

Integration of Palliative Care into Primary Care: A Collaborative Effort Between the Indian Association of Palliative Care and the Indian Association of Preventive and Social Medicine

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Abstract

India staggers at the 59th position (out of 81 countries globally) in the quality of death and dying index. A chronic life-threatening illness is often complicated by marginalized living, out-of-pocket health expenditure, illiteracy, and poor social support, and pushes the population further into the vicious spiral of suffering. The Indian Association of Palliative Care and the Indian Association of Preventive and Social Medicine joined hands in April 2023 to address the gap in the demand and availability of palliative care and proposed to empower Community Medicine physicians to provide primary palliative care. They put forth recommendations for education, service, and research developments in primary palliative care. In April 2023, the Indian Association of Palliative Care and the Indian Association of Preventive and Social Medicine joined hands to disseminate palliative care services to the community. Subsequently, a task force comprising faculties from Palliative Medicine and Community Medicine was formed. The position paper on primary palliative care jointly published by the Indian Association of Palliative Care and the Association of Family Physicians of India provided the framework for this position paper. The paper focused on education, service development, and research. The task force recommended the following: 1. Empower faculties and residents of the Department of Community Medicine, undergraduate students from medical and allied specialties posted to the department to provide primary palliative care. 2. Integrate palliative care into outpatient clinics (general OPDs in the hospital), community health centers, and home care as a part of the family adoption program. 3. Improve access to essential medications, including opioids, in urban and rural areas 4. Follow the recommendations of the National Health Policy 2017 to develop blended training programs for faculties and students. 5. Engage the community to identify patients with chronic life-threatening illnesses and allocate resources to support patients at home. 6. Collaborate to develop a protocol for regular audits and research for service improvisation.

Keywords: Chronic life-threatening illnesses, integration, primary palliative care

INTRODUCTION

The rising trend in both non-communicable and communicable diseases increases the vulnerability of the population to high morbidity and mortality,^[1] with the highest burden borne by low- and middle-income countries^[1] High rates of mortality among the younger population causing a decline in the productivity and all these culminate into the vicious

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spiral of suffering.^[1-3] Poor health insurance coverage and high out-of-pocket expenditure inhibit people from seeking healthcare even for the most treatable conditions.^[3,4]

Palliative care aims at improving the quality of life of patients and their families by alleviating physical symptoms and psychosocial and spiritual concerns.^[5] Palliative care is an integral component of universal health coverage as per the sustainable development goal 3.8.1.^[4] The World Health Organization (WHO) recognizes palliative care as a major public health priority.^[3] However, India ranks at the 59th position on the global quality of death and dying index with poor acceptance of palliative care by the healthcare system.^[6]

Annually, around 40 million people are known to benefit from palliative care with 78% of them living in LMIC.^[5] The lack of palliative care registries across LMICs makes it challenging to gauge the number of patients accessing palliative care.^[5] There is regional disparity in the delivery of palliative care^[7] and most patients needing palliative care are in rural and tribal communities.^[8] The 2017 Lancet Commission highlighted the need for universal access to palliative care, especially in LMICs, and exhorted the need for global action.^[9,10] Palliative care and primary care, both have person-centered, holistic, well-coordinated, cost-effective care delivered as close to the patient as possible, as their central tenet.^[9] A panel of experts with a focus on primary palliative care defined primary palliative care as; *“care practiced by primary healthcare workers, who are the principal providers of integrated healthcare for people in local communities throughout their life. It includes early identification and triggering of palliative care as part of integrated and holistic chronic disease management, collaborating with specialist palliative care services where they exist, and strengthening underlying professional capabilities in primary care.”*^[10] A primary care physician is an integral person and often the first point of contact for patients with chronic life-threatening illnesses.^[11] Primary care physicians facilitate primary palliative care by identifying palliative care needs and providing basic physical and psychosocial support to their patients.^[12] Furthermore, the long-standing therapeutic relationship with the patient–family unit elevates their position as a primary palliative care physician and continues their support throughout the disease trajectory.^[13,14] Primary care physicians play a vital role in navigating patients across disease trajectories, thus ensuring quality care delivery, patient advocacy, and coordinating with community teams such as ASHA and health and wellness centers to provide comprehensive palliative care.^[14,15] Although work on primary palliative care is in progress in the country with developments of primary palliative care modules for family physicians and general practitioners and collaboration has been established between the Indian Association of Palliative Care and the Indian Association of Preventive and Social Medicine, future work must focus on the need assessment and impact evaluation. There is a need for defining the role of primary palliative care physicians including clear clinical pathways and referral criteria back and forth between primary care physicians and palliative care specialists.

Community-based models of palliative care

Palliative care can be delivered at various levels in alignment with the patient’s needs and the availability of resources to fulfill those needs.^[16] Traditionally, palliative care models have been divided into hospital-based, community-based, and hospice-based models.^[17] Different models are applicable to various settings depending on the patient’s needs, space, and staff availability. We shall focus on some of the best practice community-based palliative care models that have driven palliative care for many years and some of them are included as the WHO demonstration projects.

Neighborhood network in Palliative care (NNPC): Kerala model^[18]

This model was implemented at the start of 2001 in Kerala and has now received international recognition as one of the most feasible and robust community-based palliative care models. Started as a WHO project, this model has become a social movement. The success of this model is dependent on community mobilization and participation by volunteers who emerge from the local community. Every individual in the community acts as an advocates for palliative care. They identify palliative care patients and mobilize resources to meet their needs. Volunteers provide non-medical support and guide and accompany the medical team to the patient’s homes. Government also invests in ongoing capacity building of healthcare professionals, volunteers, and leaders in the community and patient caregivers.

Hub and Spike Model–Tata Memorial Hospital (TMH) home care model^[19]

The home care team was started by the Department of Palliative Medicine at TMH, Mumbai, in 1997. The home care program is led by a palliative care nurse in assistance with the medical social worker. Nurses identify the palliative care needs of the patient and family and refer the patient to the appropriate team members. They coordinate the visit by a doctor, psychologist, or physiotherapist as per the patient’s requirements. The home care team actively liaises with the general practitioner to ensure continuity of care close to the patient’s home in case of an emergency or complex palliative care needs. Community volunteers play an active role in identifying social issues associated with the patient. TMH model is also a successful example of home care as complementary to institution-based care.

Nurse-led palliative care model: Uganda model

Systematic palliative care was started in Uganda in 1993 with the establishment of Hospice Africa Uganda. The program caters to the palliative care needs of patients with HIV and AIDS. This is a nurse-led program. Nurses trained in palliative care provide good-quality palliative care in liaison with the physician. They are also trained in dispensing morphine in the community.^[20] In a cross-country comparison of the quality of death and dying in 2021, Uganda was the only country to rank the highest among LMICs.^[6]

Primary palliative care can be delivered successfully in a community in resource-constrained settings. The following are ways to integrate primary palliative care with specialist palliative care.

1. Collaborative model: Community physicians work in collaboration with palliative care specialists. Community physicians collaborate with specialists to develop personalized pain management strategies, symptom control, and communication plans.
2. Integrative model: Community physicians incorporate palliative care principles into routine care.
3. Teleconsultation: Community physicians can consult with palliative care specialists remotely to discuss complex cases, review treatment plans, and receive guidance on symptom management.
4. Training and education: Training programs and workshops can enhance physicians' abilities to manage pain and symptoms, have sensitive conversations, and provide emotional support. This model empowers physicians to address the palliative care needs of their patients directly, reducing the need for immediate specialist referrals.

Challenges and opportunities in palliative care implementation in the community

Despite a good body of evidence on the benefits of palliative care, the availability of palliative care services across the country continues to be scarce.^[21,22] Many barriers have been identified for poor availability of palliative care.^[15,23] Some of these are:

1. Lack of and poor implementation of existing national and state level policies for palliative care, which could be related to poor utilization of funds from the state and center and poor allocation of funds and staff toward palliative care.
2. Although, training has been implemented at various cadres of health personnel; however, this has not been streamlined. There is also a lack of standardization in the training programs across the country resulting in fragmentation of care.
3. Lack of awareness across the healthcare delivery system about the benefits of early integration of palliative care and home- or hospice-based care results in a large population of patients dying in hospitals against the patient's choice. Lack of palliative care training at undergraduate and postgraduate levels is the major contributor to this.
4. Palliative care services get the least priority resulting in a lack of allocation of government and private insurance coverage for PC services (especially home-based and outpatient care).
5. Poor awareness among communities about PC-related issues.
6. Lack of caregiver support resulting from migrations to urban areas, disintegration of joint families, lack of alternate arrangements, and dedicated financial schemes for employment opportunities by the state.

However, several opportunities within the existing milieu may facilitate the availability of primary palliative care.

1. Availability of comprehensive frameworks for the provision of PC by various national and state bodies of palliative care.
2. Presence of several overlapping principles between palliative care and primary health care.
3. Palliative care can be embedded into the National Health Policy (2017) and enlisted services can be provided by health and wellness centers.
4. Existence of several successful community-based PC models within India.

The fraternity of community medicine with its wide reach across communities, medical education, public health programs, and policymakers is thus well poised to overcome these barriers and capitalize on the facilitators to further the cause of palliative care.

Education in primary palliative care

End-of-life care is perceived by most primary care physicians as challenging and feel apprehensive about delivering palliative care.^[24,25] Lack of formal education in palliative and end-of-life care (EOLC), anxieties surrounding the complexity of care, and negative emotions related to failure to cure all inhibit them from providing palliative/end-of-life care.^[26–28] This was further complicated by the distrust in their capability to provide care by dissatisfied bereaved family members.^[29,30]

A recent systematic review revealed that primary care physicians feel motivated to learn end-of-life care provided the learning is aligned with their learning preferences and synchronizes with the content and context.^[27,31,32] Some of the challenges mentioned in the review included difficult communication surrounding conflict resolution or managing angry families, management of complex symptom clusters, knowing when to refer to specialists palliative care team, and dynamics of teamwork and how to sustain the teamwork.^[27] Most primary care physicians felt reflecting on their past experience and juxtaposing it with their current encounter and work-based case discussions under a specialist palliative care team improved their knowledge and confidence in providing end-of-life care.^[27] Recent evidence showed that primary care physicians felt training in end-of-life care was relevant only when the training programs synchronized with the context of practice and filled the gaps in knowledge and skills.^[31–33] Some studies that followed up with their patients also demonstrated a reduction in hospital utilization rates and rational use of limited resources, a reduction in patient and caregiver distress, and better patient and caregiver satisfaction.^[34–36]

Research in primary palliative care

Research forms the foundation for evidence-based palliative care. This informs patient care, service development, and policy. It supports decision-makers in planning discussions surrounding care goals, patient preference for place of care, and advance care planning. Researchers across the world have invested in primary palliative care research across the disease spectrum, in different settings, and different contexts.^[9,37–48]

Studies have endorsed that patients and caregivers feel highly satisfied when community teams collaborate with specialist palliative care teams as this can reduce the cost of travel and waiting time in the outpatient clinic.^[9,44] Furthermore, this increases their confidence in their community teams. Likewise, community teams feel comfortable providing care to their patients only if they receive ongoing support from specialist palliative care teams.^[44,46] In the studies, the community teams expressed the need for a toolkit that clearly defined the criteria for selecting a patient for home care and one that helped determine the referral to specialists.^[9,44] Research has demonstrated the benefits of collaborative efforts between community and palliative care teams. The collaboration can facilitate proactive goals of care discussion and timely documentation of the care plan, reducing hospital admissions or emergency visits.^[38,44,46] Unscheduled visits and emergency admissions are the key challenges for elderly patients and those suffering from chronic life-threatening illnesses.^[49] Early identification of patients at risk of deterioration in health, proactive goals of care discussion and documentation, easily accessible electronic care coordination, and the availability of a community professional to coordinate the care can seamlessly resolve the challenges.^[49] Studies have explored multiple modalities of palliative care delivery in the community.^[37,39,48,50] In addition to collaborative work and its benefits in community-based palliative care, research on interventions by community health workers (CHW) is increasing globally.^[50] The community health workers, under the guidance of palliative care specialists, provide home visits at distant locations, do a comprehensive assessment of the patient's condition, and liaise with the primary care physician or palliative care specialist for further support. Studies have revealed that intervention by CHWs significantly reduced patients' physical and psychosocial symptom burden, improved documentation of advanced care planning, and increased patient compliance with treatment.^[50,51] Tele-palliative care played a vital role during the COVID-19 pandemic and continues to be accessed by patients who are unable to visit the health care facility either in view of debility or financial and geographical constraints.^[37,48] Tele-palliative care can reduce travel time, waiting time, and the associated out-of-pocket expenditure for patients.^[37] It allows patients to be connected to the healthcare team, thus allaying the fear of being abandoned or loss to follow-up.^[37] Tele-palliative care has proven to be highly satisfying for healthcare professionals due to its patient-centered nature, increased peer support, and enhanced professional development.^[52] Also, it can generate equivalent remuneration, and bring greater efficiency by allowing palliative care to reach more patients and improve job satisfaction.^[52]

There is poor evidence to support primary palliative care in our country. The primary areas that require research include an assessment of primary palliative care with standardized tools, an understanding of primary palliative care, its role, and where it fits within palliative care. Furthermore, the impact of

primary palliative care education on patients and caregivers is lacking and whether that aligns with patient's wishes and expectations. The scope of the research is to broadly evaluate its impact on their care through the illness trajectory; from early identification until end-of-life care and their bereaving families.

Work done so far in the country and the way forward

- In 2017, the first collaboration was established between the Indian Association of Palliative Care and the Association of Family Physicians of India to formalize the primary palliative care model and integrate primary palliative care into the post-graduate family medicine curriculum.^[53]
- Following this, the Indian Association of Palliative Care and the Association of Family Physicians of India jointly published a position paper in 2018, which explicitly discussed the need for primary palliative care and the tenets of primary palliative care education and delivery.^[53] Some of the important recommendations of the position paper were to integrate palliative care into primary healthcare, empower postgraduate and undergraduate (MBBS) students by providing training, develop primary palliative care service, make the essential medicines available to patients in need, and advocate for primary palliative care in the community.^[53]
- In 2019, the associations published a competency framework paper that outlined the competency required for primary care physicians to provide primary palliative care.^[54]
- As an expansion to this work, in 2023, the Indian Association of Palliative Care and the Indian Association of Preventive and Social Medicine collaborated to expand palliative care into the community. The associations aimed to engage community medicine physicians to provide primary palliative care. A memorandum of understanding was signed to this effect. Considering the expanse of service that community medicine departments, empowering community medicine physicians will ensure primary palliative care is delivered at urban and rural health centers and home visits.

RECOMMENDATIONS AND CONCLUSION

- For palliative care to reach the larger community, it is essential to integrate primary palliative care into the primary healthcare curriculum, empower faculties and residents of departments of community medicine, and induct undergraduate MBBS students and other students posted to community medicine departments.
- Trained community medicine faculty can closely work with local palliative care champions to develop outpatient palliative care clinics, and home-based palliative care, and make essential drugs, including opioids, available.
- Several concepts of palliative care can be integrated into the curriculum of community medicine such as home-based palliative care and community engagement through family adoption programs.
- An ongoing training program via a blended learning approach and a seamless coordination of care between

palliative care specialists and community medicine physicians will ensure continuity of service.

- Two specialties can collaborate to conduct regular audits of the service. This will even give them the opportunity to reflect on their experience, share each other's experience, and appropriate best practices to streamline the service and overcome some of the barriers. Also, the duo can advocate for palliative care to be integrated as an essential list of services provided by rural and urban health centers.

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Conflicts of interest

There are no conflicts of interest.

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