

# Palliative Care: A Hope to Live Life to the Fullest a Descriptive Study

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**Abstract**—WHO definition of palliative care is “An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

*Palliative care run parallel with the medical treatment. Palliative Care mainly include medication, nutritional support, spiritual guidance, relaxation techniques, emotional support, patient and family awareness regarding the disease.*

*Palliative care starts as soon as the patient is diagnosed with the life threatening disease. Patients can receive their palliative care in their hospital, rehabilitation centres, long term care centres, or in the patient’s home.*

*Palliative care team mainly include Physician, Nurses, Physical and Occupational Therapist, Dietitian, Social Worker, Chaplain, Social Worker, Grief Coordinator.*

*Palliative care management work on the principles: Knowledge and skills, Seamless care, Holistic care, Multidisciplinary care, Effective communication, Scope of care, Timing of palliative care, Patient and Family centred care.*

*According to WHO more than four million patients would benefit from palliative care .Less than one percent of those who need palliative care services have access to such services in India. Palliative care is must need to mitigate the sufferings of the patient and there is need to encourage this care in developing countries as well.*

**Keywords:** *Palliative Care, Multidisciplinary, Quality of life, Life threatening disease.*

## 1. DEFINITION

The word ‘palliative’ has been originated from the Latin word ‘pallium’ meaning to cloak or cover. The palliative care definition given by WHO in 2002 is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [1]

Palliative care for children and young people focuses on comfort and quality of life for the child and support for the whole family. As per WHO(1998):1.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.2.It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.3. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.4.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.4. It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Palliative care is also called as comfort care and supportive care .Palliative care focus on treating people suffering from the symptoms and stress of serious illnesses such as cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney disease, Alzheimer’s, Parkinson’s, Amyotrophic Lateral Sclerosis (ALS) and many more. This type of care treats pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and any other symptoms that may be causing distress.

## 2. HISTORY

Palliative medicine is the result of the long struggle to accept life on its own terms, openly and accepted worldwide. The term first developed by a physician Dame Cicely Saunders in the year 1960 for terminally ill patients, he was the founder of first hospice St. Christopher’s in London. In 1969, physician Kubler Ross had given 5 stages of death in his book emphasizing the need of death and dying. In 1974, Dr. Balfour Mount, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal, Canada, coined the term “palliative care” and introduced Dr. Saunders’ innovations into academic teaching hospitals. He first demonstrated the holistic care for people with chronic or life-limiting diseases

and their families who were experiencing physical, psychological, social, or spiritual distress. In 1997, the Institute of Medicine report, "Approaching Death: improving care at the end of life" documented glaring deficiencies in end-of-life care in the United States. With the support of the Robert Wood Johnson Foundation and George Soros' Open Society Institute, a major effort to bring palliative care into mainstream medicine and nursing was launched. In 2006, the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education recognized the subspecialty of Hospice and Palliative Medicine. [3]

### 3. AIMS AND GOALS

Palliative care aims:

- To improve the quality of life
- To give relief from pain and other distressing symptoms
- To support life and keeping people as healthy as possible, regarding dying as a normal process
- It doesn't quicken or postpone death
- To combine psychological and spiritual aspects of care
- To offer a support system to help people live as actively as possible until death
- To offer a support system to help the family cope during a person's treatment and in bereavement
- To use a team approach to address the needs of the person who is ill and their families
- To cover the earlier stages of illness, along with other therapies that are aimed at prolonging life
- To provide care in hospitals, hospices and also in patient's homes.

The goal of palliative care works on the components of palliative care: Hope, Honesty, symptom relief Psychological support, Team work and Partnership.

### 4. PALLIATIVE CARE TEAM

Palliative care is an interdisciplinary team work to provide the maximum benefit to the patient and family. The Palliative care team includes Palliative care specialist or Physician, Nurses, Counsellor, Psychologists, Chaplains/Spiritual care practitioners, Social workers, Occupational therapists and Physiotherapists, Pharmacists, Dietitian and Volunteers.

The skills needed for a palliative care giver: Committed to work, A good listener, A good communicator, Provide empathy not sympathy, Understand the patient's priority, Able to feel the pain of the patients and their families, Supportive in multiple directions on the patient's needs. [2]

### 5. NEED FOR PALLIATIVE CARE

Palliative care covers a broad issues and needs of the patient:

- Physical Need: for example pain, fatigue, weakness, vomiting, insomnia, breathlessness, and hypertension.
- Emotional Need: palliative care helps to deal with the emotions, Depression, Anxiety, and Fear.
- Spiritual Needs: Palliative care helps to bring the patient closer to their spiritual beliefs and develop their faith.
- Caregiver need: To help the patient's caregivers to handle their emotions and help their patient to cope up bravely.

### 6. STAGES OF GRIEF

The 5 stages are some of the responses to loss that many people have. However everyone grieve in their own way. The five stages of grief are denial, anger, bargaining, depression and acceptance and they are a part of the process of learning to live the life. Everyone may not go through all the stages and the order of stages may be different. Understanding the stages helps to cope up and better equip people to deal with loss.

### 7. STAGES OF PALLIATIVE CARE

#### Stage 1: Planning for end of life care

To encourage the patient to make decisions regarding their care in advance wherever possible. This way they retain control over their lives for as long as possible, and friends. Advance planning also helps to clarify the need of the patient and where that help will come from for example insurance arrangements and do everything to reduce financial worries for patients and those around them.

#### Stage 2: Spiritual and emotional care

It runs in parallel with other care from day one to the very end of life. Palliative Care employs chaplains, social workers, and counsellors to help the patients and their loved ones to understand and accept death, and be ready for it when the time comes.

#### Stage 3: Help at home

Help to make home more comfortable and easier place for those with terminal illnesses, and both medical professionals and a team of trained volunteers are available to help with household chores and with care at home. Pain control can also be a priority.

#### Stage 4: Inpatient care

Patients who need inpatient care, palliative services for those to be available in hospitals or nursing facilities.

### Stage 5: Bereavement support

Palliative care does not end when the patient passed on. Palliative Care provides bereavement counselling in individual and group sessions to anyone in the community who needs it.

### 8. PRINCIPLES OF PALLIATIVE CARE

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspect of care
- Offers a support system to help patients live as possible until death
- Offers a support system to help patient's families cope during the patient's illness and in their own bereavement

### 9. ETHICS OF PALLIATIVE CARE

- **Autonomy:** Autonomy is about the respect for a person's right to make decisions concerning their care. It promotes the development of a trusting relationship between a healthcare worker and a patient.
- **Communication:** The patient has a right to know about the diagnosis, the treatment that is proposed, its effects and any side effects
- **Consent:** Once the patient is given sufficient information, they have the prerogative to accept or not accept the care or treatment offered.
- **Confidentiality:** Confidentiality protects the autonomy of the patient by allowing them to control information about themselves.
- **Privacy:** Central to a respect for personal autonomy is the concept that the privacy of the individual must be respected.
- **Beneficence:** Doctor should act in the best interest of the patient.

### 10. PALLIATIVE CARE VS. HOSPICE CARE

Hospice care and palliative care are very similar when it comes to the most important issue for dying people care. The difference between the two are:

- Both focus on comfort and care. Palliative care programmes have curative and life prolonging challenge whereas in Hospice care there is no curative or life prolonging measures.
- There is no time restrictions in palliative care whereas illnesses with prognosis of six months or less are in Hospice care.

- Palliative care usually administered in hospitals as this care starts as soon as the patient is diagnosed, whereas Hospice care usually administered through visits of Hospice care givers in the patient's home.

### 11. COMMON MYTHS ABOUT PALLIATIVE CARE

- Palliative care is often misunderstood and some people believe things about it that aren't true.
- **Myth:** If I need palliative care it means I'll have to go to a hospice, one can receive palliative care in a range of settings including in your home, in hospital, in a care home or a hospice.
- **Myth:** If I have palliative care it means my doctors have given up and I'll no longer receive active treatment for my illness, one can receive palliative care alongside active treatments for your illness, such as chemotherapy and radiotherapy.
- **Myth:** If I have palliative care I'll no longer be seen by other specialists who know about my particular disease. One can receive support alongside treatment from the clinicians who have been treating your particular illness.
- **Myth:** Palliative care is just about treating pain and other physical symptoms. It aims to give a holistic approach to give you the best quality of life possible. This means caring for all your physical, emotional, psychological, social and other needs.
- **Myth:** Only people who are ill or dying can benefit from palliative care
- Palliative care teams are very aware that caring for someone with an advanced illness can have a big impact on family members and friends. They do what they can to help people cope.

### 12. PALLIATIVE CARE IN INDIA

Palliative care in India is still at an early stage of development and faces numerous problems. The concept of palliative care is relatively new to India, it have been introduced in the mid-1980s. Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries. In 1975, the Government of India initiated a National Cancer Control Program. By 1984, this plan was modified to make pain relief one of the basic services to be delivered at the primary health care level. The hospice and palliative care movement in India started tentatively in the mid-1980s and has slowly increased over the last two decades. [4]

In India, the earliest facilities to deliver palliative care within cancer centres were established in some places like

Ahmedabad, Bangalore, Mumbai, Trivandrum, and Delhi in the late 1980s and the early 1990s. Palliative Care was initiated in Gujarat in 1980s with the opening of a pain clinic and palliative care service under the department of Anaesthesiology at Gujarat Cancer and Research Institute, a Regional Cancer Centre in Western India. One of the important steps in the history of palliative care development in India was also began from here; forming of Indian Association of Palliative Care (IAPC).

The Kerala network has more than 60 units covering a population of greater than 12 million and is one of the largest networks in the world. In April 2008, Kerala became the first state in India to announce a palliative care policy [4]

Cancer and other Non-Communicable Diseases have emerged as major public health problems in India. The National Cancer Control Program of the Government of India is an initiative though it constitutes one of the very few such models in the world. Cancer control and other life threatening disease need a multidisciplinary approach and palliative care is an important component of this approach. Despite its limited coverage, palliative care has been present in India for about 20 years.

### 13. BARRIERS TO PALLIATIVE CARE IN INDIA

There are over 135 hospice and palliative care services in 16 states in India, concentrated in large cities. There are 19 states or Union territories in which no palliative care provision was identified.

Barriers to the development of palliative care include:

- Poverty
- Population
- Geographical distances
- Opioid availability
- Limited national palliative care policy
- Inadequate training of health care personnel
- Inadequate standard of care
- Lack of information
- Lack of financial resources

### 14. SUMMARY

Palliative care is necessary part of health care services. Palliative care gives hope and improves the quality of life of terminally ill patients, it helps them to make as independent as possible even in their last stages of life. Palliative care helps the patients to cope up and gives physical, emotional and spiritual support to the patient. But awareness among people about Palliative care still needed in developing countries like India. Therefore, a lot of work to be done for creating awareness among people and training in Palliative care.

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