

Integration of primary palliative care into geriatric care from the Indian perspective

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ABSTRACT

The rising trend in the ageing population alongside social, cultural, and economic changes poses a major threat to the health care system in the country. Elderly population have dynamic and complex health care needs, are debilitated by the progressive chronic life-threatening diseases, and live a compromised quality of life. Palliative care, with its multifaceted approach, can provide respite to the elderly population. A decentralized approach in which palliative care is provided by the local community will ensure seamless continuity of care and care at an affordable cost. General practitioners or family physicians play a vital role in delivering primary palliative care to the elderly population in the community. An integrating primary palliative-geriatric care model will ensure that care is provided in alignment with the patients' and their families' wishes along the trajectory of the life-threatening illness and at the patients' preferred place. However, delivering primary palliative care in the community can be riddled with challenges at various levels, such as identification of patients in need of palliative care, interpersonal communication, addressing patients' and caregivers' needs, clarity in roles and responsibilities between general practitioner and family physicians and specialist palliative care teams, coordination of services with specialists, and lack of standard guidelines for palliative care referral. Various geriatric-palliative care models have been tested over the years, such as delivering palliative and end-of-life care for disease-specific conditions at specified care settings (home or hospice) and provision of care by different specialist palliative care teams and general practitioners or family physicians. Akin to the aforementioned models, the National Health Program in the country envisages to strengthen the integration of geriatric and palliative care. The integrated geriatric-palliative care model will ensure continuity of care, equitable distribution of service, impeccable inter-sectoral collaboration and care at an affordable cost.

Keywords: Elderly, geriatric care, integration, primary palliative care

Introduction

India is experiencing a rising trend in the ageing population, with an estimated increase of 10.1% in 2021 to a projected increase to 13.1% in 2031 with similar trends in rural and urban population.^[1] This unprecedented rise is occurring alongside social, cultural, and economic changes taking place globally.^[2] The problem of ageing is

further compounded by their progressive frailty and concomitant comorbidities.^[3,4] This can result in episodic symptom exacerbation and recurrent hospitalizations, decline in daily activities, and deterioration in functionality and quality of life.^[4,5]

Governments all over the world have pledged to achieve universal health and well-being for all ages by 2030.^[5] Palliative care is an integral facet of universal health coverage. It aims to alleviate suffering and restore quality of life in patients with chronic life-threatening illnesses.^[6] Additionally, the elderly population has complex needs that demand impeccable care coordination, shared decision-making, clear goals of care, and a seamless transition to

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the community.^[7] This will prevent unwarranted hospitalizations and ensure provision of care in alignment with patients' and their families' wishes and values.^[7] Geriatric and palliative care have received increased attention in recent years due to their ability to address complex population problems, provide interventions that balance comorbidities, alleviate symptoms, and maximize the quality of life.^[8] An integrated geriatric–palliative care model will lead to better patient outcomes and patient and family satisfaction.^[9]

The goal of this article is to explore the burden of serious health-related suffering among older adults living with chronic life-threatening illnesses in the community. We will examine the current evidence available on integrated geriatric–palliative care models across the globe and the strategies used to overcome the barriers of continuity of care in the community. Finally, the paper concludes by discussing the current government initiatives to integrate geriatric care with palliative care.

Burden of Chronic Life-Threatening Illnesses in Older Adults

People aged 60 years and above contribute to 23.1% of the total burden of disease, with 19.9% of this population living in low- and middle-income countries (LMIC).^[10] In India, the proportion of ailing elders among the elderly population is as high as 50%.^[11] This is further compounded by their vulnerability to various socio-economic, geographic, and demographic factors.^[11] Non-communicable diseases account for 71% of mortality globally, with developing countries facing a burden as high as 77% (and among the elders in India, it ranges between 19.5%–31.5%).^[1,12] As the global burden of chronic life-threatening illnesses rises, the number of older adults suffering from these illnesses will also increase exponentially.^[13]

The introduction of palliative care intervention is known to alleviate suffering and improve the quality of life of both patients and their families,^[14] as well as reduce expenditure on both the health care system and society.^[15] It is estimated that 40 million people each year will need palliative care, and 78% of this population lives in LMICs.^[12] Despite the high demand for palliative care, only about 14% of this population currently receives it, and most are in high-income countries.^[12,16]

Care in Alignment with the Patient's and Family's Wishes

Older adults with chronic life-threatening illnesses have complex needs^[17] and to provide person-centered care to this population, it is important to align care with their preferences for care.^[18] The preference is determined by contextual factors, such as a person's past experience, illness-related factors and their impact on performance, and socio-economic factors such as family and social support systems and standard of living and financial support.^[19–21] Preference for location of care varies globally ranging from 25%–87% for home care to 9%–30% for inpatient hospice care.^[19,22] Home-based care was preferred by older adults

with severe physical and psychological illnesses.^[23] Strong family support, fortified by the ongoing continuous support by their general practitioner or family physician or home hospice teams, increases the likelihood of home-based care.^[20,23] Older adults with cognitive impairment may not express their wishes overtly,^[24] raising the importance of the care context and family support.^[18] Recognizing family preferences is also important for seamless care.^[25] Home deaths are associated with better bereavement responses and overall caregiver satisfaction.^[26] 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 health care teams.^[19]

Frailty and Suffering in Older Adults

Frailty, with its associated complications, is a major cause of concern in older adults as it can have a detrimental effect on the quality of life.^[27,28] Comorbidities, high symptom burden, debility, and psychosocial distress increase the risk of frailty.^[29] The progressive decline in the health of older adults can often be slow and gradual and often unpredictable, with inter-individual variation.^[29] To explain this further, individuals are usually resilient at a particular level of frailty.^[29] Therefore, it is the rapidity with which frailty increases that increases the risk of mortality.^[27,29]

One of the main goals of good medical practice is to alleviate the patient's suffering.^[30] Patients with chronic life-threatening illnesses suffer from multiple concurrent symptoms that can have a detrimental effect on their quality of life.^[28,31] As patients progress towards end-of-life, there is a rise in the physical and psychological symptom burden.^[28,32] As many as 63.1% of patients have moderate-to-severe symptoms at the end of life, and 24.4% of patients have a cluster of at least three symptoms of moderate-to-severe intensity.^[28] A systematic review published by Moens *et al.*^[31] demonstrated commonalities in problem prevalence between advanced malignancy and non-malignant life-threatening illnesses. Suffering is further exacerbated by the meaning patients attribute to their symptoms and the association of these symptoms with their perceptions of existence.^[30,33] 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.^[33]

Integration of Primary Palliative Care into Geriatric Care

Strong therapeutic bond developed between general practitioners (GPs) or family physicians and patients over a prolonged period of care raise the importance of general practitioners or family physicians in the continuity of geriatric palliative care in the community.^[34] Patients and families consider their GPs as confidants who traverse the journey with them until the end of life.^[34,35] GPs ensure a person-centered care and integrate families as a unit of care. GPs provide continuous support to patients and families and facilitate seamless transition to end of life.^[36]

Continuity of care is a vital concept gaining importance in current research, and a decentralized approach to care will reduce the burden on the health care system.^[15] Continuity of care is influenced by factors such as identification of patients in need of palliative care, interpersonal communication skills between general practitioners or family physicians and the palliative care team, addressing patients' and caregivers' needs, clarity in roles and responsibilities between the GP or family physician and the palliative care team, and coordination of service. Identification of patients in need of palliative care can be challenging despite robust standardized tools and is largely dependent on the clinician's own clinical knowledge or discharge information.^[37,38] This challenge is further compounded by the indolent nature of certain diseases and the unpredictable trajectory due to variable causes and nature of the illness.^[37,39,40] This makes prognostication a daunting task.^[39,40] Communication is enabled by trust, shared norms and values, and alignment of tasks between professionals.^[41] Insufficient information with regard to prognostication and goals of care discussion can hinder continuity of care in the community.^[42] Poor interpersonal communication and conflicts between the general practitioner or family physician and the palliative care team can compromise the quality of care and patient outcomes.^[43] Some of the strategies that could aid in better interpersonal communication include structured referral formats,^[39,44,45] shared decision-making through multidisciplinary team meetings,^[39,46] collaborative care (between general practitioners or family physicians and the specialist palliative care team),^[47] or case conferences.^[47] Addressing patients' and caregivers' needs is vital in the continuity of care. They expect their physician to preemptively explore their needs, including psychological and emotional issues, and be compassionate, honest, and reassuring throughout the disease trajectory.^[42,44] Clarity in roles and responsibilities between both specialties is essential for effective collaboration, amicable partnership, and shared care that complement one another's skills.^[46,47] Patients and families value the GP's or family physician's approachability and availability to conduct home visits.^[43,45] Especially during out-of-hours, patients and families feel more secure if they feel confident that their GP/or family physician will be available in case of an emergency.^[45] This often may be impacted by an unstructured liaison service in the health care system and poor coordination between treating teams.^[48] Most patients prefer a shared care model in which both the GP or family physician and the palliative care team collaborate with each.^[47] Although patients and family prefer a multidisciplinary care, they wish to have their GP or family physician as a key point of contact for care coordination.^[49] Bureaucracy, organization of care, and compartmentalization of care influence continuity of care in the community.^[50] 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 compartmentalization of care can further hamper continuity of care as terminally ill patients have to be transferred to a health care facility for relatively simple and straightforward

procedures.^[50] Late referral of palliative care patients to the GP or family physician and lack of a standardized clinical pathway for end-of-life care can fragment the health care system and impede continuity of care.^[41]

Integrated Palliative–Geriatric Care Model: Current Community Models

Across the globe, various service delivery models have been tested over the years, delivering palliative and end-of-life care for disease-specific conditions,^[51] at specified care settings (home or hospice),^[52] and provision of care by different specialist palliative care teams and GPs or family physicians.^[53] Considering the burdensome symptoms and dwindling prognosis in geriatric patients heading towards end of life, there is a need for initiating a comprehensive geriatric–palliative care model. A geriatric–palliative care model will advocate for a comprehensive assessment of geriatric patients by a multidisciplinary team and emphasize on symptom management, focus on restoring physical and mental capabilities, and preserving quality of life.^[54] An “integrated geriatric care model” that focuses on person-centered care through a multidisciplinary team approach will facilitate seamless transition to end of life.^[56] Care is initiated at an early stage of the illness to preserve the patient's functionality and quality of life.^[36] Another model, the integrated palliative care model, is akin to the aforementioned model; however, it is initiated late in the illness trajectory and focuses on preserving quality of life by alleviating physical, psychosocial, and spiritual distress.^[36] In order for the model to sustain, it must be fortified by impeccable care coordination between specialist palliative care teams and the GP or family physicians in the community.^[53] Telemedicine is emerging as an important consultative procedure connecting patients with their physicians when both are separated by a crisis such as the COVID-19 pandemic or geographic barrier.^[55] Telehealth consultation that has a human-centered approach will have better acceptance by the trio of physician, patient and family and will be perceived as meaningful and satisfying by the end-users.^[56]

Elderly and Palliative Care Service Development in India

The National Health Program envisages to strengthen the integration of geriatric and palliative care as envisioned in the Ayushman Bharat program. And primordial step in this direction is universal access to equitable, affordable, and quality health care. The three other relevant health programs would be National Health Program for Healthcare of the Elderly, National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke, and National Program for Palliative Care. The programs will be premised on a person-centered approach, being mindful of the patient's values and dignity. In order to achieve this, the existing primary health care services and sub-health centers will be converted to health and wellness

centers with the intention of improving the accessibility and timeliness of service delivery. The Primary Health Centers will provide comprehensive care through outpatient clinics, outreach programs such as mobile medical units, community health camps, domiciliary care, teleconsultation, and community empowerment and engagement. This will ensure continuity of care, equitable distribution of service, impeccable inter-sectoral collaboration and care at an affordable cost. The care will be provided by a multidisciplinary team comprising medical officers, nurses, multi-purpose workers, and accredited social health activists (ASHA). This will broaden the range of services and each individual will complement one another in care provision. The service will be further strengthened by ongoing capacity building and supportive superfixes.^[57]

Conclusion

The rising numbers of ageing population and the resulting increase in chronic life-threatening illnesses pose a great challenge to the health care system. The elderly have complex physical and psychosocial needs that demand impeccable assessment, care coordination, and seamless transition into the community. A comprehensive geriatric-palliative care model is an eclectic model that combines the expertise from both specialties and aims to provide comprehensive care to older adults. The integrated model will help alleviate symptoms, restore physical and mental functionality, and prevent unwarranted hospitalizations. It will help overcome the challenges of community-based care, ensure care provision is in alignment with the patients' and families' wishes, and enhance the quality of life of both patients and families.

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Conflicts of interest

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