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*Brigham Young University*

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Critical-Care Nurses' Suggestions to Improve End-of-Life  
Care Obstacles: Minimal Change Over 17 Years

Kacie Hart Hadley

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' Suggestions to Improve End-of-Life Care Obstacles: Minimal Change Over 17 Years

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**Background:** Critical-care nurses (CCN) provide end-of life (EOL) care on a daily basis as one in five patients dies while in Intensive Care Units (ICU). CCNs overcome many obstacles to perform quality EOL care for dying patients.

**Objectives:** The purposes of this study were to collect CCNs' current suggestions for improving EOL care and determine if EOL care obstacles have changed by comparing results to data gathered in 1998.

**Methods:** A 72-item questionnaire regarding EOL care perceptions was mailed to a national, geographically dispersed, random sample of 2,000 members of the American Association of Critical-Care Nurses. Nurses were asked for suggestions to improve EOL care.

**Results:** Of the 509 returned questionnaires, 322 (63.3%) had 385 written suggestions for improving EOL care. Major themes identified were ensuring characteristics of a good death, improving physician communication with patients and families, adjusting nurse/patient ratios to 1:1, recognizing and avoiding futile care, increasing EOL education, physicians who are present and "on the same page," not allowing families to override patients' wishes, and the need for more support staff. When compared to data gathered 17 years previously, major themes remained the same, but in a few cases, changed in order and possible causation.

**Conclusion:** Critical-care nurses' suggestions were similar to those recommendations from 17 years ago. Although the order of importance changed minimally, the number of similar themes indicated obstacles to providing EOL care to dying ICU patients continue to exist over time.

**Keywords:** end-of-life care, critical-care, obstacles, nurses' perceptions, suggestions

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## Critical-Care Nurses' Suggestions to Improve End-of-Life

### Care Obstacles: Minimal Change Over 17 Years

Patients with complex medical conditions, or those who have experienced trauma, are admitted to Intensive Care Units (ICUs) to receive lifesaving treatments. Patients' and families' expectations of healing treatments in ICUs can lead to difficult work environments for nurses. Despite advancements in medicine, patients admitted to ICUs do not always survive their illnesses and require end-of-life (EOL) care. Nurses can experience obstacles as they work to save patients' lives while also attempting to provide EOL care when treatments are unsuccessful (Attia, Abd-Elaziz, & Kandeel, 2012).

The National Institute of Nursing Research's (NINR, 2013) strategic plan describes five main areas of focus with the third-listed priority being EOL and Palliative Care. EOL care is important as critical-care nurses deal with death on a daily basis as one in five patients dies while in ICUs (Angus et al., 2004). Nurses are continuously at the bedside providing EOL care to dying patients (Beckstrand & Kirchhoff, 2005). When patients are dying, nurses must overcome obstacles to provide quality EOL care. Identifying obstacles in EOL care is the first step toward developing strategies to improve quality of care provided to dying patients and families.

### **Literature Review**

The SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) investigators were the first to report obstacles in EOL care (SUPPORT, 1995). Obstacles included lack of communication between patients and physicians, aggressive treatments being provided to dying patients, and negative characteristics of hospital deaths (SUPPORT, 1995). The SUPPORT study was published two decades ago, but other studies have also identified common EOL care obstacles in ICUs.

In a pilot study, with data gathered in 1998, a small ( $n = 288$ ) random national sample of critical-care nurses identified issues with patients' families along with physicians' behaviors as causing the largest obstacles to providing EOL care (Kirchhoff & Beckstrand, 2000). A year later, the same authors replicated the study using a larger national random sample ( $n = 1409$ ) (Beckstrand & Kirchhoff, 2005). Qualitative data included critical-care nurses' suggestions for improving EOL care which focused primarily on providing a good death for patients, including the elements of both dignity and peace at death. A specific obstacle to providing a good death were nurse staffing shortages leading to inadequate time for nurses to devote to dying patients and families (Beckstrand, Callister, & Kirchhoff, 2006).

Espinosa, Young, and Walsh (2008) prepared a literature review reporting common EOL obstacles such as (a) deficiency of nurses' involvement in planning EOL care, (b) healthcare team members disagreeing about patients' prognoses, (c) inadequate pain control, (d) families having unrealistic expectations, (e) insufficient staffing, (f) lack of nurses' education, and (g) environmental obstacles such as small rooms or no place for families to grieve. These obstacles negatively affected the EOL care that critical-care nurses were able to provide to patients and families.

While many studies have reported obstacles to optimal EOL care for dying ICU patients (Attia, et al., 2012; Beckstrand & Kirchhoff, 2005; Beckstrand, et al., 2006; Espinosa, et al., 2008; Holms, Milligan, & Kydd, 2014; Kirchhoff & Beckstrand, 2000; McCallum & McConigley, 2013), it is unknown if critical-care nurses' suggestions to improve EOL care have changed since the original data were obtained in the late '90s. Therefore, the two-fold purpose of this study was to collect critical-care nurses' current suggestions for improving EOL care and then determine if EOL care obstacles, as suggested by critical-care nurses, have changed over the



past 17 years by comparing these results to previously published data (Kirchhoff & Beckstrand, 2000; Beckstrand, et al., 2006).

## **Methods**

### **Study Design**

This study used a national, geographically dispersed, random sample of members of the American Association of Critical-Care Nurses (AACN) for this cross-sectional, mailed survey research study. Critical-care nurses were eligible to participate if they read English, were members of AACN, and had cared for at least one patient at the EOL.

After receiving Institutional Review Board (IRB) approval, a 72-item questionnaire was mailed to 2,000 members of AACN. For nurses who did not respond to the first mailing, a post card reminder was sent followed by a second complete mailing of the cover letter, questionnaire, and return envelope several weeks later.

### **Data Collection Instrument**

The 72-item questionnaire measured critical-care nurses' perceptions of size and frequency of EOL care obstacles and helpful behaviors. This questionnaire was nearly identical to the pilot study completed in 1998 which included asking respondents to provide suggestions for improvement of EOL care in ICUs (Beckstrand, et al., 2006). The questionnaire contained 4 open-ended, 15 demographic, and 53 Likert-type items. The entire questionnaire took approximately 30 minutes to complete.

### **Research Questions**

The research questions for this study were: 1) what are the current major suggestions for improvement of EOL care, for dying ICU patients, as perceived by critical-care nurses; and, 2) was there a change in themes to improve end-of-life care for dying ICU patients as compared to

suggestions provided in 1998? To answer these research questions, one open-ended item asked, “*If you had the ability to change just one aspect of the end-of-life care given to dying ICU patients, what would it be?*”

Individual responses were entered into a *Microsoft Excel*® spreadsheet then analyzed independently by two primary investigators for themes using content analysis. Final categories were then confirmed by two other expert researchers until consensus was achieved.

## **Results**

Of the 509 completed questionnaires returned, 322 (63.3%) had suggestions to improve EOL care. Even though nurses were asked to suggest only one improvement in EOL care, many offered more than one. Four unreadable responses were eliminated, resulting in a total of 385 usable suggestions (an average of 1.2 suggestions/respondent).

Of those nurses reporting gender, 283 were female (87.9%) and 38 were male (11.8%). Participants ranged in age from 24 to 73 years ( $M = 45$ ,  $SD = 12$ ) with an average of 17 years ( $SD = 11.9$ ) of experience as a registered nurse. An overwhelming majority ( $n = 210$ , 65%) had each cared for more than 30 dying patients (see Table 1).

Content analysis of data was completed by an experienced research team, resulting in eight major themes (>20 suggestions) and three minor themes ( $\leq 20$  suggestions) for the improvement of EOL care (see Table 2).

## **Major Themes**

The overarching theme encompassing many suggestions to improve EOL care centered on nurses’ desires to allow patients a good death, which specifically included improving the environment, realistic physician communication to families, increasing nursing time spent with patients and families, and ending care that seemed futile. Additionally, nurses suggested the need

for more EOL education, more physician involvement and consistency, less intrusion by family members to override patients' wishes, and more ancillary staff assistance when patients were dying.

**Ensuring a good death.** Critical-care nurses offered many suggestions ( $n = 71$ ) toward ensuring patients were allowed a good death through changes in the environment such as larger rooms that would accommodate family members and more privacy for grieving. One nurse suggested, "*Greater control over the environment [such as] removing or camouflaging monitors/suction/equipment...the ability to adjust lighting that is too harsh and control ambient noise.*" Another nurse commented, "*To be able to provide a better environment for both patient and family during the process of grieving to maintain/promote dignity and support.*"

Ensuring a good death also included pain control, letting patients die with dignity, and assuring patients did not die alone. One nurse responded, "*Absolutely ensure that patients will not have pain, shortness of breath, air hunger, panic, or other horrific dying experiences.*" Another nurse expressed frustration at endless treatments that were extending the dying process rather than being curative and obstructed dying with dignity, "*Too many patients are 'beaten' to death.*" Many nurses commented on the importance of having someone with dying patients. One nurse stated, "*Make it a rule that no person should die alone.*"

**Earlier, honest, and more realistic physician communication.** Critical-care nurses ( $n = 63$ ) suggested earlier physician communication with patients and families should occur regarding prognoses that are "*realistic,*" "*honest,*" and do not offer false hope. One nurse commented, "*MDs are usually overly optimistic and don't begin discussing the likelihood of death until 24 to 48 hours before the patient actually dies even though the whole team sees it coming weeks*

*before.*” Another nurse related a common occurrence she had noted with forthright physician communication to families by saying:

*The physicians, so often, are the ones who set the expectation. Families can get a totally mixed and confusing picture. There are times when we all know there’s no way the patient will ever make it, but we do “everything” anyway because the MD won’t sit down and talk frankly with the family. This should be a NEVER event rather than a frequent one.*

**Nurses want 1:1 staffing.** Nurses want staffing to accommodate being with dying patients on a 1:1 basis ( $n = 49$ ). One nurse replied, *“To be allowed more time. The RN usually has other assignments and does not have the time for the patient or family that they would like to spend.”* Another nurse suggested, *“I would give the dying patient one nurse whose only patient is that one. It is very distracting to have to care for a patient who is requiring care and attention when there is a dying patient next door [that is also my patient].”* A final nurse summarized many of the nurses’ suggestions by simply stating, *“More one-on-one time.”*

**Recognizing and then ending futile care.** Several nurses ( $n = 39$ ) reported that patients received unnecessary treatments that do not prevent death, but only prolong dying. One nurse responded, *“Acknowledge [futile care] earlier to prevent needless pain and suffering which will not change the patient outcome. Don’t wait or deny the inevitable.”* Another nurse agreed writing, *“[I would suggest] not dragging out life-sustaining treatments for days/weeks on dying patients. I feel as though I torture them—not care for them.”* Another similar suggestion was, *“[I wish] physicians would refuse to perform or order care that does not lead to real improvement in patient condition or comfort.”* Finally, a nurse responded, *“Allow [dying] patients to die!”*

**Increase EOL care education.** Better EOL education for families and patients was suggested by many nurses ( $n = 35$ ). “*Better education [on EOL] for families to help them make decisions regarding a patient’s diagnosis,*” was suggested by one nurse. Another suggestion was ensuring, “*more patients and families are adequately prepared and understand what to expect.*” Similar support for these comments was evident through this suggestion offered by another nurse, “*Better understanding by family members of the limits of modern medicine and what is really involved in prolonging life (i.e., often very painful and distressing).*”

Some nurses suggested education not only for families and patients, but for nurses and physicians to be better prepared to care for dying patients while also doing a better job at interacting with families. One nurse commented, “*More education to staff (including physicians) about what is helpful and necessary during [the EOL].*”

**Physician involvement and consistency in plan of care.** Suggestions for physician involvement revolved around two main ideas ( $n = 30$ ). First, nurses suggested the importance of physicians being physically present with the family and patient at the EOL. One nurse replied, “*More physician support and interaction with the family.*” Another stated, “*I believe that if there was a physician available more frequently to answer families’ questions the family would be more comfortable with what to expect.*” Second, having all health care providers on the “same page” was a common suggestion. One said, “*That all physicians have the same perspective and explanation to the family and patients regarding care and patient status.*” Another nurse commented on the obstacle of having physicians differ about prognoses, “*Often times, [physicians] will come into the room and tell the family differing opinions.*”

**Families not allowed to override patient wishes.** Many nurses made suggestions about honoring patients’ predetermined wishes at the EOL ( $n = 28$ ). One nurse responded, “*The most*

*troubling aspect is when patients' wishes are not followed.*" Similarly, another nurse stated, *"Respect patients' wishes—NOT families!"* One nurse commented from her clinical experience, *"Follow the patient's DNR/POLST form regardless of the family's wishes. The patient filled it out for a reason."*

**More ancillary support staff.** Critical-care nurses commonly suggested the need for not only more support staff, but for support staff to be available 24/7 ( $n = 26$ ). One nurse stated, *"MORE social and religious service personnel."* Another nurse commented, *"Having ancillary staff to assist with care of the patient and family."* Several noted the need for support staff availability around the clock, as suggested by a nurse who responded, *"Staffed team in house 24/7 so that a patient that dies at 10 P.M. on a Saturday, and whose family is present, is given the same care and attention as someone [who dies] at 10 A.M. on a Tuesday."*

### **Minor Themes**

Minor themes were: (1) miscellaneous suggestions unable to be categorized into the major themes ( $n = 20$ ), (2) suggestions regarding earlier initiation of palliative care ( $n = 18$ ) and, (3) issues surrounding ethics committees ( $n = 6$ ).

**Miscellaneous suggestions.** Miscellaneous suggestions included nurses wanting refreshments for family members, allowing families to assist in patient care, and suggesting that dying patients not be transferred out of ICUs for EOL care.

**Earlier initiation of palliative care.** Most nurses suggested that palliative care should be utilized earlier as in this response, *"Have palliative [care] involved earlier in the process."*

**Ethics committee involvement.** A small number suggested involving ethics committees in EOL decision making, while one nurse offered an alternative point of view regarding ethics committees by suggesting that, *"ethics committees [are a] waste of time."*

## Discussion

This highly experienced sample of nurses was passionate about improving EOL care for dying ICU patients and their families as demonstrated by the large number of submitted suggestions. Suggestions indicated there are still many obstacles nurses encounter while providing EOL care. Overwhelmingly, suggestions revolved around nurses wanting patients to experience a good death through improving environments, having earlier and more honest communication between physicians and families, nurses spending more time with patients at the EOL, and recognizing when care was futile. Comparison of results with data gathered 17 years ago showed that although the frequency of concerns mentioned were different, the obstacles nurses reported were almost identical.

**Improved Environments.** Previous findings included the need to provide quiet, peaceful environments for patients and families (Holms, et al., 2014; Fridh, 2014) and better pain control at the EOL (Attia, et al., 2012, Espinosa, et al., 2008). Several other researchers reported similar obstacles that inhibited a good death (Attia, et al., 2012; Beckstrand, et al., 2006; Espinosa, et al., 2008; Holms, et al., 2014; McCallum & McConigley, 2013).

**Communication at the EOL.** Researchers have reported a substantial need for improved communication among patients, family, and other healthcare members during EOL care (Attia, et al., 2012; Puntillo & McAdam, 2006). Literature regarding effective communication being essential during EOL care supported this study's nurses' recommendations that earlier, honest, and more realistic communication needs to occur with the patients and families (Attia, et al., 2012, Puntillo & McAdam, 2006). Additionally, Nelson et al. (2006) reported that effective communication between families and physicians improved EOL care and helped decrease distress and anxiety for family members.

**Nurses Need 1:1 Time.** Quality EOL care seems to be closely linked to the amount of time nurses care for dying patients. Attia et al. (2012) found that the more time nurses spend with patients at the EOL was linked to better overall care.

**Ending Futile Care.** Findings from this study reinforced critical-care nurses' attitudes that futile care is a frequent EOL barrier. Nurses acknowledged the importance of physicians not offering or starting futile care that leads to unnecessary suffering and prolong dying (Beckstrand, et al., 2006).

### **Comparison Data**

**Study Details and Demographics.** Comparison data for sample size, number of respondents'/return rate, mean age, and nurse experience are provided in Table 3. A higher percentage of nurses responded with suggestions for the current study than in the previous study suggesting EOL care obstacles still exist and nurses continue to want improvements.

**EOL Obstacles Remain the Same.** All currently identified obstacles were also noted in the previous study (Beckstrand, et al., 2006). Overall, both groups of nurses' overarching goals were the same: to ensure a good death for ICU patients.

While there was no change in major theme categories such as lack of nurse time, issues with physician communication, poor environments, and obstacles impeding a good death (i.e., controlling pain, not following patients' wishes, and futile treatments), some differences were noted. Themes changed in order and causation over time.

**Changing Order.** Suggestions for lack of nurse time to care for dying patients decreased in importance while issues with futile care, increasing the amount of EOL education, and physicians being on "the same page" had more suggestions than the earlier study. Only one item suggested by nurses from 17 years ago was absent from current suggestions and that was



regarding valuable resources (like blood products) not being “wasted” on dying patients (Beckstrand, et al., 2006).

**Changes in Causation.** Nurses (17 years ago) reporting the need for more time spent with dying patients was partially due to lack of availability of nursing staff (nursing shortage). No current respondent mentioned nursing shortages as a perceived cause of decreased time with patients which could suggest the nursing shortage experienced during the late 1990’s initially improved (Staiger, Auerback, & Buerhaus, 2012). Current research suggests, however, that the nursing profession will be experiencing another shortage over the next decade (U.S. Department of Health and Human Services, 2014). Additionally, nurses previously suggested poor physician communication with families was partially the result of physicians’ seeing patient deaths as personal failures. Again, no current respondent offered a similar rationale for inadequate physician communication. The increase in suggestions for limiting futile care could reflect the increasing amount of ICU technology available at the bedside, over time, that has the potential to extend life---even when ultimately futile.

### **Limitations**

This study only sampled members of AACN. Of the nurses that responded to the questionnaire, 36.7% did not answer what aspect they would change about EOL care. Reported findings may not be representative of the non-respondents’ views, or generalizable to all critical-care nurses’ perceptions of obstacles.

### **Recommendations**

Understanding critical-care nurses’ suggestions is an important step towards improving EOL care for patients and families. Based on the results of this study, nurses should assess their own specific unit needs regarding obstacles that can be limited, diminished, or moderated.

Nurses can identify obstacles within their control and initiate policy revisions addressing needed changes. Additionally, improving health literacy for patients and families by developing terminology sheets, handouts, wall posters, or informational folders available in ICU waiting rooms could be a way to begin the difficult EOL conversations so needed today.

### **Conclusion**

EOL care obstacles continue to exist with almost identical themes identified by nurses 17 years ago that are still evident today. While order and possible causation of some item themes changed, the realization that the overarching theme of providing a good death, along with the consistent major themes including the need for improving physician communication, adjusting nurse/patient ratios, limiting futile care, and increasing EOL education have not changed. These minimally changing themes over time provide an update to all health-care professionals regarding the current status of EOL care obstacles as perceived by ICU nurses.

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## TABLES

**Table 1. Demographics of Critical-Care Nurses (N = 322)**

Characteristics			
Sex	<i>n</i> (%)		
Male	38 (11.8%)		
Female	283 (87.9%)		
	<u><i>M</i></u>	<u><i>SD</i></u>	<u>Range</u>
Age	45	12	24-73
Years as RN	17	11.9	1.5-50
Years in ICU	14.4	10.6	1-48
Years as CCRN	8.2	8.2	0.5-33
Hours worked per week	35.5	7.9	8-72
Dying patients cared for:	<u>%</u>		
>30	65.2%		
21-30	12.4%		
11-20	13.7%		
5-10	6.8%		
<5	1.9%		
Highest degree:	<u>%</u>		
Diploma	2.2%		
Associate	13%		
Bachelor	70.5%		
Master	13.4%		
Doctoral	0.9%		
Position held at facility:	<u>%</u>		
Direct care/bedside nurse	53.7%		
Charge/staff nurse	39.8%		
Clinical Nurse Specialist	0.9%		
Manager/Educator	3.4%		
Other	1.6%		

**Table 2. Major and Minor Themes**Major Themes: >20 responses

1. Ensuring a good death for patients by having a private, peaceful environment while controlling pain, not dying alone, and maintaining dignity at the EOL ( $n = 71$ ).
2. Physician communication earlier to patients and families that is honest and realistic about a patient's prognosis so that appropriate EOL care is not delayed and there is no false hope ( $n = 63$ ).
3. Nurses staffed appropriately (1:1) so that nurses have adequate time to care for dying patients and their families ( $n = 49$ ).
4. Not initiating futile care in ICUs ( $n = 39$ ).
5. More EOL education for families, patients, nurses, and physicians ( $n = 35$ ).
6. Physicians involved in the care of patients and their families to help everyone be on the same page ( $n = 30$ ).
7. Families not being able to override EOL wishes ( $n = 28$ ).
8. More ancillary staff including chaplains and social workers available 24/7 ( $n = 26$ ).

Minor Themes: ( $\leq 20$  responses)

1. MISC: food for family, transferring out of ICU ( $n = 20$ ).
2. Palliative care initiated earlier ( $n = 18$ ).
3. Ethics committee involvement ( $n = 6$ ).

**Table 3. Comparison Sample and Demographic Data**

<b>Study Details</b>	<b>Data gathered in 1998<sup>^</sup></b>		<b>Current Data</b>	
<b>Sample size<sup>#</sup></b>	<i>n</i> = 1409	RR = 61%	<i>n</i> = 2000	RR = 26.7%
<b>Sample size for current research question<sup>*</sup>/total number of suggestions (%)</b>	<i>n</i> = 485	485 (56.3%)	<i>n</i> = 322	385 (63.3%)
Average # of suggestions per respondent	1.093		1.196	
<b>Demographic Data</b>				
	Female	Male	Female	Male
Sex <i>n</i> (%)	796 (93%)	57 (6.7%)	283 (87.9%)	38 (11.8%)
Mean age in years ( <i>SD</i> )	45.1 (8.1)		45.0 (12)	
Mean years as RN ( <i>SD</i> )	19 (8.2)		17 (11.9)	
Mean years working in ICU ( <i>SD</i> )	15.4 (7.0)		14.4 (10.6)	
<i>n</i> (%) of nurses having cared for more than 30 dying patients	597 (70%)		210 (65%)	

<sup>^</sup>Beckstrand, Callister, & Kirchhoff, 2006

<sup>#</sup>Reflects the sample size for the primary EOL care obstacle questionnaire study that this data was also obtained from.

<sup>\*</sup>Reflects number of respondents to one item from the major study: “If you could change one item to improve EOL care provided to ICU patients, what would it be?”