REVIEW ARTICLE

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End-of-Life Cancer Care: Present Scenario and the Future Ahead

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Abstract

Background: End-of-life (EOL) care is an emerging yet essential part of cancer care in India. With over 1.4 million new cancer cases and more than 0.9 million deaths annually (GLOBOCAN 2022), the need for accessible palliative and EOL services is rapidly increasing. However, current access remains limited to less than 1% of the population.

Methods: This narrative review evaluates the present landscape of EOL care in India by examining existing initiatives, care models, and key barriers affecting implementation and accessibility. Empirical and non-empirical research was searched in the databases PubMed/MEDLINE, Web of Science, Scopus, EMBASE, and Google Scholar from inception to December 2024 using the keywords "Hospice care," "End-of-life care," "Palliative care," "Terminal illness care," "Terminal care in India," and "Palliative care programs in India." Relevant studies were screened and assessed for quality before narrative synthesis.

Results: Progress has been observed in selected regions through pilot programs and the efforts of institutional, government, and non-government organizations. Despite these advancements, nationwide coverage remains limited due to policy gaps, insufficient infrastructure, workforce shortages, and sociocultural challenges surrounding EOL discussions.

Conclusion: Strengthening policy frameworks, expanding service delivery, improving training, and promoting culturally sensitive approaches are critical to developing accessible and well-structured EOL care across India.

Keywords: End-of-life care • Palliative Care • Oncology • Hospice • India • Community-based models

Introduction

The concept of end-of-life (EOL) care for cancer patients is still emerging in India, with numerous unmet needs requiring recognition and action. According to GLOBOCAN 2022, cancer incidence in India exceeds 1.4 million cases annually, with more than 0.9 million deaths (1). This growing burden underscores the urgent requirement for well-structured palliative and EOL care services.

Palliative care in India began with the establishment of Shanti Avedna Sadan hospice in Mumbai in 1986. Over the next five years, two additional branches were established in Delhi and Goa. Two major developments followed in the 1990s: the formation of the Pain and Palliative Care Society (PPCS) in Calicut, Kerala, in 1993, and the formation of the Indian Association of Palliative Care in 1994 (2).

EOL care, an integral component of palliative care, focuses on providing comfort, dignity, and psychosocial support to patients with terminal illness. However, despite increasing awareness, EOL care in India often remains fragmented and underprioritized within mainstream cancer care systems.

Methodology

This narrative review was conducted using the databases PubMed/MEDLINE, Web of Science, Scopus, EMBASE, and Google Scholar from inception to December 2024, using the keywords "Hospice care," "End-of-life care," "Palliative care," "Terminal illness care," "Terminal care in India," and "Palliative care programs in India." Studies measuring or analyzing palliative or hospice care access and recommendations by various societies in India were included. The quality of the narrative review was assessed using the Scale for the Assessment of Narrative Review Articles checklist (3).

From History to Current Status of End-of-Life Care in India

A systematic review and meta-analysis by Chandra et al estimated that 6.21 per 1000 people in India require palliative care, with a higher prevalence among individuals over 60 years (37.86 per 1000) (4). However, accessibility remains disproportionately low— only around 908 palliative care centers currently exist, catering to less than 1% of the na tion's 1.3 billion population (5).A survey involving 223 palliative care centers in India showed that only 33% of centres had day-care services with only one of three modalities for t reatment, i.e., surgery, chemotherapy or radiotherapy, but no inpatient beds dedicated to palliative care delivery, therefore, recorded no in-patient services. Uninterrupted opioid access to patients with cancer was a significant challenge (6).

The WHO Cancer Country Profile 2020 highlights the limited availability of community- and home-based palliative services in India (7). Similarly, the Quality of Death and Dying Index (2021) ranked India 59th among 81 nations, reflecting the lack of standardized EOL frameworks and infrastructural support (8).

Although global cancer societies, such as the National Comprehensive Cancer Network (NCCN), have developed survivorship and supportive care guidelines, regional customization remains necessary. India's cultural and socioeconomic diversity demands locally relevant EOL care

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models that accommodate distinct beliefs, healthcare resources, and community structures.

Various programs launched by the Government of India (GoI), charitable organizations, and other institutions to enhance palliative and end-of-life care in India are as follows:

1. The Indian Association of Palliative Care (IAPC) was registered as a Public Trust and Society in March 1994 in Ahmedabad. It established a Palliative Care Drugs Committee and an Educational Task Force (9).
2. Can Support, a non-profit organization, was founded in 1997 in Delhi and initiated a home care program that provided the first free palliative home care support service in North India (2,10).
3. In Pune, Maharashtra, central India, the Cipla Cancer Palliative Care Centre was established (2).
4. The GoI launched the National Program for Palliative Care (NPPC) in 2012. Since then, funds have been allocated under the National Rural Health Mission (NRHM) flexi pool for initiating and scaling up palliative care services in various states, depending on the implementation plan submitted by each state. The NPPC strategy to achieve universal access to palliative care as part of Universal Health Coverage (UHC) is in accordance with the World Health Assembly Resolution 2014 (11,12).
5. The Cancer Treatment Centre Palliative Care Program (CTC-PC), launched in 2016, is a prominent initiative in India aimed at building sustainable, institution-based palliative care services. Partnering with the Lien Foundation, Asia Pacific Hospice Palliative Care Network (APHN), and the All-India Institute of Medical Sciences, Delhi (AIIMS), it trains teams to establish in-hospital palliative outpatient services, improves opioid accessibility, and empowers palliative care professionals to provide comprehensive pain relief and psychosocial support (13,14). In 2023, the CTC-PC is running the fifth edition of its program. In its first three editions, an audit showed that the CTC-PC developed palliative care services in 23 out of 31 centers enrolled in the program and helped improve opioid availability (15,16).
6. The Palliative Care–Promoting Access and Improvement of the Cancer Experience (PC-PAICE) Project is an international quality improvement (QI) collaborative launched in 2017. It pairs international mentors with Indian cancer centers to build palliative care capacity, improve access, and enhance patient experience, now known as EQuIP-India. The program is integrated into the National Cancer Grid and supports national collaborations and training in quality improvement throughout India. Across three cohorts from 2017 to 2020, PAICE provided capacity-building support to 22 Indian palliative care and cancer programs (17).

Ongoing Efforts and Successful Models

Several pioneering initiatives have demonstrated feasible approaches for extending palliative and EOL care in India. One landmark example is the Neighborhood Network in Palliative Care (NNPC) in Kerala, a WHO demonstration project that empowered local communities to collaborate with healthcare professionals and deliver home-based palliative care (18,19). This model showcased the effectiveness of community engagement and volunteer-driven service delivery.

Another initiative was undertaken by the IAPC through the development of a National Quality Standards Audit Tool for palliative care services in India to drive quality improvement in 2008. This audit tool was divided into "Essential" and "Desirable" sections, which were further divided into five and seven sections, respectively. The essential components relate to documentation, essential medicines, training of team members in palliative care practice, degree of integration with the community, and team professional development. Desirable components relate to program features, including providing access to free morphine and palliative drugs; fostering an organizational culture that promotes self-care and is supported within the wider organization; and strengthening education, training, and quality improvement (6,20).

Similarly, Dhiliwal et al. developed a six-year home-based palliative care program linking rural communities to a tertiary cancer center (21). Their initiative involved training general physicians in palliative care principles, offering bereavement services, and providing 24-hour telephonic support. The model significantly improved patient comfort and reduced caregiver burden.

A 2019 qualitative study in rural West Bengal also reported that employing community health workers to deliver palliative care was both feasible and effective in low-resource settings (22). These examples underscore the viability of community-led programs for extending palliative and EOL services beyond urban institutions.

Policy Frameworks and National Recommendations

The Indian Association of Palliative Care (IAPC) and the Academy of Family Physicians of India (AFPI) have jointly advocated for integrating palliative care within primary healthcare through policy, education, and service delivery reforms (23). Their recommendations include:

- Incorporating palliative care training at all levels of medical education.
- Improving the availability of essential medications for pain management.
- Promoting community awareness regarding palliative and EOL care.
- Empowering local communities to identify and support individuals preferring home-based care.

While these recommendations provide a strong foundation, effective implementation requires clear operational strategies, consistent funding, and a unified national training framework to standardize care delivery across regions.

Challenges in End-of-Life Care Delivery

Despite progress, several systemic challenges persist:

- **Limited infrastructure:** Most oncology centers lack dedicated EOL or hospice units.
- **Shortage of trained professionals:** There is a deficit of palliative care specialists, psychologists, and social workers.
- **Inadequate medication availability:** Access to opioids and essential drugs remains inconsistent.
- **Cultural barriers:** Misconceptions and social taboos surrounding death often prevent timely referral to palliative services.
- **Policy gaps:** The absence of a centralized framework delays integration into mainstream healthcare systems.

Recommendations and Future Directions

To strengthen EOL care delivery in India, the following strategic measures are proposed (Figure 1):

- **Quantification of need:** All cancer care institutions should systematically document and report EOL service requirements and hospice utilization.
- **Integrated care units:** Instead of establishing separate hospices, existing cancer centers should develop EOL units with multidisciplinary teams comprising palliative specialists, psychologists, nutritionists, trained nurses, and spiritual care coordinators.
- **Use of standardized assessment tools:** Instruments such as

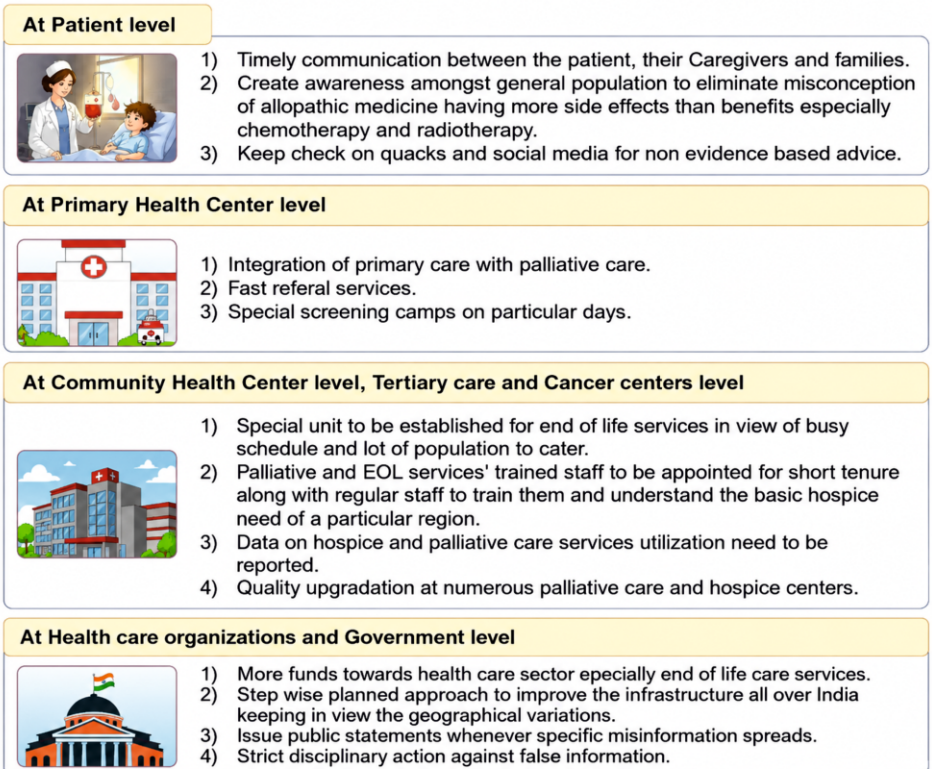

Figure 1: Suggestions/Recommendations at various levels of health care in India.

the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL and the Problems and Needs in Palliative Care (PNPC) scales should be implemented in local languages to assess patient needs and tailor interventions accordingly (24,25).

- **Medication accessibility:** Ensure a consistent supply of essential palliative drugs in both urban and rural regions.
- **Home-based support:** The availability of home nursing services and equipment (e.g., suction devices, tracheostomy care, and bed sore management) must always be ensured.
- **Community engagement:** Encourage volunteer participation and incentivize community health workers. Successful Kerala-based models can serve as prototypes for replication in other states.
- **Government involvement:** Regional and central authorities must allocate dedicated funds for palliative care infrastructure and integrate centers.
- **Technology integration:** Deploy artificial intelligence and telemedicine tools to enhance outreach and optimize patient monitoring in remote areas.
- **Monitoring and evaluation:** Establish measurable goals, quarterly audits, and progress reviews to ensure accountability and continuous improvement.

The IAPC continues to play a pivotal role in guiding and coordinating these initiatives. However, sustained governmental commitment and localized implementation strategies are essential for long-term success. Directions at specific levels of healthcare are summarized in Figure 1.

Challenges

Existence of multiple alternative medical practices contributing to the decreased utilization of allopathic palliative care in India since they are often presented as more compassionate and holistic approaches.

Conclusion

End-of-life care in India stands at a critical juncture—recognized but not yet fully realized. While several successful community-based models exist, the challenge lies in expanding their reach through policy reform, capacity building, and sustainable funding. A unified approach involving healthcare professionals, policymakers, and community networks can transform EOL care into an accessible, compassionate, and dignified service for every cancer patient in India.

Ethical Approval

This article is a review-based study and does not involve human participants, patient data, or experimental animals. Therefore, ethical approval was not required.

Informed Consent

Not applicable, as this study does not involve human subjects or patient data.

Conflict of Interest

The author(s) declared that there is no conflict of interest regarding the publication of this paper.

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