

Outpatient Neuropalliative Care Services in a Tertiary Hospital Setting

Dear Editor,

Advancements in technology have played a pivotal role in minimizing challenges associated with neurologic disabilities.^[1] Global prevalence of neurologic disorders is on the rise, affecting over 1 billion worldwide, approximately one-tenth of reported mortalities.^[2] The majority of people who need palliative care services, constituted by nearly 80% of individuals with “serious health-related suffering,” reside in low- and-middle-income nations.^[3] Persons with neurodegenerative conditions have distinct needs as they struggle with no known cure, reduced life expectancy, long-term caregiving, and diminished quality of life. The multifaceted suffering, spanning physical, psychological,

social, and spiritual dimensions, is often challenging to manage.^[4] In such situations, palliative care approach proves invaluable to patients with neurologic illness and family caregivers.

In India, studies have aimed to assess requirements of patients and families seeking neuropalliative care,^[5] consensus among practicing neurologists,^[6] integration of various approaches to optimize care delivery, and deliberations concerning legal and policy implications.^[7] Management of complex symptoms, discussions on care objectives, and holistic well-being of patients and carers can ideally be part of an outpatient setting.^[8] Integration of a specialized neuropalliative care service into routine neurology care, with services extending to follow-up

through telephone and home-based supportive care, is crucial to support transitions in care.

A multidisciplinary outpatient neuropalliative care clinic, “SANTVANA,” was launched within a public health-care hospital through support of corporate social responsibility initiative dedicated to expanding access to palliative care among diverse populations. The neuropalliative service was conceptualized with the objectives of provision of patient care services, understanding the specific needs, and identifying critical transition points for specific neurologic diseases. Sensitization and upskilling of health-care professionals to recognize and provide neuropalliative care interventions was also targeted. The clinic commenced in December 2021 at the National Institute of Mental Health and Neurosciences under the guidance of a core committee of advisors, with extensive consensus-building discussions. It operates on all weekdays, providing multidisciplinary consultations to approximately 5–10 patients per day, with each patient and family receiving five to eight interventions.

The neurology team refers the patient to palliative care from the clinic, based on the presence of any one of seven triggers, which include issues such as swallowing difficulties, recurrent infections, significant deterioration in physical health, the first occurrence of aspiration pneumonia, cognitive impairments, weight loss, and the presence of complex symptoms such as pain and spasticity, as well as psychosocial and spiritual concerns that interfere with the optimal long-term care of the patient.^[9] The team comprises a medical officer, a project coordinator, social workers, nurses, a speech pathologist, and an occupational therapist. The services are integrated into routine multidisciplinary care, seeking consultation and cooperation with specialists such as physiatrists, physiotherapists, psychiatrists, pulmonologists, gastroenterologists, and urologists as per the specific needs. A score of 15 or less in functional status (modified Barthel Index^[10]) is used to indicate active neuropalliative care services.

Motor neuron disease, dementias (Alzheimer’s, vascular, and frontotemporal), advanced Parkinson’s disease, multiple system atrophy, progressive supranuclear palsy, vascular parkinsonism, advanced Wilson’s disease, adrenoleukodystrophy, and Huntington’s disease are among the diseases supported. Patient inclusion for neuropalliative care services varies based on established criteria specific to the disease. Spinal muscular atrophy, Duchenne muscular dystrophy, as well as inborn errors of metabolism, and other genetic diseases with guarded prognosis and high support needs are supported through the services. The total number of patients from May to December 2022 was 302 (male: 184, female: 118). Motor neuron disease (MND)/ Amyotrophic lateral sclerosis (ALS) ($n = 171$), followed by dementia ($n = 41$), Parkinson’s disease and related disorders (PDRD) ($n = 30$), pediatric neurologic disorders ($n = 27$), and other diseases ($n = 32$) comprising stroke, specific epilepsy syndromes, and global developmental delay with high support needs were the primary diseases

receiving specialist services. Majority of patients were referred from neurology outpatient department ($n = 162$) and inpatient department ($n = 133$), while seven patients were referred from outside hospitals and agencies. Needs identified using standardized proforma included information needs, physical well-being, psychologic support, financial considerations, spiritual dimensions, caregiving, and assistance for care provision and assistive devices. Care is tailored to address the identified needs effectively through evidence-based interventions initiated in the clinic and continuum of care ensured through telephonic and home-based care. Steps are taken to ensure that the patients are supported from early, sensitive communication of diagnosis to end-of-life care. At the time of this profiling, 23 patients had succumbed to the illness (from aspiration pneumonia, respiratory failure, cardiac arrest, and multiple organ failure); 21 passed away in their houses and two in outside hospitals.

As an emerging field, the team contributes to competency development among the multidisciplinary health-care professionals through a guided learning experience in neuropalliative care. It is imperative to integrate research efforts and monitor the outcomes of the services. In the coming days, the team envisions the program to expand organically, with integrated initiatives dedicated to specific neurologic disorders, capacity building, and collaboration with the primary and secondary health-care systems.

The challenges encountered during this process are *perceptual barriers* (limited understanding of palliative care within the referral base and establishment of effective alliances with community health-care teams, nursing homes, and hospices) and *implementation barriers* (development of a strategy for sustained growth, fostering interdisciplinary collaboration, and defining critical transition points for the integration of palliative care services with disease-specific management). A concern continues to be lack of awareness among hospital staff, patients, and families regarding the need for shift from “cure” to “care” that is essential to accept and deal with the illness.

The team is part of continued education programs in areas such as effective communication, symptom management, and end-of-life care. The necessity for interprofessional education, team building and upskilling the team members’ competencies to meet the unique needs of patients is evident. These challenges are acknowledged and proactively addressed to ensure delivery of optimal care to individuals with complex neurologic conditions.

By emphasizing the physical, psychologic, and social facets of patients’ well-being, the clinic plays a critical role in improving their quality of life and is a catalyst for better communication among patients, health-care providers, and their family caregivers. Such a service brings in more awareness on neuropalliative care needs and, through increasing referrals and fostering a seamless integration of palliative care into the neurology care framework, contributes toward achieving

the universal health coverage and reaching closer toward sustainable development goals. Moreover, this approach can contribute significantly to the sustainability of the health-care system by alleviating burden on resources.

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