

The State of Palliative End-of-Life Care in India: An Analysis

Anuj Kumar*

Department of Palliative Medicine, Tata Memorial Centre, Mumbai, Maharashtra, India

Abstract

End-of-life care is a compassionate approach that aims to provide a high standard of living for patients and their families who are facing life-limiting illnesses in medical settings. It requires a comprehensive evaluation through interdisciplinary interventions to effectively address the patient's emotional distress, social isolation, and mental turmoil. Despite this, end-of-life care is largely unrecognized in most parts of the Indian subcontinent. Countries such as the UK, America, Canada, Australia, and New Zealand have advanced healthcare systems that are capable of delivering a good death in the face of painful, life-threatening illnesses. The primary objective of end-of-life care is neither to shorten nor extend the patient's life, but to focus on reducing pain and enhancing the quality of life. However, 80% of terminally ill patients in India do not receive end-of-life care. The current challenges in Indian palliative end-of-life care are the effective implementation of plans and policies, the maximum availability of essential medications, and public awareness.

Keywords: End-of-life care; Ethical principles; Challenges; Well-being; Palliative care

Introduction

The main objective of this study is to investigate why India is often referred to as a country where people should not die. Specifically, the study aims to assess the status of palliative end-of-life care and the challenges that exist in providing a dignified and meaningful death in clinical practices. The proposed methodology for this study involves an analytical approach that will rely on existing documents and literature. In modern times, with the advancements in medical technology, the place of death has shifted from the home to hospitals and other nursing care centers. End-of-life care is a global phenomenon that seeks to improve the quality of life and overall well-being of patients with advanced medical illnesses such as HIV and cancer. The primary objective of end-of-life care is to address the various dimensions of a patient's needs, including physical pain and symptom control, ethical considerations regarding death and dying, and legal principles in critical care. Despite the importance of end-of-life care, it remains an overlooked topic in many Indian healthcare systems. Dying with dignity and a good death are rarely discussed, and palliative end-of-life care is one of the most neglected areas of care in India, with 80% of the population not having access to it thus far. The advancement of medical technology, diagnostics, and antibiotic therapies has created ethical challenges for clinicians in critical care units. The process of dying has become more prolonged due to medical advances, and an increasing number of people require long-term care for chronic conditions. However, clinicians are often not adequately trained to provide holistic care, including addressing psycho-emotional suffering, social isolation, and spiritual distress experienced by dying patients.

End-of-life care is an interdisciplinary medical field that focuses on preventing and relieving psycho-emotional suffering and mental conflict for patients and families dealing with advanced medical illness. It aims to provide supportive care that delivers a quality of life and works in the best interest of the patient and family. Effective end-of-life care requires both hospice and palliative care, which help those with life-threatening incurable medical illnesses to live as well as possible until death [1]. Hospice care is an integrated approach that prioritizes caring over curing for patients facing the end of life. It focuses on treating the person and symptoms of the disease rather than the disease itself. Hospice care involves a team-oriented approach to expert medical care, pain management, and psychological and

spiritual support that is personalized to the patient's needs and wishes. The core concept of hospice care acknowledges death as the final stage of human life and aims to neither hasten nor postpone it. It is also family-centered, including the patient and family in decision-making at any level [2]. Palliative care, on the other hand, is an approach that aims to improve the quality of life of patients and their families facing problems associated with life-threatening illness. Palliative care can be provided at any stage in the course of an illness, not just near the end of life, and can be extended to the family bereavement period [3]. The current status of palliative end-of-life care in India can be traced back to the establishment of the Shanti Avedna Sadan in Mumbai in 1986 by Lucito D'Souza. The Pain and Palliative Care Society was founded in Calicut in 1993, followed by the Indian Institute of Palliative Care in 1994. Other notable establishments include the first free Palliative Care Services in North India in 1997 and the Guwahati Pain and Palliative Care Society in the North-Eastern region [4,5]. Pallium India was established in 2003 to establish palliative care centers in 11 more states across the country.

While palliative care is visible in 16 states, it mainly focuses on relieving physical pain symptoms. Kerala, in particular, has 230 clinics for 3% of the population. The National Program for Palliative Care (NPPC) was formed in 2012, aiming to establish palliative end-of-life care services in every district hospital across the country. West Bengal, Kerala, and Assam have taken steps to operationalize palliative care units in selected district hospitals, and three types of palliative care are available: Home-Based Care, Outpatient Services, and Hospice Care Services [6]. However, despite efforts to raise awareness and advocate for palliative end-of-life care, the lack of facilities, poor quality of death index, and inadequate medical infrastructure continue to make India a challenging place to die [7].

*Corresponding author: Anuj Kumar, Department of Palliative Medicine, Tata Memorial Centre, Mumbai, Maharashtra, India, E-mail: anuj_k@gmail.com

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Since the beginning, palliative end-of-life care was not given much attention in India, and there were no clear legal principles surrounding death and dying until the Aruna Shambaug case. In 2009, the Supreme Court allowed passive euthanasia in exceptional cases, and in 2011 and 2014, issued notices to legalize passive euthanasia for patients in a vegetative state. However, euthanasia is not recognized as a law in India. The definition of death is based on the Transplantation of Human Organs Act of 1994, but the Birth and Death Registration Act of 1969 states that the death of the brain stem alone is not enough to declare someone deceased. Advance Will was previously prohibited to avoid misuse, but in 2012, the Law Commission of India allowed euthanasia under humanitarian grounds and to protect medical practitioners who act in the best interest of the patient and their family [8,9]. However, there are still no clear guidelines for end-of-life care and euthanasia, and the right to make decisions on behalf of a patient in the last phase of life is not given to anyone. The main concern in end-of-life care is justice, which prioritizes the patient's overall well-being and quality of life through an integrated approach. Clinicians should assess patients appropriately to maximize their welfare, but they must also uphold medical ethics, policies, and professional treatment standards. Physicians are not supposed to fulfill every wish of the patient but should respect their choices regarding the refusal of ongoing medical treatment, even if it results in death. The physician's role is to provide detailed medical information and leave decision-making to the individual. The law requires physicians to act in the patient's best interest and provide a good death by allowing patients and families to prepare for the inevitable end. Medical ethics guide medical professionals to follow moral principles while performing their duties according to the medical standard. Patients have the right to know their diagnosis and decide whether to accept or refuse treatment.

The principles of medical ethics do not carry the force of law, but they are critical in providing care for individuals with serious medical conditions such as HIV and cancer. The Indian Palliative End-of-Life Care is based on ethical foundations such as patient autonomy, beneficence, non-maleficence, social justice, and appropriate treatment [10,11]. Patient autonomy is particularly crucial in end-of-life care, as it allows patients to make decisions about their treatment independently. Patients must be active participants in the decision-making process and management team in clinical practice [12,13]. Autonomy allows patients to regain a sense of control over their illness, assess risks and benefits, and weigh the burdensome issues. In end-of-life care, physicians must make decisions that benefit the patient and their family, considering all truthful information about medical treatment policies and the patient's condition. The aim of palliative end-of-life care is not to shorten or extend the patient's life, but to improve their quality of life and well-being. Physicians must have adequate knowledge of pain and symptom management to achieve this goal [14-16]. However, mercy killing or any other means of relieving a patient's pain and distress is not an option, and ethical principles allow only the use of opioids to alleviate pain and distressful symptoms [17-20].

Findings

- a. The topic of end-of-life care for improving the quality of life and death is not widely discussed in clinical settings in India.
- b. India faces several challenges in managing pain and non-pain symptoms in end-of-life care.
- c. It is crucial to implement effective end-of-life care policies, ensure availability of essential medicines and medical facilities, and increase public education and awareness.

- d. Proper implementation of end-of-life care can prevent unnecessary medical expenses, such as chemotherapy in the final stages of a terminal illness diagnosis. It is also important to address the issue of essential drugs for pain management in palliative end-of-life care, which are not always available in some parts of India.

Discussion

In India, the biggest challenge in palliative care is the misconception that it only relates to end-of-life care. This false belief is prevalent even among physicians and oncologists, leading to patients not being referred to palliative care when needed. Palliative care aims to provide the best possible quality of life at all stages of treatment. Early access to palliative care has several positive outcomes, but the lack of awareness among medical practitioners means that many patients and families are left without relief during their diagnosis period. The core concept of hospice care acknowledges death as the final stage of human life and aims to neither hasten nor postpone it. It is also family-centered, including the patient and family in decision-making at any level. Palliative care, on the other hand, is an approach that aims to improve the quality of life of patients and their families facing problems associated with life-threatening illness. Palliative care can be provided at any stage in the course of an illness, not just near the end of life, and can be extended to the family bereavement period. The proposed methodology for this study involves an analytical approach that will rely on existing documents and literature. In modern times, with the advancements in medical technology, the place of death has shifted from the home to hospitals and other nursing care centers. End-of-life care is a global phenomenon that seeks to improve the quality of life and overall well-being of patients with advanced medical illnesses such as HIV and cancer. The primary objective of end-of-life care is to address the various dimensions of a patient's needs, including physical pain and symptom control, ethical considerations regarding death and dying, and legal principles in critical care. Despite the importance of end-of-life care, it remains an overlooked topic in many Indian healthcare systems. Dying with dignity and a good death are rarely discussed, and palliative end-of-life care is one of the most neglected areas of care in India, with 80% of the population not having access to it thus far. India faced a number of challenges in the areas of health and wellbeing, particularly in the management of pain and non-pain symptoms. With 2.5 million cancer sufferers in modern India, the number would certainly rise by 50% by 2020 if governmental and non-governmental organisations did not immediately implement a plan of action. It typically results in a paralysing situation after the killer cells multiply and begin to impact the patient's loss of bodily locations, necessitating a multidisciplinary team for the therapy operations. Contrarily, the terms dying with dignity or peaceful death are foreign in the Indian health care system, primarily because pain and symptom management are not covered in the medical curriculum for undergraduate and graduate medical students. Currently, only 1%-2% of the population in India has access to end-of-life care or pain management. Additionally, the majority of Indian medical students do not have access to curriculum on pain management, including the use of opioids for managing severe pain in terminal illness or major trauma. It is crucial to effectively implement the end-of-life care policy and plan in India, including availability of essential medicines and medical facilities, public education, and awareness. Proper implementation of end-of-life care will avoid unnecessary medical expenses such as chemotherapy at the final stage of terminal illness. Special consideration is needed for the unavailability of essential drugs for pain management in palliative end-of-life care in some parts of the Indian sub-continent.

Conclusion

It is crucial to incorporate palliative end-of-life care into the healthcare system of the country, as well as the training of medical practitioners. The provision of social support and addressing the psycho-spiritual needs of the patients in palliative end-of-life care is also a critical area that needs immediate attention. This is essential to provide dying patients with a good quality of life, promote the overall well-being of the patient, and ensure a peaceful and dignified death.

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Conflict of Interest

Author declares no conflict of interest.

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