Palliative Care in Neurology

Maisha T. Robinson, MD, MS, and Robert G. Holloway, MD, MPH

From the Department of Neurology, Mayo Clinic, Jacksonville, FL (M.T.R.); and Department of Neurology, University of Rochester Medical Center, Rochester, NY (R.G.H.).

CME Activity

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Abstract

Palliative medicine is a specialty that focuses on improving the quality of life for patients with serious or advanced medical conditions, and it is appropriate at any stage of disease, including at the time of diagnosis. Neurologic conditions tend to have high symptom burdens, variable disease courses, and poor prognoses that affect not only patients but also their families and caregivers. Patients with a variety of neurologic conditions such as Parkinson disease, dementia, amyotrophic lateral sclerosis, brain tumors, stroke, and acute neurologic illnesses have substantial unmet needs that can be addressed through a combination of primary and specialty palliative care. The complex needs of these patients are ideally managed with a comprehensive approach to care that addresses the physical, psychological, social, and spiritual aspects of care in an effort to reduce suffering. Early discussions about prognosis, goals of care, and advance care planning are critical as they can provide guidance for treatment decisions and allow patients to retain a sense of autonomy despite progressive cognitive or functional decline. With the rapid growth in palliative care across the United States, there are opportunities to improve the palliative care knowledge of neurology trainees, the delivery of palliative care to patients with neurologic disease by both neurologists and nonneurologists, and the research agenda for neuropalliative care.

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Palliative medicine is a specialty that aims to recognize, prevent, and alleviate suffering in patients with serious illnesses and their families.[1] Eight domains of care are included in the comprehensive evaluation, including assessing patients' understanding of their clinical condition, evaluating physical symptoms, assessing psychological

Mayo Clin Proc. ■ October 2017;92(10):1592-1601 ■ http://dx.doi.org/10.1016/j.mayocp.2017.08.003
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TABLE. Neuropalliative Care Skill Set

Effectively communicate prognosis
Estimates from literature
Communicate "best case/worse case"
Manage uncertainty
Master common preference-sensitive decisions
Know major decisions within each subspecialty
Elicit preference accurately
Listen more than talk
Hypervigilant shared decision making
Know how to run family meetings
Be aware of cognitive biases
Effective use of time-limited trials
Detect and manage whole-body pain
Physical symptoms and pain
Psychological symptoms
Existential distress
Social pain
Palliative options at end of life
Withdrawing life-sustaining treatments
Palliative sedation to unconsciousness
Voluntary stopping eating and drinking
Physician-assisted dying
Brain death

symptoms, identifying spiritual needs, discussing social support, reviewing cultural influences, addressing ethical and legal issues, and providing end-of-life care.[2] The focus of care is to improve overall quality of life for patients and their families, to assess goals of care, and to align treatment options with their stated goals.

There has been considerable growth in palliative medicine over the past decade. As of 2015, 67% of US hospitals with 50 beds or more had palliative medicine services; among larger hospitals with 300 beds or more, more than 90% have palliative care programs.[3] This trend has been attributed in part to increasing longevity and to the prevalence of chronic diseases.[4] Additionally, the palliative care literature suggests that it is beneficial to patients and families and to the health care system by improving symptom management and patient/family satisfaction, by reducing unnecessary hospitalizations and procedures in patients near the end of life, and by decreasing prolonged grief and posttraumatic stress disorder among family members.[5-7]

CLINICAL NEED IN NEUROLOGY

Patients with neurologic diseases often have incurable and progressive illnesses associated with major morbidity and mortality. The mainstay of treatment is palliative for many of these conditions, with an emphasis on managing symptoms, maintaining mobility, adjusting to functional and cognitive decline, and supporting caregivers. Despite efforts to provide high-quality care for these patients, the literature suggests that there are unmet palliative needs in this patient population. The routine incorporation of palliative care principles into the care plans for patients could improve their quality of life. A core palliative care skill set for patients with neurologic disease includes the following: effectively estimating prognosis, mastering common preference-sensitive decisions, hypervigilant shared decision making, detecting and managing whole-body pain, and understanding palliative care options of last resort (Table). In this article, we review selected, more common diseases with high levels of palliative care needs, but they are representative of the approach that could benefit all patients and families presenting with serious neurologic symptoms.

SCIENTIFIC OVERVIEW

Parkinson Disease

Parkinson disease is a prolonged illness that leads to progressive debility by impairing balance, mobility, speech, and cognition. In the early stages, patients are often responsive to dopamine replacement therapy. As the disease progresses, however, they experience more nonmotor symptoms that contribute to disease burden.[8]

Patients with Parkinson disease and their caregivers acknowledge that there are considerable needs throughout the course of illness.[8,9] Nonmotor symptoms including orthostatic hypotension, dysphagia, cognitive decline, psychiatric symptoms, pain, and constipation are common, yet often inadequately addressed.[9-11] A variation on the Edmonton Symptom Assessment Scale for Parkinson Disease was developed and implemented in Toronto, Ontario, Canada to assess symptoms specific to Parkinson disease.[9] Administration of the scale in a palliative care program was feasible, and it provided data to guide palliative interventions related to common symptoms such as dysphagia, constipation, anxiety, pain, stiffness, and drowsiness.

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