



Review Article

# Public Health Perspective of Primary Palliative Care: A Review through the Lenses of General Practitioners

Shrikant Atreya<sup>1</sup>, Soumitra Datta<sup>2</sup>, Naveen Salins<sup>3</sup>

<sup>1</sup>Department of Palliative Care and Psycho-oncology, Tata Medical Center, Kolkata, Departments of <sup>2</sup>Palliative Care and Psycho-oncology, <sup>3</sup>Palliative Medicine and Supportive Care, Kasturba Medical College Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India.

## ABSTRACT

The rising trend of chronic life-threatening illnesses is accompanied by an exponential increase in serious health-related suffering. Palliative care is known to ameliorate physical and psychosocial suffering and restore quality of life. However, the contemporary challenges of palliative care delivery, such as changing demographics, social isolation, inequity in service delivery, and professionalisation of dying, have prompted many to adopt a public health approach to palliative care delivery. A more decentralised approach in which palliative care is integrated into primary care will ensure that the care is available locally to those who need it and at a cost that they can afford. General practitioners (GPs) play a pivotal role in providing primary palliative care in the community. They ensure that care is provided in alignment with patients' and their families' wishes along the trajectory of the life-threatening illness and at the patient's preferred place. GPs use an interdisciplinary approach by collaborating with specialist palliative care teams and other healthcare professionals. However, they face challenges in providing end-of-life care in the community, which include identification of patients in need of palliative care, interpersonal communication, addressing patients' and caregivers' needs, clarity in roles and responsibilities between GPs and specialist palliative care teams, coordination of service with specialists and lack of confidence in providing palliative care in view of deficiencies in knowledge and skills in palliative care. Multiple training formats and learning styles for GPs in end-of-life care have been explored across studies. The research has yielded mixed results in terms of physician performance and patient outcomes. This calls for more research on GPs' views on end-of-life care learning preferences, as this might inform policy and practice and facilitate future training programs in end-of-life care.

**Keywords:** Primary palliative care, Chronic life-threatening illnesses, Integration, Continuing medical education, General practitioner

## INTRODUCTION

Primary palliative care is an integral component of patient-centred primary care<sup>[1]</sup> and general practitioners (GPs) play a pivotal role in providing palliative care in the community.<sup>[2-5]</sup> Primary palliative care physicians provide symptom management for patients with chronic life-threatening illnesses and ensure that the care is provided in alignment with the patient's and family's wishes and values.<sup>[6]</sup> They facilitate discussions around the goals of medical care, coordinate care between specialists and patients in the community, and provide appropriate referrals to a specialist palliative care team for complicated end-of-life needs.<sup>[4,7]</sup> Therefore, integrating palliative care into primary healthcare will ensure universal access to palliative care.<sup>[8]</sup>

## SEEING PRIMARY PALLIATIVE CARE THROUGH THE LENS OF PUBLIC HEALTH

Disease, grief, and death are impacted by socio-cultural beliefs, relationships within family and society, and community engagement.<sup>[9]</sup> An integrated public health palliative care model uses an evidence-based and cost-effective approach to address aspects of the sociocultural contexts of palliative care.<sup>[9,10]</sup> It adopts a multidisciplinary approach, utilises social care systems, and ensures universal access to care.<sup>[9-11]</sup> The supplementary document depicts the evolution of the public health palliative care association [Table 1].<sup>[10,12-17]</sup>

The contemporary challenges of palliative care delivery, such as changing demographics, social isolation, inequity in service delivery, and professionalisation of dying, have

\*Corresponding author: Naveen Salins, Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, India. naveen.salins@manipal.edu

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**Table 1:** Evolution of public health palliative care association.

Paper	Key objectives
World Health Organization, 1986	Reviewed papers on cancer pain and provide strategies to relieve cancer pain and enhance the quality of life of patients. It predicated on three salient components; education of healthcare workers and the public; opioid availability and appropriate policies to implement the first two components
World Health Organization, 1990-1998	Expanded the focus to include pain and palliative care to relieve the sufferings of terminally ill cancer patients by providing holistic care encompassing physical, psychological, and spiritual care. Subsequently in 1998, published the guidelines on principles of symptom management in terminally ill cancer and HIV/AIDS patients
World Health Organization, 2002	WHO further refined the definition by including prevention and early identification of symptoms earlier in the trajectory of any life-threatening illnesses across age groups. It further broadened its scope to include the health and well-being of family members and caregivers of the patient. It also emphasised on the importance of community- and home-based approach
National Cancer Control Programmes: Policies and Managerial Guidelines, 2 <sup>nd</sup> ed., June 2002	Clearly spelt out the need for palliative care for cancer and non-cancer conditions. Provided guidelines for principles of the management of patients and families facing chronic life-threatening illnesses. It also reiterated the importance of education, opioid availability, and government policies to achieve the above
Stjernsward <i>et al.</i> , 2007	Reaffirmed the WHO palliative care goals and further emphasised on the strategies to achieve the goals of policy development, opioid availability, and policy development
World Health Organization, 2014	Generated a report entitled 'Strengthening of palliative care as a component of integrated treatment throughout the life course.' This report summarised the following points: <ol style="list-style-type: none"> <li>1. Formulating and implementing national policies that integrate palliative care into the health system of the country with special emphasis on primary care, community- and home-based care to ensure universal health coverage</li> <li>2. Improvement in the quality standards of palliative care</li> <li>3. Education in 'holistic palliative care' covering undergraduate medical and nursing schools and to healthcare providers at all levels</li> <li>4. Ensuring drug availability and minimising the risks of diversion of controlled drugs</li> </ol>

prompted many to adopt a public health approach to palliative care delivery.<sup>[8]</sup> The public health approach to palliative care is premised on the principle of community engagement, in which people in society own the responsibility of caring for each other.<sup>[18]</sup> This approach empowers people in the community to support patients and families facing the end of life by responding to the needs and wishes of the dying patients and their families, creating leaders from within the community for sustainability, developing collaborations with community groups and stakeholders, and working in alignment with healthcare professionals.<sup>[12,18-20]</sup>

### THE BURDEN OF CHRONIC LIFE-THREATENING ILLNESSES IN A PRIMARY CARE SETTING

Worldwide, countries are experiencing an epidemiological transition with a rise in the morbidity and mortality from both non-communicable and communicable diseases, with non-communicable diseases alone accounting for 71% of mortality globally and low- and middle-income countries (LMICs) facing a burden as high as 77%.<sup>[21]</sup> Internationally, cardiovascular diseases, cancer, respiratory diseases, and diabetes account for higher premature mortality than communicable diseases.<sup>[21-23]</sup> The impact of this burden is greater on LMICs as a result of their vulnerability to socioeconomic, geographic, and demographic factors.<sup>[24]</sup> The double burden of communicable

and non-communicable diseases threatens survival, obstructs education, and reduces productivity, impeding socio-economic growth.<sup>[24]</sup> This is further compounded by poverty and out-of-pocket health expenditure, which inhibits people from accessing healthcare services for the most treatable conditions.<sup>[25]</sup> As a part of the sustainable development goals 3.8, palliative care was recognised as a fundamental component of universal health coverage.<sup>[25]</sup> It is estimated that 40 million people each year will need palliative care, and 78% of this population lives in LMIC.<sup>[16]</sup> Despite the high demand for specialist palliative care, only 14% of the world's population currently receives it at the end of life.<sup>[26]</sup> GPs act as fulcrums in the community and ensure that palliative care reaches those in need of it.<sup>[27]</sup> They continue following on their patients through various trajectories of the disease, even while they are undergoing disease-directed treatment.<sup>[27,28]</sup> Long-standing relationships with their patients and knowledge about their patient's social and economic context act as facilitators for initiating early palliative care.<sup>[29,30]</sup>

### CARE IN ALIGNMENT WITH THE PATIENT'S AND FAMILY'S WISHES

Patients at the end of life feel secure in their home environment as they can exercise control over the situation.<sup>[31,32]</sup> Research has revealed a wide variation in the preference for place

of death among the population globally,<sup>[33]</sup> ranging from 25% to 87% of the population preferring home death to 9–30% preferring inpatient hospice death.<sup>[30,34,35]</sup> Patients with poor functional performance and severe physical or psychological symptoms prefer to be cared for at home.<sup>[31,36]</sup> Strong family support, fortified by the ongoing continuous support by their GPs or home hospice teams, increases the likelihood of home-based care.<sup>[31,33,36]</sup> Some patients prefer hospice- or hospital-based care when they feel that they are burdening their family members with the increasing intensity of nursing care<sup>[31,33,36]</sup> or when they experience skeletal support from GPs or home hospice teams.<sup>[30]</sup>

Caregivers' preference for continuing home-based care for their patients ranged between 25% and 64%.<sup>[30]</sup> Furthermore, home deaths are associated with better bereavement responses and overall caregiver satisfaction.<sup>[32]</sup> Their response could be dictated by need rather than preference, their perceived level of competency in providing care, and the extent of support from community-based healthcare teams.<sup>[30,37]</sup>

### SUFFERING AT THE END OF LIFE

One of the main goals of good medical practice is to alleviate patients' suffering.<sup>[38]</sup> Patients suffering from chronic life-threatening illnesses experience multiple concurrent symptoms, which can have a negative impact on their quality of life.<sup>[39,40]</sup> As many as, 63.1% of patients have moderate-to-severe physical and psychological symptoms at the end of life, and 24.4% of patients have a cluster of at least three symptoms of moderate-to-severe intensity.<sup>[40-44]</sup> A systematic review published by Moens *et al.*<sup>[39]</sup> demonstrated commonalities in physical and psychological suffering between advanced malignancy and non-malignant chronic life-threatening illnesses. Suffering is further exacerbated by the meaning patients attribute to their symptoms and by the association of these symptoms with their perceptions of existence.<sup>[45]</sup> The fear of impending death, loss of autonomy and control over one's surroundings, and a constant sense of insecurity about one's future add to the complexity of suffering.<sup>[45]</sup>

### INTEGRATION OF PALLIATIVE CARE INTO PRIMARY HEALTH CARE

Patients and families develop a strong therapeutic bond with their GPs over prolonged years of care.<sup>[46]</sup> They perceive a sense of security in their GPs and continue to seek advice from them until the end of life<sup>[46,47]</sup> as their GPs are approachable, accessible, and would take time to listen to their concerns and feelings.<sup>[48]</sup> An integrated primary palliative care model will ensure person-centred care and provide continuous support to patients and families facing chronic life-threatening illnesses.<sup>[49]</sup>

Research shows that continuity of care is a vital concept that is known to strengthen the healthcare system.<sup>[50]</sup> This occurs at three levels: Provider continuity (determined by the

patient-doctor bond over time and harmonious relationships with colleagues and multidisciplinary teams), information continuity (the accessibility of patient information across the care continuum), and management continuity (coordinated care by a multidisciplinary team and resource mobilisation).<sup>[51]</sup> However, GPs face challenges in providing end-of-life care in the community, which include identification of patients in need of palliative care, interpersonal communication, addressing patients' and caregivers' needs, clarity in roles and responsibilities between GPs and specialist palliative care teams, and coordination of service with specialists.

### Identification of patients in need of palliative care

In most countries, the identification of patients in need of palliative care is largely dependent on the GPs own clinical knowledge or discharge information.<sup>[29,52]</sup> They also receive subtle signals from patients, relatives, and specialist colleagues when patients become increasingly debilitated or bedridden, or when relatives indicate care as being burdensome or when specialists give a clear signal that the disease is incurable.<sup>[29,48]</sup> Unlike cancer, non-malignant life-threatening illnesses have an unpredictable trajectory due to their variable causes and nature, making decisions to initiate end-of-life care difficult.<sup>[29,48,53,54]</sup> Furthermore, practitioners are concerned about causing harm to their patients and prematurely taking away their hopes.<sup>[48,53]</sup> Simple and standardised tool kits have been developed to serve as practical guides in identifying patients in need of palliative care.<sup>[47,55]</sup>

### Interprofessional communication

Communication is vital to seamless collaboration between teams, especially one that is appropriate, timely, and relevant.<sup>[47]</sup> This is enabled by trust, shared norms and values, and the alignment of tasks between professionals.<sup>[56]</sup> Poor communication between specialist palliative care teams and GPs can compromise the quality of care provision.<sup>[57]</sup> GPs feel uncomfortable continuing care for patients in the community when they receive insufficient information from the specialist team.<sup>[47]</sup> Conflicts in care between patients' treating physicians can result in significant distress and insecurity among patients and caregivers.<sup>[58]</sup>

Collaboration between teams can be strengthened with improvement in the processes involved in interpersonal communication.<sup>[59]</sup> Some of these strategies include improving interpersonal communication by attending multidisciplinary team meetings,<sup>[48,60]</sup> liaison with specialist palliative care in local hospice/palliative care units, or case conferences.<sup>[61]</sup> Structured referral formats with appropriate information are considered important for a seamless transition to community-based palliative care.<sup>[48,59,62-64]</sup>

### Addressing patients' and caregivers' needs

Patients and families value the care provided by their GP, provided their physician is sensitive to their needs,

compassionate, honest, and has good communication skills.<sup>[42]</sup> They expect their physician to pre-emptively explore their needs, including psychological and emotional issues, throughout the disease trajectory.<sup>[62]</sup>

### Clearly defined roles and responsibilities

The clarity in roles and responsibilities between specialists and GPs is essential to ensure effective collaboration, amicable partnership, and shared care that complements one another's skills.<sup>[65]</sup> However, the line is frequently blurred due to the polarity of care.<sup>[61]</sup> This can result in power issues, breaches in partnership between the GP and specialists, and fragmented coordination of care.<sup>[66]</sup>

### Accessibility to GPs

Accessibility to GPs in the community is an important aspect of continuity of care for patients at the end of life.<sup>[58,63,67]</sup> Patients and families value GPs' approachability and availability to conduct home visits.<sup>[58,63,67]</sup> Especially during out of hours, patients and families feel more secure if they feel confident that their GP will be available in the event of an emergency.<sup>[63]</sup>

### Coordination of services

Coordination of patient care is critical for successful community collaboration.<sup>[68]</sup> However, the absence of a structured liaison service in the healthcare system complicates coordination.<sup>[68]</sup> Primary care plays a crucial role in this process and is found to be cost-effective, sustainable, and of high quality.<sup>[60,67]</sup> Although patients prefer their GPs to be involved in their care, the intensity of this care can vary across the disease trajectory.<sup>[48]</sup> Most prefer a 'shared care' model in which both their specialists and GPs collaborate with each other.<sup>[59]</sup> Although many people prefer multidisciplinary care, they want a single point of contact who will coordinate their care.<sup>[69]</sup>

### Organisation of service

Bureaucracy, organisation of care, and compartmentalisation of care influence continuity of care in the community.<sup>[70]</sup> Delays in care provision due to bureaucracy and lack of specialists can increase the physical and mental burden of patients and their families.<sup>[70]</sup> Even organising logistics in the community can be obstructed by bureaucratic procedures. Continuity of care is often a challenge in the community due to the temporary nature of the team and multiple members involved in care provision. Problems with compartmentalisation of care can further hamper continuity of care as terminally ill patients have to be transferred to a healthcare facility for relatively simple and straightforward procedures.<sup>[70]</sup> Late referral of palliative care patients and lack of a standardised clinical pathway for end-of-life care can fragment the healthcare system and hinder the continuity of care.<sup>[56,71]</sup>

## EDUCATIONAL PROGRAMMES IN PRIMARY PALLIATIVE CARE

GPs often have limited formal education in end-of-life care and their knowledge, skills and confidence in end-of-life care vary.<sup>[3]</sup> Often, the first exposure to end-of-life care occurs in their clinical practice<sup>[3]</sup>. Therefore, it is essential to train GPs in end-of-life care to meet the growing demand for end-of-life care.<sup>[72]</sup>

The training needs of GPs in end-of-life care have been explored in scientific literature, with most training focused on pain control and other symptoms of advanced cancer.<sup>[3]</sup> The knowledge gap includes ignorance about what palliative care entails and the possibilities of specific medical or nursing interventions in the home situation.<sup>[59,73]</sup> They feel overwhelmed when they encounter an enormous range of complex symptoms.<sup>[59,73]</sup> Furthermore, the inability to manage conflicts within the family and limited awareness of the patient's preferred place of death preclude palliative care provision.<sup>[59,74]</sup>

Multiple approaches to training in end-of-life care have been researched.<sup>[75]</sup> For instance, didactic styles of training have been proven to change knowledge, skills, or attitudes, but are not effective in changing physician performance or behaviour.<sup>[75]</sup> However, when learning is self-directed, self-regulated, engaging, and reinforcing, this can lead to a more definitive change in the physician's performance.<sup>[76]</sup> Training programmes that are interactive and involve the sharing of real-life experiences are shown to change physician performance and behaviour.<sup>[75]</sup>

Multiple formats of training have been researched in end-of-life care and all of them have demonstrated positive outcomes in the knowledge and attitudes of GPs and their overall satisfaction with training.<sup>[77]</sup> However, these interventions have shown only minimal improvement in professional practice or patient outcomes.<sup>[77,78]</sup> Multifaceted interventions that include two or more training formats can have beneficial effects on GPs' caregiving and patient-related outcomes.<sup>[79-82]</sup> However, it is important to note that the complexity and concurrence of multiple symptoms and the seriousness of the targeted outcomes can impact patient-related outcomes.<sup>[83]</sup> Feedback and reinforcement have been studied as integral components of educational interventions and found to be effective when specialist colleagues provide clear goals and specific action plans.<sup>[83]</sup> Patient-mediated health interventions improve the performance of healthcare professionals through patient-reported health information, patient-led counselling and education, and patient feedback.<sup>[84]</sup> This will increase the physician's adherence to recommended clinical practice guidelines and recommendations as a measure for the quality of professional practice.<sup>[84]</sup>

In addition to the training-related constraints, GPs' own perspectives, values, and attitudes toward end-of-life care can affect care provision and patient outcomes.<sup>[85]</sup> Among

the external environmental factors, challenges at a personal and professional level and resource limitations constrain palliative care provision.<sup>[59,73,85]</sup>

## CONCLUSION

The rising burden of chronic life-threatening illnesses poses a great challenge to the healthcare system. The paucity of palliative care specialists increases the demand for a more decentralised approach to end-of-life care.<sup>[12]</sup> GPs act as an important fulcrum in the community, supporting patients and families through the bitter experiences of end of life. Despite considering palliative care as an integral part of their clinical care, GPs have apprehensions about end-of-life care provision. They find managing physical symptoms, addressing patients' and families' emotional needs, and advance care planning, particularly challenging. Although studies have explored GPs' training and educational requirements, there are no studies in India that have explored the motivations and challenges concerning their end-of-life care learning preferences. Moreover, research findings on GPs' views on end-of-life care learning preferences might inform policy and practice and facilitate future training programmes in end-of-life care.

### Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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### Conflicts of interest

There are no conflicts of interest.

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