



# Emerging Subspecialties in Neurology: Palliative care

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As we work to find cures for so many devastating neurologic injuries and diseases, our patients suffer tremendously on a daily basis. Individuals with conditions including stroke, multiple sclerosis, Parkinson disease (PD), muscular dystrophies, amyotrophic lateral sclerosis (ALS), and nervous system malignancies share a host of physical, emotional, and existential symptoms that can be difficult to treat. In addition, patients and their families face the realities of loss of function, loss of ability to communicate, and lifespans limited by the neurologic diagnosis or complications related to it (e.g., dysphagia, immobility, infection). We may not always be able to reverse damage to the nervous system, but we can optimize quality of life for our patients by providing expertise in communicating difficult news, pain and symptom management, and advance planning and end-of-life care.

Palliative care is an approach to caring for a patient with a life-limiting illness from the time of diagnosis through family bereavement support. Palliative care clinicians are trained experts in patient/family-centered communication; conflict resolution; advanced management for symptoms including pain, dyspnea, nausea/emesis, constipation, sialorrhea, pressure sores, pruritus, delirium, anorexia, fatigue, depression, anxiety, and spiritual distress; planning for anticipated and unanticipated changes in patient status; facilitating a peaceful death; and providing bereavement services. Palliative care is typically provided by a multidisciplinary team headed by a palliative care-trained physician. The team can include nurses, social workers, chaplains, complementary and alternative medicine providers, case managers, physical therapists, occupational therapists, speech therapists, wound specialists, psychologists, dietitians, and others. Palliative care is available through inpatient consultation, outpatient clinic visits, and occasionally through specialized palliative home care. Patients with a prognosis of less than 6 months are eligible for additional supportive services through hospice care in the home or in a dedicated hospital unit or facility.

Both family caregivers and clinicians have described the unmet palliative care needs of the neurology patient population. Currently, unmet needs exist across diagnoses and include clear communication regarding diagnosis and

prognosis, advanced pain and symptom management, and planning for end of life.<sup>1,2</sup> Pain, for example, while not traditionally believed to affect individuals with PD and ALS, has been found to profoundly affect individuals with both diagnoses. A recent retrospective study documented moderately severe or worse pain in the last month of life in 42% of patients with PD and related disorders and in 52% of patients with ALS. Twenty-seven percent of the patients with PD and related disorders and pain received no pain medications and 19% of the patients with ALS with pain received no pain medications.<sup>3</sup>

The American Academy of Neurology calls on neurologists to acquire basic palliative care skills: “many patients with neurologic diseases die after long illnesses during which a neurologist acts as the principal or consulting physician. Therefore, it is imperative that neurologists understand, and learn to apply, the principles of palliative medicine.”<sup>4</sup> While neurologists can also consult and collaborate with palliative care colleagues in caring for patients, there is great value in neurologists becoming involved directly in palliative care. A neurologist’s clinical experience poises him or her to best understand and support patient experiences across the lifespan; the course of neurologic disease is different from the course of many other diseases (cancer, heart disease, lung disease) typically treated by palliative care clinicians.

There are several unique aspects of palliative care in neurology as compared with palliative care in other patient populations. First, neurologic disease can have a prolonged and often-fluctuating course characterized by unexpected declines and gradual accumulation of impairments. Patients may require more frequent grief support for repeated losses than patients with more predictable disease courses. Second, there can be enormous prognostic uncertainty in neurologic diagnoses, with few validated prognostic markers. This creates a formidable challenge in preparing for the last months to years of life and makes careful monitoring of neurologic status particularly important. Finally, because neurology patients can lose mobility, communication ability, and cognitive function long before death, they may be seen less frequently in ambulatory settings during the last phases of progression of disease, and opportunities for

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advance decision-making about end-of-life treatments and location for last days of life can be lost unless carefully attended to early in the disease process.

Rigorous data on the optimal timing of palliative care intervention and the impact of palliative care interventions in neurology are only beginning to emerge. A prospective study on the impact of early palliative care in small-cell lung cancer recently showed improvement in quality of life and mood and less use of aggressive treatments at end of life.<sup>5</sup> Extrapolation to neurologic conditions, especially those with largely overlapping symptom burden with small-cell lung cancer (e.g., glioblastoma multiforme), suggests that early palliative care involvement could affect these neurology patients in similarly positive ways.

Expert opinion in neurology calls for early involvement of palliative care in the management of life-limiting catastrophic and degenerative neurologic diagnoses. Unfortunately, lack of education and experience in palliative care among neurologists contributes to the ongoing underutilization of palliative care for patients with long-term neurologic conditions.<sup>6,7</sup>

The Accreditation Council for Graduate Medical Education (ACGME) requires neurology residency programs to provide training in end-of-life/palliative care. Typical palliative care didactic lecture topics include decision-making around advance directives, running family meetings, managing pain and other symptoms, and identifying and managing symptoms of dying. Typical clinical rotations involve joining an inpatient palliative care consult team and seeing a mix of diagnoses, mostly oncology, cardiology, pulmonary, and neurology. However, only about half of neurology residency programs offer didactic experiences in palliative care. Fewer than 5% provide internal clinical rotations, and fewer than 3% provide external clinical rotations.<sup>8</sup>

MD and DO adult and child neurology residency graduates are eligible to apply for ACGME- and American Osteopathic Association (AOA)-accredited palliative care fellowship training. According to the American Academy of Hospice and Palliative Medicine, as of May 2012, there are 78 ACGME-accredited and 7 AOA-accredited programs, with more than 234 positions available.<sup>9</sup> Fellowship applications are submitted via the Electronic Residency Application Service and are typically submitted during postgraduate year (PGY) 3 for a PGY-5 fellowship position. Mid-career applications are accepted as well.

Fellowship training is generally 1 year, although some programs offer an optional additional research year. Some programs allow fellows to combine the palliative care fellowship with other medical subspecialty fellowships or with a public health or geriatrics focus. All palliative care fellowships include clinical and didactic training in advanced pain and symptom management, communication and conflict resolution,

and interdisciplinary teamwork. Symptom management focuses on, but is not limited to, pain, nausea/emesis, constipation, pruritus, dyspnea, delirium, fatigue, anorexia, sialorrhea, seizures, incontinence, pressure ulcers, and active dying.

The ACGME requires that fellows see adult and pediatric patients with a broad range of life-limiting diagnoses, including neurologic diagnoses, which, in our experience, tend to comprise ~5%–10% of patients. Fellows see patients in the inpatient and ambulatory settings, as well as in dedicated hospice/palliative care units and in patient homes. Fellows must also follow several patients longitudinally. A scholarly project is required, which can be in the form of research, presentation, or committee membership. Fellows participate in interdisciplinary team meetings and are taught palliative care skills by both physicians and nonphysicians.

After completing the year of palliative medicine training, fellows are eligible to sit for the Hospice and Palliative Medicine subspecialty examination offered by the American Board of Psychiatry and Neurology (ABPN).<sup>10</sup> The ABPN offered the first Hospice and Palliative Medicine examination in 2008 and offers it now every other year. Fellowship training is now required in order to be eligible to sit for the examination/become board-certified.

Currently, fewer than 1% of neurologists are board-certified in hospice and palliative medicine,<sup>10</sup> and fewer than 2% of palliative care clinicians are neurologists. The need for neurologists to provide palliative care for patients and families is expanding as the burden of chronic and neurodegenerative diseases increases and as the population ages. Symptom management and patient and family support can begin at the time of diagnosis in life-altering neurologic disease if clinicians are trained to provide it, and it can be offered concurrently with disease-modifying treatments.

Every neurologist has the opportunity to apply palliative care skills in any setting in which neurologists work. Neurologists with board certification in hospice and palliative medicine have the additional opportunities to run palliative care teams in hospitals, in ambulatory care settings, and for home care organizations, and to advocate most strongly for our sickest neurology patients. Because the subfield of palliative care in neurology is so nascent, opportunities for research and leadership abound. Neurologists are needed to contribute their expertise to the palliative care body of knowledge—expertise about disease diagnosis and management, advances in treatments and prognosis for neurologic disease, and the sharing of care for patients with life-limiting neurologic disease. Most importantly, by directly teaching their trainees and colleagues, and by their example, neurologists can continue to pursue the relief of suffering for neurology patients and families stricken with ongoing devastating loss.

## AUTHOR CONTRIBUTIONS

Dr. Dallara: study concept and design, acquisition of data, analysis and interpretation, critical revision of the manuscript for important intellectual content, study supervision. Dr. Tolchin: study concept and design, acquisition of data, analysis and interpretation, critical revision of the manuscript for important intellectual content, study supervision.

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