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

Renea L. Beckstrand  
*Brigham Young University - Provo*

Kacie Hart Hadley  
*Brigham Young University - Provo*

Karlen E. Luthy  
*Brigham Young University - Provo*

Janelle L. B. Macintosh  
*Brigham Young University - Provo*, janelle-macintosh@byu.edu

Follow this and additional works at: https://scholarsarchive.byu.edu/facpub

Part of the Critical Care Nursing Commons, and the Other Nursing Commons

Original Publication Citation

BYU ScholarsArchive Citation
https://scholarsarchive.byu.edu/facpub/5200

This Peer-Reviewed Article is brought to you for free and open access by BYU ScholarsArchive. It has been accepted for inclusion in Faculty Publications by an authorized administrator of BYU ScholarsArchive. For more information, please contact ellen_amatangelo@byu.edu.
Critical Care Nurses’ Suggestions to Improve End-of-Life Care Obstacles
Minimal Change Over 17 Years

Renea L. Beckstrand, PhD, RN, CCRN, CNE; Kacie Hart Hadley, BS, RN; Karlen E. Luthy, DNP, FNP-c, FAAN; Janelle L. B. Macintosh, PhD, RN

Background: Critical-care nurses (CCNs) provide end-of-life (EOL) care on a daily basis as 1 in 5 patients dies while in intensive care units. Critical-care nurses 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 2000 members of the American Association of Critical-Care Nurses. One of 3 qualitative questions asked CCNs for suggestions to improve EOL care. Comparative obstacle size (quantitative) data were previously published.

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-to-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 with 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 that obstacles to providing EOL care to dying intensive care unit patients continue to exist over time.
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.1

The National Institute of Nursing Research’s strategic plan describes 5 main areas of focus, with the third-listed priority being EOL and palliative care.2 End-of-life care is important as critical-care nurses deal with death on a daily basis as 1 in 5 patients dies while in ICUs.3 Nurses are continuously at the bedside providing EOL care to dying patients.4 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.5 Obstacles included lack of communication between patients and physicians, aggressive treatments being provided to dying patients, and negative characteristics of hospital deaths.5 The SUPPORT study was published 2 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.6 A year later, the same authors replicated the study using a larger national random sample (n = 1409) and a mixed-methods approach.4 Published qualitative data from the larger sample included critical-care nurses’ suggestions for improving EOL care that focused primarily on providing a good death for patients, including the elements of both dignity and peace at death.7 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.7

Espinosa et al8 prepared a literature review reporting common EOL obstacles such as (a) deficiency of nurses’ involvement in planning EOL care, (b) health care 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,1,4,6-10 it is unknown if critical-care nurses’ suggestions to improve EOL care have changed since the original data were obtained in the late 1990s. Therefore, the purpose of this study was to report critical-care nurses’ current suggestions for improving EOL care and then determine if EOL care obstacles had changed over the past 17 years by comparing these results to previously published data.6,7

Methods
Study Design
This report is the second published article from data obtained using a national, geographically dispersed, random sample of members of the American Association of Critical-Care Nurses (AACN) for a cross-sectional, mailed survey research study. Comparative obstacle size (quantitative) data were previously published.11

After receiving institutional review board approval, a 72-item questionnaire was mailed to 2000 members of AACN. Nurses were eligible to participate if they read English, were members of AACN, and reported having cared for at least 1 patient at the end of life. For nurses who did not respond to the first mailing, a postcard reminder was sent 2 months after initial mailing followed by a second complete mailing of the cover letter, questionnaire, and return envelope several weeks after the postcard was mailed.

Data Collection Instrument
Data for this report were obtained from a 72-item questionnaire measuring critical-care nurses’ perceptions of size and frequency of EOL care obstacles and helpful behaviors. The questionnaire contained 4 open-ended, 15 demographic, and 33 Likert-type items. This questionnaire was nearly identical to the pilot study used in 1998, which included asking respondents to provide suggestions for improvement of EOL care in ICUs.7 The entire questionnaire took approximately 30 minutes to complete.
Research Questions

Research questions for this report were as follows: (1) What are the current major suggestions for improvement of EOL care, for dying ICU patients, as perceived by critical-care nurses? (2) Were there changes in themes to improve EOL care for dying ICU patients as compared with suggestions provided in 1998? To answer these research questions, 1 open-ended item asked, “If you had the ability to change just 1 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 (Microsoft, Redmond, Washington) then analyzed independently by 2 primary investigators for themes using content analysis. Final categories were then confirmed by 2 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 1 improvement in EOL care, many offered more than 1. 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 (mean, 45 [SD, 12] years) with an average of 17 (SD, 11.9) years of experience as a registered nurse. An overwhelming majority (n = 210, 65%) had each cared for more than 30 dying patients (Table 1).

An experienced research team completed content analysis of data. Analysis of data resulted in 8 major themes (266 suggestions) and 3 minor themes (20 suggestions) for the improvement of EOL care (Table 2).

Major Themes

The overarching theme encompassing many suggestions to improve EOL care centered around nurses’ desires to ensure a good death, which specifically included improving the environment, controlling pain and other symptoms, and allowing patients to die with dignity while not dying alone. Nurses also suggested the need for earlier, honest, and realistic physician communication to patients and families, 1:1 nurse staffing, and earlier recognition and termination of futile care. Additional themes included more EOL care education, more physician involvement and consistency with plans of care, not allowing families to override patient wishes, and finally more ancillary support staff assistance when patients are 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 ensuring 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...
families by saying: she had noted with forthright physician communication to weeks before. Another nurse related a common occurrence actually dies, even though the whole team sees it coming likelihood of death until 24 to 48 hours before the patient are usually overly optimistic and don't begin discussing the and do not offer false hope. One nurse commented, MDs occur regarding prognoses that are realistic and honest person should die alone. Make it a rule that no nurses commented on the importance of having someone with dignity, Too many patient symptoms; having families at the bedside and maintaining dignity (n = 71) 2. Earlier, honest, and more realistic communication to patients and families about prognosis so that appropriate end-of-life care is not delayed and there is no false hope (n = 63) 3. Nurses staffed appropriately (1:1) so that nurses have adequate amount of time to care for dying patients and their families (n = 49) 4. Recognizing earlier then ending futile care (n = 39). 5. More end-of-life 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 patients' end-of-life wishes (n = 28) 8. More ancillary staff including chaplains and social workers available 24/7 (n = 26)
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, “Oftentimes, [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 end of life (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 also 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 who dies at 10 PM on a Saturday, and whose family is present, is given the same care and attention as someone [who dies] at 10 AM on a Tuesday.”

Minor Themes
Minor themes were as follows: (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, whereas 1 nurse offered an alternative point of view regarding ethics committees by suggesting that “ethics committees [are a] waste of time.”

DISCUSSION
This is the first qualitative data analyzed from this national random sample. A comparative obstacle size (quantitative) data article was previously published. 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 improved environments and symptom control, having earlier and more honest communication between physicians and families, nurses spending more time with patients at the end of life, 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 in substance with only minor differences in wording (Table 3).

Improved environments. Previous findings included the need to provide quiet, peaceful environments for patients and families, and better pain control at the end of life. Several other researchers reported similar obstacles that inhibited a good death.

Communication at the end of life. Researchers have reported a substantial need for improved communication among patients, family, and other health care members during EOL care. 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. In addition, Nelson et al reported

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>Comparison of Old and Current Obstacle Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998-1999</td>
<td>Current</td>
</tr>
<tr>
<td>1. “Good death,” ie, treating with dignity and respect</td>
<td>1. “Good death” (includes managing pain and other symptoms; improving environment)</td>
</tr>
<tr>
<td>2. Lack of time, staffing and nursing shortage</td>
<td>2. Communication challenges</td>
</tr>
<tr>
<td>3. Communication challenges</td>
<td>3. Request for 1:1 staffing</td>
</tr>
<tr>
<td>4. Stopping futile care earlier</td>
<td>4. Recognizing and then ending futile care</td>
</tr>
<tr>
<td>5. Environment improvements</td>
<td>5. Increased end-of-life education</td>
</tr>
<tr>
<td>7. Patient wishes known and followed</td>
<td>7. Family not allowed to override patient wishes</td>
</tr>
<tr>
<td>8. Health care providers on the “same page”</td>
<td>8. Increased support staff at the end of life</td>
</tr>
<tr>
<td>10. Increased end-of-life education</td>
<td>10. Earlier initiation of palliative care</td>
</tr>
<tr>
<td>11. Miscellaneous suggestions</td>
<td>11. Ethics committees</td>
</tr>
</tbody>
</table>
that effective communication between families and physicians improved EOL care and may help to 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. Atti et al. found that the more time nurses spend with patients at the end of life was linked to better overall care.

**Ending futile care.** Findings from our 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.\(^7\)

**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 4. 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.\(^7\)

### TABLE 4 Comparison Sample and Demographic Data

<table>
<thead>
<tr>
<th>Study Details</th>
<th>Data Gathered in 1998*</th>
<th>Current Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size(^b)</td>
<td>n = 1409</td>
<td>RR = 61%</td>
</tr>
<tr>
<td>Sample size for current research question(^c) (%)/total no. of suggestions</td>
<td>n = 485 (56.3)</td>
<td>530</td>
</tr>
<tr>
<td>Average no. of suggestions per respondent</td>
<td>1.093</td>
<td>1.196</td>
</tr>
</tbody>
</table>

**Demographic data**

<table>
<thead>
<tr>
<th>Sex, n (%)</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD) [range], y</td>
<td>44.8 (8.1) [26-74]</td>
<td>45.0 (12) [24-73]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years as RN, mean (SD)</td>
<td>19.8 (8.2)</td>
<td>17 (11.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years working in intensive care unit, mean (SD)</td>
<td>16.0 (7.0)</td>
<td>14.4 (10.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses having cared for &gt;30 dying patients, n (%)</td>
<td>339 (70)</td>
<td>210 (65)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviation: RR, response rate.

*Beckstrand et al.\(^7\)

\(^a\)Reflects sample size for primary end-of-life care questionnaire study that these data were obtained from.

\(^b\)Reflects number of respondents to 1 open-ended item from the question, “If you could change 1 item to improve end-of-life care provided to intensive care unit patients, what would it be?”

Overall, both groups of nurses’ overarching goals were the same, which was 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 (ie, 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 increasing the amount of EOL education and physicians being on “the same page” had more suggestions than the earlier study. Only 1 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.\(^7\)

**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 1990s initially improved.\(^1^5\) Current research suggests, however, that the nursing profession will be experiencing another shortage over the next decade.\(^1^6\)

In addition, 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 numbers of suggestions for limiting futile care could reflect both continuing with old and adding new ICU technology, at the bedside, which has the potential to extend life—even when ultimately futile.

**LIMITATIONS**

This study sampled only members of AACN. Of the nurses who 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 nonrespondents’ views or generalizable to all critical-care nurses’ perceptions of obstacles.

**RECOMMENDATIONS**

Understanding critical-care nurses’ suggestions is an important step toward improving EOL care for patients and families. Based on our results, 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 needed changes for improving EOL care for adults.

Suggestions for improving EOL care for adults include nurses understanding patients’ wishes and desires at the
end of life along with timely and effective symptom management. Nurses can assess availability of written EOL documentation and determine if expressed preferences are still applicable. Revisiting patients’ EOL care desires should be routine part of EOL care. Symptom management can include spiritual, psychological, and physical concerns with symptoms associated with pain, fatigue, nausea, respiratory distress, and constipation being most common. In addition, compassionate communication can be implemented recognizing dying patients’ special needs. Compassionate communication begins with development of an empathetic relationship with the patient, use of active listening, and simply “being there” for patients. Nurses can self-assess their own communication styles and their ability to adapt to different patient situations. 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**

End-of-life care obstacles continue to exist, with almost identical themes identified by nurses 17 years ago being evident today. While order and possible causation of some item themes changed minimally, 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, has not changed. These minimally changing themes over time provide an update to all health care professionals regarding the current state of EOL care obstacles as perceived by ICU nurses. Nurses can work to decrease obstacles by improving assessment of patients EOL wishes, using compassionate communication, and assisting to improve common symptoms.

**References**


**ABOUT THE AUTHORS**

Renea L. Beckstrand, PhD, RN, CCRN, CNE, is a professor at Brigham Young University College of Nursing, Provo, Utah. In addition to teaching, she works as a staff nurse in the CVICU at Utah Valley Hospital, Provo, Utah. Kacie Hart Hadley, BS, RN, is a graduate student in the Family Nurse Practitioner Master Program at Brigham Young University College of Nursing. She also works as a staff RN on the CPU at Utah Valley Hospital, Provo, Utah. Karlen E. Luthy, DNP, FNP-c, FAAN, is an associate professor, Brigham Young University College of Nursing, Provo, Utah. She also works as a Family Nurse Practitioner. Janelle L. B. Macintosh, PhD, RN, is an associate professor, Brigham Young University College of Nursing, Provo, Utah. She is an expert in qualitative research. This study was funded, in part, by the College of Nursing, Brigham Young University. The authors have disclosed that they have no significant relationship with, or financial interest in, any commercial companies pertaining to this article.

Address correspondence and reprint requests to: Renea L. Beckstrand, PhD, RN, CCRN, CNE, Brigham Young University College of Nursing, 422 SWKT, PO Box 25432, Provo, UT 84602 (renea@byu.edu).

Copyright © 2017 Wolters Kluwer Health, Inc. All rights reserved.