

Neuropalliative Care in India – Barriers, Challenges and Future Directions

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Abstract

Neuropalliative care is an emerging sub-specialty of neurology and palliative care that aims to relieve suffering from symptoms, reduce distress and improve the quality of life of people with life-limiting neurological conditions and their family caregivers. As advances are being made in the prevention, diagnosis, and treatment of neurological illnesses, there is an increasing need to guide and support patients and their families through complex choices involving immense uncertainty and important life-changing outcomes. The unmet need for palliative care in neurological illnesses is high, especially in a low-resource setting like India. This article discusses the scope of neuropalliative care in India, the barriers and challenges that impede the specialty's development, and the factors that could facilitate the development and scale-up delivery of neuropalliative services. The article also attempts to highlight priority areas for advancing neuropalliative care in India which include context-specific assessment tools, sensitization of the healthcare system, identification of intervention outcomes, the need for developing culturally sensitive models based on home-based or community-based care, evidence-based practices, and development of manpower and training resources.

Keywords: Caregiving, end of life care, India, life limiting diseases, neuropalliative care, quality of life, supportive care

INTRODUCTION

Palliative care is an approach to the care of patients and families facing progressive and chronic illnesses that focuses on improving quality of life, and preventing and relieving suffering due to physical symptoms, psychosocial issues, and spiritual distress.^[1] It is estimated that nearly 5.4 million patients need palliative care every year in India, though it is accessible to only 1-2% of them.^[2] In 2014, the World Health Organization (WHO) and World Palliative Care Alliance released a global atlas to assess the provision of palliative care, which reported that only 14% of those in need are receiving palliative care. Out of this, 78% of the unmet need was in low- or middle-income countries.^[3] Even though, palliative care research is growing steadily in India, the implementation of this new knowledge is at a much slower rate when compared to the rest of the world. According to the availability of palliative care, India was ranked 67 out of 80 countries.^[4]

In India, the prevalence rates of the spectrum of neurological disorders (excluding neuroinfections and traumatic injuries) are estimated over 30 million and is expected to continue increasing.^[5] With its massive population, diverse and non-uniform healthcare service delivery and intervening social factors (like poverty, illiteracy), it is difficult to gauge the real estimate of the burden of neurological diseases in India, which could be much higher than what is reported.^[6] India with its growing population carries a huge burden of patients suffering from life-limiting diseases. Many of whom have exhausted all meaningful treatment options especially in the later stage of

the diseases.^[7] Due to lack of palliative care services, patients often receive inapt and unnecessary medical interventions which takes a heavy toll on the resources of patients and their families.^[8,9]

Patients with a life-limiting neurologic illness often have a long and variable disease progression punctuated by cognitive impairment, behavioral issues, and communication problems, in addition to motor symptoms.^[10] This trajectory differs from the patients with cancer, where the patients usually show a sharp decline.^[11] Evidence has shown that patients with motor neuron disease experience more demoralization, hopelessness, and suicidal ideation than patients with metastatic cancer^[12]; and patients with Huntington disease have distinctive social work needs as the result of combined behavioral, psychiatric, movement, and cognitive issues.^[13] The physical and cognitive disabilities

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associated with neurologic illness contribute to feelings of being “useless” or a “burden” and may contribute to higher rates of demoralization.^[12] Neurologic diseases are associated with distress and reduced quality of life related to caregiving.^[14] Caregivers of patients with dementia are more adversely affected by their role, have unique psychological issues compared with cancer caregivers,^[15] and are at high risk of complicated bereavement.^[16] Thus, we propose that there is a need for an approach that specifically address the palliative care needs of patients with neurological diseases.

Neuropalliative care services should take into consideration the predominant problems associated with neurological illnesses including physical symptoms, swallowing difficulties, cognitive impairment, behavioral issues, difficulties in communication, caregiver needs, and other psychosocial issues.^[10,17]

In India, most palliative care models have been centered around cancer. The models of palliative care service in India include inpatient care, which is provided in hospices or hospitals; outpatient clinical settings like in hospitals or clinics; community-based palliative care, which is an innovative community-led sustainable approach run by volunteer networks; and home-based care services which are again provided by hospitals and hospices or are run by volunteers.^[18,19] Many such initiatives are led by voluntary organizations and patient-caregiver associations such as “Neighborhood Network in Palliative Care” in Kerala, India.^[20] The community-based palliative care model and the home-based care services have been found to be effective and sustainable for resource poor settings where specialist led services are limited and not accessible. Adaptation of similar models of community-based and home-based care services for providing neuropalliative care services should be explored and evaluated. A larger number of patients in India, including those suffering from life-limiting neurologic illness, come to the hospital at more advanced stages of the disease, as compared to the western world. Following this, many protract their treatment at tertiary care hospitals due to lack of other provisions at a primary or secondary level. The tertiary referral centers in India are overburdened and are treating terminally ill patients from different states and parts of the country, which reflects the lack of basic neuropalliative care services in India. This adds to the cost of care for the patients, fatigue, and burnout for the healthcare team and inefficient use of the infrastructure and resources in these apex centers. Enabling care of such patients at a local secondary care hospital may prove to be more cost-effective and more efficient use of health care resources.^[21] Setting up of neuropalliative care units in secondary care hospitals which consists of a multidisciplinary team that includes nursing staff trained in palliative care, neurologists with training or interest in palliative care, a neurorehabilitation physician, a psychiatric social worker or psychologist, and a speech and occupational therapist could go a long way providing services to the community at large.

BARRIERS AND CHALLENGES

Neuropalliative care in India is forced to contend with the existing barriers and challenges in provision of palliative care. Additionally, neuropalliative care has to grapple with unique challenges due to the diverse trajectory and nature of the illnesses, low knowledge and awareness and inadequate and insufficient research. The primary bequeathed challenge is the common misconception that palliative care implies merely end-of-life care or as care provided in hospices, which limits its application, scope, and value. The goal of palliative care is in fact to provide the best possible quality of life, at every stage of treatment, starting from diagnosis. The advantage of early palliative care has been demonstrated to influence patient-related outcomes too.^[22] The training capacity in India for palliative care is limited, and there is a reluctance on the part of health professionals to pursue this field, which could be due to lack of knowledge regarding employability and career growth. Palliative care is not considered mainstream or mainstay of the treatment due to lack of awareness and stigma around palliative care being “not doing much” for the patient or feeling of failure when unable to “cure”. Myths about palliative care being equal to end-of-life care among health professionals, myths about morphine, and fears of addiction among medical fraternity and general community and unavailability of non-cancer palliative care services add to the barriers in seeking and providing palliation at an early stage.^[22]

Despite the growing interest in incorporating palliative care in neurological illnesses, India faces several challenges in trying to meet population needs for quality neuropalliative care. Barriers in the form of shortages of trained manpower, insufficient drugs for symptom relief, dearth of essential amenities including beds, equipment, and other basic infrastructure and insufficient funding in neurology contribute to limiting the growth of the field.^[23-28] Accessibility- and awareness-related factors, like lack of knowledge about resources, higher cost of treatment, low perceived need for care and rehabilitation, distance to care facilities, reluctance on part of healthcare provider to refer, also play a significant role in underuse of the existing services.^[24,29-32] There is low awareness about seeking and availing neuropalliative care and in most cases, care is restricted to addressing medical needs. The lack of awareness about the needs as well as the availability of support services results in the bigger issue of nearly non-existent referral of patients requiring neuropalliative care by the specialists or primary treating team.

There is insufficient research on specific palliative care needs in neurological diseases. This in turn impedes the development of intervention plans and strategies which should be designed to cater to the needs of the patients and caregivers. Skills required for working in the area, especially communication skills needed to deliver bad news and discuss care plans, are often an unfamiliar territory for health care professionals along with insufficient knowledge and attitude.^[32] Another challenge lies in deficient knowledge about the capture and

course of neurological illnesses in patients, the families, and the public. This coupled with the existential distress resulting from uncertainty of prognosis, loss of function, loss of autonomy, and death, which are specific to neurological diseases, can manifest in different ways for all the stakeholders.^[28,33]

THE WAY FORWARD/FUTURE DIRECTIONS

Neuropalliative care is an emerging field in India; however, there is a long journey ahead to fulfill the potential of the field in a way that it reaches everyone in need of such care and services. In a welcome change in this direction, the Indian Association of Palliative care (IAPC: <https://www.palliativecare.in>) has made several forays into non-oncology palliative care in terms of training and capacity building initiatives for professionals working in the field.

In terms of healthcare policies and programs, a National Palliative Care Program was launched in 2012 and the Ministry of Health and Family Welfare has proposed Strategies for Palliative Care in India that would initiate activities related to palliative care with a vision of facilitating access to affordable, safe, and quality pain relief and palliative care to all those requiring it in the country. However, no separate budget was allocated for the implementation of the same and palliative care in the aforementioned programs was mainly targeted towards patients with cancer, AIDS, and not specifically for neurological conditions. In such scenarios, the arduous task of generating funds and engaging trained professionals falls on the non-government palliative care organizations, who struggle with resources themselves and might not be aware of the nuances of neuropalliative care. It is encouraging that palliative care has been included as part of the “Mission Flexipool” under National Health Mission (NHM) and the National Palliative Care Program is a welcome step in overcoming some barriers to access palliative care in India. However, augmenting the scope of the program by encompassing the issues inherent to patients with life-limiting neurologic illnesses also could add to the growth of neuropalliative care services in India.

The way ahead needs to be forged with evidenced based practices. Research should be targeted to identify and address the palliative care needs of patients with neurological diseases and their families. As neuropalliative care encompasses dealing with sensitive topics on death and dying, evidence-based guidelines would enable better delivery of care and enhance decision-making in the area especially in view of advance medical directives honoring the autonomy of the person with terminal illness. Other areas for research include how to deal with specific complications like loss of communication, lack of personal autonomy, development, and effectiveness of psychosocial services to address with palliative care needs.^[32,33] The cultural and ethical considerations associated with palliative care in neurological diseases and reducing the stigma surrounding neuropalliative care are also important areas for consideration.^[34]

Delivery of neuropalliative care requires a holistic approach, and it stipulates close collaboration between the disciplines of neurology, neurorehabilitation, and palliative care. Developing evidence-based educational resources on neuropalliative care for training of palliative care professionals, neurologists, and neurorehabilitation physicians, creation, and promotion of specialized courses and training programs in neuropalliative care, and establishment of neuropalliative care centers are the essential to the growth of the field.^[8,35] Home-based care interventions and innovative, multidisciplinary, community-based interventions also have the potential to address the issue of lack of trained manpower and care facilities in India. Another solution to make neuropalliative care services accessible to different parts of the country is using telemedicine services which can provide expert medical advice to remote places or reach people who might not be able to come to the cities where such services are generally available.^[36] Telemedicine could facilitate the monitoring of patients with life-limiting neurological illnesses at their own homes. Several such initiatives targeting oncology palliative care are introduced in recent years through different agencies, and these could provide a useful model to scale-up for neuropalliative care services for the country. Concurrently, to address the issue of lack of public funding, public–private partnership can be established to develop neuropalliative care services.

The transition in care from medical model to more integrated holistic model starts from the shift in attitudes, knowledge, and practice among the neurologists/healthcare professionals. Attitudes need to be shifted from ‘treating the disease’ to ‘treating the person’, focusing on care beyond cure. Shift in knowledge would involve right information about prescribing opioids for pain management among medical professionals, the practice of a referral system and involving a multidisciplinary team in the care of the patients. Another aspect of neuropalliative care that is currently lacking in current healthcare system in India is communication about patient goals and preferences for care. Research on these aspects should be a priority in order to ensure that patient’s preferences are adequately met. Education of the professionals and sensitization of the public through awareness campaigns is vital for improving access to neuropalliative care in India. Process of implementing neuropalliative care plan into action requires strong advocacy, political support, and integration across all levels of care. The deep-rooted belief in India about ensuring a peaceful and dignified death, which is considered a moral obligation of the close family members, can act a facilitator in the process of improving the quality of life of persons with life-limiting illnesses.^[34]

The declaration by the World Health Assembly asking all member states to integrate palliative care with routine health care comes as a major tool in advocacy and hopefully will boost the current efforts.^[37] Fundamental to the enhancement of neuropalliative care in India is starting communication about end-of-life care and choices early in the course of the illness, providing opportunities to discuss about future

and goals of care, emphasis on psychosocial issues, crisis prevention, proper utilization of services, and by training and empowering families and volunteers to provide effective and sustainable palliative care.^[8,14] Establishment of a sustainable public health model in palliative care in the state of Kerala has effectively proved that it is possible to achieve good quality and coverage in palliative care even in low-income and middle-income countries. On a larger scale, policy-level changes should be attempted with the involvement of the policymakers along with establishment of neuropalliative care centers with adequate supply of symptom relieving drugs and adequate infrastructure to provide the required impetus to the development of neuropalliative care services in India. Advocacy and education of the politicians, social activists, healthcare professionals, and the public are essential to ensure the success of the initiative along with improving referral pathways and clinical care pathways. Emphasis should be on a multidimensional approach that focuses on care and involves an array of services delivered by professionals who all have equally important roles to play—including neurologists, primary care physicians, physical medicine and rehabilitation specialists, social workers, psychologists, nursing, support workers, paramedics, pharmacists, physiotherapists, and volunteers—in support of the patient and their family.

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Conflicts of interest

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