

Providers' Perspectives on Palliative Care in a Neuromedicine-Intensive Care Unit: End-of-Life Expertise and Barriers to Referral

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Abstract

Objective: This study identifies health care providers' perspectives on palliative care at end of life (EOL) in a neuromedicine-intensive care unit (Neuro-ICU) and barriers to providing palliative care.

Background: Provider's EOL expertise is crucial in making timely referrals to palliative care as expectation of patient death can be high. Barriers to referral need to be clearly identified so as to engage quality initiatives that improve EOL care delivery.

Design and Participants: The study is a survey design using a mixed-methods approach. Providers at a large academic medical center, including doctors, nurses, and social workers, completed a quality improvement survey.

Measurements: Forty-one providers responded to Likert-type scales assessing their perspectives on palliative care. Their EOL expertise was independently assessed. In addition, barriers to palliative care referral were collected using a checklist and open-ended responses. The latter were reliably content analyzed through a card-sort technique.

Results: Three palliative care perspectives were identified: foundational perspective, comfort-care perspective, and holistic perspective. Regression analysis shows that providers' perspectives are differentially related to their EOL expertise. Frequencies of provider-reported barriers to referring patients to palliative care (e.g., lack of care coordination) were determined.

Conclusions: Health care providers hold multiple perspectives on what they consider palliative care. Their perspectives are related systematically to different aspects of their EOL expertise. In-house training and quality initiatives could focus on unifying providers' perspectives to create a common language for understanding palliative care. Eliminating individual, intergroup, and organizational barriers is necessary for creating an optimal environment for patients and their families who find themselves, often suddenly, in a Neuro-ICU.

Keywords: barriers to palliative care; end-of-life care; neurology ICU

Introduction

PALLIATIVE CARE is essential at end of life (EOL)¹ to reduce pain, manage symptoms, and provide support for patients transitioning away from curative care. Palliative care has recently been a major research emphasis² in part because the majority of Americans die in acute care settings.³ In a neuromedicine-intensive care unit (Neuro-ICU), specifically, all patients have life-limiting conditions. Thus, Neuro-ICU providers need to understand the benefits of comprehensive palliative care at EOL. Patients, families,⁴ and the health care

system all benefit from early implementation of palliative care.⁵ The traditional medical model, however, has often emphasized "doing everything possible," sometimes referred to as *aggressive care*.⁶ This study focused on a Neuro-ICU unit that is transitioning to earlier implementation of palliative services for patients at EOL.

Quality of palliative care varies depending on providers' perspectives of what palliative care entails.⁷ Some providers focus largely on physical pain and symptom management, whereas others include cultural, psychosocial, and spiritual care in their perspective, reflecting a holistic model.⁸ These

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differing views providers hold may relate to their extent and type of expertise in EOL care. Expertise can include, for example, knowledge of advance directives, understanding the value of ethics consults, and stance on *futile care*. In addition, the first step, procedurally, to a patient receiving palliative care in a Neuro-ICU is often referral for a palliative care consult. As such, if providers face barriers to making that referral, care delivery will not be optimized.

Palliative care at EOL: The Neuro-ICU setting

Providing support for patients with life-limiting conditions is an important goal that is not always met by health care systems.⁹ This study focuses particularly on the Neuro-ICU because of the need in such units for swift prognostication and relevant application of palliative care.¹⁰ Neuro-ICU patients are often admitted in serious condition after planned neurosurgical intervention, catastrophic trauma, or illness due to issues, including stroke, brain injury, or disease.

Expertise in palliative care practices and EOL communication is fundamental for providing comfort and increasing the quality of life for patient and family. Specialized training to increase such expertise has only recently become widely available. Providers working in hospital units, particularly those specialized in neurological care, have often not had the opportunity to undergo comprehensive palliative care training¹¹ and have little time to pursue this type of targeted education once they are in the health care system.

Palliative care at EOL: Voice of the provider

This research focused on providers: hearing their perspectives on what palliative care encompasses and the daily barriers they face in attempting to implement high-quality care. Traditions in medical education and the prevailing medical model's curative philosophy can serve to narrow providers' perspectives on palliative care. More recent models posit that EOL palliative care goes far beyond symptom management to include psychosocial care, family support, spiritual assistance, and even follow-up with bereavement services after death.⁷ As such, there is much room for variation in current providers' perspectives on what palliative care entails. Providers' relatively uniform endorsement of a comprehensive definition of palliative care may be important in reaching the unit-level goal of implementing quality care.¹²

In addition, regardless of providers' perspectives, systemic barriers in their daily work as part of a health care organization may also impede implementation.¹³ Previous research has identified barriers to providing palliative care in ICU settings (e.g., competing demands for providers' time and unrealistic expectations about patient prognosis). That work has relied largely on methods that ask providers to select from a set of predetermined barriers, and may thereby avoid assessing barriers that providers themselves may generate, particularly in ICU settings.

Current Study: Specific Aims

This research contributes to a fuller understanding of how high-quality palliative care can be delivered to patients at EOL. The specific aims are to (1) investigate how providers' perspectives on palliative care relate to their EOL expertise

and (2) assess barriers providers face to making palliative care referrals.

Design, setting, and procedure

To address the specific aims, the study used a closed and open-ended survey design allowing for mixed methods analyses. The data were collected as part of a Continuing Quality Improvement Institutional Review Board-certified initiative in a 30-bed Neuro-ICU at a large academic medical center. A workgroup of nurses, physicians, community hospice employees, social workers, and scholars was created to discuss provision of quality palliative care. The constructs included in the study survey were derived from the literature and refined through interactions with this workgroup.

All "nontraveling" health care professionals within the Neuro-ICU were invited to participate, voluntarily and anonymously. Paper copies of the survey were offered for completion during the regular work day. Survey completion took ~10–15 minutes. Response rate was 38%.

Participants

Participants were 42 health care professionals (18 men and 22 women) in a Neuro-ICU, including residents and fellows (18), nurses (10), attending physicians (6), advanced practitioners (2), case managers (1), quality improvement specialists (2), and other (3). Participants' age ranged from 27 to 67 years (mean [M]=36.86, standard deviation [SD]=9.24). They identified as Caucasian (68%), Asian/Pacific Islander (20%), African American (2%), Hispanic (2%), and other (8%).

Materials: Survey measures

Palliative care perspectives. Participants used Likert-type scales ranging from strongly disagree (1) to strongly agree (5) to answer 25 questions regarding the extent to which their perspective includes various important components of palliative care. The items were based on domains of palliative care outlined in the literature (i.e., physical, mental, social, spiritual, cultural, ethical, and imminently dying¹⁴). High scores reflect a clear sophisticated understanding of EOL palliative care.

EOL expertise. This assessment focuses on aspects of providers' expertise, assessed in terms of understanding: (1) ethical care delivery, (2) futile care involvement, (3) palliative care knowledge, (4) understanding advance directives, and (5) previous experience delivering palliative care. Each is described as follows.

Ethical care delivery dealt with sensitivity to individual needs in EOL care (i.e., *When an ethics consult is conducted, it offers little solution to the issue*; reversed item; $M=2.82$, $SD=1.14$). Futile care involvement measures provider's tendency to continue to provide curative care despite terminal prognosis (i.e., *I am involved in providing care that will NOT impact patients' outcomes*; reversed item; $M=2.67$, $SD=1.26$). Participants answered on 5-point Likert-type scales ranging from strongly disagree (1) to strongly agree (5). To assess comprehensiveness of palliative care knowledge, participants selected as many items as relevant, responding to the prompt: "Palliative care for patients [in my unit] currently involves...." Fourteen aspects of palliative care were listed (e.g., pain

management and pastoral care). Endorsed items were tallied to create a palliative care knowledge score. Higher totals indicate more comprehensive knowledge of what is included in palliative care, $M=9.34$, $SD=3.77$. For understating advance directives, participants responded to the prompt: "Advance Directives include the following...." Four main components were listed (i.e., living will, do not resuscitate [DNR] order, health care surrogate, and burial/cremation/funeral plans). Endorsed items were tallied to create a score of understanding advance directives. Higher scores indicate a more current inclusive view of advance directives; $M=3.00$, $SD=1.07$. Finally, previous experience delivering palliative care was assessed using a Likert-type scale from not at all (1) to a great deal (7); $M=4.64$, $SD=1.72$.

Barriers. Participants endorsed any of four listed barriers (i.e., lack of care coordination, limited time, excessive paperwork, and narrow knowledge base) that interfere with them making referrals to palliative care. After this, participants responded to a prompt to provide open-ended responses: "List what you see as the top three barriers to patients receiving palliative care."

Results

Preliminary analyses: Identifying palliative care perspectives

Analyses identified three distinct perspectives on palliative care: holistic perspective, comfort-care perspective, and foundational perspective. Exploratory (Varimax rotation) rather than confirmatory factor analysis was used to delineate these perspectives as there was no clear theory to guide factors. A three-factor solution revealed a strong conceptually relevant set of factors with high internal reliability (Table 1). Based on Cliff and Hamburger,¹⁵ a factor loading cutoff of 0.40 was

used to eliminate 5 items. Factors were interpreted as a: holistic perspective (9 items; $M=3.30$, $SD=0.68$; Cronbach's $\alpha=0.82$; variance explained=18.89%; factor represents concern for nuanced psychosocial and spiritual care); comfort-care perspective (6 items, $M=3.82$, $SD=0.64$; Cronbach's $\alpha=0.78$; variance explained=14.41%, represents focus on physical and social palliative care); and foundational perspective (5 items, $M=3.30$, $SD=0.71$; Cronbach's $\alpha=0.57$; variance explained=10.97, represents theoretical understanding of palliative care). The holistic perspective and comfort-care perspective were positively related ($r=0.47$, $p<0.01$). Note also that age of provider played a role: older providers were less likely to endorse the foundational perspective ($r=-0.50$, $p<0.01$).

To provide descriptive analysis of participants' perspectives, we present frequency with which they endorsed the three palliative care perspectives. Scores on each perspective were split, by those scoring high on a given perspective (i.e., 4 or 5) and those scoring low (i.e., 1–3). Across participants, 56.10% did not score high on any of the perspectives. Of those who scored high on at least one (43.90%), 50.00% scored high on a single perspective and 44.44% scored high on two. Only 5.56% scored high on all three perspectives.

Care perspectives predict EOL expertise

Findings show that providers' palliative care perspectives predict different types of EOL expertise (aim 1). That is, regressions indicated significant relationships for three EOL expertise items: ethical care delivery, $R^2=0.36$, $F(3,30)=5.50$, $p<0.05$, palliative care knowledge score, $R^2=0.25$, $F(3,31)=3.47$, $p<0.05$, and previous experience delivering palliative care, $R^2=0.26$, $F(3,31)=3.59$, $p<0.05$. Trends emerged for futile care involvement, $R^2=0.21$,

TABLE 1. PALLIATIVE CARE PERSPECTIVE FACTORS WITH FACTOR LOADINGS: 3-FACTOR ANALYSIS (VARIMAX ROTATION)

Perspective	Item	Factor loading
Holistic	1. The need for patients to get undisturbed sleep is part of care for patients	0.59
	2. I am unclear what mental health services are available to patients (RS)	0.55
	3. When appropriate, I advocate for mental health services for patients	0.64
	4. Most patients who need mental health services do not get them (RS)	0.61
	5. Spiritual, religious, or existential services are available to all patients	0.65
	6. Spiritual, religious, or existential needs of patients are addressed	0.86
	7. Spiritual, religious, or existential needs are not being addressed consistently across patients (RS)	0.70
	8. Cultural needs of patients are not adequately met (RS)	0.73
	9. When death is imminent, it is adequately communicated to patients	0.48
Comfort-care	10. Physical discomfort is well managed in patients	0.70
	11. I am unclear about how to manage pain symptoms in patients (RS)	0.86
	12. Knowing a patient's social history allows me to provide better care	0.54
	13. I am unclear how to integrate patients' social history into care (RS)	0.46
	14. It is unclear when a patient is imminently dying (RS)	0.60
	15. There is a decrease in care for patients who are imminently dying (RS)	0.42
Foundational	16. I am unclear when a patient is in need of palliative care (RS)	0.58
	17. When I feel it is appropriate, I advocate that patients get palliative care	0.62
	18. My view of when patients need palliative care is respected by my colleagues at all levels	0.52
	19. Advance directives are not more important than professional medical decision making (RS)	0.52
	20. Barriers are resolved for five patients who do not have English language proficiency (RS)	0.60

Note: Reverse-scored items are signified by the label "(RS)."

$F(3,30)=2.60, p=0.07$, and understanding advance directives, $R^2=0.20, F(3,31)=2.56, p=0.07$.

Greater endorsement of the holistic perspective predicted a greater endorsement of ethical care delivery ($B=0.96, p<0.01$) and lower futile care involvement ($B=0.68, p=0.05$). Greater endorsement of the comfort-care perspective was related to having more previous palliative care involvement ($B=1.23, p<0.01$). More strongly endorsing the foundational perspective was related to a higher palliative care knowledge score ($B=2.34, p<0.01$) and higher advance directive knowledge score ($B=1.23, p<0.05$). Bivariate correlations are reported in Table 2.

Barriers to referral

Eight major barriers to referring patients to palliative care in the Neuro-ICU were found through survey and open-ended reporting (aim 2). In the closed-ended checklist, 50% of providers endorsed lack of care coordination, 21% endorsed limited time, 17% endorsed excessive paperwork, and 21% endorsed having a narrow knowledge base. Note that 33% felt they faced no barriers at all. For the open-ended barriers reporting, 29 participants (70.1%) wrote down at least one additional barrier, and a total of 76 barriers were included in content analysis. Based on previous literature regarding barriers to palliative care,^{16,17} eight categories were constructed. Four mapped on to the categories that had been presented in the closed-ended checklist. Four unique barriers categories were added: incorporation of advance directives, patient and family interaction, ethical issues, and persistence in futile efforts.

To content analyze responses, four coders engaged in a closed single-criterion sort activity.^{18,19} Category inclusion was considered reliable if the barrier was sorted into the same category by 75% of coders. Seventy-three of the 76 barriers (96.1%) were reliably sorted. Final categories are patient and family interaction (18.4%); narrow knowledge base (18.4%); limited time or staff resources (15.8%); incorporation of advance directives (13.2%); lack of care coordination (11.8%); policies, procedure, or excessive paperwork (10.5%); ethical issues (3.9%); and persistence in futile efforts (3.9%). See Table 3 for exemplars.

Discussion

This study empirically identified health care providers' perspectives on palliative care at EOL in a large academic medical center Neuro-ICU, where the expectation of patient

death can be high. Providers' perspectives were then related to their EOL expertise. Given that a large number of Americans die in acute care settings,³ such expertise is crucial in making timely appropriate referrals to palliative care and assuring quality in delivery. Barriers that providers face in making such referrals were also examined. The findings suggest that quality initiatives to improve comprehensive EOL care delivery should ideally be targeted at unit-specific barriers that providers report facing in their daily work. This adds to previous work focused on the importance of tailoring interventions to improve palliative care to provider's discipline and level of training.¹³

Perspectives on palliative care and relation to EOL expertise

Health care providers showed distinct perspectives on what palliative care entails. This emphasizes that what providers construe, when talking about palliative care, can vary even within the same unit. Understanding the varying perspectives providers hold is important given that EOL care is often not systematically integrated into ongoing care,⁸ so providers must communicate clearly to engage such care. Three perspectives were identified in this study: (1) The holistic care perspective included psychological, spiritual, and cultural aspects of care; (2) the comfort care perspective focused on continued physical symptom and pain management up until death; and (3) the foundational perspective emphasized advocating for palliative care, including understanding the importance of advance directives in EOL care models.

Note that while providers could hold each of these perspectives to varying extents, relatively few scored highly on even one perspective. This suggests that providers were not clear and confident in their views. It could, thus, be useful to implement quality improvement efforts focused on creating and sharing a multidimensional unit-level or organizational definition of EOL palliative care.¹¹ This could serve as common ground for clear interprovider communication and is in line with one of the highly cited barriers to palliative care referral in this study: lack of care coordination across providers for patients at EOL.

The extent to which providers endorsed each of the different palliative care perspectives was related to particular aspects of their EOL expertise, again emphasizing the differences between these perspectives. Endorsing a holistic perspective was related to a sophisticated delivery of care that includes ethics consults when needed to aid complex

TABLE 2. CORRELATIONS AMONG PALLIATIVE CARE PERSPECTIVES AND END-OF-LIFE EXPERTISE ITEMS

Variable	1	2	3	5	6	9	10	11
1 Holistic care perspective	—							
2 Comfort-care perspective	0.47**	—						
3 Foundational perspective	-0.10	-0.12	—					
5 Futile care involvement	0.45**	0.33*	-0.07	—				
6 Ethical care delivery	0.58***	0.29	0.06	0.14	—			
9 Previous experience delivering palliative care	0.28	0.53**	0.06	0.09	-0.09	—		
10 Palliative care knowledge	-0.01	0.13	0.45**	0.01	0.10	-0.17	—	
11 Advance directive knowledge score	0.11	0.11	0.40*	0.10	0.01	-0.05	0.59***	—

Note: * $p<0.05$, ** $p<0.01$, *** $p<0.001$.

TABLE 3. CONTENT CODING: BARRIERS TO PROVIDING REFERRAL TO PALLIATIVE CARE

<i>Barrier category</i>	<i>Frequency (%)</i>	<i>Exemplar</i>
Lack of care coordination	11.8	Registered nurses and medical doctors continually question which doctor can write which note, as well as who can actually order
Limited time or staff resources	15.8	“Man power”; palliative care needs more people
Policies, procedure, or excessive paperwork	10.5	Ease of ordering
Narrow knowledge base	18.4	Nurses/doctors not clear on what palliative care does for patients/families
Incorporation of advance directives	13.2	We do not acknowledge (patients) advance directives. We consistently trach/PEG (patients) who have written they would not want (those procedures)
Patient and family interaction	18.4	Poor communication from physicians to family members in regard to prognosis and the options. Trach and PEGS are often presented as the only option
Ethical issues	3.9	Lack of understanding how ethics consult impacts patients
Persistence in futile efforts	3.9	Stigma of “giving up”

Note: Frequency is percent of barriers produced by providers that were coded into each category.

decisions, and to less delivery of aggressive⁶ or futile care to patients at EOL. The comfort care perspective emphasized comprehensive physical symptom and pain management right up until death with ongoing respect for the patient's social history. More strongly endorsing this perspective was related to a different sort of expertise: greater overall past experience in palliative care delivery. Finally, more strongly endorsing the basic foundational perspective was related to expertise in the form of holding comprehensive knowledge of the multiple components of palliative care and of advance directives.

Barriers to palliative care referral

Given that patients benefit from early implementation of palliative care,⁵ the second aim of the study was to identify barriers to palliative care referral. Overall, the use of a mixed-methods approach in this study allowed an understanding of the barriers to palliative care referral that more comprehensively reflects of providers' most pressing concerns.

About one-third of respondents reported no barriers to making referrals to palliative care from the Neuro-ICU. Lack of reported barriers among this portion of respondents may highlight inconsistency in efforts to provide palliative care to patients when appropriate, as rarely are there no barriers to palliative care referrals in health care settings. Although some may truly not face barriers, some portion of these respondents may not “know what they do not know” or lack comfort in reporting that they face barriers, even when reporting anonymously.

Several categories of reported barriers, however, arose consistently across the closed- and open-ended assessments. Frequently cited barriers included lack of care coordination, limited time or staffing, the excessive procedures/paperwork necessary for a referral, and having narrow knowledge concerning palliative care. Content analysis was also, however, crucial for revealing additional barriers, including patient/family interaction, and to a lesser extent, issues related to advance directives, use of ethics consults, and provision of futile care.

Hospital-based providers have often not had comprehensive palliative care training.¹¹ Lack of knowledge of pallia-

tive care and decision-making skills regarding life-sustaining measures have been cited as barriers in previous research in the oncology context.²⁰ That past research mirrors the current findings regarding concern with patient/family communication, for example, how to communicate with family members if they appear to have unrealistic expectations given patient prognosis, or do not fully understand the implications of particular medical procedures at EOL.⁸

Limitations

The study has at least two limitations. Although our response rate was comparable to many studies in the literature, it would have been optimal to have a stronger response rate, inclusive of more “voices” in the unit. Furthermore, one major finding was that care coordination is perceived as a prominent barrier to care delivery. Although our open-ended data provided a glimpse at what better care coordination might entail, use of an unstructured interview methodology would have provided more specific direction for positive changes to be made on the unit. Future research using structured interviews of a range of providers could provide more depth on this issue.

Conclusion

In the past decade, the field has moved toward a model of palliative care that, instead of juxtaposing it to curative care, views palliation as a gold standard for all individuals with life-threatening illnesses.¹ Palliative care is now a thriving field yet still faces challenges in implementation of consistent high-quality services to meet the patients' needs. Addressing these challenges will be particularly crucial as the Baby Boomers extend into old age and die over the next two decades.²¹ Many individuals of that generation, regardless of their preference for place of death (e.g., often to die at home^{3,22}), will die in a Neuro-ICU. Understanding providers' perspectives, and the barriers they face, is crucial to a medical system that is evolving to embrace the idea that hospitals can provide a place to die with dignity.

Author Disclosure Statement

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