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Physician Behaviors, Nursing, and Other Obstacles in End-of-Life Care:
Additional Critical Care Nurse Perceptions

Elizabeth Elouise Willmore

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

Physician Behaviors, Nursing, and Other Obstacles in End-of-Life Care: Additional Critical Care Nurse Perceptions

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Master of Science

Background: Critical Care Nurses (CCNs) frequently provide end of life (EOL) care in intensive care units (ICUs). Barriers to EOL care in ICUs exist and have been previously published, but qualitative reports from CCNs themselves remain scarce. Qualitative data exploring barriers faced during ICU EOL care may increase awareness of obstacles and help remove them.

Objective: Excluding family experiences, what are the major themes recounted by CCNs when asked to share common obstacles experienced in providing ICU EOL care?

Methods: Members of the American Association of Critical-Care Nurses were randomly surveyed and responses to a single qualitative question were used.

Results: There were 104 participants who provided 146 responses reflecting EOL obstacles which were divided into 11 themes; 6 physician- related obstacles and 5 nursing-and-other related obstacles. Top three EOL ICU barrier themes were inadequate physician communication, physicians giving false hope and nursing-related obstacles.

Conclusion: Poor physician communication is the main obstacle noted by CCNs during ICU EOL care followed by physicians giving false hope. Heavy patient workloads were also a major barrier in CCNs providing EOL care.

Keywords: end of life, dying, ICU, intensive care, critical care, obstacles, physician, nursing, environment

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My first and only nursing job has been in the Medical Intensive Care Unit at the University of Utah Hospital. I have been involved in EOL care for many of my patients and have found some of my most fulfilling moments in helping someone pass away in comfort, surrounded by family. In contrast, I have been distressed by futile care given to terminal patients who eventually died during the chaos of a code. Dying is something we all must go through and I believe it is important that people die with as much control as possible. EOL care in ICUs is complicated, but I believe we can do better than we are currently doing.

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Physician Behaviors, Nursing, and Other Obstacles in End-of-Life Care:

Additional Critical Care Nurse Perceptions

The intensive care unit (ICU) is designed to extend life and cure disease, yet 10-29% of critical care patients will not survive to ICU discharge.¹ Given this high mortality rate, end-of-life (EOL) care in ICUs is common and is primarily performed by critical care nurses (CCNs). CCNs spend the most time with patients, are often the first to recognize futile medical treatment,² and hold a prime position to observe obstacles to ICU EOL care. CCNs' perspectives on quality of death in ICUs are reliable³ and should be used when evaluating all aspects of patient deaths in ICUs.

Background

Previous research has detailed obstacles CCNs face when providing EOL care in ICUs.⁴
¹² Understanding and removing EOL obstacles can help improve the dying experience in inevitable patient deaths.

Obstacles

CCNs face many obstacles while providing EOL care in ICUs including problems with both family and physician behaviors.^{4,5,7,12} In 2000, 199 CCNs rated top family-related obstacles as excessive phone calls for patient updates, not understanding what the phrase "life support" means, and families not accepting patients' poor prognoses.¹² These CCNs suggested adding physician-related obstacle items. In a follow-up research paper completed in 2005, researchers reported 864 CCNs rated different physician behaviors as three of the top-ten obstacles in ICU EOL care.⁷ Obstacles included physicians having different opinions regarding direction of patient care, evading families, and not letting patients die from their disease.⁷

In addition to physician-related obstacles, CCNs have also reported heavy workloads and environmental privacy issues as barriers to EOL care.⁶ Caring for a dying patient can be time consuming and involves CCNs preparing for terminal removal of life support while managing patient and family distress during the dying process. Additionally, terminal withdrawal when caring for patients and families limits time nurses are available to help other patients.^{6,13} Poor unit design, which limits privacy at the EOL, has been shown as another obstacle to dying in ICUs.^{6,14}

Another obstacle faced while transitioning ICU patients to EOL care are the complex and uncertain processes of dying in ICUs. Many critically-ill patients' prognoses are uncertain and even physicians cannot reliably predict chances of survival.¹⁵ Such uncertainty about the time to death along with some societal trends to deny death leads to continuing ICU interventions,^{16,17} sacrifices in quality of life,¹⁶ and delays transitioning to EOL care.¹⁸

In summary, family and physician behaviors, heavy CCN's workloads, poor unit design, and the uncertain processes of dying in ICUs are among obstacles CCNs face in providing EOL care. What is unknown at this time is the extent of non-family related obstacles in EOL care as qualitatively reported by CCNs.

Purpose

The purpose of this study was to explore additional, non-family-specific obstacles as reported by CCNs. CCNs are care-providers who routinely observe barriers to EOL care and publishing their experiences may help remove these obstacles.

Research Question

Besides family-related issues, what themes are noted when CCNs report personal experiences of obstacles in providing ICU EOL care?

Methods

Sample and Design

Participants were members of the American Association of Critical Care Nurses (AACN). From a pool of 104,000 members of AACN, 2,000 were randomly selected and mailed a questionnaire. Criteria for inclusion included members of AACN who read and understood English and cared for at least one ICU patient at the end of life. Participants who reported feeling unqualified to participate or who did not meet the requirements were excluded.

Instruments

In 2005 Beckstrand et al. reported results from data collected through a questionnaire titled, *National Survey of Critical Care Nurses' Regarding End-of-Life Care*.⁷ The questionnaire contained 72 items: 29 items for rating obstacles and 24 items for rating supportive or helpful behaviors. Additionally, there were 4 open-ended items and 15 demographic questions.

In this original questionnaire there were instances of data returned with stories written in the margins detailing extreme EOL experiences CCNs had witnessed in ICUs. Because of these additional stories an item, not present on the original questionnaire, was added to the version used in this replication study. The new open-ended item asked 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.*" After data were returned, responses related only to family issues were analyzed and a paper reporting those specific obstacle stories was published.⁴ This paper serves to present results from the remaining non-family related data.

Procedure

Data gathering for this study proceeded after obtaining approval from the Human Subjects Committee at Brigham Young University. A national random sample of AACN

members were mailed a survey packet which included a cover letter introducing the survey and the questionnaire with a self-addressed, stamped return envelope. If no response was received after two months a postcard was sent to remind participants to complete the survey. Six weeks after the reminder postcard, another questionnaire packet was sent to all non-responders. Consent to participate was assumed upon return of the questionnaire.

Data Analysis

From 2,000 original questionnaires sent, 604 were returned, 65 were eliminated due to CCNs feeling ineligible and 30 questionnaires could not be delivered. Of the 509 usable questionnaires there were 171 questionnaires returned with CCNs reporting EOL obstacles, which were coded for content themes in 2018. A previous study used CCN's survey results to report on family-specific obstacles and EOL in ICUs;⁴ however, due to the high volume of responses there remained unreported data.

Of the 171 nurses who reported EOL obstacles, 64 participants provided 67 unique experiences related specifically to family obstacles which was previously reported.⁴ Of the remaining 107 respondent comments, three were removed due to the inability to decipher hand writing and five were removed as they related "good" end of life experiences instead of obstacles, leaving 99 participants who provided 146 responses reflecting additional EOL obstacles unrelated to families. Obstacles related to several aspects of physician behavior was the largest (n = 93) while the remaining responses (n = 53) reflected obstacles with nursing, environmental and other issues.

Results

Demographics

Data from 104 participants for this qualitative analysis showed most were female ($n = 95$ [90.5%]) with a few reporting being male ($n = 9$ [8.6%]). Age ranged from 24 to 65 years ($M = 46.5$ years [$SD, 11.84$]). Average RN experience was 19.9 years [$SD, 11.9$] with ICU experience averaging 16.6 years [$SD, 10.6$]. Most nurses ($n = 66$ [63.5%]) had cared for more than 30 dying patients (see Table 1).

Obstacle Themes

Eleven EOL obstacle themes were identified (see Table 2). Six themes related directly to physician behavior including obstacles surrounding inadequate physician communication ($n = 32$), giving false hope to families ($n = 31$), providing futile care ($n = 15$), physicians not agreeing about direction of care ($n = 6$), physicians with seemingly ulterior motives for extending care at the EOL ($n = 5$), and physicians not ordering adequate pain medication ($n = 4$).

Five other EOL obstacle themes were identified including nursing-related obstacles ($n = 26$), obstacles with transferring dying patients out of ICU ($n = 8$), environmental obstacles ($n = 5$), ethical obstacles ($n = 4$), and other miscellaneous EOL obstacles ($n = 10$). There were also five participants who reported “good” EOL stories which were not example of EOL obstacles and therefore excluded.

Physician Behaviors

Physician Behavior – Inadequate Physician Communication

Inadequate physician communication was the largest obstacle topic ($n = 32$) and included physicians failing to educate patients and families, being unwilling to communicate with and involve palliative care teams, having poor communication between treating physicians, having

EOL discussions too late, showing a lack of empathy when communicating with families, and failing to communicate with RNs.

Failing to Educate Patients and Families in a Timely Manner (n = 16). One nurse expressed her frustration with physicians' failing to educate patients and families by saying, *"Doctors don't know how to talk to families about the pain and suffering that goes along with "Do Everything!" [Physicians] are not able to get a DNR and they don't even think about it."* Another nurse stated, *"MD's not explaining well enough [about] trach for vent dependent patients, feeding tubes...much teaching needs to be done so people know what "life support" means."* Similarly, a nurse stated, *"Physicians underestimate the importance of having a conversation early in the patient's stay regarding code status. [Physicians] will ask a very ill patient if they want "everything done" not explaining what "everything" means."*

Two other nurses shared comments regarding physicians failing to communicate with patients and families. One said, *"Physicians rarely take the time to do a face-to-face chat with family, let alone give an overall progress report."* Another nurse reported her conversation with a family member who had just been informed the patient was dying. *"No one told us he could die from this. If they would have been honest with us and told us he was going to die, we would have gone home, had a barbeque, drank a beer, and let him die at home with his family."*

Physicians Unwilling to Communicate with and Involve Palliative Care (n = 5). The perception that physicians rarely consult, or consult too late, with palliative care team members was stated by a few nurses. One nurse reported, *"Palliative care is often consulted too late – after life-saving procedures have been performed and then families are faced with "removing" life support versus allowing a natural death [which] I [the nurse] find leads to more guilt on the family's behalf. Palliative care...is almost seen as a "social work" team [expected] to have these*

crucial [EOL] conversations with families” Another stated, “...there are a few MDs who refuse to get a palliative care [consult] until the very end which is a great injustice to the patient and family.”

Poor Communication between Treating Physicians (n = 5). Poor intra-physician communication was expressed by five nurses. One nurse summed up this obstacle by telling this story of a dying patient:

“[There was] a 48 year-old heroin addict who was hospitalized in septic shock from endocarditis. He had OHS for valve replacement but it was too late. He was in DIC, renal failure, [had] multiple pressors, blood, [and] blood products. He was blue & cold. His mother and sister were realistic and knew his wishes. They wanted to stop life support. All MDs were on board. Then the intensivist told the family not to give up. Now [the family] was torn about what to do...they dialyzed him, continued to give blood, blood products, more vasopressors for three days before they coded him and he died.”

Physicians Having EOL Discussions too Late (n = 4). One nurse remarked about the difficulty in having some physicians instigate difficult EOL conversations with families at night and rather push off those conversations for the day shift. Another nurse stated, “*[An] obstacle I have encountered is the timing of discussion with the family regarding EOL care. Sometimes the decision [to stop care] is made hours before the patient dies. [This is] definitely not enough time to help family members.*”

Physician’s Lack of Empathy When Communicating to Families (n = 1). One nurse told this story about a physician’s lack of empathy when communicating bad news to a family:

“A 20 year-old male patient who [had] bacterial meningitis was in ICU on a vent. ICU MD conducted first brain death study. Patient’s family was understandably distraught and

ICU MD was great with [family]. Next day, neurologist came in to perform second [brain death] test. He was so unsympathetic to the family and never addressed [or talked to] the patient's parents. He just ushered them out of the room without explanation and [then] when he saw the family [after the second test] he said, "He's gone." That was it. He was lacking any human emotion or sympathy. The parents were beside themselves with this awful news and heartbroken. I was left doing damage control and crying to the mother apologizing for the neurologist's lack of human kindness. It was the worst end-of-life situation I have experienced----and I have a lot of experience."

Physician Not Communicating Information to Nurse (n = 1). Another example of inadequate physician communication was shared by a nurse who was never told her dying patient was to go for an autopsy after death. This lack of communication by the physician regarding after-death care caused confusion and embarrassment to the nursing staff.

Physician Behavior – Giving False Hope

Physicians giving families false hope was the second largest obstacle theme (n = 31). A nurse reported physicians, "who side-step, beat around the bush, and give false hope were big obstacles to providing EOL care." As an example, one nurse reported,

"We had a patient who had massive cranial hemorrhage who had met clinical exam for brain death and nuclear medicine read scan as consistent with brain death so the neurosurgeon informed the family of findings. [The family] asked for a second opinion...and that neurologist looked at the same test and performed a clinical exam and told the family there was a "trace" amount or trickle of blood flow and this led the family holding false hope and extended the [patient's] stay for almost two additional weeks of

multiple codes, multiple pressors, until she progressed to brain death conclusive with brain angiogram. Because of the conflict, many nurses requested not to take care of her.”

Another nurse shared this story: “[I had a patient] admitted with CHF, with an ejection fraction of <10%, and severe aortic stenosis. Cardiologist told the family, "This is what's happening, but with these meds we can get him turned up, he can have a TAVR, and he'll be okay." Post multiple days of ICU stay the patient coded, CPR was initiated and continued >1.5 hours, then the patient died.” Similarly, this nurse reported,

“I recently had a surgical patient who had multiple abdominal surgeries and spent about 6 months in the hospital – in and out of the ICU. He had an open abdomen with multiple fistulas and needed nearly continuous dressing changes, he also was CRE [and], septic, in liver failure/kidney failure and on TPN for months. The surgeon told the patient he would be fine and everything was going well – totally unrealistic. After [the last] week [in ICU] the patient changed his code status to no intubation -- no compressions, he died in the ICU [after] a chemical code.”

Physician Behavior – Physicians Providing Futile Care

Futility at the EOL was the third most common theme expressed by nurses (n = 25). Nurses shared perceptions of physicians who cannot or do not know when to “let go” or who proceed with medical care long beyond reason causing needless pain and suffering to both patients and families. This example typifies most nurse perceptions of futile EOL care where a physician could not accept that the patient was dying:

“We had an elderly patient that had a valve replacement and never recovered. The patient had a history of severe COPD and could never be weaned from the ventilator. The patient was in poor health prior to surgery, despite all measures with medications, therapy,

nutrition, a trach/PEG—the patient did not progress. The patient’s skin began to slough, fingers/toes turned black, bed sores developed. We had all specialties on board with PT/OT, wound care, RT, dietary—and no measures seemed to help. The patient constantly grimaced in pain and was tense/stiff. The primary surgeon would not allow pain meds because it may “sedate” the patient. The patient suffered for 14 weeks before he finally died maxed on vasopressors. He was made a DNR 3 weeks prior to his death, but had coded at least 3 times prior to his death. The nurses felt like they were performing human torture. The MD would not accept the patient’s diagnosis.”

Physician Behavior – Physicians Not Agreeing About the Direction of Patient Care

Physicians caring for the same patient who do not agree about the direction of care (n = 6) was the fourth largest obstacle theme. Many responses echoed these nurses’ comments that, physicians are often not on “the same page” or physicians’ have “differing opinions” regarding care. Another nurse shared this experience with physicians who did not agree about care:

“The husband of a liver transplant patient who had been on our unit for more than 3 months, made the decision to withdraw care. He did that after speaking with an Intensivist that had never cared for his wife before. He asked [this new] MD, “Have you ever seen a patient survive that is as sick as my wife?” Honestly, the MD said “No, your wife has no chance of survival.” The primary transplant MD was advised of the husband’s wish to withdraw care & he rushed to our unit & argued with the husband for over ½ hour to get him to change his decision. The [transplant] MD said, “I am a Christian & believe that only GOD has the right to end a life.” We withdrew care later that day, but what should have been a peaceful end-of-life was tainted by the transplant doctor’s words and guilt passed onto a loving husband.”

Physician Behavior – Perceived Ulterior Motives

As a fifth theme, some of our participants ($n = 5$) reported feeling an obstacle to EOL care was when physicians seemingly needed to extend a patient's life to meet reporting guidelines or when EOL care was ignored because the physician was only paid for admitting and consulting on patients. Typical nurse reports were that physicians extended patients' life for, "...the 30 day outcome evaluation criteria [for surgeons]" or, "... extended life saving measures to meet the "goal" of days post-op" or, "...the patient was kept alive for either financial or statistical gain."

Physician Behavior – Not Ordering Enough Pain Medication

The final physician-behavior obstacle theme was the lack of orders for adequate pain medication ($n = 4$). One experience reported by a nurse was, "Recently a doc wrote EOL orders but the IVP Morphine and Ativan wasn't enough. I received more orders for IVP/PRN and a gtt [drip]. But it took too long to get the drip started. The meds should have been ordered earlier to provide better EOL care."

Nursing Obstacles

Nurse-related EOL obstacles. Nurse-related obstacles ($n = 26$) included a majority of responses regarding not having either enough time or poor staffing assignments that limited nurses' abilities to properly care for dying patients. Other nursing themes included the lack of EOL care knowledge, the emotional toll caring for dying patients had on nurses, and the lack of EOL resources.

Nursing – Not Enough Time/Poor Staffing Assignments

Overwhelmingly, nurses reported being unable to provide good EOL care due to the common staffing scenario where the dying patient is paired with an acutely-ill patient who requires significant time and care. One nurse typified this scenario by her story:

“I had a 26 year-old male w/mets who we were terminally extubating and another sick/busy ICU patient. The [dying] patient needed my undivided attention as he was fully cognizant of what was going to happen when we pulled his ETT. I knew my emotional, physical, and pharmacologic support was going to be very demanding and this patient needed as much attention as I could give him. With my patient load I decided I would chart when my shift was over so I would not be distracted or unable to give both my patients the time and care they needed. I wish all EOL care situations could meet criteria for a 1:1 patient...but many variables and limitation may contribute to ‘less than ideal’ situations (high patient acuity/ full census).”

Another nurse shared this story:

“While providing EOL care for one patient I have often had another patient that was very unstable. It is difficult to be in two places at once. Both patients deserve your attention. Saving someone's life is just as important as providing a peaceful and dignified environment during their EOL...[and sometimes there is] the perception by the family of possibly not being as important or even burdensome.”

Nursing – Lack of EOL Care Education

Participants reported that some nurses lack EOL education including not knowing how to care for a dying patient. One nurse stated, “Not being trained in EOL care I found myself feeling left out—didn’t know what to do.” Another responded that some ICU nurses avoid dying

patients once the comfort care decision is made due to lack of EOL education. Other reports consisted of nurses who are uncomfortable delivering comfort care orders for Morphine and Ativan in the fear of hastening death.

Nursing – Emotional Distress

Caring for dying patients can take a toll on nurses as noted in this report by one nurse who had recently experienced her own husband's death.

“Six weeks ago my own husband died. I was assigned to a young man who was dying and if he made it through that night was going to be sent to hospice. Glancing in the room I saw a grieving wife at the bedside and all my raw emotions came over me. My own husband died at a younger age and the patient in the bed was the same age as my husband. I pleaded with another nurse to switch assignments with me as I wasn't feeling emotional capable of providing this patient & his wife the care they needed. I was told to “get over it – it has been over a month – you need to move on.”

Nursing – Lack of Resources

One nurse reported the lack of resources, specifically during night shifts, was an obstacle to EOL care.

“Working nights means no support from Chaplin, Social Worker, and other staff and key players that would help support me, the patient and the patient's family. As a night shift RN I have to wear all the hats and take care of my other patients.”

Other Obstacle Themes

Transferring Dying Patients during the EOL

Nurses reported that a common occurrence in EOL care in ICUs was that once the dying patient was made comfort care, there was pressure to quickly transfer them to a different unit (*n*

= 8). A nurse recounted this experience, “Discontinued life support on a patient in ICU, had to inform family almost right away that I will need to transfer the patient out of the unit because we needed the bed for another patient. It just broke my heart to tell the emotionally shaken family that!” Another nurse shared her experience of a patient being transferred so close to death they actually died during the transfer.

“[My] patient was on a morphine drip but had been on our unit only a short time. The patient was more and more restless/agitated/tachycardia so I frequently increased the drip rate. We were forced to transfer her out suddenly and when we arrived with her on the receiving unit she had already died. Needless to say, receiving staff was extremely angry and upset.”

Environmental Obstacles

Unlimited visiting hours and lack of space for large numbers of visitors were seen as obstacles by some nurses ($n = 5$). One nurse stated, “Open visitation in an ICU is miserable. When the traffic is non-stop for the rest of the unit, it interferes with patient care as well as the family grieving process.” Another stated, “[It is] difficult to care for the patient at times with the many relatives who want to be in the room.”

Ethical Obstacles

The last reported obstacle related to nurses’ perceptions of ethical breeches ($n = 4$). Some nurses shared that ethics committees were either powerless to direct physicians or were involved too late in the process to help dying patients. One nurse shared this experience where the ethics board rebuked a physician.

“[A] former nurse had CABG but couldn’t wean off vent--stoked out. Had living will and specified “no feeding tube” but MD pressed daughter to trach & peg [patient]

(temporarily). The surgeon kept going on about how her “kidney numbers” were improving. Daughter wanted to honor mom’s wishes but felt like going against MD “advice” was “killing” her mom. [This was the] only case I ever saw go to ethics committee who agreed MD was wrong.”

Miscellaneous Obstacles

Unique EOL obstacle responses were received ($n = 10$). These obstacles items, not easily categorized into other themes, included the lack of advance directives or living wills, incorrect perceptions by families from TV shows that every illness can be fixed quickly, fear of legal reprisal, requests for more tort reform that would provide legal protection to health care providers, and working with physicians who’s personal beliefs do not allow for removal of life-extending care, such as ventilators, even at the EOL.

Discussion

While most physicians care for dying patients in the best way possible, issues with physician behaviors were the predominant obstacles reported by CCNs in ICU EOL care. Other obstacles reported in EOL care included nursing-related issues and other miscellaneous items.

Physician Behavior Themes

Inadequate Physician Communication

ICU physicians have limited time and may not be able to have lengthy discussions about the patient transitioning to comfort care when death is unavoidable.^{19,20} Code-status discussions with patients and families are challenging^{20,21} and researchers have reported providers may not recommend withholding cardiopulmonary resuscitation (CPR) even when those providers felt CPR would be unhelpful.²² Physicians who delay in ordering DNR code status or delay in having EOL discussions cause prolonged patient suffering and extend invasive ICU therapies. Delayed

EOL discussions, occurring just prior to inevitable patient deaths, can result from medical uncertainty,¹⁸ an ICU culture which places cure above quality of life,¹⁶ or is a result of living in a death-denying society.¹⁶ Including providers with expertise in palliative care in patient discussions can fill this communication gap at the EOL; however, barriers to seeking expert provider's consultations exist and include lack of care coordination, limited physician time, excessive paperwork, and a narrow knowledge of what palliative care providers do.²³

In addition to limited time as an obstacle leading to inadequate physician communication, the inclusion of multiple physicians for a single ICU patient is common.²⁴ Multiple physicians caring for the same patient generally try to reach consensus medical recommendations.²⁵ Although consensus is the goal, multiple physicians caring for one patient can lead to conflict²⁶ and cause patient and family distress. Insensitive communications by physicians when giving bad news can also increase patient distress and may originate from physicians having frequent difficult EOL discussions. These taxing meetings can overload normal emotional functions and cause physicians to flounder when initiating EOL talks.²⁷

Physician Giving False Hope and Physician-led Futile Care

One of the most difficult aspects of the ICU is knowing when to stop aggressive care and transition from curative to EOL care.²⁸ Failure to address EOL issues, lack of agreement within the treatment team,²⁹ pressure from referring physicians,³⁰ viewing death as a medical failure,³¹ legal pressures, lack of training in EOL discussions,²⁰ and financial incentives to continue futile treatment³¹ are possible reasons futile care frequently occurs in ICUs.^{29,32}

Additionally, physicians may give futile hope to dying patients because of prognostic uncertainty.³³ This uncertainty can cause physicians to fear that by stopping curative treatment

patient death was caused by a self-fulfilling prophecy instead of an incurable pathologic process.^{34,35}

Physicians Not Agreeing About Direction of Care

When making difficult decisions about patient care, disagreements can arise between treating physicians.^{25,36} Some specialists disregard the primary team and treat patients based on the physicians' specialty³⁶ and the involvement of multiple physicians can lead to fragmented care.^{16,31} Such disagreements causes discontinuity of care while creating confusion for patients and families.²⁵ CCNs have ranked physician agreement about direction of care as very helpful at the EOL.¹²

Physician Ulterior Motive for Extending Life

CCNs cited ulterior motives for extending patient's life as another obstacle in transitioning to EOL care in ICUs, a finding supported by a Canadian study where researchers found physician financial incentive as one of eight reasons for providing futile care.³¹ Additionally, increasingly popular pay-for performance programs can unintentionally create conflict between caring for the patient as a whole and complying with performance measures.³⁷ These performance measures can incentivize unnecessary care,³⁷ and may be a cause for CCNs perceptions of physicians using excessive treatments as a means to help patients meet quality measurement goals.

Physician not ordering Enough Pain Medications

Inadequate pain medications can cause unnecessary patient suffering during the dying processes. A study from the Netherlands found many physicians believe using increasing dosages of opioids and sedatives at EOL may hasten death and for this reason are reluctant to

prescribe these medications.³⁸ Despite the physicians' fears, the study concluded that appropriate use of these medications did not hasten death.³⁸

Nursing Related Barriers to EOL Care

CCNs Not Having Enough Time or Staff to Care for EOL Patients

Heavy CCN workloads has been previously reported as a significant barrier in providing EOL care.⁶ Providing for comfort and emotional needs of both patients and families at EOL can be complex, and CCNs may not have enough time to help dying patients when they are simultaneously trying to save the life of another critically-ill patient.⁷

Lack of CCN EOL Education and Resources

CCNs are trained in providing aggressive therapies which will sustain life but EOL education may be limited.^{6,28} Lack of training can leave CCNs unprepared to discuss death with patients and families. Poor training can also leave CCNs inadequately prepared to provide the patient with a comfortable and pain-free death.⁶

CCN Emotional Distress

CCNs experience higher levels of distress when providing futile care than do physicians.^{30,39,40} CCNs spend more time with patients and family than any other provider, and are more aware of patient suffering than physicians.³² When deciding on direction of care, consulting with CCNs may help ensure that the planned care matches patients' values, and could help decrease patient suffering and moral distress among nursing staff.

Other EOL Obstacles

Transfer Out of ICU at EOL and Environmental Obstacles

CCNs in this study cited transferring patients to lower levels of care during EOL as an extremely negative experience as patients died during or shortly after transfer. Environmental

issues were also specified by CCNs as obstacles in dying. Lack of privacy and cramped rooms hinder EOL care,¹⁴ while a peaceful and private setting promotes family and patient interaction,⁴¹ and improves quality of dying. ICU rooms specifically designed for grieving families facilitate good EOL care are extremely helpful to CCNs, patients, and families.⁶

Ethical Issues

Ethics committees exist in part to achieve resolutions when conflicts about EOL care arise and have been sanctioned by the American Medical Association for resolving such conflicts.⁴² Use of an ethics committee decreases ICU stay length without increasing mortality, and significantly helps to achieve consensus with goals of medical care.⁴³

Limitations

Results are generalizable only to members of AACN. Responses may represent the most drastic and memorable EOL experiences, therefore results may be skewed towards more extreme care, not necessarily most common EOL obstacles.

Recommendations

Improving physician communication between treatment teams, CCNs, patients and families is key to improving EOL care in ICUs. Communication should be educational, provide uniform medical recommendations, initiate EOL discussions sooner rather than later, and avoid giving false hope. Physician training specific to EOL discussions could help decrease physician discomfort, increase patient and family comprehension, and support deciding the correct direction in which to proceed with difficult EOL situations.

Even with training, physicians frequently do not have time to conduct adequate EOL conversations and involving palliative specialists earlier could be beneficial in time-limited situations as palliative care providers have both more time and training for such conversations.

Future research analyzing physicians' perceived barriers to ICU EOL care could yield additional insights into the subject of obstacles to EOL care in ICUs.

Pairing EOL patients with a lighter workload would allow CCNs more time to attend to the needs of dying patients and their families. Training CCNs on high quality EOL care could also be beneficial. Care guidelines and education for withdrawing life support have been created, and could help ensure CCNs promote high quality ICU deaths consistently.^{44,45}

Conclusion

Barriers to EOL care exist in the ICU. When accounting for family-related obstacles previously reported,⁴ inadequate physician communication represented the majority of obstacles in ICU EOL care as reported by CCNs. Nursing and other obstacles also contributed a significant portion of responses. Improving physician communication to patients, family, and medical staff could help remove EOL ICU obstacles. Removing obstacles to nursing care would also be beneficial.

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Table 1

Demographics of CCNs Responding to Open-ended Question on Obstacle Experiences (n=104)

CCN characteristics			
Sex	n	%	
Female	95	(90.5%)	
Male	9	(8.6%)	
Did not report	1	(1.0%)	
		M	SD
Age		46.5	11.84
Years as an RN		19.9	11.9
Years working in ICU		16.6	10.6
Years as a CCRN		7.3	6.5
Hours worked per week		37.0	7.7
Number of unit beds		20.7	9.1
			Range
Age			24-65
Years as an RN			2-43
Years working in ICU			2-43
Years as a CCRN			0.5-26
Hours worked per week			12-72
Number of unit beds			7-56
CCRN Certification			
Ever certified	n	%	
Yes	97	(92.4%)	
No	7	(6.7%)	
Missing	1	(1.0%)	
Currently Certified			
Yes	70	(66.7%)	
No	10	(9.5%)	
Number of Dying Patients Cared for:			
>30	66	(63.5%)	
21-30	10	(9.6%)	
11-20	10	(9.6%)	
5-10	6	(5.8%)	
<5	1	(1.0%)	
Highest Academic Degree:			
Diploma	1	(1.0%)	
Associate	14	(13.5%)	
Bachelor	78	(75.0%)	
Master	10	(9.6%)	
Doctoral	1	(1.0%)	
Position held at facility:			
Direct care/bedside nurse	54	(61.9%)	
Charge/staff nurse	37	(35.6%)	
Manager/Educator	2	(1.9%)	
Other	11	(10.6%)	
Type of Facility			
Community hospital; non-profit	62	(59.0%)	
University Medical Center	21	(20.0%)	
Community hospital; profit	17	(16.2%)	
County hospital	1	(1.0%)	
Federal hospital	2	(1.9%)	
Other (University; non-profit city)	2	(1.9%)	

Table 2.

Physician Behavior, Nursing, and Other Obstacle Themes

Physician Behavior Themes	Nursing and Other Themes*
1. Inadequate physician communication (n = 32)	1. Nursing related obstacles (n = 26)
2. Physicians giving false hope (n = 31)	2. Transferring dying patient during EOL (n = 8)
3. Physician-led futile care (n = 15)	3. Environmental obstacles (n = 5)
4. Physicians not agreeing about direction of care (n = 6)	4. Ethical obstacles (n = 4)
5. Physician perceived to have ulterior motives for extending care (n = 5)	5. Miscellaneous (n = 10)
6. Physician not ordering adequate pain medications at EOL (n = 4)	

*Five participants provided positive EOL submissions which were not obstacles and, therefore, not included.