

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

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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.

Results: Progress has been observed in selected regions through pilot programs and institutional efforts. 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 in 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). The growing burden underscores the urgent requirement for well-structured palliative and EOL care services. 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 accomplished using the databases Pubmed/Medline, Web of Sciences, Scopus, EMBASE and Google Scholar from January 2010 to December 2024 using keywords ‘Hospice care’, ‘End of life care’, ‘Palliative care’, ‘Terminal illness care’ or ‘Terminal Care in India’, ‘Palliative care programs in India’. Studies measuring or analyzing palliative or hospice care access in India and recommendations by various societies in India were included.

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) (2). However, accessibility remains disproportionately low— only around 908 palliative care centers currently exist, catering to less than 1% of the nation's 1.3 billion population (3).

The WHO Cancer Country Profile 2020 highlights the limited availability of community- and home-based palliative services in India (4). 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 (5).

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

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 (6, 7). This model showcased the effectiveness of community engagement and volunteer-driven service delivery.

Similarly, Dhiliwal et al. developed a six- year home-based palliative care program linking rural communities to a tertiary cancer center (8). 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 (9). 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 integrating palliative care within primary healthcare through policy, education, and service delivery reforms (10). 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 demands 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: 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:

- 1) Quantification of Need: All cancer care institutions should systematically document and report EOL service requirements and hospice utilization.
- 2) 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.
- 3) Use of Standardized Assessment Tools: Instruments such as The European Organization for Research and Treatment of Cancer (EORTC) QLQ-C15-PAL, The Problems and Need in Palliative Care (PNPC) scales should be implemented in local languages to assess patient needs and tailor interventions accordingly.
- 4) Medication Accessibility: Ensure consistent supply of essential palliative drugs in both urban and rural regions.
- 5) Home-Based Support: Availability of home nursing services and equipment (e.g., suction devices, tracheostomy care, bed sore management) must be always ensured.
- 6) Community Engagement: Encourage volunteer participation and incentivize community health workers. Successful Kerala-based models can serve as prototypes for replication in other states.
- 7) Government Involvement: Regional and central authorities must allocate dedicated funds for palliative care infrastructure and integrate centers.
- 8) Technology Integration: Deploy artificial intelligence and telemedicine tools to enhance outreach and optimize patient monitoring in remote areas.
- 9) Monitoring and Evaluation: Establish measurable goals, quarterly audits, and progress reviews to ensure accountability and continuous improvement.

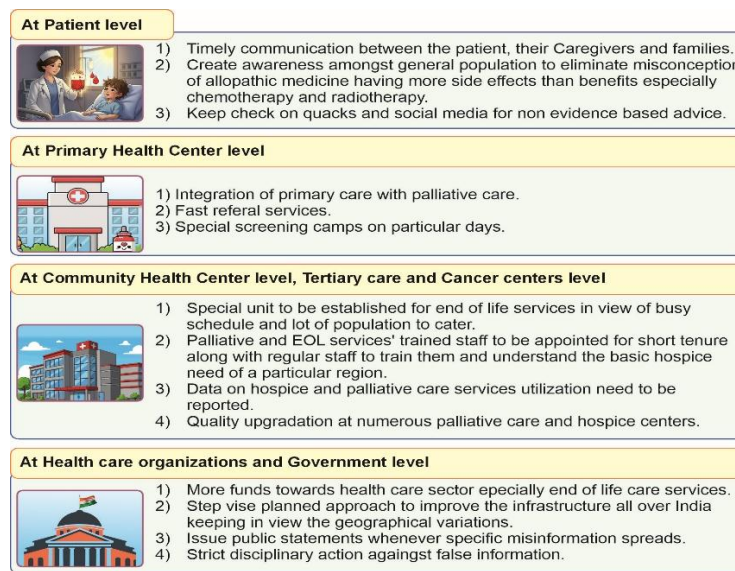


Fig. 1: Suggestions/ Recommendations at various levels of healthcare in India.

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 particular levels in health care are summarized in the figure. (Fig 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) declare that there is no conflict of interest regarding the publication of this paper.

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