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## Providing a "Good Death": Critical Care Nurses' Suggestions for Improving End-of-Life Care

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# PROVIDING A “GOOD DEATH”: CRITICAL CARE NURSES’ SUGGESTIONS FOR IMPROVING END-OF-LIFE CARE

By Renea L. Beckstrand, RN, PhD, CCRN, Lynn Clark Callister, RN, PhD, and Karin T. Kirchhoff, RN, PhD. From College of Nursing, Brigham Young University, Provo, Utah (RLB, LCC), and University of Wisconsin at Madison, Madison Wis (KTK).

- **BACKGROUND** Providing appropriate end-of-life care has become a primary concern of nurses and the public. The highly technological critical care environment may not facilitate such care.
- **OBJECTIVE** To collect suggestions from critical care nurses for improving end-of-life care in intensive care units.
- **METHODS** A geographically dispersed, random sample of 1409 members of the American Association of Critical-Care Nurses was sent a 72-item survey on perceptions of end-of-life care. The survey included a request for suggestions on ways to improve end-of-life care.
- **RESULTS** Of the 861 critical care nurses who responded to the survey, 485 offered 530 suggestions for improving end-of-life care. Providing a “good death” was the major theme; specific suggestions included ways to help ensure death with dignity and peace. Barriers to providing good deaths included nursing time constraints, staffing patterns, communication challenges, and treatment decisions that were based on physicians’ rather than patients’ needs. Suggestions for providing a good death included facilitating dying with dignity; not allowing patients to be alone while dying; managing patients’ pain and discomfort; knowing, and then following, patients’ wishes for end-of-life care; promoting earlier cessation of treatment or not initiating aggressive treatment at all; and communicating effectively as a health-care team. Educational initiatives for professionals and the public were also suggested.
- **CONCLUSIONS** Implementation of specific suggestions provided by experienced critical care nurses might increase the quality of end-of-life care, facilitating a good death for intensive care patients. (*American Journal of Critical Care*. 2006;15:38-46)

## CE

### Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

1. Discuss defining criteria of a “good death” by critical care nurses.
2. Discuss barriers to providing death with dignity in a critical care environment.
3. Discuss additional identified research opportunities to provide a “good death” in critical care environments.

Providing quality care for patients who are dying is of primary concern in the United States today.<sup>1</sup> More than 2.4 million deaths are recorded annually in the United States,<sup>2</sup> and most of these deaths (80%) occur in hospitals.<sup>3</sup> Often, critical care nurses are responsible for caring for these dying patients, because about 20% of intensive care unit (ICU) patients die while hospitalized.<sup>4</sup>

Death in the ICU environment can be complicated and is often unnatural.<sup>5</sup> According to Tilden,<sup>6(p162)</sup>

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“Technological advancements in aggressive medical management at the end of life have led more Americans to fear how they die rather than death itself.”

*More Americans fear how they will die than death itself.*

In 2 studies, 1 conducted in the United States<sup>7</sup> and 1 in Australia,<sup>8</sup> investigators examined, in part, the perceptions of critical care nurses of end-of-life care. Asch et al<sup>7</sup> surveyed critical care nurses in the United States on issues of euthanasia and then did a content analysis of text comments from the 468 nurses who responded. The respondents had extremely complex feelings about issues at the end of life. A total of 37 concepts were coded from the nurses’ responses and then synthesized into 8 themes. In general, the nurses wished they had more say in the care of dying patients, reported that no consistency existed in the way dying patients were cared for, and did not think that the critical care environment adequately fostered the compassion that dying patients need.

*Critical care nurses wish they had more say in the care of dying patients.*

In the second study, Cartwright et al<sup>8</sup> mailed a 30-page questionnaire on many issues associated with the care of dying patients to a random sample of 1200 Australian healthcare professionals, of whom 299 were critical care nurses. The response rate from the nurses’ subsample was 77% (n = 231). These nurses reported needing better pain control measures for dying patients, emphasized the need to improve communication between physicians and patients and also between physicians and nurses, and thought of themselves as important advocates for patients.

The Institute of Medicine<sup>9</sup> has recommended strengthening the knowledge base on end-of-life care. However, research on ways to change the critical care environment to facilitate improved care is limited.<sup>1,10,11</sup> Gaining an increased understanding of the perceptions of critical care nurses of changes that would facilitate appropriate end-of-life care is important to ultimately improve the care of dying patients. Because the studies by Asch et al and Cartwright et al were conducted in single locations and regional variation in end-of-life care has been identified,<sup>12</sup> we determined that a national survey was needed. The use of a geographically dis-

persed national sample helps overcome potential regional differences in care of dying patients in ICUs. Further, accessing a large sample increases the likelihood of having responses from nurses who work in a variety of roles and in diverse practice settings across the United States.

With advancements in the diagnosis and treatment of acute and chronic diseases, patients are spared impending death only to experience subsequent prolonged death. Issues about care at the end of life will continue to increase in importance. Deficiencies in end-of-life care have been documented in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.<sup>13-15</sup> Concerns noted in the current critical care practice environment have not diminished despite attention from policy makers, researchers, and clinicians. Researchers concluded that patients’ preferences for resuscitation were not routinely known to physicians, the presence of an advance directive had no effect on treatment decisions, most patients preferred that their families and physicians make critical decisions about resuscitation, and patients’ families perceived that their loved ones often experienced moderate to severe pain when the patients died in critical care units.<sup>14,15</sup>

*Patients’ preferences for resuscitation are not routinely known, and the presence of advance directives has no effect on treatment decisions.*

In this article, we report findings that are a separate part of a larger national survey<sup>16</sup> of critical care nurses’ perceptions of end-of-life care. We focus on the following research question: Which aspect of end-of-life care in ICUs would critical care nurses most like to see changed?

## Methods

After approval was received from the appropriate human subjects committee, questionnaires were sent to a geographically dispersed, random sample of 1409 members of the American Association of Critical-Care Nurses. Of the 861 nurses who returned completed questionnaires during the course of 3 mailings (a response rate of 61% for the main study), 485 (56%) offered 1 or more suggestions in response to an open-ended question about how they would change end-of-life care in ICUs. These responses (n = 530) were coded and synthesized by a critical care nurse researcher with

expertise in qualitative inquiry. A second researcher with critical care nursing experience also coded and synthesized data, and then codes were compared. The interrater reliability was .92. Agreement on the importance of having more time to care for dying patients was 100%. Findings were verified with 7 participating critical care nurses (mean 19 years of critical care experience) to confirm that the barriers and facilitators identified reflected the experiences of those 7 nurses.

## Results

The 485 respondents who provided suggestions for changing end-of-life care in critical care units were 26 to 74 years old (mean 44.6 years). A total of 93% were women. They were employed as staff nurses (53%), charge nurses (36%), clinical nurse specialists (4%), or in other roles (6%). Practice settings included intensive care and critical care units (61%), cardiovascular/shock trauma/neurological ICUs (18%), medical/surgical ICUs (13%), and other settings (9%). Respondents had been registered nurses for a mean of 19.8 years and had worked in critical care for a mean of 16 years. Among the respondents, 70% had cared for at least 30 dying patients.

Providing patients (and their families) with a “good death” was the major theme identified by the overwhelming majority of respondents (n=128). This theme was expressed by one study participant who wrote, “Death is the most critical point of illness. We must learn to treat [death] with [the] dignity and respect it deserves. Learning to know when enough is enough is the best place to start.”

*Death is the most critical point of illness and must be treated with the dignity and respect it deserves.*

### Barriers to Facilitating a Good Death

Respondents identified several barriers or obstacles to providing a good death in ICUs, including staffing patterns and a shortage of nurses that contribute to a lack of time to care for dying patients appropriately. Also mentioned were communication challenges, including unrealistic expectations of patients’ families, inappropriate treatment decisions, and some aspects of physicians’ behaviors. The most frequently cited barrier was lack of time (n=72).

*Staffing Patterns and Shortage of Nurses.* One nurse expressed frustration in her practice setting about the lack of time for caring: “Now that ICU patients are

sicker, one is never afforded the ability to care for just this patient. Assignments do not allow for this much needed time.” Another nurse reported the desire to “be able to give my needed time to the patient and family members without being taken away to care for other patients.” Another study participant thought it was imperative that “the nurse caring for the dying patient have that patient as a 1:1 assignment when death was predictably imminent, in order to meet both the patient and family’s needs adequately.” One nurse expressed frustration with staffing policies:

[I would provide] more time to care for [dying] patients. They are designated as “less work”—lower priority—so often float/agency/ travelers get “dying patients” while regular ICU staff care for critical ones. There needs to be understanding and awareness that a dying ICU patient requires and needs highly skilled nursing [care].

Some nurses blamed the shortage of nurses for the lack of time for nursing care of the dying. This notion was articulated by one nurse who said, “Often, if we are short staffed, we have little time to spend with the patient and family. With the critical care [nursing] shortage, it’s only going to get worse.” Another stated, “It’s rare that dying patients are 1:1 ratio. We don’t have the staff or are told we have to float staff instead of making [the dying patient] 1:1’s.”

*Lack of time was the most frequent barrier to providing a “good death.”*

*Communication Challenges.* According to some respondents (n=47), another barrier to providing a good death was physicians’ behaviors, such as being less than truthful and/or somewhat unrealistic about a patient’s prognosis. For example, a nurse with 34 years of ICU experience raised this issue: “[I would] require physicians to be realistic about the patient’s condition. Would they care for their mother or father this way?” Nurses also recommended that conferences between the physicians and the patient’s family members occur in a more timely fashion, suggesting, “If physicians were honest about prognosis with families [earlier] it would give [the family] time to prepare and have quality time with the dying patient. It would also help us help families prepare [for the impending death].”

One nurse commented at length about the problems of “unrealistic family expectations” fostered by lack of

clear communication by the healthcare team (n = 44) and then illustrated the problem with the following statement:

Physicians frequently abdicate their role in dying issues and ask the nurse, "Would you do it?" If [physicians] give the slightest bit of hope in a totally hopeless situation, the nurse is caught in the middle. Families want to know the truth, but often their denial prevents them from accepting the inevitable. Thus, it becomes extremely important for the entire healthcare team to be on the same wavelength with end-of-life issues [given our] advances in technology.

*Treatment Decisions Based on Physicians' Needs Rather Than Patients' Needs.* Some study participants (n = 24) thought that some physicians tended to see a patient's death as a personal failure, suggesting that "doctors really hate admitting defeat." Other nurses wrote, "Physicians need to realize that death is a part of life and not view it as a failure," and "Doctors [should] understand that everyone dies and that death is okay. [They should understand] that death is a part of life." Another nurse suggested the following:

What is needed is more realistic and compassionate response from physicians to the needs of terminally ill patients. Too many [physicians] see death as a personal affront to their professional abilities and do not visualize the dying process as a part of life itself. Thus, many patients suffer needlessly without adequate pain control and supportive care.

### Facilitators to Providing a Good Death

Suggestions for providing a good death for dying patients are listed in the Table.

*Making Environmental Changes to Facilitate Dying With Dignity.* One nurse envisioned the following: "I would . . . encourage family members to stay with the patient. Beds should be made available for family members and also food and showering facilities. Soothing music would add a nice touch. There should also be quiet places for prayer and meditation and family gathering." Another envisioned the creation of the following environment: "I would build a chapel in the intensive care area for use of patient families and hospital staff. In ICU areas, I would build bathrooms for patient families as well as a small walking garden."

Another study participant suggested facilitating transport of patients to their homes to die with hospice

#### Facilitators to providing a good death

- Making environmental changes to promote dying with dignity
- Being present
- Managing patients' pain and discomfort
- Knowing and following patients' wishes for end-of-life care
- Promoting earlier cessation of treatment or not initiating aggressive treatment at all
- Communicating effectively as a healthcare team

support. Others suggested moving patients to private rooms; one stated, "The ICU is no place to die. It would be nice to have a comfortable, quiet, spacious room for those who are dying. Let everyone in and let the rest of the ICU function as it should."

Many nurses thought that no patient should face death alone. This common theme was articulated by a nurse who said, "Every patient needs to have someone present with them at the moment of death—to touch them, speak to them, to let them know it's okay to go." An associated theme to being present was that a patient's primary nurse should be relieved of all other responsibilities and focus on caring for the dying patient and the patient's family.

### No patient should face death alone.

*Managing Pain and Discomfort.* Controlling a dying patient's pain was another suggestion made by the respondents (n = 43). This intervention was described by a nurse as "minimizing patient suffering by administering adequate comfort measures, ie, intravenous drugs and withdrawing vasopressors, hemodialysis, IABP [intra-aortic balloon pump], and blood products, depending on the patient's level of consciousness and whether or not there is an advance directive."

*Knowing and Following Patients' Wishes for End-of-Life Care.* Some nurses (n = 39) wanted to have a better understanding of their dying patients' wishes about end-of-life care. One nurse said, "Living will documents should be legally binding. [Sometimes] they seem to be worthless pieces of paper. In most cases they are used as [only] a guideline that the family may or may not follow."

*Promoting Earlier Cessation of Treatments or Not Initiating Aggressive Treatments, Especially When Care Seems Futile.* Stopping procedures and treatments ear-

lier was mentioned by many nurses (n=35). One nurse stated, "I would eliminate painful procedures (for example, Swan-Ganz catheters, dialysis catheters, central line placements)." Another study participant stated, "Learning to know when 'enough is enough' is the best place to start." One nurse described the need "to admit our imperfections, that sometimes despite our best efforts, the patient is going to die, that God determines the outcome."

*Living will documents should be legally binding.*

Some critical care nurses thought more care should be taken when using valuable resources such as blood products and that these resources should not be given to patients who were dying. One nurse stated, "[I would change] intentionally wasting blood products on someone who is not viable when someone [else] could have [the] benefits." Another suggested the following:

Instead of giving the family the option of discontinuing the ventilator and extubating the patient, simply place the patient on CPAP [continuous positive airway pressure] and allow the patient to die. This might prevent the feeling that the family "pulled the plug." Just discontinuing drugs or decreasing them would prevent this after-the-fact feeling.

Several nurses (n=27) noted the frustration of continuing aggressive treatments when there was little hope of the patient surviving. One nurse said, "Too many times we give false hope and offer futile care." Another echoed this sentiment, ". . . [W]e have patients with wide open pressors, fluids, etc, even though we've told the family nothing can be done; we're running around fruitlessly not accomplishing anything." A third nurse stated, "Stop aggressive measures in a futile situation."

*Communicating Effectively as a Healthcare Team.*

Nurses (n=34) suggested that improved communication between physicians and nurses would ultimately facilitate a good death because everyone could work toward the same goal or plan of care. One specific suggestion that was offered was that critical care units should have

. . . [an] advanced practice nurse to pull together interdisciplinary teams early in the

admission to develop a consistent plan of care focusing on the family spokesperson, identification of decision makers (family), identification of primary physician spokesperson (may not be the primary doctor), and identification of a primary nurse (caregiver or advanced practice nurse). [This team would] identify [the] patient's predicted quality of life and prognosis.

One nurse with 15 years of ICU experience suggested that "a dedicated individual or team [be brought in] that could be consulted . . . who would focus on end-of-life issues to enhance quality of care." Another suggested "a specialized counselor to work with families in denial." Another study participant suggested it might be helpful to have a dedicated specialty team similar to an in-house hospice that could be consulted the same as social services or a wound care team. Such a team could focus on end-of-life issues to enhance quality of care.

**Educational Initiatives**

Study participants also mentioned that all members of the healthcare team should receive education on end-of-life care. Nurses thought that their nursing education had not adequately prepared them to provide end-of-life care and that they often learned "the hard way." Nurses suggested that it was also important to "teach physicians when it is okay to allow the patient to die with dignity so the patient isn't unnecessarily stressed and [the physician's] feelings of guilt are less."

The need for education of patients' families and the community about critical care units, organ donation, advance directives, durable power of attorney, and clarification about what healthcare providers can realistically do for dying patients was also described. One nurse suggested, "Somehow we must teach that death is a fact of life . . . and is something that should not be feared." Another nurse remarked, "Improve public education to reflect the reality that 'modern medicine' cannot always fix what is broken. Sometimes death is the most natural thing that can happen in an ICU. We are trapped between technology and reality."

**Miscellaneous Findings**

Some miscellaneous comments could not be categorized into any of the main categories (n=37). Examples include suggestions for more involvement from ancillary support personnel such as pastoral staff, palliative care specialists, and ethics committee members. A few respondents noted that care continued for dying patients because of the fear of being sued.

## Discussion

These results confirm the findings of other studies and contribute to the body of knowledge; critical care nurses working in the United States, from a wide variety of geographically diverse practice settings, support the need for improvement in the critical care environment in the provision of end-of-life care. The results also provide information for a continuing discussion of improving end-of-life care in critical care units. Ongoing dialogue is essential to make visible the voices of nurses and to describe nurses' visions for future improvement of end-of-life care.

The high number of responses to the research question (Which aspect of end-of-life care in ICUs would critical care nurses most like to see changed?) suggests that experienced nurses have noted deficiencies in current end-of-life care practices in ICUs; one study participant remarked, "We often cross the line of 'doing for' to what we 'do to' patients." Critical care nurses who participated in the study formulated clear opinions and recommendations for changes that should be made. Nurses want to ensure that dying patients experience a good death.<sup>5,17,18</sup>

Unfortunately, these experienced nurses did not think that good deaths were routinely possible while patients were in an ICU. Many deaths nurses have witnessed in ICUs were less than ideal because of inherent problems with the intensive care environment (created to save lives), the lack of sufficient time for nurses to care for dying patients and the patients' families, problems with communication between physicians and patients' family members, the lack of appropriate education for physicians and nurses, and problems of keeping patients comfortable and following the patients' wishes.

Nurses placed importance on dying with dignity and on not dying while alone. "Dignified dying" has been defined as maintaining personal comfort and control as the end of life approaches.<sup>19</sup> This dying, then, is a process rather than an event. In interviews with family members of those who had recently died, Berns and Colvin<sup>20</sup> found that being present (or absent) at the time of the death of the loved one was a significant memory for survivors. Nearly all of the family members they studied who were present at the death wanted to be with the dying patient. Of those who were not present at the death, most indicated that they had planned to be at the bedside. Some reported feelings of guilt related to their unplanned absence.

We also found congruity between nurses' descriptions of factors that contribute to providing a good death and reports of similar descriptions from dying patients. For example, in a study by Singer et al,<sup>18</sup>

patients with end-stage cancer identified the components of a good death as having adequate pain and symptom management, avoiding a prolonged death, having control, limiting burden, and strengthening relationships with loved ones. In another study,<sup>21</sup> patients, patients' family members, physicians, and other healthcare providers (n = 1462) were asked to rate the importance of 44 attributes commonly experienced at the end of life. Of the 44 attributes, 26 were rated as being important by all 4 groups of participants. In general, participants reported wanting to be kept clean, to decide who will make critical decisions, to be cared for by a nurse with whom they felt comfortable, to know what to expect about their physical condition, to have someone who would listen, and to maintain their own personal dignity at the end of life. Further, participants endorsed management of pain and symptoms at the end of life and stressed the importance of having time to prepare for their death.

The nurses in our survey reported that end-of-life care would be further improved if communication procedures ensured that all members of the healthcare team were working toward the same goals for patients and the patients' families, if treatments given to dying patients were stopped earlier in the dying process (or never started, especially when futile), and if some physicians could be helped to understand that death is a natural process and not a direct reflection of a physician's skill or care. These findings are supported in the literature.

In a comparative study<sup>22</sup> of physicians and nurses, nurses were less satisfied with the decision-making process than were physicians. Nurses are seldom involved in end-of-life decision making, a situation that often is extremely frustrating for nurses and may create moral distress.<sup>23</sup> Walter et al<sup>24</sup> found that house medical staff and critical care nurses differed in their perceptions of the appropriateness of levels of care (from comfort only to very aggressive). Walter et al also found evidence indicating that treatments should not be implemented whenever information indicates that a patient would not want them. This restraint in implementing treatments is especially crucial when the treatments are also most likely to be futile.<sup>25</sup>

When nurses feel frustration about prolonging a patient's inevitable death to carry out requests of the patient's family or the orders of a physician, moral distress occurs.<sup>26-28</sup> Study participants' emphasis on dying with dignity and not dying alone is a reflection of nurses' personal attitudes, fears, experiences, or regrets possibly related to specific care experiences that created moral distress. Further research is indicated to clarify the meaning of these concepts, such as

the tension between technological and humanized care to critical care nurses, which is referred to as being trapped between technology and reality.

*Moral distress occurs when nurses feel frustration about prolonging a patient's inevitable death.*

Barriers continue to exist in providing quality end-of-life care in critical care units, and some clinicians seem impervious to change despite the evidence that exists about the provision of a good death. A multidisciplinary team of clinicians and researchers should investigate ways of incorporating these results into interventions that decrease or eliminate obstacles to providing end-of-life care and enhance or support helpful care practices at the end of life. With the establishment of the Nursing Leadership Academy for End-of-Life Care, 22 nursing organizations, including the American Association of Critical-Care Nurses, are collaborating to improve both palliative and end-of-life care.<sup>29</sup> Recommendations from such groups should be helpful.

Further research is needed on better ways of communicating information to patients, patients' families, and other members of the healthcare team. For example, with the current availability of Internet technologies, a program could be designed in which frequent updates of the status of ICU patients would be posted so that a patient's family members (provided with a special code to protect confidentiality) could retrieve information on the patient at any time.

*Strategies to improve end-of-life care may include a multidisciplinary approach, use of the Internet for updates on patients' status, and training in end-of-life care.*

The respondents to the survey also provided practical suggestions for initiating end-of-life discussions between members of the healthcare team, patients, and patients' families, including the goals of treatment (prolongation of life vs an emphasis on quality of life) and representative questions that could be used to guide the discussion about goals, values, advance directives, do-not-resuscitate orders, and palliative care. Quill<sup>30</sup> emphasized the importance of honesty,

expertise, advocacy, compassion, and commitment in providing end-of-life care. These same suggestions were confirmed by participants in our study.

Work is being done on the development and validation of a tool known as the Preferences for Care Near the End-of-Life Scale, which would be completed by adults as part of advance healthcare planning.<sup>31</sup> Subscales include autonomous physiological decision making, decision making by healthcare providers, spirituality, family, and effective communication. Such tools may be helpful in ameliorating the difficulties that occur when a patient is no longer able to participate in making decisions about end-of-life care. Another suggestion for research is to query patients' families about their perceptions of end-of-life care as it currently exists in ICUs.

The importance of conducting qualitative research and the usefulness of such inquiry are becoming increasingly evident, especially in end-of-life care. According to Sandelowski,<sup>32(p1369)</sup> "Such inquiry is critical to excellent care that is drawn from and produced in [irreplaceable] interactions between practitioners and their patients [and their families]."

Educational programs need to be developed to educate healthcare providers about quality end-of-life care.<sup>33,34</sup> Including content on end-of-life care in basic nursing education programs is imperative. Recommended competencies for baccalaureate nursing graduates, the End-of-Life Competency Statements for a Peaceful Death,<sup>35</sup> have been generated by the American Association of Colleges of Nursing and should be used to guide curricular changes.

These efforts can be enhanced by use of a new multimedia kit for nurse educators that has been developed and provided to all basic nursing programs in the United States.<sup>36</sup> The outcomes of such educational interventions should be documented. Outcomes evaluation of innovative programs should be shared and disseminated to foster evidence-based end-of-life care.

Through dissemination of the findings of our study, additional research studies, and educational offerings, the care of dying patients in ICUs can be improved to ensure a good death. Dialogue should continue on ways to overcome barriers to the implementation of such findings in clinical practice. Nurses have a major involvement and high-level responsibilities but limited participation in end-of-life decision making. It is important to enhance the visibility and power of nursing by changing the critical care milieu in ways that would be more supportive in providing a good death.

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