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Development and Dissemination of a Neurology Palliative Care Curriculum

Education in Palliative and End-of-Life Care Neurology

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Abstract

Despite increasing awareness of the importance of a palliative care approach to meet the needs of persons living with neurologic illness, residency and fellowship programs report meeting this educational need due to a limited pool of neuropalliative care educators and a lack of adequate educational resources. To meet this need, a group of experts in neuropalliative care and palliative medicine leveraged resources from the Education in Palliative and End-of-life Care (EPEC) program and the National Institutes of Nursing Research to create a library of modules addressing topics relevant for neurology trainees, palliative medicine fellows, and clinicians in practice. In this article, we describe the development and dissemination plan of the EPEC Neurology program, initial evidence of efficacy, and opportunities for neurology educators and health services researchers to use these resources.

Palliative care is an approach to the care of persons living with serious illness and their families that focuses on improving quality of life and relieving suffering caused by physical, psychosocial, and spiritual challenges.[1] Training in the basics of palliative care has been recommended by national and international organizations, including the American Academy of Neurology and the Accreditation Council for Graduate Medical Education, for over 20 years.[2-4] Despite this recommendation, neurology residents report little to no training in palliative care and have gaps on formal assessment.[5] Neurology residency program directors similarly report a great deal of heterogeneity in how palliative care is taught with many dissatisfied with their current approach.[6] There have been few efforts to create educational materials,[7] and there are currently no agreed upon curriculum, educational materials, or competencies. An additional barrier is the paucity of neurology programs that currently include faculty with expertise in neuropalliative care.[8]

Context and Curriculum Development

In recognition of the need to develop models of palliative care that can feasibly and effectively be disseminated, we launched a comparative effectiveness trial of a model of community-based palliative care for Parkinson disease (PD) centered on training community neurologists in the basics of primary palliative care funded by the National Institute of Nursing Research (NCT 03076671). To standardize training, we partnered with the Education in Palliative and End-of-life Care (EPEC) program, an international leader in primary palliative care training,[9] to

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develop an initial curriculum of 10 modules. Leveraging the resources of EPEC, our grant funding, and an active community of neuropalliative care experts, we sought to expand this curriculum to meet neuropalliative care educational needs of neurologists and palliative medicine specialists more broadly.

Our initial set of 10 modules was determined based on the length of training (one 8-hour day), clinicians' requests for topics in qualitative interviews, and our expert panel's opinion on the core primary palliative care skills needed to adequately care for people with PD. Community clinicians specifically requested additional guidance around pain management, medicinal uses of cannabinoids, behavioral management in dementia, and requests for hastened death including options for participation under state-specific medical aid in dying legislation. Table 1 shows our training agenda for the PD study.

At the time of the start of this grant, an international group of neuropalliative care experts began work on a now published textbook.[10] This book was used as a guide to fill in other palliative topics relevant to neurologists and palliative care approaches to other neurologic illnesses and conditions. As this curriculum developed, we added 4 additional modules to supplement omissions noted since the completion of the textbook. Modules for the comprehensive EPEC Neurology (EPEC-N) curriculum were developed by authors (see Acknowledgment) with feedback from a core team of associate editors (C.J.C., L.A.F., R.G.H., M.K., and C.L.V.) and a central editorial team (J.H., B.M.K., and N.M.K.) that reviewed all modules for consistency in content and style.

EPEC-N Curriculum and Materials

There are currently 26 modules in EPEC-N (see Table 2 and also bioethics.northwestern.edu/programs/epec/curricula/neurology-modules.html). Each module is associated with a clean PowerPoint slide set, an annotated slide set with trainer's notes, and a list of reading materials, particularly relevant for presenters not familiar with the subject matter. The accordion-style slide set is designed such that presenters can use each slide set as a starting point and edit the presentation to meet the needs of the target audience.[11] Each module can standalone, or series of lectures may be chosen for target audiences to meet broader learning goals.

Learning objectives consider not only knowledge, but, particularly important to many palliative care topics, communication skills, clinician attitudes, and motivation to change behavior. A fundamental tenet of the EPEC train-the-trainer program is that simply presenting information (e.g., by talking through PowerPoint slides) is rarely sufficient to motivate behavior change.[12] Thus, in addition to providing content and background reading for facilitators, the EPEC program provides teaching strategies to maximize the utility of time spent with learners,[11] and there is a module that

Table 1 Agenda From Community Neurologist Training in Palliative Care for Parkinson Disease

8:00 AM	Module 1: Introduction to neuropalliative care
8:50 AM	Module 2: Important conversations
9:40 AM	Break
9:50 AM	Module 3: Complex symptom management: pain
10:40 AM	Module 4: Goals of care and advance directives
11:30 AM	Module 5: Self-care: making our caregiving sustainable
12:00 PM	Lunch
12:30 PM	Module 6: Spiritual well-being and difficult emotions
1:20 PM	Module 7: Caregiver assessment and support
2:10 PM	Break
2:20 PM	Module 8: Dementia and behavioral issues
3:10 PM	Module 9: End-of-life care
4:00 PM	Module 10: Bringing it all together (practical implementation)

describes teaching approaches, including interactive lectures, small group case-based teaching, and role plays.

Initial Evidence of Effectiveness and Acceptability

Thirty-six clinicians (31 physicians and 5 advanced practice providers) participating in the clinical trial completed pre- and post-course surveys (see eAppendix 1, links.lww.com/CPJ/A329) to evaluate their comfort with palliative care, their palliative care knowledge, and satisfaction with the course. There was a statistically significant 11.3% improvement on the knowledge assessment (pre 54.6 ± 11.3 vs post 65.9 ± 9.8, $p < 0.001$) and a greater than 13-point increase in comfort (equivalent of shifting from somewhat to very comfortable for 13 of 22 items) on our comfort assessment (pre 71.9 ± 12.9 vs post 84.7 ± 10.7, $p < 0.001$). Table 3 summarizes learners' ratings of key measures of acceptability and satisfaction.

Current Dissemination Efforts and Other Associated Opportunities

EPEC-N occurs on the foundation of other EPEC programs, including the core (adult) curriculum, Professional Development and Train-the-Trainer Workshops (for training in advanced teaching skills and quality improvement), and multiple other adaptations (e.g., pediatrics and oncology).[13] As EPEC-N continues to develop and disseminate, we are mindful of the need to continue to train not only clinicians but also educators in neuropalliative care. Therefore, we are actively encouraging our colleagues with teaching roles to take the annual Professional Development Workshop to develop greater comfort with the material and teaching methods.

Table 2 Modules and Learning Objectives

Module title	Learning objectives
Introduction, teaching, and implementation	
Module 1: Introduction to neuropalliative care	Define palliative care as an approach to caring for persons affected by serious illness Understand some of the unique palliative care issues that persons living with neurologic illness and their families face Identify the core components of primary palliative care relevant to neurology Understand various models that can be used to provide neuropalliative care
Module 2: Teaching with EPEC-Neurology	Identify principles of adult education informing EPEC Describe 3 teaching approaches that can be used to teach EPEC-Neurology

Module 3: Implementing neuropalliative care in inpatient and outpatient settings	Understand the range of options and the training required for incorporating palliative care into neurology
	Describe the advantages, limitations, and barriers to the following approaches:
	    Consultative model
	    Primary palliative care
	    Integrated models
	    General neuropalliative care
	Incorporating neuropalliative care into inpatient, outpatient, and community settings

Disease-specific modules	
Module 4: Severe acute brain injury	Define severe acute brain injury (SABI) Describe the care trajectory of patients with SABI Identify symptom management needs for patients and support needs for families
Module 5: Disorders of consciousness	Identify and diagnose disorders of consciousness (DOC) Distinguish between different levels of DOC Discuss management issues for patients in DOC Outline basics of caregiver support and shared decision making for these conditions Improve prognostication and end-of-life care for patients with DOC Identify triggers for a serious conversation in DOC
Module 6: Parkinson disease and related disorders	Understand the role of palliative care in Parkinson disease and related disorders (PDRDs) Diagnose and manage common PDRD symptoms Identify prognostic indicators in PDRD Understand when to refer to hospice and how to manage medications near end of life Understand the prevalence and impact of dementia on patients and their families
Module 7: Dementia	Lead important conversations including delivery of a dementia diagnosis Recognize and manage common safety issues in this population Assess the capacity of patients to make decisions Manage common behavioral issues
Module 8: Multiple sclerosis	Define multiple sclerosis (MS) clinical types and symptomatology Identify the potential palliative care needs of patients with MS Describe treatment strategies for specific symptoms frequently experienced by patients with MS

Module 9: Neuromuscular disorders	Describe the role of palliative care for people living with neuromuscular (NM) diseases
	    Childhood-onset genetic NM diseases
	    NM diseases with normal life expectancy
	    Motor neuron disease (ALS)
	Manage common symptoms in patients with motor neuron disease
	Structure advance care planning (ACP) and goals of care discussions for people living with ALS

Module 10: Neuro-oncology	Define CNS tumors as either primary or secondary Understand the epidemiology of primary CNS tumors Recognize, diagnose, and treat common symptoms experienced by neuro-oncology patients
Module 11: Epilepsy	Understand basic definitions, prevalence, and incidence of seizures and epilepsy Identify common symptoms and complications of acute seizures Describe unique challenges for palliative care in epilepsy Recognize the long-term implications, complications, and relevant natural history of seizures and epilepsy Identify triggers for referral to palliative care
Module 12: Pediatric neurology	Understand the types of conditions and demographics of children receiving pediatric palliative care (PPC) and highlight the need for pediatric neuropalliative care Recognize triggers for introduction of PPC and anticipate common barriers to the integration of PPC into the care of children with neurologic disease Discuss the importance of language in PPC and highlight strategies for family engagement Review analgesic considerations for pediatrics
Primary palliative care modules	
Module 13: Improving medical decisions	Develop a framework of the decision-making process Review key concepts in the decision-making process

Table 2 Modules and Learning Objectives *(continued)*

Module title	Learning objectives
Module 14: Communication and delivering difficult news	Reflect on the impact of skilled and compassionate communication on patient care and provider satisfaction Overcome the barriers to serious illness communication Identify the triggers for serious illness communication Implement the SPIKES framework for delivering difficult news Use NURSE statements to respond to emotion Engage in role play to practice communication tasks
Module 15: Goals of care	Review the concept of goals of care Identify key practices for success in discussing goals of care Identify practices to avoid when discussing goals of care Practice a conversation using a role play
Module 16: Prognostication in neurologic disease	Define prognostication Enumerate the reasons prognostication is important but challenging Suggest approaches for formulating and communicating prognostic information Identify how to use this information to guide clinical decision making Engage in role play to practice prognostic communication
Module 17: Withdrawing or withholding life-sustaining therapies	Define life-sustaining therapies (LSTs) List differences between withholding/withdrawing LST and euthanasia/assisted death Define a framework for analyzing LST and communicating with patients and families
Module 18: Responding to requests for hastened death	Define medical aid in dying and voluntary active euthanasia Identify some root causes of suffering that prompt requests Review the current legal status of hastening death in the United States Learn a 6-step protocol for responding to requests
Module 19: Advance care planning	Define ACP, including definitions of advance directives and assigning proxy Appreciate the bioethical principles and history underlying ACP and the variability of ACP across cultures and jurisdictions (states and nations) Apply a semistructured format for effectively facilitating ACP conversations
Module 20: Hospice and end-of-life care	Define hospice as a philosophy of care and as a service Describe prognosis and predictors of mortality in patients with neurologic disorders Describe relevant hospice criteria Define and describe physician-assisted dying and alternative methods of hastening death Identify root causes of suffering that prompt requests for aid in dying Understand protocol for responding to such requests
Module 21: Pain assessment and management	To feel more empowered to work with pain patients Comprehensively assess pain in patients with neurologic disease using a palliative care framework Identify and overcome barriers to effective pain management Approach pain management in a targeted and systematic way, with non- and pharmacologic strategies
Module 22: Spiritual well-being and difficult emotions	Define spirituality and spiritual care Identify barriers and benefits to providing spiritual care Identify potential challenges to spiritual well-being Describe techniques for building resilience Describe a framework for assessing the psychological, social, and spiritual needs of the patient and family facing serious illness and dying
Module 23: Working with families	Identify interventions, including the use of family meetings, that can be helpful in optimizing communication and care planning with patients and their caregivers
Module 24: Caregiver assessment and support	Appreciate the importance of caregivers for neurology patients Understand the impact caregiving may have on family members Perform an assessment of the most common issues confronting caregivers Provide support for caregivers Know when to refer caregivers for specialized care
Module 25: Self-care: making our caregiving sustainable	Recognize signs and symptoms of burnout Overcome barriers to self-care and understand its benefits Learn practices to build and maintain resilience
Module 26: Cannabinoids for neurologic disorders	Understand cannabinoid terminology and the basic mechanisms of action for cannabinoids in the nervous system Describe the potential benefits of cannabinoids in neurologic disorders (movement disorders, MS, and epilepsy) and symptoms (neuropathic pain, sleep, nausea, and appetite) Review the clinical evidence and guidelines for use of cannabinoids in neurologic disorders Recognize potential side effects of cannabinoids Discuss practical considerations for prescribing practitioners

The International Neuropalliative Care Society's Education Committee has created a task force to disseminate, pilot, and evaluate the EPEC-N curriculum across various training programs.[14] The task force group posted messages announcing the open access curriculum to the American Academy of Neurology (AAN) Graduate Education

Table 3 Learners' Ratings of Satisfaction With the Course

	Frequency	Percent	Cumulative frequency	Cumulative percent
The facilitator(s)/presenter(s) demonstrated content expertise				
Strongly agree	25	96.15	25	96.15
Neither agree nor disagree	1	3.85	26	100.00
This activity met my expectations based on the stated goals and objectives				
Strongly agree	23	88.46	23	88.46
Agree	2	7.69	25	96.15
Neither agree nor disagree	1	3.85	26	100.00
The teaching method(s) used were effective for learning				
Strongly agree	24	92.31	24	92.31
Agree	1	3.85	25	96.15
Neither agree nor disagree	1	3.85	26	100.00
I intend to apply the knowledge and/or skills I have acquired from this activity to my practice team				
Strongly agree	24	92.31	24	92.31
Agree	1	3.85	25	96.15
Neither agree nor disagree	1	3.85	26	100.00
The knowledge and/or skills I have acquired from this activity are directly applicable to my professional practice				
Strongly agree	24	92.31	24	93.31
Agree	1	3.85	25	96.15
Neither agree nor disagree	1	3.85	26	100.00
The day-long palliative care training improved my knowledge of palliative care relevant to patients I see in my practice				
Strongly agree	24	92.31	24	92.31
Agree	2	7.69	26	100.00
I learned valuable skills for helping my patients in the day-long palliative care training				
Strongly agree	23	88.46	23	88.46
Agree	3	11.54	26	100.00
My comfort with palliative care has improved as a result of the day-long palliative care training				
Strongly agree	20	76.92	20	76.92
Agree	6	23.08	26	100.00
I would recommend the day-long palliative care training to my colleagues				
Strongly agree	22	84.62	22	84.62
Agree	4	15.38	26	100.00
The length of the course was:				
Too short	2	8.00	2	8.0
Just right	20	80.00	22	88.00
Too long	3	12.00	25	100.00

Subcommittee message boards; the American Academy of Hospice and Palliative Medicine Education, Program Director and Neuropalliative Specialty Interest Groups; the European Association for Palliative Care reference group on Neurology and Palliative Care; and the European Academy of Neurology specialty panel on Palliative Care. The task

force seeks collaborators to study this curriculum, starting with US neurology residency programs and then expanding to other contexts (e.g., hospice and palliative medicine fellowships and non-US programs) in the future. The Education Committee is planning a remote learning course with recorded webinars, live group assignments, and real-time tutoring. Finally, the EPEC-N curriculum is currently in the process of being translated into Spanish for international distribution.

Discussion

EPEC-N is the first comprehensive neuropalliative care curriculum that is widely available at no cost to clinicians, educators, and researchers. Our data using a day-long agenda of these modules with community-based neurologists, as well as our experiences using these modules for resident didactics, neurology grand rounds, and other lecture formats, suggest that they are well received by intended learners. One of the goals of this curriculum has been to expand access to neuropalliative care education and create a pool of trained facilitators. Towards this end, the available modules and associated readings will lower time and knowledge barriers for neurologists and palliative care providers to create educational experiences for their trainees.

Although EPEC-N was initially designed with neurologists as the intended audience, collaborations with palliative medicine specialists suggested that neuropalliative care content is a gap in palliative medicine training programs.[15,16] As neuropalliative care is a multidisciplinary field, it is likely that clinicians from other medical specialties (e.g., geriatrics) and disciplines (e.g., nursing, social work, and chaplaincy) could also use these modules, possibly with modifications to make them more interprofessional in content and delivery. These modules may also prove useful to researchers interested in using standardized materials for primary palliative care interventions, education research, or health services research.

EPEC-N is but one of several available tools for individuals interested in improving their knowledge, skills, and comfort with palliative care. Other opportunities to learn these skills include neuropalliative care lectures and workshops at general and subspecialty neurology meetings and primary palliative care seminars, workshops, and tools available online and in person including through VitalTalk, Ariadne Labs, and the Center to Advance Palliative Care.[17-19] Notably, these other organizations offer tools and skills that are complementary to EPEC-N, for example, in-depth training on serious illness communication. In addition, there are 2 recent textbooks[10,20] and an increasing number of articles dealing with neuropalliative care in general and related to specific illnesses.

There are also an increasing number of neurologists and palliative medicine clinicians to turn to as mentors in this emerging field. Other opportunities for networking and mentorship include the AAN's Palliative Care section, the American Academy of Hospice and Palliative Medicine's Neuropalliative Care Special Interest Group, a palliative care specialty group in the World Federation of Neurology, and a new International Neuropalliative Care Society (neuropalliativecare.org).

EPEC-N provides foundational materials to begin to integrate palliative care into the training of neurologists and the training of neurology in palliative care. Further study, particularly in training programs, is needed to fully validate and optimize these materials. Other future directions include developing standard curriculum for training programs and developing procedures for identifying and assessing core competencies.

Appendix Authors

Name	Location	Contribution
Benzi M. Kluger, MD, MS	Departments of Neurology and Medicine, University of Rochester Medical Center, NY	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; and analysis or interpretation of data
Neha M. Kramer, MD	Department of Internal Medicine, Rush University Medical College, Chicago, IL	Drafting/revision of the manuscript for content, including medical writing for content, and study concept or design

Continued

Appendix *(continued)*

Name	Location	Contribution
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Nicholas B. Galifianakis, MD, MPH	Division of Palliative Medicine and Department of Medicine, University of California, San Francisco	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; and study concept or design
Steven Pantilat, MD	Division of Palliative Medicine and Department of Medicine, University of California, San Francisco	Drafting/revision of the manuscript for content, including medical writing for content, and study concept or design
Judith Long, BCC	Division of Palliative Medicine and Department of Medicine, University of California, San Francisco	Drafting/revision of the manuscript for content, including medical writing for content, and study concept or design
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Laura A. Foster, MD	Department of Neurology, University of Colorado Anschutz Medical Campus, Aurora	Drafting/revision of the manuscript for content, including medical writing for content, and study concept or design
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Stefan Sillau, PhD	Department of Neurology, University of Colorado Anschutz Medical Campus, Aurora	Drafting/revision of the manuscript for content, including medical writing for content, and analysis or interpretation of data

Appendix *(continued)*

Name	Location	Contribution
Joshua Hauser, MD	Departments of Palliative and Internal Medicine, Northwestern University, Chicago, IL	Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data; study concept or design; and analysis or interpretation of data

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