



Palliative Care and End of Life Decision-making: The Neglected Care Element in Health Service Delivery in India

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ABSTRACT

Palliative Care aims to improve the quality of life of patients who are facing health issues arising from life-threatening or terminal illnesses. This care segment requires a unique combination of physical, psychological, social or spiritual health, which has to be customized according to the need of the patient. With the ever-increasing elderly and dependents' population, rising NCDs, in India, the need of palliative care is growing exponentially; and only 4% of India's population has access to palliative care, much less than the 14% global average. While India has National Programme for Palliative Care, which covers all integral aspects of this care segment; and Operational Guidelines for Palliative Care at Ayushman Bharat Health & Wellness Centers (AB-HWCs) were also launched to supplement, the implementation still lags behind. The paper highlights these implementation challenges and outlines some important bottlenecks in the execution of the programme. Various suggestions to overcome the programme challenges have also been discussed in the paper. The policy and programme should reinvigorate and reinforce the case for personalized nature of palliative care required for the affected people, irrespective of age, race, gender and cause of illness, with a sole aim of dignified end-of-life care to the needful patients.

Keywords: Palliative care, End of life Care (EOLC), Elderly, Caregivers, Spiritual Health, Terminal Illness

INTRODUCTION

Palliative Care aims to improve the quality of life of patients and caregivers who are facing health issues arising from life-threatening or terminal illnesses. This unique care segment forms a differentiated combination of physical, psychological, social or spiritual health. The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illnesses.¹ Contrary to the belief that palliative care is only for cancer patients, life-threatening illnesses can arise due to other diseases as well, such as cardiovascular diseases, diabetes, chronic respiratory diseases, AIDS, kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Palliative care is quite different from other care approaches as it includes the ever-neglected spiritual health and existential dimensions of healing. This makes understanding patients' spiritual and cultural background critical to palliative care delivery and reemphasize the role of providing compassionate and personalized care to patients.

Table 1: Data highlighting the growing need of Palliative Care in India

1.	Longitudinal Ageing Study of India (LASI) 2021 highlighted that elderly population comprise 12% of population, which is projected to rise to 19.5% (319 million) by 2050. ^[1]
2.	Sex ratio among the elderly stands at 1,065 females per 1,000 males, with women



	accounting for 58% of the elderly population.
3.	Overall dependency ratio of India is 62 dependents per 100 working-age individuals - highlighting the increasing social and economic implications of aging population.
4.	India had an estimated 100.4 incident cancer cases per 100,000 people in 2022, which is expected to rise in the coming years.
5.	NCDs account for about 16,939 DALYs per 100,000 in India.
6.	In 2017, it was estimated that approximately 4.7 million deaths had occurred in India due to Non-Communicable Diseases (NCDs) - 49% of all-cause mortality.
7.	Life expectancy rose from 58.6 years in 1990 to 72 years in 2023.
8.	Community-level palliative care needs in India ranges widely from 1.5/1000 population to 43.1/1000 population.

Keeping in mind the ever-increasing elderly population in our country,ⁱⁱ rising NCDs, increasing life expectancy and the unique characteristics of Palliative Care, as outlined in Table 1, it becomes critical to prioritise palliative care in India. The paper reviews the program implementation gaps and gives an outline effort that will help in enhancing patient and caregiver empowerment through awareness, advocacy, education, financial and psychosocial support.

METHODOLOGY

This is a review article developed following a PSALSAR framework (Protocol, Search, Appraisal, Synthesis, Analysis, Reporting). The research question was about the current scenario of palliative care in India; what are the implementation gaps or challenges related to palliative care needs in India. We searched all the major search databases such as PubMed, Scopus, Google Scholar using the tailored keywords like 'palliative care in India', 'implementation gaps in palliative care delivery in India', 'elderly care needs', 'end-of-life care' in various states of India. The findings were synthesized and reviewed by the authors through their experience and expertise for developing the current review article.

Need of Palliative Care in India

According to the Population Projection Report, India's elderly population (> 60 years) will reach 230 million by 2036, about 15% of the total population.ⁱⁱⁱ Punjab, Himachal Pradesh and Southern states such as Kerala and Tamil Nadu have a higher elderly population. There are significant regional disparities with respect to the ageing population, and this demographic shift is non-uniform across the country. While only 4% of India's population has access to palliative care,^{iv} much less than the global average of 14%.^v Various research studies point towards fragmented palliative care and End-of-Life Care protocol – mainly concentrated in ICUs and in urban areas only.^{vi}

In a study done in an urban area in 2025,^{vii} 0.21% (2 per 1000) required home-based palliative care with neurological disorders, primarily stroke (67.8%) as the leading cause of disability. Around 60% were elderly males, out of which more than 50% were illiterate. The average score on Barthel Index was 33, indicating severe dependence in around 50% of participants.

A systematic review and meta-analysis done by AIIMS, New Delhi, outlined the need for palliative care in India to be 6.21 individuals/1000 population.^{viii} According to this review, prevalence of palliative care in urban areas was 3.34/1000, and in rural areas, it was 7.69/1000. Higher prevalence was noted in females (9.64/1000) than in males (6.77/1000). Another important point outlined in the review was that individuals aged over 60 years had a higher prevalence of palliative care needs, with a rate of 37.86/1000 population.

One of integral component of Palliative Care is the role of caregivers. Full-time caregivers are often requ-

ired for taking care of the patient, which can either be a family member or a professional; thus, another important consideration is the inclusion of caregivers in the 'patient care' approach. This care includes focus



on mental health, grief management, and supportive care, which adds to the total cost involved in the patient management, adding to the cost of long-term care required during terminal illnesses. Training of caregivers is a critical element in the 'care cycle'; this training includes understanding palliative care medications, pain management, psychosocial management, etc.^{ix}

Review

Need for Palliative Care Directives & Better Implementation in India

The World Health Assembly (WHA) passed a palliative care resolution, WHA67.19, in 2014, which states that palliative care is a core component of Universal Health Coverage (UHC) and a global ethical responsibility.^x The resolution calls on member states to integrate palliative care into health systems, especially primary care and in community-based settings; to develop policies and necessary legislation; to provide funds for research and implementation and strengthen the quality of palliative care services.

India launched the National Programme for Palliative Care (NPPC) in the 12th Five-Year Plan in 2012, to integrate palliative care services into existing healthcare systems. Operational guidelines for Palliative care at Ayushman Bharat - Health and Wellness Centres (AB-HWCs) were released in 2017. The main aim of the program is to make pain relief and supportive care accessible for serious illnesses, focusing on home/community-based services, training healthcare workers (doctors, nurses, ASHAs), improving opioid access, and building capacity for end-of-life care (EOLC). The programme provides an overarching framework for designing initiatives for this sensitive population who are in need of urgent care.

The program activities are envisaged to be included in and implemented through the National Program for Prevention and control of cancer, cardiovascular diseases (CVDs), Diabetes & Stroke (NPCDCS) program. The program ensures access to medical and scientific use of Opioids for palliative care patients in coordination with the Department of Revenue and the Central Drug Standards Control Organization (CDSCO). The major strategies proposed in the program include the provision of funds for establishing a state palliative care cell and palliative care services at the district hospital.

Many research studies have highlighted the multiple implementation challenges in the ongoing NPPC (as mentioned in Table 2).^{xi,xii} In the current scenario, the lack of clear policy directives and program initiatives shows that many important components are lacking by design. The program activities are expected to be integrated and implemented as 'synergistic activities' with NPCDCS. Thus, it is envisioned that strategies proposed for NCDs gradually merge with palliative care activities and those for targeting elderly populations. 'Health' being a state subject, and the flexibility offered here might lead to a greater focus on either of the care components, neglecting the others. Moreover, funding through NHM flexipool gives States/UTs a choice whether to invest in Palliative care or not.

Table 2: Challenges	
S.No.	Challenges
1.	Lack of dedicated HR for palliative care health services for people, especially in rural and remote areas; escalated costs in urban areas.
2.	Regional disparities in quality of palliative care and EOLC, further complicated by patchy service delivery.
3.	Absence of a dedicated and trained palliative care workforce; misconceptions among HR and community members that Palliative care is only for the elderly and for cancer patients;
4.	Focus on palliative care data and research, and the subsequent need for dedicated funding for R&D;
5.	Lack of emphasis on the need for psychological support required for the caregivers.
6.	Availability of adequate service delivery - home-based or community-based; poor data management;
7.	Securing investment for palliative care awareness campaigns to raise community

	awareness about death, dying and palliative care;
8.	Lack of awareness among policy makers regarding palliative care;
9.	Poor coordination between various government departments (such as AB-PMJAY, MoRD & MoHUA, AYUSH, NMC, etc.) & Private Sector – in the delivery of Palliative care;
10.	Lack of community infrastructure to deliver palliative care in the community, including assistive devices;
11.	Limited accessibility of Palliative care medications, poor knowledge among HR regarding these medications, leading to their unavailability to patients in need;
12.	Lack of focus on End-of-Life Care (EOLC) and Human Resources to deliver this integral support. The understanding and affirmation that life and dying are a normal process, and Palliative care should neither hasten nor postpone death.

Suggestions for Policy & Programme

According to the WHO, palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves the quality of life for patients but also reduces unnecessary hospitalisations and extensive use of healthcare services.

As India's population continues to age, bringing the palliative care component to the forefront is critical. Engaging policy makers, training service delivery personnel, including medical and paramedical staff, and motivating them for palliative care, is core to the enhanced focus on palliative care. Figure 1 explains the Kerala Model of Palliative Care in detail.^{xiii, xiv}

Figure 1: Kerala Model of Palliative Care

- Robust model for inclusive well-being, based on the principles of 'Care Beyond Cure' & 'de-professionalization of compassion'
- Provides a replicable strategy for Indian states facing the growing challenge of terminal illness & growing elderly population
- Neighbourhood Network in Palliative Care (NNPC): Trained non-professional volunteers act as first responders – responsible for home-based care, emotional support, and social assistance; while dedicated team of doctors and nurses anchor home care, symptom control, pain management, wound care, etc.
- Decentralised & Community-based Framework: Enhances patients' QoL & preserves dignity at the end of life; while leveraging social capital - trust, reciprocity, and civic engagement; ensures long-term sustainability.

Allocating dedicated funds for palliative care and redefining policy directives and program activities would help in streamlining the vision, mission and goals of the program, including EOLC decision making. It should be clear that Palliative care is not 'optional', will help in promoting accountability, responsibility and its prioritization. Some of the important steps would be improving HR allocation and monitoring their

efficiency; encouraging quality palliative care service delivery; mitigating risks through timely referrals and ensuring continuity of care. Sorting out ethical concerns for EOLC; provision of bereavement services, training support to caregivers are also important steps for palliative care delivery.

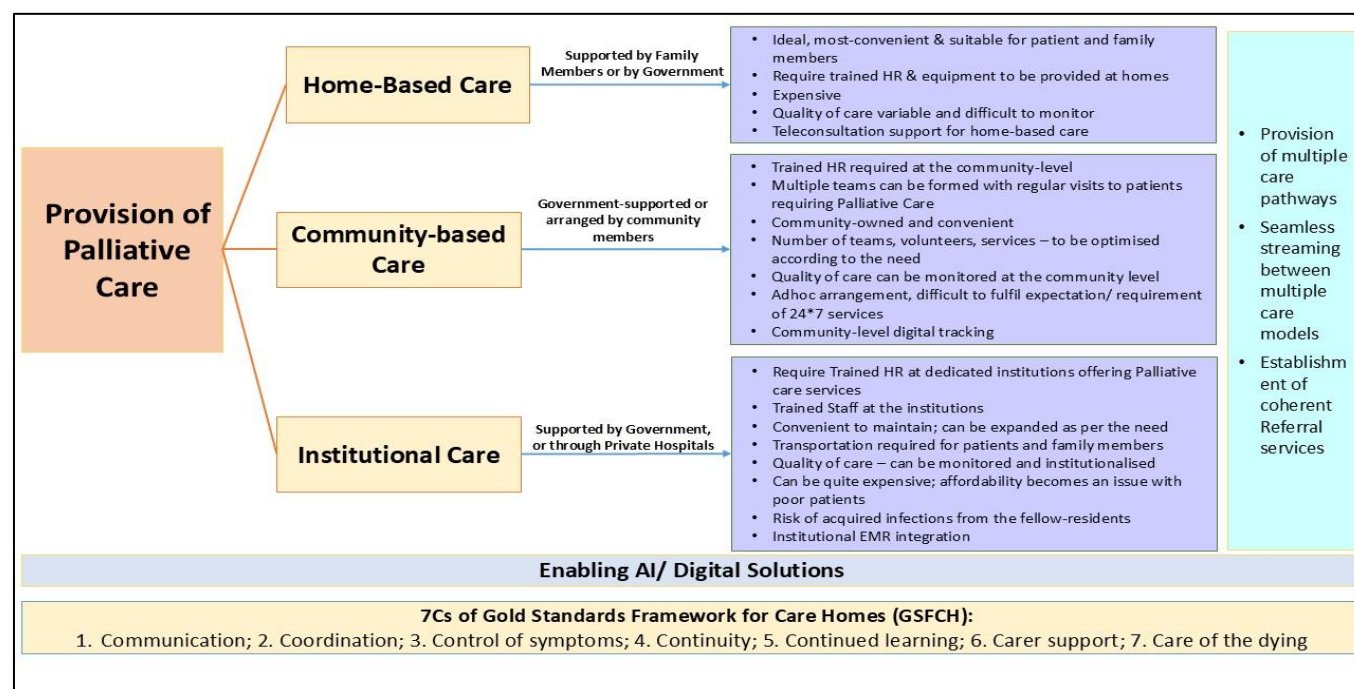
Engaging the thriving private sector effectively and efficiently in palliative care, especially for the poor and needy (percentage allocation). Involving NGOs, CSOs, and/or CSR funds brings about a positive change in palliative care service delivery across the country. India, being a spiritual and ‘yoga’ capital of the world, bringing in the AYUSH services and spiritual component to the forefront will help in improving patients’ response and satisfaction. Investment in country-specific research related to palliative care and EOLC is integral to promoting evidence-based medicine and practice.^{xv}

Integration of digital or Artificial Intelligence solutions into the provision of palliative care is critical and cannot be overlooked. Some of the digital solutions can be – digital integration and EMR of palliative care patients to allow for digital tracking, continuous monitoring and follow-ups; teleconsultation applications can help in 24*7 care for the needy.

Palliative Care Models

Whether a state would want a ‘home-based care’ model or ‘community-based care’ model of ‘Institutional-based care’ model – this decision depends on a number of factors such as population, number of patients requiring palliative care treatment, efficiency of levels of healthcare, etc. This decision becomes critical as it would further determine whether the investment would be done on integrating basic palliative care into the district healthcare system, or on training frontline health workers, such as CHOs and ASHAs or community members; or separate cadres or teams would be made for this care component. Involvement of ministries and departments like Ministry of Women and Child Development (WCD), Ministry of Rural Development (MoRD), Ministry of Housing and Urban Affairs (MoHUA), Ministry of Panchayati Raj Institutions, and Ministry of Social Justice and Empowerment (MoSJE), is also important as much as defining their roles in palliative care service delivery. Ensuring opioid access, pain relief and symptom management is a key to ensure quality palliative care service delivery. Figure 2 outlines the Palliative Care Models and their integral components, including 7Cs of the Gold Standards Framework (GSF) for care homes (GSFCH).^{xvi}

Figure 2: Palliative Care Models



The end goal should be making personalised palliative care accessible to vulnerable terminal care patients in rural and urban areas, whether it is for the elderly or children, and cost-effective for the masses, with the inclusion of supporting families during illness and bereavement.

CONCLUSION

There is a need to strengthen the National Palliative Care policy and program efforts owing to the rising concern of NCDs, the elderly, dependent population in India. The policy should bring in a mandate to develop a coordinated and well-structured programmatic response, along with allocation of the required resources for palliative care services. Apart from enhancing accessibility and availability of services to people, the economic implications arising from the cost of long-term care should also be accounted for. The policy should reinvigorate and reinforce the case for personalized nature of palliative care required for the affected people, irrespective of age, race, gender and cause of illness, with a sole aim of dignified end-of-life care to the needful patients.

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