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Critical Care Nurses' Experiences of Family Behaviors
as Obstacles in End-of-Life Care

Caitlin Brook Mallory

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Critical Care Nurses' Experiences of Family Behaviors as Obstacles in End-of-Life Care

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Background: Critical care nurses (CCNs) frequently provide end-of-life care for critically ill patients. CCNs may face many obstacles while trying to provide quality EOL care. Some research focusing on obstacles CCNs face while trying to provide quality EOL care has been published; however, research focusing on family behavior obstacles is limited. Research focusing on family behavior as an EOL care obstacle may provide additional insight and improvement in care.

Objective: What are the predominant themes noted when CCNs share their experiences of common obstacles, relating to families in providing EOL care?

Methods: A random geographically dispersed sample of 2,000 members of the American Association of Critical-Care Nurses was surveyed. Responses from a qualitative question on the questionnaire were analyzed.

Results: Sixty-seven EOL obstacle experiences surrounding issues with families' behavior were analyzed for this study. Experiences were categorized into 8 themes. Top three common obstacle experiences included families in denial, families going against patient wishes and advance directives, and families directing care which negatively impacted patients.

Conclusions: In overcoming EOL obstacles, it may be beneficial to have proactive family meetings to align treatment goals and to involve palliative care earlier in the ICU stay.

Keywords: obstacles, intensive care units, end-of-life, nurses

ACKNOWLEDGEMENTS

I am thrilled to be submitting this thesis, but I could not have done it without the help and guidance of Dr. Renea Beckstrand as well as Dr. Janelle Macintosh and Dr. Beth Luthy. I am especially grateful for all the hours that Renea has put in to help complete this paper. Her experience in caring for patients in the ICU and her expertise in research and writing has been unmatched while completing this thesis.

End-of-life care is something that I have had the opportunity to be part of many times over the last 5 years that I have spent as a bedside nurse in the ICU. I have had patients both young and old who have made an impression on me as I have cared for them during the last days or hours of their lives. I am grateful for the opportunity to care for patients and their families. This thesis has inspired me to be a better nurse, especially during end-of-life moments.

This program for Family Nurse Practitioner and completion of this thesis would not have been possible were it not for my supportive husband Mitch. He has always been there to cheer me on. He is my rock. I also have to say how grateful I am that my parents showed me through example how important hard work and a good education are. Thank you and love to you all!

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Critical Care Nurses' Experiences of Family Behaviors as Obstacles in End-of-Life Care

Critical care nurses (CCNs) are essential in providing end-of-life (EOL) care for critically-ill patients. CCNs are torn between providing aggressive medical care, with the aim to save a patient's life, and providing EOL care for patients who are dying. Providing both curative and EOL care simultaneously is challenging, and CCNs face obstacles working in intensive care units (ICUs) as they attempt to provide quality EOL care.¹

In the United States, approximately one in every five patient deaths occur in ICUs.² Death is an inevitable part of life, yet in ICUs, nurses have unique roles in trying to provide good deaths for patients. Characteristics of a patient receiving a good death, focuses on maintaining the dying patients' dignity and comfort as well as providing support for families.¹

Background

Research focusing on obstacles CCNs face while trying to provide quality EOL care has been published. Such research is important because understanding CCNs perceptions regarding EOL care obstacles may provide additional insight and improvement in care.

Obstacles

In 2000, a study was published on CCNs perceptions of EOL care obstacles.³ This nationally random sample included 300 members of the American Association of Critical-Care Nurses (AACN) who had at least 2 years of critical care experience. Researchers found that the most frequently identified EOL obstacles were those dealing with the patients' family or physician behaviors. Largest perceived obstacles included family behaviors that removed nurses from caring for patients, families not understanding treatment or terminology, and families not accepting a poor prognosis. Additional obstacles included families requesting life-saving

measures despite patients' wishes on advanced directives, nurses dealing with angry family members or family members fighting each other about the use of life support, and physicians who were overly optimistic about patient survival.³

A follow-up study adding frequency of occurrence data, published in 2005, surveyed a larger nationally acquired random sample of 1500 CCNs.⁴ Five of the top ten obstacles with highest magnitude scores (obstacle size mean multiplied by obstacle frequency of occurrence mean) were specific to family behaviors. These family behavior obstacles included families continually calling the nurse for updates, families not understanding "life-saving" terminology, families not accepting poor patient prognoses, and nurses dealing with either angry or distraught family members. Top ten obstacles not related to family behaviors were physician behaviors disregarding patient family wishes for care, physician evasiveness of families, and physicians who continue with futile care.⁴

Additional research has been completed since the pilot study in 2000.³ A replication EOL study³ used a sample of 180 CCNs in a Midwestern urban trauma center.⁵ Obstacles identified proved similar to previous studies in that family obstacles ranked highest.⁵ Other researchers investigated EOL care obstacles by surveying nurses, physicians, residents, and medical students in two hospitals in New York and Rhode Island.⁶ Relating to family behavior in EOL care, the top noted obstacles were disagreements between families, patients, and ICU staff; unrealistic expectations about prognosis and treatments; dealing with cultural beliefs about death and dying; and continuing forward with life-sustaining treatments due to religious reasons.⁶

Family EOL obstacle data has also been obtained outside the United States. A 2013 article replicated Beckstrand and Kirchhoff⁴ study by surveying 472 critical care nurses in Spain.⁷ Common family obstacles to providing EOL care included families not accepting patient

poor prognosis, families requesting life-saving measures against patient wishes, and families threatening legal action if care was not continued.⁷

In summary, researchers studying CCNs perceptions of EOL care obstacles consistently show that obstacles exist as nurses strive to provide quality EOL care for patients. Obstacles decrease the quality of EOL care provided to dying patients and their families.

Purpose

CCNs have important roles in providing quality EOL care; therefore, investigating which obstacles impede care of dying patients is important. The purpose of this study was to analyze CCN obstacle experiences in providing EOL care. By analyzing EOL obstacles through CCNs' experiences, more compassionate and meaningful care may be provided to dying patients and their families.

Research Question

What are the predominant themes noted when CCNs share their experiences of common obstacles in providing EOL care to patients and families?

Methods

Design and Sample

A cross-sectional mailed survey design was used for this study. Of the 104,000 total members of AACN, 2,000 randomly selected participants were used. Participants were members of AACN, had cared for at least one patient at the EOL, and read English.

Instrument

Participants were mailed a questionnaire titled the, “*National Survey of Critical Care Nurses' Perception of End-of-life Care.*”⁵ The questionnaire had 72 items including 54 Likert-type questions, 14 demographic questions, and 4 open-ended questions. Quantitative data for

comparative obstacle size over 17 years⁸ and qualitative data looking at CCN's suggestions for improvement of EOL care were previously published.⁹ One open-ended item asked for participants to, "Please share an experience you have had caring for a dying patient that typifies the obstacles ICU nurses see in end-of-life care." Participants' responses to this one item were analyzed for this report.

Procedure

After obtaining IRB approval, a national random sample of members of AACN were mailed a survey packet. Included in the packet were a cover letter explaining the study, the questionnaire, and a self-addressed stamped return envelope. A post card reminding participants to complete and return the questionnaire was mailed three months after the initial mailing to all non-responders. A second mailing was then completed six weeks after the post card to the remaining non-responders. Return of the questionnaire was considered consent to participate.

Data Analysis

Of the 604 questionnaires returned, 95 were eliminated from the study because participants reported being ineligible ($n=65$) or questionnaires could not be delivered ($n=30$) leaving 509 useable returned questionnaires. Of the 509 useable responses, 171 nurses provided an EOL care obstacle experience. Responses were initially reviewed to determine if the data fit criteria to be considered an experience. For this study, an experience was defined as a sequence of events described in chronological order. Responses not meeting criteria were generally noted to be brief suggestions or lists where specific details regarding EOL care obstacles were missing and thus were not analyzed. A similar report of nurses' experiences highlighting EOL obstacles was recently published using rural emergency nurses as participants.¹⁰

Experiences were analyzed and coded for content themes by an experienced EOL care researcher, a qualitative research expert, a content expert, and a graduate nursing student who works as a CCN in a neuro-shock trauma unit.

Results

Of 171 nurses who responded to this open-ended item, 64 participants provided 67 unique family obstacle experiences. Due to vast amount of returned data, other reported experiences reflecting issues with physicians, nurses, and environmental factors were not analyzed with this data set and will be reported in the future.

Demographics

Data from 64 participants were included in this analysis. Reported sex for participants was females ($n=57$; 89.1%). Age ranged from 26 to 67 years ($M=45.7$; $SD=11.2$). Average years of experience as an RN or ICU CCN was 17.4 ($SD=11.4$) and 14.8 ($SD= 10.5$) years respectively. Most nurses $n=50$ (78.1%) had cared for more than 30 dying patients (see Table 1).

Identified Themes

Multiple emerging themes on families as obstacles in EOL care were evident (see Table 2). The most common themes included family not accepting the patients' poor prognosis and being in denial, family disregarding patient wishes, and family directing and delaying care which negatively affected patients. Other noted themes included unacceptable family behavior, family legal matters, family avoiding patient or medical staff, family lack of EOL education, and family prolonging patients' lives' due to financial gain.

Family not accepting prognosis and being in denial. The most prominent theme was families not accepting poor prognoses of patients ($n=28$). In many instances nurses shared that one or more family members were in denial or unrealistic about the severity of their loved one's

prognosis. One nurse stated, “*The family couldn’t accept that this time was different [than previous admissions], and were unable [in denial] to recognize futility. The patient was barely kept alive for almost a week past when staff knew it was the end.*” Many nurses expressed similar sentiments such as, “*Families don’t accept the reality of death,*” “*Families are unrealistic [in expectation] of care and therapies,*” and, “*Families still insist on medical treatment although the treatment is futile.*” In a tragic case that powerfully described family denial a nurse shared:

“I admitted a young woman who had end stage multiple sclerosis. She had been discharged on home hospice from an outside hospital two days earlier. At home, her gastrostomy tube fell out. Her mom didn’t understand why the hospice nurse didn’t replace it so [mom] called 911 and came in through our emergency department.

The patient had severe contractures, was tracheostomy/ventilator dependent, and had multiple stage IV pressure injuries of the pelvis; all necrotic. I had moral distress caring for this young woman. The care I provided caused her physical pain, her mother didn’t understand that she wouldn’t get better, and insisted on surgical debridement of the pressure ulcers and reinsertion of the feeding tube. Caring for this patient made my heart ache for her.”

Advance directives or patient wishes not followed. Patient advance directives refusing intubation or resuscitation were described as being overturned by family members’ wishes ($n=13$). Some nurses described patients’ wishes for EOL care and then how those wishes were overturned by family. A nurse commented, “*I frequently find patients’ advance directives are not honored. They may have a Provider Order for Life-Sustaining Treatment form [POLST] requesting no Advance Life support and still end up ventilated in the ICU – families frequently over-ride [patient] wishes.*” Another nurse shared this poignant experience:

“A retired nurse had a do-not-resuscitate order in place long before she ever became ill, and she knew exactly what she did not want done to her. She came to my unit after a difficult surgery for metastatic cancer. Once her ET tube was removed, she specifically stated, ‘no more.’ She was perfectly within her right mind and knew exactly what her prognosis was.

A few days later, she was diagnosed with necrotizing pancreatitis. Her insides were slowly falling apart. Within a week she was infected and intubated again. She coded during the day, and once she was unresponsive, her family demanded the staff ‘do everything’ to save her. [The family] had overridden her wishes, because they weren’t ready for her to die.

We tried to control her pain; bathed her every few hours because her skin had begun to swell and split everywhere. She was miserable and I could see in her eyes that she knew it wasn’t our fault; she knew what her family had done. When her daughter came back to visit one night, [the patient] wouldn’t look her in the eyes.

This patient stands out to me because she was an ICU nurse herself...so she knew what her family had done and understood why she was still alive. But most patients don’t.

When they wake up with a tube in their throat, they become angry at the nurses and the doctors because they believe we have betrayed them. And in a sense, we have. If there was a way to prevent family members from overriding the patient’s wishes, and allowing them to die with dignity, and in peace, that would be the best gift we could give them.”

Family directing care. Families directing care which lead to negative patient consequences was another theme ($n=7$). Experiences vacillated from families delaying making decisions which made the patient suffer needlessly to families dictating when or how much pain

medication should be given. An example of family directing and delaying EOL care was expressed by one CCN, *“We had a patient that went to [the] operating room and was found to have dead bowel from stomach to rectum – closed up – inoperable. Family wanted [to wait] five days before putting her on comfort care. Very unfair for patient to suffer.”*

In two similar experiences, nurses shared times when families directing delivery of pain medication resulted in increased suffering for the patient. One nurse commented, *“His family wouldn’t let us give him pain medications, even when he appeared to be in pain, because they wanted him to ‘wake up.’”* A second nurse said, *“I was giving pain medication based on what family wanted, not what I thought patient was comfortable with.”*

Family member’s inappropriate behavior. Critical care nurses found that inappropriate family behavior was an obstacle in providing EOL care ($n=6$). Various behaviors ranged from hostile and threatening to bullying. For example, a nurse reported her experience with one wife who, *“...threatened lawsuits daily, kept records, photos, recordings, and created an abusive environment towards staff that was allowed to continue [unchecked].”* As a result of this experience, the nurse described suffering from compassion fatigue and even nightmares.

In another example, a nurse described the experience of a patient with peritonitis from peritoneal dialysis who coded just as the run of hemodialysis began. Return of spontaneous circulation was achieved and the patient was transferred to ICU where he coded again. After several more rounds of cardiopulmonary resuscitation (CPR), 3-4 vasoactive IV medications, and CRRT for 60 days, he coded a last time. Heroic life-saving measures, including CPR for an hour, were completed at the family’s demand. The nurse concluded the experience by saying, *“Then, a physician finally ‘called it’ [and the patient died]. At this point we were called ‘murderers,’ [by the family].”*

Family legal matters. Another theme focused on the legal aspects of EOL care that involved family members being legally designated as next of kin to make decisions or having a legal family member present to make decisions ($n=5$). One nurse's comment related to legal obstacles with family was, "*A dying patient. . . had no clear next of kin. We were unable to verify that the adult adopted son was the legal next of kin.*" Another nurse described a dilemma when the closest support person, the patient's long-time significant other, was not allowed to be involved in care decisions because they, "*were not the legal next of kin.*"

Another nurse expressed frustrations on not having family present or willing to make legal medical decisions: "*There was no family who wanted to make the decisions for this person's care and a court ordered surrogate was appointed. It was frustrating to have this patient be on our unit for so long and eventually die alone, while receiving invasive therapies such as dialysis.*"

Families who avoid. Nurses reported that an obstacle in EOL care was family avoiding the patient or medical staff ($n=3$). One nurse reported that a family wouldn't come to the hospital or would come at 2:00 a.m. to avoid doctors. Another family was also reported as refusing to meet with medical staff and therefore spent very little time at the bedside with their family member. In an extreme case, one nurse stated:

"I cared for a patient that was dying and waiting to go to hospice. The family kept delaying coming to the hospital, she remained on vasopressors for five days and spent those days basically alone other than the time the doctors and nurses spent with her. It was so sad, when we finally got to the bottom of the situation the family said they did not have the money to bury her."

Family not educated on EOL. Family not understanding health concepts relating to EOL or having basic health literacy was a family related obstacle noted by CCNs ($n=3$). One nurse described it as, “*The biggest obstacle I see is having the families understand survival rate verses functional outcome.*” Another nurse also stated that level of understanding was a major obstacle. “*The major obstacle is the health literacy skills of the family members understanding disease process and end-of-life care.*”

Family financial gains. Family members who had financial gain by keeping family members alive was noted to be an obstacle ($n=2$). This obstacle was clearly stated by a CCN who reported the following experiences with families.

“[One family] wanted to continue treatment for selfish reasons . . . in some cases they are getting welfare checks and know the money will stop once the patient has passed. We’ve had some families go to get attorneys to try and keep patients alive or [obtain a] durable power of attorney status to try and keep them alive. Not only is it hurting patients but it is making them suffer longer.”

In this last experience the family used legal means to keep the patient alive for welfare checks. In another reported experience, the family also prolonged death for financial gain.

“*Many times, they keep the patient alive longer because the patient receives money from the government. Families tend to visit but once the critical care team approaches them about a do-not-resuscitate status, they disappear.*”

Discussion

Critical care nurses play a vital role in EOL care for many patients. Part of that role includes caring for and involving the family. Consequently, barriers arise for nurses whose roles are both caregiver and advocate. The cumulative experiences shared in this study highlight

barriers, specifically related to family behaviors, that CCNs face when trying to provide quality EOL care. Family obstacle themes included family being unrealistic about poor prognosis, family not following the patient wishes, and family directing care. Each theme negatively impacted the patient in EOL care which led to increased suffering or care that was against the patient's wishes. Other family behavior obstacle themes included bad behavior, legal matters, family avoiding patient or staff, family misunderstanding, and family benefiting financially by keeping patient alive.

Family not Accepting Prognosis and Being in Denial

Families in denial of prognosis or having unrealistic expectations about EOL care can be a challenge for CCNs. The obstacle of denial in EOL situations has been discussed in scholarly literature and has been categorized either as a conscious choice or as an unconscious coping mechanism.¹¹ A literature review of 30 articles found that conscious denial by families may arise when families feels threatened by another family member dying. Conscious denial may also be defined as refusal of acceptance of death which may explain why it was such a prominent obstacle in ICUs.¹¹ In contrast, family denial as an unconscious coping mechanism is also reported in scholarly literature.¹¹ In a scholarly literature review of denial in EOL settings, researchers found that both conscious and unconscious denial may be present, or, one or the other may play a part in a family's denial in EOL care situations.¹¹ Regardless of the type of denial exhibited by family members, CCNs should come to expect that many family interactions involving a critically-ill family member, will include denial as a common coping mechanism.

Advance Directives or Patient Wishes not Followed

Not honoring patient wishes or patient advance directives is also a common obstacle in EOL care and was a prominent theme in our study. Previous research has reported family going

against patient wishes as a major obstacle.^{5,7} Our research found nurses experience this obstacle frequently with the results of negative impact for dying patients. Nurses supporting patient wishes in EOL care, and acting as patient advocate, is an important aspect in maintaining the dignity of patients in their final days.

Family Directing Care and Family Conflict

Family involvement in EOL care has the potential to negatively impact the patient by prolonging suffering. CCNs reported that families may make decisions extending life that negatively impact patients by prolonging or increasing suffering. Previous qualitative researchers interviewed 406 nurses and physicians and found prolonging life-sustaining treatment was a significant source of conflict between different family members and between family and staff members.¹² In addition to family members making decisions on prolonging life-support or not, research focusing on whether conflict was present or not found there was conflict involving decision making of EOL pain management and interpersonal family dynamic conflict similar to our research.¹²

Other Obstacles

Three identified obstacles center around lack of family participation, lack of legal representation, or lack of knowledge. Understandably, participation in EOL care decision making, as family members, is difficult and emotionally taxing. Family members may be further hindered in their ability or desire to appropriately participate in EOL care decision making if they have not previously had experience in this role or had previous discussions about patient EOL care wishes.¹³ Further compounding difficulties with decision making are family member's diminished understanding of medical terminology and prognoses. Adequate health literacy, or, the ability for families to receive health information or services and be capable to process

information to make health decisions has been identified as lacking in up to one third of Americans.¹⁴ Providing handouts, posters, or informational packets to families in crisis explaining terminology and defining technology may be helpful.

Limitations

Only members of AACN were included in this study. Therefore, results may not be generalizable or fully represent the obstacles perceived by all critical care nurses nationwide. The response rate of 26.7% may also contribute to limited representation of CCN views. Additionally, stories shared may represent the most memorable obstacle in EOL care, not necessarily the most common obstacle in providing EOL care. Finally, when the remaining reported experiences, not related to family behaviors, are analyzed additional information regarding relative impact of families as obstacles may be more clearly demarcated.

Recommendations

Understanding family related obstacles through CCNs experiences is important when trying to improve ways of providing good EOL care. One way to effectively address family obstacles is improving the communication between patients, families, and staff. Effective and caring communication is a valuable bridge between family, patients, and health care providers when navigating difficult EOL care decisions. One simple tool that ICUs may use to improve communication between families and providers is a structured family conference. Proactive and structured family conferences have been studied as a help in improving communication between providers and families by enabling all to be on the same page.¹⁵

In addition to stronger communication with patients and family, involving palliative care may be useful in overcoming obstacles in EOL care.¹⁶ Palliative care that is collaborative with

the patient, family, and ICU team may help improve EOL by focusing on patient and family decision making, open communication, and symptom management.¹⁶

Conclusion

Providing EOL care can be challenging for CCNs due to obstacles that arise. Family behavior obstacles have been identified as a common obstacle in EOL care. Examining experiences of CCNs has given further insight to these family related obstacles. In particular, families in denial, with unrealistic ideas about prognosis, was an over-arching theme. In order to provide better EOL care it may be beneficial to have proactive family meetings to clarify realistic prognoses, align treatment goals, and to potentially involve palliative care treatments earlier in the ICU stay. Additionally, working toward better health literacy through informational pamphlets or posters in ICUs may help improve understanding at the very moment of crisis for family members.

References

1. Attia A, Abd-Elaziz W, Kandeel N. Critical care nurses' perception of barriers and supportive behaviors in end-of-life care. *American Journal of Hospice & Palliative Medicine*. 2012;30(3):297-304.
2. Angus D, Barnato A, Linde-Zwirble W, et al. Use of intensive care at the end of life in the united states: An epidemiologic study. *Critical Care Medicine*. 2004;32(3):638-643.
3. Kirchhoff K, Beckstrand R. Critical care nurses' perceptions of obstacles and helpful behaviors in providing end-of-life care to dying patients. *American Journal of Critical Care*. 2000;9(2):96-105.
4. Beckstrand R, Kirchhoff K. Providing end-of-life care to patients: critical care nurses' perceived obstacles and supportive behaviors. *American Journal of Critical Care*. 2005;14(5):395-403.
5. Crump S, Schaffer M, Schulte E. Critical care nurses' perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care. *Dimensions of Critical Care Nursing*. 2010;29(6):297-306.
6. FriedenberG M, Levy M, Ross S, Evans L. Barriers to end-of-life care in the intensive care unit: Perceptions vary by level of training, discipline, and institution. *Journal of Palliative Medicine*. 2012;15(4):404-411.
7. Losa Iglesias ME, Pascual C, Becerro de Bengoa Vallejo R. Obstacles and helpful behaviors in providing end-of-life care to dying patients in intensive care units. *Dimensions of Critical Care Nursing*. 2013;32(2):106-108.

8. Beckstrand R, Lamoreaux N, Luthy KE, Macintosh J. Critical care nurses' perceptions of end-of-life care obstacles: Comparative 17-year data. *Dimensions of Critical Care Nursing*. 2017;36(2):94-105.
9. Beckstrand R, Hadley KH, Luthy KE, Macintosh JLB. Critical-care nurses' suggestions to improve end-of-life care obstacles: Minimal change over 17 years. *Dimensions of Critical Care Nursing*. 2017;36(4):264-270. doi:10.1097/DCC.0000000000000252
10. Beckstrand R, Rohwer J, Luthy KE, Macintosh J, Rasmussen R. Rural emergency nurses' end-of-life care obstacle experiences: Stories from the last frontier. *Journal of Emergency Nursing*. 2015;43(1):40-48.
11. Zimmermann C. Denial of impending death: A discourse analysis of the palliative care literature. *Social Science & Medicine*. 2004;59(8):1769-1780.
12. Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of General Internal Medicine*. 2001;16(5):283-9.
13. Majesko A, Hong SY, Weissfeld L, White DB. Identifying family members who may struggle in the role of surrogate decision maker. *Critical Care Medicine*. 2012;40(8):2281-2286.
14. Riley JB, Cloonan P, Norton C. Low health literacy: a challenge to critical care. *Critical Care Nursing Quarterly*. 2006;29(2):174-178.
15. Fineberg I, Kawashima M, Asch S. Communication with families facing life-threatening illness: A research-based model for family conferences. *Journal of Palliative Medicine*. 2011;14(4):421-427.
16. Nelson J. Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit. *Critical Care Medicine*. 2006;34(11):324-331.

Table 1
Demographics of CCNs Responding to Open-ended Question on Obstacle Experiences ($n = 64$)

Characteristics			
Sex	<u><i>n</i></u> (<u><i>%</i></u>)		
Female	57 (89.1%)		
Male	7 (10.9%)		
	<u><i>M</i></u>	<u><i>SD</i></u>	<u>Range</u>
Age	45.7	11.2	26-67
Years as RN	17.4	11.4	1.5-40
Years in ICU	14.8	10.5	1.5-40
Years as CCRN	7.3	6.5	0.5-26
Hours worked per week	35.2	6.3	12-50
Number of unit beds	20.4	9.1	7-42
CCRN Certification			
<u>Ever certified</u>			
Yes	57 (90.5%)		
No	6 (9.5%)		
Missing	1 (1.6)		
<u>Currently certified</u>			
Yes	46 (90.2%)		
No	5 (9.8%)		
Dying patients cared for:	<u><i>n</i></u>	<u><i>%</i></u>	
>30	50	78.1	
21-30	5	7.8	
11-20	6	9.4	
5-10	1	1.6	
<5	2	3.1	
Highest degree:	<u><i>n</i></u>	<u><i>%</i></u>	
Associate	9	14.1	
Bachelor	43	67.2	
Master	8	12.5	
Doctoral	1	1.6	
Position held at facility:	<u><i>n</i></u>	<u><i>%</i></u>	
Direct care/bedside nurse	33	51.6	
Charge/staff nurse	25	39.1	
Manager/Educator	3	4.7	
Other	3	4.7	
Type of Facility	<u><i>n</i></u>	<u><i>%</i></u>	
Community hospital; non-profit	43	68.3	
University Medical Center	13	20.6	
Community hospital; profit	3	4.8	
County hospital	2	3.2	
State hospital	1	1.6	
Military hospital	1	1.6	

Table 2

Family Obstacle Themes

1. Families in denial of patient prognosis; families have unrealistic expectations regarding patient prognosis (n=28).
2. Families go against patient wishes; families overturn patient advance directives (n=13).
3. Families directing aspects of care which impacts patient negatively (n=7).
4. Families on bad behavior; family interpersonal conflict interferes with EOL care; family bullies medical staff (n=6).
5. Legal matters involving EOL decisions; significant other not allowed to participate in EOL care decisions; no family available, willing, or designated to make EOL care decisions (n=5).
6. Family avoids patient or medical staff (n=3).
7. Family not educated or fully understanding of patient condition which impacts EOL (n=3).
8. Family has financial gains by keeping patient alive (n=2).