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Palliative Care Consultations in the Neuro-ICU - A Qualitative Study

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Abstract

Background—Integration of palliative care into the neurological intensive care unit (neuro-ICU) is increasingly recommended, but evidence regarding best practice is lacking. We conducted a qualitative analysis exploring current practices and key themes of specialist palliative care consultations in patients admitted to a single neuro-ICU.

Methods—We retrospectively identified all patients who were admitted to the neuro-ICU for 24 hours and received a palliative care consultation between January and August 2014. We reviewed palliative care consultation notes and neuro-ICU progress notes from the electronic health records of these patients. We performed content analysis on the palliative care notes.

Results—Twenty-five neuro-ICU patients (4%) received a palliative care consultation over 8 months with the most prevalent reason of clarifying goals of care. The main distinctions between patients with and those without (n=580) a palliative care consultation were ICU length of stay (median 8.2 vs. 2.8 days) and death in the neuro-ICU (56 vs. 11%). The most prevalent themes addressed in the palliative care consultation notes were (1) discussing prognosis, (2) eliciting patient and family values, (3) understanding medical options, and (4) identifying conflict.

Conclusions—Palliative care consultations in the neuro-ICU emphasize family coping and decision-making by helping discuss prognosis and exploring patient and family values as well as their ability to understand the medical information. Several features suggest that earlier integration of palliative care into neuro-ICU care may enhance both coping and the decision-making process.

Introduction

Palliative care (PC) is specialized medical care for people living with serious illness, but has received little attention in the neurological intensive care unit (neuro-ICU). Early integration of palliative care into the care of critically ill patients has been associated with a reduction in hospital costs¹ and length of stay.² The best evidence supporting the benefits of integrating palliative care into serious illness care comes from cancer, which may or may not offer some parallels for severe neurological illness. Randomized studies demonstrate that early integrated palliative care improves mood, symptoms, quality of life and survival.^{3, 4, 5} How these benefits are realized is still being studied, but a recent qualitative analysis of palliative care consultations in cancer patients identified the following 7 key elements or themes of the

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palliative care visits that were started at the time of diagnosis with metastatic cancer: (1) relationship and rapport building; (2) addressing symptoms; (3) addressing coping; (4) engaging family members; (5) establishing illness understanding; (6) discussing cancer treatments; and (7) end-of-life planning.⁶

Patients with severe acute brain injury such as stroke, traumatic brain injury or cardiac arrest present acutely neurologically devastated. In contrast to cancer, the clinical presentation of these patients means that family members face complex early decisions that typically must be made in circumstances of uncertain prognosis because patients have lost decisional capacity.⁷ These situations challenge clinicians in the neuro-ICU in ways that might benefit from palliative care expertise.⁸ Recent guidelines from the neurocritical care society recommend implementing palliative care for patients with devastating brain injury in the neuro-ICU and their surrogates.⁹ However, the exact indication or best timing for specialist palliative care consultations in the neuro-ICU is unknown, and studies exploring how palliative care issues present in the neuro-ICU are limited.

The goal of this study was to explore how specialist palliative care is delivered to patients with severe acute brain injury admitted to a hospital with a large neuro-ICU and a well-established palliative care consultation service. Using chart documentation from both the palliative care and the neuro-ICU teams, we studied a consecutive series of neuro-ICU patients to describe the palliative care issues that the palliative care consultants addressed. We aimed to (1) identify the content and key themes of the palliative care consultation, (2) explore the reason a palliative care consultation was sought, and (3) describe the most prevalent recommendations put forth from the palliative care specialists.

Methods

Study Design

We performed a qualitative study of the clinical documentation from patients in the neuro-ICU at Harborview Medical Center (HMC) who had a palliative care consult during their neuro-ICU hospitalization.

Setting

As the only Joint Commission-certified Comprehensive Stroke Center and Level I Trauma Center in the Pacific Northwest 5-state region, HMC admits over 1800 patients to their 30-bed neuro-ICU every year. The HMC neuro-ICU physician teams use a co-management approach with either (1) the critical care team (board-certified intensivists with residents in anesthesia, neurosurgery, neurology and emergency medicine, critical care fellows, and nurse practitioners) plus the neurology team (board-certified neurologists, neurology residents, and stroke fellows), or (2) the critical care team plus the neurosurgery team (board-certified neurosurgeons and neurosurgery residents and fellows) involved in patient management. During the study period, no structured training in communication skills was provided for fellows, attendings, or nurse practitioners, either by training programs or the medical center. The Palliative Care team at Harborview is typically staffed by one board certified palliative care physician with a palliative care fellow, an internal medicine resident,

a Physician Assistant, a Social Worker and a Spiritual Care provider, and is available 24/7 for consultation. No special screening for PC consults was performed in the neuro-ICU during the study period.

Participant selection

Patients meeting study criteria were identified through retrospective review of admissions to the HMC neuro-ICU. Starting with patients admitted on January 1st 2014, we identified consecutive patients admitted to the neuro-ICU whose admission lasted at least 24 hours and who underwent a palliative care consultation while they were in the neuro-ICU.

Clinical Data Capture

Clinical notes for all PC encounters and neuro-ICU encounters for corresponding days from study participants were extracted from the electronic health record (EHR) and saved as Microsoft Word documents.

Qualitative Analysis

After a preliminary reading of documentation from the first 5 cases by the interdisciplinary investigator team, a prototype coding scheme was devised to identify emergent themes and concepts addressed in the initial palliative care consultation notes. The coding scheme was refined with subsequent cases through multiple readings by adding, removing, or grouping the themes into primary thematic codes, each containing subcodes. The investigators (A.L.B., C.J.C., and L.T.) met on a bimonthly basis to discuss the cases, refine the coding scheme, ensure concordance with the coding scheme and monitor for thematic saturation. The final coding scheme included 15 primary codes and 17 subcodes. The coding and content analysis were performed using Dedoose, a web-based qualitative data analysis software program. To assess accuracy and agreement, the investigative team (A.L.B., C.J.C., and L.T.) reviewed and finalized the analysis and qualitative findings. The team included clinicians who are part of the neuro-ICU team (C.J.C) and not part of the neuro-ICU team, as well as different disciplinary perspectives (bioethics, oncology) to address potential biases, and an audit trail was maintained to ensure trustworthiness^{10,11}. Because the aim of this study was to identify the range of reasons and issues addressed in palliative care consultations (rather than a generalizable estimate of the frequency of particular reasons or issues), the number of cases analyzed was determined by thematic saturation, the point at which no new themes were emerging from the data.¹²

The study protocol was reviewed and approved by the Institutional Review Board of the University of Washington.

Results

Patient Characteristics

The final sample consisted of 25 neuro-ICU patients who had a PC consultation between January and August 2014. This sample represents 4.1% of 606 patients admitted to our neuro-ICU for 24 hours or more during that time period. Compared to the group of patients who did not receive a PC consultation, those who did were older with a higher proportion of

women and white race (see table 1). Stroke and traumatic brain injury made up one third of patients in both groups. Palliative care consultations occurred late, and patients with a PC consultation had a longer stay in the neuro-ICU ($p<0.0001$). Over half of patients with PC consultation died vs. only 11% of those without.

Neuro-ICU Clinician Notes

The daily progress notes written by intensivists, neurosurgeons and/or neurologists were largely in a templated format, and addressed almost exclusively clinical changes, diagnostic and treatment options. Family meetings or ‘bedside updates’ were mentioned but the content of such meetings was rarely described. Typical excerpts from the clinician notes included “wife updated at bedside” or “Discussion with family regarding prognosis and clear decision to transition to comfort measures.” Our original analysis plan included coding these daily progress notes, but we found that these notes rarely included the content issues that our study sought to characterize. In addition, in over half of cases ($14/25 = 56\%$), at least one member of the primary team participated in at least one of the family meetings documented by the palliative care providers, and it appears that the primary team left detailed palliative care content documentation to the palliative care team. We therefore decided to omit the neuro-ICU progress notes from coding.

Referring Clinician Reasons for Consulting Palliative Care

The most common reason for consultation as documented by the Palliative Care team was assistance with “clarifying goals of care” (in 22/25 patients). Other reasons (some patients had more than 1 reason documented) included “family support” (11), “decision-making” (11), “discharge planning” (3) and “communication” (1).

Clinical Issues Addressed in Palliative Care Consultations

Thematic analysis identified 4 clinical issues that were emphasized in palliative care consultations: 1) Discussing prognosis, 2) Eliciting patient and family values, 3) Understanding medical options, and 4) Identifying conflict. These themes are described herein with representative quotations in table 2.

THEME 1: Discussing prognosis involved the patient’s chance to recover physical and cognitive functions and quality of life but rarely survival or length of life. The terms “survive” or “survival” were not mentioned in any one of the palliative care consultation notes; the term “mortality”, typically followed by a time descriptor such as days, weeks, month or one-year, came up in 4 patients, 3 of which had other life-limiting comorbidities (cirrhosis; metastatic adenocarcinoma; renal cancer), and one was about to have respiratory life support withdrawn. Typical phrases coded under *prognosis* included the chance of “a return to baseline,” regaining “independence,” or the ability to complete “activities of daily living.” In cases where the prognosis discussion focused on the patient’s acute illness (18/25 patients) rather than on the imminent withdrawal of life-sustaining treatment and comfort measures (6/25), the word “prognosis” was accompanied by the word “uncertain” or “unpredictable”.

The palliative care consultants rarely prognosticated themselves. Instead, they documented either what the primary team had described in a family meeting (for example, “Dr.____ thought that best case scenario, over the coming months, he would regain a good portion of his strength on the R side, but hopefully some on the left but it was uncertain how much or if he would be independent in his ambulation or ADLs again”) or what the family was able to reflect (for example, “____ says he has been told that the stroke is serious and that it is highly unlikely that she would return to her prior baseline, and that she would most likely be in a nursing home [...], that if she recovers it would be slow over months, and uncertain...”).

THEME 2: Eliciting patient and family values involved anecdotes and stories about the patient and family and eliciting family member descriptions of who this patient was as a person prior to their injury. For example, one note described a family member reporting that “[the patient’s] self perception was one of beauty & she weighed 70lbs most of her life. She was an actress, a beautiful woman (they say she looked like Elizabeth Taylor) with nice things, and ‘adequate’ was not a part of ____’s vocabulary.”). Palliative care consultants sought to understand the patient’s view of what brought meaning to their life and spiritual values. Discussions of treatment preferences prior to the neurological illness prompting the admission were rare (for example whether the patient would have wanted a feeding tube or intubation); only 3 of the 25 patients had advance directives or a living will, but family members still struggled to apply those to the medical circumstances of this hospitalization. For example, one “[patient’s husband] describes [the patient] as having directives that entail not wanting a trach/PEG”, but he later states that “he feels a peg/trach would be okay if he knew it would be temporary”. The most commonly elicited values were “independence” and the “ability to interact” (in a meaningful way). Of note, and consistent with the literature,⁸ the majority of patients (19/25 =76%) were independent prior to hospitalization.

THEME 3: Understanding medical options involved the families’ understanding of the patient’s illness, available medical treatments, and the consequences of each treatment option. Most of the patients lacked capacity to participate in these discussions, and only 2 cases involved direct discussion with the patient. Palliative care consultants often documented the family’s previous experiences with serious illness, and often described explaining medical options for the family, for example “In light of this, I outlined 3 potential options, a) move to comfort care immediately b) continue full medical care/life sustaining treatment but if he has a major setback/complication we would switch to comfort care (and not reintubate if needed after extubation) or c) full treatment including reintubation if necessary knowing that the move to comfort care in the future remains available.” PC consultants frequently documented counseling the family that they had time to deliberate and that a final decision did not need to be reached right away. The consultants’ notes were also directed towards the primary team with assessments about family coping and understanding, often seeming to validate the family’s decisions, for example “the patient’s family demonstrate excellent understanding of the patient’s condition and prognosis”.

THEME 4: Identifying conflict involved naming discord between the primary team and family, and eliciting detailed views of families and providers in these situations, and occasionally between the primary team and consulting teams. Documentation generally took the form of nonjudgmental descriptions of differences in perceptions, beliefs, and

assessments of the situation. The most commonly stated conflicts were those between family members and the medical team and could have involved (a) family “mistrust” about provider’s treatment goals, for example family members feeling pressured towards withdrawal of life-sustaining treatment; or (b) “miscommunication” about prognosis or treatment options, for example family members perceiving conflicting information from different providers. Conflict among family members typically arose when decisions had to be made, for example “when the decision was made to transition _____ to comfort care [...] his daughter is angry at him [...] and people were storming out of the room”.

Palliative Care Recommendations

The most common category of palliative care consultant recommendations involved ways to match the communication with the individual patient and/or family. Palliative care consultants commented on family member’s readiness, comprehension or coping level, followed by a recommendation on how best to communicate with family members. Examples include optimal timing of updates, the content of updates or the involvement of chaplains or a cultural mediator:

““They would prefer updates every other day at 11am. They do not like the 5am phone calls for planned procedures, but want to know about them.”

“If [patient] were to develop a life-threatening infection, they would want to know before treatment is begun.”

“Please use caution when noting and discussing reflexive/posturing type movements vs. signs of true neurologic improvement (tracking, intentional movements, following commands – holding up 2 fingers), so as not to provide confusing messages/false hope to [family].”

Discussion

This study provides a qualitative description of the clinical issues addressed by palliative care consultants in a large neuro-ICU. Our qualitative analysis identified the following 4 major themes in the palliative care consultations of neuro-ICU patients and suggest an emphasis on family coping and decision-making: 1) Discussing prognosis, 2) Eliciting patient and family values, 3) Understanding medical options, and 4) Identifying conflict. The most common PC recommendations were directed at improving neuro-ICU provider communication with the family. Our observations suggest that integration of palliative care principles, practices, and services could play an important role in improving the quality of care in the neuro-ICU.

Our findings contrast the palliative care needs of patients with severe acute brain injury with those of patients with other serious illnesses such as cancer. For example, palliative care consultations for cancer patients often begin with control of the patient’s distressing symptoms.^{6,13} We found the main focus of PC in the neuro-ICU to be discussions about prognosis, and the main recipients of palliative care in the neuro-ICU were not patients but family members acting as surrogate decision-makers. Second, with the majority of our patients having been independent before hospitalization, the value of independence as

identified by their family members is important but may require some education about people's ability to adapt to dependence.^{14,15} Third, the common perception of receiving 'conflicting information' regarding prognosis may be indicative of the prognostic uncertainty of the illness and underlines the importance of all providers painting a similar picture.

Our findings also show that palliative care in the neuro-ICU may address different issues than in a medical ICU. While PC in medical ICUs has focused on symptom management with the use of sedatives and analgesics and the process of withdrawing life support in the ICU in addition to communication with family members about the goals of care and withdrawal of life support,^{16–18} the issues addressed by PC consults in the neuro-ICU focus on the prognosis for a patient's functional recovery, patient values for living a life with neurological limitations, and medical options for prolonging life that involve long term care. This difference in issues suggests to us that PC providers working in neuro-ICUs need familiarity with different clinical issues and communication than PC providers who work in medical ICUs.

While the PC consultations spent a lot of time discussing prognosis and the family's understanding of prognosis, the *prognostication* is left to the neurologists and intensivists. This task-sharing seems reasonable as the neurologists are likely the most knowledgeable about the patient's potential for recovery and able to describe a 'best-case' scenario (i.e. the optimistic 25th percentile), a 'worst-case' (i.e. the pessimistic 75th percentile) and a 'most-likely case'. It is important to match this sensitive discussion with knowledge about the patient values and the family's understanding, both of which require thoughtful and skillful communication. These tasks are relevant to both neurology/neurocritical care providers (who are practicing 'primary palliative care') and palliative care consultants (who are practicing 'specialist palliative care').^{19,20} Family meetings offer the opportunity for a team-based approach with all medical teams present. Finally, conflict can be an impediment to the process of shared decision-making. Interestingly, in the cases of conflict regarding treatment preferences, the family was always in the role of hanging on but feeling 'pushed' towards withdrawal of LST by the providers, but never the other way around.

The main limitation of our study is that the data were collected by retrospective chart review: first, not every detail discussed during the meeting was transcribed, including elements of nonverbal communication. We were able to analyze only what was documented, which in some cases may not correlate with what was said or done. In addition, the provision of primary palliative care (management of palliative care needs by the neurocritical care team) was infrequently documented. Second, with no guidelines as to when or why to consult palliative care, nor a mandate to consult palliative care early, the timing to the consultation varied widely and tended to be late in the hospital stay, possibly when palliative care needs were already very high. By 8 days after hospital admission (mean time of PC consult), 75% of patients without PC consultation had already been discharged from the neuro-ICU. Third, our observations were from one institution only and may thus not be generalizable to others.

In conclusion, our study adds qualitative evidence to the unique palliative care needs of neuro-ICU patients and their families, and highlights ways in which these are addressed. Further research is needed to understand appropriate indications and timing for palliative care consultations, and to explore how increased integration of palliative care into the neuro-ICU can improve the quality of care, communication and decision-making, and ultimately the long-term outcomes for patients and their families.

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Table 1

Basic Demographics of Neuro-ICU Patients.

	Neuro-ICU patients receiving PC Consultation (n=25)	Neuro-ICU patients not receiving PC Consultation (n=580)
Age, mean (SD)	62.1 (18.8)	55.4 (17.3)
Female	13 (52%)	249 (43%)
Ethnicity white Caucasian	21 (84%)	437 (75%)
Primary Diagnosis: Stroke	8 (32%)	199 (34%)
Traumatic Brain Injury	8 (32%)	176 (30%)
Length of ICU stay in days, median (IQR)	7.8 (4.7–13.6)	2.3 (1.5–4.8)
Discharge disposition	14 (56%)	64 (11%)
Died in hospital or discharged to hospice	14 (100%)	52 (81%)
- of those, documented comfort measures only	11 (44%)	105 (18%)
Skilled Nursing or intermediate Care facility	2 (8%)	298 (51%)
Home		
Days from admission to PC consult, median (IQR)	9 (3.5 – 13.5)	Not applicable
GCS on day of PC consult, median (IQR)	10 (7 – 11)	
Patient able to participate in initial PC consult	3 (12%)*	

SD = Standard Deviation; GCS = Glasgow Coma Scale; PC = palliative care; IQR = interquartile range; ICU = intensive care unit.

* Of these 3 patients, one was able to participate in the first meeting but not in follow-up meetings, one other participated but was 'slightly delirious'

Table 2

Representative quotes of Key Themes Addressed in Palliative Care Consultations for Neuro-ICU patients

Clinical Issue	Representative quote
Discussing Prognosis	<p>“[The husband] says he has been told that the stroke is serious and that it is highly unlikely that [the patient] would return to her prior baseline, and that she would most likely be in a nursing home dependent on some, if not all of her [activities of daily living], that if she recovers it would be slow over months, and uncertain as to how much independence she would regain.”</p> <p>“His prognosis is uncertain, but per neurosurgery will certainly involve a L hemiplegia and likely more debilitating deficits.”</p>
Eliciting Patient Values	<p>“His brother states that [he] values his ability to talk with others and this clearly brought his life a lot of joy and meaning. [The patient] had to be the “life of the party” and had so many friends. He enjoyed company and joined a church at one point not because of his religious beliefs but because of the sense of community that came with it.”</p> <p>“[He] was very clear that what is most important is his independence [and] he was only willing to undergo medical care, including brief intubation, if it would be enable him to live independently.”</p>
Eliciting Family Values	<p>“Role of Faith/Spirituality/Religion: Their spirituality is paramount and a way of life. Meditation and prayer take place throughout the day. The word ‘please’ is the most important word to them. They pray and express their thanks throughout the day, from thanking the vegetables that they eat for allowing them to sustain life to thanking the providers here. They pray for us, our health, and our children that we will not be in a similar situation as them, and they pray for the safety of healthcare workers when they drive by a hospital.”</p> <p>“Also pointed out that putting [the patient] back on the ventilator would be to relieve [the family’s] suffering, not [the patient’s], and this is not in line with what they ultimately want for her, which is to allow her to pass peacefully and not to prolong her suffering with the ventilator.”</p>
Understanding Medical Options	<p>“[Husband] is articulate as he describes a ‘sobering prognosis’ from Dr. _____. He clearly understands the severity of [patient]’s injury, explains potential complications, and recounts best case/worst case scenarios. “</p> <p>“We had a long conversation about his prognosis and treatment options and discussed 3 potential paths 1) continue current aggressive care including trach and long term vent if needed 2) Trial of getting him off the vent, but if he fails again then move to comfort care or 3) move to comfort care now. She wanted to talk with other family members and needs time to think about things. We emphasized there was not any pressure on her to make a decision right now...”</p>
Identifying conflict	<p>“[The husband] is aware that her parents would like all treatment to continue. They have been hostile to the idea of shifting the focus to comfort care and they would not speak [to the] palliative care team when we attempted to speak with them, although they did tell us ‘the doctors want to pull the plug...’”</p> <p>“Both [names of family members] understand their sister’s injuries, however they both say they are struggling with receiving conflicting information re prognosis.”</p>