

eAppendix 1

Neurology Residents Survey of Medical Education in Palliative Care

Opening page to survey

Thank you for participating in this survey. The survey should take between 10-15 minutes to complete.

This is a confidential survey and your participation is entirely voluntary. Results will remain anonymous and de-identified. By completing the survey, you are indicating your consent to participate in the study. You may decide to stop completing the survey at any time.

If you have any questions or concerns, please contact Tara Cook, MD at cookte2@upmc.edu.

In this survey, we will be asking about your experience during your neurology residency in caring for patients with late-stage neurologic disease and at the end-of-life, which is care in the last 12 months of life. Examples include, but are not limited to, stroke, Parkinson's disease, multiple sclerosis, motor neuron disease, and dementia. We are interested in both your clinical experiences as well as in your observations and thoughts about the training you have received.

AMOUNT OF TEACHING

Thinking about all of the formal training that you have had during your residency (such as lectures, case discussions, and standardized patients), how would you rate the AMOUNT of teaching in the following areas:

	None at all	Infrequent teaching (1-2 hours)	Occasional teaching (3-10 hours)	A moderate amount of teaching (11-50 hours)	A lot of teaching (More than 50 hours)
	1	2	3	4	5
Managing a patient with a stroke					
Managing a patient with temporal arteritis					
Managing a patient with late-stage neurologic disease					

QUALITY OF TEACHING

Thinking about all of the formal training (such as lectures, case discussions, and standardized patients) that you have had during your residency, how would you rate the QUALITY of teaching in the following areas:

	None at all	Poor	Fair	Good	Very Good	Excellent
	0	1	2	3	4	5
Managing a patient with a stroke						
Managing a patient with temporal arteritis						
Managing a patient with late-stage neurologic disease						

IMPORTANCE OF LEARNING

	Not at all important	Not very important	Somewhat important	Moderately important	Very important
	1	2	3	4	5
Given your own personal interests and career goals, how important is it to you to learn about how to provide care for patients at end of life ?					
In general, how important do you think it is to your attending physicians and fellows that residents learn how to provide care for patients at end of life ?					
Given your own personal interests and career goals, how important is it to you to learn about how to provide care for patients with late-stage neurologic disease ?					
In general, how important do you think it is to your attending physicians and fellows that residents learn how to provide care for patients with late-stage neurologic disease ?					

MENTORING AND ROLE MODELS

We'd like to find out about the mentors and role models you have had during your residency. Please rate your faculty---
on average---on their ability to:

	Poor	Fair	Good	Very Good	Excellent	Not Observed
	1	2	3	4	5	0
Manage pain in patients at the end of life						
Manage dyspnea in patients at the end of life						
Discuss the goals of therapy and treatment options with a patient with a life-limiting illness						
Talk with a patient and his or her family about withdrawal of life-sustaining treatment						
Work up a patient for acute stroke						
Treat migraine headache						

RESIDENCY EXPERIENCE

We'd like to find out about the training you have had during your residency:

	Never	1-2 times	3-6 times	7-10 times	>10 times
How many total times have you performed an EMG?					
How many times have you performed an EMG while being observed by an attending or fellow?					
How many times have you been given feedback by an attending or fellow about the specific strengths or weaknesses of your EMG technique?					
How many times have you conducted a family meeting regarding goals of care for a patient with life-limiting illness?					
How many times have you conducted such a meeting while being observed by an attending or fellow?					
How many times have you been given feedback by an attending or fellow about the specific strengths or weaknesses of your technique?					

Thinking **only about the last year**, about how many **patients with chronic neurodegenerative disease** have you cared for during the **last six months** of their lives?

1. Never
2. Rarely (1-2 times)
3. Sometimes (3-6 times)
4. A moderate amount (7-10 times)
5. A great deal (more than 10 times)

Of these **patients with chronic neurodegenerative disease** from the question above who died in the last year, how many were referred to hospice?

1. None
2. About 25%
3. About 50%
4. About 75%
5. All
6. I don't know

PREPAREDNESS

Sometimes people learn from being explicitly taught (meaning that others teach them) and sometimes they learn skills on their own (teaching themselves).

For the next series of questions, please consider what you have been **explicitly taught** in your medical education (including **medical school and residency**):

Please indicate the choice for how well prepared you feel overall to:

	Limited	Fair	Average	Very Good	Expert
	1	2	3	4	5
Managing neuropathic pain					
Managing somatic or visceral pain					
Managing the pain of a patient at the end of life					
Managing dyspnea in patients at the end of life					
Managing depression and anxiety in patients with life-limiting illness					
Discussing end of life care decisions with a patient or a patient's family					
Discussing advanced directives					
Discussing code status					
Talking with a patient about his or her thoughts and fears about dying					
Respond to a patient's emotions					
Determining when to refer a patient to hospice					
Caring for a patient after withdrawal of life-sustaining treatment					
Managing your own feelings about a patient's death					

	Limited	Fair	Average	Very Good	Expert
	1	2	3	4	5
Determine whether or not to give a patient with an acute stroke tPa					
Manage a patient with temporal arteritis					
Discuss goals of care with a patient late-stage neurologic disease					
Manage a patient at the end of life					

ATTITUDES

For each of the following statements about end of life care, please tell us how much you agree with the following statements:

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
	1	2	3	4	5	6
Caring for dying patients is depressing.						
It is possible to tell patients the truth about a terminal prognosis and still maintain hope.						
Depression and anxiety are treatable among patients with life-limiting illness.						
Pain is treatable among patients with life-limiting illness.						
Non-pain symptoms are treatable among patients with life-limiting illness.						
Talking about death discourages patients						
Families see palliative care as giving up						
Given the lack of curative options in neurology, neurologists need to be skilled in talking to patients about balancing treatment options with quality of life						
Neurologists need to be skilled in eliciting patient values						
Neurologists need to be skilled in discussing end-of-life care and hospice with their patients						

KNOWLEDGE

Which of the following is true about advance directives?

- A. A durable power of attorney must be written in English in order to be valid.
- B. Changes to advance directives must always be made in writing.
- C. Do Not Resuscitate (DNR) orders are not binding documents.
- D. Patients may change their advance directives at any time as long as they are of sound mind.

Which of the following is true about reimbursement and hospice?

- A. A patient must have Medicare to be eligible to receive hospice benefits.
- B. Hospice care is only provided in the patient's home.
- C. The hospice benefit pays for everything, including 24/7 care.
- D. One physician must certify that a patient is terminally ill, having less than 6 months to live.

Which of the following is required to be documented in the patient's chart to assess medical decision-making capacity?

- A. A patient interview
- B. Formal cognitive testing
- C. Neurology consultation
- D. Psychiatry consultation

Which statement is true about the difference between hospice and palliative care?

- A. Hospice care is delivered to patients in the last days to weeks of life whereas palliative care is mainly pain management.
- B. Hospice care is for patients with prognosis of six months or less whereas palliative care can be delivered to any patient with a life-limiting illness.
- C. Hospice care is only delivered at the patient's home while palliative care is only delivered in the hospital.
- D. There is no difference between hospice and palliative care. They are the same.

Which of the following is true about dyspnea at the end of life?

- A. Morphine administration for dyspnea will cause respiratory depression, hastening death
- B. Morphine administration is unlikely to improve dyspnea in patients with underlying pulmonary disease
- C. Twenty-five percent (25%) of patients will experience dyspnea at the end of life
- D. Using a fan to blow air into a patient's face is not effective for dyspnea

QUALITATIVE QUESTIONS

In your opinion, what one change would most improve end-of-life care education for residents in Neurology?

What would you like to see in a palliative care curriculum?

Describe a patient encounter that was emotionally distressing for you. What made it distressing?

ASSESSMENT OF TYPES OF PALLIATIVE CARE TRAINING

What types of palliative care education (i.e. lectures, case discussions, and standardized patients) did you receive in RESIDENCY? Please check all that apply.

1. None
2. Lecture-based
3. Workshop
4. Online education including webinars
5. Informal role playing
6. Simulated patients
7. Watching senior team members have end-of-life or palliative discussions
8. Having senior team members watch you lead end-of-life or palliative discussions

What types of palliative care education (i.e. lectures, case discussions, and standardized patients) did you receive in MEDICAL SCHOOL? Please check all that apply.

1. None
2. Lecture-based
3. Workshop
4. Online education including webinars
5. Informal role playing
6. Simulated patients
7. Watching senior team members have end-of-life or palliative discussions
8. Having senior team members watch you lead end-of-life or palliative discussions

RESPONDENT CHARACTERISTICS

Physicians commonly try to balance all aspects of patient care, including the social and emotional aspects of care and the technological and scientific aspects. Virtually no one is exactly equal on these two aspects. Do you think you are more inclined towards the social and emotional aspects of patient care or more inclined towards the technological and scientific aspects? [Select one]

1. Social and emotional
2. Technological and scientific

Are you a little more inclined towards the aspects you indicated in the question above or a lot more inclined? [Select one]

1. A little more inclined
2. A lot more inclined

What is your gender?

1. Female
2. Male

What is your racial or ethnic background? Select one or more of the following.

1. Asian
2. Black or African American
3. Native American or Alaska native
4. Native Hawaiian or other Pacific Islander
5. White
6. Something else (specify: _____)
7. Prefer not to answer

Is your residency program in an academic or community hospital?

1. Community

2. Academic

How many adult neurology residents are in your graduating class? _____

Did you go to medical school in the United States? Yes/No

In what year did you graduate medical school? 20____

Please choose the statement that best describes your current status:

1. I am a 4th year neurology resident (PGY-4)
2. I am a 3rd year neurology resident (PGY-3)
3. I am a 2nd year neurology resident (PGY-2)
4. I am an intern (PGY-1)
5. None of these statements apply to me (Please EXPLAIN: _____)

Please provide your email address? (To be used track who has completed the survey to facilitate reminder emails. Will not be associated with individual responses.