End-of-Life Decision Making in Intensive Care

Mary Thelen, RN, MSN, CCRN

Mrs J., a 75-year-old widow, was admitted to the intensive care unit (ICU) after heart surgery. Before the surgery, she had been active in her community and enjoyed canning, quilting, and helping her elderly friends. Her greatest fear about surgery was that she might have a stroke, and she asked her daughter, Grace, who was the designated decision maker on Mrs J.’s advance directive, to promise that if something happened to prevent Mrs J. from returning to her independent lifestyle, Grace would make sure that life-prolonging treatment was not continued.

Initially, Mrs J. did well after surgery, but she had a debilitating brain stem stroke several days later and required intubation, mechanical ventilation, and tube feedings. Grace, being very clear about her mother’s wishes, asked the physicians to stop the mechanical ventilation and the tube feedings. Three physicians were involved in Mrs J.’s care. Because of philosophical differences related to their specialties, they could not agree on a decision to discontinue treatment, despite repeated requests from Grace. Grace began to feel angry, and nurses caring for Mrs J. felt torn and frustrated.

Scenarios such as this are not uncommon in ICUs and require that those caring for patients in the unit be proficient not only in saving lives but also in providing expert care at the end of life. In this article, I focus on one aspect of end-of-life care in the ICU, namely, end-of-life decision making. On the basis of recent research in nursing, medicine, and social sciences, I describe end-of-life decision making in the ICU and suggest strategies for improving the process for healthcare providers as well as patients and patients’ families.

Why Consider End-of-Life Decision Making in the ICU?

New drugs, devices, and tools are developed every day for use in ICUs that increase the ability to counteract or modify the effects of diseases that, in the past, were surely fatal. These possibilities can be exciting, and “enthusiasm for high technology and sophisticated interventions characterize the culture of American medicine.”1 In fact, both caregivers and patients have high expectations for cure in the ICU because of all the resources for treatment that are available.2

However, in the enthusiasm for technology and cure, often patients’ wishes, quality of life, and consideration of the burden of treatment compared with the benefit are overlooked. Furthermore, the complexity of ICU situations often makes it difficult to determine patients’ preferences and values with certainty. Communication and relationships with patients and their families can be lost in the technological intensity of the ICU.2

In the past several years, increased attention has been paid to improving end-of-life care for both patients and their families. An exam-
ple is the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT), a landmark study about patients’ preferences for end-of-life care. Many patients die in the ICU, most often after life-sustaining therapy has been withheld or withdrawn. However, despite the growing emphasis on end-of-life care, neither physicians nor nurses think that their educational preparation or clinical experiences have prepared them well to help patients and patients’ families at the end of life.

Another common form of end-of-life decision making centers on resuscitative efforts. These decisions may result in DNR orders and can vary in content; some patients may request no resuscitative efforts, whereas others may wish to have limited efforts, such as medications or defibrillation only, if a cardiac arrest occurs. In a study by Simpson, 36% of all patients admitted to 2 British ICUs on an emergency basis during a 3-month period eventually had DNR orders written, and 77% of all ICU deaths occurred after DNR orders had been written. Although Weiss and Hite found that patients who had DNR orders were less likely than patients without such orders to be admitted to an ICU again and were less likely to be receiving mechanical ventilation or to be in the ICU at the time of death, others found that many patients continued to receive all other aggressive treatments, with the aim of cure, when a decision had been made not to resuscitate the patients if a cardiac or respiratory arrest occurred.

A third form of end-of-life decision making is withholding or withdrawing life-sustaining therapies, such as antibiotic therapy, use of vasopressors, dialysis, administration of fluids and nutritional feedings, and mechanical ventilation. Although cultural differences exist between acceptance of withholding therapies and acceptance of withdrawing the therapies, many agree that withdrawing therapies is “morally equivalent” to withholding them. Patients’ family members are often asked to consider withholding or withdrawing life-sustaining therapies in the ICU, and in a Canadian study, 90% of ICU deaths occurred after some sort of life-sustaining treatment had been withheld or withdrawn. Decisions about these therapies most often occur simultaneously with or after decisions to forgo resuscitation (DNR orders).

When decisions have been made to withdraw or withhold therapies, a decision to pursue “comfort care” may follow. Comfort care involves discontinuing any diagnostic or therapeutic procedures, such as obtaining blood samples for laboratory tests or physical therapy, that do not contribute to the patient’s comfort, as well as ensuring that adequate amounts of analgesics and sedatives are given to control pain, dyspnea, or other uncomfortable symptoms. In the study by Fins et al., 46% of 200 consecutive patients who died in one medical center had comfort care plans in place at the time of death. These comfort care measures were implemented, on average, 2 days before death. These findings parallel those of the SUPPORT study, in which end-of-life decisions to forgo resuscitation were often made within 2 days of death. Patients in the SUPPORT study were seriously ill and knowledge of their impending death was clear, yet decisions about end-of-life care were delayed. These findings suggest that for these types of patients, consideration of the timeliness of this decision making is needed.

Who Participates in End-of-Life Decision Making?

Most often in Western healthcare, the physician is the major decision maker in the end-of-life process. In an integrated review of current research, Baggs and Schmitt found that physicians often make these decisions alone or with minimal
input from others. Other investigators\(^{26,27}\) found that physicians make treatment decisions in consultation with other physicians. When patients’ family members are involved, physicians are most commonly the initiators of discussions about end-of-life treatment issues\(^{15}\) and often dominate the discussions. This dominance may occur because physicians think they have superior knowledge, have difficulty understanding the lay perspective, or try to relieve patients’ families of guilt and confusion.\(^ {19}\)

Several studies\(^ {11,12,19}\) have indicated that in the ICU, patients are rarely involved in the end-of-life decision making. The reported percentage of ICU patients involved in making their own DNR decisions ranges from 0% to 32%.\(^ {11,12,20,22}\) Because of the severity of patients’ illnesses in the ICU, this finding may be understandable; patients may not be physically or mentally able to participate. Another explanation for this finding may exist, however. Although healthcare providers in a US study,\(^ {7}\) including physicians, nurses, chaplains, and social workers, stated that patients should be the initiators of end-of-life discussions, almost all of the providers (93%) expressed a belief that not all patients have the right to make end-of-life decisions. It is unclear how patients’ “rights” were defined in this study,\(^ {7}\) and reasons for the healthcare providers’ beliefs were not explored. In a more recent study,\(^ {21}\) 96% of participants, which included nurses, physicians, pharmacists, dieticians, administrators, and others, agreed that patients have the “absolute right” to determine what care the patients receive at the end of life.

Most often, physicians look to the family members of ICU patients as surrogate decision makers for the patients. Studies\(^ {12,14}\) have indicated that patients’ family members are involved with end-of-life decisions 60% to 80% of the time. Involvement of patients’ family members in decision making is more common in the United States than in other countries; in the United States, patients’ family members are legally recognized as surrogate decision makers when patients are incapacitated.\(^ {5,24}\) In other countries, decisions to limit treatment at the end of life are often made by a physician without involving the patient’s family or with notification of the family of the decision after the fact.\(^ {16,20,22}\)

Evidence of nurses’ involvement in the end-of-life decision making is limited. In studies that included nurses,\(^ {4,25}\) most nurses reported participating in end-of-life discussions with patients or patients’ families at some time, but in the majority of studies on this issue, the focus was on physicians, patients, and patients’ family members.

What Is the Process of End-of-Life Decision Making?

With the exception of advance directives, which patients ideally write before a life-threatening illness occurs, most end-of-life decision making occurs as a patient is nearing death.\(^ {3,5}\) Stroud\(^ {4}\) found that end-of-life decision making occurs in a stepwise fashion. Usually, the decision to forego resuscitation (DNR orders) is made first; 1 to 5 days later, decisions are made to withhold or withdraw other therapies, such as dialysis, parenteral nutrition, or mechanical ventilation.

Two groups of researchers\(^ {26,27}\) explored the process that patients’ family members go through as the family members make decisions to withdraw life-sustaining therapies. Tilden et al\(^ {26}\) found that families first begin to “recognize the futility” of a loved one’s situation by asking questions and closely watching care providers for cues to the prognosis of the loved one. As the family members begin to realize the probable bleak outcome, they move to the next step of coming to terms with the reality of the patient’s suffering and begin to imagine what the patient would want, on the basis of known values or expressed preferences.

Shouldering the surrogate role is the third step and involves the work of taking on the responsibility of making decisions on their loved one’s behalf. Finally, facing the question of whether to forgo life-sustaining therapies is the last step in making these decisions. In this study,\(^ {26}\) which included ICU patients with a variety of diagnoses, most families moved through these steps in a linear fashion.

Similarly, Swigart et al\(^ {27}\) found that surrogate family decision makers move through a series of steps in making end-of-life decisions. Understanding the critical illness by seeking information about the irreversible physiological processes that are occurring and developing trust in the healthcare team and the care provided are the first step of the process. Reviewing the patient’s life and bringing closure to that life story are the second step; this step involves considering the patient’s role in the family, thinking about the patient’s values, and evaluating the patient’s quality of life. The third step involves taking on the role of surrogate decision maker as a way to maintain family roles and relationships, seeing
the surrogate role as a way to continue to act as a responsible, caring family member for the patient and others in the family.27 This process takes time and allows the family to develop the sense of doing the right thing.

The results of another study28 illustrated similar steps, but from the point of view of the healthcare team rather than patients’ family members. The first step in the process is laying the groundwork, which is done by building trust and relationship with the patient or the patient’s family members, teaching about the illness, and “planting seeds” related to end-of-life issues. This step is followed by a step called shifting the picture. In this step, the members of the healthcare team work together to present consistent information to the patient’s family, create new expectations, and change the scope of treatment choices available. Finally, the team helps the family members accept a new picture, by reiterating information, involving other disciplines to assist the family, and helping family members redirect their hope from cure to a comfortable death.

All of the research reviewed illustrates that end-of-life decision making demands that patients’ families understand and process information, emotions, and responsibilities in order to make choices with which the families feel comfortable. The Figure provides a synthesis of the processes of healthcare providers and patients’ family members.

### What Factors Influence End-of-Life Decision Making?

#### Factors Associated With Healthcare Providers

Healthcare providers’ past education and experience related to end-of-life care in general have an effect on the end-of-life decision making.20 A majority of physicians and nurses feel unprepared to facilitate end-of-life decision making,27 and in a US study,9 96% of physicians, nurses, pastoral care providers, and social workers were unclear on the role of the durable power of attorney for healthcare. In another study,8 nurses reported learning to provide care for patients at the end of life by “trial and error.”

Culture is an important factor in end-of-life decision making. Some countries do not have laws on advance directives or DNR orders, resulting in more difficult decision making in some situations.24,30 A comparison of physicians trained in the United States with physicians trained in Eastern Europe indicated a significant difference in the percentage of physicians who discussed decisions to forgo life-sustaining treatment with patients’ families (93% compared with 19%, respectively).16 Withdrawal of life-sustaining therapies is not readily discussed in some countries, such as Israel,16 although withholding therapies is considered ethically acceptable.

Several examples illustrate these cultural influences. In a study37 of Italian intensive care physicians, 70% of the physicians said that when making decisions to withhold or withdraw
treatment, if a patient was not competent to make a decision for himself or herself, they would not seek to determine if the patient had ever expressed any wishes about end-of-life care. Researchers examining end-of-life practices found that in Japan care is rarely withheld or withdrawn. In France, 50% to 53% of deaths in ICUs occurred after decisions to limit care, although families participated in the decision making only 17% to 44% of the time.24

A physician’s specialty also influences end-of-life decision making.24,25 Cassell et al found that surgeons approached end-of-life decision making differently than did intensivists. Surgeons thought they had made a covenant with the patient to preserve the patient’s life and were more reluctant to forgo lifesaving measures. Intensivists’ perspectives were more global; their considerations included the patient’s quality of life and overall use of healthcare resources.

Factors Associated With Patients and Patients’ Family Members

Patients’ diagnoses and level of acuity play a clear role in the decisions made at the end of life. Diagnoses of multisystem organ failure, severe neurological injury, and end-stage heart failure or respiratory failure are most commonly associated with DNR orders.14,31 In interviews with seriously ill hospitalized patients, Lloyd et al found that chance of survival and predicted quality of life influenced patients’ willingness to undergo ICU care with mechanical ventilation; interestingly, quality of life before hospitalization did not influence patients’ decision making.

Although findings about the influence of advance directives on choices made for end-of-life care have been contradictory,3,10,11 some evidence indicates that families’ awareness of patients’ preferences, either through written documents such as advance directives or through previous conversations with the patients, clearly influences decisions made by patients’ families and eases the burden of decision making for the families.

How Do Healthcare Providers View End-of-Life Decision Making?

Both nurses and physicians have identified end-of-life decision making as the most frequent ethical problem in clinical practice.22 Because physicians write the orders, they often feel a heavy burden of responsibility when making end-of-life decisions.22,32 They ask themselves questions such as, Who am I to make these decisions?32 Nurses acknowledge that physicians have a difficult task and must live with the responsibility for decisions made, noting that physicians “have to sleep at night.”34 However, nurses report that they often have feelings of dissonance when caring for patients near the end of life.10,25,32,34 Nurses often disagree with physicians’ decisions, thinking that treatment was either stopped too soon or continued too long in futility.25,32,34 In a study by Punttillo et al,36 40% of nurses surveyed reported they had acted against their conscience at some time when caring for patients at the end of life. When nurses disagree with decisions, moral distress often results: nurses feel they are contributing to a patient’s suffering without providing any benefit to the patient.25,32,34 Physicians commonly are unaware of the ethical concerns nurses experience in these situations.8,19 Although nurses have some awareness of physicians’ ethical dilemmas,34 this lack of understanding of each others’ perspectives most likely is mutual.

In the process of end-of-life decision making, nurses see themselves as liaisons between physicians and patients’ families. Nurses describe serving as “interpreters” for patients’ families, explaining what physicians have said in lay terms.8,34 Nurses’ relationships with patients’ families help the nurses perceive what and how much information family members can receive at one time.24 In this relationship, nurses address the issues raised by physicians in a way and at a pace that patients’ families can understand. Sometimes patients’ families look to nurses for the “real answer” related to prognosis and quality of life for the patients.

How Do Patients and Their Family Members View End-of-Life Decision Making?

Little is written about patients’ perspectives on end-of-life decision making, except to show that patients want to be involved in the process. In a study by Heyland et al,37 three quarters of seriously ill, hospitalized patients had thought about and were willing to talk about their preferences for end-of-life care. In another study,4 90% of patients’ family members or surrogate decision makers wanted to share decision making related to end-of-life care with a physician; only 8% wanted to leave all decision making to a physician.

Although patients’ families want to be involved, being involved is not an easy process, and it is fraught with strong emotional reactions. In 2 studies,26,38 in which investigators focused on the experiences of patients’ family members with withdrawal of
life-sustaining therapies, stress and guilt were identified as 2 major components of end-of-life decision making for the families. Measuring stress with a psychometric tool, Tilden et al. found that 1 to 2 months after the experience of making a decision to withdraw life-sustaining therapy for a loved one, family members' stress was extremely high. Six months later, stress levels were still high. Family members described making these decisions for patients as work that was “overwhelming” and “devastating.” Patients’ families also reported feeling guilt that they selfishly allowed the patients to suffer if decisions were not made or carried out soon enough. In contrast, some family members felt empowered or proud that they were able to honor their loved ones’ wishes.

Family members who have made end-of-life decisions for a patient have identified behaviors of healthcare providers that are helpful and those that hinder good decision making (see Table). Swigart et al. suggested that patients’ family members see end-of-life decision making through a “wide-angle lens,” taking into account the patients’ life, values, personality, and interests, whereas the healthcare team views end-of-life decision making through a narrow window in time.

What Strategies Facilitate End-of-Life Decision Making? Change in Perspective

In the past, end-of-life decision making was approached as a “last resort,” something that was done when death of a patient was imminent, often after the patient was no longer able to participate in making decisions. This perspective needs to change. Patients want to talk about and be involved in decisions about what will happen at the end of their life. Patients’ family members recommend that issues related to end-of-life care be brought up early in the course of a life-threatening illness.

A proactive approach, identifying patients at high risk for dying and initiating discussions about prognosis and options with the patient’s families, can increase the use of DNR orders and comfort care.

Another perspective that needs to change is how healthcare providers value palliative care. Palliative care is defined as “care that aims to relieve suffering and improve quality of life for patients with a life-threatening illness and their families.” Palliative care is not something that is offered because “there is nothing more we can do”; it is an active, aggressive plan of care designed to alleviate patients’ symptoms and meet the diverse needs of patients and patients’ families. Unlike hospice care, which requires that patients forgo all curative treatment, palliative care can be offered while patients are still actively seeking care for a disease condition. As a patient’s disease progresses, however, palliative care can help the patient and his or her family shift their hopes from cure to comfort and peace.

Healthcare providers can also change the way they think about providing palliative care. It is just as important to be expert, skilled, and timely when providing palliative care as it is to know how to provide medications and interventions for a patient in the midst of an acute illness. Assisting with end-of-life decision making and providing end-of-life care should be included in educational curricula for nurses, physicians, and other healthcare personnel.

Awareness of Meaning for Patients’ Family Members

Intensive care healthcare providers deal with life and death issues every day. Patients’ family members, however, may have never faced these issues before, and the memory of this experience will be with them for a lifetime. Family members have described the experience of making end-of-life decisions for a loved one as “surreal,” “overwhelming,” and “devastating.” Family members are

<table>
<thead>
<tr>
<th>Behaviors of healthcare providers that influence end-of-life decision making by patients’ families</th>
<th>Behaviors that hinder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assisting with advance planning</td>
<td>Avoiding or postponing discussions about a patient’s poor prognosis</td>
</tr>
<tr>
<td>Providing timely communication</td>
<td>Being reluctant to use the words “death” or “dying”</td>
</tr>
<tr>
<td>Providing consistent care providers</td>
<td>Using medical terms</td>
</tr>
<tr>
<td>Treating the family with compassion and respect</td>
<td>Not knowing the patient</td>
</tr>
<tr>
<td>Acting as an arbitrator between family members</td>
<td>Giving inconsistent messages from other members of the healthcare team</td>
</tr>
<tr>
<td>Helping achieve consensus among family members</td>
<td>Placing full responsibility for decision making on one person</td>
</tr>
<tr>
<td>Providing emotional and grief support</td>
<td>Defining death as a failure</td>
</tr>
<tr>
<td>Providing access to the patient</td>
<td>Withdrawing from interactions with the family</td>
</tr>
</tbody>
</table>
making decisions in the midst of stress, anxiety, and powerful emotions and often need others who know and love the patient to affirm their decisions and may ask for information repeatedly to corroborate their decisions.26,39

The decisions made by patients’ family members will have a long-term impact on the members’ daily lives. Patients have a role in their families, and the patients’ living or dying will change the families forever; how decisions are made can also alter relationships between surviving family members.27,39,45 We, as healthcare providers, cannot take lightly what we are asking of patients’ family members when we ask them to participate in these decisions.

Interdisciplinary Approach

End-of-life decision making is most effective when members of the healthcare team work together in assisting patients and the patients’ families.6 Trust between team members is crucial in this process.34 Collaboration between physicians and nurses when dealing with end-of-life issues in the ICU may decrease the moral distress experienced by each group, especially when each group recognizes the unique moral dilemmas that the other group faces in these situations.32 The healthcare team, which may include physicians, nurses, social workers, chaplains, and others, needs to communicate a consistent message to patients and the patients’ families in order to best support and facilitate decision making.28 Implementation of palliative care teams (interdisciplinary teams devoted to supporting patients and their families through life-threatening illnesses or injuries) is one strategy to improve collaboration and coordination of end-of-life care.41,42

Relationship and Communication

Developing trust is one of the first steps in laying the groundwork for end-of-life decision making.24 Nurses in the ICU often quickly develop close, trusting relationships and emotional connections with patients and the patients’ families, because of the intensity of the care and the time the 3 groups spend together. Nurses serve as patients’ advocates and often as “go-betweens” between patients’ families and physicians,34 illustrating the trust patients and patients’ families place in ICU nurses. Trust also develops between patients’ family members and members of the healthcare team when care providers ask about a patient’s life, values, and interests; address conflicts and offer apologies when needed; relate personal experiences; and acknowledge what this decision making means to the patient’s family.15 In order for families to feel safe and supported in this decision-making process, a relationship of trust is crucial.

Another aspect of this relationship that strongly influences end-of-life decision making is attending and listening. Attending to the psychosocial effect of this process on patients and their family members lessens long-term adverse effects the process can have on all their lives.26,38 Family members have asked that healthcare providers “stop and listen” to their concerns and requests; stopping and listening helps decrease feelings of guilt and burden for family members when they feel they have been able to speak up for their loved one and have been heard.40

Timing and style of communication with patients and patients’ families also play an important role in effectiveness of end-of-life decision making. Communication with patients and their families needs to happen early and often, without the families having to ask to have the conversation.25,40 Delaying difficult conversations increases the burden on patients’ families29,40 and increases the moral distress of nurses, because the nurses feel they are causing unnecessary suffering for a patient.29,12 Stressed family members may need to have the same conversation several times before they can fully comprehend the information.

Communications should be clear, direct, and honest. Patients’ families have reported they want physicians and nurses to be frank and not avoid talking about bad news.15,26,40 Use of the words “death” and “dying” is more helpful to families than use of euphemisms.29,40 Positive words, such as “hope” or “better,” without specific details often confuse a patient’s family members and send mixed messages about the patient’s prognosis.29,40 Other words to avoid include medical terms, so familiar to nurses’ everyday lives but foreign to patients and patients’ families.15,40 Finally, using language that does not put the full weight of responsibility for decision making on patients’ family members helps ease the burden for them. Giving family members the facts and asking, What do you want us to do? is much more difficult for them than is presenting the facts, making recommendations, and then coming to a decision as a group.26
Conclusions

End-of-life decision making will continue to be a growing need in the ICU as medical technologies enhance the ability to prolong life. Despite the initial roadblocks, Mrs J.’s situation illustrates many of the elements that contribute to satisfying end-of-life decision making for all involved.

First, Mrs J. had expressed her preferences both in writing and in discussions with her daughter in advance of a life-threatening situation. Grace, Mrs J.’s daughter, had a strong desire to honor her mother’s wishes and persisted in communicating with the healthcare team about those wishes. Through continuity of assignments, Mrs J.’s nurses developed a close and caring relationship both with her and her daughter, coming to know and understand Mrs J.’s values and what was most important to her in life. Her nurses also persisted in advocating for her with physicians and the whole healthcare team, eventually calling for a meeting of the multidisciplinary ethics committee. Grace attended this meeting and spoke eloquently about her mother’s life. As a result of this meeting, the decision was made to discontinue mechanical ventilation and to stop tube feedings. Orders for comfort care were written, and Mrs J. died peacefully a few days later with her daughter at her side.

Relationship and communication — between patients and their families, between patients and patients’ families and the healthcare team, and between members of the healthcare team—are the key elements that will enhance the end-of-life decision making. Improving this process will decrease the distress experienced by both healthcare providers and patients’ families, honor our patients, and make the ICU a more humane and caring place in which to die.

References
34. Simpson SH. Reconnecting: the experiences experienced by both healthcare providers and patients’ families, honor our patients, and make the ICU a more humane and caring place in which to die.
Learning objectives:
1. Recognize barriers to providing end-of-life care in the intensive care unit
2. Describe steps commonly encountered in end-of-life decision making by the family
3. Understand supportive behaviors that nurses can provide to enhance end-of-life decision making

1. In the case study, what was the primary barrier in meeting Mrs. J's end-of-life desires?
   a. Lack of advance directives
   b. The daughter who failed to advocate for her mother’s wishes
   c. Patients and caregivers who have low expectations for a cure in the ICU
   d. Refusal to withdraw care by the intensive care nursing staff

2. Which of the following is true regarding the provision of end-of-life care in the intensive care unit (ICU)?
   a. Physicians and nurses are well educated within their programs to provide quality end-of-life care.
   b. In the enthusiasm for cure, patients' wishes are often prioritized.
   c. Patients and caregivers have low expectations for a cure in the ICU.
   d. Communication and relationships with patients and their families can be lost in the technological intensity of the ICU.

3. Which of the following is true regarding advance directives prepared by patients in the ICU?
   a. Advance directives have little impact on the actual care received by patients at the end of life.
   b. Specific instructions left by patients in advance directives are followed 75% of the time in the ICU.
   c. Intensive care patients who have advance directives are less likely to have a do-not-resuscitate (DNR) order.
   d. Advance directives are commonly used to direct care in the ICU.

4. What time frame similarities were found between studies regarding actual time of death and decisions for comfort care or DNR status?
   a. No correlation was found between time of death and these decisions.
   b. These decisions most often occurred within 2 days of death.
   c. These decisions most often occurred within 24 hours of death.
   d. These decisions most often occurred more than 1 week before time of death.

5. In Western healthcare, who is generally the major decision maker in the end-of-life process?
   a. Nursing staff
   b. Family
   c. Patient
   d. Physician

6. On the basis of several studies, what percentage of patients in the ICU actually are involved in making their own DNR decisions?
   a. 50%
   b. 60% to 70%
   c. 0% to 32%
   d. 80% to 90%

7. Which of the following best describes the fashion in which end-of-life decision making generally occurs?
   a. The decision to forego resuscitation is usually made first; followed 1 to 5 days later by decisions to withhold or withdraw other therapies.
   b. No specific order has been found in end-of-life decision making.
   c. Initially, decisions are made to withhold or withdraw therapies, followed by DNR orders.
   d. Because the majority of patients in the ICU have advance directives, end-of-life care is based on these documents.

8. What is the first process that family members usually go through in making end-of-life decisions?
   a. Taking on the role of surrogate decision maker.
   b. Understanding the critical illness.
   c. Come to terms with what the illness or injury means for the patient.
   d. Face the questions to forgo life-sustaining therapies.

9. Which of the following is a behavior by healthcare providers that is helpful to families making end-of-life decisions?
   a. Providing access to the patient
   b. Placing full responsibility for decision making on one person
   c. Acting as an arbitrator between family members
   d. Assisting with advance planning

10. Which of the following is a behavior by healthcare providers that hinders families making end-of-life decisions?
    a. End-of-life decision making is identified by both nurses and physicians as the most frequent ethical problem in clinical practice.
    b. Nurses rarely acknowledge the difficult task that physicians encounter in end-of-life decision making.
    c. Nurses rarely disagree with physicians' decisions about end-of-life care.
    d. Nurses have little involvement and impact on the end-of-life communications between physicians and families.

11. Which of the following is true regarding the view of end-of-life decision making by healthcare providers?
    a. Establishing the next of kin and formal decision maker
    b. Withdrawing from interactions and allowing the family members to come to a decision on their own.
    c. Acting as an arbitrator between family members
    d. Face the questions to forgo life-sustaining therapies.

12. Which of the following is a vital first step in supporting end-of-life decision making for the family?
    a. Establishing the next of kin and formal decision maker
    b. Developing trust between the patient, family, and healthcare team
    c. Describing the stages commonly encountered in end-of-life decision making
    d. Calling a family meeting to initiate end-of-life decision making

Test ID: C056
Test ID: C056: End-of-Life Decision Making in Intensive Care

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

1.  2.  3.  4.  5.  6.  7.  8.  9.  10.  11.  12.
   a  b  a  c  b  a  b  c  c  c  d  d

Program evaluation
Objective 1 was met Yes No
Objective 2 was met Yes No
Objective 3 was met Yes No
Content was relevant to my nursing practice Yes No
My expectations were met Yes No
This method of CE is effective for this content Yes No
The level of difficulty of this test was: Easy Medium Difficult
To complete this program, it took me ___ hours/minutes.

Name
Address
City State ZIP
Country Phone
E-mail
RN Lic. 1/2 St.
Payment by: Visa M/C AMEX Discover Check
Card # Expiration Date
Signature

The American Association of Critical-Care Nurses is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center’s Commission on Accreditation.
End-of-Life Decision Making in Intensive Care
Mary Thelen

Crit Care Nurse 2005;25 28-37
Copyright © 2005 by the American Association of Critical-Care Nurses
Published online http://ccn.aacnjournals.org/

Personal use only. For copyright permission information:
http://ccn.aacnjournals.org/cgi/external_ref?link_type=PERMISSIONDIRECT

Subscription Information
http://ccn.aacnjournals.org/subscriptions/

Information for authors
http://ccn.aacnjournals.org/misc/ifora.xhtml

Submit a manuscript
http://www.editorialmanager.com/ccn

Email alerts
http://ccn.aacnjournals.org/subscriptions/etoc.xhtml