Emerging Subspecialties in Neurology: Cortical Careers in Neuropalliative Care

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Abstract:
Serious neurological illnesses are associated with significant palliative care needs, including symptom management, complex decision-making, support for caregivers, and end-of-life care. While all neurologists are responsible for the provision of primary palliative care, there is an increasing need for trained neurologists with expertise in palliative medicine to manage refractory symptoms, mitigate conflict around goals of care, and provide specialized end-of-life care. This has led to the emergence of neuropalliative care as a subspecialty. There are different ways to acquire palliative care skills, incorporate them into one’s neurology practice, and develop a neuropalliative career. We interviewed three leaders in the field of neuropalliative care, Dr. Robert Holloway, Dr. Jessica McFarlin, and Dr. Janis Miyasaki, who are all neurologists with different subspecialties and training pathways working in academic centers. They share their career paths, their advice for neurology trainees interested in pursuing a career in neuropalliative care, and their thoughts on the future of the field.

Introduction:
Neuropalliative care (NPC) is an emerging subspecialty at the intersection of neurology and palliative care (PC), dedicated to improving quality of life for patients with serious neurological illnesses. A PC approach can be applied to many neurological diseases, including severe acute brain injury, neurodegenerative movement disorders, motor neuron disease, epilepsy, and dementia. It is appropriate at any stage of disease, from the time of diagnosis to help with coping and anticipatory guidance, to symptom management and advance care planning along the disease course, to complex decision-making and end-of-life care in the terminal phase. Compared with PC providers, NPC specialists are positioned to provide disease-specific expertise regarding disease trajectory, prognosis, unique symptom management and specialized end-of-life care.

Neurologists must have competence in primary PC skills, including assessing for and managing symptoms, providing basic psychosocial and spiritual support, communicating prognosis sensitively, and engaging in shared decision-making, however there are training gaps in neurology residency programs to adequately equip trainees with these skills. Neurologists can strengthen these skills through PC electives, courses, and online curricula. They can also pursue a 12-month ACGME fellowship in Hospice and Palliative Medicine (HPM), two of which have dedicated NPC tracks.

We interviewed Drs. Robert Holloway, Jessica McFarlin, and Janis Miyasaki to provide insight into their careers in NPC, with a focus on training and career pathways, concrete advice for neurology trainees, and future directions of the field.
Early interest
Memorable patient experiences were a common catalyst for early interest in NPC for our interviewees, which led to other ways of nurturing this interest, such as attending conferences or engaging in research. During residency, Dr. Holloway found participating in family meetings rewarding and gravitated towards patients faced with difficult decision-making. He later attended the Education in Palliative and End-of-Life Care conference, where he discovered a community of PC providers who found joy in the same things he did and set him on a neuropalliative path. Dr. McFarlin’s interest also began in residency when she cared for a patient with rapidly progressive dementia. She assumed the family would value a feeding tube, but they declined and enrolled him in home hospice. After reviewing the literature on feeding tubes in dementia, she discovered there is a science behind decision-making and communication. As a movement disorders specialist, Dr. Miyasaki saw patients with advanced disease for whom it seemed there was “nothing” to offer but had sources of suffering to relieve. She then received a research grant from the Parkinson’s Foundation to develop the first neurologist-directed PC program for Parkinson’s disease.

Training pathway
NPC experts often have diverse backgrounds and training pathways which may include one or multiple fellowships in neurology subspecialties and/or HPM, certificate, masters or doctorate programs in PC, PC or NPC courses (Table), or electives. A common thread is the combination of extended clinical experience in PC and training in the previously mentioned PC skills.

Dr. Holloway was “grandfathered in,” the practice pathway that allowed physicians to sit for HPM boards based on work experience. Board certification now requires fellowship completion. Dr. Miyasaki collaborated with PC doctors because at the time, there was no straightforward training pathway in Canada for neurologists to become PC physicians. Dr. McFarlin completed fellowships in neurocritical care and PC.

Despite taking different paths, our interviewees all recommended that interested neurologists pursue HPM fellowship. While not necessary to become NPC specialists, fellowship training provides neurologists with structured opportunities for research, mentorship, and mastering communication skills in a variety of clinical situations. It also provides the flexibility to practice independently, as noted by Dr. Miyasaki, who relies on collaboration with the PC department. Fellowship can be completed following residency, before or after another fellowship, or mid-career. Applications open annually in the summer as part of the National Resident Matching Program.

Incorporating NPC into practice
There are numerous ways to incorporate NPC into a career. PC skills can be used to strengthen one’s neurology practice, regardless of specialty, or applied to a specialized NPC setting. They can be used in inpatient settings, for example a neurocritical care unit, or outpatient settings, such as an NPC clinic. HPM fellowship training also opens other practice pathways for neurologists, as it allows them to practice specialty PC in non-neurology settings such as within Departments of Medicine, Divisions of PC, or hospice organizations. There are also opportunities in leadership to grow NPC service lines and divisions among institutions, in research to identify gaps in care models, and in education to raise awareness among patients and develop curricula for neurology and PC providers alike. Many NPC specialists choose a combination of settings and roles, molding their jobs to align their unique skillsets and personal interests with institutional needs. This may result in creating a new position, building specialized neuropalliative service lines, and assembling an interdisciplinary team. As the field grows, more well-defined opportunities will be available.

As examples of how our interviewees have incorporated NPC into their practices, Dr. Holloway attends on the inpatient PC service at the University of Rochester. He is also faculty within the growing outpatient NPC division. Dr. McFarlin’s clinical role is split between general PC, inpatient vascular neurology, and stroke intensive care at the University of Kentucky. As Division Chief of PC, she helps develop the program and provide PC education. Dr. Miyasaki is Co-Director of the Neuropalliative and Advanced Symptom Management Clinic at the University of Alberta. Every week, she runs a half-day NPC clinic and will also be implementing high yield PC concepts such as advance care planning and routine caregiver screening to the general movement disorders clinic.

**Seeking mentorship**

Mentorship is particularly important in a burgeoning subspecialty such as NPC, where training pathways and career opportunities are limitless and not yet well-defined. Trainees should connect with NPC specialists externally if there are none at their institution. Professional organizations often have mentorship programs, which serve as a helpful starting point to identify mentors. The Neuropalliative Special Interest Group of the American Academy of Hospice and Palliative Medicine (AAHPM) hosts mentorship panels, and the International Neuropalliative Care Society (INPCS) is developing a research mentor list (Table). Dr. Holloway recommends identifying mentors early on and being proactive in setting up frequent meetings and soliciting feedback for manuscripts and grants. Dr. McFarlin believes that mentors may be unexpected, for example, one of her leadership mentors is head of the chaplaincy department.

**Lessons learned**

As they reflect on their careers, a common lesson learned by our interviewees is that PC skills are highly transferable. They are also useful leadership skills, notes Dr. Holloway, for example masterfully communicating, running meetings, and confronting tough facts, and can be used to
develop programs and advocate for high quality person-centered care. Similarly, Dr. McFarlin learned that PC skills can be applied to any field, which opened clinical and leadership opportunities. Dr. Miyasaki reflected on the importance of being generous to those who follow behind. She encourages trainees to have a circle of people to help them, and to be part of other people’s circles too.

Advice for trainees
Attending national meetings, such as the annual meetings of the American Academy of Neurology (AAN), INPCS, and AAHPM, presents valuable opportunities to network with like-minded colleagues and identify mentors. Trainees should sign up for the AAN Palliative Care section and the AAHPM Neuropalliative Special Interest Group (AAHPM membership is free for residents). Following NPC accounts on social media can help trainees stay connected and current with the field. Our interviewees also recommended seeking out PC electives or collaborating with their PC department to create an elective if it does not exist. Dr. McFarlin advises partnering with interdisciplinary providers to learn from the wealth of their experience. Research opportunities, including narrative work, help strengthen fellowship applications. Dr. Holloway recommends referring to books on leadership and writing. Dr. Miyasaki notes that more journals, including Neurology and Neurology Clinical Practice, are welcoming neuropalliative content.

Future of NPC
A shared sentiment among our interviewees is that interest in NPC will continue to grow. Dr. Miyasaki envisions that NPC will become a recognized subspecialty that every academic institution will covet. Research in the field is expanding and Dr. Holloway notes a particular need to address gaps in current models of care such as hospital NPC. Curriculum development to address gaps in training is also an ongoing area of research, and Dr. McFarlin hopes that primary PC skills will expand in neurology training. Dr. Miyasaki adds that in the future, the public needs to create demand for access to PC to combat work force pressures and influence policy decisions. She hopes that with Medicare moving to time-based billing, NPC physicians will be fairly compensated for the effort they put towards patients and families.

Conclusions:
The field of NPC is growing with the recognition that there are unmet PC needs among patients with serious neurological illnesses. There are many resources available to help build one’s PC skillset and career, and a growing number of neuropalliative communities through which to share knowledge and find mentorship.
References:


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<td>American Academy of Hospice and Palliative Medicine (AAHPM)</td>
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<td>Courses for physicians to develop a neuropalliative skill set</td>
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