Neuropalliative Care Curriculum for Neurology Residents

This curriculum, developed in collaboration with the Graduate Education Subcommittee, provides a comprehensive outline of the relevant neuropalliative care educational goals for future generations of neurologists-in-training. The clinical scope of this curriculum encompasses evaluating palliative needs, conducting serious illness and goals-of-care conversations, assessing and communicating prognosis, and undertaking symptom management for selected common and uncommon neurologic conditions. This outline serves to aid in the development of neuropalliative learning objectives and educational material, and thus is aimed primarily at neurology residency directors and educators who seek to provide a framework for primary neuropalliatve skills for neurology trainees. These objectives can serve as the basis for a dedicated neuropalliative rotation, or can be applied throughout residency when addressing topics pertinent to serious neurological conditions. Additionally, a list of resources to aid in teaching communication skills, symptom assessment, and other neuropalliative topics are provided in the index.

Authors:

Lead Author
Peter Hannon, MD
Peter.hannon@hsc.utah.edu
University of Utah

Hannah Louise Kirsch. MD
Stanford University

Jessica Besbris, MD
Cedar-Sinai Medical Center

Wendy Peltier
Medical College of Wisconsin

Claudia Z Chou, MD
Mayo Clinic, Rochester, MN

David Y. Hwang, MD
University of North Carolina School of Medicine

Nawaz Hack MD
University of Riogrande School of medicine

Sushant Puri, MBBS
National Cancer Institute, National Institutes of Health, Bethesda, MD
Johns Hopkins University School of Medicine

Usha Ramanathan, MD
University of Toronto

Winnie Lau, MD
University of North Carolina

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NEUROPALLIATIVE CARE CURRICULUM - Competencies

Part I. General Clinical Approach

Clinical evaluation:

History

Efficiently obtains a complete, relevant, and organized neurologic history and comprehensive review of systems pertinent to neurologic disorders.
Establishes initial code status on admission
Obtains a patient/family's baseline understanding of disease and prognosis, including previously imparted medical information
Identifies a patient/family's communication preferences for information sharing
Obtains efficient and relevant family, spiritual/cultural, and social histories, and attends to potential psychosocial influences on care (e.g. insurance status, financial and caregiving resources, support structure, medical/health literacy, medical mistrust, gender-related competency, cultural humility, etc.).
Identifies medical power of attorney (MPOA), or, in the absence of an advance directive, surrogate decision maker as determined by legal standards in the local region of practice.
Obtains a general caregiver assessment, with emphasis on identifying caregiver burnout.
Obtains a loss history, and knowledge of prior experience with hospice or palliative care services.

Neurological, general, and palliative exams

Efficiently performs a relevant general physical exam accurately incorporating all additional appropriate maneuvers

Performs focused neurologic exam appropriate to the clinical context, focusing on aspects relevant to comfort and function and avoiding necessary noxious maneuvers. This may include:

- Assessing for pain, dyspnea, and anxiety in nonverbal patients
- Assessing for mood, affect, and pseudobulbar symptoms
- Assessing need for formal assessment of capacity, including impact of CNS-altering medications
- Assessing for agitation
- Recognizing respiratory distress
- Performing a wound/skin assessment
- Recognizing common end-of-life findings

Clinical scales

Demonstrates awareness that clinical scales exist in different domains (function, caregiver strain, symptom burden, mood) and can be applied with expert input where clinically relevant (see appendix for domain-specific scale examples).

Diagnostic evaluation:

Integrates and understands the influence of potential factors in evaluating palliative needs and assessing prognosis, including

- Clinical assessment
- Psychosocial assessment
- Spiritual assessment
- *(See appendix for specific clinical, psychosocial and spiritual assessments)*

Integrates special clinical considerations into evaluating palliative needs and prognosis, including

Neuropsychiatry testing
Respiratory parameters
Rehabilitation evaluations
Special neurological tests

Integrates social work, chaplain, and other psychosocial evaluations into evaluating palliative needs and prognosis

Is aware of the benefits and limitations of population-level prognostication and prognostication scores, algorithms, and biomarkers.

Treatment strategies and side effects:

Symptom management

Appropriately recognizes acute need for symptomatic treatment for

Existential distress
Pain
Spasticity
Nausea/vomiting
Constipation/diarrhea
Depression/anxiety/insomnia
Dyspnea and respiratory distress, including at end of life
Sialorrhea, including at end of life
Seizure at end of life
Agitation/psychosis/delirium
Pseudobulbar affect

Appropriately recognizes the need for symptom management in chronic progressive neurologic conditions.

Procedures

Regarding family conferences and serious illness conversations:

Demonstrates an awareness of resources for navigating challenging serious illness communication scenarios (see appendix for resources)
Demonstrates an awareness of techniques to communicate about prognosis, including strategies to address prognostic uncertainty (e.g. best case/worst case, offering time-limited trials)
Demonstrates ability to recognize and appropriately respond to strong emotions and navigate family conflict
Facilitates medical decision-making to reflect a patient's values and goals of care, as well as an awareness when senior or expert guidance is required
Demonstrates awareness of the importance of cultural competency and the impact of cultural beliefs in communication and shared decision-making

Regarding advance care planning:

Demonstrates ability to discuss basics of advance care planning and code status with patients and their families
Assesses the existence of advance directives for health care at initial encounter and reviews content when available
Encourages advance directive completion for patients with serious neurological conditions
Readdresses code status appropriately upon changes in clinical status and/or trajectory of care
Recognizes local and institutional requirements for code status documentation

Recognizes local and institutional requirements for associated durable documentation, such as Medical Orders for Life-Sustaining Treatment (MOLST) and Physician Orders for Life-Sustaining Treatment (POLST)

Regarding prognostication:

Uses prognostic communication as a key element for shared decision-making

Recognizes and mitigates cognitive biases, including self-fulfilling prophecy and disability paradox

Understands the difference between palliative care and hospice

Understands the principle of double effect and its significance in end-of-life care for neurological patients

Appropriately refers patients with advanced palliative needs for consultation with specialty palliative care, ethics, bereavement services, spiritual support, child life services, neuropsychiatry, and other ancillary services

Recognizes the availability of disease-specific societies and support groups, and refers if appropriate.

Demonstrates a basic understanding of special considerations with pediatric palliative care, including family dynamics and psychosocial considerations.

Part II. Syndromes and specific disorders

Can identify role of primary palliative care support, advance are planning, and major symptom-management challenges for specific neurologic conditions, including:

Acute
Severe acute traumatic brain injury
Acute disorders of consciousness
Acute neurovascular injury
New-onset refractory status epilepticus
New-onset autoimmune neurological disease
Death by neurological criteria
Refractory status epilepticus

Chronic/progressive
Movement disorders, with a focus on Parkinson's disease and Huntington's disease
Chronic disorders of consciousness
Dementia, with a focus on Alzheimer's disease
Autoimmune neurological disease, with a focus on multiple sclerosis

Neuromuscular disorders, including amyotrophic lateral sclerosis and muscular dystrophies
Malignant brain tumors
Refractory epilepsy and severe epilepsy syndromes
Congenital and pediatric progressive neurological disease

Part III. Appendix

- Communication skills training
    - *VitalTalk*. Accessed November 11, 2021. https://vitaltalk.org.
    - *Welcome to the Center to Advance Palliative Care*. CAPC. Retrieved November 9, 2021. https://capc.org.
    - *Tools for Clinicians*. Ariadne Labs. Accessed November 13, 2021. https://ariadnelabs.org/serious-illness-care/for-clinicians/.
- The Neuropalliative Open-Access Curriculum
    - The curriculum itself: *Education*. International Neuropalliative Care Society. Accessed October 20, 2021. https://www.inpcs.org/pages/index.cfm?pageid=3351.
    - Background: Creutzfeldt CJ et al. (2018) Neuropalliative care: Priorities to move the field forward. *Neurology*, 91(5), 217–226. doi: 10.1212/WNL.0000000000005916.
    - Background: Goyal T, Robinson MT, and Gold CA. (2021) Opinion & Special Articles: Competency in Serious Illness Communication for Neurology Residents. *Neurology*, 96(12), 587–589. doi: 10.1212/WNL.0000000000011048.
- Supplemental reading
    - Creutzfeldt CJ, Kluger BM, Holloway RG, eds. Neuropalliative Care: A Guide to Improving the Lives of Patients and Families Affected by Neurologic Disease. Springer, 2019.
    - Robinson MT, ed. Case Studies in Neuropalliative Care. Cambridge University Press, 2018.
    - Aberger K, Wang D, eds. Palliative Skills for Frontline Clinicians: Case Vignettes in Everyday Hospital Medicine. Springer, 2020.
    - Back A, Arnold R, Tulsky J. Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope. Cambridge University Press, 2009.
    - Kubler-Ross, E. Living with Death and Dying. Simon and Schuster, 2009.
- Serious illness communication strategies
    - NURSE: Back A, Arnold R, Tulsky J. Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope. Cambridge University Press, 2009.
    - SPIKES: Baile WF, Buckman R, Lenzi R, Glober G et al. SPIKES--A Six-Step Protocol for Delivering Bad News. *The Oncologist*. 2000; 5:302-311.
    - Ask-Tell-Ask: Bernacki RE et al. Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices. *JAMA Int Med*. 2014; 174(12):1994-2003.

    - VALUE: Lautrette A, Darmon M, Megarbane B et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*. 2007 Feb; 356(5): 469-78.
    - REMAP: Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care Conversations. *J Oncol Pract*. 2017; 13(10): e844.
    - Best Case/Worst Case: https://patientpreferences.org/best-case-worst-case/
    - Time-Limited Trials: Quill TE, Holloway R. Time-Limited Trials Near the End of Life. *JAMA.* 2011;306(13):1483–1484. doi:10.1001/jama.2011.1413
- Domain-specific scales
    - Functional ability
        - Palliative Performance Scale (PPS)
        - Karnofsky Performance Scale (KPS)
    - Caregiver burnout
        - Zarit caregiver burden scale (Zarit)
        - Caregiver burden inventory (CBI)
    - Palliative symptom assessment
        - Edmonton Symptom Assessment System (ESAS; ESAS-PD for Parkinson disease)
    - Dementia
        - Mini-Mental State Exam (MMSE)
        - Montreal Cognitive Assessment (MoCA)
        - Functional Assessment Staging Tool (FAST)
    - Delirium
        - Confusion Assessment Method for the ICU (CAM-ICU)
    - Depression
        - Patient Health Questionnaire (either PHQ-2 or the full PHQ-9)
        - Edinburgh Postnatal Depression Scale (EPDS)
    - Anxiety
        - General Anxiety Disorder (GAD-7)
    - Spiritual
        - Spiritual Distress Assessment Tool (SDAT)
        - Professional Chaplains (PC-7)