



# 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.).

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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.<sup>1</sup> Eight domains of

care are included in the comprehensive evaluation, including assessing patients' understanding of their clinical condition, evaluating physical symptoms, assessing psychological

**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.<sup>2</sup> 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.<sup>3</sup> This trend has been attributed in part to increasing longevity and to the prevalence of chronic diseases.<sup>4</sup> 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.<sup>5-7</sup>

### 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.<sup>8</sup>

Patients with Parkinson disease and their caregivers acknowledge that there are considerable needs throughout the course of illness.<sup>8,9</sup> Nonmotor symptoms including orthostatic hypotension, dysphagia, cognitive decline, psychiatric symptoms, pain, and constipation are common, yet often inadequately addressed.<sup>9-11</sup> 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.<sup>9</sup> 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.

Parkinson-related medication adjustments were made, and the scale also guided referrals to day programs, speech pathologists, psychiatrists, nutritionists, and a variety of therapists and other medical and surgical subspecialists. Patients' Edmonton Symptom Assessment System Scale for Parkinson Disease scores improved with subsequent testing, suggesting that palliative interventions were beneficial in this population.

In addition to symptom control, the provision of more information about the disease earlier in the course is desired by patients and caregivers.<sup>12,13</sup> Discussions regarding prognosis, options for support, and advance care planning were common themes that were identified in qualitative studies on patient and family experiences with Parkinson disease.<sup>12-14</sup> Patients expressed a sense of social isolation due to symptom progression and concern regarding their future cognitive and functional states.<sup>12</sup> Some patients wanted to maintain a sense of autonomy by making decisions about their future care while their cognition remained intact.<sup>14</sup>

### Dementia

Anticipating the loss of cognitive skills and decision-making capacity, clinicians should discuss the disease trajectory early with patients with dementia and their caregivers or surrogate decision makers.<sup>15,16</sup> Common sequelae in advanced dementia include recurrent infections, hospitalizations, and eating and swallowing difficulties.<sup>15</sup> Other symptoms that may occur at the end of life include pain, dyspnea, and agitation.<sup>15,17</sup> Plans regarding how to manage these aspects of the disease can be made early through the use of goals of care conversations and advance care planning discussions. The literature suggests that caregivers who have engaged in discussions regarding prognosis and care preferences are more likely to focus on quality of life and comfort for their loved ones at the end of life.<sup>15</sup>

Decisions regarding feeding options, skilled nursing care transitions, and hospice care should be addressed. In advanced dementia, gastrostomy tubes for dysphagia and poor oral intake do not prevent aspiration or improve wound healing, functional status, or survival.<sup>18,19</sup> They tend to increase agitation and the need for restraints, and they reduce

the amount of personal daily interaction that patients receive. The variation in the use of feeding tubes and mechanical ventilation in patients with dementia suggests additional work is needed to better understand the process of shared decision making for therapies without a clear survival benefit.<sup>20,21</sup> At the end of life, comfort or hand-feeding is encouraged.<sup>16</sup> Hospice can provide high-quality care for patients with dementia that is acceptable and appreciated by caregivers.<sup>22</sup>

### Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS) is one of the most devastating illnesses because of the rapid decline in motor and respiratory function, leading to a loss of independence and severe disability. Opportunities for palliative care integration into the multidisciplinary program are abundant. Patients have numerous symptoms including pain, sialorrhea, spasticity, pseudobulbar affect, dysphagia, weight loss, and respiratory insufficiency that require intensive treatment by the care team.<sup>23,24</sup> The preservation of communication and mobility are also integral aspects of their care that can improve overall quality of life.<sup>23,24</sup>

Preparation for the expected decline in swallowing and respiratory function is essential. Although patients may differ in their treatment choices in advancing ALS, there is likely a several-month survival benefit to feeding tubes when placed before an emergency situation.<sup>25</sup> Noninvasive positive pressure ventilation is recommended when the functional vital capacity falls below 50% or when patients become symptomatic from neuromuscular respiratory muscle weakness.<sup>26</sup> In addition to improving survival, noninvasive positive pressure ventilation also improves quality of life.<sup>27,28</sup> Early discussions regarding prognosis, invasive procedures, and the transition to hospice care are crucial to provide patients and families with adequate information and the time to make informed decisions.<sup>24,29</sup>

Patients with other neuromuscular diseases such as Duchenne muscular dystrophy and spinal muscular atrophy may also benefit from palliative considerations that are similar to those for patients with ALS. With the increasing life span of patients with severe myopathies and muscular dystrophies, symptom management and ongoing discussions

regarding treatment decisions and quality of life can be addressed through a palliative approach.<sup>30,31</sup>

### Brain Tumors

There is a growing evidence base for the benefits of palliative care in the management of patients with cancer as it relates to symptom management and quality of life.<sup>32,33</sup> However, despite the common presence of physical and psychological symptoms attributable to tumor growth and to treatment effects, few of these studies have focused on patients with brain tumors.<sup>34-36</sup>

Throughout the course of disease, but particularly at the end of life, patients with high-grade gliomas have symptoms, such as headaches, dysphagia, seizures, drowsiness, difficulty communicating, and focal deficits, that would benefit from more aggressive management.<sup>37</sup> Of 160 patients with a primary brain tumor who died in a large, urban hospice over a 4-year time span, more than half of the patients were admitted within 14 days of death.<sup>38</sup> Late hospice referrals deny patients the comprehensive benefits of high-quality end-of-life care through hospice services.

A retrospective study at a single institution identified functional decline with gait instability and weakness, cognitive decline and personality changes, seizures, and encephalopathy as the primary symptoms in a hospitalized cohort of patients with primary and metastatic brain tumors.<sup>39</sup> Many challenges to providing palliative care to patients with brain tumors exist because cognitive functioning may be impaired and the focus of cancer care may remain “curative” in nature until late in the disease course.<sup>38,40</sup>

### Stroke

Patients with stroke have substantial palliative needs in the poststroke period, although the severity and the course of illness are highly variable.<sup>41-43</sup> Symptoms such as pain, fatigue, depression, anxiety, and dysphagia should be identified and addressed as they can impact early and longer-term rehabilitation efforts. A single center's experience with palliative care consultations for patients with stroke revealed that they differ from patients with other serious illnesses.<sup>44</sup> They are less likely to have the capacity to make medical decisions,

and discussions tend to focus on decisions regarding life-sustaining measures including artificial nutrition, mechanical ventilation, and tracheostomy.

Stroke is the fifth leading cause of death in the United States, and early mortality after stroke is most often attributed to the withdrawal or withholding of life-sustaining measures.<sup>45,46</sup> It is also a leading cause of long-term disability.<sup>47</sup> Estimates suggest that 15% to 30% of patients are permanently disabled and 20% require long-term care at 3 months poststroke.<sup>41</sup> Given these statistics, clinicians should elicit treatment preferences in the early poststroke period to help guide care that aligns with patients' and caregivers' wishes.<sup>48</sup>

Palliative care provided by both the primary stroke team and a palliative care service should be available to patients and families at the time of diagnosis.<sup>49,50</sup> In stroke, key palliative care topics to consider are the effective estimation of prognosis, mastering common preference-sensitive decisions, the development of goals of care, the management of biopsychosocial symptoms, the delivery of end-of-life care, and the provision of bereavement services.<sup>49</sup>

### Critical Care Neurology

Critically ill patients generally have acute-onset serious illnesses that require early and aggressive treatment in the setting of uncertain prognoses. Families are faced with difficult decisions regarding treatment options and goals of care. For the patients who survive the hospitalization, they often experience some degree of disability that challenges their daily functioning. Palliative care approaches can provide assistance with complex decision making, adjusting to new caregiver roles, symptom management, and goal setting given the realities of the situation.<sup>51</sup>

A recent article described the palliative needs in the neurologic intensive care unit (ICU) after implementing a daily screening tool that assessed the physical, psychological, and social needs of patients.<sup>52</sup> Similar to patients in the medical ICU, patients in the neurologic ICU who were screened for palliative care needs had an increased frequency of family meetings, and after assessing goals of care, these patients tended to receive formal palliative care consultations.<sup>52,53</sup> Of the 62%

of patients in the neurologic ICU who were identified as having at least one care need, the majority of the patients and their families needed social support, thus underlying the importance of caregiver assessments.

Identifying critically ill patients who may benefit from palliative care can be achieved through the use of screening tools, checklists, or trigger criteria. Additionally, patients who have certain cerebrovascular conditions with specific clinical and radiographic findings that have been associated with poor neurologic recovery may also be appropriate.<sup>54,55</sup> Trigger criteria for palliative care consultations in the critical care setting have been suggested for patients with metastatic cancer who require mechanical ventilation, those who have prolonged hospitalizations, older patients with multiple chronic medical illnesses, and survivors of cardiac arrest who have markers of poor prognosis.<sup>55</sup> Patients with some of these characteristics may be admitted to a neurologic ICU or neurologists may be consulted about these patients. Such patients and their families may benefit from a palliative care assessment.

### Models of Palliative Care in Neurology

Palliative care is provided through inpatient consultation services, inpatient palliative care units, outpatient clinics, home visits, and hospice services.<sup>56</sup> Recently, neurology-related palliative and supportive care clinics have emerged to focus on the complex needs of patients and their families.<sup>57</sup> These clinics are interdisciplinary and take a holistic approach to care, addressing religion and spirituality, physical symptoms, social support, and caregiver assessments.

Proposed models of care include (1) the incorporation of palliative care by the primary care service into the routine management plan for patients with serious and chronic illnesses, known as an “integrative model” or (2) a “consultative model,” which involves formal palliative care consultations for patients with palliative needs.<sup>58</sup> The ideal model is likely a combination of the two, with primary palliative care offered by clinicians with extensive knowledge of the disease process and by palliative medicine specialists who have expertise in assessing and alleviating pain and suffering.<sup>52,58</sup>

## CHALLENGES AND PITFALLS

### Primary vs Specialty Palliative Care

Primary palliative care principles are essential tools for all neurologists because the management of chronic and progressive disorders relies on knowledge of symptom management, communication of prognosis, and discussions about goals of care. Specialty palliative care, which is provided by professionals trained in palliative medicine, focuses on more complex or intractable symptoms, difficult family conflicts, challenging decision making, and complicated end-of-life care.<sup>59</sup> With a growing number of patients with chronic diseases who could benefit from palliative care and with limited palliative care resources resulting from a shortage of palliative care physicians (estimated in the range of 6000-18,000<sup>60</sup>) and a high rate of burnout,<sup>61</sup> primary care physicians and specialists—including neurologists—are necessary providers of palliative care to meet patients’ needs.<sup>29</sup>

### Distinguishing Palliative Care From Hospice Care

When patients and their families, and even clinicians, hear the term *palliative care*, they often equate it to hospice care. Palliative care focuses on improving quality of life for people who have serious illnesses, and it can be provided at any stage of disease, even at the time of diagnosis and independent of the goals of care.<sup>62</sup>

Hospice care in the United States is a subset of palliative care. Although all hospice care is palliative care, all palliative care is not hospice care. In the United States, hospice services are appropriate for people who are at the end of their lives or who are estimated by Medicare criteria to have a life expectancy of 6 months or less.<sup>63</sup> In the United States, late transition to hospice care is common, due, in part, to a trend toward more aggressive care at the end of life and late or nonexistent advance care planning and goals of care conversations.<sup>64,65</sup> The median duration of stay in hospice in 2014 was 17.4 days.<sup>66</sup>

Four of the top 11 noncancer diagnoses for hospice patients in the United States in 2014 were neurologic disorders—dementia (14.8%), stroke or coma (6.4%), and ALS and non-ALS motor neuron diseases

(2.5%).<sup>66</sup> Hospice guidelines for neurologic diseases include measures that are suggestive of severe debility, which likely contributes to delayed conversations about transitioning to hospice care. The Centers for Medicare and Medicaid Services is currently evaluating a new option for Medicare beneficiaries to receive hospicelike support services from certain hospice providers while concurrently receiving curative therapies. Earlier consideration of hospice would maximize the benefit of the comprehensive nursing, spiritual, psychosocial, and physician support for patients and their families.

### Timing of Palliative Care

Early access to palliative care in a randomized trial of patients with non–small cell lung cancer demonstrated improved symptom management, better quality of life, higher rates of advance care planning, and longer survival in the cohort that was randomized to the palliative intervention at the time of diagnosis.<sup>32</sup> Earlier palliative care referrals in patients with advanced cancer can also reduce health care utilization in the last month of life.<sup>67</sup> The American Society of Clinical Oncology indicates that the provision of high-quality oncological care is inclusive of palliative care at the time of diagnosis.<sup>68</sup> Although it may be reasonable to consider extrapolating this data for use in patients with neurologic diseases because the symptom complexes may be similarly burdensome,<sup>9</sup> additional studies are needed to properly define the best timing and the extent of palliative care engagement during the course of neurologic illnesses.

Specific symptoms or time points in the course of a disease may also be used as triggers for conversations regarding care preferences.<sup>69</sup> In neurologic diseases, certain triggers include second-line chemotherapy in patients with malignant brain tumors, symptoms necessitating consideration of artificial nutrition or mechanical ventilation in those with ALS, and significant decreases in functional capacity or increases in caregiver strain in patients with Parkinson disease or dementia.<sup>29</sup> Routine discussions regarding prognosis and the progression of disease offer opportunities for patients to reevaluate their disease-related priorities throughout the continuum of disease.

### Prognostic Uncertainty in Neurologic Disease

Patients and families often want to know what to expect with regard to their disease, how it may progress over time, and how affected they may be secondary to the disease.<sup>70,71</sup> Clinical trajectories for neurologic illnesses provide a framework for discussions regarding prognosis, and utilizing prognostic tools such as the Glasgow Coma Scale, the Hunt and Hess grade, the intracerebral hemorrhage score, the National Institutes of Health Stroke Scale, and the FUNC score can further refine outcome estimations in acute illnesses.<sup>51,70</sup> One criticism of these scales, however, is that they do not predict quality of life, which is subjective but of great importance to patients and families. Estimating outcome in neurologic illness is more challenging than in the oncology population.<sup>9</sup>

Offering a “best case, worst case, and most likely case scenario” acknowledges the lack of certainty and it provides patients and families with hope, tempered by realistic expectations.<sup>29</sup> Time-limited trials of therapies are another option for managing this uncertainty.<sup>70,72</sup> These trials may be particularly beneficial in acute illness as surrogate decision makers are often tasked with the decision-making responsibility, often without full knowledge of the patients’ preferences.

Acknowledging the uncertainty that exists in medical practice—and even embracing it—is an essential skill for all clinicians.<sup>73</sup> Even in the face of prognostic uncertainty, discussions regarding expected decline and death are necessary and desired to provide patients and families with enough information to guide important decisions on treatments, goals of care, living environments, and hospice transition.<sup>74</sup>

### Education of Neurologists in Palliative Care

Neurologists indicate that there are gaps in knowledge of palliative care principles and that more education in pain and symptom management is needed.<sup>75,76</sup> Resident assessments similarly demonstrate that their understanding of palliative care is limited.<sup>77,78</sup> The Accreditation Council for Graduate Medical Education mandates that neurology residency programs incorporate pain and palliative care didactics into the curriculum.<sup>79</sup>

A variety of methods for teaching communication skills, pain and symptom management, and end-of-life care have been used to introduce trainees to these key concepts, and postintervention assessments have revealed increased knowledge among residents.<sup>77</sup> According to a survey of neurology residency program directors, however, only 7.8% of programs have a dedicated rotation experience available, and 52% of programs offer a didactic course.<sup>80</sup> Trainees may benefit from the growing interest in palliative care among neurologists because one of the cited barriers to educating residents is a lack of suitable faculty within the department.<sup>80,81</sup> According to the American Board of Psychiatry and Neurology, as of April 2016, 51 neurologists were board-certified in hospice and palliative medicine. Opportunities exist for neurologists to expand their knowledge in palliative care through formal fellowship training, continuing medical education courses, and rotation experiences.

### Quality Measurement and Improving Medical Decisions

More work is needed to define and measure palliative care practices to improve patient-centered care. Too often critical discussions about patient preferences and end-of-life treatment approaches are not well documented in the medical record.<sup>48</sup> A new wave of quality measures, such as “comfortable dying” and “documentation of treatment preference,” are being developed and endorsed by the National Quality Forum that can hopefully motivate continuous quality improvement efforts.<sup>82</sup> Existing measures such as all-cause short-term mortality may not be aligned well with what patients and families desire when seriously ill with neurologic disease. In addition, the cost of being ill-equipped to make the right choices is greater now than ever. More work is needed to understand how to effectively structure the decision-making environments to “nudge” choices in wise directions, as is the concept of choice architecture.<sup>83</sup> For example, the use of cognitive strategies to minimize bias or the use of decision aids to assist in arriving at decisions with limited extraneous influence or the framing of code status conversations.

### Reimbursement and Aligning Incentives

In 2016, the Centers for Medicare and Medicaid Services began reimbursing clinicians for advance care planning conversations.<sup>84</sup> This decision was intended to incentivize these critical discussions and to provide clinicians with dedicated visits to address complex decisions. With this legislative measure to encourage goals of care and end-of-life care discussions, the neurology community has a responsibility to ensure that the content of these conversations is substantive and well documented.

### UNRESOLVED CLINICAL QUESTIONS

The subspecialty of neuropalliative care is in its early stages, and the most efficient and cost-effective methods for providing palliative care to our unique patient population are not yet known. More research is necessary to understand (1) which patients with neurologic disease may derive the most benefit from palliative care interventions, (2) the ideal timing of these interventions, and (3) the model for delivery.

The growing trend for the use of teleneurosology for acute stroke assessments and remote office visits may prompt its consideration for use in palliative care because mobility restrictions may limit in-person appointments.<sup>85</sup> Group visits modeled after support groups may also be a viable option through which palliative care and advance care planning can be delivered.<sup>86</sup> As a next step in the evolution of neuropalliative care, we could consider extrapolating best practices from other disciplines and tailoring them to fit specific neurologic conditions.

### CONCLUSION

Patients with neurologic disorders often have very complex needs that are amenable to a palliative approach. A focus on early communication about the disease trajectory, common symptoms, treatment options, and prognosis are necessary and may be helpful to allay some of the concerns that patients and family members experience. Shared decision making regarding critical decisions throughout the continuum of disease is an essential component of the clinician-patient relationship to ensure that the care provided aligns with the preferences of the patient. More research is

needed to determine the ideal method of incorporating palliative care into the management plans for patients with a variety of neurologic conditions.

**Abbreviations and Acronyms:** ALS = amyotrophic lateral sclerosis; ICU = intensive care unit

**Correspondence:** Address to Maisha T. Robinson, MD, MS, Department of Neurology, Mayo Clinic, 4500 San Pablo Rd, Jacksonville, FL 32224 (Robinson.maisha@mayo.edu). Individual reprints of this article and a bound reprint of the entire Symposium on Neurosciences will be available for purchase from our website [www.mayoclinicproceedings.org](http://www.mayoclinicproceedings.org).

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