

Editorial

# Scope for Integration of Palliative Care in Neurological and Neurosurgical Patients

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Palliative care focuses on improving the quality of life of patients with serious or advanced medical illnesses.<sup>1</sup> Neurological and neurosurgical conditions tend to have enormous symptom burden, variable disease trajectory, and poor prognoses that affect patients as well as their families and caregivers.<sup>2,3</sup> General as well as specialized palliative care is required in neurologically injured patients, such as those with Parkinson disease (PD), dementia, amyotrophic lateral sclerosis, brain tumors, stroke, and acute neurologic illnesses to address their complex needs.<sup>3–5</sup> The comprehensive approach includes care of physical, psychological, social, and spiritual aspects of patients to provide comfort and to improve their quality of life. Palliative care also assesses and treats other sources of distress such as normal reactions to living with a life-threatening, progressive, and/or disabling illness. In neurological and neurosurgical patients, the concept of autonomy in clinical practice can only be achieved by adopting the principles of palliative care. With declining cognitive or physical function, the discussion about prognosis, goals of care, and advance care planning will improve the patient outcome and caregiver satisfaction.

Neurological diseases are largely incurable due to multiple factors and considerably reduce the quality of life due to associated pain, anxiety, depression and other symptoms that are difficult to control. Hence, early integration of palliative care in neurological patients will improve the overall well-being of patients and their family members.<sup>6–8</sup> Miyasaki et al showed that symptom burden on patients and caregivers in advanced (PD) is similar to that in advanced malignancy.<sup>9</sup> Hence, there is growing need of integration of palliative care approach in neurology practice.<sup>1,10</sup> The palliative approach in traditional neurology benefits patients in many ways. As traditional approaches concentrate more on the preservation of function and prolongation of life, palliative care emphasizes more on symptom management and relief from suffering. It also prepares the patient and family

members to accept death as natural outcome rather than as a failure of medical treatment.<sup>3,4</sup> Neurologists have a primary responsibility to assess and treat nonmotor symptoms, such as pain, depression, anxiety, fatigue, sleep, constipation, urinary urgency, and sexual dysfunction. Studies in different type of neurological populations have shown that nonmotor symptoms are the most debilitating for patients, and these symptoms affect caregiver burden and overall quality of life more than motor symptoms.<sup>11–13</sup> Most common neurological and neurosurgical diseases that require palliative care are chronic neurodegenerative disorders, motor neuron disease, ischemic or hemorrhagic stroke, demyelinating diseases, movement disorders, and brain tumors.

This is high time to incorporate fundamental palliative care skills, including communicating bad news, nonmotor symptom assessment and management, advance care planning, and caregiver assessment in neurology practice and specialist palliative care referral for more complex or advanced patients. The modes of specialist palliative care services can be inpatient palliative care consultation, outpatient palliative care clinics, home palliative care, or hospice. But traditional models of palliative care may not sufficiently address the specific needs of patients and family members living with a neurological diagnosis. Patients with a life-limiting neurological illness have a different disease trajectory as compared to cancer patients. Apart from physical symptoms, other predominant problems include cognitive impairment, behavioral issues, and communication difficulties.<sup>14,15</sup> The notable differences between neurology and other patients include symptom profiles, psychosocial issues, caregiver needs, and effects on spiritual well-being. The patients with motor neuron disease have more demoralization, hopelessness, and suicidal ideation than patients with metastatic cancer.<sup>16</sup> Similarly, patients with brain tumors have distinct issues, including cognitive problems, seizures, and communication difficulties, than patients living with other types of cancers.<sup>17</sup>; Patients with Huntington

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disease have special social needs as a result of combined behavioral, psychiatric, movement, and cognitive issues.<sup>18</sup> Palliative care needs of patients with malignant gliomas are also quite different from others in the cancer patient population. This is because of different trajectory of disease, short life expectancy, and the presence of specific symptoms related to neurological deterioration. The specific issues include management of seizures, peritumoral edema, venous thromboembolism, depression, and opportunistic infections. The other problems include psychological issues, communication problems, need for rehabilitation, and decision on end-of-life treatments and choices.<sup>19–22</sup>

Specialist palliative care referral may be warranted in end-of-life care, feeding tube discussions or other complex interventions, spiritual issues arising from prolonged illness, distressing psychological issues, and in intractable physical symptoms. Also, frequent hospital admissions due to pneumonia, falls, and urinary tract infection, ongoing weight loss, progressive dysphagia, restricted activities of daily living, or a rapid decline in function may signify the need for referral to hospice.<sup>4</sup>

Neuropalliative care is developing as a subspecialty but there are several questions that need to be answered including:

1. Development and validation of prognostic predictors.
2. Tools for identification of high-risk patients to be referred to specialist palliative care services.
3. Developing evidences for better control of nonmotor symptoms.
4. Cost-effectiveness of palliative care interventions and the model for palliative care delivery.

To conclude, though the patients with neurological disorders frequently have very complex needs, these are still manageable using a palliative approach. Early communication with patients and family members about various issues, such as disease trajectory, common symptoms, treatment options, and prognosis, may be helpful in alleviating distress experienced by them. This timely communication helps in building a strong clinician–patient relationship that forms the basis of good care. Further, to ensure that the care provided by clinician aligns with the patient preferences, shared decision making regarding critical decisions throughout the continuum of disease is essential. However, more research is needed to determine the ideal method of incorporating palliative care into the management plans for patients with a variety of neurological conditions.

#### Conflict of Interest

None declared.

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