

An Indian Primer of Palliative Care

For Medical students and doctors



Editors:

M.R. Rajagopal

Vallath Nandini, Lulu Mathews

Rajashree K.C, Max Watson

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Preface

Are you a medical student or a doctor?

Your various experiences in the hospital must have made you cognizant of the fact that only a minority of your patients are cured. Over time, you may have heard your seniors saying, “There is nothing more we can do.” You may have learned to live with the knowledge that medical science has a minimal chance of success.

It does not have to be this way. The art and science of palliative medicine can equip you to “heal” and improve quality of life, even when cure is not possible. The western world has embraced palliative medicine as a part of medical practice. The World Health Assembly, in 2014, passed a resolution asking all countries to integrate palliative care into health care “at all levels.” But by and large, most of the developing world, including India, has little access to palliative care. This is sad because the developing world, in which delayed diagnosis and inadequate health care cause more incurability and suffering, needs palliative care even more than the west.

It is all about the right combination of science with compassion. There is no situation when “nothing more can be done.” When we learn to treat pain and symptoms and to offer psycho-socio-spiritual support, and when we learn to work as a team with fellow professionals and volunteers, we gain strength to relieve much of the suffering that we turn away from today, and to walk with the patient and family in their struggles. Then frustration begins to give way to satisfaction from our work. And we get closer to being the healer—and not just a medical technologist - that a doctor can be.

A team of experts from India and abroad, many of them spending their own money and time, got together to create this book. Let us thank them.

Best wishes to you for enjoyment in the practice of our profession.

PRINCIPLES OF PALLIATIVE CARE



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 his condition is irreversible. He was also told, “Nothing can be done; there is no use of coming back to the hospital again.” He has been bedridden since then and 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 very 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 the 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 is 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 equipment, there are patients who cannot be totally cured. Aren't these patients also the responsibility of the health care system? 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: Health has physical, emotional, social and spiritual dimensions. The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

Modern medicine has been competent in handling acute medical problems through analytical research and intense study of etiological and therapeutic factors. It includes prevention through public health measures, immunisation programs and health education.

Presently most of our health services are disease-centred, specifically designed for acute episodic treatment with curative intent.

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

Can you list the diseases that we see commonly, for which we can achieve 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 whether cure is possible or not.

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

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 currently building on these ancient traditions as well as the expertise and wisdom of pioneers in this field to develop palliative care services.

¹ Forman, W. B. (ed.) Historical development of Hospice and Palliative Care; In Hospice and Palliative Care: Concepts



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 a thrice-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 hospice/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 some one should care enough to try.

Dam 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.

Clarification of terms:

Life-limiting illnesses: This term describes illnesses where many 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: Hospice care refers to a philosophy of care of the whole person and all that matters to her/him. The word "hospice" may be used to denote a place where such care is provided. The terms hospice care and palliative care are often used synonymously; but in some countries like USA, the word hospice care is used only in the context of terminal care.

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

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

treatment, cure, death and bereavement. In other words, palliative care goes hand in hand with disease-specific treatment.

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 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 includes terminal care. 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. It is also called ‘end of life care’.

Continuum of care: An integrated system of care should guide and support patients with chronic illnesses through a comprehensive array of health services. This includes out-patient care (assessment, evaluation, management), education of patient and family, linking with community based care facilities (GPs, home based care programs, link centres) and also acute episodic needs and care during advanced stages of the disease (in-patient services).

Caregivers: Caregivers are relatives or friends, who take care of the patient. The term may also refer to any paramedical professional who may be 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 and volunteers have significant roles to play along with doctors and nurses. This approach aims at the best possible outcome based on physical and psychosocial needs of a patient and family. As the 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 meaning or 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?” “I am of no use to anyone. What is the point of me being alive?”

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

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.

Dying with dignity: A terminally ill person should be allowed to have peaceful, natural and comfortable death rather than 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:

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

- 1 Define Palliative care.
- 2 Outline the essential principles of palliative care.
- 3 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 with life-threatening illness and their families through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

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 a hospital, as an outpatient, or 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 organs and their diseases. Palliative care recognizes that people are much more than organs put together; their mind, spirit and emotions are all part of who they are. It also recognizes the patient's families and communities. So the problems faced by a sick person and his/her family are not just confined to the disease; there may be pain and other symptoms in conjunction with psychological, social and spiritual concerns. Sometimes problems in one area may worsen others e.g. pain is often worse when people are anxious or depressed. When we address all these areas, we are helping the whole person. It is this holistic approach that distinguishes palliative care from the conventional medical care.

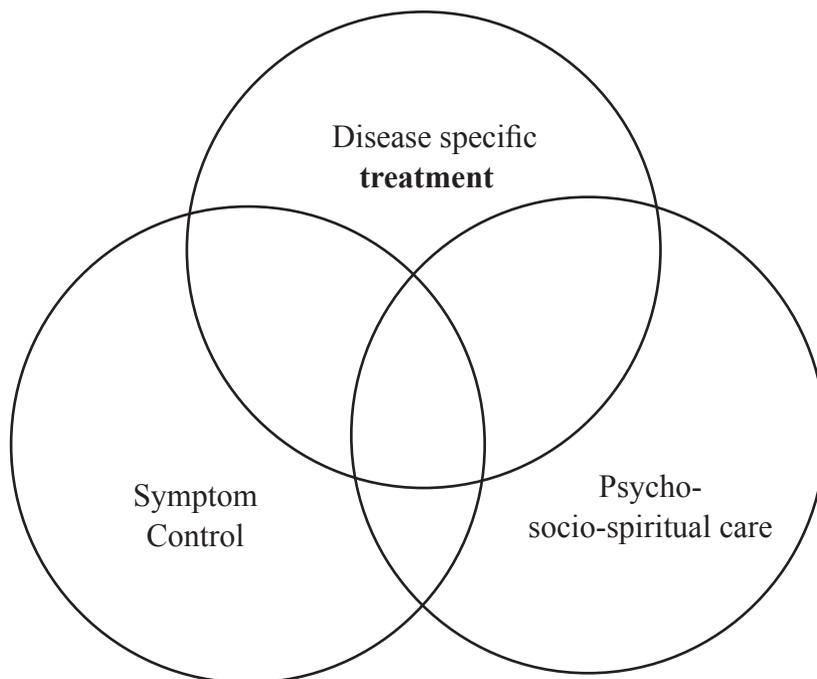


Fig 1.2 – Components of Palliative Care

No single sphere of care is adequate without considering its 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
<p>Disease is the central concern</p> <ul style="list-style-type: none"> ▪ 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. 	<p>Patient is sovereign</p> <ul style="list-style-type: none"> ▪ Intent – healing ▪ Disease an experience to be lived ▪ “Don’t just do something... be there.” ▪ Goal is also to ensure life and death with dignity ▪ Death: An inevitable reality, neither to be hastened nor postponed at the cost of quality of life ▪ Valuable approach in caring for chronic progressive disease.

Palliative care is about the quality of life of the person with a life-limiting disease and of his family

Palliative care is not primarily aimed at length of life, but at *improving quality of life* so that the time remaining, be it days, 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. Let us begin by focusing on what we can do to care, *rather than be discouraged by what we cannot cure.*

***There is no situation where nothing can be done.
There may be a limit to cure, but no limit to care.***



We should try to understand the chief concerns of patients suffering from life limiting illnesses and use our knowledge and caring approach to seek ways of helping them. These are perhaps the greatest healing inputs we can give especially 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 to their days, not just days to their life.”

Nairobi Hospice 1988

Test your knowledge

1. *What is the chief aim of Palliative Care?*

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

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 reader should be able to:

Explain the need of palliative care in regular clinical practice.

The need for palliative care worldwide³

There is a shift in global burden of disease towards non-communicable disease. Although the mortality has come down with average life expectancy in India of 66.21 years (*68.2 years for men and 73.2 years for women – 2012*) 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; about five million of which die of cancer. The rest die of chronic progressive diseases. Many of them die with needless suffering, which has been well documented in many studies and published in scientific journals.*
- *Palliative care can improve the quality of life of all these patients.*

Human Rights Watch points out that denial of access to palliative care is a violation of human right and recommends integration of meaningful palliative care strategies into national programs for chronic diseases⁵.

The five modules on Palliative Care-the principles, communication skills, management of pain, assessment and management of symptoms and optimisation of care, discuss the general approach in managing patients in life limiting disease states, and help orient the reader in managing the complex concerns of these patients and of their families.

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

⁵ Human Right Watch. Unbearable Pain: India's Obligation to Ensure Palliative Care. Available at [http://www. hrw. org/reports/2009/10/28/unbearable-pain-0](http://www.hrw.org/reports/2009/10/28/unbearable-pain-0)

PALLIATIVE CARE NEED IN INDIA⁶

These figures have been quoted to emphasise the enormity of the problem and the likelihood of facing this need in our clinical practice, regardless of our clinical specialty. Specialised knowledge and skill is needed to take care of a person with a progressive illness.

- 1. About 2.5 million live with cancer in India; more than 80% of them are incurable at diagnosis.*
- 2. Approximately 2.5 million live with HIV in India.*
- 3. Combined with other diseases, at least 5.5 million need palliative care in India.*
- 4. Less than 1% has access to Palliative Care.*

Test your knowledge:

Choose the correct answer from following options:

Why should palliative care be included in the undergraduate medical curriculum?

- So that basic principles of palliative care may be utilised by all professionals for patient care.
- To make appropriate referrals to specialists in the field.
- To reorient the attitude of health care professionals in the management of chronic diseases.
- To provide a platform for decision-making when there is dilemma regarding quality and quantity of life.
- All of the above

Ans: All of the above

⁶ WHO. The Global Burden of Disease. Available at http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf

WHO NEEDS PALLIATIVE CARE?

In the following situations, choose those conditions where palliative care may be needed:

Adult with cancer



Child with Retino-blastoma



Adult with Chronic Renal Failure



Diabetic foot ulcer



Debility/dementia



Paraplegia

Learning Objectives

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

- Identify the person in need of palliative care.
- List the key misconceptions that are prevalent with regard to who may be suitable for receiving palliative care.

You may note from the earlier discussions that all these patients would benefit from palliative care.

Today, there is some recognition in India that patients with cancer need palliative care. 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 and paralysis
- Progressive systemic diseases
 - COPD, ILD
 - Heart diseases
 - Liver and kidney dysfunctions due to various causes
- Debility of 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, family members are usually 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.

CANCER

India has 2.5 million people with cancer at any given time. There are one million 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 oncology interventions. Due to all these reasons, palliative care is ideally required to be incorporated into comprehensive cancer care programs.

HIV-AIDS

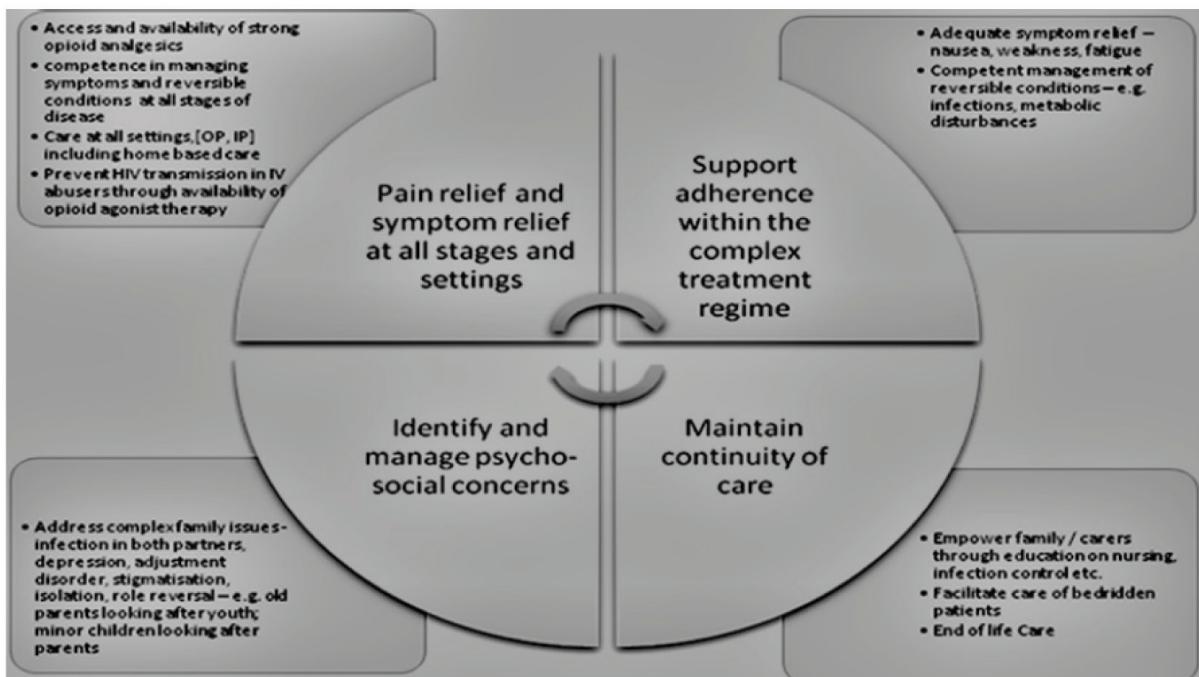
HIV/AIDS is now a chronic disease. Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS, because of the burden of distressing symptoms they may experience—pain, diarrhoea, cough, shortness of breath, nausea, weakness, fatigue, fever, and confusion. 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: Interface of Palliative Care and HIV Care



Dementia

Dementia is the 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 palliative care (PC). Here, the palliative care needs of the carers could be more than those of the patient.

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 include stroke, paralysis, motor neurone disease and others.

Advanced non-communicable diseases (NCD)

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

Major psychiatric illness

Any other situation where there is significant health-related suffering including old age.

*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 the 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 reader should be able to:

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

Simultaneous therapy⁷

Palliative care works alongside and within other treatment regimen. 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 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 treatment itself.

Palliative care, when integrated into such programs, can provide comprehensive care 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.

⁷ 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.

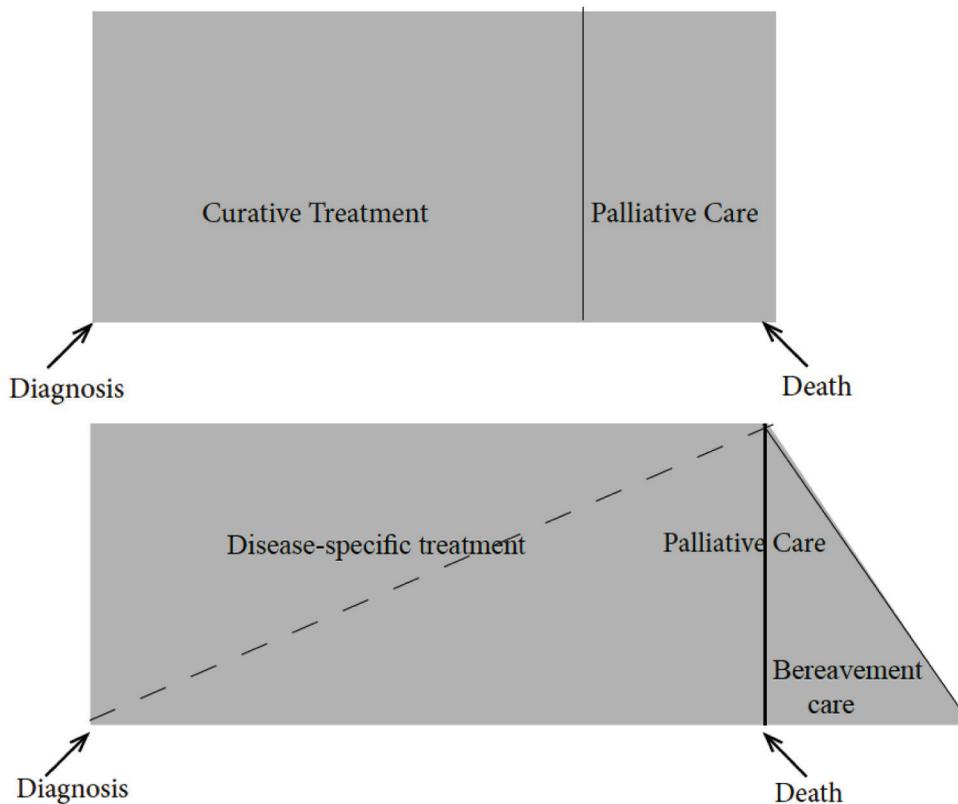


Fig 1.4: Relevance of palliative care during the course of a chronic disease⁸

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 communication here. 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 the patient and family for rational decision making. It is important to communicate effectively with patient and family, provide symptom control and maximize support to help complete a curative therapy.

⁸ The Scottish Government. Living and Dying Well: A national action plan for palliative and end of life care in Scotland. Available at <http://www.gov.scot/Publications/2008/10/01091608/2>

Post-cure phase

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

At recurrence or when cancer becomes unresponsive to disease-modifying therapies

Here the symptoms and psychosocial 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. Some people go into pathological grief and may need psychiatric treatment. Supporting them through this process is an important and essential part of palliative 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
 - 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 is called

Ans: 1 – c; 2 – F; 3 - bereavement

WHERE CAN PALLIATIVE CARE BE GIVEN?

Learning Objectives

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

1. Acquire the knowledge to provide palliative care in various health care settings.
2. Describe the importance of community in delivering palliative care.

Models of palliative care provision:

Whenever possible, the service should facilitate the patient's stay and care in the home setting. The following are ways in which care can be delivered.

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 visits.

Hospital-based inpatient service

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 inpatient 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 for patients living at home but brought in on a day-to-day basis for clinical and social care. These are community-based service centres run by non-governmental organizations.

Home visit for palliative care:

There is a continued need for the care of home-bound patients. This intervention meets the needs of patients to be at home, amongst their family and friends, during a time in life when they are most vulnerable. This intervention is 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. This model is being effectively practiced in Kerala through the Neighbourhood Network in Palliative Care [NNPC]¹⁰. The training of volunteers can positively influence the overall response of the community to the health care needs and related policies.

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.



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.

Models of Care

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

¹⁰ Public Health and Palliative care. Public Health Approach In Palliative Care – The Evolving Kerala Model. Available at http://www.publichealthpalliativecare.org/_literature_120214/The_Evolving_Kerala_Model
Kumar S, Numpeli M. Neighborhood network in palliative care. Indian J Palliat Care 2005;11:6-9

Test your knowledge

Choose the correct answer from following:

1. Which of the following healthcare settings can provide palliative care services?
 - a. Tertiary care hospital
 - b. Primary health care centre
 - c. Hospice
 - d. Home based care programs
 - e. All of the above

2. The chief benefit of home based palliative care services is
 - a. Doctor's precious time within the hospitals does not get wasted.
 - b. All modern facilities of advanced medical care can reach the patient at home.
 - c. Terminal patients do not need any more diagnostic investigations, treatments or hospital admissions.
 - 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 the patient attain complete physical fitness
 - b. To make the patient fit enough to attend hospital services
 - c. To help the patient maximize opportunity, control, independence and dignity
 - d. To help him/her achieve the functional capacity as it was prior to diagnosis

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 since 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 for him, conveying our empathy and willingness to listen and care for him throughout his illness.

Holistic Approach

Through effective communication, 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, through appropriate education on back care and bed-making. It can be allowed to heal by the use of good wound care, which would also eliminate the foul smell. Since he already has an air-bed, we can teach the family how to use it appropriately and how to maintain it.



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. 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.

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 example, 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 his newly found self-confidence, we can expect Ravi to get back to social 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 a vital basic need and apt communication is no less than an art.”

Scenario I:

Smt. Sudha, a patient with acute exacerbation of bronchial asthma, is brought to OPD 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.”

Physician: “Don’t worry!”

Smt. Sudha: “But I feel anxious; I stay 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 OPD 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.”

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 from the days when we or one of our loved ones were 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 with gratitude, those professionals and interactions that brought 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 well-being of the patient and the family and for the professionals' satisfaction from work. Research in communication between the physician and the patient has consistently shown that there is room for improvement in the way physicians interact with their patients. Studies indicate that 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. Identify the barriers to effective communication.
3. Recognize the do's and don'ts 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 express his needs to the treating team more effectively. 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 to deal with uncertainty.

Good communication enables the physician to better understand the symptoms, their trajectories and their impact on the patient's quality of life and brings clarity to the clinical condition. It can help us better understand the patient's thought process and the meaning that the patient attaches to his or her situation. Through good communication, the physician can convey the required information about the disease or plan of care to the patient in a manner which helps him/her feel supported.

Effective communication helps build trust which will sustain a long term clinical relationship. This encourages rational and shared decisions about treatment. The patient is then more likely to complete the prescribed therapeutic plan and to adopt health promoting behaviours. The physician can allow a shared and balanced decision to evolve, *based on patient's values, beliefs and priorities, yet supported by clinical evidence and rationale.*

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



Common areas where communication skills become essential

- a. Responding with empathy to patients
- b. Recognizing and responding to cues from patient for information and emotional support
- c. Understanding the patient's priorities
- d. Encouraging the patient to ask questions
- e. Providing information in a supportive manner
- f. Shared decision-making
- g. Delivering prognostic information
- h. Communicating bad news
- i. Checking patient's understanding
- j. Discussing transitions in goals of care from curative to palliative
- k. Handling collusion

What if we fail to communicate adequately?

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

What are communication skills?

Communication includes acknowledging and understanding the concerns of the patient and family, and responding in the most appropriate manner to bring clarity to 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, 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. In particular, care is 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 necessarily adequate communication. A good conversation on general topics such as travel, politics or weather is NOT adequate communication.
2. Trying to convince the patient to follow the agenda decided unilaterally by the clinical team is NOT good communication.
3. Conversing in a soothing and gently manner, without allowing for their participation, is NOT good communication.

Barriers to effective communication



Fig 2.1: Concentrating only on physical tasks can be a barrier for communication.

Possible barriers that may hinder the professionals:

- Too busy to spend time to understand thoughts and feelings of patient
- Worried about upsetting the patient and handling reactions
- Not having the knowledge and the skill
- Uncomfortable to enter into unpracticed area of interaction
- Unable to say - “I do not know!”
- Concentrating on physical concerns, which are easier for the doctor
- Not perceiving communication as **part of their job**
- Worried about being blamed or fear of worsening the situation
- Unfamiliar with language and dialect can be a barrier.

Possible barriers that patients may face:

- The physician perceived as too busy
- Lack of privacy and unfamiliarity of the surroundings
- Perception that only physical problems are to be conveyed
- Fear of confirmation of bad news
- Fear of treatment being denied if they raise questions / doubts
- Fear of losing control over emotions
- Stumped by the medical jargon and technical terms
- Authoritative hierarchy of the hospital environment

Complexity of Communication Process

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

The listener hears the words and perceives the non-verbal cues as well → these are processed based on the 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.

The physician should observe and process the patient’s non-verbal and verbal behaviour. This process allows the physician to acknowledge any unstated or unexpressed needs and agendas that the patient may have.’

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

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

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

Non-verbal Communication

We all know that communication occurs verbally and non-verbally. But we are unaware that non-verbal communication accounts for the bulk of our daily communication process. It can be the sole means of communication in young children and in people who are terminally ill, differently-abled, or emotionally overwhelmed.



Fig 2.2: Non-verbal communication can convey loud messages.

Frequently used strategies for effective clinical consultation:

Beginning the consultation

After the greetings and introductions, begin with open-ended questions (those that cannot be answered with Yes or No) 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. Beginning with open-ended questions allows the consultation to be based on the patient’s agenda and can then proceed with information sharing and setting priorities.

In case of an important perceived need, the 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’s 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 the discussion so as to reinforce joint decision-making e.g. “I just want to go over what we’ve been talking about. This will ensure 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 the next time we meet on ...”

Response strategies

Responding to information cues

This can begin with clarification on the patient’s statement that gave you the cue (“I don’t know much about the different treatments”). Once we check with the patient and confirm the need for information, we may provide a preview of options and proceed with empathy based on patient’s 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 diseases.

It is important to avoid overload of information and medical jargon. The patient should be encouraged to ask questions, and an attempt should be made to address each of them. Here again, checking the patient’s understanding is an important aspect of effective communication.

Summarizing statements like, “So, in a nutshell, we will start this medication today and then, after 3 weeks of physiotherapy, we shall review how you feel,” are useful to convey that we have listened and understood their concerns, and this helps in building trust.

Responding to emotional cues

Acknowledge and validate the emotion that came across (“At times, I just can’t think clearly; I wonder why.”). 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 with.”

It is useful to state it as normal under the circumstances and acknowledge the patient’s efforts in coping with the situation. e.g. “It not uncommon to feel this way, under the circumstances,” or “It is natural to feel tired and unable to focus on work. It would be very reasonable to take a holiday after this cycle of chemotherapy.”

Silences

It is very important to permit intervals of silence during 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 silence 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 is 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, and may block further communication.

Responding to patient barriers

Periodic summarising helps to organise thoughts and to prepare for further discussion. 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 emphasis on shared decision-making. 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.”

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 question and allows the patient to talk about what is the most important issue for her / him
Be empathetic e.g. Patient: 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 to stay 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 old. I have not disclosed this to anyone.	Dr: Were you not married then? This question cannot help in any way and may reinforce guilt.	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: If you were not able to take the medicine as advised, there must be a reason. Would you like to talk about it? Did you have any trouble when you started the tablets? Do you have any questions or clarifications before using them?

Now, let us review 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 to help her sleep. He has not explored the reasons behind her apprehension.

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

Is she worried about how long her illness will continue?

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

Eliciting and addressing these are the most important aspects of treating her insomnia. Prescribing anxiolytics without exploring her concerns will limit self-expression and will definitely 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 intention. But Gopal has his own genuine reasons to refuse. Here the physician could have spent little more time with Gopal, given him proton pump inhibitors, antibiotics for H. Pylori and maybe a prokinetic for two weeks and reviewed the situation after 2 weeks. 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 needs skills and practice. Patients with advanced and progressive diseases have issues other than physical ones and they require compassionate listening and empathetic responses.



25-year-old Ms. Gita has come to meet the doctor. She has been diagnosed with 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 to her little niece, one of her favourite pastimes.

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 Ms. Gita’s request?

“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 mantra 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!”

- f. “It is a squamous cell carcinoma. It is quite radiosensitive. You have a good chance of remission.”
- g. “Oh, so you are waiting for your final visa?! Ha, ha. But we can get your passport renewed!”

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

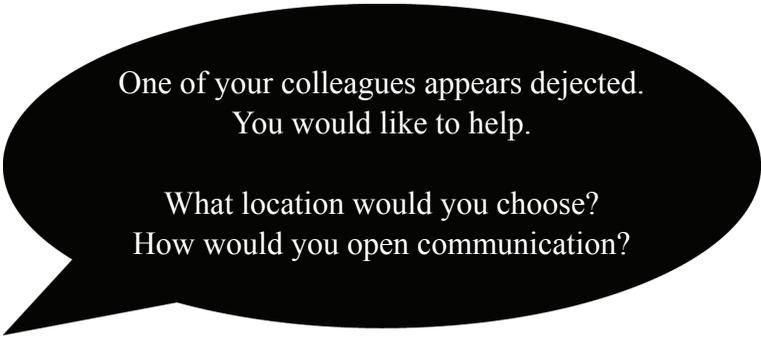
If not, why?

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

What is not recommended during clinical communication?

- 1 Do not immediately reply to the patient’s words. It is useful to inquire into feelings or real questions behind patient’s spoken words.
 - e.g. To Gita’s request; 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 could be, “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.” Such statements may hurt the patient’s feelings and may act as 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 (disenfranchised grief). And this too is a conversation stopper. Instead we should listen to the person and allow venting of feelings. Eventually if the person herself comes to feel, “After all, my troubles are less than that person over there,” that may give her some comfort.
- 4 Avoid meaningless words like, “There is nothing to be afraid of.” They prevent further communication.
- 5 Avoid medical words (jargon). Technical language tends to overwhelm patients and prevents them from asking questions.
- 6 Avoid false reassurance. e.g. “When your general health improves, we shall try more chemotherapy. That will cure you.” Any reassurance provided by this is short-lived and then it destroys trust. Reassurance is essential to maintain hope after but it must be based on truth. For example, “Even though this disease is incurable, we can help you to live as comfortably as possible. I think you may yet be able to get back to work at the office.”

- 7 Do not make assumptions. Check the patient's insight into 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 mantra regularly for strength to endure this" is imposing your own beliefs on the patient. The person is unlikely to question you, but may not bring her problems to you any more.
- 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. 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 and can be hurtful.
- 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."



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

What location would you choose?
How would you open communication?

Steps for effective communication

1. Build a relationship
2. Open the discussion
3. Gather information
4. Understand the patient's perspective
5. Share information
6. Arrive at 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 the need arises.
- Convey empathy with your expression and with a statement such as, "I see that you are very worried." The important thing is to convey that you care.

2. Open the discussion

- Acknowledge feelings like pain or loss. In the case of Gita, it would be appropriate to say, "It looks like life is a burden for you right now." Acknowledgement of suffering makes the patient feel that she is understood.
- Listen actively. Active listening involves eye contact, appropriate facial expression (empathy), body language (leaning forward) and verbal responses like "Yes, I see...," "and?," "hmmm," "oh..." etc. It also involves encouraging the patient by repeating her last few words and paraphrasing.
- Listen to what is said, but also to what is not said, specifically facial expression and body language, which might indicate suffering.

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 such as:

- “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 an emotional reaction (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 a 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.
 - 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 negotiable.
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 that she is not alone. We may have found some way of encouraging communication between her and the 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 (relief from pain and other symptoms, regular sleep, improved functionality and of course Gita spending quality time with her dear niece) might have become 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 (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 reassure the patient that he/she will not be abandoned.

Elisabeth 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 while, a patient may continue in denial. For some time, it is a good coping strategy. When the person is unable to deny any more, there may be a higher emotional impact to the bad news.
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, such as 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 grieving people 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 of unhelpful communication styles:

1. Hit and run approach

Doctor: “You have stomach cancer. We must start treatment by Monday.”

The patient may feel shattered.

2. Straight answer to straight questions

Patient: “How much more time do I have?”

Doctor: “Cannot say precisely. But we have seen people living up to one year!”

The patient may feel worried and depressed.

3. Talking only to the relative

Patient: “Doctor, please tell me about my condition!”

Doctor: “Don’t worry, I have explained everything to your son. He will tell you.”

The patient may feel suspicious and worried.

4. Blunt and 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.”

The patient may feel upset, lonely and abandoned.

5. Destroying hope

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!”

The patient may feel hopeless.

6. Sad, feeling inadequate and protective about self

Doctor feels very upset and unprepared to speak to the mother of an ill child who will die. Here, the doctor may avoid or postpone speaking, or give the responsibility to someone else.

The patient and mother may feel alone and desperate.

Some examples of helpful communication styles:

Sharing sadness, yet conveying truth and offering realistic hope:

Doctor: “I wish I had better news to tell you. It is sad that your child has limited time left. But we will do our best to keep him as comfortable as possible. We will be here for 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 (pauses, waits for response and cues to continue). We are unable to offer cure. (pauses). 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 usually well-intentioned, acting in what is believed to be the best interests of the patient, to protect the patient from emotional harm. However, this usually creates tension when the patient wants to know the truth and has the right to information.

Collusion must be 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 trying to “convert” the relative. The approach should be, “You want the best for your mother. 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 their 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.
 - Identify whether they have a correct understanding of the clinical situation.
3. Reassure and explain.
 - Reassure that you will not walk in and impose information.
 - Find out if the family has already felt the adverse effects of the withholding of information from the patient. Has he been anxious? Has he been in the “bargaining” phase making unrealistic demands about treatment?
 - Explore how much 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 to find out what the patient already knows.
4. Share information as it becomes necessary.
 - Explore the patient’s understanding, and assess their wishes for further information.

- Inform the family members about the patient's wishes.
- Share information in digestible chunks; avoid information-overload.
- Inform the family members what has been discussed with the patient.
- Encourage open communication between the family and patient.
- If the 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 fear. It may also be a negative result of an ineffective communication between health care professionals and the patient/carers/family members.

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

Anger is often the source of medico–legal suits. A direct simple and empathetic approach helps. Have the person sit down. Acknowledge and name the emotion. Then address the need of the patient or family to be understood.

For example, “I can see that you are angry. Can we sit down and talk? Tell me what you thought went wrong. I shall try my best to help.” Remember:

- The patient may direct anger at you whether or not you are the source of distress. Try to understand that the anger is directed at the situation, and not personally at you.
- Be calm, empathetic and use positive non-verbal signals throughout the conversation.
- Give the patient time to express himself; do not jump in with explanations prematurely.
- Allow the patient to express his emotions and 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 needs 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 behavior 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 accept the bad news. It is avoiding thoughts and feelings that are painful or difficult. It occurs to some degree in everyone who has a serious illness, though usually only briefly. It is a shock absorber that helps one 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, even when they have been proven futile or ineffective

Denial appears to be a common defence mechanism in the 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, whereas in others, it results in excessive delay in seeking help and poor compliance to treatment.

The following questions can help gain an understanding about the degree of denial.

- What do you think about your illness?
- What is your understanding about the seriousness of your illness?
- What are your future plans?
- Do you have another plan (Plan B) if your current plan does not work?

Assessment of denial

- A cognitive evaluation is essential to rule out the possibilities of any psychiatric disorders.
- Check patient's insight—establish what he knows. This should include his understanding of the diagnosis, prognosis and the chances of success with the current treatment regime.
- Listen to the words used and observe for non-verbal signs. This might tell you how much the patient knows and 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. treatment not done because of denial).
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 concerns.
6. Adopt a non-confrontational approach. If denial is causing significant problems, direct confrontation may only reinforce the state of denial.
7. Last but not least, emphasise to patients that they will not be abandoned. They will be supported no matter which treatment plan is selected.

Conclusion

The physician should be the centre of clarity to allow shared and balanced decision-making to evolve, based on patient's values, beliefs and priorities along with clinical evidence.

Good clinical communication will help the patient understand his perceptions better, remove baseless apprehensions, find support to handle the emotional aspect of illness, deal with uncertainty and build trust that will sustain a long term clinical relationship. This encourages rational, shared decisions about treatment. The patient is more likely to complete the 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 and readiness to support the patient, irrespective of time. Most patients do not fall in the advanced disease category and do not require a great deal of time to complete the clinical interactions. The important starting point for the treating unit is acknowledging the fundamental role of communications on therapeutic outcomes. We should create systems to assure the regular practice of good communication through modifications in our documentation and in involving appropriately trained team members for this important task. The multidisciplinary team approach is 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 questions

1. What is necessary in effective communication?
 - a. Active listening
 - b. Giving medical advice
 - c. Normalizing
 - d. Reassuring
2. Which is the most appropriate way to overcome denial?
 - a. Be short and precise
 - b. Involve colleagues as testimonial

- c. Non-confrontational approach
 - d. Rational and assertive explanation
3. True or false questions
- a. Collusion makes the work for doctors easy.
 - b. Sensitive truth telling is harmful for the patients.
 - c. Doctors can show emotions even at the clinic; it is helpful for patients.
 - d. Medical students need to be trained in good communication skills.

Ans: 1 – a; 2 – c;

True/False: 3a – F; 3b – F; 3c – T; 3d - 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
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3. ASSESSMENT AND MANAGEMENT OF PAIN

Pain is what the patient says hurts



Chennayya, a 50 year-old man, was diagnosed with cancer of the buccal mucosa. He attended a busy outpatient clinic with persistent pain over the jaw. It has become more severe in the last 2 weeks. He has not had any relief with the medications prescribed by his primary care 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 is now unable to work due to illness.

**What is the impact of severe persistent pain on Chennaya's life?
How will you approach the total pain reflected in his eyes?**

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

1. Differentiate between acute and chronic/persistent pain.
2. Assess chronic/persistent pain.
3. Recognize pain relief as an important aspect of quality of care.
4. Describe pathophysiology and impact of persistent pain.
5. Describe the 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.

International Association for Study of Pain (IASP)

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

**Pain is what the patient says hurts; when he or she says it does;
Believe the patient regarding his or her pain.**

Free nerve endings of A δ 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.

**Pain is not just a sensation or information appraisal;
it is 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 disease and the pain. This is the psychological aspect of his pain. Each worsens the other. The net result is his "pain experience."

Until recently he was the breadwinner of the house, caring for his family. Now, he is no longer contributes economically to his family. He is dependent and feels desolate. Moreover since there is a foul smell emanating from his wound, he shuns company and friends, and does not leave the house. He feels isolated. This is the social component of pain.

He is only 50 years old. 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 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.

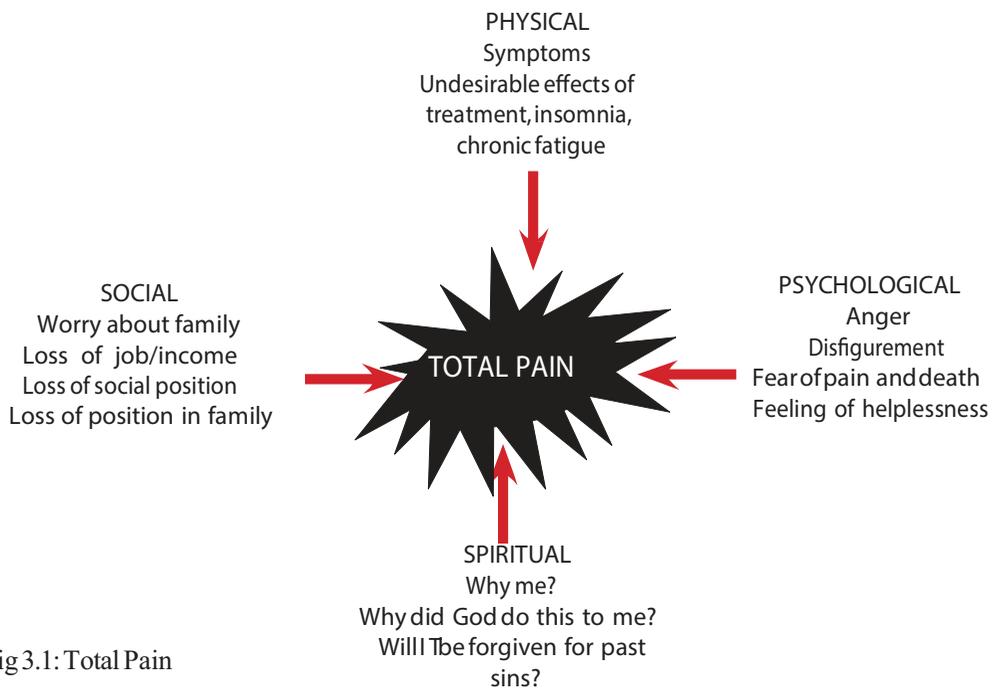


Fig 3.1: Total Pain



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?

Total pain is “the suffering that encompasses all of a person’s physical, psychological, social, spiritual and practical struggles.”

Let us consider Chennayya's pain history:

Is his pain acute or chronic?

What is the severity of pain?

Acute pain	Chronic pain
Indicates potential or actual tissue injury	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
Plays a protective role	Chronic pain takes on characteristics of a disease

Chennayya had pain for two years, which had led to diagnosis of the carcinoma of buccal mucosa. His pain is persistent and should be acknowledged as such. Often we disregard chronic or persistent pain as mild, since the patient does not fit with the image that we have of a person in pain (crying or shouting in pain).

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. Persistent pain is more than 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 central nervous system. The emotional consequences are also worse in long-standing pain.

What is the pathophysiology of chronic or persistent pain?

- Pain receptors do not adapt over time. They continue to sense noxious stimuli.
- With persistent pain:
 - There is further sensitisation of active nociceptors. Neurochemicals such as prostaglandins, potassium, and bradykinin accumulate and sensitise the nociceptors so that successive stimuli cause progressively increasing nociception.
 - Silent (sleepy) nociceptors are recruited, which increases the intensity of pain.
 - The intensity is also amplified by sensitisation of dorsal horn cells-the "wind-up" phenomenon via N-methyl-D aspartate (NMDA) receptors.
 - Gradually the adjacent spinal segments are also recruited into the firing of signals and this widens the painful area.

- Persistent reflex muscular response to pain causes areas of sustained muscular contraction (myofascial trigger points), which may cause additional pain.
- Reflex vasoconstriction in the area of pain can worsen ischaemic pain.
- The inhibitory descending inputs from brainstem get over-whelmed and become ineffective over time.

End result: Worsening of pain in intensity, severity and extent with time.

In a patient with cancer or other major diagnosis, cancer may not be the only cause for pain. Chronic pain may have several contributors. Let us consider another clinical scenario to understand this:

Ramani is a 35 year old woman with HIV with painful lesions in the face and neck. 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 and is found to have candidiasis. This pain is a result of her debility and poor immunity. A new pain may develop at anytime if she develops infection or ulcerations at any site. This would be pain due to co-morbidity.

Table 3.1 – In chronic disease, not all pain is related to the disease.

Disease related	Treatment related	Debility related	Co-morbidity
Soft tissue infiltration	Surgery	Constipation	Spondylitis
Visceral/nerve compression	Post operative care	Deep vein thrombosis	Migraine
Nerve infiltration	Scars	Pressure sores	Arthritis
Spread to bone	Adhesions	Catheter sepsis	Infections
Muscle spasm	Radiotherapy dermatitis	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. Breakthrough pain- often high intensity. It comes on predictably with weight bearing, movement, or change of dressing; OR it occurs spontaneously without warning such as

colic, or shooting pain. The breakthrough pain lasts between few seconds to 30 minutes.

3. Incidental pain -associated with precipitating factor such as movement.
4. “End of dose” pain-occurs prior to the next scheduled dose and is gradual in onset and lasts until the pain medicine is dosed again.

What is the pathological type of Chennaiya’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.

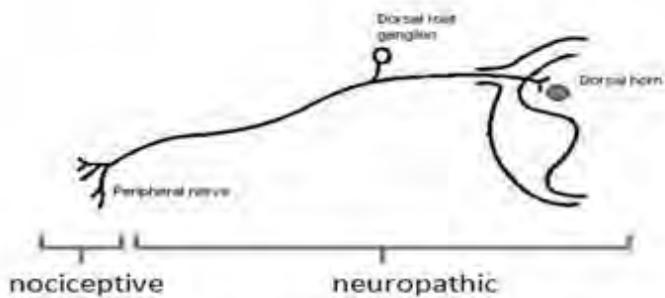


Fig 3.2 - Diagrammatic representation of types of pain

Table 3.2 - Features of Nociceptive and neuropathic pain

Features	Nociceptive pain	Neuropathic pain
Cause	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	None	Allodynia, hyperalgesia

Now what is your assessment of Chennaiya’s pain?

Chennaiya has persistent pain over the jaw, which is gripping in character and is almost always present. Apart from that, he also has transient intermittent shooting pain radiating down from the jaw up to the ear. He has a burning sensation in the lower part of his jaw. He describes the persistent pain as having a score of 6/10 in intensity and the shooting pain as 10/10, very severe, spontaneous and unpredictable.

Thus he has both types of pain:

- nociceptive pain, the background continuous pain.

- intermittent neuropathic pain with a shooting and burning component.
- breakthrough/ incident pain provoked by chewing and swallowing.

All of these components need to be considered when deciding on a treatment plan.

Allodynia and Hyperalgesia



Ms. Hema has severe lymphedema following modified radical mastectomy and in addition, now has recurrence with possible infiltration in her brachial plexus. She has severe pain on touch and cannot bear it when the fabric of her clothes rubs against her skin.

A stimulus which ordinarily does not cause pain, such as light touch, is called allodynia.

Pressure on her edematous arm causes excruciating pain. An exaggerated pain response to a painful stimulus is called hyperalgesia.

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; e.g. burning, aching)

R - Radiation of pain

S - Site, Severity

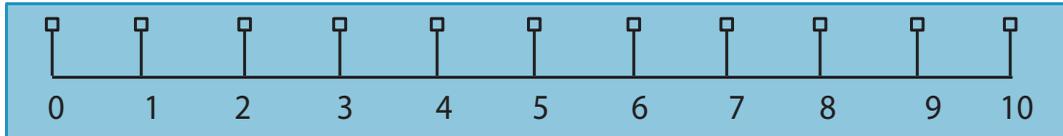
T - Temporal factors (duration, diurnal variation of pain, continuous or intermittent)

In addition, always evaluate: how is the pain affecting the person?

Assessment of Pain

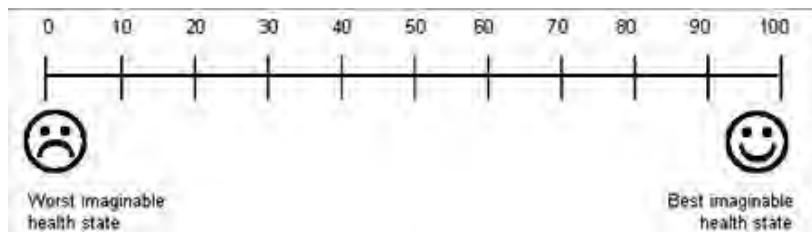
This may be done using various pain scales available. The commonly used ones are:

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



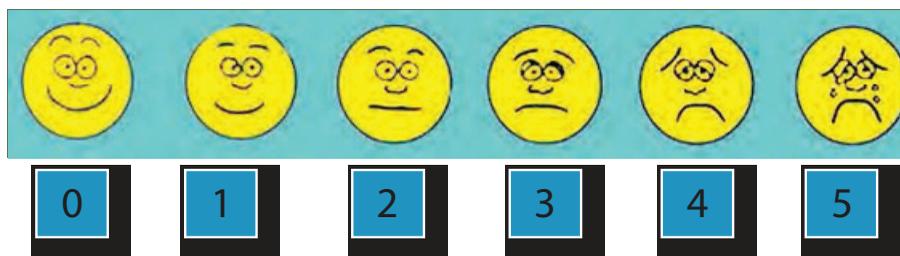
It is explained to the patient that zero represents “no pain” and 10 represents the “worst imaginable pain”. Then, the patient is asked to score his pain on this scale according to the severity.

3. Visual Analogue Scale (VAS):



One side of VAS has no markings except the two extreme points. The other side has marks from zero to 100. The unmarked side is shown to the patient who is asked to mark the pain according to the severity. Then the assessor will view the pain on a 0-100 scale on the reverse side.

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



Pain scores of 0-1 may be considered MILD PAIN.

Pain score of 2-3 may be considered MODERATE PAIN.

Pain score of 4-5 may be considered SEVERE PAIN.

The aim of pain management is to keep the pain score at a level that the patient considers satisfactory.

Location:

Many patients have more than one pain. Two pains may be of different types and of different etiology. It is important to document them so that we can monitor progress. The site of each pain is marked on a body chart.

Meaning:

Assessment of pain is not complete without going into the impact of the pain on the person. What is the meaning of the pain for Chennayya? Does he see it as punishment for his sins? Does he read impending death in it? Is he feeling guilty that the whole family is troubled because of his pain?



Meaning of the pain - The meaning that the patient may attribute to the suffering is very significant. It is important to know what the patient thinks about the pain experience; his/her understanding of the cause and reason for the pain, as well as how it affects him/her as a person. This aspect needs to be acknowledge and addressed within the therapeutic plan.

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. Most cancer pain responds to WHO analgesic ladder.
 - c. Cancer pain is always nociceptive.
 - d. The pain experience decreases as time passes.

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 Key:

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 3.3 - WHO Analgesic ladder

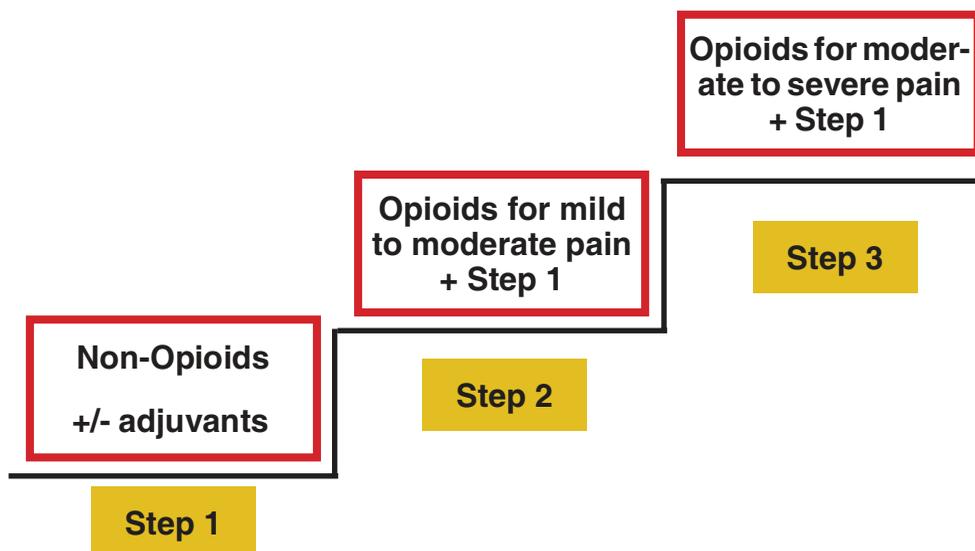


Table 3.3 - Principles of WHO analgesic ladder use:

By the clock	Continuous pain needs continuous relief. Prescribe drugs according to their duration of action; not arbitrarily or on as-needed basis.
By the mouth	Give medicines orally as much as possible. This is the simplest route. A well-informed patient can use the oral medications by himself. Injections require professional help, are a source of pain by themselves, and are best avoided.
By the ladder	Choose medications from the WHO ladder, according to severity of pain, but with flexibility. In severe pain, it is permissible to start at step III.
Individualised approach	Prescription should mention dose for breakthrough pain. This improves the effectiveness, level of control and helps to fine tune the dose. Choose the 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 and holistically and managed accordingly.

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 naproxen indomethacin ketorolac etoricoxib	codeine tramadol tapentadol	morphine fentanyl methadone (not yet sold in India for pain relief)	tricyclic <u>antidepressants</u> (amitriptyline, imipramine) <u>anticonvulsants</u> (carbamazepine, valproate, gabapentin, pregabalin) <u>Anticholinergic</u> (hyoscine) <u>Muscle relaxants</u> (diazepam) <u>NMDA receptor blocker</u> ketamine <u>Bisphosphonates</u> <u>Local anesthetics</u> <u>Corticosteroids</u>

Step 1 Drugs from the WHO Analgesic Ladder

Non-opioid analgesics

These include paracetamol and a broad class of drugs, the non-steroidal anti-inflammatory drugs (NSAIDs). Sometimes paracetamol is included amongst NSAIDs, but it is very different in its analgesic mechanism and can be safely combined with other NSAIDs.

Paracetamol is an analgesic with good safety margin; it is a good analgesic for its additive effect. It is usually given 6 hourly to maximum of 4g per day. In those with liver dysfunction, it is used with caution. Unlike the NSAIDs, it has a predominant central action.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs exert anti-inflammatory action by inhibiting prostaglandin synthesis through the cyclo-oxygenase (COX) pathways and hence are very effective in nociceptive pain associated with inflammation. NSAIDs may be useful in neuropathic pain also if there is associated nociceptive component (mixed pain) or if the neuropathic pain is associated with a process of inflammation as in malignancy or acute injury. It is unlikely to be helpful where the neuropathic pain does not have an inflammatory component as in post-herpetic neuralgia.

NSAIDs can be divided into following groups.

- Non-selective NSAIDs: These inhibit both COX-1 and COX-2 enzymes. These have more gastrointestinal side effects than selective COX-2 inhibitors and have the potential to worsen bleeding.
- COX-2 selective NSAIDs: They selectively inhibit COX-2 enzymes. These have less gastrointestinal side effects. They do not inhibit platelets and so would be safe in presence of bleeding tendency. On the other hand, they may have a pro-thrombotic effect and so may be associated with increased cardiovascular and cerebrovascular incidents. They are specially indicated for short-term use when bleeding or gastritis is a particular concern.

It is important to remember that both selective and non-selective NSAIDs can cause renal dysfunction in presence of hypovolemia or in pre-existing kidney disease. The potentially diminished renal function may also predispose to water retention thereby worsening hypertension or heart failure.

There is recent evidence that diclofenac may be significantly COX-2 selective and so carries the risk of adverse coronary or cerebral events in long term use.¹³ Ibuprofen and naproxen were shown to be the safest in coronary and cerebral events. However, their relative safety is valid only if the dose is restricted as shown in the table below

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

¹³ Fosbol E.L et al; Circulation; Circ Cardiovasc Qual Outcomes 2010;3:395-405

Table 3.5 - Examples of Non-selective COX inhibitors

Drug	Dose	Frequency	Route
Ibuprofen	400 mg	TDS or QDS	PO
Naproxen	250-500 mg	BD	PO, suppository

Table 3.5 - Examples of Non-selective COX inhibitors

Drug	Dose	Frequency	Route
Ibuprofen	400 mg	TDS or QDS	PO
Naproxen	250-500 mg	BD	PO, suppository

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 increases 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 pro-thrombotic action
<ul style="list-style-type: none"> ▪ High NSAID dose ▪ History of upper GI symptoms ▪ Advanced age ▪ Concurrent aspirin or corticosteroid use ▪ Comorbidities (e.g rheumatoid arthritis) 	<ul style="list-style-type: none"> ▪ Advanced age ▪ Poorly controlled diabetes ▪ Dehydration ▪ Concurrent nephrotoxic ▪ Dyes used in imaging. ▪ Poor kidney perfusion. 	<ul style="list-style-type: none"> ▪ Use of COX-2 drugs ▪ Advanced age ▪ Hypertension ▪ Hyperlipidaemia ▪ Diabetes ▪ Smoking

Recommendations for safe prescription of NSAIDs

1. Drugs are to be given by mouth, by the clock, by the ladder for effective and sustained pain relief.
2. Use the lowest possible effective dose for the required duration of treatment.
3. Elderly patients, smokers, alcoholics, those using steroids or aspirin concurrently, or those with a past history of peptic ulceration, GI bleeding or gastroduodenal perforation are more at risk for adverse effects from NSAIDs.
 - A proton pump inhibitor such as omeprazole 20 mg a day on empty stomach is recommended for gastroprophylaxis in high risk patients (age > 65, high-dose NSAID, concurrent steroids or anticoagulant, less than one month of NSAID treatment, debility, prior NSAID-induced ulcer).
 - They are to be avoided in presence of dehydration, gastroenteritis, diuretics, or diabetes.
 - Special caution is advised with concurrent use of nephrotoxic drugs such as contrast agents for radiology procedures.
 - Special caution is advised in patients with possible coronary artery disease, hypertension, asthma, hyperlipidemia, diabetes, renal dysfunction and smokers.
 - COX-2 selective inhibitors are contraindicated in patients with atherosclerotic disease, ischaemic heart disease, cerebrovascular disease or peripheral arterial disease

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

Test your knowledge

Choose the more appropriate group of non-opioid step I analgesic in following situations.

1. Mr. M., a 66-year-old with diabetes and hypertension
2. Ms. K., a 32-year-old with a history of peptic ulcer disease
3. Mr. L, a 50-year-old with diabetes for 20 years and a serum creatinine of 2.8 mg%
4. Mr. G., a 57-year-old with bleeding polyps

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

Adjuvant Group of Drugs in Step 1 of the WHO Ladder

The term “adjuvant analgesic” is used for a drug that has a primary indication other than pain but is active also for pain. Adjuvants may be used alone or may be used in combination with a primary analgesic such as NSAID or opioids. They may be classified as:

- Those that improve pain from a specific etiology e.g. tricyclic antidepressants for neuropathic pain or antispasmodics for intestinal colic
- Those improving co-existing conditions thereby contributing to therapeutic response to analgesics e.g. antibiotics when infection is present; bisphosphonates for bone pain

Sometimes, the term “adjuvant” is also used to include those that counter 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 inflammation or by elevated intracranial pressure
Tricyclic antidepressants Anticonvulsants	Neuropathic pain
Antidepressants in regular dose	Clinical depression is contributing to the pain
Skeletal muscle relaxants	Muscle cramps
Antibiotics	Pain related to infection
Night sedatives	Lack of sleep is lowering pain threshold
Anxiolytic	Anxiety is aggravating the pain
Antispasmodics	For colic from tubular structures.

Management of Neuropathic Pain:

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

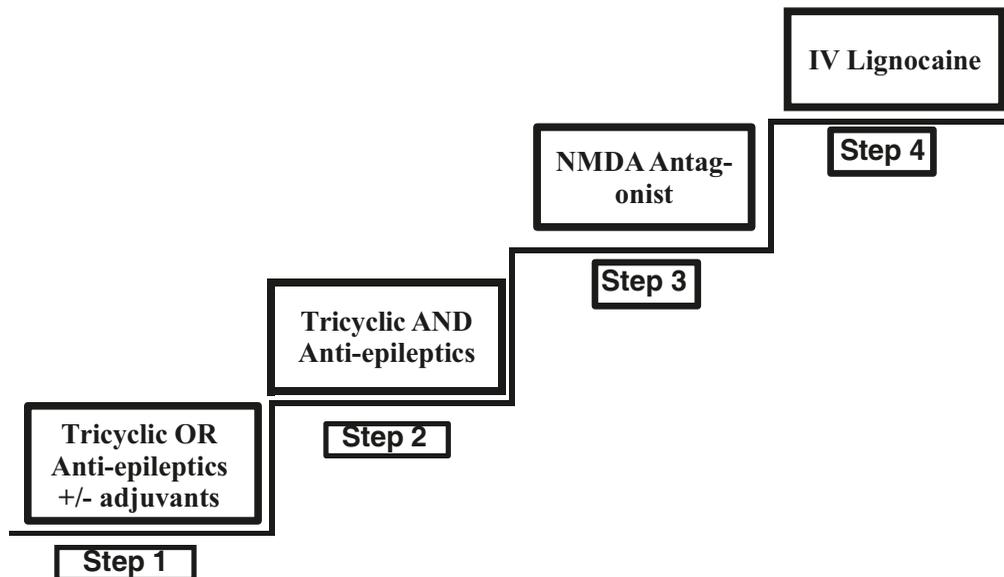


Fig 3.4 – Approach to choosing adjuvants other than corticosteroids for managing neuropathic pain. In presence of significant inflammation contributing to nerve compression or of elevated intracranial tension, corticosteroids may be indicated.

Table 3.8– Common medications used in Neuropathic Pain

Drug	Dosage	S. Effects & Comments
Antidepressants Amitriptyline Imipramine Nortriptyline	Start with 12.5 to 25 mg HS, increase 12.5 to 25 mg every 3-5 days, up to 100 mg / day	Early morning sedation, anti-muscarinic side effects
Duloxetine	30-60 mg /day HS	Nausea, dizziness, dry mouth, sleepiness
Anti-epileptics		
Sodium Valproate	Start with 200mg at bedtime, titrate up by 200 mg every 3-5 days, up to 1 G/day	Gastrointestinal upset, drowsiness, tremor, ataxia
Carbamazepine	Start with 50-100 mg TDS, increase every 2 weeks by 200 mg, up to 1G/day	Ataxia, diplopia, nystagmus, blood dyscrasias

¹⁴ Modified from Twycross R. *Introducing Palliative Care* 2002. Radcliffe Medica Press. Oxford.

Gabapentin	Start with 100 mg TDS, increase 300 mg TDS every week up to 900 mg TDS	Drowsiness, peripheral oedema.
Pregabalin	Start with 75 mg HS and gradually increase to BD or TDS dosage. Max 600 mg/day	Dizziness, sleep disturbances, ataxia, mood disturbances, dry mouth, constipation.
Ketamine	0.2-0.5 mg/kg bodyweight/ dose TDS –QDS PO (sub- anaesthetic dose). Also as continuous subcutaneous infusion at 50-100mg/day; Maximum dose – 200mg / day	Dysphoria, hallucinations, nausea and vomiting, dizziness.
Lignocaine	1-2 mg/kg over 20 minutes followed by 1-2 mg/kg over 60 minutes (dose could be repeated every 24 hours or may be changed to a continuous infusion)	Serious toxicity is rare at these doses, however, patient should be monitored for signs of mild toxicity: tinnitus, perioral numbness, headache, metallic taste, or drowsiness, and the infusion may be slowed if symptoms become significant. Slowing of the heart rate is common, but bradycardia is rare.

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

- Empathy, counseling and therapeutic relationship is essential to address the subjective emotional component of the pain experience.
- Physical therapies – heat, transcutaneous electrical nerve stimulation (TENS), ultrasound and exercise
- Radiation therapy for bony pain
- Injection of trigger points with local anaesthetic agent
- 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 anesthetic agents with or without opioid analgesics.
- Modification of the patient's living environment or use of assistive devices (ramps, toilet risers, walkers, wheelchairs).
- Complimentary therapies including yoga, acupuncture and cognitive behavioral therapy (CBT) in improving pain-related behavior and perceived self-efficacy.
- Involvement in activities that bring in joy to the individual's daily life helps in moving beyond the constant presence that pain has in a person's life.

Test your knowledge

1. In the WHO analgesic ladder, non-opioid analgesics are:
 - a. Used only in step 1
 - b. Used in all the 3 steps
 - c. Not used with strong opioids
 - d. Avoided with adjuvants

2. Which of the following is NOT an adjuvant?
 - a. Bisacodyl
 - b. Codeine
 - c. Amitriptyline
 - d. Ondansetron

Answers: 1 – b; 2 - b

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

Opioid analgesics include naturally occurring, semi-synthetic and synthetic drugs. 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 “controlled drugs,” so they are more widely available. 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 in step I.

If step 2 medications are not adequate, proceed to step 3. It is conventional to wait for 2 days before climbing up the ladder, but in case of severe pain, the switch to step 3 can be earlier.

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 its sale is suspended due to concerns regarding safety and efficacy. Palliative care professionals have appealed to the Government of India against this suspension.

TRAMADOL

In addition to being a weak mu receptor agonist, tramadol inhibits the reuptake of serotonin and norepinephrine in the inhibitory pain pathways. 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 of 50-100 mg Q6-8 H up to a maximum of 400 mg/ day. It shares all the opioid side effects of the class like nausea, vomiting, constipation, neuropsychiatric symptoms, and pruritus. It also reduces seizure threshold.

TAPENTADOL¹⁵

This is a relatively new drug. This too is a mu receptor agonist which also inhibits the reuptake of serotonin and nor-epinephrine in the inhibitory pain pathways. It seems to have a better side effect profile than tramadol, but it still has the potential to contribute to/precipitate serotonin syndrome and to induce physical/psychological dependence. It is usually used in doses of 50-150 mg Q6-8 hours up to maximum of 400 mg/ day.

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. There is a limit to analgesia that can be

¹⁵ Guay DR. Is tapentadol an advance on tramadol? Consult Pharm. 2009;24(11):833-40.

achieved without significant side effects or toxicity. Buprenorphine has poor oral bioavailability and is available as sublingual, transdermal and parenteral preparations.

Step 3 medications of WHO Analgesic Ladder

Step 3 medicines are used when step 2 medicines are inadequate or when pain is excruciating at the onset. Step 1 medicines are continued along with step 3 opioids.

MORPHINE

Oral morphine is the gold standard for treatment of cancer pain.

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

It acts mainly on the mu 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 significantly contributes to pain relief and M3G is believed to produce CNS adverse effects like myoclonus, dysphoria and delirium.

Administered orally, morphine will take about 24-36 hours to achieve steady state level in the blood. If at the end of 36 hours or so, pain relief lasts for less than 4 hours or the patient has to take two or more PRN doses, the 4 hourly dose should be increased by 50% and thereafter reviewed every two days.

Comparison of step 2 opioids with morphine

Codeine is a pro-drug of morphine. It is converted to morphine in the body and is 1/10th as potent as morphine (for example, 10 mg codeine is equivalent to 1 mg of morphine). But a proportion of patients have an in-born genetic inability to convert codeine to morphine and hence such people will not get pain relief with codeine. Other populations convert more readily and these patients can experience opiate toxicity. Codeine is more constipating than morphine. All opiates suppress cough so it is not necessary to use a codeine preparation to quiet a cough.

Tramadol is 1/5th to 1/10th as potent as Morphine¹⁷. It may be useful in pain associated with a neuropathic component. Tramadol appears to be more emetogenic, but produces less constipation and dependence when compared with equianalgesic doses of morphine.

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 or when a trial of the step 2 drug does not relieve pain.
2. The usual starting dose for a patient with normal renal function is 5-10 mg 4 hourly. The patient is advised to take rescue doses for breakthrough pain 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. The sedation due to the extra dose is often helpful.

4. The first review should be within 2 days. The overall pain relief over that period is noted. If it is considered satisfactory, i.e. the pain scale stays < 3 most of the time and the patient becomes more functional, then total daily requirement for pain relief is calculated by adding the regular and the rescue doses. This total daily requirement is divided into 6 doses and continued.

e.g. Suppose a patient is on 15mg 4th hourly and he also takes two rescue doses each of 15 mg, then the total intake during a day is $(15 \times 6 = 90\text{mg}) + (15 \times 2 = 30 \text{ mg}) = 90 + 30 = 120 \text{ mg}$.

This is then divided by 6. Hence this person's requirement may be calculated as 20mg 4th hourly. This is usually administered as 20 mg each on waking up, at 10 AM, 2 PM, 6 PM and 40 mg at bed-time. The person is still allowed to take a rescue dose of 20 mg if required.

5. The next review would be in the next 2 days to assess for stable pain relief with particular attention to bowel function and other adverse effects.
6. With 2 or 3 reviews over a week the average daily dose may be estimated and reviews can be less frequent.
7. Once the daily requirement of regular morphine for sustained pain relief is estimated, one may also consider converting the short acting formulation to equipotent slow release preparations based on the 24-hour requirement of morphine. For example, if morphine 20mg every 4 hours gives adequate pain relief around 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.
8. The rescue dose for breakthrough pain should be given as immediate release morphine. It is generally calculated as equivalent to $1/6$ th of the patient's current daily opioid dose. That is, a patient who is receiving 60 mg of sustained release morphine every 12 hours should have a rescue dose of $120 \text{ mg}/6 = 20 \text{ mg}$ of immediate release morphine Q4H.

The supply, stocking and dispensing of step 3 opioids are governed by the Narcotic Drugs and Psychotropic Substances Act – NDPS Act 1985 and by its recent amendment – the Narcotics Amendment Act, 2014.

¹⁷Grond S, Clinical pharmacology of tramadol: ClinPharmacokinet. 2004;43(13):879-923

Regulation of Step 3 Opioids

NDPS Act 1985 was primarily aimed at curbing misuse and diversion of opioids to illicit channels. It legislated such stiff penalties for even clerical errors that hospitals and pharmacies stopped stocking opioids. Between 1985 and 1998, consumption of step 3 opioids in India decreased about 70% of pre-1985 levels. In 1998, thanks to the initiative of palliative care activists, the government of India gave an instruction to all states to amend and simplify their narcotic rules. Unfortunately, only a few states complied.

At this time different states have different rules. Most of the time, multiple licenses from different governmental agencies are required. Due to these bureaucratic regulations, oral morphine is not available in most of India. It is estimated that only about 1% of the patients in need have access to morphine.

NDPS Amendment bill 2014

On February 21, 2014, the Parliament of India enacted the NDPS amendment bill which brings in uniformity of access to opioid analgesics throughout the country. Essentially the amendment shifts the responsibility for enacting state rules from the state Government to the central Government. Once the state rules are framed by the government of India and implemented, a single order by the drug controller of the state will be sufficient for any institution to stock and dispense morphine, subject to the applicant institution following minimum standards.

FENTANYL CITRATE

Fentanyl is a selective mu receptor agonist.

In India, it is available as injections of 50 ug/ml and as 72-hour transdermal patch formulation in strengths of 12.5, 25 and 50 µg/hour. There is a transmucosal preparation for oral/nasal administration that is available for quick relief of incident pain.



Fig 3.5 Transdermal preparations of fentanyl citrate

Considerations while using fentanyl patch

- Fentanyl is unsuitable for patients with unstable pain.
- Peak plasma concentrations are achieved after 12-24 hours and a depot reservoir remains in the skin for some 24 hours after the patch is removed.
- Rescue doses of opioid will be necessary during the first 24 hours of application.
- It is expensive.
- 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.
- Daily dose of 50-60 mg of oral morphine is equivalent to 25 mcg/hr transdermal fentanyl. 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 switched over to fentanyl. They may require oral morphine on a PRN basis to manage the withdrawal symptoms for a day or two.

Patient cannot have their pain medications titrated using patch delivery.

Some specific indications for using transdermal fentanyl.

- a) Dysphagia.
- b) Intolerable side effects with morphine - nausea, vomiting, constipation, disorientation, delirium.
- c) Renal failure.
- d) Dislike for tablets or poor compliance to oral therapy

**Ways of improving effectiveness of
the WHO Analgesic Ladder**

1. Manage the known side effects of the medicines actively from the first prescription onwards e.g. prophylactic proton pump inhibitors in high risk patients on NSAIDs; stimulant laxative with opioids.
2. While prescribing, educate and provide information on where the medicines are available: Oral Morphine is available in hospitals and centres that are “Recognised Medical Institutions” (RMI) which have been authorised by the state drug controller in the states with simplified NDPS rules in our country.
3. Pharmaco-economics: Many patients may need long term medications for pain relief. Hence due attention is to be paid in choosing medications that would keep the cost of the treatment as low as possible.
4. Communicate with patients and understand phobias that exist regarding certain groups of drugs, especially opioids. Compliance will be better when questions are answered and doubts are addressed.
5. Review and re-evaluate for changes in clinical condition, side effects, responsiveness to treatment, or appearance of new pain.

Test your knowledge

1. The primary consideration for starting morphine is:
 - a) The disease is incurable.
 - b) The pain cannot be adequately controlled on optimal dose of step 2 medicines.
 - c) The life expectancy is judged to be short.
 - d) The patient does not have a history of drug abuse or addiction.

2. A medicine that should always be given when prescribing morphine is
 - a) A non-opioid
 - b) A non-steroid anti-inflammatory drug
 - c) A laxative
 - d) An anti-emetic

3. A patient with Pancoast tumor is complaining of burning type of pain radiating over his left arm. The adjuvant that will benefit him most is likely to be:
 - a) Amitriptyline
 - b) Dicyclomine
 - c) Lorazepam
 - d) Ondansetron

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 (e.g. bisacodyl 10 mg HS) Softeners/ lubricant (liquid paraffin) Bulk-forming laxatives are unsuitable for opioid-induced constipation.
Nausea and vomiting	33 %	Usually self-limiting in a week. Treat with: haloperidol 1-3 mg HS or metoclopramide 10 mg tds. Prophylactic anti-emetics can be given for first 3 days of morphine therapy.
Sleepiness and tiredness	33 %	Often self-limiting in a week. Reduce dose and review if it persists.
Dry mouth		Mouth care; soda bicarbonate mouth wash.
Urinary hesitancy due to prostate hyperplasia		Alpha blockers (tamsulosin 0.4 mg HS)
Itching		Keep skin moist. 5HT3 blockers: ondansetron 4-8 mg OD-BD Anti-histamines.

A number of different approaches may 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 is less constipating than morphine possibly because of the nature 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.

The objective is to achieve effective pain management with improved sleep and function with minimal adverse effects.

SIGNS OF OVERDOSE WITH ORAL OPIOIDS

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

Respiratory depression is NOT common with oral morphine unless there is a deliberate or accidental overdose.

If the medicine is titrated to achieve pain relief with regular review, an overdose 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
Extreme drowsiness	Dose reduction
Respiratory Depression: R.R < 8-9 / minute; SaO ₂ < 85%; and pinpoint pupils	Titrated dose of IV Naloxone, skip next dose and reduce dose.

Opioid-induced respiratory depression:

The common misconception that oral morphine is associated with respiratory depression keeps medical professionals from prescribing this useful medicine. Pain antagonizes the central depressant effects of opioids and hence doses adequate for pain relief do not cause respiratory depression.

Respiratory depression is NOT LIKELY, when opioid has been titrated according to the type and severity of pain with regular review.

Opioid withdrawal symptoms and pain can happen if long-term opioids are abruptly stopped. 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 is characterised by rhinorrhea, lacrimation, disorientation, hyperthermia, emesis, myoclonus, anxiety, agitation, delirium, abdominal cramps, yawning and 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 as necessary.

CLARIFICATION OF TERMS

Addiction

Addiction 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.

Take home message in managing persistent pain

- Acknowledge pain
- Evaluate with attention to detail
- Provide explanation to the patient
- Aim for graded pain relief
- Respect patient's expectations
- Review frequently
- The use of strong opioids is dictated by therapeutic need and response. Remember: not all pain responds to opioids.

Table 3.11 – Myths and facts about morphine.

MYTHS	FACTS
Respiratory depression is common with regular use of step 3 drugs.	Respiratory depression is very rare if the analgesic dose is appropriately titrated for pain relief.
All patients on step 3 drugs become addicted to them.	The chance of addiction with good monitoring is low.
Step 3 drugs are to be used for managing pain only in terminal illness.	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 among the least expensive medicines. Transdermal fentanyl is expensive.
The therapeutic range is narrow and toxic effects occur within the therapeutic range.	Oral formulations of step 3 drugs such as morphine have wide range of therapeutic efficacy and do not have ceiling effect. The dose may be gradually increased and individualized.

NOW LET US SEE HOW WE CAN MANAGE OUR PATIENT CHENNAYYA.

He has a mixed type of pain with both nociceptive and neuropathic pain. His pain is provoked by chewing. He also has a foul-smelling wound, which adds emotional, social and spiritual components to his pain.

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

- Step 2 drug e.g. tramadol 50mg 6th hourly
- Non-opioid e.g. paracetamol 650 mg QID after food
- Local care for the foul smelling wound with metronidazole gargle (injectable metronidazole in saline) with additional powdered tablet metronidazole in biolingauze over the wound
- Antibiotic e.g. amoxicillin 500mg 8th hourly
- Amitriptyline 12.5 mg at bedtime, with a gradual increase in dose up to 50 – 75 mg at night for the neuropathic component
- If there is severe inflammation contributing to pain, ibuprofen 400 mg TID can be given after food, along with gastro-protectant such as omeprazole 20 mg OD on empty stomach. Ensure adequate hydration. Avoid if the patient is on steroids.

The opioid may be increased later to morphine (instead of tramadol) in case of unsatisfactory pain relief or progressive disease. Education on mouth care and wound care are important contributors to relief.

Once the smell disappears, his social isolation will also improve. Building a therapeutic relationship through regular communication to understand his distress is important. The family could be involved in his care with appropriate communication by the 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.b; 3.b

Suggested Reading

1. Introduction to Palliative Care by Robert Twycross, 4th Edition

Guidelines by the American Society of Interventional Pain Physicians (ASIPP) for responsible opioid-prescribing in chronic non-cancer pain²¹

(level of evidence is given in brackets)

1. Essential to establish medical necessity prior to initiation or maintenance of opioid therapy (EVIDENCE: good)
2. Comprehensive assessment and documentation is recommended before initiating opioid therapy, including documentation of comprehensive history, general medical condition, psychosocial history, psychiatric status, and substance use history. (EVIDENCE: good)
3. Establish appropriate physical diagnosis and psychological diagnosis if available prior to initiating opioid therapy. (EVIDENCE: good)
4. Establish treatment goals of opioid therapy with regard to pain relief and improvement in function. (EVIDENCE: good)
5. Urine drug testing (UDT) and prescription monitoring programs are recommended for implementation from initiation along with subsequent adherence monitoring to decrease prescription drug abuse or illicit drug use when patients are in chronic pain management therapy. (EVIDENCE: good) This may be difficult in Indian clinical settings.
6. A consultation with a pain specialist may be helpful when initiating high-dose opioid therapy (EVIDENCE: fair)
7. Ordering diagnostic tests such as x-rays and laboratory tests must be done thoughtfully, as tests can heighten fear, restrict activity, and cause requests for increased opioids or cause maladaptive behaviours. (EVIDENCE: good)
8. The relative and absolute contraindications to opioid use in chronic non-cancer pain must be evaluated including respiratory instability, acute psychiatric instability, uncontrolled suicide risk, active or history of alcohol or substance abuse, allergy to opioid agents, co-administration of drugs capable of inducing life-limiting drug interaction, concomitant use of benzodiazepines, active diversion of controlled substances, and concomitant use of heavy doses of central nervous system depressants. (EVIDENCE: fair to limited)
9. Constipation must be closely monitored and a bowel regimen when opiates are prescribed. (EVIDENCE: good)
10. Chronic opioid therapy may be continued, with continuous adherence monitoring, in well-selected populations, in conjunction with or after failure of other modalities if there is significant improvement in physical and functional status and minimal adverse effects.

²¹ Manchikanti L et al. American Society of Interventional Pain Physicians (ASIPP) guidelines for responsible opioid prescribing in chronic non-cancer pain: part 2 - guidance. [2012, 15 (3 Suppl): S 67-116

INTERVENTIONAL TECHNIQUES FOR MANAGEMENT OF PAIN

Objectives

1. Enumerate common intervention techniques available for managing persistent pain.
2. Describe the fundamental criteria for choosing intervention techniques for a pain patient.
3. Recognize when to refer a patient for interventional pain procedures.

Definition

Interventional pain management is the discipline of medicine devoted to the diagnosis and treatment of pain and related disorders by the application of interventional techniques in managing pain, independently or in conjunction with other modalities. Interventions include trigger point injections, nerve blocks, autonomic or sympathetic plexus blocks, minimally invasive spinal interventional techniques (ablation of targeted nerves, intrathecal infusion pumps or spinal cord stimulators).

Interventional techniques are possible options for patients with failed oral or transdermal analgesic therapy. This section familiarises the student with few of the commonly applied techniques.

Spinal interventional techniques

These techniques have traditionally evolved for managing persistent back pain. The low back pain may occur because of the involvement of the intervertebral discs, facet joints, sacroiliac joints, ligaments, fascia, muscles and nerve roots. Diagnostic blocks can confirm that these structures are the causative sites for the pain syndrome. The common interventions are:

1. Epidural injections – Thoracic, lumbar or cervical. The approach may be inter-laminar, trans-foraminal or caudal based on the source of pain.
2. Facet joint blocks – intra-articular injections, medial branch blocks, or neurolysis of medial branches e.g. radio-frequency ablation
3. Sacroiliac joint injections – for lower back pain with identified source
4. Spinal cord stimulation – this has been utilised for neuropathic pain of failed back surgery syndrome (FBSS) and complex regional pain syndrome (CRPS). It is an intervention of last resort.

The common drugs used neuraxially in low back pain

- Methylprednisolone 40-80mg
- Triamcinalone acetonide 40-80 mg
- Betamethasone sodium phosphate (or non-particulate formulation) 6-12 mg
- Dexamethasone sodium phosphate 8-16 mg

Interventional techniques in cancer

Interventional technique may be considered as a strategy at any phase of the management of severe pain or as the 4th step of analgesic ladder. A regional block might bring relief by blocking the transmission of nociception from the diseased area.²⁴

A peripheral nerve block using local anaesthetic is useful for quick relief of severe nociceptive pain. For example, pain due to an osteogenic sarcoma of the femur in a child may be temporarily controlled with a triple block in the inguinal region (if this area is not invaded by the tumour) as a short term measure, while waiting for analgesics to take effect. However, to maintain pain relief on long term, oral pharmacotherapy is ideal as it is affordable and sustainable in the domiciliary setting.

Neuraxial analgesic infusions

In the case of pain which is not controlled by oral medications, continuous infusions of opioid/local anesthetic combinations may be considered, with catheters placed neuraxially i.e. in the epidural or spinal spaces. The cost of the technique, materials and maintenance required could be cost prohibitive. It is a highly individualised decision to be taken with due consideration of the benefit, the duration of utility and the adverse consequences.

Neuraxial analgesic measures may be considered for patients with continuous excruciating pain involving major nerve plexus e.g. brachial/lumbo-sacral plexopathy due to spread of tumour. For this, the patients are to be referred to specialized doctors in the field of interventional pain management.

The common drugs that are used as infusions neuraxially

- Opioids: morphine (0.03-0.05mg/ml @2-5ml/hr), fentanyl (1-2ug/kg/hr). The concentration and the volume used per hour changes when the infusion is used intrathecally.
- Local anaesthetic agents: bupivacaine (0.0625% - 0.125% @ 5 ml/hr), ropivacaine (0.1% @5 ml/hr)

Neurolysis

Neurolytic techniques in general have a narrow risk-benefit ratio and have been largely replaced by neuraxial analgesic techniques as mentioned above. However, the indications for interventional techniques are less frequent in pain due to cancer, as the pain is not limited to the distributions of a nerve or a plexus nor are they purely somatic or autonomic in nature. Usually cancer pain has mixed etiologies with pathological neuroplasticities and additional major psycho-social components.

²⁴ Medscape. Available at http://www.medscape.com/viewarticle/408976_6

Possible Indications for Neurolysis

1. In patients with severe, intractable pain in whom less aggressive manoeuvres are ineffective or intolerable because of either poor physical condition or the development of side effects.
2. The goal of neurolysis i.e. analgesia, may produce undesirable side effects, including sphincter weakness and limb paralysis. In most but not all cases, these are unacceptable complications. Hence the prognosis and quality of life are significant considerations.
3. The risk of de-afferentation pain is significantly increased after a neurolytic block to a peripheral nerve.
4. Patients / family are made cognizant of pros and cons of making or not making the choice as well as the alternatives for handling the situation.

Neurolytic blocks may be:

- Chemical – 50-100% alcohol or 7-12% phenol
- Thermal – cryotherapy, radiofrequency thermo-coagulation.

Preconditions for successful block

1. Pain that has not responded to pharmaceutical interventions, or other non-surgical management, including physical therapy.
2. Duration of pain of at least 3 months intermittently or continuously with average pain levels of ≥ 6 and causing significant functional disability.
3. Availability of trained specialist pain physician.
4. Clarity on mechanism of the particular pain state, so that the choice of technique is informed and appropriate.
5. No contraindications related to the nature of the procedure, needle placement, or sedation.
6. No history of allergy to contrast administration, local anaesthetics, steroids, or other drugs.
7. Fully informed consent.
8. Diagnostic block using local anaesthetic is mandatory to validate indication for a future neurolytic block. If the painful area shows definite response to diagnostic block with a local anesthetic, then one may proceed with neurolysis of the same.

A few situations where neurolytic blocks are commonly employed:

- In areas where pain is limited to a circumscribed section, such as rib invasion/metastases, the pain may be treated with intercostal neurolysis.
- Stellate ganglion block is useful to evaluate or treat the autonomic component in upper limb or facial pain.
- Gasserian ganglion block at the level of foramen ovale at the base of the skull, or its branches, using radiofrequency technique or neurolytic solutions may benefit certain kinds of facial pain.
- Coeliac plexus block for pain limited within the viscera supplied by it.
- Lumbar sympathetic plexus may be blocked for managing ischemic pain as seen in patients with thrombo-angitis obliterans.
- Superior hypogastric plexus block may help for pain of sympathetic origin from cervical cancer or for any type of pelvic pain except ovarian pain.

Neurolysis rarely is permanent, and pain returns after an interval, either from a re-growth of neural structures or by progression of the underlying disease beyond the treated area.

Surgical interventional techniques

Surgical neurolysis is generally being replaced by interventions by pain medicine specialists.

Certain situations merit limited surgical considerations, such as the use of percutaneous vertebroplasty with injection of methyl-methacrylate to stabilize vertebra weakened by lytic disease. Percutaneous chordotomies and rhizotomies are among other procedures undertaken. The risk–benefit ratio is very variable and the decision for considering surgical interventions are highly individualised.

Conclusion

Pain is a multi-factorial condition. Much of the needless suffering may be mitigated by adequate communication with the patient in understanding the nature of pain, building rapport and confidence and competent application of current knowledge in pain medicine. Being available throughout the trajectory of chronic diseases with regular review and evaluation through a multi-disciplinary team approach is a necessity for positive outcomes and improved quality of care. The role of non-pharmacological interventions such as physical therapy and occupational therapy is to be utilised early. The WHO analgesic ladder drugs are useful in 75% of cancer patients up to terminal stages²⁵. They are to be used with awareness of their pharmacology and altered physiology of patients with advanced illness. The use of interventional techniques for pain is an option, yet an extremely challenging decision and requires clarity regarding etiology, patient's condition and expected outcomes.

²⁵ Grond S, Zech D, Schug SA, et al. Validation of World Health Organization guidelines for cancer pain relief during the last days and hours of life. *J Pain Symptom Manage.* 1991;6:411-422.

4. SYMPTOM ASSESSMENT AND MANAGEMENT

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



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 is now unable to work due to illness.

**What is the impact of illness on Mr. Sukumar’s life?
How will you approach these issues in a holistic manner?**

Learning Objectives of this Chapter

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

- 1 Enumerate the common symptoms in patients with chronic illness and their implications on quality of life.
- 2 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. Detailed history-taking is important.

The assessment of symptoms is a vital aspect of clinical care 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 person in the physical, psychological, social and spiritual domains.

The mnemonic “EEMMA²⁶” might help in assessment and management of symptoms.

EEMMA Approach to Symptom Assessment

Evaluation	Evaluate details of the symptoms. Understand the person with symptoms.
Explanation	Understand all the contributing factors.
	Explain clinical symptoms according to what the patient wants to know.
Management	Manage symptoms based on etiology—including symptom control, psychosocial support and relevant non-pharmacological interventions.
Monitoring	Review regularly for relief of symptoms, side effects and the need to optimize the dose.
Attention to details	Fine tune the control and individualize the treatment.

The key points in managing symptoms are as follows:

1. Base the care components on the patient’s idea of quality of life.
2. Follow the five “A”s of chronic care – “Assess, Advice, Agree, Assist, Arrange.”
3. Correct the correctable contributory factors.
4. Involve the multidisciplinary team to address the care needs in all dimensions – 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. For any continuous pain, analgesia is better achieved with round the clock administration of analgesics rather than giving them p.r.n basis.
7. Keep the treatment regimen as simple and clear as possible for the patient.
8. A formatted prescription with names of drugs, reason for use, dose and timings is more advisable than a verbal advice.

²⁶ Twycross, R. Introduction to Palliative Care.

9. Seek a colleague's advice in intractable situations.
10. Avoid false re-assurances yet maintain realistic hope "Even if a cure is not possible, your pain can be treated, and we shall do our best to get you back to office."
11. Prioritise concerns from patient's point of view.
12. Review and fine-tune care inputs.

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 brain-stem. This is stimulated by the mechanical receptors in the airways, intercostal muscles and the diaphragm, and by hypoxia and hypercapnoea. When there is a mismatch between the perceived demand and the ventilatory effort, it is experienced as breathlessness by the patient.

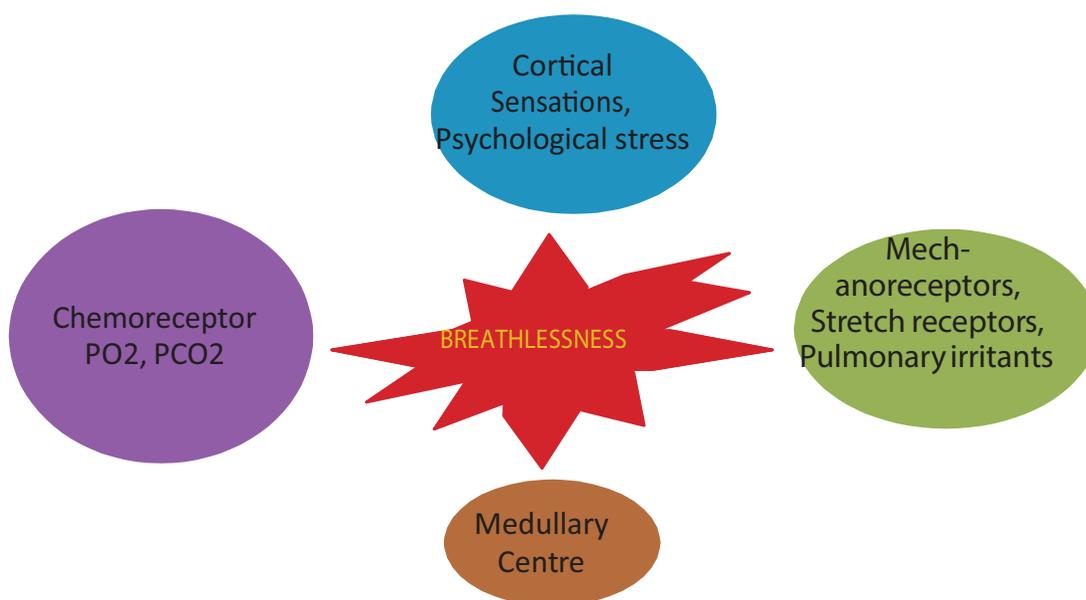


Fig 4.1 – Mechanisms of Breathlessness

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

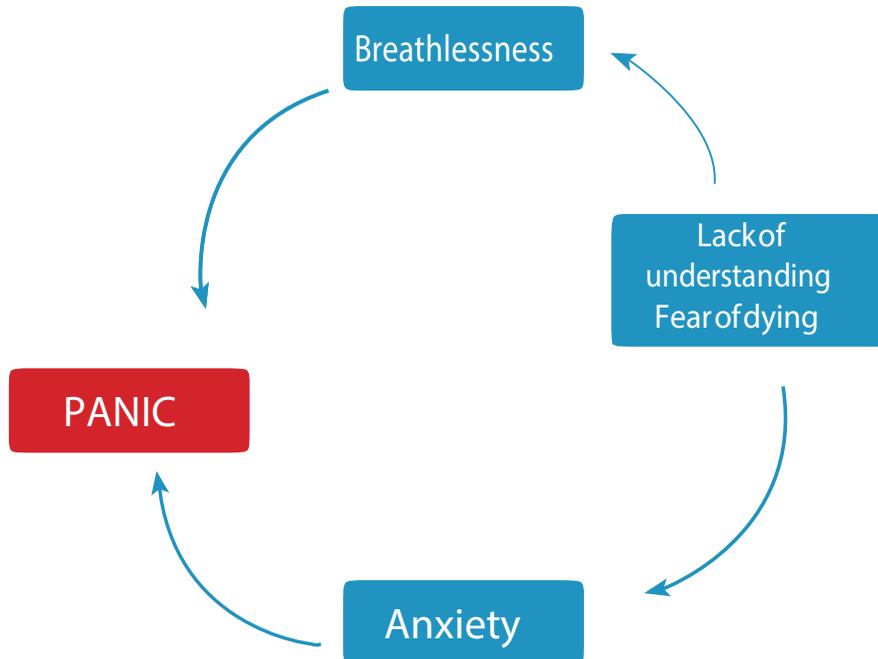


Fig 4.2 – Cycle of breathlessness at the end of life

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

Category	Dyspnoea	Activity level that causes dyspnoea
0	Nil	
1	Mild	Rapid walk on level or normal walk up 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 level ground.
4	Severe	Stops for breath after walking about 100 yards OR after a few minutes on level ground..
5	Very severe	Breathless when dressing or undressing. Cannot leave the house.

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	Can the person describe the feeling when he has breathlessness?
Related symptoms	Any other symptoms associated? (e.g. cough, anxiety, isolation).
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 what effect did they have?
Understanding	How does the symptom affect the person and the family?
Values	What is the comfort level which the person expects from treatment?

Investigations are not very useful in assessing chronic breathlessness due to advanced diseases, except to exclude treatable problems such as pleural effusion. X Ray, blood gases etc. can be normal in a patient with moderate to severe breathlessness.

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

<ul style="list-style-type: none"> ▪ Bronchial asthma ▪ Superior vena cava obstruction ▪ Pulmonary embolism ▪ Lymphangitis carcinomatosa ▪ Respiratory muscle weakness 	<ul style="list-style-type: none"> ▪ Ascites ▪ Anemia ▪ Metabolic acidosis ▪ Panic attacks ▪ Early Acute Respiratory Distress Syndrome (ARDS)
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Management of Breathlessness

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

Table 4.4 - Controllable causes of breathlessness

1. Respiratory infection	6. Pleural, pericardial effusion
2. COPD / Bronchial asthma	7. Ascites
3. Hypoxia	8. Anaemia
4. Superior vena-caval obstruction	9. Cardiac failure
5. Lymphangitis carcinomatosa	10. Pulmonary embolism

Non- pharmacological measures for controlling breathlessness

- Calm presence of the healthcare team conveying empathy will relieve anxiety and make breathing easier. Anxiety causes the patient to attempt deep breaths, which increase the negative pressure in the lungs and may worsen any airway obstruction. On the other hand, it would be counter-productive to ask patients to “calm down”.
- Loosening the patient’s clothes.
- Using a table fan to maintain air circulation.
- Keeping room windows open to improve perception of space.
- Comfortable positioning of the patient
- Teaching modified breathing to improve efficiency of breathing: pursed lip breathing or diaphragmatic breathing with relaxed abdomen
- Music – if desired.

Supporting coping

- Addressing the patient’s fear which could be the central element. “One of us is going to stay here until you feel better” may work better than many medicines.
- Exploring anxiety and the meaning of breathlessness to the patient.
- Meaningful communication 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

Bronchodilators may have a role and are often helpful when wheezes are present OR the patient cannot move any air, and wheezing is absent.

b) Corticosteroids

They help in reducing the peri-tumor oedema or oedema of airways which often contribute to obstruction. The dose is variable between 8–32 mg orally, subcutaneously or intravenously once a day.

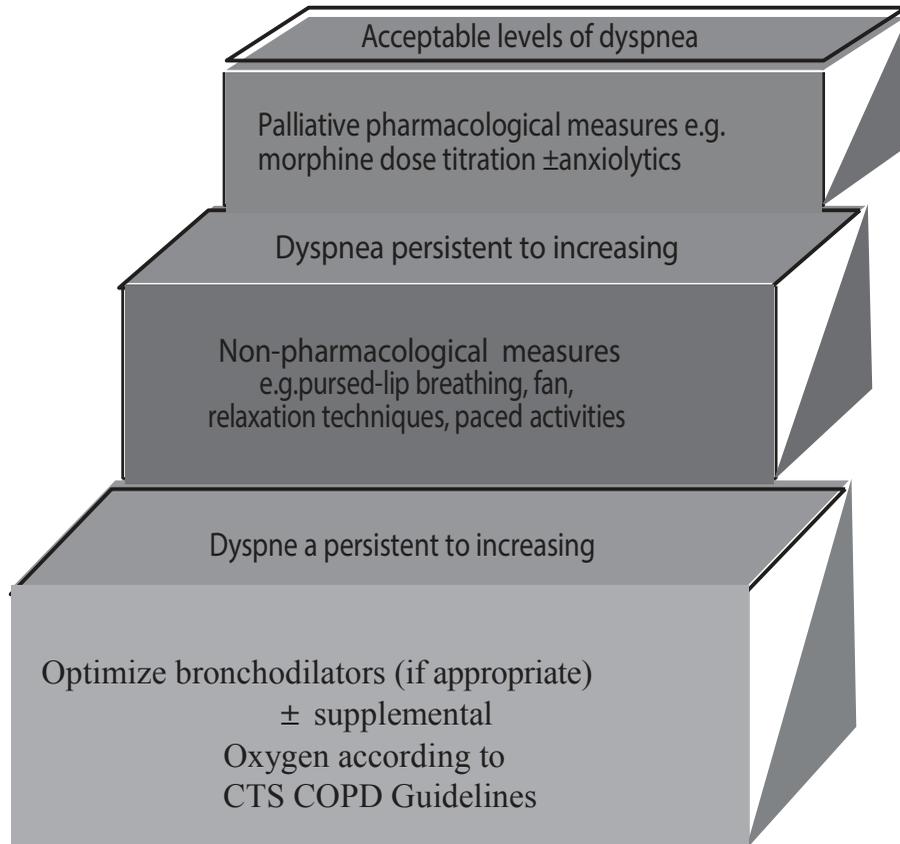


Fig 4.3 – Steps of managing dyspnoea in COPD

c) Opioids

Opioids have been the most widely studied agents in the treatment of intractable dyspnea in advanced stages of cancer and have been found to be safe and effective²⁹. Morphine reduces inappropriate and excessive respiratory drive and substantially reduces ventilatory response to hypoxia and hypercarbia. By slowing respiratory rate, *breathing is made more efficient and the sensation of breathlessness is reduced*.

Short-term administration of morphine reduces breathlessness in patients with a variety of conditions, including advanced COPD, interstitial lung disease, cancer and chronic heart failure. In opioid-naïve patients, morphine is usually started at 2.5 - 5 mg Q6H and titrated according to breathlessness.

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

²⁹ A.L. Jennigs et al. A Systematic Review of the use of opioids in the management of dyspnea; Thorax 2002, 57; 939-944

If the patient is already on morphine for pain and then develops breathlessness, it may help to step the dose up by 50%.

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 - 1 mg sublingually (for longer term effect) or midazolam 1-2 mg SC or oral for the short term, can be used. Theoretically, the combination of opioid and benzodiazepine can worsen the chances of respiratory depression, though this is hardly relevant with the doses of either that we use.

e) A trial of oxygen

Though oxygen via nasal cannula may help, but should be discontinued if it does not help. Though a face-mask is more efficient in providing increased inspired oxygen, it may cause a sense of suffocation and worsen the situation. In advanced illnesses, breathlessness usually 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 stages of illnesses. However, sometimes oxygen may help by correcting hypoxia as well as by reducing panic attacks. Hence we can give a trial of oxygen for 10-15 minutes. Prior explanation to the patient / family is necessary to avoid misunderstanding when oxygen therapy is discontinued. If there is no improvement in symptom during the trial, this fact has to be explained to the family and 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 may thereafter be on oxygen and the attendant paraphernalia.

So, how was Sukumaran managed at home by the home care team (HCT)?

The HCT first talked to Sukumaran and his family to evaluate his symptoms and to understand the family's concerns. They positioned him in a comfortable posture and assessed the effectiveness of non-pharmacologic measures. He was started on bronchodilators, 5 mg oral morphine Q8H and oral dexamethasone 4 mg once daily after breakfast. Since his renal function was abnormal, morphine was started 8th hourly.

CONSTIPATION

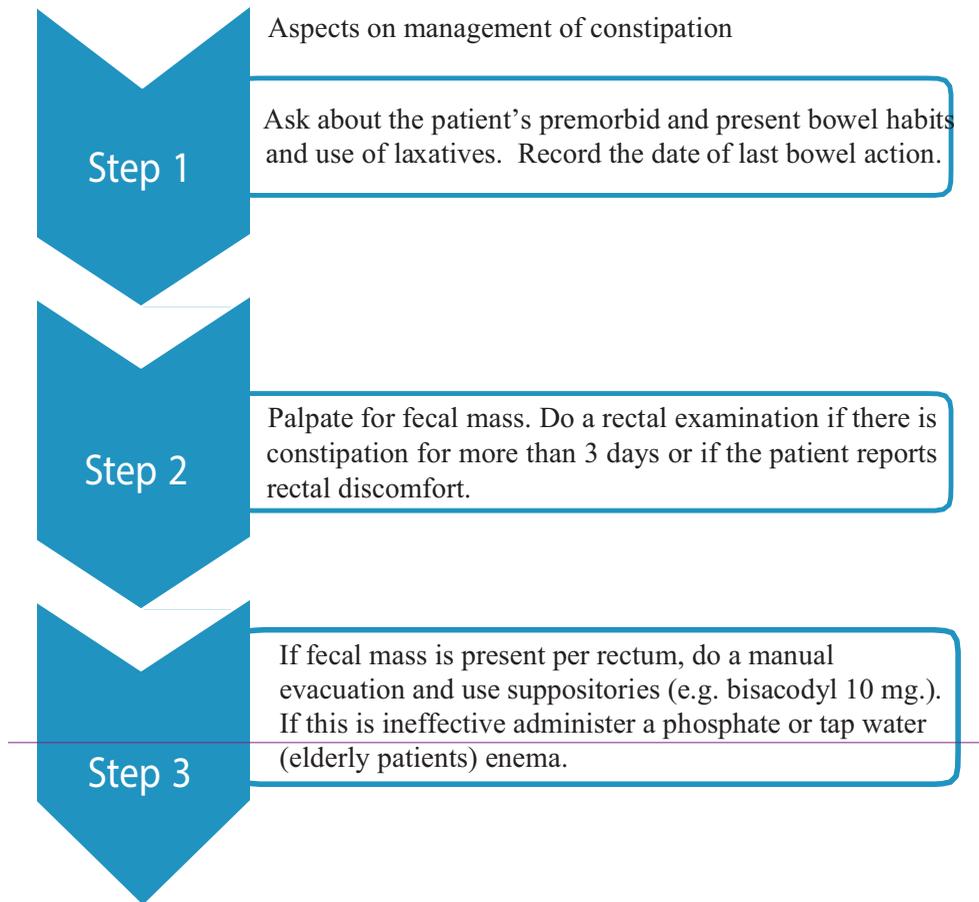
Constipation can be said to be present when there is infrequent passage, small quantity, hard faeces or passage with difficulty.

Table 4.5 Causes of Constipation

Medications	Opioids, tricyclic antidepressants, anticholinergics, 5-HT ₃ 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 the sense of well-being of the patient. Constipation leads to inadequate symptom control through its complications such as loss of appetite, abdominal pain, distension and urinary retention.

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



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 a toilet may be more important than a supply of laxatives.
- Timing and privacy – impatience may lead to straining. Straining compromises defecation and damages pelvic floor function
- Taking warm water at a pre-decided time every morning and massaging the left lower abdomen may assist in bowel movement.

- A squatting position facilitates efficient funneling of the pelvic floor, favoring defecation.

Classification of laxative

Table 4.6 Types of Laxatives

Drug Class	Examples
Bulk forming	Methyl cellulose, Ispagula husk
Lubricants	Liquid paraffin
Surface wetting	Docusate sodium
Osmotic	Lactulose, polyethylene glycol, milk of magnesia
Stimulants	Bisacodyl, senna, sodium picosulphate

* Remember to avoid using phosphate enemas in the elderly and inpatients with renal failure.

What was done for Sukumaran’s constipation by the home care team?

He had not moved his bowel for the past 9 days and 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. Rectal examination showed hard fecal matter. Phosphate enema was given followed by bowel evacuation and Sukumaran was very relieved.

Carers were given advice regarding diet modification and Sukumaran was started on bisacodyl tablet 10 mg daily at bed time. Since the toilet was away from his bedroom, the home care team also arranged for a chair commode and advised the family regarding responding early to his defecation urge and maintaining privacy during the time of bowel movement.

Diarrhoea

Diarrhoea is less common than constipation in patients requiring palliative care. It is the passage of more than three unformed stools within a 24 hour period.

Common causes of diarrhoea in palliative care setting:

- Imbalance in laxative therapy
- Drugs (antibiotics, NSAIDs)
- Faecal impaction leading to spurious diarrhoea
- Radiotherapy to abdomen
- Bowel fistula
- Endocrine tumours
- Odd dietary habits

Table 4.6 Types of Laxatives

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 (steatorrhea)	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 anti-diarrhoeal agents — loperamide (up to 16 mg daily). There are certain specific conditions, which should be treated with specific agents like:

- ranitidine for Zollinger-Ellison syndrome,
- metronidazole for pseudomembranous colitis,
- cholestyramine for cholestasis as well as radiation-induced diarrhoea.

Supportive measures include oral rehydration with home-made sugar and salt-containing fluids or commercially available ORS (oral rehydration solution). Parenteral re-hydration 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 sensation associated with autonomic symptoms like sweating and alterations in heart rate, 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.

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, chemotherapy, raised intra-cranial pressure 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.
- A few mouthfuls given frequently are often more effective than infrequent large meals.

Pharmacological management:

Table 4.8 Management of nausea and 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 mg tds. Neurokinin-1 antagonists e.g. aprepitant (very expensive).
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	Gastro-intestinal obstruction - partial (caused by cancer) Gastro-intestinal obstruction – total	Dexamethasone 8-24 mg/day along with metoclopramide 60-90 mg/day as SC or IV infusion to try to overcome obstruction. Hyoscine butyl bromide 60 mg SC over 24 hr to reduce gastrointestinal secretions. Alternatively, Octreotide SQ 150 to 300 mcg/day (more efficient; expensive).
CNS causes	Radiation colitis Raised intracranial pressure, e.g. from tumour or intracranial bleed; meningeal infiltration	Ondansetron 4-8 mg bd Dexamethasone 16-32 mg (even up to 100 mg/day) SC/ 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 a second anti-emetic is added, choose one from a different 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 (e.g. metoclopramide) and anti-spasmodics (e.g. hyoscine butyl bromide) is not advised.
- Opioids can cause nausea and vomiting through a number of mechanisms. These include stimulation of chemoreceptor trigger zone, increased vestibular sensitivity, gastric stasis, impaired intestinal motility and constipation. If nausea and vomiting are not controlled by anti-emetics, consider switching over to another opioid.

How was Sukumaran's nausea and vomiting managed by the Home Care Team (HCT) ?

Sukumaran 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. Constipation could be another cause for his vomiting.

The home care team advised his 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 1.5 mg at bed time as the etiological factor was suspected to be uraemia stimulating the CTZ.³¹

Nutrition and Hydration

Requests for nutrition and hydration are common at the end of life. Understanding the pathophysiology, ethics and the appropriate treatment are paramount in assessing and managing these requests.

Anorexia

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

It is important to look for secondary anorexia which may be reversible. e.g. dyspepsia, altered taste, malodour, nausea, vomiting, constipation, sore mouth, pain, biochemical abnormalities, drugs, radiotherapy, chemotherapy, anxiety and depression

Cachexia

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. 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

Progesterones (megestrol acetate and medroxyprogesterone acetate) are the first-line therapy for cancer anorexia. They are 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 progesterones (up to 800 mg/day of megestrol acetate and up to 1000 mg/day of medroxyprogesterone acetate) improve food intake and to a lesser extent, body weight and performance status.

Dexamethasone may be used at doses of 2-4 mg daily as an appetite stimulant and to treat nausea. Its effect is generally short. Side effects limit its use as an appetite stimulant.

Prokinetic drugs such as metoclopramide may help in anorexia due to gastric stasis.

Thalidomide, omega-3-fatty acids, melatonin and NSAIDs are also considered as emerging medicines in the management of anorexia-cachexia but they need more research.

Hydration in Terminally ill patients

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

- In ambulatory patients, common sites for SC injections include the abdomen, upper chest above the breast, over an intercostal space and the scapular area.
- In bedridden patients, the preferred sites are the thighs, the abdomen and the outer aspect of the upper arm.
- Normal saline can be delivered subcutaneously by gravity at a rate of not more than 100 ml per hour at one site; thus, about 1.5 L can be delivered at one site and 3 L at two separate sites over 24 hours.
- Average duration for which the subcutaneous cannula can be retained at a single site is 4-7 days.
- Subcutaneous route is usually used for administration of common medications like morphine, midazolam, haloperidol, metoclopramide, hyoscine butyl bromide and glycopyrrolate.

Table 4.9 Advantages and disadvantages of subcutaneous infusion

Advantages	Disadvantages
Low cost, easily taught to lay person	Local oedema (usually not significant)
More comfortable than IV administration, does not cause thrombophlebitis	Local reactions (rare)
Less likely than IV to cause fluid overload	Not good for rapid rehydration; limited total volume per day
Simple insertion, less pain than IV	Contra-indicated in bleeding disorders
Usually does not cause systemic infections	Local infection more visible

Anxiety and Agitation

Anxiety is 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.

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 death, of uncertainty, of uncontrolled symptoms and of being left alone to die.

Assessment of Anxiety

Symptoms like excessive worrying or 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

DELIRIUM

Delirium is characterized by acute and fluctuating cognitive impairment. It is important to differentiate delirium from dementia, the latter being a state of progressive impairment. 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 that usually has an organic cause.

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

Predisposing factors for delirium:

- Severe medical illness
- Poor functional state
- Primary or metastatic malignancy in brain
- Other parenchymal brain lesions
- Faecal impaction
- Unfamiliar environment
- Sensory deprivation (hearing, vision)
- Psychological stress
- Metabolic imbalances, including hyponatremia and hypercalcemia
- Urinary tract infection
- Indwelling urinary catheter.

The typical patient is elderly, has advanced disease, forgets a hearing aid and/or reading glasses when moving to the unfamiliar environment of the hospital and gets disoriented on the next day.

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

Early in the course of delirium, the patient has transient momentary forgetfulness and short periods of impairment of cognition. It is important to identify it at this phase, and treat it to prevent it from worsening to distressing delirium or even agitation.

Agitation

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

There are many causes for agitation including delirium, dementia, schizophrenia etc. Diagnosis of terminal agitation is made when reversible conditions are excluded and when it is associated with other signs of the dying process.

Management of delirium and agitation:

Delirium is one of the most under-diagnosed clinical conditions and grossly disturbs the quality of life. It is entirely a clinical diagnosis.³² 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.

³² Hospital Elder Life Program. Long CAM Instrument. Available at <http://www.hospitalelderlifeprogram.org/private/cam-disclaimer.php>

Pharmacological Management of Delirium:

- Haloperidol is the most commonly used medication for symptomatic treatment of delirium. If started early, 1-3 mg/day of haloperidol can often effectively palliate the symptoms of delirium.
- Other atypical anti-psychotics like risperidone and olanzapine are also used in management of delirium.
- If delirium does not easily respond to haloperidol, the dose may have to be increased. In some cases, doses as high as 20 mg per day (in divided doses) may be necessary.
- In refractory delirium/agitation, it may become necessary to add a benzodiazepine if haloperidol alone is inadequate. Usual doses are lorazepam at doses of 0.5-1 mg given 1-2 hourly orally/intravenously; or titrated infusions of midazolam along with haloperidol may be effective in rapidly. Sedating the agitated delirious patients may help minimize the extra-pyramidal side effects associated with haloperidol.

MALIGNANT WOUNDS

Malignant wounds occur when cancerous cells invade the epithelium and infiltrate the supporting blood and lymph vessels. 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 polymicrobial, 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.

Table 4.11 - Problems of a malignant wound

Physical problems	Psycho-social problems
Malodour	Body image alteration
Exudate	Depression
Bleeding	Embarrassment, shame
Pain	Social isolation, rejection by relatives
Pruritus	Problems with sexuality
Infection	Fear
Nausea and anorexia	Anxiety

Wound assessment

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

- Type of wound, e.g. adherent/non-adherent, black/necrotic, green/yellow slough
- Amount of exudate produced
- Depth, e.g. superficial/deep
- Presence/absence of odour
- History of bleeding
- Description and intensity of pain
- Signs of fistula/sinus formation
- Condition of the surrounding skin – e.g. red, macerated, fragile, showing signs of infection
- Site, location, surface area and presence of nodules
- 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 by boiled and cooled water, if so desired, with a pinch of common salt. Use of normal saline or other sterile intravenous fluid is needless and an unjustifiable expense in a country like India. Cleaning is best achieved, if possible, by showering the wound. Swabbing can be painful and traumatic, and should be avoided. The 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.



Fig 4.5. Empowering the family to apply a simple dressing helps not only to keep the wound clean, but also to improve body image.

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, foam dressings, papaya and many other home remedies have been used to reduce the smell and exudate.

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, periwound maceration, leakage and odour will not be effectively managed. To contain and remove excess exudate from the wound, a plethora of absorbent dressings have been developed. Major categories of dressings include foams, alginates, and hydrofibers, along with super absorbent products based on diaper technology.

Silicone polymers, zinc oxide/petrolatum inorganic compounds, acrylates, hydrocolloid or adhesive film dressing can be used to protect the normal peri-wound skin.

Management of pain

Pain during dressing changes can be managed by local and systemic agents. Local anesthetic agents like lignocaine 1% and bupivacaine 0.25% (with or without further dilution) could be applied over a piece of gauze covering the wound about 15 minutes ahead of dressing to reduce the pain.

Management of bleeding

Bleeding occurs mainly during cleaning, dressing, dressing removal and any 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 towels during severe bleeding may be useful to decrease the anxiety and fear of the patient and family.

The dressing should be soaked with normal saline or home-made saline before its removal in order to reduce the pain of removal. Local pressure should be applied carefully, as the tissues are fragile. Application of powdered sucalfate will help to reduce the bleeding. Adrenaline may help to control bleeding by local vasoconstriction, but carries the risk of systemic absorption, increase in blood pressure and rebound bleeding. Oral or parenteral ethamsylate (increases platelet adhesion) and tranexamic acid (antifibrinolytic) may help. If the bleeding is very severe and if patient has a very advanced disease, 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.

Management of maggots:

If there are maggots, a piece of gauze soaked in turpentine can be held close to the wound. This will bring the maggots out so that they can easily be removed.

What more is required for our patient Sukumaran?

We managed his breathlessness, constipation and nausea. He was moving his bowels regularly, his nausea had settled and his sleep too had improved. His family informed the home care team that he was talking irrelevantly and that his sleep was disturbed. He was accusing his wife of plotting to poison him. This was diagnosed as delirium. His distraught and devoted wife was given explanations about the cause for his behaviour and educated regarding non-pharmacological measures as described above. His haloperidol dose was stepped up. The team followed him up and found his symptoms resolving.

He and his family would continue to require regular visits and communication 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. AL 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 Care23, 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,
and we will do all we can, not only
to help you die peacefully,
but also to live until you die.”*

--Dame Cicely Saunders



62 year old Raj has 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 IV fluids and diuretics and started on ventilator support. Invasive monitoring is established, IV antibiotics are started after blood and urine cultures and on the third day, he receives hemodialysis 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 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 the 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 and most importantly on the informed decision of the person.

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 etc. Under such a circumstance, looking for all reversible contributory factors and considering an aggressive line of management is justifiable if financially feasible and if so desired by Raj and his family. After communicating with the family about the chances of recovery, this aggressive line of management could be considered appropriate.

Raj might be successfully weaned of the ventilator and recover close to his previous health status.

Scenario 2

Let us now consider that Raj, a retired school teacher, had been diagnosed with advanced lung cancer, multiple disseminated metastases and multiple comorbidities. He is unaware of the diagnosis. The treating team suggested chemotherapy with palliative intent. Though financially burdened, the family opted for the chemotherapy, believing it would be curative. They had not understood the medical language including “percentages of median survival.” While on chemotherapy, Raj had intolerable side effects. His general condition worsened due to disease progression. He was bed-bound most of the time with persistent breathlessness, cough, poor food intake, sleep and severe fatigue. 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 some parameters show improvement, weaning him off the ventilator is attempted but not successful. He is now confined to the ICU, started on tube feeds and isolated from his caring family. Family is allowed to see him only for a few minutes every day. His wife and son are distressed with the condition of Raj in the ICU. When the effect of the paralytic drug lightens, he coughs on the endotracheal tube. From the anguish on his face and the tears in his eyes, they perceive the deep distress that he is experiencing. They are desperate to be with 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 about the uncertain outcome and also about his own job security.

Let us analyse this situation

Raj’s admission to the hospital was consequent on 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, this line of management cannot be considered 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 aiming at “Quality of Life” would be considered appropriate line of management.

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 function.

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

Daugherty CK

Quality of Life (QOL)

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 QOL³⁴ is useful to guide health care inputs because it helps the practitioner to take the best decisions regarding patient care. Care 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 treatment is no longer applicable, we start him on morphine (5 mg Q6H), which is also an antitussive, along with dexamethasone (8mg 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, oxygen was discontinued³⁵.

Delirium is acute psychotic behaviour, a common symptom in late stages of progressive diseases. It compromises the fabric of QOL for the patient and family. Reversible contributory factors are electrolyte disturbances, infection and dehydration were looked for and corrected³⁶. Symptomatic management of delirium was then initiated using haloperidol (2.5mg SC³⁷/ 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.

As panic reinforces breathlessness and works to maintain the vicious cycle, lorazepam 1mg was given sublingually for quick anxiolytic effect³⁸.

³⁴ World Health Organization. Measuring Quality of Life. Available at http://www.who.int/mental_health/media/68.pdf

³⁵ Putting the patient under continuous oxygen is a carefully considered decision and not a routine intervention.

³⁶ The strange in-patient environment, and lack of exposure to day / night rhythm and inaccessibility to their visual / auditory aids itself can provoke delirium.

³⁷ Subcutaneous

³⁸ Alternative is Inj. Midazolam 2mg, subcutaneously. For details, refer to Introduction to Palliative Care 4th Edition by Robert Twycross.'

Emotional issues

We have already mentioned many of the elements of psychological distress 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.

What did we do to help him?

While admitted to the inpatient palliative care unit, we had a few meetings with Raj and his family. Raj was initially a bit delirious. The poor prognosis was first conveyed to the family. They were hesitant initially about including Raj in discussions on future plans regarding his care, like place of care, decision on aggressive interventions in case of a critical event and so on. It was acknowledged to the family that the team understood that their affection was the basis for such a step. Subsequently they agreed to an open discussion in Raj's presence. It was then apparent that Raj had already guessed the diagnosis but had hesitated to clarify his doubts because of "silence" on the part of his family and also because he did not want to distress his family. The advanced nature of the disease and futility of aggressive management were thus made clear to both Raj and his family, they were now empowered in participating in the planning of care inputs.

Home based Care

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

Essential care

Prior to discharge from the inpatient unit, we reviewed his medication schedule including anti-hypertensives, hypoglycaemic agents, anti-anginal medicines, anticoagulants and cholesterol lowering agents. With due consideration to his poor food intake, cachexia and poor haemodynamic status, we could discontinue many of the medications except the essential ones needed for symptom relief, the anti-anginal drug and essential hypoglycaemic medication.

Anticipatory prescription

His family was educated regarding management of 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 general practitioner to support the family in case of need.

We also discussed a 'living will'. Raj and the family opted against cardio-pulmonary resuscitation and invasive interventions and this was documented.

We must tackle the subject of expected death very sensitively and with empathy. This is on everybody's mind, but seldom talked about.

It helps to get the patient and family mentally prepared, to close unfinished business like legalities, to make arrangements for religious / spiritual affairs and to say the final good bye to relatives and close friends. It also permits preparation of a "living will" to avoid undignified over-medicalized deaths.

Living will (Advance Health Directive)

When a life-limiting 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 with-out wisdom and discrimination a living will gives an opportunity to the sick person to choose a natural death process³⁹.

Living will OR Advance directive:

This is a legal document that expresses the patient's wishes and desires for one's own health care and 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 extent that the health care providers may proceed with aggressive and invasive interventions.

³⁹ Indian Journal of Critical Care Medicine Vol 9; issue 2; 2005

Reconsidering Cardiopulmonary Resuscitation (CPR)

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.

Death is the inevitable consequence of life and should happen with dignity.

In conditions such as advanced cancer with multiple organ failure OR persistent vegetative state due to irreversible neurological damage, CPR is clearly inappropriate. Honest communications needs to be initiated with the patient and family to help prepare advance directives on resuscitation and other interventions.



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

What happened to Raj at home?

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

THE TERMINAL PHASE

The terminal phase is the period when day to day deterioration occurs particularly of strength, appetite and awareness. At this phase, we must 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 for those left behind, by care and support given to the dying patient and the family.

Nutrition in terminal stage

He was soon unable to swallow 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 don’t want 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 small frequent sips of fluids and soft feeds as much as he was comfortable with.

Raj’s statement also led to a discussion regarding 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 closely bonded during these days.

The last 48 hours is a crucial period in care for the person, family and the 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.

Dying Phase

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, often intuitively pick up subtle signs of global deterioration. They are sometimes quite accurate at predicting approaching death than professionals.

Table 5.1: Symptoms and signs of dying phase

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

Can we predict death?

We cannot 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 the previous, then we may suspect that there are just weeks left; if each day is worse than the previous, we may suspect that there are not more than days left... and so on...

To anticipate needs and meet them, rather than to predict exact time of death, it is useful to understand the situation with as much clarity as possible.

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

As days passed, Raj became profoundly weak, gaunt in appearance, totally bed bound and needing assistance for all activities, drowsy, without any food intake, with difficulty in taking his medications and with abnormal patterns of breathing. With these signs 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 according to their belief.

What is dignified dying?

It is 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 the potential to cause pain and suffering, rather than to improve quality of life.

In Raj’s case, his death is expected and understood as a natural consequence of disease progression. It is not taken as failure of medical treatment. He is not chained to the ventilator, isolated within the ICU. He is at home surrounded and cared for by his family and friends. His distressing symptoms are under control and he is reasonably in control of his situation (nothing being forced e.g. tube feeds). His wish to see his daughter and grandson has been fulfilled; he has completed all legal formalities. He has had the chance to express his love and affection and to 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 and understand the futility of hospitalisation.

Thus Raj died peacefully at home amidst those he loved, after a 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.”*

Julia Neuberger

6. ETHICS BASED DECISION MAKING

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

Part of being a professional is to be 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. 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.

Clinical judgements need to be based on science; but the management must also be based on the patient's and family's values. In situations where there is "clear right" and "clear wrong" answers, decision making is easy. But in many clinical situations, more than one option may look right, leading to dilemmas and difficulties.

Codes of ethics

In some cases the perceived 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 Concepts⁴⁰

The four fundamental principles of medical ethics must be balanced in each case:

1. **Autonomy:** This principle states that each individual has the right to make decisions about his/her own life. The patient is allowed to defer decisions to someone else. But even in the practice of this principle, there can be conflicts and limitations. For example:
 - Should we comply with the patient's wishes even if it would be harmful to him or others?
 - Can there be situations in which we should refuse to do what the patient wants?⁴¹ We must remember that an individual's autonomy is limited by what the society thinks is right.
 - What if an individual wants to commit suicide and asks for your help?

The key part of autonomy is the ability of the patient to consent to or refuse treatment or care. Their wishes should be respected. All ethical principles must be weighed to determine the right course of action.

⁴⁰ Kenneth Calman. Oxford Textbook of Palliative Medicine

⁴¹ E.g. A chronic renal failure patient might request that he be continuously dialysed to maintain renal parameters.

“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)

2. **Beneficence:** This principle states that we should choose the best action for our patients. One must ensure that the “best action” is also considered by the patient as a benefit⁴². In some cases, we must refer the patient to another health care provider to ensure the best care.
3. **Non-maleficence:** This principle states that we should not do anything that may cause a potential harm to the patient. All medicines and interventions can have some undesirable effects. We shall aim to do no harm, but there can be unexpected and unintentional adverse effects of our intervention (double-effect).
4. **Justice:** This principle states that we should ensure equity and equality of care for all. Clearly this is impossible to achieve in all instances, as there are conflicting pressures on how health care is reimbursed or allocated.

Practical application of principle of medical ethics in palliative care:

- **Informed consent:** If we respect autonomy, it automatically follows that we should never do anything on the patient without the person’s consent. For ordinary, everyday procedures and medications, consent is implied; that is, the very fact that the person comes to us for treatment is taken to mean that the person is willing to receive medicines or be subjected to usual injections. But for any significant intervention, such as a surgical procedure or the person being subjected to a medical research, written/informed consent is essential. In the context of illiteracy, written consent often becomes meaningless. With the imbalance of power between the medical system and the person, he/she may sign any document without understanding it. It is our responsibility to ensure, whether literate or illiterate, that every person understands the implications of the procedures that we perform on them.
- **Duty to alleviate suffering:** Beneficence is too often considered only in the context of disease and cure. This is not right. The physician has an obvious duty to alleviate suffering.
- **Respect:** Every human being needs to be treated with respect and courtesy and their dignity should be preserved.
- **Confidentiality:** We have the duty to preserve the person’s confidentiality and do not have the right to discuss matters related to his disease or psychological/social/spiritual issues with anyone other than the members of the treating team. In the context of today’s world of information-sharing and computerization, confidentiality can be easily breached. Respect for confidentiality requires our constant vigilance.
- **Human Rights:** It is important for health care personnel to understand current concepts of human rights –the right to be respected, the right for full disclosure of health information, the right to access to pain relief and the right to life and death with dignity.

⁴² Reduction in the size of a laryngeal tumor in a scan from 14 cm to 3 cms might be a beneficial effect from an oncologist’s point of view. But the patient might view cure or the ability to speak as a beneficial response to treatment.

⁴³ Suppose there is just one bed in a critical care unit and there are 2 patients waiting; one is a 25 year old man with multiple trauma and the other is a 72 year old delirious patient with unstable haemodynamics with reversible co-morbidities such as pyelonephritis. Who should be given this bed?

- Ethics and the law: It is possible that what is ethically correct may be legally wrong. As citizens of a country, we need to respect the law despite our feelings of moral distress/ conflict about the ethics of a situation.
 - **Euthanasia:** In India, euthanasia is illegal. While a nurse or doctor might find euthanasia morally or ethically permissible, it is not legally permissible to practice euthanasia in India. (It is interesting to note that patients' requests for euthanasia are frequently withdrawn once high quality palliative care is provided.)
- Ethics committee: There may be situations in which the ethical decision is not apparent. It is advised that the institution appoint an ethics committee to address serious ethical issues.

The aim of treatment is maximum longevity with the best possible quality of life; sacrificing one for the other can only be done with the patient's informed choice.

Benefit vs. Effect and Futile care

Effect is a response to an intervention limited to improvement in investigation parameter or function of an organ (e.g. 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 (e.g. an unconscious ventilated patient becoming oriented and ambulatory)

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, namely autonomy, beneficence, non-maleficence and justice.

Lala is a 33 year old middle class man, running a small shop for his livelihood, diagnosed oesophageal carcinoma. He has had a recurrence of the disease six months after completing the surgery and radiotherapy. He now 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	<ul style="list-style-type: none"> ▪ Does Lala understand all the implications of the procedure itself and post procedure issues?
	<ul style="list-style-type: none"> ▪ Does he understand the financial aspects of the procedure and its implications? Is his choice an informed one?
Beneficence	<ul style="list-style-type: none"> ▪ Is stent insertion possible in his current clinical condition?
	<ul style="list-style-type: none"> ▪ Will the stent definitely improve dysphagia? If yes, how long would it be before the disease blocks or displaces the stent? Is it worth doing it?
	<ul style="list-style-type: none"> ▪ Will the stent impact his quality of life?
Non maleficence	<ul style="list-style-type: none"> ▪ Is there possibility of unacceptable harm due to the procedure? E.g. tear, tracheo-esophageal fistula formation etc.
Justice	<ul style="list-style-type: none"> ▪ 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’s education?

ETHICS-BASED DECISION MAKING

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

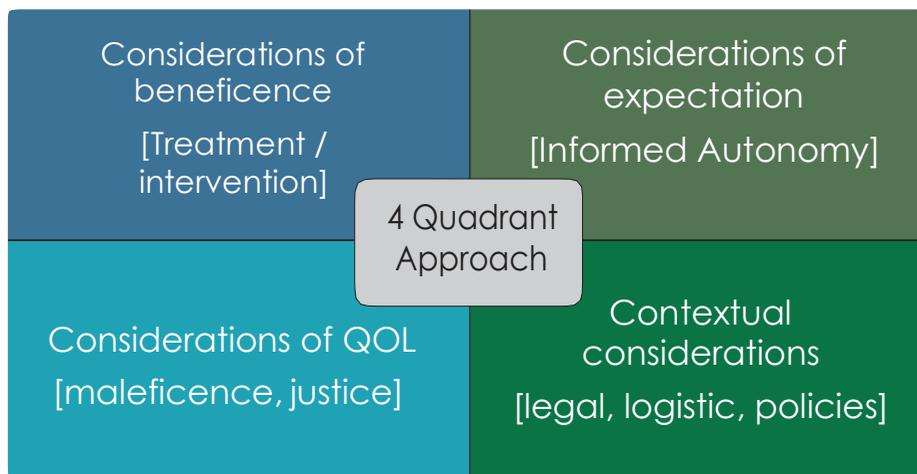


Fig 6.1 – Approach to Ethics based decisions⁴⁴

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.
- Often there is 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. It is critical to have a flexible and compassionate approach.

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>
7. [http://www.who.int/bulletin/archives/79\(4\)373.pdf](http://www.who.int/bulletin/archives/79(4)373.pdf)

⁴⁴ A. Jonsen, M. Siegler, and W. Winslade. J Leg Med. Clinical Ethics 1993 Jun;14(2):355-7.

7. PALLIATIVE CARE FOR THE VULNERABLE AGE GROUPS

Palliative Care for Children



Everyone loves children, but often we do not consider them individuals; often they are considered almost inanimate beings and their feelings are ignored. They too have rights to be considered as individuals and to be treated with respect, not just affection.

The World Health Organization defines “palliative care for children” as⁴⁵:

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

⁴⁵ World Health Organization. WHO Definition of Palliative Care for Children. Available at <http://www.who.int/cancer/palliative/definition/en/>

Depending on their age, there can be considerable differences in their thought processes. Though generalizations are always liable to error in individuals, the following developmental stages may be good for general guidance.

In children younger than 2 years of age, it is particularly important to provide physical comfort through symptom control and by avoiding procedure-related pain. Their comfort can be enhanced by assured presence of a parent even during intensive care unit (ICU) admissions or during procedures. ICU experience with parental separation may even cause post-traumatic stress disorder similar to victims of torture.

Children in the age group of 2-6 years may not understand the finality of death. They may see disease or death as punishment for their own mistakes or sins. They need explanations and reassurance and continuous parental presence to endure the experience of a chronic disease.

Children in the age group of 6-12 years may fear abandonment. Avoiding parental separation is again an important consideration in planning tests and procedures. Communication is best done in a succinct manner. Older children have developed the ability to hear, evaluate and analyse information. For this reason, older children might be best served by facilitating their participation in decision-making.

Religious faith of children tends to be absolute, and prayers can be a source of comfort. This can also create grave problems, such as a sense of guilt that “it all happened because I was a bad boy” or “I did not pray hard enough!” Absolute faith also gives rise to fear of celestial punishment, even for minimal infractions.

Teenagers are often already struggling between the need for independence and the need for love and attention. While facing a progressive disease, their typical sense of indestructibility gets challenged by loss at different levels – physical capacities, roles, access to peers, opportunity to dream, sexuality etc. They may go through extremes of emotion, and will require empathetic non-judgmental listening and counseling.

Children as a family member of a sick person

There are usually major changes in the family dynamics when a family member is diagnosed with a serious illness or is undergoing multiple hospital admissions. The family's reserves are strained and the child may find himself/herself under the care of relatives or other strangers. Their familiar world collapses and he/she may see the disease as punishment for mistakes. They may irrationally worry about their own death or death of a surviving parent.

Children desperately need explanations regarding the illness and the changes in their lives.

Siblings of the children with disease are particularly at risk of neglect, because all the parents' attention may be focused on the ill child. It is important to recognize and discuss this with the parents. The parents' verbal and physical affection to the siblings are essential therapeutic tools to reassure the child of his/her important role in the family. Requesting them to help with care for the ill child might help them feel included in the family and may add to their emotional health in some settings.

WHO RECOMMENDATION FOR PAIN RELIEF IN CHILDREN

WHO uses the term “persisting pain” to address long-term pain related to medical illness, including pain associated with major infections (e.g. HIV), cancer, chronic neuropathic pain (e.g. following amputation), and episodic pain as in sickle cell crisis.

Behavioural indicators of acute pain in children are seen by observing facial expression, body movement and body posture, inability to be consoled, crying and groaning.

When pain continues unabated, these normal indicators might disappear.

Behavioural indicators of persisting pain in children
<ul style="list-style-type: none">▪ abnormal posturing▪ fear of being moved▪ lack of facial expression▪ lack of interest in surroundings▪ undue quietness▪ increased irritability▪ low mood▪ sleep disruption▪ anger▪ changes in appetite▪ poor school performance▪ fear of strangers

Undernourished children may not express pain through facial expressions and crying, but may whimper or faintly moan instead. They might have limited physical responses because of underdevelopment and apathy.

Assessment Tools

Caregivers are often the primary source of information, especially for preverbal children, as caregivers know the child’s previous pain experiences and behaviour related to pain. The caregivers’ behaviour, beliefs and perceptions can have a significant impact on the child’s response to pain. The approaches used by parents and caregivers to console the child, such as rocking, touch and verbal reassurance must be considered when observing distressed behaviour.

Goals of care:

- **Relief of suffering**
- **Improvement in quality of life**
- **Strengthening the experience of childhood**

There are special vulnerabilities faced by children needing with serious illness. The child is often too small, too sick and too disempowered to ask for palliative care; the parents are often exhausted from the care of a chronically ill child and their other family commitments. The parents may also be unable to come to acceptance of incurability, and may therefore demand curative attempts even when futile, thus adding to the child's suffering.

Medications

WHO recommends that all moderate and severe pain in children should always be addressed. Inability to establish an underlying cause should not be a reason to conclude that the pain is not real.

Depending on the situation, the treatment of moderate to severe pain may include non-pharmacological methods, treatment with non-opioid analgesics⁴⁶ and treatment with opioid analgesics.

The benefits of using an effective strong opioid analgesic (morphine) outweigh the benefits of intermediate potency opioids (tramadol, codeine) in the paediatric population. The risks associated with strong opioids are acceptable when compared with the uncertainty associated with the response to codeine and tramadol in children.

It is important to select routes of administration that may easily be used in children e.g. liquid formulations. Intramuscular route is painful and is best avoided. Rectal route also may not be suitable due to unreliable bioavailability, but may be considered based on the setting.

Medicine	Neonates 0-29 days	Infants 30 days -3 months	Infants and children 3 months to 12 years	Maximum dose
Paracetamol	5-10 mg/ kg every 6-8 hours*	10 mg/ kg every 4-6 hours*	10-15 mg/kg every 4-6 hours* #	Limited to: 12mg/kg every 6 hours, if for longer than 4 doses/day.
Ibuprofen	(Not Recommended)		5-10 mg/kg every 6-8 hours	Child: 40 mg/ kg/day
<p>*- Children who are malnourished are more likely to be susceptible to toxicity at standard dose regimens due to reduced natural detoxifying glutathione enzyme.</p> <p># - do not exceed > 1 gm per dose at a time.</p> <p>Morphine is the recommended 1st line opioid.</p>				

⁴⁶ World Health Organization. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. Available at http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf

The appropriate dose of the opioid is the dose that produces pain relief for the individual child. The goal of titration to pain relief is to select a dose that prevents the child from experiencing pain between two doses using the lowest effective dose. This is best achieved by frequent assessment of the child's pain relief response and adjusting the analgesic doses as necessary.

Starting dosages for opioid analgesics for opioid-naive neonates		
Medicine	Route of administration	Starting dose
Morphine	IV injection b	25–50 mcg/kg every 6 hrs
	IV infusion	Initial IV dose ^a 25–50 mcg/kg, then 5–10 mcg/kg/hr 100 mcg/kg every 6 or 4 hrs
Fentanyl	IV injection b	1–2 mcg/kg every 2–4 hrs
	IV infusion b	Initial IV dose ^c 1–2 mcg/kg, then 0.5–1 mcg/kg/hr ^c
<p>a. Administer IV morphine slowly over at least 5 minutes.</p> <p>b. The intravenous doses for neonates are based on acute pain management and sedation dosing information. Lower doses may be required for non-ventilated neonates.</p> <p>c. Administer IV fentanyl slowly over 3–5 minutes.</p>		

Starting dosages for opioid analgesics for opioid-naive children (1–12 years)

Medicine	Route of administration	Starting dose
Morphine	Oral (immediate release)	1–2 years: 200–400 mcg/kg every 4 hrs 2–12 years: 200–500 mcg/kg every 4 hrs (max 5 mg)
	Oral (prolonged release)	200–800 mcg/kg every 12 hrs
	IV injection a	1–2 years: 100 mcg/kg every 4 hrs 2–12 years: 100–200 mcg/kg every 4 hrs (max 2.5 mg)
	SQ injection	20 mcg/kg/hr
	IV infusion	Initial IV dose : 100–200mcg/kg, then 20–30 mcg/kg/hr
	SC infusion	20 mcg/kg/hr
Fentanyl	IV injection b	1–2 mcg/kgb, repeated every 30–60 minutes
	IV infusion b	Initial IV dose 1–2 mcg/kgb, then 1 mcg/kg/hr
Methadonec	Oral (immediate release)	100–200 mcg/kg
	IV injection ^d and SC injection	every 4 hrs for the first 2–3 doses, then every 6–12 hrs (max 5 mg/dose initially) ^e

- a. Administer IV morphine slowly over at least 5 minutes.
- b. Administer IV fentanyl slowly over 3–5 minutes.
- c. Due to the complex nature and wide inter-individual variation in the pharmacokinetics of methadone, methadone should only be commenced by practitioners experienced with its use.
- d. Administer IV methadone slowly over 3–5 minutes.
- e. Methadone should initially be titrated like other strong opioids. The dosage may need to be reduced by 50% 2–3 days after the effective dose has been found to prevent adverse effects due to methadone accumulation. From then on dosage increases should be performed at intervals of one week or over and with a maximum increase of 50%.

Episodic or recurrent pain occurs intermittently over a long period of time and the child can be pain free in between each painful episode. Painful episodes can often fluctuate in intensity, quality and frequency over time and are consequently unpredictable. This type of pain may be indistinguishable from recurrent acute pain but might be associated with a more severe impact on the affected child’s physical and psychosocial life. Examples of this type of pain include migraine, episodic sickle cell disease pain, recurrent abdominal pain. Persisting and recurrent pain can coexist, especially in conditions such as in sickle cell disease.

Breakthrough pain is characterized as a temporary increase in the severity of pain over and above the pre-existing baseline pain level. For example, if a child is taking pain medicines and has good pain control with a stable analgesic regimen and suddenly develops acute exacerbation of pain, this is considered breakthrough pain. It is usually of sudden onset, severe, and of short duration. A number of episodes of breakthrough pain can occur each day. It is a well-known feature in cancer pain but it is also seen in non-malignant pain conditions. Breakthrough pain can occur unexpectedly and independently of any stimulus, i.e. without a preceding incident or an obvious precipitating factor.

Incident pain or pain due to movement has an identifiable cause. The pain can be induced by simple movements, such as walking, or by physical movements that exacerbate pain, such as weight bearing, coughing or urination. Diagnostic or therapeutic procedures can also cause incident pain.

End of dose pain results when the blood level of the medicine falls below the minimum effective analgesic level towards the end of dosing interval.

Further learning:

A free e-learning program on palliative care in children is available with the International Children's Palliative Care Network (ICPCN) - <http://www.icpcn.org/icpcns-new-elearning-programme/>

Palliative Care for the Elderly

'National Policy on Older Persons' [January, 1999] by Government of India, defines 'senior citizen' or 'elderly' as a person who is of age 60 years or above. In India, the elders (7.4% in 2001) will account for 12.17 percent of overall population by 2026, which reflects the low birth rates and the long life expectancies achieved over the years. Being a vast country, India may face several problems with majority of seniors being illiterate and far poorer than their counterparts in the developed countries.

There is relatively higher ratio of females to males in the elderly population than in the general population since independence. The problems faced by the elderly women are exacerbated by their low literacy rate, customary ownership of property by men and lack of employment. About 70% of elderly women are totally dependent on others as compared to 30% of elderly men. Migration of youth to regions offering employment contributes to social isolation and helplessness of elders. It is not uncommon to see an 84 year old accompanied by an 81 year wife as the main carer.

Evaluation

Detailed history, examination and early specific laboratory and radiologic tests will help diagnostically to evaluate the elderly patient with a change in the clinical status. Clinical presentations for the elderly patient are often different than in younger patients, such as a sudden issue with intelligence, instability, incontinence, immobility – also known as the “Big Four” in geriatric care. Each of these symptoms should be investigated for reversible causes and not assumed to be a part of normal aging.

Investigations

Investigation is an essential tool in the diagnosis of elderly patients and best done early.

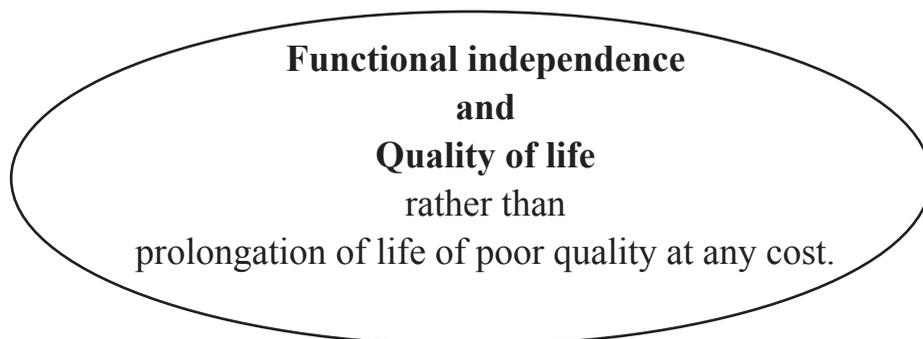
- Investigate only to plan care that may improve the quality of life, not just to make a diagnosis.
- It is important to know the age related variables while interpreting the results.
- Non-invasive tests are preferred, if available.

The older person may be searching for the meaning of life while trying to cope with losses of close friends and relatives and a sense of worthlessness. Death may no longer be a distant vague possibility, and can be the source of persistent anxiety. Routine screening for spiritual despair, delirium, depression or dementia can uncover these common issues

Goals of care in elderly

- Enabling functional independence
- Improving quality of life
- Preventing morbidities from those disorders to which elderly are at high risk – e.g. delirium, falls, fractures, infections
- Preventing neglect and abuse
- Maintaining dignity and self-worth
- Address family and caregiver issues

Goals of care



When planning care, we shall keep asking ourselves: will this step help the person to improve functional independence and quality of life? If there has been an acute deterioration, then effort must be to bring it back to the level prior to the acute condition. In chronic progressive conditions, the aim is to reorient expectations to realistic levels, optimize the medical condition and make arrangements for maximum functional independence and support for patient and family to endure the situation.

Pain relief in elderly

Pain is often not expressed and needs to be elicited through direct questions. In patients with cognition dysfunction, visual pain scales are used to decide if analgesic therapy is required.

Medications

It is important to check renal/hepatic function and reduce the dose when needed.

Polypharmacy is common which can in turn lead to drug overdose, drug interactions and poor drug compliance. Regular review of the medications can prevent these issues and reduce the out-of-pocket expenses.

Non-adherence in elderly can be due to cognitive impairment, complexity of the regime, more than one prescriber or poor understanding of the disease and the medications.

Pain management:

The principles of pain management are the same as in younger adults, remembering particularly that:

- NSAIDs are often poorly tolerated due to greater incidence of gastric and renal dysfunction. If essential, use gastroprophylaxis and avoid dehydration.
- Opioids may be the safest agents, but the dose and frequency of administration must be decided based on renal dysfunction. For example, in advanced age, it may be prudent to start with morphine six hourly rather than the customary four hourly.
- Dehydration is an important factor for toxic side effects of opioids and needs to be corrected while titrating opioids.

Advice on nutrition with emphasis more on the quality rather than the quantity can be useful. Every consultation should also be considered an opportunity for preventing further deterioration.

Preventing further deterioration

- Life style modifications – high nutrition diet, alcohol, tobacco
- Exercise – physical and mental (for example, reading)
- Use of physical aids (walker, cane) since some medications such as opioids or antidepressants may increase falls
- Supplements – Calcium, Vit D
- Vaccinations
- Polyvalent Pneumococcal vaccination during 1st consult and every 10 years
- Tetanus

References

1. Situation Analysis Of The Elderly in India [June 2011] Central Statistics Office, Ministry of Statistics & Programme Implementation, Government of India

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
 - c. Low dose oral morphine
 - d. Intravenous naloxone
 - e. Blood gas estimation
2. Sree, a patient with carcinoma of the 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 “breakthrough 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.
 - c. Pain that makes the person suicidal.
 - d. Pain that lasts for several days once it has started.
 - e. 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 disease, 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.
 - c. Euphoric action which reduces panic.
 - d. Inducing sleep.
 - e. 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
 - e. 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. Extrapiramidal symptoms
 - d. Endogenous depression
 - e. Myoclonus
13. A patient is tormented with the following thought, “I am a teetotaller and I do not smoke. I did not harm anyone. How could I get cancer?”
- 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 hasten death
 - d. Integrates the psychological and spiritual aspects of patient care
 - e. Focuses on quality of life.
15. Which of the following NSAIDs carries the least chance of adverse coronary and cerebral catastrophes ?
- a. Diclofenac
 - b. Mefenamic acid
 - c. Etoricoxib
 - d. Ibuprofen
 - e. Celecoxib
16. Which is incorrect 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 5 mg Q6H.
 - c. The doses required for breathlessness are higher than that required for pain relief.
 - d. Reduces 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 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 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 pain.
 - c. Dyspnoea
 - d. Diarrhoea
 - e. Sedation
21. All the following are not responsive to morphine EXCEPT
- a. Tension headache
 - b. Gastric malignancy
 - c. Biliary colic
 - d. Skeletal muscle spasm(cramp)
 - e. Intestinal spasmodic pain (colic)
22. A patient getting oral morphine Q4H has satisfactory relief but complains of pain half an 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 the most predictable side effect of appropriately titrated oral morphine therapy?
- Respiratory depression
 - Constipation
 - Severe drowsiness
 - Delirium
 - Myoclonus

True or False questions

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

- Pain is not just a sensation but an emotional experience.
- Pain and suffering are synonymous.
- Autonomic responses are more dominant in chronic pain.
- Chronic pain is a temporal extension of acute pain.
- Pain caused by a stimulus that does not normally provoke pain is allodynia.
- 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.
- 'Curing' or 'not curing' is the sole responsibility of medical professionals.
- Living will is an important document that states patient's preferences in end of life care.
- In palliative care setting, prognostication includes predicting impending death.
- Medical professionals should focus more on the overall benefit to a patient and not get carried away by focussing on responses based on blood chemistry or imaging.
- Symptoms are inherently subjective and hence self-report must be the primary source of information on symptoms.
- Panic is often an accompaniment of breathlessness and can worsen breathlessness.
- Biochemical and blood gas investigations are the most useful parameters in assessing chronic breathlessness due to advanced cancer.
- Impacted faecal matter can lead to overflow diarrhea.
- Diagnosing presence of delirium requires specific laboratory investigations.

Answer Key

Answers to Multiple Choice 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

Answers to True / False Questions:

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

Are you a medical student or a doctor?

Your years in a hospital must have brought it home to you that only a minority of your patients get cured. Over time, you may have heard your seniors saying, “There is nothing more we can do.” You may have learnt to live with the knowledge that the science that you studied has such a minimal chance of success. Or, if you have not, it may be leaving you disgruntled and frustrated.

It does not have to be this way. The art and science of palliative medicine can equip you to heal and improve quality of life, even when cure is not possible.

Trivandrum Institute of Palliative Sciences (TIPS)

WHO Collaborating Centre for Training and Policy on Access to Pain Relief

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