

Understanding Palliative Care

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Palliative care has been in practice informally for centuries. It has gained formal status recently. The concept has evolved from unorganized origins to the current complex interdisciplinary approach.

Origin :

In the pre-historic times, focus of individuals and cultures was on circumstances **after** death. The concept of care of the dying or the **hospice care** gained attention at a later date. The providers of such care were religious institutions and the recipients were those with limited resources and no family members. The term “hospice” has its origin in the latin word “*hospes*”, that referred to a travelling guest or a traveller’s host. And the first houses dedicated to the care of the dying were set up to manage care for travellers and crusaders who became ill. Such care still continued to be provided by religious institutions.¹ The concept evolved during the 18th and 19th century, but the care still continued to be limited to patients and was not extended to patient’s relatives.

Modern times :

The 20th century medical advances, while offering a cure for many illnesses, also resulted in health system ignoring those people who could not be cured. Dr. Cecily Saunders (1918-2005) originally a registered nurse, then a social worker in Great Britain, studied medicine to meet this challenge. She is recognised as the founder of the modern Hospice Care. Her work in recognising the multidimensional nature of suffering and the need for emotional, psychological and spiritual support for both, the **terminally ill patients and their family** was the foundation of the modern hospice and palliative care.

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Dr. Balfour Mount (Born in April 1939), a Canadian physician, surgeon and academician is considered the father of Palliative care. He was a Surgical oncologist at the Royal Victoria hospital of McGill University in Montreal Canada and coined the term ‘Palliative Care’ in 1974.² He demonstrated first, what palliative care meant to be. It meant to provide ‘whole person care’, the philosophy first put forward by Sir William Osler, a Canadian physician (1849-1919) - “The good physician treats the disease; the great physician treats the person who has the disease”. Palliative care provides holistic care for people with chronic or life-limiting diseases, and their families who experience physical, psychological, social and spiritual distress.

Clinical practice guidelines for quality palliative care were first released in 2004, expanding the focus of palliative care to include not just the dying patients, but also patients diagnosed with life-limiting diseases.²

The ‘**World Health Organization**’ defined Palliative care in 2013, as 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.³

It is very clear from the above definition that palliative care must

1. Include dying patients and those with life limiting or life-threatening diseases
2. Include patients as well as relatives
3. Include physical, psychological, social and spiritual problems while caring.

All these aspects make palliative care a complex interdisciplinary speciality focussing on improving quality of life for **persons** with serious illnesses **and their families**.

The **core components** of such care include^{4,5}

- assessment and treatment of physical and psychological symptoms
- identification of and support for spiritual distress
- expert communication to establish care goals
- assist with complex medical decision making and coordination of care
- practical aid for patients and their family care givers
- mobilization of community resources to ensure a secure and safe living environment
- collaborative and seamless models of care across a range of care settings such as hospital, home, nursing home and hospice.

The **team** includes primary treating clinicians, nurses and social workers along with support from professionals in nutrition, rehabilitation, pharmacy and religious institutions.^{4,5}

Paradigm Shift :

- **Role expansion** - The role of palliative care has expanded in recent times, so that palliative care specialities now also provide palliative treatment in the earlier stages of disease alongside disease-directed medical care, improving quality of care and medical decision making irrespective of the stage of illness.⁶
- **Palliative care beyond malignancy** - Historically, palliative care was focussed on patients with incurable cancer. However, the

current view is that, access to palliative care should be based on need rather than diagnosis. Based on this criterion many patients with non-malignant diseases qualify for such care, eg. Patients with chronic heart failure, end stage renal failure, chronic lung disease and long-term neurological diseases.⁷

In this issue of the journal, P. Karandikar has given a detailed review on neuro-palliative care and its role in modern medicine. She has discussed neuro-palliative care as an emerging sub-speciality in neurology. Describing various terminologies associated with palliation, the growing need for such care, the team approach and adjuvant skills required to offer such care, she has concluded that there is definite need to extend palliative care in neurology and train the practicing neuro-physicians on this aspect of care.

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