

# Current State of Palliative End-of-Life Care in India

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## Abstract

End-of-life care is a humanistic approach that aims to deliver the quality of life for those patients and families facing life-limiting advanced medical illnesses in clinical practices. It demands a holistic assessment through multidisciplinary team interventions to effectively encounter the patient's psychological sufferings, social isolation, and mental disharmony. However, end-of-life care is still an unheard area of care in most parts of the Indian sub-continent. The health care systems in the country like UK, America, Canada, Australia, New Zealand, etc., were at an advanced stage of delivering 'good death' in the face of painful, life-threatening medical illness. The goal of end-of-life care is not to shorten neither prolong the patient's life but to focus on alleviating pain and improving quality of life. Yet, 80% of the terminally ill patients in India failed to receive end-of-life care. Effective implementation of plan and policy, maximum availability of essential medications, and public awareness are the current challenges in Indian palliative end-of-life care.

**Keywords:** End-of-life care; Ethical principles; Legal norms; Palliative care

## Introduction

**Objective** The primary aim is to explore why India is called a country not to die by many. The study is to understand the status of palliative end-of-life care and the current challenges in delivering excellent or meaningful death in its clinical practices.

## Methodology

The proposed study is an analytical method basing on the existing documents and literature and with the advance of medical technologies, death in the modern era has evolved from home to hospital and other nursing care centres. End-of-life care is a worldwide phenomenon that helps in improving the patient quality of life and well-being of the whole for those with advance medical illnesses like HIV and cancer. The primary aim of end-of-life care is to acknowledge the several dimensions of a patient's need, such as; physical pain and symptom control, safeguarding the ethical norms regarding death and dying, and the legal principles in critical care. However, India is still considering a place not to pass by many. Dying with dignity and good death are the two unheard topics of discussion in most Indian healthcare systems. Palliative end-of-life care in India at present is visible as the most neglected area of care, in which 80% of the total population did not access it so far.

## Defining end-of-life care

The recent advances in medical technology, diagnostics, and other related antibiotic therapies created bioethical dilemmas confronting clinicians in critical care units. Due to the new advancement in modern medicine, the process of dying becomes more prolonged, and an increasing number of people require long-term care for chronic conditions. On the other hand, the clinicians are less trained in providing holistic assessment while encountering the psycho-emotional sufferings, social isolations, and spiritual disharmony experienced by the dying patients. End-of-life care is an interdisciplinary medical field focusing on preventing and relieving psycho-emotional sufferings and mental conflict for patients/families dealing with advanced medical illness. It is a supportive care approach aiming to deliver a quality of life and work in the best interest of the patient and family [1]. Effective end-of-life care requires both hospice and palliative care that helps those with life-threatening incurable medical illnesses to live as well as possible until the inevitable death strikes.

Modern hospice care is an interdisciplinary, integrated approach that aims at caring rather than curing those facing end of life. Hospice care focuses on treating the person and symptoms of the disease rather than the disease itself. The hospice involves a team-oriented approach to expert medical care, pain management, and psychological and spiritual support that expressly personalized to the patient's needs and wishes. The core concept of hospice care accepts death as the final stage of human life and affirms to neither hastens nor postpones death. Hospice care is also family-centered that includes the patient and the family in decisions making at any level [2]. Palliative care is not for patients near the end of life alone but in both acute and long-term settings. The World Health Organization (WHO) states that: "Palliative care is an approach that improves the quality of life of the patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering utilizing early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual [3]." Unlike hospice, palliative care can be provided at any stage in the course of an illness and extended to the family bereavement period.

## The current state of palliative end-of-life care in India

End-of-life care in India originated in Shanti Avedna Sadan in Mumbai, founded in 1986 by Lucito D'Souza. The second phase of its development was in Kerala, with the formation of the Pain and Palliative Care Society in 1993 in Calicut and the Indian Institute of Palliative Care in 1994. The first free Palliative Care Services in North India was in 1997 in Delhi, while the Guwahati Pain and Palliative Care Society becomes the first in the North-Eastern part of the country. The formation of Pallium India in 2003 was another milestone for the establishment of palliative care centers in another eleven states of

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the country through its charitable organization. In 2010 the Medical Council of India accepted palliative end-of-life care medicines as an integrated course in medical sciences. However, the Ministry of Health in 2012 advocated that the National Program for Palliative care was merely theoretical propaganda with minimal implementation. The underlying reason being the insufficient funds from the government and lack of awareness and education [4, 5].

At present, palliative end-of-life care is visible functioning in 16 states intending to relieve physical pain symptoms alone. Kerala alone has 230 clinics located in its 12 districts, which caters to only 3% of the total population [6]. In 2008 the Indian public health system, in collaboration with WHO and other non-governmental organizations, made some efforts to develop manual guidelines for palliative care services at the hospital and community level. It also aims to improve the existing palliative care and quality pain management in the country. The effort resulted in forming the National Programme for Palliative Care (NPPC) under the National Health Mission (NHM) in 2012. The program operates under the National Programme for Prevention and Control of Cancer, CVD, Diabetes, and Stroke (NPCDCS), with a provision for establishing palliative end-of-life care services in every district hospital of the country. It was to set up palliative end-of-life care centers, distributed in a 60:40 proportion between the Centre and state, while 90:10 in the North-Eastern parts of the country [7]. As per the 2017 report, West Bengal, Kerala, and Assam were visible setting up the operationalizing palliative care units in selected district hospitals. The technical support and training of the health care professionals are the two contributing factors for the advocacy and raising awareness of palliative end-of-life care in the country. Though it is minimally functioning, three types of palliative end-of-life care are visible available in the country: Home-Based Care, Outpatient Services, and Hospice Care Services. Home-based care is one of the effective ways patients in rural areas can access palliative end-of-life care. In the WHO report, India in 2010 has around 60 million people above 65 years, increasing to 227 million by 2050, constituting 20% of the total population. However, lack of palliative care facilities, poor quality of death index, and lack of medical infrastructure, India becomes a place not to die for many.

### The legal position of end-of-life care in India

Since its infancy, palliative end-of-life care was a neglected area of care in the country; there were no sound legal principles around death and dying until the Aruna Shambaug case (a nurse who was gang rape and lived in a vegetative state for 42 years in Mumbai). It would be true to say that it was in 2009 the Supreme Court passed the bill for the first time by allowing passive euthanasia on the 42 years of vegetative patient Aruna Shambaugh however, though the government accepted passive euthanasia, but only on few exceptional cases. It also stated that euthanasia was never a law in this country. With strict instructions, the Supreme Court on March 2011 and July 16, 2014, issued a public notice on legalizing passive euthanasia that allows the patient and the family to withdraw the ongoing medical treatment only to those who are in the vegetative state and need to be in the rarest case in its clinical practices.

Another legal challenge in end-of-life care lies in the issue of death and dying. Basing on the Transplantation of the Human Organs Act of 1994, the end of the patient is when they permanently lost the evidence of life and living, in regards to the death of the brain stem or in the case of cardio-pulmonary, which is when the blood circulation and the breathing stop functioning in the dying individual. Section 46 of the Indian Panel Code, death of a person, is when the normal organs in the

human body stop working, but the code also holds onto its situational ethics on end. The brain stem here mainly refers to the part of the human brain that is responsible for breathing. However, the Indian Legislation Section 2 (b) of the Birth and Death Registration Act of 1969 holds that the death of the brain stem alone is not a good criterion to declare a person as deceased. The Act acknowledges the process of ventilation breathing as life under living and cannot be pronounced dead. Sometimes, in the Intensive Care Unit, patients experience the death of the brain stem but still breathing with the help of ventilation, which could be living from the heart. The best example is in the Aruna Shambaug case, a girl who survived and breathed for 42 years even after the death of her brain stem.

Based on the 196th report of The Law Commission of India in 2006, a patient declaring their "Advance Will" was strictly prohibited mainly to avoid misusing it for personal gain. On the other hand, in the joint statement of The Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC) stated that at present, there are no proper guidelines for the provision of the moral and ethical dilemmas with regards to end-of-life care, especially in the policy connected to euthanasia. However, the Law Commission of India, in their 241st report of 2012, permitted the practices of euthanasia, which would be mainly based on the humanitarian ground and the law also agree to protect those medical practitioners who genuinely act for the best interest of the dying patient's and the family. The definition of euthanasia as per the Law Commission of India is mercy killing through the help of lethal drugs used in the clinical practices on the sincere request of the patient, in which the family is not permissible to make any decision in connection to euthanasia on the patient behalf. However, the definition of euthanasia given by the Forgoing of Life Support Treatments (FLSTs) proposes a process of 'letting die of the patient' without the intervention of any other factors, and refusal of the on-going medical treatment does not mean to attempt suicide either. Even though in the last phase of the patients in end-of-life commonly experience loss of sense and cannot decide on their own, the right to act on the patient's behalf given to none.

### The ethical principles or issues in end-of-life care

Justice in palliative end-of-life care is the underlying concern for the well-being of the whole and enhances the patient's quality of life. It is an appropriate assessment of the patient to maximize the patient's welfares through an integrated approach and avoid unproductive evaluations in the clinical practices. In end-of-life care, the responsibility of the clinicians is not to fulfil every wish of the patients, instead to maintain the medical ethics, policy, and professional treatment standard in any given situation. On the other hand, the law also upholds that the physicians in the end-of-life care settings are strictly advised not to go against the patient's will/choices regarding the refusal of the on-going medical treatment even if it causes the patient's death. The physician's responsibility is to provide the medical treatment information in detail and leave the individual's decision-making part. The law demands the physicians to always act in the patient's best interest without any obligation and deliver good death by giving the patient and the family to prepare well for the inevitable end. Medical ethics is a set of rules that governs the activities of medical professionals and perfume their tasks according to the medical standard through its moral principles. The patient has full right to the details of their diagnosis information and either accept the treatment or refuses it.

The medical ethical principles are not a law but a guiding factor that has uttermost importance in caring for those with a medically advanced illness like HIV and cancer. The Indian Palliative End-of-Life

Care laid its ethical foundation on patient autonomy, beneficence, non-maleficence, social justice, or appropriate treatment. The autonomy of the patient is an important domain in palliative end-of-life care. It is self-right and self-respect to be independent, mainly regarding decision-making on treatment policy. The patient's autonomy in clinical practices requires their presence as an active member of the management team and decision-making. The autonomy gives the patient to restore the sense of having full authority over their illness, risks versus benefits, and the core deciding factor to outweigh the burdensome issues. It is also important for the physicians working in end-of-life care to decide for the patient's welfare and what benefits the dying patient and family the most by knowing all the truthful information about the medical treatment policy or the patient's condition. Since palliative end-of-life care aims not to shorten nor prolong patient life but to deliver the quality of life and well-being of the whole through any possible means, the physicians should possess adequate knowledge of pain and symptom management. However, relieving the pain and distress of the patient through mercy killing or by any means is not an option; the ethical principle, on the other hand, allows the use of opioids to do away with the pain and distressful symptoms.

Non-maleficence is the state of doing no harmful activities while attending to the needs of the palliative end-of-life care patient. It avoids ineffective medical treatment with no possible benefits that would possibly increase the risk factors in the terminal diagnosis. The prime focus in end-of-life care is to make dying more meaningful rather than a fearful or dreadful inpatient experience. The process of dying in individual experience should be when they find meaning in suffering and time all the various needs of the dying individual addressed and taken care of through any possible means. It is also important for the health care providers to earn the trust of their patients, which would help in having quality communication where the patient can share their thoughts and wishes without any hesitation. Even in the last phase of terminal ill diagnosis, where patients normally lose their sense and ability to decide on their own, the clinicians should respect and value. The principle compelled the physicians not to continue aggressive life-prolonging or the withdrawal of the ongoing treatment without the patient's concern. Overall, fair treatment gives the patient the right to claim what they are legitimately entitled to be the core emphasis of the ethical principle in end-of-life care.

### A good death: what constitutes a meaningful death?

End-of-life care for the quality of life and death is still an unheard topic in most Indian clinical settings. The developed countries like UK, USA, Canada, Australia, etc., are at the advanced stage aiming to deliver "good death" in the face of painful terminal experiences. A meaningful death is free from death anxiety, distress, and suffering consistent with the cultural and ethical norms. Death anxiety is the degree of anxiety regarding the anticipation of death, which is persistent and interferes with everyday life functioning, also commonly understood as the fear of death or the fear of dying process. The sign and symptoms can be visible in solicitude, dread, extreme timidity, and distress that cause disorder, which requires a maximum amount of care and emotional support. A good death a meaningful dying process that occurs when the patient is physical, psychological, spiritually, and emotionally supported by their family, caregivers, and friends. In one research finding the successful dying or good death has three main preferences for the dying process (94% of reports), pain-free status (81%) and emotional well-being (64%). The followings are the elements of a good death in clinical practices:

- Adequate pain and symptom management.

- Avoiding a prolonged dying process and feeling a sense of control.
- Clear communication about decisions by patients, family and physician.
- Adequate preparation for death, for both patient and loved ones.
- Finding a spiritual or emotional sense of completion and affirming the patient as a unique and worthy person.
- Strengthening relationships with loved ones and not being alone.
- To achieve a "good death" for any person who is dying, irrespective of the situation, place, diagnosis, or duration of illness.
- Emphasis on quality of life and quality of death.
- Acknowledge that good EOLC is a human right, and every individual has a right to a good, peaceful, and dignified death.

Though many religions and legal systems do not encourage. Knowing when death is coming and prepared for is another element of a good death. Respecting the wishes of the dying patients and allowing them to choose death could also be another practical element in delivering a good end. However, in India, such provision does not exist, resulting in considering India a place not to die by many. At present, there is an appeal submitted to the Supreme Court on allowing advance directive care in the Indian clinical setting.

Looking at the current situation, the majority of the terminally ill patients in India experience disadvantage dying. The reason is the absence of 'good death' principles and its infrastructural requirement in Indian palliative end-of-life care. The disadvantage dying refers to the group of people whose physical, social, and spiritual care are at risk of undermined or neglected because of societal attitude, ignorance, or discrimination in their end of life. Most commonly, people with HIV/AIDS, learning disabilities, older people, most commonly cancer patients from poverty, and dementia. Even the third gender community is also at greater risk. Thus, modern India fails to deliver holistic care, which is an urgent need.

### Findings

1. End-of-life care for the quality of life and death is still an unheard topic in most Indian clinical settings.
2. India had several issues in health and well-being, mainly in pain and non-pain symptom management.
3. The need of the hour is to effectively implement the end-of-life care policy and plan, availability of essential medicines and medical facilities, public education, and awareness.
4. The proper implementation of end-of-life care will avoid unnecessary medical expenses, like undergoing chemotherapy at the final stage of terminal ill diagnosis. The unavailability of essential drugs for pain management in palliative end-of-life care in some parts of the Indian sub-continent needs special consideration

### The current challenges and discussion

The misconception about palliative care by confining mainly to end-of-life care is the most significant challenge in India. This misconception is common even among oncologists and physicians, resulting in failing to referred needed patients to palliative care. Palliative care aims to provide the best possible quality of life at every

stage of treatment in clinical practices. Several positive outcomes have been visible to those access to palliative care at the early stages. Such misconceptions or the lack of awareness even among the medical practitioners fail to acknowledge the maximum numbers of patients and families with no access to seek relief during their diagnosis period.

Palliative end-of-life care is the most neglected area of care in Indian medical care. Only 1%-2% of the total population in India have access to end-of-life care or pain management at present. Even the majority of the Indian medical students also failed to access the curriculum on pain management. The use of opioids for managing severe pain in terminal ill-treatment and major trauma needs special considerations among medical students and other clinicians. The need of the hour is to effectively implement the end-of-life care policy and plan, availability of essential medicines and medical facilities, public education, and awareness. The proper implementation of end-of-life care will avoid unnecessary medical expenses, like undergoing chemotherapy at the final stage of terminal ill diagnosis. The unavailability of essential drugs for pain management in palliative end-of-life care in some parts of the Indian sub-continent needs special consideration.

In health and well-being, India had several issues to deal with, mainly in pain and non-pain symptom management. Modern India turns out to be a cancer hub with 2.5 million cancer-affected people, which is likely to be increased by 50% in 2020 if the governmental and non-governmental agencies had done no immediate action plan. Once the killer cells grow and affect the patient's start losing their body sites, it usually leads to a paralyzing condition, requiring a multidisciplinary team for the treatment procedures. On the other hand, dying with dignity or peaceful death in the Indian health care system is an alien term, mainly due to the absence of pain and symptom management in its medical syllabus in undergraduate and postgraduate medical students. The minimum availability of the palliative end-of-life care centers and the higher prices of medical treatment fees are also the underlying reason for many terminally ill patients not receiving end-

of-life care. The urgent need is to integrate palliative end-of-life care as primary health education in the training of medical professionals in the country. The negligence of the holistic needs of the dying patients in end-of-life care in the medical-related curriculums needs an immediate revitalization to deliver the whole person treatment and quality of life. Clinical management in terminal diagnosis, peaceful death, dying with dignity, dealing with several mental disharmonies, and psychological issues in the undergraduate medical curriculum are also significant challenges. The exceptional attention should be on the various dimensions of the patient's needs while maintaining the country's ethical principles and legal norms and uplifting the urgent necessity of palliative end-of-life care in India today.

## Conclusion

The need of the hour is to integrate palliative end-of-life care in the country's health care system and the training of the medical practitioners. The inclusion of social involvement and addressing the psycho-spirituality needs in palliative end-of-life care is also an important domain and the immediate needs of the dying patient for the quality of life, well-being of the whole, peace, and dying with dignity.

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