication - opioids,Tricyclic antidepressants, steroids Anxiety and fear

Delirium

Delirium is characterized by acute and fluctuating cognitive impairment. It is important to differentiate delirium from dementia which is a state of progressive impairment and in some cases delirium might complicate an underlying dementia.

Delirium is a disorder of consciousness and attention combined with abnormalities of cognition and perception. Delirium is an acute syndrome as opposed to dementia, and an organic cause affecting the brain is usually identified or likely.

Table 4.10 - Differentiating delirium and dementia

Delirium	Dementia
Acute	Chronic
Incoherent speech	Speaks less
Aware & anxious	Unaware & not concerned
Lucid intervals may be present	No lucid interval
Reversible except in terminal phase	Progressive and irreversible

Clinical features and assessment of delirium

1. Acute onset of altered level of consciousness
2. impaired attention
3. altered sleep-wake cycle
4. motor and affective changes
5. hallucinations, delusions
6. cognitive performance failure at formal testing
7. involuntary movements

Management of delirium

Delirium is one of the most underdiagnosed clinical conditions and grossly disturbs the quality of

life. It is entirely a clinical diagnosis[29]. An attempt should be made to help the patient to express their distress. Family needs education and support to understand the pathological process.

Non-drug treatment:

- Keep calm and avoid confrontation
- Respond to patient's comments
- Clarify perceptions and validate those which are accurate
- Explain what is happening to the family and why
- State what can be done to help
- Repeat important and helpful information
- Explain to the patient and family that delirium is not madness.
- Continue to treat the patient with courtesy and respect
- Avoid restraints
- Patient should be allowed to walk about with an accompanying person
- Allay fear and suspicion and reduce misinterpretation by using night lights, -explaining every procedure and event in detail and ensuring the presence of a family member or a close friend with the patient
- Reorientation and grounding of the person to space and time – dentures, hearing aids, spectacles, albums, photos, clock, calendar etc. [Fig 4.6]

Fig 4.5 Useful inputs in managing Delirium

[29] http://www.hospitalelderlifeprogram.org/private/cam-disclaimer.php

Management of Delirium with drugs

- Haloperidol is the most commonly used medication for symptomatic treatment of delirium. Some guidelines suggest 1-3 mg/ day of haloperidol can effectively palliate the symptoms of delirium.
- Other atypical anti-psychotics like risperidone and olanzapine are also used in management of delirium.
- A common strategy in the management of delirium is to add Lorazepam to a regimen of haloperidol. Lorazepam 0.5 mg -1mg 1-2 hourly orally or intravenously, along with haloperidol may be more effective in rapidly sedating agitated delirious patients and may help minimize extra pyramidal side effect associated with haloperidol.

Malignant wounds

Malignant wounds occur when cancerous cells invade the epithelium, infiltrate the supporting blood and lymph vessels, and penetrate the epidermis. This results in a loss of vascularity and therefore nourishment to the skin, leading to tissue death and necrosis.

Fungating lesions are fast growing and typically resemble a cauliflower or fungus-shaped structure extending beyond the skin surface. On the other hand, ulcerative lesions are characterized by deep craters with raised margins .

Malodorous wounds result from bacteria that reside in necrotic wound tissue. They are usually polymicrobic, containing both aerobic and anaerobic bacteria. For the most part, it is the anaerobic bacteria that emit putrescine and cadaverine, which result in foul odours. Some aerobic bacteria such as Proteus and Klebsiella can also produce offensive odours (3).

Table 4.12 - Problems of a malignant wound

Physical problems	Psychological problems
Malodour	Body image alteration
Exudate	Depression, guilt
Bleeding	Embarrassment, shame
Pain	Social isolation, Denial.
Pruritus	Problems with sexuality
Infection	Fear
Nausea and anorexia	

Wound assessment

There are a variety of wound assessment tools in current use, which may include the following baseline measurements (2)

- Type of wound, e.g. adherent/non-adherent, black/ necrotic, green/yellow sloughy
- Amount of exudate produced
- Depth, e.g. superficial / deep / layers of skin involved
- Presence/absence of odour
- History of bleeding
- Description and intensity of pain
- Signs of fistula /sinus formation

- Condition of the surrounding skin – is it red or macerated or is the skin fragile or showing signs of infection
- The site, location, surface area are documented and also if there are nodules present.
- Patient should be assessed in a holistic manner to elicit physical, psychological, social and spiritual problems due to wound.

Management of malignant wounds

The proper approach to the management of malignant fungating wounds shifts from healing to addressing quality of life.

Wound cleaning

Unless otherwise indicated the fluid of choice for cleaning is normal saline or ordinary tap water. Cleaning is best achieved, if possible, by showering the wound. Swabbing can be painful and traumatic, and should be avoided. Saline and water used for cleansing should be warmed to at least room temperature. Chemical or surgical debridement of these wounds is not recommended. Maintaining a moist environment also prevents trauma resulting from wound drying and fissuring and stimulates epithelial cell migration over any normal tissue to facilitate resurfacing (2)

Management of malodour

Malodour is one of the most distressing problems associated with fungating malignant wounds. The use of topical metronidazole in the fungating wound avoids the side effects like nausea and vomiting normally associated with oral metronidazole Laboratory studies suggest that 0.8% metronidazole is active against a range of microorganisms, not just the anaerobic species with which malodour is most generally associated. Dressing with charcoal, form dressings, honey, papaya and many other home remedies have been used to reduce the smell and exudate (1,2).

Management of exudate

Fungating wounds often produce moderate or large quantities of exudate, as a result of increased permeability of vessels within the tumour and the action of bacterial enzymes. Unless exudate is controlled, related problems such as soiling, peri wound maceration, leakage and odour will not be effectively managed. To contain and remove excess exudate from the wound, a plethora of absorbent dressings has been developed. Major categories of dressings include foams, alginates, and hydrofibers, along with super absorbent products based on diaper technology (1,2)

Silicone Polymers, zinc oxide/petrolatum Inorganic compounds, acrylates, hydrocolloid or adhesive film dressing can be used to protect the normal peri wound skin (1,2)

Management of pain

Pain during dressing changes can be managed by local and systemic agents. Local agents like Lignocaine 1% and bupivacaine 0.25 %, use of systemic agents well ahead of dressing and cleaning wounds can reduce the pain.

Management of bleeding

Bleeding occurs mainly during cleaning and dressing, dressing removal and also due to other traumas. Profuse bleeding may occur sometimes due to infiltration of large vessels. The patient and family should be informed if there is a chance of bleeding. Use of green or red towel during sever bleeding may be useful to decrease the anxiety and fear of the patient and family.

The dressing should be soaked with normal saline or homemade saline before removing the dressing which can reduce pain and bleeding due to tissue trauma. Local pressure should be applied carefully as the tissues are fragile. Application of powdered sucralfate will help to reduce the bleeding. Local application of farcrylum, adrenaline may be tried. Oral agents like etamsylate and tranexemic acid can be used. If the bleeding is very severe and if patient has a very advanced disease, usually any interventions to stop bleeding may not be useful. In such cases, the non-pharmacological management (described above) along with anxiety reduction measures can be instituted.

What more is required for our patient Sukumaran?

We managed his breathlessness, constipation and nausea. He was moving his bowel regularly, his nausea had settled and his sleep too had improved. His family informed the HCT that he was talking irrelevantly and the sleep was disturbed. He was accusing his wife of plotting to poison him. It was understood to be due to disturbed day night rhythm and disorientation seen in early delirium. We did not start any sedatives. His distraught and devoted wife was explained the cause for his behaviour and educated regarding non-pharmacological inputs as described above. His Haloperidol dose was stepped up. HCT followed him up and found his symptoms resolving.

He and family would continue to require regular care inputs and communications based on the progress of his renal failure and other concerns that come up. They may need assistance in decision making for acute episodic issues and in understanding the prognosis and course better. All these aspects are discussed in the module on optimisation.

Suggested Reading:

1. http://www.who.int/hiv/pub/imai/generalprinciples082004.pdf
2. A L Jennigs et al - A Systematic Review of the use of opioids in the management of dyspnea; Thorax 2002, 57; 939-944
3. Wilson .V. 2005. Assessment and management of fungating wounds. *Wound Care*, S28-32.
4. Woo.K.Y. & Sibbald.R.G.2010. Local wound care and malignant and palliative wounds. *Advances in Skin and Wound Care*23, pp.417-428
5. Brien.C.O. 2012.Malignant wounds-managing odour. *Candian Family Physician*, 58,pp. 272-274.
6. http://www.hospitalelderlifeprogram.org/private/cam-disclaimer.php

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 medical 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 background 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 management[30]

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

30 Ref: module on communication

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 measures 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 QOL[31] 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.

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. Reducing his symptom load would improve his QOL.

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 discontinued[32].

As Panic reinforces breathlessness and works to maintain the vicious cycle, lorazepam 1mg was given sublingually for quick anxiolytic effect[33].

Delirium is acute psychotic behaviour, a common symptom in late stages of progressive

[31] http://www.who.int/mental_health/media/68.pdf

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

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

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 corrected[34]. Symptomatic management of delirium was then initiated using haloperidol (2.5mg SC[35] / 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.

> 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.

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

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

35 Subcutaneous

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, antico-agulants 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.

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 (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] living will gives an opportunity to the sick person to choose a natural death process[36].

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 the extend that the health care providers may proceed with aggressive and invasive interventions.

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.

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

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

Can we predict death? [37]

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?

A practical way to answer the question on "how long" in the background of a chronic progressive disease trajectory is as follows; 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…….and so on…

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?"***

37 http://www.goldstandardsframework.org.uk/

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 fulfilles, 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

Ethics Based Decision Making

Fig 2 - Hippocrates refuses the gifts of Artaxerxes.
Copy of oil on canvas by Anne-Louis Girodet-Trioson (1792).

Medical ethics is a system of moral principles that apply values and judgments to the practice of medicine

Part of being a professional is being concerned with ethical issues. It is necessary therefore to take time to learn about the concepts which are relevant and to be able to justify one's own position[38]. The purpose of this section is to assist the professional to be able to analyse a clinical issue from an ethical point of view and to take decisions on how best to manage the complex problems related to patient care.

The clinical judgements are based on values held by the patient, the family, and the doctor. In situations where there is "clear right "and "clear wrong" answers decision making is easy. There may well be differences in views, and almost always there will be uncertainty. Practically speaking, in many clinical situations, more than one option may look right, leading to dilemmas and difficulties.

38 http://weill.cornell.edu/deans/pdf/hippocratic_oath.pdf

Codes of ethics. In some cases the perceived important values have been codified and written down. The most famous of these is the Hippocratic Oath, which sets out some of the ethical principles which the doctor should follow. There are many others, including the Helsinki Declaration and the Declaration of Human Rights. These provide useful checks and prompts for those practising palliative medicine.

Some Key Ethical Concepts[39]

- ***A duty to alleviate suffering*.** This is an obvious concept, but like all such concepts not as simple as it seems. Of course we should alleviate suffering, but at what cost, either Quality of Life or financial? How far should we go to alleviate suffering? What if the symptom is difficult to alleviate and we fail? Have we failed in our duty?

- ***Respect for persons*.** We should consider the patient and his dignity in the clinical care setting. This includes our communication with him and his family, treating him with respect and courtesy, and respecting the patient's wishes even if they differ from our own. At times this can be a source of conflict.
- Respect for persons is associated with the concept of confidentiality. This is an important principle and sets out the right of the patient to have information about them, or their condition, kept within a limited number of members of the team. The patient may not like details of his illness to be made known to all. But this can be easily breached as treating teams become larger and access to information easier.
  Dilemma appears when this right conflicts with one's responsibility to the law, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient himself. In such cases, one must take all reasonable steps to inform the patient that confidentiality will be breached.
- ***Autonomy*.** This is a concept, related to respect. It states that each individual has a right to make decisions about his/her own life. It is difficult to disagree with this concept but it can, like so many other issues, raise problems. These include how far we can comply with patient's wishes, and whether we should at any time refuse to do what the patient wants[40]. A

39 Oxford Textbook of Palliative Medicine - Kenneth Calman

40 E.g.A chronic renal failure patient demands that he be continuously dialysed to maintain renal parameters

key part of autonomy is the ability of the patient to consent to treatment or care. Their wishes should be respected and they have a right to refuse treatment offered whether or not it makes sense to the doctor.

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body." **Justice Benjamin Cardozo (1914)**

- ***Non-maleficence*.** This at first sight seems entirely appropriate. We should not do anything which may cause a potential harm to the patient. Once again, in practice is more difficult. Much of what we do, for example, in cancer treatment has severe adverse effects, and the benefit might not always be very clear. The dictum, *primum non nocere*—first do no harm—can be difficult to live up to.
- ***Beneficence*.** This implies that we should always do the best for our patients. Difficult to disagree with. However, one has to be clear whether what we find beneficial effect is also considered by the patient as a benefit[41]. It also implies that we as individual professionals have the skills and expertise to deal with the problem, and the wisdom to refer the patient to someone else if we already have not.
- ***Justice*.** This implies fairness for all and equity and equality of care. Clearly this is impossible to achieve in all instances[42].
- ***Human rights*.** A good case can be made for using a rights-based approach. This begins by defining what such rights are and how they can be enforced. The right to life, the right to respect, the right to information, are all part of this approach.

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.

41 Reduction in size of a Cancer of Larynx size in a scan from 14 cm to 3 cms would be a beneficial effect from the oncologist's point of view. But it is ability to speak or cure that patient the would consider to be a beneficial response to a treatment.

42 Suppose there is just one bed in a critical care unit and there are 2 patients waiting; one is a 25 year old man brought with multiple trauma and the other a 72 year old delirious patient, unstable haemodynamics with reversible co-morbidities such as pyelonephritis. Who should be given this bed?

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 unconcious ventilated patient becoming oriented and ambulant)

We as medical 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.

Let us look at another clinical scenario to understand the dilemmas and reason based on the four cardinal principles of medical ethics i.e. Respect for Autonomy, Beneficence, Non maleficence and Justice

Lala is a 33 year old man, running a small shop for his livelihood, belonging to middle income group diagnosed to be having carcinoma esophagus. He has had a recurrence of the disease six months after completing the surgery and radiotherapy and has progressive dysphagia. Lala knew about his prognosis. He has read about an expensive stent and asks you about it as he wishes to relieve his dysphagia.

Table 5.2: Discussion on ethical dilemmas in decision making based on Lala's clinical situation

Ethical Principle	Dilemmas
Autonomy	• Does Lala understand all the implications of the procedure itself and post procedure issues? Does he understand the financial aspects of the procedure and its complications? Is his choice an informed one?
Beneficence	• Is stent insertion possible with the current pathological status of disease in Lala? • Will it surely improve dysphagia? If yes, how long would it be before the disease blocks or displaces it? Is it worth doing it? • Will it impact his biological prospects and quality of life?
Non maleficence	• Is there possibility of unacceptable harm due to the procedure? E.g. tear, trachea-esophageal fistula formation etc.
Justice	Is this fair allocation of resources? Is this fair utilisation of family funds? Would this deplete the savings of the family, kept aside for their children educational?

Ethics Based Decision Making

Interaction with patient and family with honest and clear information sharing is the key to ethical decision making.

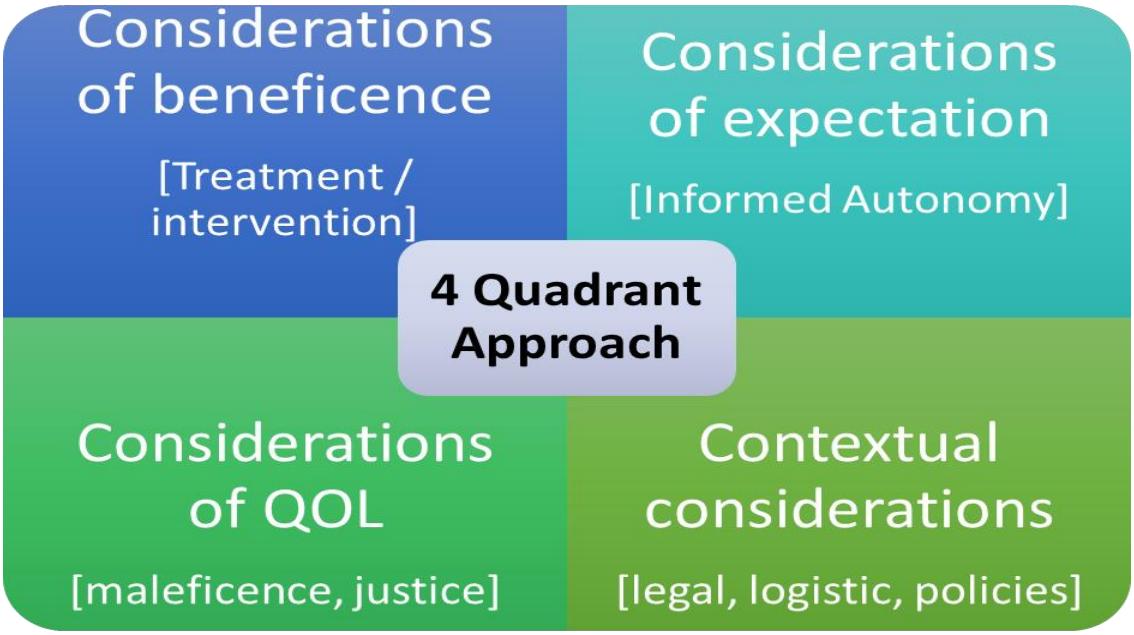


Fig 5.3 – Approach to Ethics based decisions[43]

Conclusion

The framework adopted by any individual be it patient, family member, or professional; may vary on these factors -duties, right, and principles. From this brief discussion certain conclusions can be drawn.

- There are many frameworks for ethical decision-making
- Decisions may have to be taken at times in the face of uncertainty, and thus judgements will be required. So there is ample scope for disagreement on what to do.
- There can be no right or wrong approach, just differences between different value bases held by individuals.

When one adds the differences in social, cultural, and spiritual aspects of life, then the possibilities become much more complex. So all the important that a flexible and compassionate approach is needed. When one adds into these differences in social, cultural, and spiritual aspects of life, then the possibilities become much more complex and entails a flexible and compassionate approach.

43 J Leg Med. 1993 Jun;14(2):355-7. Clinical Ethics, by A. Jonsen, M. Siegler, and W. Winslade

Suggested Reading

1. http://weill.cornell.edu/deans/pdf/hippocratic_oath.pdf
2. The Indian Journal of Critical Care Medicine [by the ISCCM] Vol 9; issue 2; 2005
3. J Leg Med. 1993 Jun;14(2):355-7. Clinical Ethics, by A. Jonsen, M. Siegler, and W. Winslade
4. http://www.gmc-uk.org/guidance/good_medical_practice.asp
5. Ethics by Kenneth Calman in Oxford Textbook of Palliative Medicine
6. http://www.suffolk.nhs.uk
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Questions

To
The Chairman and the Members of the Governing Council,
Medical Council of India,
New Delhi

The conventional medical curriculum mainly evaluated the knowledge and skills of the student. The submitted modules on Palliative Care have tried to address the component of attitude i.e. the affective domain required for clinical practice. We have added few questions at the end of each module.
An additional question bank containing 40 questions based on the prepared modules on the concept of palliative care and pain relief is attached herewith.

Sincerely,
The Editorial Team

Multiple Choice Questions

Choose the most correct answer:

1. Which is the most appropriate immediate line of management for a patient with advanced incurable cancer of the lung presenting with breathlessness and panic?

a) Immediate endotracheal intubation and artificial ventilation

b) Palliative chemotherapy

e) Low dose oral morphine

d) Intravenous naloxone

e) Blood gas estimation

2. Sri a patient with carcinoma tongue has pain when chewing. This kind of pain is called :

a) Base line pain

b) Neuropathic pain

c) Incidental pain

d) Functional pain

e) Muscular pain

3. The term break through pain is appropriate to describe:

a) Pain in a person whose pain is controlled with medication some of the time.

b) Excruciating pain that the person finds difficult to live with.

b) Pain that makes the person suicidal.

c) Pain that lasts for several days once it has started.

d) Headache that makes the person feel that his head is about to burst.

4. In a 0-10 Numerical Rating Scale for assessing severity of pain, 10 is best described as:

a) Moderate to severe pain.

b) The worst pain that the person has experienced.

c) Worst possible pain that can be imagined.

d) Pain that is present throughout the day.

e) Pain that affects functionality.

5. In the WHO analgesic ladder, Tramadol is considered

a) Step I drug.

b) Step II drug.

c) Step III drug.

d) Adjuvant analgesic.

e) Combined step I and step II drug.

6. Which of the following statements is closest to the WHO's definition of health

a) Health is a state in which every citizen has access to medical attention within reasonable time and at affordable cost.

b) Health is a state of absence of any disease or infirmity that has the potential for significant impact on life.

c) Health is a state of adequate physical performance status which enables a person to live as a useful member of the society.

d) Health is not just absence of diseases, but a state of physical, social and mental well-being.

e) Health is a state of well-being which enables a person to be disease-free and to live in unison with nature.

7. Corticosteroids can improve breathlessness in advanced cancer by

a) Bronchodilator activity.

b) Reducing peri-tumour oedema.

b) Euphoric action which reduces panic.

c) Inducing sleep.

d) Anti-tumor activity.

8. Which among the following types is the best laxative to be given along with oral opioids?

a) Methyl cellulose

b) Ispagula husk

c) Diphenoxylate

d) Bisacodyl

d) Docusate sodium

9. Which among the following is the ideal antiemetic in a patient with hypercalcemia?

a) Haloperidol

b) Metoclopramide

c) Domperidone

d) Dexamethasone

e) Ondansetron

10. The most appropriate analgesic for a patient whose Serum creatinine is 4.0mg/dl is

a) Dose adjusted Morphine

b) Dose adjusted Diclofenac

c) Dose adjusted Ibuprofen

d) Dose adjusted Pethidine

e) Dose adjusted Aspirin

11. The following has significant anti NMDA (N-Methyl D-Aspartate) activity contributing to pain relief:

a) Ketamine

b) Nitrous oxide inhalation

c) Morphine

d) Intravenous lignocaine

e) Naloxone

12. The following is a common manifestation of oral morphine overdose which dictates reduction in dose.

a) Orofacial pruritus

b) Proximal myopathy

c) Extrapyramidal symptoms

d) Endogenous depression

e) Myoclonus

13. A patient is tormented with following thought, “I am a teetotaller, I do not smoke, I did not harm anyone knowingly. How could I get carcinoma stomach?” What dimension of pain does this reflect?

a) Physical pain

b) Social pain

c) Emotional pain

d) Spiritual pain

e) Functional pain

14. Which is NOT true regarding palliative care approach?
    a) Provides relief from pain and other distressing symptoms
    b) Affirms life and regards dying as a natural process
    c) Aims to prepone death
    d) Integrates the psychological and spiritual aspects of patient care
    e) Focus is on quality of life

15. Neighbourhood Network in Palliative Care [NNPC] is an example of :
    a) Hospital based palliative care services
    b) Day palliative care services
    c) Hospice based care services
    d) Community based palliative care services
    e) Out patient palliative care services

16. Which is <u>incorrect</u> regarding use of opioids in managing breathlessness?
    a) Safe in the treatment of intractable dyspnea in advanced stages of cancer.
    b) In opioid naïve patients, start Morphine 2.5 mg-5 mg QDS
    c) The doses required for breathlessness are higher than that required for pain relief.
    d) Reduces the tachypnea and makes breathing more efficient
    e)The antitussive action is helpful

17. For someone on 30 mg Sustained Release Morphine twice daily, the rescue dose of immediate release Morphine for break through pain is
    a) 5 mg
    b) 7.5 mg
    c) 10 mg
    d) 15mg
    e) 30 mg

18. Opioids induce constipation by all the following mechanisms EXCEPT
    a) Relaxing the circular smooth muscles of the large intestine
    b) Increased tone of anal sphincter
    c) Suppressing forward propulsive movement of colonic smooth muscles

d) Impaired defecation reflex.
e) Allowing greater transit time of faecal matter

19. Reduction of frequency of oral morphine dose may be needed in patients with
    a) Respiratory alkalosis
    b) Hepatic metastasis
    c) Lung metastasis
    d) Renal failure
    e) Past history of drug abuse.

20. The indications for morphine in advanced cancer include all EXCEPT
    a) Moderate to severe Nociceptive Pain
    b) Moderate to severe Neuropathic
    c) Dyspnoea
    d) Diarrhoea
    e) Sedation

21. All the following are morphine non-responsive pain EXCEPT
    a) Tension head ache
    b) Gastric malignancy
    c) Biliary colic
    d) Muscle spasm(cramp)
    e) Intestinal spasmodic pain

22. A patient getting oral morphine 4th hourly has satisfactory relief but complains of pain half hour before the next dose. The next logical step is to
    a) Increase the frequency of morphine
    b) Increase the dose
    c) Add a sedative
    d) Add an adjuvant drug
    e) Assess for addiction potential

23. When oral morphine is to be converted to continuous subcutaneous infusion, the total daily dose should be
    a) Halved

b) Quartered
c) Maintained same
d) Doubled
e) Trebled

24. Indications for converting oral to parenteral Morphine are all EXCEPT
    a) Nausea and vomiting
    b) Urgent pain relief
    c) Inability to swallow
    d) Renal dysfunction
    e) Terminal stages of disease

25. Which of the following is a definite side effect of appropriate titrated oral morphine therapy?
    a) Respiratory depression
    b) Constipation
    c) severe drowziness
    d) Delirium
    e) Myoclonus

True or False questions

Write T if the statement is True and F if the state is false

1. Pain is not just a sensation but an emotional experience
2. Pain and suffering are synonymous
3. Autonomic responses are more dominant in chronic pain
4. Chronic pain is a temporal extension of acute pain.
5. Pain caused by a stimulus that does not normally provoke pain is Allodynia
6. An intervention for pain that is appropriate at an early stage of the disease may not be appropriate in the same patient at a later stage.
7. 'Curing' or 'not curing' is the sole responsibility of medical professionals.
8. Living Will is an important document that states patient's preferences in end of life care.
9. In Palliative Care setting, prognostication includes would be predicting impending death.
10. Medical professionals should focus more on the overall benefit to a patient and not get carried away by focussing on responses on an investigational parameter.
11. Symptoms are inherently subjective and hence self-report must be the primary source of information.
12. Panic is often an accompaniment of breathlessness and can worsen breathlessness.
13. Biochemical and blood gas investigations are the most useful parameters in assessing chronic breathlessness due to advanced cancer.
14. Impacted faecal matter can lead to overflow diarrhoea
15. Diagnosing presence of delirium requires specific laboratory investigations

Answer Key

Answers to Multiple Choice Questions:	Answers to True / False Questions:
1. c 2. c 3. a 4. c 5. b 6. d 7. b 8. d 9. a 10. a 11. a 12. e 13.d 14.c 15.d 16.c 17.c 18.a 19.d 20.e 21.b 22.b 23. a 24.d 25.b	1. T 2. F 3. F 4. F 5. T 6. T 7. F 8. T 9. T 10. T 11. T 12. T 13. F 14. T 15. F