



# **An Indian Primer of Palliative Care**

For medical students and doctors

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## 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)<sup>1</sup> 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.

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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.<sup>2</sup>”

**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 outpatient 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.

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<sup>2</sup> 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.

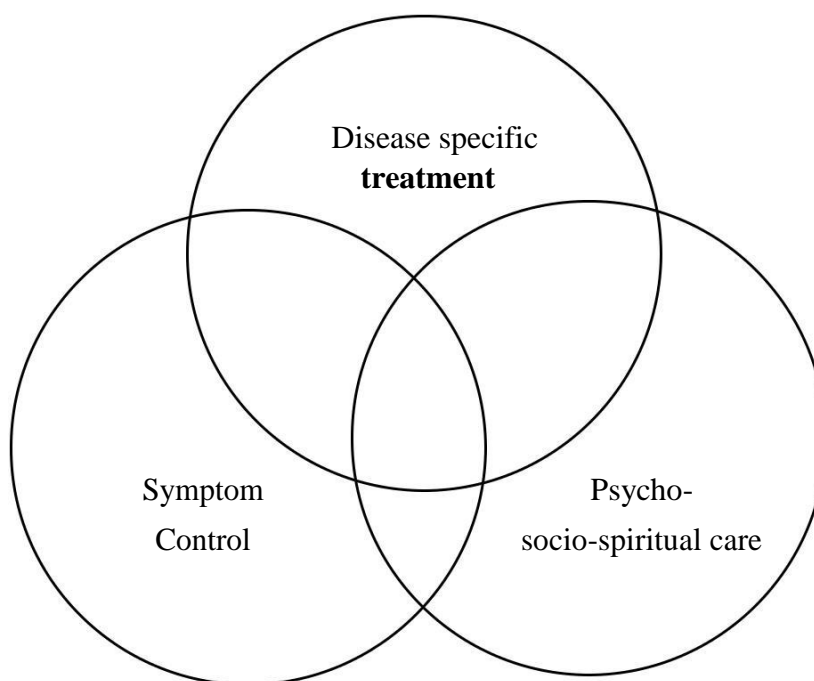


Fig 1.2 – Components of Palliative Care

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"> <li>▪ Physician is the general</li> <li>▪ Intent – curing</li> <li>▪ Disease, a problem to be solved</li> <li>▪ “Don’t just be there, do something.”</li> <li>▪ Goal is to improve quantity of life</li> <li>▪ Death: A failure of treatment, to be prevented at all cost</li> <li>▪ Valuable approach in caring for acute episodic diseases.</li> </ul>	<p>Patient is sovereign</p> <ul style="list-style-type: none"> <li>▪ Intent – healing</li> <li>▪ Disease an experience to be lived</li> <li>▪ “Don’t just do something... be there.”</li> <li>▪ Goal is also to ensure life and death with dignity</li> <li>▪ Death: An inevitable reality, neither to be hastened nor postponed at the cost of quality of life</li> <li>▪ Valuable approach in caring for chronic progressive disease.</li> </ul>

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

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

## WHY IS PALLIATIVE CARE TRAINING REQUIRED?

Learning Objectives:

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

Explain the need of palliative care in regular clinical practice.

### **The need for palliative care worldwide**

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 diseases<sup>5</sup>.

*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.*

<sup>3</sup> Murtagh, F. E. et al. How many people need Palliative Care? Palliative Medicine online: 21 May 2013

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

<sup>5</sup> 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>

## PALLIATIVE CARE NEED IN INDIA<sub>6</sub>

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?

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

Ans: All of the above

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<sup>6</sup> WHO. The Global Burden of Disease. Available at [http://www.who.int/healthinfo/global\\_burden\\_disease/GBD\\_report\\_2004update\\_full.pdf](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
  - o Parkinson's disease
  - o Multiple sclerosis
  - o Motor neuron disease o
 Stroke and paralysis
- Progressive systemic diseases
  - o COPD, ILD
  - o Heart diseases
  - o 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.

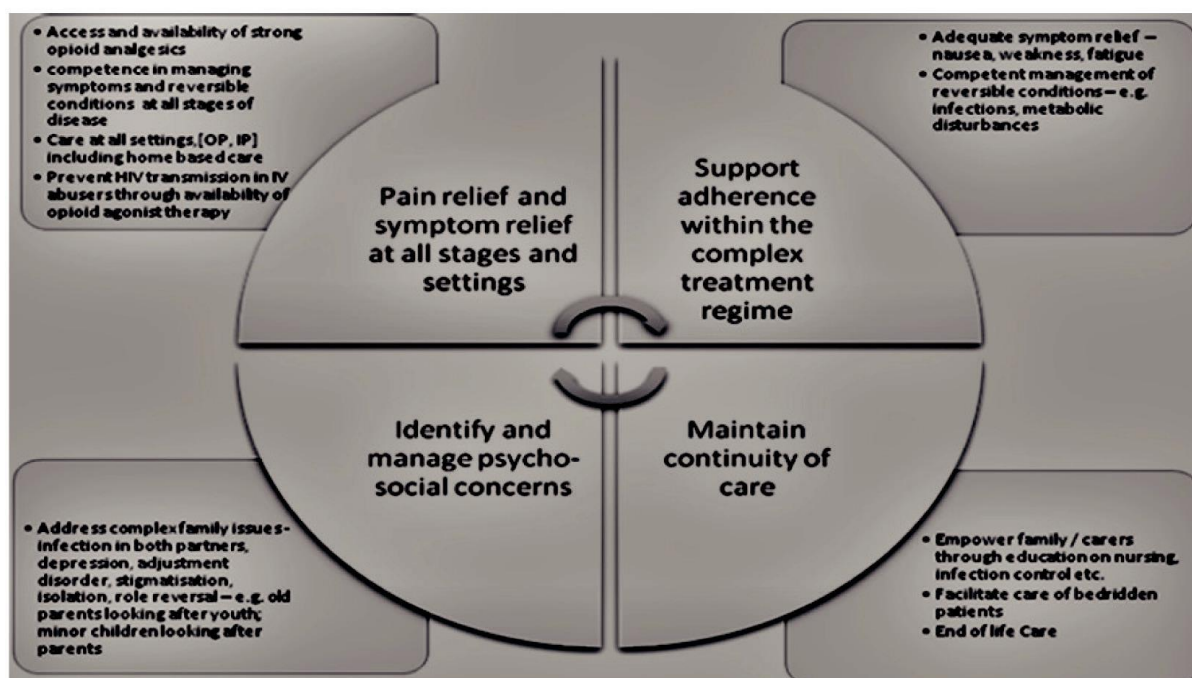


*In countries with a high burden of HIV infection, palliative care should be part of a comprehensive care and support package, which can be provided in hospitals and clinics or at home by caregivers and relatives.*

*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

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# 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 therapy<sup>7</sup>

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.

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<sup>7</sup> 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.

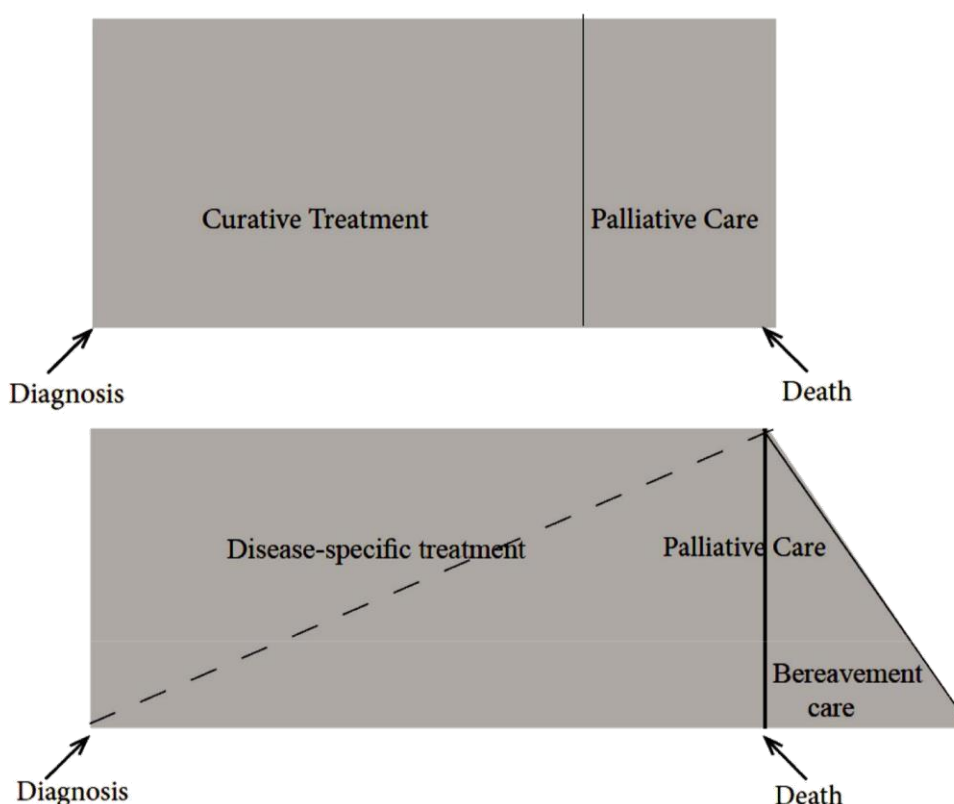


Fig 1.4: Relevance of palliative care during the course of a chronic diseases<sup>8</sup>

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.

<sup>8</sup> 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]<sup>10</sup>. 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.*

<sup>10</sup> 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](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.



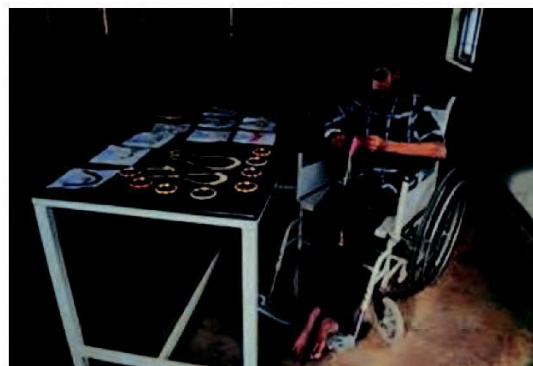
We can educate and empower Ravi on bowel and catheter care and thereby give him a sense of control. If he is motivated, we may teach him Clean Intermittent Self Catheterisation technique (CISC) and eliminate the need for a permanent indwelling catheter. This can also prevent repeated febrile episodes 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](http://www.palliativecare.in)
4. [www.palliumindia.org](http://www.palliumindia.org)
5. <http://www.instituteofpalliativemedicine.org/>