

Improving Family Intensive Care Unit Experiences at the End of Life: Barriers and Facilitators

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Experiencing the end of life of a family member in the intensive care unit is clearly difficult. An important role of critical care nurses is to help family members through this challenging period. This article highlights a few clinically significant barriers and facilitators related to improving family experiences at the patient's end of life that have received less attention in the literature thus far. Facilitators include specific aspects of communication, the nurse's role as the coordinator of care, bereavement care, promoting a "good death," and caring for health care providers. Barriers include medical uncertainty and differences in values and culture. (*Critical Care Nurse*. 2019;39[3]:52-58)

The past 5 to 10 years have seen a groundswell of literature on caring for critically ill patients at the end of their lives. Many perspectives have been discussed, including those of the patients, family members, nurses, physicians, other health care professionals, and institutional administrators. Recently, the Society for Critical Care Medicine issued clinical practice guidelines on family-centered care in the intensive care unit (ICU), based on an extensive review of the experiences of family members of ICU patients.¹ As a whole, this literature makes clear that family members undergo an extremely difficult experience when their loved one is hospitalized at the end of life, one that has sometimes been characterized as a "vortex"² or "roller coaster."³

CE 1.0 hour, CERP B

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Describe how nurses can facilitate family ICU experiences at the end of life
2. Describe some of the barriers to positive family ICU experiences at the end of life
3. Describe interventions that nurses as members of the health care team can take to improve family ICU experiences at the end of life

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An important role of critical care nurses is to help family members of dying patients through this difficult time.¹ The challenge is how best to accomplish this, given the complexity of the situation and the barriers to meeting family members' needs. Despite the vast body of literature on the topic of family-centered care in the ICU, a few specific barriers and facilitators related to promoting positive family experiences have been less well described. Therefore, this article, while not a full, systematic review, is intended to highlight some of these specific factors that have been relatively neglected thus far. Facilitators include specific aspects of communication, the nurse's role as the coordinator of care, bereavement care, promoting a "good death," and caring for health care providers. Barriers include medical uncertainty and differences in values and culture.

Facilitators Communication

One of the most commonly cited facilitators of improved family experiences at the patient's end of life is communication.^{1,4,5} The centrality of clear, open communication among all involved—including the patient (when appropriate), family, nurses, physicians, and other health care providers—has been repeatedly emphasized in the literature.^{1,6,7} A thorough discussion of family-centered communication at the end of life is included in the Society for Critical Care Medicine clinical guidelines mentioned previously.¹ Important and practical aspects of communication that have received less attention in the literature include the language and timing of communication.

Language. Although the need for effective communication has been widely discussed, the specific choice of language in such conversations has been rarely addressed. Several authors⁸⁻¹⁰ have stated that the words and phrases used by family members and health care

providers can be significant. For example, we often hear family members using the phrase, "Do everything." Family members may not understand the complexity of this directive. One physician described his frustration on hearing this phrase, noting that "everything" can mean different things to different people.⁸ He recommended that clinicians encourage family members to be more specific and define their terms clearly in order to make their wishes understood. In a review of how nurses prepare and support families during withdrawal of life-sustaining treatment, Coombs et al⁹ concluded that greater understanding is needed of the language that can be used with families to describe death and dying in the ICU. Another study¹⁰ showed that perceived risk of patient death among surrogates (family members who make medical decisions for patients who are unable to do so) differed according to whether the phrase "chance of death" or "chances of survival" was used. The authors also found a significant difference in the surrogates' understanding of the level of risk when it was presented as a frequency (eg, 1 in 50) versus as a percentage (eg, 2%). The authors concluded that health care providers should be aware of the unintended consequences of their choice of words when discussing end-of-life issues.

Another aspect of the language of communication is translation. Good communication is based not only on what we say but also on how we say it. Health care institutions are becoming more aware of the need to communicate with patients and their families in their native tongue. Interpreters are sometimes used in family meetings.¹¹ Even in these cases, however, health care providers should be aware of the need to monitor whether the full meaning of their words and those of the family members is correctly translated. For example, investigators found that interpreters altered the majority of verbal transactions (55%) in 10 ICU family meetings through additions, omissions, substitutions, or editorializing.¹² A group of palliative care physicians recommended that the health care staff brief interpreters before they meet the patient or the family.¹¹ They also recommended that providers maintain eye contact and speak to the family members rather than to the interpreter, speak in short and simple sentences, and encourage questions.¹¹

Time and Timing. A second characteristic of good communication relates to time: how much time is spent with the patient and family and when the conversations

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are held (their timing). Events can occur very quickly in the ICU, and families often feel that they do not have enough time to emotionally process what is happening.^{3,13} In addition, family members often perceive that there is not enough time for discussions with health care providers.¹⁴ Therefore, health care providers should try to proactively solicit information from families about patient wishes, values, and preferences^{15,16} and dedicate sufficient time to such conversations.

One strategy often cited as improving communication is the use of the family conference.¹ However, studies have shown that family members speak less than clinicians during these meetings¹⁷ and that there are many missed opportunities to emotionally support the family.¹⁸ A study of 51 family conferences indicated that family members spoke 29% of the time and clinicians spoke 71% of the time.¹⁷ The authors found a statistically significant association between the proportion of time family members spoke during the conference and degree of family satisfaction with physician communication as well as family ratings of conflict, with higher proportions associated with increased satisfaction and decreased conflict.

Good communication leading to decision-making is not a onetime event but rather a process¹⁴ that should be started soon after patient admission.¹⁹ An ethnographic study of an American ICU by Gutierrez¹³ showed that

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the timing of end-of-life discussions and decision-making with family mem-

bers was determined primarily by physician perceptions of the patient's prognosis rather than the needs of the family. Gutierrez¹³ also found that physicians tended to delay conversations with the family until sufficient prognostic data were collected. She highlighted the need to distinguish between communication related to prognosis and that related to decision-making and recommended that staff members discuss the uncertainty surrounding the determination of a poor prognosis.

In summary, time is of the essence not only for the physical care provided to patients but also for conversations with family members. Health care providers should talk with families frequently and try to initiate conversations when they perceive that the family needs to talk and center them on what the family wants to discuss.

Nurse Role as the Coordinator of Patient Care

A second potential facilitator of improved family experiences in the ICU is supporting the role of the nurse as the coordinator of patient care at the end of life. Family members tend to appreciate the round-the-clock nursing care that they and their loved one receive.²⁰ Nurses are always at the patient's bedside and so are most able to facilitate positive family experiences and to serve as the center of communication among all involved, including members of the health care team and family members.^{21,22} Families rely on nurses for information about the patient's condition and response to therapy² and for support when going through the decision-making process.² A key role of nurses is to facilitate communication between the health care team and the family so that all participants in the process have as much information and support as possible.

Nurses can also coordinate end-of-life decision-making. Studies have shown that, in general, nurses are involved in end-of-life decision-making but do not make the actual decisions.²³⁻²⁶ In a review of the literature on the process of end-of-life decision-making, Flannery and colleagues²⁷ found that nurses were not viewed as integral to the decision-making process. They also reported that although nurses were usually the first to recognize medical futility, the level of their involvement in decision-making was related to the physician in charge and the nurse's seniority. Other qualitative studies indicated that nurses felt that they did not contribute enough to the decision-making process²⁸ and that they were often excluded from discussions and decision-making,²⁹ although they wanted to be more involved.²⁹

Many end-of-life decisions are made during family conferences. However, one study³⁰ showed that these meetings often take place without a nurse present. The same study also indicated that nurse involvement at the end of life is not well documented in medical records.³⁰ Another study³¹ showed that ICU nurses described their role in family meetings as that of an intermediary. These nurses stated that although they acted as patient advocates, they perceived the presence of barriers that limited their involvement and felt that their importance to the family meeting was undermined.

In many settings, the role of the nurse at the end of life remains unclear.^{30,32} Several possible solutions have been proposed to encourage nurses to work to the full scope of their practice in dealing with families in this

situation. Formal processes and structures could be initiated to incorporate nurses into discussions and the decision-making process.^{19,28} For example, nurses should participate in joint rounds with the entire health care team.²⁴ Nurses should be encouraged to not only actively participate in family conferences but also prepare the family for the conference, coordinate it, and reinforce what was discussed with the family after the meeting.³² When nurses work to the full scope of their practice and act as coordinators of care, the needs of patients and their families at the end of life are more likely to be met, and the patient's place at the center of care is ensured.

Bereavement Care

As members of an acute care team, ICU nurses focus on events that occur in the ICU and are often not encouraged to provide support for families after patient discharge or death. Increasing numbers of studies have shown that family members can benefit from bereavement support from ICU clinicians or from follow-up services or follow-up family meetings.^{20,33-36} Bereavement support also includes staff debriefing,³³ especially for emotionally charged or complicated deaths.

It should also be acknowledged that family member bereavement begins before the patient has physically expired. Families can be comforted and assured that they will not be abandoned.³⁷ In addition, family members may want to be present at the bedside when the patient dies.³⁷ Therefore, efforts should be made to allow family members of dying patients extended visiting hours, even in units that normally have limited visiting hours. It should also be kept in mind that some family members may not want to be present during the patient's final hours, and their wishes should also be respected.

Promoting a Good Death

Another facilitator of positive family experiences at the end of life in the ICU is the promotion of a good death. Several studies spanning more than 2 decades have explored ICU nurses' and families' definition of this concept. A good death includes the following characteristics: death with dignity, ensuring that the patient does not die alone, an appropriate environment, good symptom management, following patient wishes regarding end-of-life care, acceptance of the impending death by the patient and the family, respect for individual differences, and good, timely communication.^{4,38-42}

Several practical nursing interventions can be implemented in order to promote a good death. One is, as mentioned previously, extending visiting hours for families of dying patients^{4,5,20,33} and allowing family members the opportunity to say goodbye.⁵ A recent European study found that only 24% of ICUs had an open visiting policy, with a mean visiting time of only 4.75 hours per day.³² In addition, many family members preferred a private place in the patient's final hours; however, a private place is not always available to families.^{4,20,35} To accommodate this preference, nurses could try to transfer patients to a single room in their final hours.

Several other nursing interventions can improve the quality of death and family member satisfaction with the dying process. One is allowing family members to help provide direct physical care for the patient toward the end of life. Two qualitative studies showed that family members appreciated this opportunity to provide care for their

loved one.^{6,20} Those who provided such care had greater peace of mind

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and a sense of being needed, although they described fears of interfering with medical devices or with the health care provider's routine activities.⁶ Family members were also more satisfied when they were provided with spiritual care^{20,43} or spiritual support.⁴⁴ Therefore, nurses must be available to the patient and family to provide assistance when needed. Although not all families want spiritual support, the option should be available. Promoting a peaceful environment at the end of life, exhibiting caring behaviors, and providing family support were found to be important aspects of nursing care in a recent metasynthesis of 12 qualitative studies of family member experiences of end-of-life care.⁵ Therefore, one of the most important final acts that nurses can do is to provide an appropriate environment for a good death.

Caring for the Health Care Provider

One of the difficulties affecting end-of-life family experiences is that nurses and physicians often lack the proper training and support needed to provide good end-of-life care. When this is the case, both patients and

family members may not receive optimal care. Therefore, training and supporting health care providers can be considered a facilitator of improved family experiences in the ICU. Role models and leaders are needed to help nurses provide high-quality end-of-life care.⁷ Good nursing leadership is also necessary when encouraging collaborative practice,²³ in which nurses feel empowered to participate in end-of-life discussions and decision-making. More than 10 years ago, one of the initial recommendations for improving end-of-life care in the ICU was providing support to clinicians during this difficult and complicated process.⁴⁵ More recently, Canadian nurses identified several types of stressors they experienced when providing end-of-life care.⁴⁶ These included organizational stressors such as lack of continuity of care, professional stressors such as lack of palliative care competencies, and emotional stressors such as lack of emotional support. The

Disagreement can arise between family members as a result of differences in values and the definition of high-quality care at the end of life. authors recommended that managers develop both emo-

tional support and educational programs for their staff related to end-of-life care. Others have recommended increased collaborative discussions between providers related to end-of-life issues and learner-centered skills training.^{7,47} An educational intervention that included didactic, practice, and affective elements was successful in improving participants' self-perceived skills.⁴⁷

In summary, staff nurses and nursing leadership can facilitate positive family experiences by returning the family to the center of care. This includes improving communication, working to the full scope of our practice as effective coordinators of end-of-life care, providing the emotional and environmental framework for a good death and healthy bereavement, and caring for ourselves as caregivers.

Barriers

Some important yet relatively neglected barriers to the provision of high-quality end-of-life care are medical uncertainty and differences in values and culture.

Medical Uncertainty

One common barrier to high-quality end-of-life care is that, despite their best efforts, clinicians can be poor

predictors of patient outcomes.⁴⁸ One of the consequences of medical uncertainty is a delay in end-of-life decision-making. In addition, possibly because of uncertainty, family members can have difficulty accepting a poor prognosis.² As Azoulay and colleagues¹⁴ have noted, it is easy to make decisions when the medical prognosis is very good. When the prognosis is very bad, the decision to move from curative to comfort care is also relatively easy. However, difficulty can arise when the prognosis is uncertain. Caregivers need to learn how to help family members cope with this uncertainty.^{14,17,49} One study showed that surrogate decision makers experienced higher levels of uncertainty (decisional conflict) when making end-of-life decisions than when making other types of medical decisions.⁵⁰ In a review of possible outcome measures for family experiences in the ICU, the concept of decisional conflict was recommended as an outcome measure that could be used to improve communication with families.⁵¹

Differences in Values and Culture

Intensive care units were established in order to save the lives of people with critical illnesses. Therefore, an ICU culture developed in which the value of life was placed above all other values, including quality of life.⁵² Over time, this value system has shifted toward a balance between length of life and its quality. However, a rescue culture and a tendency toward denial of death,^{52,53} among caregivers as well as family members, are still pervasive in the ICU. Denial of impending death tends to delay an open discussion of end-of-life decision-making and acts as a barrier to the provision of high-quality end-of-life care.

Conflicts surrounding the end of life between the medical staff and the family are considered to be relatively rare⁵⁴ and usually arise when the family insists on curative care when the medical staff deems such treatment futile. Disagreement can also arise between family members as a result of differences in values⁴⁹ and the definition of high-quality care at the end of life.⁵⁵ More broadly, differences in end-of-life decisions across countries and regions due to variations in cultural and religious values have been documented.^{24,56} Therefore, it is important to understand cultural beliefs at the end of life,⁵⁷ and to realize that one size does not necessarily fit all family members.⁵⁸ Some families consistently prefer life-sustaining treatments, whereas others uniformly

reject them or exhibit uncertainty.⁵⁸ When family members remain unsure about the best course of action, they may be unable to make decisions, leading to increased conflict with the medical team.⁵⁹ To reduce the psychological burden on families, family members should be free to determine how much they want to participate in decision-making, and each decision-making process should be tailored to the individual circumstances.⁸

Conclusion

Recent clinical guidelines¹ for family-centered care in the ICU recommend family presence in the ICU, family support, good communication with the family, and the provision of operational and environmental support for high-quality end-of-life care. This article has highlighted specific nursing practices that support these guidelines. Nurses should maintain ongoing, open communication with family members, while monitoring their choice of words and the timing of conversations. An important role of the nurse is to comfort the family throughout the bereavement process and provide a supportive environment, both physically and emotionally. Nurses are the primary coordinators of patient and family care. Therefore, they must take an active role in end-of-life care and decision-making, including family conferences. Nurses must help families navigate through the uncertainties of the dying process, remaining cognizant and respectful of individual, family, and cultural differences. Perhaps most importantly, nurses must have access to educational opportunities and emotional support from their colleagues and managers if they are to provide the highest-quality care to critically ill patients and their families. **CCN**

Financial Disclosures
None reported.

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See also

To learn more about end-of-life care, read "Ensuring Breathing Comfort at the End of Life: The Integral Role of the Critical Care Nurse" by Campbell in the *American Journal of Critical Care*, July 2018;27:264-269. Available at www.ajconline.org.

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