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

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. 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. 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. 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. 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 authors 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. 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 al concluded that greater understanding is needed of the language that can be used with families to describe death and dying in the ICU. Another study 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. 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. A group of palliative care physicians recommended that the health care staff brief interpreters before they meet the patient or the family. 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.

**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...
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 happen-
ing.\(^3,13\) 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 cli-
cians during these meetings\(^17\) 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 mem-
bers spoke during the conference and degree of family
satisfaction with physician communication as well as
family ratings of conflict, with higher proportions associ-
ated with increased satisfaction and decreased conflict.

Good communication leading to decision-making is
not a onetime event but rather a process\(^14\) that should
be started soon after patient admission.\(^19\) An ethnographic
study of an American ICU by Gutierrez\(^13\) showed that
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. Gutierrez\(^13\) 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 pro-
gnosis and that related to decision-making and recom-
mended 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 conversa-
tions with family members. Health care providers should
talk with families frequently and try to initiate conver-
sations 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 therapy\(^2\)
and for support when going through the decision-

making process.\(^2\) A key role of nurses is to facilitate com-
munication 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 col-
leagues\(^27\) 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 medi-
cal 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 process\(^28\) 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 study\(^30\) 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 study\(^31\) showed that ICU nurses described their
role in family meetings as that of an intermediary. These
nurses stated that although they acted as patient adva-
cates, they perceived the presence of barriers that lim-
ited 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
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.

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 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 care20,43 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
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.

**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. 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. As Azoulay and colleagues 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.

**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. 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, 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 rare 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 values and the definition of high-quality care at the end of life. More broadly, differences in end-of-life decisions across countries and regions due to variations in cultural and religious values have been documented. Therefore, it is important to understand cultural beliefs at the end of life, and to realize that one size does not necessarily fit all family members. Some families consistently prefer life-sustaining treatments, whereas others uniformly...
should be tailored to the individual circumstances. 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. 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.

**Conclusion**

Recent clinical guidelines 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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