Organ donation occurs as a culmination of 2 processes: the ending of a patient’s life and the gaining of permission for donation from the patient or the patient’s family. Donation cannot occur outside these contexts, and thus understanding end-of-life issues and having a commitment to a caring request process are essential. Nurses are the caregivers most intimately involved in end-of-life care and so have the capacity to greatly affect requests for organ donation.

Without appropriate, skilled end-of-life care and skilled, knowledgeable communication with patients’ families, donation (and the opportunity to help recipients) will not occur. Nurses share responsibility with other healthcare providers for the quality of both end-of-life care and the conditions that may affect the donation process.

In this article, I set the stage for other articles in this issue of Critical Care Nurse by briefly summarizing current norms regarding end-of-life care and persistent areas of concern. I also specify the contributions critical care nurses can make to improvements in end-of-life care and organ donation.

End-of-Life Care and Norms
End-of-life decision making has undergone enormous change during the past 50 years. Societal attitudes and beliefs about death, dying, and healthcare at the end of life have evolved in response to the rapid expansion in technical, pharmacological, and surgical innovations. With these innovations have come complex challenges for patients, patients’ families, and the professionals who provide care. In particular, the ability to prolong life in patients with severe injury or advanced stages of disease has raised deep questions about the desirability and moral acceptability of limiting and forgoing treatment.

In facing these difficult moral questions, healthcare professionals have also struggled to develop systems of care that meet the needs of patients and patients’ families at the end of life. The principle of autonomy, the right of patients or their proxies to accept or forgo medical interventions, has been widely accepted as the foundation for decision making. The development of hospice services and palliative care programs has been associated with great strides in the knowledge of how to manage signs and symptoms of advanced illness and improve the quality of life of
dying persons. Nevertheless, healthcare professionals continue to struggle with their own ambivalence, concerns, and fears about death, struggles that may impede the search for effective ways to support patients and patients’ families during this difficult time.

End-of-Life Decision Making

A tremendous amount of research has been done on end-of-life decision making in the context of acute care. Most studies have been investigations of patients’ attitudes and preferences, the preferences of patients’ families and the families’ ability to predict patients’ choices, and nurses’ and physicians’ attitudes toward and knowledge of end-of-life care and issues. Although little is known about decision making specific to organ donation, these more general studies provide important insights into the supports and barriers that may affect organ donation processes.

The largest study to date of end-of-life care and decisions in the acute care setting has been the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. This investigation, conducted in 5 teaching hospitals, gathered information about care processes in 9105 adults with life-threatening illnesses. In addition to data on aspects of the care patients received, the study provided a wealth of information relevant to the decision-making process, confirming the results of other studies with fewer patients. The findings of this investigation and other studies established a number of patterns. Regardless of who made up the study sample, researchers consistently found that discussions with patients about limitation of treatment occurred relatively infrequently, even in the context of serious or terminal illnesses; do-not-attempt-resuscitation decisions were left until late in the illness, usually just days before death; and it was much more common for patients’ families rather than the patients to be the decision makers.1-6

The pivotal role of patients’ family members in making decisions about the extent of treatment is related in part to the timing of decisions to limit treatment, which tend to occur after patients have lost the capacity to participate. However, relying on patient’s families as decision makers seems to be consistent with the preferences of patients; when asked, a reasonable majority of patients preferred that decisions about resuscitation and treatment at the end of life be shared among their family members and physicians.1,7,8

Families have been recognized as legally sanctioned surrogate decision makers at least since the report of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983. The burden families bear in shouldering the responsibility for decisions and the difficulties they experience have been well recognized. Although it was hoped that the increasing use of advance directives, prompted by the Patient Self-Directed Act of 1990, would help reduce uncertainty by fostering discussion and providing evidence of a patient’s wishes, little evidence indicates that such a reduction has occurred. Research has consistently indicated that few patients have advance directives, and when such directives exist, they are too general or vague to be of much assistance.10-14 Consequently, evaluating when aggressive care should be continued and when it should be withheld, and establishing a process for making these evaluations, remains difficult for both clinicians and patients’ families.15-17

Most of the research to date has centered on discrete decisions, particularly the decision to withhold resuscitative efforts in the event of a cardiac arrest (ie, do-not-attempt-resuscitation decisions). Few investigations of the actual process of decision making about organ donation have been done, although a number of retrospective studies have been done about the outcome of requests for donation and the perceptions of patients’ families of the donation process. A consistent finding in these studies is the importance of communication and the families’ perceptions of the quality of care of their loved ones.18-21

These results are similar to those of other studies of family support and end-of-life investigations. Communication between patients’ families and the healthcare team is well recognized as one of the most important factors in reducing the families’ stress, helping family members cope, and increasing satisfaction with care. Access to reliable information about the condition and prognosis of their loved one repeatedly has been the most important factor for all families in the critical care setting, particularly the families of patients with terminal illnesses.22-25

Transitions in Goals

A key phase in making decisions related to either limiting or withdrawing life support or life-sustaining therapy in critical illness and injury is the transition from the objective of cure to another objective, such as
ensuring a peaceful death or minimizing suffering. Often when family members must make decisions for a patient for whom cure is not possible, honoring the patient’s wishes or at least acting in accord with the patient’s values and beliefs is the most important goal. However, the typical environment of critical care units, with the focus on cure, is not oriented to the types of processes and communication most needed by families who are struggling with making this transition in goals. Most intensive care units are strongly centered on providing aggressive, life-prolonging therapies and may not have care processes that support the gradual adoption of goals other than those that support biological survival. Asch et al, who surveyed 468 critical care nurses about end-of-life care, reported that “the most compelling concept expressed by the nurses was that the environment of critical care is often insufficiently responsive” to the needs and suffering of patients and patients’ families.

Perhaps the most important factors leading to the infrequency with which goals of care are discussed or explicit consideration is given to limiting treatment are the ambiguity patients and their families and healthcare providers experience when confronting death and the ambiguity of poorly defined situations. In an ethnographic study of how death occurs in hospitals, with a focus on elderly patients in intensive care units, Kaufman identified culturally defined “problems” that surround death and dying. She noted the consistent pattern of the “technologic imperative”—that is, the assumption that if a treatment is available, it must be used—and the strong tendency to avoid considering the goals of care until a persistent deterioration in a patient’s clinical condition was obvious. She concluded that the difficulty surrounding the dying process is “not merely about an obvious choice between ‘heroics’ and ‘humanity.’ The actual situation is both much more muddled and far less rational than the cultural conversation suggests. . . . It is about not knowing what to want, or how to decide.” This ambivalence is also evident in studies that indicate that although nurses generally report positive attitudes toward the idea of donation, the nurses’ actual behavior in terms of a stated willingness to donate their own organs or the organs of their family members suggests either some uncertainty or other barriers to donation.

Both the difficulty in changing goals of care during the process of accepting new clinical realities and the importance of making this transition have been recognized by scholars and clinicians, particularly in the field of palliative care. Davies et al studied the impact on families of having a family member with advanced cancer. Using a grounded theory method, the authors described the series of changes and reactions that occurred as a transition with many phases or dimensions; these phases included feeling burdened, contending with changes, struggling with the paradox between wanting to give up and wanting to keep fighting, and coming to realize the ill person will not recover. Arnold, in his personal narrative of experience as a palliative care physician on an in-patient service, also noted the critical importance of having clinicians acknowledge this transition process and recognize the variability of it. He particularly noted the special challenges of helping families of patients in acute care who, unlike those in hospice care, have not already made a conscious decision to emphasize quality over quantity.

The challenges of helping patients’ families make the transition from curative to end-of-life goals were also noted by Kirchhoff and Beckstrand in an article on the perceptions of intensive care unit nurses of end-of-life care and barriers to good care. Supporting patients’ families and allowing time for transition was one of the most important aspects of good care, yet nurses perceived marked dissonance and barriers surrounding the change in goals. Specifically, nurses related the difficulty of identifying the appropriate time for transition and the lack of a process to support the transition.

Clearly, most families of patients who may be candidates for organ
donation face enormous challenges in making this transition. Organ donation usually occurs in the context of a sudden trauma or catastrophic event (e.g., intracerebral hemorrhage) that trigger an initial concentrated attempt to save the life of the patient or at least restore some level of acceptable function. With the detection of either brain death or severe and irreversible brain damage, clinicians and patient’s families must then confront the question of new goals.

Avoiding or paying inadequate attention to the difficult process of determining goals and ensuring that plans and decisions are consistent with those goals has many serious consequences. Because values and beliefs related to death and dying are intrinsically idiosyncratic, no valid criteria exist for the characteristics of a “good death” or a preferred course of an illness in all instances. However, considerable evidence indicates that failure to develop a consensus among clinicians and patients’ families about treatment goals, inadequate preparation for likely outcomes, and lack of communication about decisions generate distress and dissatisfaction among patients and their families, often related to prolonging the dying process. In a qualitative study of surrogate decision makers, Jeffers35 noted the frequent theme of significant dissatisfaction related to “disharmony” and lack of attention to the mutuality of goals. Confirming the variability in preferences, Hanson et al,36 in their interviews of 461 bereaved family members, found common perceptions of disagreement between patients’ families and healthcare professionals. A total of 6% of the families reported that they wanted more treatment than the physician wanted to provide, and 18% reported that they refused interventions that the physician encouraged. In another study, by Abbott et al,37 46% of patients’ families interviewed 1 year after discussions of limiting treatment for a loved one described conflict with healthcare professionals over the decision to withdraw or withhold interventions. In a study by Singer et al38 of patients’ perspectives on quality end-of-life care, 61% of 126 seriously ill patients said that avoiding inappropriate prolongation of dying was important, second only to adequate management of pain.

In addition to this failure to provide effective support, inadequate or poor communication with families of potential organ donors may also result in a second failure: lack of opportunity for a patient’s family to honor the patient’s previous wish, act in accord with the patient’s previously expressed values, and have the solace of having helped others through the gift of donation. Thus, providing adequate communication and support for patients’ families who are considering organ donation is of utmost importance during the transition away from the goal of cure.

Issues and Barriers in Organ Donation

The complexity of the issues and factors associated with end-of-life care are also operative in all phases of organ donation. Since the first transplantations in the 1960s, patients, patients’ families, and healthcare providers have all been challenged to recognize, evaluate, and come to consensus about the moral, social, and economic aspects of organ donation and transplantation. Organ donation requires that healthcare professionals and a patient’s family members recognize the incurable nature of the patient’s injury, believe in at least the moral permissibility (if not moral obligation) to stop using ineffective therapies and stop prolonging the dying process, and evaluate organ donation and transplantation as a medical and social good. In addition, of course, the environment must include the technical resources and personnel needed for the donation process itself.

Organ transplantation, in addition to being an end-of-life issue, is embedded with many social, psychological, and cultural meanings. As noted by Youngner et al,39 organ donation is “intrinsically and profoundly connected with experiences and questions concerning the human condition that are at once elemental, transcendent, and fraught with ambiguity and mystery.” Understanding how and why a patient’s family members request, agree to, or refuse donation of the organs of their loved one requires both sensitivity to and appreciation of the many complex dimensions of the act of donation.

Organ donation, with its ability to both improve the quality of life and potentially save lives, is a national healthcare priority. This fact is reflected in the activities of government-sponsored groups, such as the Organ Donation Breakthrough Collaborative40 of the Department of Health and Human Services and the workshop on non–heart-beating donors41 of the Institute of Medicine, and in the numerous initiatives of professional organizations, including the Society of Critical Care Medicine and the American Association
of Critical-Care Nurses. Although these efforts have been successful in increasing donations from deceased individuals, from 5099 in 1994 to 7150 in 2004, the rate of increase has not kept pace with the growing waiting list of potential transplant recipients. To some extent, the increasing gap between demand and supply reflects the increased ability to support potential transplant recipients through medical crises and into a period of stabilization, thus making more patients eligible for transplantation.

Numerous factors can act as barriers to organ donation. Among the most widely acknowledged are failure on the part of healthcare professionals to identify potential donors and initiate the referral and request process and beliefs and attitudes of the families of potential donors. Many of the government initiatives, such as the 1998 required request regulations of the Health Care Financing Administration, and efforts by professional associations, such as the recommendations of the American Medical Association Council on Scientific Affairs for physicians’ training and involvement in the request process, are intended to address failures on the part of healthcare professionals. Public education programs and studies to identify modifiable factors associated with refusal to donate have been attempts to address the public’s attitudes. However, with regard to both professionals and the public, 2 areas in particular remain problematic: the definition and meaning of brain death and the more recent donation after cardiac death (DCD).

Complete and irreversible cessation of all brain activity (ie, brain death) has been legally sanctioned as a definition of death since the 1980s, as recommended by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. All states have accepted the Uniform Determination of Death Act, confirming the legal status of this definition. Nevertheless, persistent misunderstandings remain among both healthcare professionals and the public about the criteria for establishing brain death, as well as the meaning of the term. In a survey of 1351 Ohio residents, Siminoff et al found that almost all of the respondents had heard of brain death, but most had mistaken views of the difference between brain death and coma and the typical medical features of each (eg, inability to hear, irreversibility). Most important, only one third thought that someone who was brain dead was legally dead. Continuing challenges to both the philosophical and medical bases of the concept of brain death have led some authors to suggest that we abandon reliance on the “dead donor rule,” which prohibits the retrieval of organs from persons who are not dead, and instead rely on the moral analysis that stems from adherence to patients’ wishes and the obligation to refrain from harm. Clearly, this complex philosophical debate will continue to require careful discussion.

In the early 1990s, interest was reawakened in procuring organs from “asystolic,” or non–heart-beating, donors (ie, DCD) as a possible way to increase the number of organ donations. As explained more fully in another article in this issue, DCD refers to the retrieval of organs from patients who have been declared dead on the basis of cardiopulmonary criteria. Although organ retrieval can be an option after unexpected, sudden cardiac arrest, most DCD programs in the United States are limited to situations in which the donor’s family has made a decision to have life support withdrawn, with the expectation that death will occur soon enough for the retrieval of viable organs. Although many hospitals are able to offer the option of organ donation to patients’ families who have made a decision to have life-sustaining treatment discontinued, important issues exist related to the timing of the request for donation, the need for the families to be exceptionally well informed before they consent to donation, and the precise procedural elements of treatment withdrawal and pronouncement of death.

In 1997, the Institute of Medicine convened a panel of experts to generate recommendations for DCD programs. Although these recommendations have been widely adopted, situations in which DCD is an option present even more challenges to medical and nursing staff charged with caring for a potential donor and the donor’s family.

Many additional concerns can act as barriers to organ donation and transplantation, including questions about the fairness of allocation of organs, lack of trust of medical professionals, and economic constraints on eligibility for transplantation. However, the ability to provide sensitive and technically competent care of dying patients and their families, along with compatible attitudes toward death itself, are prerequisites to the success of any transplant program.
Contributions of Critical Care Nurses to Improvements in Organ Donation

Without question, progress in organ donation and transplantation requires the concerted efforts of all healthcare professionals, including nurses, physicians, social workers, and hospital clergy. What is less clear is how to make progress and determine what specific steps can be taken to address the ongoing shortage of organs needed to both improve quality of life and save lives. The request for organ donation is an extraordinarily complex process that requires knowledge of medical facts and moral and legal principles as well as an understanding of the myriad psychological and social factors that influence human decision making in times of crisis. All nurses, whether bedside caregivers, managers, educators, or advanced practice nurses, have numerous opportunities to contribute to improvements in both the quality and quantity of donation efforts.

One component of end-of-life care, the request to a patient’s grieving family members to consider organ donation, is extremely important to the quality and comprehensiveness of that care. The quality of care at the end of life is also affected by the knowledge, beliefs, and attitudes of care providers and by environmental features that either support or hinder the provision of care. To make positive and significant contributions to increase access to transplantation, nurses, singly and in concert, will need to incorporate promotion of organ donation as a formal part of their care plan.

Knowledge, Beliefs, and Attitudes

Education is the simplest and most obvious way to improve the ability of nurses to help identify potential organ donors and provide appropriate support to patients’ families in the families’ decision making. In addition to the classes and materials specific to organ donation provided by local organ procurement organizations, a wide variety of other educational materials and courses on nursing care at the end of life are available. The amount and scope of these materials reflect the widespread recognition of the need to make improvements in the quality of end-of-life care. Table 1 provides a list of organizations, Web sites, and text references that can be used for educational activities. Materials from the End-of-Life Nursing Education Consortium and the Toolkit for Nurse Educators for End of Life are particularly well developed and helpful.

Because behavior is the result of a complex interaction among knowledge, beliefs, and attitudes, simply providing periodic classes or printed materials will be insufficient to affect the quality of care. Like all aspects of nursing education, end-of-life care is best addressed as a program, rather than with sporadic activities, and planning must begin with a needs assessment.

Table 1 Resources related to end-of-life care

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<tr>
<th>Author/organization</th>
<th>Citation/Web site</th>
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<tr>
<td>American Hospice Foundation</td>
<td><a href="http://www.americanhospice.org">www.americanhospice.org</a></td>
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<tr>
<td>Americans for Better Care of the Dying</td>
<td><a href="http://www.abcd-caring.org">www.abcd-caring.org</a></td>
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<tr>
<td>Palliative Care Policy Center</td>
<td><a href="http://www.medicaring.org">www.medicaring.org</a></td>
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<tr>
<td>American Medical Association Ethics Resource Center</td>
<td><a href="http://www.ama-assn.org/ama/pub/category/2416.html">www.ama-assn.org/ama/pub/category/2416.html</a></td>
</tr>
<tr>
<td>End-of-Life Nursing Education Consortium (ELNEC)</td>
<td><a href="http://www.aacn.nche.edu/elnec">www.aacn.nche.edu/elnec</a></td>
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<tr>
<td>Institute for Healthcare Improvement</td>
<td><a href="http://www.ihi.org">www.ihi.org</a></td>
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<tr>
<td>Center to Advance Palliative Care</td>
<td><a href="http://www.capc.org">www.capc.org</a></td>
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<tr>
<td>Center for Practical Bioethics</td>
<td><a href="http://www.practicalethics.org">www.practicalethics.org</a></td>
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<tr>
<td>National Hospice and Palliative Care Organization</td>
<td><a href="http://www.nhpco.org">www.nhpco.org</a></td>
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<tr>
<td>Promoting Excellence in End-of-Life Care</td>
<td><a href="http://www.promotingexcellence.org">www.promotingexcellence.org</a></td>
</tr>
<tr>
<td>Campbell M</td>
<td>Forgoing Life-Sustaining Therapy. Aliso Viejo, Calif: American Association of Critical-Care Nurses; 1998</td>
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<tr>
<td>Institute of Medicine Committee on Care at the End of Life</td>
<td>Approaching Death. Washington, DC: National Academy Press; 1997</td>
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assessments. A number of tools are available among the resources listed in Table 1 that can be used to assess knowledge of and attitudes toward end-of-life care. These tools can be helpful to clinical nurse specialists or staff development educators in planning a comprehensive end-of-life education program.

Because communication is a critical element of supporting patients’ families and assisting in all end-of-life decision making, including decisions about organ donation, particular attention must be paid to helping nurses develop and improve skills in this area. This step requires more than didactic sessions. Role playing, feedback on performance, and planned opportunities to observe expert clinicians in meetings with patients’ families are essential for learning and will not occur without a well-developed educational plan.

**Environmental Features**

A tendency exists in healthcare, particularly in academic settings, to assume that more education is the answer to improving performance. Less appreciated is the extent to which the professional environment influences behavior. Environment in this context can be understood as more than just the physical setting. Rather, it includes the organizational structural elements that establish, reinforce, or hinder performance, including such elements as role descriptions, group norms, practice routines, and formal and informal feedback systems.

Just as an individual’s performance can be assessed by using evaluation tools, the environment of a critical care unit can also be assessed. Table 2 provides a list of areas to assess that reflect the extent to which the unit culture and structures help or hinder nurses in providing good end-of-life care. These aspects, such as the amount of educational time devoted to end-of-life topics or the incorporation of specific expectations into the performance evaluation system, not only provide tools for skill development in nurses but also contribute in large measure to the creation of the culture of the intensive care unit. Methods of assigning nurses that either place a priority on continuity or devalue it, the inclusion or lack of interdisciplinary

<table>
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<th>Table 2 Unit assessment items</th>
<th>Assessment questions</th>
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<td><strong>Aspect</strong></td>
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<tr>
<td>Nurse’s role</td>
<td>Is there an expectation that nurses will always participate in meetings with patients’ families?</td>
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<td></td>
<td>Is there a regular, formal system that ensures interdisciplinary discussion of patients' treatment plans?</td>
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<td></td>
<td>Do performance evaluation documents include items related to each nurse's skill in end-of-life care, such as evidence of aggressive pain management and other strategies for managing signs and symptoms, alternative therapies such as music, use of measures to address spiritual needs?</td>
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<tr>
<td>Continuity</td>
<td>Is there an assignment system in place to ensure that patients with a high probability of dying and patients with long-term disease have continuity and consistency in care providers?</td>
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<td>Is there a formal way to recognize nurses who assume primary responsibility for case management or consistent care over time for patients at the end of life?</td>
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<tr>
<td>Standards of care</td>
<td>Do the unit policies, standards, or procedure books have outlines, care paths, or guidelines for the care of patients undergoing treatment withdrawal and patients who are potential organ donors?</td>
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<td>Does the documentation system (medical record) have established areas for documenting goals of care?</td>
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<td></td>
<td>What are the standards for assessing and documenting pain?</td>
</tr>
<tr>
<td>Quality improvement</td>
<td>Does the quality improvement process address aspects of end-of-life care?</td>
</tr>
<tr>
<td>Education</td>
<td>How much time in orientation of staff nurses is devoted to end-of-life care?</td>
</tr>
<tr>
<td></td>
<td>How many continuing education offerings specific to end-of-life issues, ethics, organ donation, and so on are provided each year?</td>
</tr>
<tr>
<td>Resources</td>
<td>What printed or electronic resources related to end-of-life topics are readily available in the unit?</td>
</tr>
<tr>
<td></td>
<td>What personnel resources are readily available (eg, clergy, ethics consultants, palliative care consultants, hospice, pain service)?</td>
</tr>
<tr>
<td></td>
<td>How open or restricted is nurses’ access to resources?</td>
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conferences, and expectations that nurses must be included in meet-
ings with patients’ families are all active elements of the environment that direct the behavior of those within that unit.

Because organ donation occurs within end-of-life situations, progress in furthering donation most likely cannot be made without paying attention to the more general issues of end-of-life care. However, organ donation is associated with additional considerations (ie, specific educational needs and recognition of the likelihood of ambivalent attitudes and conflict) that must be addressed. One successful approach is designating a specific staff member who will assume primary responsibility for coordinating communication with the family members of potential organ donors. Dodd-McCue et al56 and French56 reported both reduced stress among critical care nurses and increased consent rates for donation after the creation of a “family communication coordinator.” This approach may not be appropriate for all settings, but it is an excellent example of an intervention designed to change an element of the critical care environment. Similarly, some organ procurement agencies and hospitals have collaborated to establish in-house organ donation coordinators to provide more timely assistance and well-integrated education in support of donation.

Conclusion

Improved end-of-life care and increased rates of organ donation are goals formally recognized by society at large and by healthcare professionals. Despite a marked amount of research and coordinated efforts sponsored by both government and private entities, we continue to struggle to find ways to better meet these goals. Considerable progress has been made, but evidence on the quality of care received by dying patients and their families and minimal gains in donation rates suggest there is much room for improvement. Specific targets for improvement include coordination of care, provision of support and recognition of the appropriate time for making explicit transitions in goals of care, clinicians’ and families’ understanding of the decision-making process, and effective interventions to support patients’ families as the families cope with the burdens of decisions and the grieving process. Critical care nurses are in a pivotal position to address all of these areas. Any plan for contributing to progress must also include a comprehensive educational plan and strategies for recognizing and modifying those aspects of the critical care unit environment that affect nurses’ performance.

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End-of-Life Decision Making, Organ Donation, and Critical Care Nurses
Barbara J. Daly

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