

## ORIGINAL RESEARCH

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# Neuropalliative Care Education for Adult Neurology Residents: Priorities to Improve Training

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### Introduction

Neuropalliative care has emerged as an important field at the intersection of neurology and palliative medicine, focusing on improving the quality of life of patients with serious neurologic illnesses.<sup>1-4</sup> This includes neurology patients that experience chronic decline of neurologic function, in addition to those with acute neurologic injury and subsequent uncertain prognosis. Neurologic patients have unique, complex palliative care needs related to the loss of function commonly experienced by patients, including language, memory, and physical independence.<sup>1</sup> Loss of language after sudden neurologic injury poses particular challenges when determining goals of care. Neurologic diseases, including dementia, amyotrophic lateral sclerosis, malignant brain tumors, and stroke, have high symptom burdens that affect patients, families, caregivers, and their healthcare providers.<sup>2,5</sup>

Neurologists have long recognized the necessity of offering high-quality care to dying patients including symptomatic management of patients at the end of life.<sup>5</sup> For two decades, Accreditation Council for Graduate Medical Education (ACGME) Program Requirements for Graduate Medical Education in Neurology residents must demonstrate competence in their knowledge of “palliative care, including adequate pain relief as well as psychosocial support and counseling for patients and families.” They must also be able to apply this knowledge to patient care.<sup>6</sup> However, multiple studies have identified gaps in training and subsequent unmet needs translating into missed opportunities in adequate delivery of neuropalliative care.<sup>2,7-9</sup> A 2009 survey of US residency program directors found less than 52% of programs had formal lectures in palliative care topics,<sup>7</sup> while a 2017 survey of adult residency programs found that 20% offered no palliative care education to residents.<sup>8</sup> Other nationwide surveys of residents have reported low knowledge in core palliative care topics.<sup>9</sup> This has been attributed to lack of faculty expertise, availability, and time for teaching.<sup>8</sup> Thus, among priorities for moving the neuropalliative field forward is the development and standardization of educational content to enhance the delivery of neuropalliative care.<sup>2-4</sup>

We developed a needs assessment to gather insight into the educational needs of adult neurology residents at the University of California, Los Angeles. The assessment asked about their perceptions of the most important palliative care topics and their confidence in providing such care. The results of this needs assessment will highlight potential gaps in education and provide a roadmap of topics to prioritize in a structured neuropalliative curriculum for current neurology residents.

### Methods

We developed an electronically disseminated, anonymous survey addressing 11 general palliative care topics and six neurological diseases that have specific palliative care needs. The topics included in the survey were based on the domains that were consistently found across multiple resources including ACGME guidelines for neurology residency, hospice and palliative care fellowships, previous studies on palliative care education in residency, literature reviews aimed at establishing an evidenced-based consensus of core principles in palliative care for patients with serious and progressive neurological disorders, and input from a domain expert on the research team (C.S.).<sup>6,8,9-14</sup>

The first section of the survey asked, “How important do you believe it is for neurology residents to receive education on the following palliative care topics?” The second section asked, “As a neurologist, how comfortable/confident are you with providing the following palliative care for your patients?” The third section asked, “How confident/comfortable are you addressing disease-specific palliative care needs of patients with the following diagnoses?” The diagnoses included Parkinson’s Disease, Amyotrophic Lateral Sclerosis (ALS), dementia, stroke, Multiple Sclerosis (MS), and malignant brain tumor(s). The survey used a 5-point Likert scale for each question. Lastly, there was an open-ended feedback section asking about any other palliative care skills that residents would like to be included in their neuropalliative curriculum not mentioned elsewhere in the survey. All questions were optional, and completion was not required to end the survey.

Qualitative responses were converted to a numerical scale (1-5). Quantitative data were analyzed using two-tailed t-tests (or Wilcoxon Signed-Rank Test for Paired Samples, which uses medians, given evidence against the null/normality assumption according to Shapiro-Wilk Test) using significance levels of  $p < 0.05$ . This allowed for identification of statistically significant differences between perceived importance of receiving education in palliative care topics and confidence in providing different types of palliative care. The average scores on each question were then used to rank palliative care topics from first to eleventh to examine whether there was concordance or discordance between importance and confidence rankings. After looking at the data in aggregate, it was then stratified by post-graduate year one through three. The same approach was taken for the analysis of section three, addressing comfort with providing disease-specific palliative care.

The University of California Los Angeles Institutional Review Board (IRB) exempted this minimal risk study from further review (IRB #23-000807). There were no financial incentives offered for completion or participation in this study and participation was voluntary.

## Results

Fifteen residents completed our electronically disseminated needs assessment in October of 2020. Nine (60%) respondents were female. Five (33%) were first year residents, 3 (20%) were second year residents, and 7 (47%) were third year residents. **Table 1** summarizes residents' ratings of how important they believed it was to receive education on each of the 11 palliative care topics included; it also summarizes responses for how confident residents were with providing palliative care in each of the 11 areas included. The cohort of residents surveyed believed, on average, it was "very important" or "extremely important" to receive education in all palliative care topics included. They also felt, on average, "slightly comfortable" or "moderately comfortable" providing all aspects of palliative care. For each palliative care topic, residents rated the importance of palliative care topics significantly higher than their comfort/confidence level ( $p < 0.05$ ).

Relative ranking of importance for receiving education on different palliative care topics and relative confidence in providing different aspects of palliative care is summarized in **Table 2**. There was concordance between relative importance and confidence for several palliative care topics. Three out of four communication skills (*bad news, empathic responses, communicating uncertain prognoses*) were perceived to be among the most important topics AND the three areas in which they had the most confidence as well. One exception was the communication skill of shared decision-making, which was tied with prognostication for most important, but was an area that residents felt relatively uncomfortable practicing (8<sup>th</sup> out of 11). Managing imminent death and end of life symptoms, managing hospice patients, and addressing psychological, existential, and religious/spiritual distress were of relatively similar importance and confidence. Psychological, existential, and religious/

spiritual distress was identified as the area of 9<sup>th</sup> most important and 9<sup>th</sup> most confidence, while imminent death management was relatively unimportant (10<sup>th</sup>) and the area of least confidence (11<sup>th</sup>). Hospice patient management was rated of intermediate importance (7<sup>th</sup>) and an area of intermediate confidence (7<sup>th</sup>).

Discordance of importance and confidence was observed between other palliative care topics. The communication skill of shared decision-making had the biggest discrepancy (1<sup>st</sup> vs 8<sup>th</sup>) (delta 7). On the other hand, non-pain symptom assessment and management was least important (11<sup>th</sup>), but it ranked as the area of 5<sup>th</sup> most confidence (delta 6). Prognostication was tied for most important, yet residents lacked confidence in this area (6<sup>th</sup> most confident) (delta 5).

When stratifying by resident year, prognostication skills and communication skills consistently ranked most important across all training levels, with psychological distress, non-pain symptom assessment/management, and imminent death ranked least important (**Table 3a**). Psychological distress, ethical/legal aspects of care, and managing imminent death and end of life symptoms were considered areas of both least importance and confidence across training levels (**Table 3a & 3b**). Communication skills were considered of highest importance and confidence, however, shared decision-making tended to be areas that residents (across training levels) found important but lacked confidence (**Table 3a & 3b**). Overall, and when stratifying by training levels, residents felt most confident in dealing with stroke (**Table 4a & 4b**).

Residents felt least confident in addressing malignant brain tumors and ALS overall, and across all training levels (**Table 4a & 4b**).

Other areas of perceived need or interest to be emphasized in the neuropalliative curriculum (that were not included in the survey) included: "*moral injury & processing our own reflections/feelings,*" (n=1) "*outlining goals with families,*" (n=1) and "*using appropriate/easy to understand patient-level terminology for specific diagnoses/symptoms*" (n=1).

## Discussion

Residents perceived palliative care skills as an important aspect of their training. Consistent with previous literature, the results suggest room to improve education across many aspects of palliative care in neurology resident training to increase comfort and confidence in providing palliative care. Overall, communication skills were relatively well-matched in importance and confidence, but results demonstrate a need to improve education and readiness to engage in shared decision-making. Psychological, existential, and religious/spiritual distress as well as hospice management were areas of relatively low importance and confidence. This may be explained by a lack of exposure and skills in providing this type of care for patients with serious illness. For these issues there may be a tendency to refer to psychiatry, chaplain/spiritual services, or primary

palliative/hospice services. This finding also indicates the need for more holistic care by specialists and the crucial role of multi-disciplinary collaboration to address all palliative care needs that a patient may have.

Prognostication and the communication skill of shared decision-making were considered the two most important palliative care topics but areas of relatively low confidence. Neurology residents are commonly asked to engage in goals of care discussions with patients, particularly after acute neurologic injury in the inpatient setting. This indicates room to improve education in these areas, which are highly relevant to their day-to-day inpatient work. Non-pain and pain symptom assessment and management were of relatively low importance, but higher confidence. This could be explained again as a perception of these topics being out of the purview of a neurologist's primary role, or areas that neurology residents already felt were adequately addressed in prior stages of training (i.e., medical school and/or preliminary internal medicine year). Our results also suggest there is adequate or strongest training in stroke management amongst all levels of residents while there is a need to improve training in malignant brain tumor and ALS. This is likely due to the primarily inpatient training that neurology residents receive, in which stroke is encountered more frequently. Analysis of aggregate and stratified data did not demonstrate striking differences in relative importance and confidence rankings, which under-scores the need for a more structured neuropalliative curriculum that builds on itself as residents progress through training.

Overall, our findings that communication and prognostication were most important while psychological/spiritual distress were least important are consistent with previous research from 2017 investigating residency training in neuropalliative care.<sup>8</sup> Review of the literature suggests improved awareness of palliative care for neurological diseases with efforts to incorporate more formal neuropalliative training in neurology residencies in the past 10-15 years. At the University of California, Los Angeles, however, there has been limited exposure to palliative

care training until the last two years, and efforts continue to hone and expand this educational programming. Equipping neurologists to meet the palliative care needs of patients with neurologic conditions remains an area of weakness that needs to be addressed, especially given the continued progress in the diagnosis and available treatment of neurologic diseases, thereby creating a growing patient population. The COVID-19 pandemic has also revealed challenges in providing optimal care for patients with troubling neurological illness, whose conditions may have been directly exacerbated by complications of COVID-19 or indirectly from consequences of altering healthcare delivery, including social distancing and the deeper reliance on telehealth services.<sup>15</sup>

Our study has limitations. Our sample size of 15 limits interpretation and generalizability of our results. Second, our needs assessment did not assess knowledge of neuropalliative care topics objectively, but rather self-perceptions of importance and confidence levels. Our response rate was 63% (15 out of 24 total residents). Those who responded may have been more interested in palliative care topics and perceived palliative care as being of higher importance than those who did not respond. While the survey was anonymous, optional, with no impact on academic standing, respondents may have rated their confidence higher to avoid embarrassment or fear of feeling incompetent.

The emergence of additional neuropalliative fellowship training opportunities will hopefully improve education for neurology residents.<sup>2</sup> Recent evidence suggests the most frequent type of palliative care education is in passive observation and lectures.<sup>4</sup> There is need for active learning methods including interactive sessions with opportunities for observed practice, debriefing, and constructive feedback like that which could be achieved through simulated patient experiences, online modules, and direct clinical coaching.<sup>3,4,14</sup> Future research should examine these types of educational interventions to identify outcomes that would improve neuropalliative care.

**Table 1. Comparison of Neurology Resident Ratings of Perceived Importance of Receiving Education in Palliative Care Topic VS. Comfort/Confidence in providing Different Types of Palliative Care in Practice (n=15)**

	<b>How important do you believe it is for neurology residents to receive education on the following palliative care topics?</b>	<b>As a neurologist, how comfortable/confident are you with providing the following palliative care for your patients?</b>	
<b>Palliative Care Topic:</b>	<b>Average/Median <math>\pm</math> SD</b>	<b>Average/Median <math>\pm</math> SD</b>	<b>p-value</b>
Prognostication (assessment of illness prognosis):	4.9 $\pm$ 0.4	2.9 $\pm$ 1.1	1.0E-05
Pain assessment and management (use of opioids, nonopioids, complementary therapies):	4.0 <sup>†</sup> $\pm$ 0.70	3.0 <sup>†</sup> $\pm$ 0.59	9.8E-04 <sup>†</sup>
Non-pain symptom assessment and management (dyspnea, constipation, nausea, vomiting, delirium, fatigue, depression/anxiety):	4.0 <sup>†</sup> $\pm$ 0.9	3.0 <sup>†</sup> $\pm$ 0.9	9.8E-04 <sup>†</sup>
Managing imminent death and end of life symptoms:	4.2 $\pm$ 0.8	2.3 $\pm$ 0.9	1.6E-05
Managing hospice patients (knowledge of hospice care system and referrals):	4.5 $\pm$ 0.7	2.8 $\pm$ 1.2	1.9E-06
Communication skills			
Delivering bad news:	4.8 $\pm$ 0.4	3.3 $\pm$ 0.8	2.3E-05
Empathic responses:	4.6 $\pm$ 0.5	3.3 $\pm$ 0.9	8.4E-05
Communicating uncertain prognoses with patients and family:	5.0 <sup>†</sup> $\pm$ 0.4	3.0 <sup>†</sup> $\pm$ 0.9	4.9E-04 <sup>†</sup>
Shared decision-making regarding initiating or withdrawing life prolonging therapies:	4.9 $\pm$ 0.4	2.8 $\pm$ 1.0	4.8E-07
Addressing psychological, existential, religious/spiritual distress (physician's role, and understanding of non-physician resources available):	4.0 <sup>†</sup> $\pm$ 0.7	3.0 <sup>†</sup> $\pm$ 0.9	9.7E-04 <sup>†</sup>
Ethical and legal aspects of care (adhering to or reversing advance directives, power of attorney, code status, assessment of decision-making capacity):	4.6 $\pm$ 0.65	2.6 $\pm$ 0.83	6.8E-06

<sup>†</sup>Wilcoxon Signed-Rank Test for Paired Samples, which uses medians, given evidence against the null/normality assumption according to Shapiro-Wilk Test (Null Hypothesis: population distribution of differences is normal).

**Table 2. Residents' Ranking of Importance of Palliative Care Topic Education Vs. Confidence in Providing Different Aspects of Palliative Care**

<b>Palliative Care Topic</b>	<b>Importance Ranking</b>	<b>Confidence Ranking</b>
Prognostication (assessment of illness prognosis):	<b>T-1st</b>	<b>6th</b>
Pain assessment and management (use of opioids, nonopioids, complementary therapies):	<b>8th</b>	<b>4th</b>
Non-pain symptom assessment and management (dyspnea, constipation, nausea, vomiting, delirium, fatigue, depression/anxiety):	<b>11th</b>	<b>5th</b>
Managing imminent death and end of life symptoms:	<b>10th</b>	<b>11th</b>
Managing hospice patients (knowledge of hospice care system and referrals):	<b>7th</b>	<b>7th</b>
Communication skills: Delivering Bad News	<b>T-3rd</b>	<b>1st</b>
Communication skills: Empathic Responses	<b>5th</b>	<b>2nd</b>
Communication skills: Communicating Uncertain Prognoses with Patients & Family	<b>T-3rd</b>	<b>3rd</b>
Communication skills: Shared decision-making regarding initiating or withdrawing life prolonging therapies:	<b>T-1st</b>	<b>8th</b>
Addressing psychological, existential, religious/spiritual distress (physician's role, and understanding of non-physician resources available):	<b>9th</b>	<b>9th</b>
Ethical and legal aspects of care (adhering to or reversing advance directives, power of attorney, code status, assessment of decision-making capacity):	<b>6th</b>	<b>10th</b>

(T = tied)

**Table 3a. Relative Importance of Palliative Care Topics by Resident Year**

<b>Rank Order</b>	<b>1<sup>st</sup> Year Residents (n=5)</b>	<b>2<sup>nd</sup> Year Residents (n=3)</b>	<b>3<sup>rd</sup> Year Residents (n=7)</b>
<b>1 (most important)</b>	T- Prognostication/ Communication: uncertain prognoses & SDM	T-Prognostication/ Communication: delivering bad news & SDM	T- Prognostication/ Communication: SDM
<b>2</b>	Communication: Bad news	Communication: uncertain prognosis	T- Communication: uncertain prognosis & delivering bad news
<b>3</b>	Communication Empathic	Managing hospice patients	Communication: Empathic Responses
<b>4</b>	Ethical/legal aspects of care	Communication: empathic responses	T- Managing hospice patients & ethical/legal aspects of care
<b>5</b>	Managing hospice patients	Ethical/legal aspects of care	Pain assess/management
<b>6</b>	Pain assess/management	Pain assess/management	Psych
<b>7</b>	Psych	Managing Imminent death	Managing Imminent death
<b>8</b>	Managing Imminent death	Non pain	Non-pain
<b>9 (least)</b>	Non-pain	Psych	

**Table 3b. Relative Confidence in Providing Aspects of Palliative Care by Resident Year**

Rank Order	1 <sup>st</sup> Year Residents (n=5)	2 <sup>nd</sup> Year Residents (n=3)	3 <sup>rd</sup> Year Residents (n=7)
1 (most confident)	Communication: empathic responses	Communication: delivering bad news	Communication: delivering bad news
2	Communication: delivering bad news	Communication: empathic responses	Communication: empathic responses
3	Communication: uncertain prognosis	Communication: uncertain prognoses	Communication: uncertain prognosis
4	Prognostication	Hospice	Prognostication
5	Pain Assess/management	Pain assess/management	Pain assess/management
6	Managing hospice	Non-pain	Non-pain
7	Non-pain	Tie- Communication: SDM & prognostication	Hospice
8	Psych	Managing Imminent death	Communication: SDM
9	Communication: SDM	Psych	Psych
10	Ethical/legal aspects of care	Ethical/legal aspects of care	Ethical/legal
11 (least confident)	Managing imminent death		Managing Imminent death

*Non-pain = Non-pain symptom assessment and management (dyspnea, constipation, nausea, vomiting, delirium, fatigue, depression/anxiety), Psych = Addressing psychological, existential, religious/spiritual distress (physician’s role, and understanding of non-physician resources available), SDM = shared decision-making, T = tied*

**Table 4a. Overall Ratings of Residents’ Confidence/Comfort in Addressing Disease-Specific Palliative Care**

Diagnoses	Average ± SD
Stroke	3.3 ± 1.0
Dementia	2.6 ± 0.8
Parkinson’s Disease	2.6 ± 0.9
Multiple Sclerosis	2.5 ± 1.0
Malignant Brain Tumor	2.3 ± 0.8
Amyotrophic Lateral Sclerosis (ALS)	2.1 ± 0.7

**Table 4b. Residents’ Confidence/Comfort in Addressing Disease-Specific Palliative Care Needs by Residency Year**

Comfort/confidence rating	1 <sup>st</sup> Year	2 <sup>nd</sup> Year	3 <sup>rd</sup> Year
1 (most confidence)	Stroke	Stroke	Stroke
2	Dementia	MS	Tie- MS & Parkinson
3	Parkinson	Parkinson	Dementia
4	MS	Dementia	Malignant Brain Tumor
5	Malignant Brain Tumor	Malignant Brain Tumor	ALS
6 (least confident)	ALS	ALS	

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