The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement

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The intensive care unit (ICU) represents a hospital setting in which death and discussion about end-of-life care are common, yet these conversations are often difficult. Such difficulties arise, in part, because a family may be facing an unexpected poor prognosis associated with an acute illness or exacerbation and, in part, because the ICU orientation is one of saving lives. Understanding and improving communication about end-of-life care between clinicians and families in the ICU is an important focus for improving the quality of care in the ICU. This communication often occurs in the "family conference" attended by several family members and members of the ICU team, including physicians, nurses, and social workers. In this article, we review the importance of communication about end-of-life care during the family conference and make specific recommendations for physicians and nurses interested in improving the quality of their communication about end-of-life care with family members. Because excellent end-of-life care is an important part of high-quality intensive care, ICU clinicians should approach the family conference with the same care and planning that they approach other ICU procedures. This article outlines specific steps that may facilitate good communication about end-of-life care in the ICU before, during, and after the conference. The article also provides direction for the future to improve physician-family and nurse-family communication about end-of-life care in the ICU and a research agenda to improve this communication. Research to examine and improve communication about end-of-life care in the ICU must proceed in conjunction with ongoing empiric efforts to improve the quality of care we provide to patients who die during or shortly after a stay in the ICU. (Crit Care Med 2001; 29[Suppl.]:N26–N33)

KEY WORDS: family conference; end-of-life care; intensive care unit

The intensive care unit (ICU) is a hospital setting where death and discussion about end-of-life care are common because of the severity of patients' illnesses. Of patients who die in the hospital, approximately half are cared for in an ICU within 3 days of their death, and one third spend ≥ 10 days in the ICU during their final hospitalization (1). A recent study showed that 90% of deaths in the ICU in 1992–1993 involved withholding or withdrawing at least one life-support-ing intervention, a dramatic increase when compared with 5 yrs previously (2). Similarly, many other studies have shown that the majority of deaths in the intensive care setting involve withholding or withdrawing multiple life-sustaining therapies (3–11). Therefore, the ICU represents a setting where decisions about managing patients' deaths are made regularly.

End-of-life care in the ICU can be difficult not only because it often involves acute illness and therefore can be unexpected and highly emotional but also because the ICU is oriented toward saving lives (12, 13). Effective communication about end-of-life care in the ICU, therefore, may be particularly difficult. Understanding and improving communication about end-of-life care between clinicians and families in the ICU is an important focus for improving the quality of care in the ICU. Although communication about all care in the ICU is important, communication about end-of-life care provides a useful model for examining, understanding, and improving communication between ICU clinicians, patients, and families.

Studies have shown that family members with loved ones in the ICU rate communication with their healthcare providers as one of the most important skills for these providers (14, 15). In fact, most families rate clinicians' communication skills, along with continuity and accessibility, as more important than their clinical skills (15, 16). These studies suggest that improving communication between clinicians and families will improve family satisfaction as well as quality of care.

Despite the emphasis by families on communication, critical care clinicians vary greatly in their attitudes toward communication with patients' families (17). Although limited data exist, it is likely that physician and nurse skills in communicating with patients' families in the ICU also vary widely. To improve this communication, it is important to identify the important components of communication, to assess the current communications skills of critical care physicians and nurses, and to improve these skills. Although improving family-

clinician communication is important for all patients cared for in the ICU, communication is particularly difficult and particularly important with families of patients for whom decisions must be made about withholding or withdrawing life-sustaining treatments.

Advance Care Planning and Communication of Treatment Preferences

In the 1980s and early 1990s, many investigators, clinicians, and legislators believed that advance directives would allow patients to inform their physicians about the kind of care they would want if they became too sick to speak for themselves (18–20). If completely successful, these directives theoretically would obviate the need for critical care clinicians to discuss end-of-life care with patients and families because the advance directives would convey the relevant information. Numerous studies, however, have shown that advances directives do not significantly affect the aggressiveness or costs of ICU care (21–23), nor do they change end-of-life decision-making in the ICU (24–26). These studies have prompted many clinicians and policymakers to lose faith in advance directives as a major means of communication (27–29). Advance care planning is a term that has been used to include communication involved in the process of creating advance directives as well as communication about broader issues. An Institute of Medicine report on end-of-life care defined advance care planning as "not only the preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions (including decisions should sudden and unexpected critical medical problems arise), and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families" (30). Identification of advance care planning that has occurred before hospitalization should remain an important component of end-of-life communication in the ICU. However, advance care planning, even under ideal circumstances, will not obviate the need for critical care clinicians to discuss palliative care, withholding and withdrawing life support, and other end-of-life care issues with patients and families in the ICU.

Family Conferences and Communication of Treatment Preferences

Prior studies have shown that < 5% of ICU patients are able to communicate with clinicians at the time that decisions are made about withholding or withdrawing life-sustaining therapies (2). Therefore, when ICU clinicians must discuss these issues, they often discuss them with patients' families. If patients can no longer communicate their wishes for medical care, the legal surrogate decision-maker is identified in a hierarchical fashion, with first priority going to an individual named in a Durable Power of Attorney for Health Care and then to family members. Most states and countries have an explicit hierarchy for decision-making within the family, such as a legal spouse first, then parent, then adult children, and then siblings. However, in most cases in the ICU, the actual decision-making process is facilitated through a series of family conferences and individual meetings with interested family members (31, 32). Although legal next-of-kin retains responsibility for decisions, consensus among family members is the ultimate goal of ICU clinicians whenever possible.

Withholding or withdrawing medical interventions usually involves detailed and complex conversations with patients' families. These conversations often occur in the setting of one or more "family conferences" attended by several family members and members of the ICU team, including physicians, nurses, and social workers. These conversations also may occur less formally at the bedside or in hallways and may include the various team members and family members (32). It is not known how much of this communication occurs in these different settings and how much this varies from institution to institution. The family conference is certainly not the only setting in which this communication occurs, but it is a focal point for this communication and is often the setting in which decisions are made to limit life-sustaining therapy. These conferences, therefore, represent an important setting for clinician-family communication about end-of-life care in the ICU, but there have been limited studies of the communication that occurs in this set-

ting and no systematic efforts to measure or improve this communication. Although we focus on the family conference in this article, many of the principles apply to communication about end-of-life care occurring outside of formal family conference settings.

The Quality of Physician-Family End-of-Life Communication

Although little is known about the quality of communication during family conferences in the ICU, one study used audiotapes of family meetings in the ICU to describe methods for seeking consensus in decisions about withdrawing or withholding life support (33). These researchers found that decisions to withhold or withdraw life-support therapy involved a series of "complex, difficult processes" that were fertile ground for further study. Another study examined the family's understanding of information presented in the family conference; investigators found that 54% of family representatives did not adequately understand the patient's diagnosis, prognosis, or treatment after a conference with the physician (34).

Researchers have assessed the quality of patient-physician communication about do-not-resuscitate orders with hospitalized patients (35). These studies found substantial shortcomings in the communication skills of physicians, noting that physicians spent 75% of the time talking and missed important opportunities to allow patients to discuss their personal values and goals of therapy. These investigators also showed that the majority of these physicians felt that they did a good job discussing do-not-resuscitate orders, despite having had very little training about how to have these types of discussion with patients (36). These data suggest that the quality of family-physician and patient-physician communication about end-of-life care is poor and unlikely to improve under our current system of medical school and residency training. Nonetheless, the quality of physicians' communication about end-of-life care likely can be improved, and studies are needed to develop and assess interventions to improve these skills.

The Role of Nurses in Communication About End-of-Life Care in the ICU

Critical care nurses play a pivotal role in clinician-family communication in the

ICU (37–39). Families rate the nurses' skill at this communication as one of the most important clinical skills of ICU clinicians (15, 16, 40, 41). In a meta-analysis of studies assessing the needs of family members with a loved one in the ICU, eight of the ten needs identified related to communication with clinicians, and the majority of these communication needs were addressed primarily by nurses (15). However, other data suggest that nurses are not better at communication about end-of-life care than physicians (42) and, consequently, also could benefit from interventions to improve the quality of this communication.

There are also data to suggest that end-of-life care in the ICU is a source of both satisfaction and extreme frustration for some critical care nurses (43, 44). In a qualitative analysis, some critical care nurses expressed frustration about their limited role in helping direct care for patients at the end of life, especially given the unique understanding they have of these patients' experiences and wishes (44). Efforts are needed to improve communication and collaboration among intensive care physicians, nurses, and family members.

The role that nurses play during ICU family conferences varies greatly by institution, although very little research documents the extent of this variability. In some institutions, clinical nurse specialists or critical care nurses may run family conferences without physicians present, but in most institutions, nurses may or may not be present during the conferences that are run by physicians. If nurses are present, their contribution is often to prompt the family to ask questions that previously have been asked of the nurses or to share information about the patient previously shared with the nurses. However, independent of their role during the conference, nurses play an important role in communication before the conference, including initiating many of the conferences, facilitating and coordinating the conference planning, contacting family members, and preparing family members for the discussion (38). In addition, after the conference, nurses explain and reinforce the information given during the conference and put the information and decisions into perspective. To understand and improve the role that critical care nurses play in clinician-family communication about end-of-life care during ICU family conferences, it is important to consider the specific tasks that nurses perform before and after the family conference. Our research group, as part of a study funded by the National Institute for Nursing Research, conducted focus groups with ICU nurses to ask them what roles they play in facilitating these family conferences. Two focus groups were conducted in December 1999 and February 2000 with 8 and 11 critical care nurses. Nurse investigators (SES, PDT) conducted the groups, and audiotapes of the focus groups were reviewed to generate a comprehensive list of the nursing activities associated with family conferences. We were interested in understanding the full range of nurse activities before and after the family conference that might contribute to a high-quality family conference. As shown in Table 1, these activities included a) giving information to the family; b) discussing with the family issues of importance to the patient and the family; and c) offering the family the opportunity to discuss their feelings and concerns. This table includes a broad range of activities that might improve the quality of communication during and concerning the ICU family conference, but further research is needed to determine the effectiveness of these activities for improving the quality of care and family satisfaction with care.

RECOMMENDATIONS FOR CLINICAL PRACTICE

There are few research studies that help ICU clinicians improve their skills at communication about end-of-life care with families. A number of review articles and books provide advice about how to communicate with patients and families concerning the delivery of bad news (45–48) and palliative medicine (49). Although these reviews provide valuable insights, they focus on communication with patients in the outpatient setting and they provide limited empirical data to support general recommendations. There are important differences in the ICU setting, including the "rescue culture" of the ICU, the severity of patient illness, the family taking on the role of surrogate decision-maker often without preparation, the high level of stress placed on families in this role, and the complicated and technical ICU diagnoses and treatments. Despite the lack of studies that can guide ICU clinicians through the ICU family conference about end-of-life care, we will propose a series of suggestions for these conferences based both on a chapter from the text *Managing Death in the Intensive Care Unit: The Transition From*

Table 1. Nurses' activities facilitating the family conference about end-of-life care in the intensive care unit

Before the Conference	After the Conference
Explain to the family about the patient's medical equipment and therapies.	Talk with the family about how the conference went.
Tell the family what to expect during their conference with the health care team members.	Talk with any other healthcare team members who were present at the conference about how the conference went.
Talk with the family about their spiritual or religious needs and take actions to address the unmet spiritual or religious needs.	Ask the family if they had any questions following the conference.
Talk with the family about specific cultural needs and take actions to address unmet cultural needs.	Talk with the family about their feelings.
Talk with the family about what the patient valued in life.	Talk with the family about any disagreement among the family concerning the plan of care.
Talk with the family about the patient's illness and treatment.	Talk with the family about changes in the patient's plan of care as a result of the conference.
Talk with the family about their feelings.	Support the decisions the family made during the conference.
Reminisce with the family about the patient.	Assure the family that the patient will be kept comfortable.
Tell the family it is all right to talk to and touch their loved one.	Tell the family it is all right to talk to and touch their loved one.
Discuss with the family what the patient might have wanted if he/she were able to participate in the treatment decision-making process.	Locate a private place or room for the family to talk among themselves.
Locate a private place or room for the family to talk among themselves.	

Table 2. Components of an intensive care unit (ICU) family conference about end-of-life care in the ICU

Making preparations before an ICU family conference about end-of-life care
   Review previous knowledge of the patient and/or family.
   Review previous knowledge of the family's attitudes and reactions.
   Review your knowledge of the disease—prognosis, treatment options.
   Examine your own personal feelings, attitudes, biases, and grieving.
   Plan the specifics of location and setting: a quiet, private place.
   Discuss with the family in advance about who will be present.
Holding an ICU family conference about end-of-life care
   Introduce everyone present.
   If appropriate, set the tone in a nonthreatening way: "This is a conversation we have with all
      families . . ."
   Discuss the goals of the specific conference.
   Find out what the family understands.
   Review what has happened and what is happening to the patient.
   Discuss prognosis frankly in a way that is meaningful to the family.
   Acknowledge uncertainty in the prognosis.
   Review the principle of substituted judgement: "What would the patient want?"
   Support the family's decision.
   Do not discourage all hope; consider redirecting hope toward a comfortable death with dignity if
      appropriate.
   Avoid temptation to give too much medical detail.
   Make it clear that withholding life-sustaining treatment is not withholding caring.
   Make explicit what care will be provided including symptom management, where the care will be
      delivered, and the family's access to the patient.
   If life-sustaining treatments will be withheld or withdrawn, discuss what the patient's death
      might be like.
   Use repetition to show that you understand what the patient or family is saying.
   Acknowledge strong emotions and use reflection to encourage patients or families to talk about
      these emotions.
   Tolerate silence.
Finishing an ICU family conference about end-of-life care
   Achieve common understanding of the disease and treatment issues.
   Make a recommendation about treatment.
   Ask if there are any questions.
   Ensure basic follow-up plan and make sure the family knows how to reach you for questions.

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Cure to Comfort (50) and on our ongoing study of this communication.

Because excellent end-of-life care is an important part of high-quality intensive care, ICU clinicians should approach the family conference with the same care and planning that they approach other ICU procedures. Table 2 outlines some steps that may facilitate good communication about end-of-life care in the ICU before, during, and after the conference. These are described in more detail next.

Preparing for the ICU Family Conference

A common mistake that some ICU clinicians make is to embark on a discussion about end-of-life care with a family without making the necessary preparations for the discussion. Clinicians should review what is known about the patient's disease process including the diagnoses, prognosis, treatment options, and likely outcomes with different treatments. It is equally important to identify areas of uncertainty or disagreement regarding the patient's diagnosis, progno-

sis, or treatment options. Clinicians should identify gaps in their knowledge by systematically reviewing the relevant information and should seek out information they need before their discussion with patients or their families.

Clinicians should consider what they know about the patient and his or her family including their relationships with one another; their attitudes toward illness, treatment, and death; and their prior reactions to information about illness and death. If, for example, there are family members who have had strong emotional reactions to bad news, it may be helpful to enlist the aid of a family member or staff member, such as a nurse, social worker, or chaplain, who can support them during and after the family conference. If this type of information is not known to the ICU clinicians, this information may be available from others, such as the patient's primary care provider.

Frequently, many different subspecialists are involved in the care of critically ill patients, and it can be beneficial to have them represented at the family confer-

ence. However, the family conference is not the forum for debating issues about prognosis and therapy. This may confuse and frustrate family members. Disagreements about patient care generally should be resolved between clinicians before the family conference.

It is useful for clinicians to consider their own feelings of grief, anxiety, or guilt before discussing end-of-life care with families. This may be especially important in cases when the clinician has known the patient or family for a long time, when the clinician and patient or family have been through a lot together, or when the clinician has some feelings of inadequacy about the patient's condition or treatment. Many patients are admitted to the ICU after complications of medical or surgical treatments. It is particularly important for the clinicians involved in the original treatment to recognize their personal feelings of investment and responsibility when formulating a discussion plan with the family. Acknowledging their own feelings explicitly to a personal support person can help clinicians avoid projecting their own feelings or biases onto the patient or family. In addition, the clinicians' own feelings of guilt or inadequacy can lead them to avoid the family or to avoid talking with the family about death. Reviewing these feelings by oneself or with another clinician is an important step to becoming more comfortable discussing dying and death with a family (51).

Another important step in preparing for an end-of-life discussion in the ICU is to plan where the discussion will take place and who will be there. Ideally, these

discussions should take place in a quiet and private room where there is some assurance that people, phones, or pagers will not interrupt the discussion. It should be a room that is comfortable for all the participants without a lot of medical machinery or other distractions such as medical diagrams. All parties should be sitting at the same level around a table or with chairs in a circle. It is best to avoid having a clinician sitting behind a desk and the family in front of a desk. If the patient can participate in the discussion but is too ill to leave his or her ICU bed, efforts should be made to make the ICU room comfortable for everyone present.

Before the scheduled conference about end-of-life care, the clinician, patient, and family should discuss who should be present. In addition, the clinician should be certain that all appropriate staff members are consulted about whether they should be present, including the medical staff, nursing staff, social workers, chaplains, and trainees who have been involved with the patient or family. Ideally, someone should take responsibility for scheduling the conference at a time when as many as possible can be present. It may be helpful for some families to be told they can write down any questions that they have before the scheduled conference to be sure their questions are answered.

A Plan for the ICU Family Conference About End-of-Life Care

The first step of a discussion about dying and death is to be sure that everyone participating in the discussion has met everyone else present. Some staff members may not have met all family members. The clinician leading the conference should take the time to introduce everyone in the room to be sure that everyone has met everyone else and knows their role either on the staff or in the family.

Introducing the issue of dying and death or end-of-life care can be an important and difficult part of these discussions. Often, by the time these conferences occur in the ICU, everyone in the room knows that the discussion will focus on how to help the patient die in comfort and with dignity. However, sometimes patients or families may not be aware that this is part of the clinician's agenda. In those situations, the clinician should make the patient or family as

comfortable as possible talking about dying and death. It may be helpful to frame the discussion by saying that these are discussions that we have with all families of severely ill patients.

Because not everyone present will have the same level of understanding of the patient's condition, it is often helpful to first find out what the patient or family understands of the patient's situation. This can be a useful way for the clinician to determine how much information can be given, the level of detail that will be understood, and the amount of technical language that can be used. Clinicians should avoid unnecessary technical jargon and particularly should be wary of using jargon to avoid saying words like "dying" or "death." It is important to avoid the temptation to give too much technical detail about the physiology or pathophysiology as a way to deal with our own discomfort, but we should be aware that families vary in their medical sophistication and some may want this level of detail. Clinicians also should be cautious about using physiologic detail to cover the uncomfortable message about the patient's prognosis. Clinicians also may find it helpful to give families the opportunity to impart what they know of they patient's medical history and to describe aspects about the patient's life that will help the ICU understand the kind of person the patient is.

During these discussions, it is important to discuss prognosis in an honest way that is meaningful to patients and their families. For example, median survival is not very meaningful to most family members. Wording prognosis in terms of "percentage chance of survival to hospital discharge" can be more useful, but it is important to acknowledge the uncertainty in these predictions and to spend time discussing patients' likely functional status and quality of life after discharge. Finally, it is also important to provide honest information about the prognosis without completely discouraging hope from those families who would like to maintain hope. This can be a tricky balancing act for clinicians, but it is a part of the art of holding these discussions. There are two specific ways that clinicians can allow families to maintain their hope in the face of a poor prognosis. First, the clinician can allow the family some time to get used to a poor prognosis. Sometimes this can take days (2), but it can be very helpful to families if they are allowed to make this transition at

their own pace (32). Second, the clinician can help the family redirect their hope, moving from hoping for recovery to hoping for some quality time together or for a comfortable death without pain or dyspnea and with as much dignity and meaning as possible.

An important goal of end-of-life discussions in the ICU is to align the clinicians' and the families' view of what is happening to the patient and what the goals of care should be. The discussions about end-of-life care that are most difficult are the ones where the families' views and the clinicians' views are dramatically different. Making the effort to discover these differences and working to minimize them can be time consuming, but it is usually time well spent because it can greatly facilitate decisions about end-of-life care. An important component of understanding families' perspectives is listening to what they have to say. Although this may seem obvious, patients and families report that this is an important component of physician skill at end-of-life care (52) and there is evidence, as noted previously, that physicians spend very little time during these discussions listening to patients and their families (36).

It is extremely important in discussions about end-of-life care in the ICU that the patient and/or family understand that if the decision is made to withhold or withdraw a particular treatment, the clinicians themselves are not withdrawing from providing care for the patient. Although this may seem obvious to some clinicians, it should be stated explicitly to families to avoid any misunderstanding. In some ICU settings, withholding or withdrawing life-sustaining therapy may mean that the patient will be transferred out of the ICU and to another set of clinicians. If this is the case, clinicians should discuss this with family members and should ensure that the transfer does not mean or give the appearance that the patient will no longer receive aggressive, timely, and appropriate treatment, although this aggressive treatment will be palliative. In fact, clinicians should stress the specific palliative treatments and benefits that can be offered when the goals of care change from cure to comfort (53, 54).

After discussing prognosis and treatment options and the family's level of understanding, it is important to spend some time exploring the family's reactions to what was discussed. Clinicians should understand that families will react to their perception of what was said and that they may not react in the way the clinician expects. There are several useful techniques

that clinicians can use to explore families' reactions. First, it can be helpful to repeat what patients or families have said as a way to show that the clinician has heard them. This can be particularly useful when the clinician and the family have different views of what is happening or what should happen. Second, it is important to acknowledge strong emotions that come up in these discussions. Whether the strong emotion is anger, anxiety, or sadness, it is useful for the clinician to acknowledge the emotion in a way that allows the person with the emotion to talk about why he or she feels that way. In acknowledging such emotions, it can be useful for the clinician to use reflection to show empathy and to encourage discussion about the emotion. For example, a clinician might say, "It seems to me that you are angry about what

is happening to your mother; can you tell me why?" as a way to allow a family member to talk about his/her anger. Finally, another technique clinicians can use in discussion with a patient or family is to tolerate silences. Sometimes it is after what seems like a long silence that patients or family members will ask a particularly difficult question or express a difficult emotion.

Finishing an ICU Family Conference About End-of-Life Care

Before finishing a discussion about end-of-life care, there are several steps that clinicians should take. First, it is important that clinicians make recommendations during the discussion. With the increasing

emphasis on patient autonomy and surrogate decision-making, some clinicians may tend to describe all possible treatment options to a family as equally reasonable and may not make a recommendation (1). On the contrary, it is important that clinicians offer their expertise to families, and part of offering their expertise is making a recommendation. This is especially important in discussions with family members concerning withholding or withdrawing life support. It is a disservice to leave a family member feeling that he or she single-handedly decided to "pull the plug" on a loved one in a situation where ongoing life support therapy is unlikely to provide significant benefit.

Before finishing discussion about end-of-life care, clinicians should summarize the major points and ask family members if there are any questions. This is a good time to tolerate silence, because it may take a while for the uncomfortable questions to surface.

Finally, before completing a discussion about end-of-life care, clinicians should ensure that there is an adequate follow-up plan. This often means a plan for when the clinician will meet with the family again and a way for the family to reach the clinician if questions arise before the next meeting.

DIRECTIONS FOR THE FUTURE

How Can Physicians Improve Communication During the ICU Family Conference?

Although research suggests that physician communication concerning end-

Table 3. Barriers to nurse-family communication about end-of-life care in the intensive care unit

System barriers	Physician barriers
Not enough nursing staff/heavy patient load.	Conflict with physicians.
Unit's visitation policy allows little time with family.	Physicians discourage nurse communication with family on certain topics.
Being unable to attend the family conference because policy is for manager or nurse specialist to attend.	Lack of communication between attending physician and nursing staff.
Being unable to attend the family conference because too busy with patient care.	Patient and/or family barriers
Being unable to attend the family conference because off duty at the time it occurred.	Patient too sick to allow nurse interaction with family.
Lack of a private place for communication to occur.	Family does not visit or call.
	Family is angry.
Nurse barriers	Family has unrealistic expectations of medical treatment.
Lack of support from nurse colleagues for family communication.	Personal difficulty with this family.
Outside the scope of my nursing practice.	Language difficulties.

Table 4. Examples of the type of research questions that should be addressed to improve the quality of communication about end-of-life care in the intensive care unit (ICU)

When do and when should providers begin to address the question of limiting life support?
How well do we communicate with families about pain and symptom control?
What is the best way to communicate about prognosis and the level of uncertainty around predictions of prognosis?
How well do we understand the psychology of decision-making about continuing or withdrawing life support, and what is the role of such issues as our tolerance for uncertainty and the "rule of rescue"?
What is the best way of communicating with families to understand patients' values, goals, and beliefs?
What are the "outcomes" of high-quality communication about end-of-life care in the ICU, and how should we measure them?
How well do we conduct substituted judgment in the ICU setting, and what methods are available to improve our ability to predict patient's treatment preferences?
How might discussion of "states worse than death" help us communicate with families about the appropriate situations for withholding and withdrawing life-sustaining treatments?
How do we assess how much information to provide families, and how could we do this better?
What effect do culture and religion have on communication about end-of-life care in the ICU, and how can we better account for cultural and religious diversity in our communication?
How might we better understand the role of spiritual beliefs and spiritual distress in communication with families in the ICU?
What is the role of medical futility in decision-making in the ICU, and how should this be communicated to family members?
What organizational pressures and issues limit our ability to communicate with family members?
How do different specialities approach communication with families about end-of-life care, and why do these differences exist?
How do we discuss CPR, and how does that differ from other treatments?
What are the limits of making CPR the center of the discussions about end-of-life care?

CPR, cardiopulmonary resuscitation.

> *There is much work to be done in improving clinician-family communication concerning end-of-life care in the intensive care unit.*

of-life care in the ICU needs to improve, there has been very little research concerning effective ways to improve this communication. The practical guidelines suggested here may sound reasonable, but how can we implement change based on these guidelines? Although educational efforts to improve physicians' communication skills are important, it seems unlikely that such interventions will have dramatic effect without simultaneous, systematic changes in the way that ICUs are structured and staffed and the way that physicians' time is structured and reimbursed. Additional research is needed to identify effective ways to implement changes that improve the quality of physician-family communication about end-of-life care and satisfaction with that care while still allowing ICUs to provide their primary service of saving the lives of the critically ill. In the meantime, physicians are left to attempt local changes in ICU structure and to improve their own skills through educational programs (such as the Education for Physicians on End-of-Life Care program; (55) and through educational materials on end-of-life care in the ICU (56).

How Can Nurses Improve Communication During the ICU Family Conference?

Although there has been little research on the role that ICU nurses play in family conferences concerning end-of-life care, data from our focus groups suggest that nurses play an important role facilitating these conferences and helping families place these conferences into context (Table 1). We also asked these focus groups to identify barriers to nurse-family communication about end-of-life care in the ICU (Table 3). They identified two kinds of barriers: a) system barriers, related to the intensive care unit polices,

staffing, or physical plant; and b) people barriers, related to nurses, physicians, and patients and their families. This list of barriers suggests that improving nurses' abilities to facilitate these conferences will require a multifaceted intervention that focuses on system changes, education for physicians and nurses, and support programs for family members. In the meantime, nurses also are left to attempt local changes in ICU structure and to improve their own skills through educational programs (such as the End of Life Nursing Education Consortium funded by the Robert Wood Johnson Foundation) and through educational materials on end-of-life care in the ICU (56, 57). In addition, there are two new textbooks for nurses concerning general end-of-life care (58, 59).

A Research Agenda for Improving Communication in the ICU Family Conference

A recent conference established the goal of identifying a research agenda for improving end-of-life care in the ICU. The conference produced a research agenda that included a call for research to improve communication between the patient-family-clinician triad (60). Although this report pointed to the importance of communication about end-of-life care, it did not provide the specific questions that need to be answered to improve this communication. Table 4 identifies some of the specific research questions concerning family-clinician communication that will need to be addressed. These questions include a broad range of issues, and answers will incorporate a broad range of disciplines and research methods. In addition to defining the current state of the art and finding innovative interventions to improve this communication, we also must identify process and outcome measures that allow us to document success. As Table 4 demonstrates, there is much work to be done in improving clinician-family communication concerning end-of-life care in the ICU. Research to examine these difficult issues must proceed in conjunction with ongoing empirical efforts to improve the quality of care we provide to patients who die during or shortly after a stay in the ICU.

REFERENCES

1. Quill TE, Brody H: Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Ann Intern Med* 1996; 25:763–769
2. Prendergast TJ, Luce JM: Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155:15–20
3. Faber-Langendoen K: A multi-institutional study of care given to patients dying in hospitals. Ethical practices and implications. *Arch Intern Med* 1996; 156:2130–2136
4. Smedira NG, Evans BH, Grais LS, et al: Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 1990; 322: 309–315
5. Vincent JL, Parquier JN, Preiser JC, et al: Terminal events in the intensive care unit: Review of 258 fatal cases in one year. *Crit Care Med* 1989; 17:530–533
6. Eidelman LA, Jakobson DJ, Pizov R, et al: Foregoing life-sustaining treatment in an Israeli ICU. *Intensive Care Med* 1998; 24: 162–166
7. Keenan SP, Busche KD, Chen LM, et al: A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. *Crit Care Med* 1997; 22:1020–1025
8. Koch K: Changing patterns of terminal care management in an intensive care unit. *Crit Care Med* 1994; 22:233–243
9. Vernon DD, Dean JM, Timmons OD, et al: Modes of death in the pediatric intensive care unit: Withdrawal and limitation of supportive care. *Crit Care Med* 1993; 21:1798–1802
10. Youngner SJ, Lewandowski W, McClish DK, et al: Do not resuscitate orders: Incidence and implications in a medical intensive care unit. *JAMA* 1985; 253:54–57
11. Bedell SE, Pelle D, Maher PL, et al: Do not resuscitate orders for critically ill patients in the hospital: How are they used and what is their impact? *JAMA* 1986; 256:233–237
12. Caswell D, Omrey A: The dying patient in the intensive care unit: Making the critical difference. *AACN Clin Issues Crit Care Nurs* 1990; 1:178–186
13. Nelson JE: Saving lives and saving deaths. *Ann Intern Med* 1999; 130:776–777
14. Shannon SE: Families' experiences with proxy decision making for critically ill patients. Paper presented at: Summer Seminar in Ethics; June 20, 1996; Copper Mountain, CO
15. Hickey M: What are the needs of families of critically ill patients? A review of the literature since 1976. *Heart Lung* 1990; 19: 401–415
16. Molter NC: Needs of relatives of critically ill patients: A descriptive study. *Heart Lung* 1979; 8:332–339
17. Cook DJ, Guyatt GH, Jaeschke R, et al: Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. *JAMA* 1995; 273:703–708
18. Singer PA, Siegler M: Advancing the cause of advance directives. *Arch Intern Med* 1992; 152:22–24

19. Emanuel LL, Emanuel EJ: The medical directive. *JAMA* 1989; 261:3288–3293

20. Emanuel LL, Barry MJ, Stoeckle JD, et al: Advance directives for medical care—A case for greater use. *N Engl J Med* 1991; 324:889–895

21. Schneiderman LJ, Kronick R, Kaplan RM, et al: Effects of offering advance directives on medical treatment and costs. *Ann Intern Med* 1992; 117:599–606

22. Danis M, Mutran E, Garrett JM: A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. *Crit Care Med* 1996; 24:1811–1817

23. Danis M, Southerland LI, Garrett JM, et al: A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991; 324:882–888

24. Teno JM, Lynn J, Connors AFJ, et al: The illusion of end-of-life savings with advance directives. *J Am Geriatr Soc* 1997; 45:513–518

25. Teno JM, Lynn J, Wegner N, et al: Advance directives for seriously ill hospitalized patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT intervention. *J Am Geriatr Soc* 1997; 45:500–507

26. Teno JM, Licks S, Lynn J, et al: Do advance directives provide instructions that direct care? *J Am Geriatr Soc* 1997; 45:508–512

27. Block JA: Living wills are overrated. *Chest* 1993; 104:1645–1646

28. Dresser R: Confronting the "near irrelevance" of advance directives. *J Clin Ethics* 1994; 5:55–56

29. Tonelli MR: Pulling the plug on living wills—A critical analysis of advance directives. *Chest* 1996; 110:816–822

30. Field MJ, Cassel CK: Approaching Death: Improving Care at the End of Life. Institute of Medicine Report. Washington, DC, National Academy Press, 1997

31. Swigart V, Lidz C, Butterworth V, et al: Letting go: Family willingness to forgo life support. *Heart Lung* 1996; 25:483–494

32. Cook DJ, Giacomini M, Johnson N, et al: Life support in the intensive care unit: A qualitative investigation of technological purposes. *Can Med Assoc J* 1999; 161:1109–1113

33. Miller DK, Coe RM, Hyers TM: Achieving consensus on withdrawing or withholding care for critically ill patients. *J Gen Intern Med* 1992; 7:475–480

34. Azoulay E, Chevret S, Leleu G, et al: Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med* 2000; 28:3044–3049

35. Tulsky JA, Chesney MA, Lo B: How do medical residents discuss resuscitation with patients? *J Gen Intern Med* 1995; 10:436–442

36. Tulsky JA, Chesney MA, Lo B: See one, do one, teach one? House staff experience discussing do-not-resuscitate orders. *Arch Intern Med* 1996; 156:1285–1289

37. Jamerson PA, Scheibmeir M, Bott MJ, et al: The experiences of families with a relative in the intensive care unit. *Heart Lung* 1996; 25:467–474

38. McClement SE, Desgner LF: Expert nursing behaviors in care of the dying adult in the intensive care unit. *Heart Lung* 1995; 24:408–419

39. Hampe SO: Needs of the grieving spouse in a hospital setting. *Nurs Res* 1975; 24:113–120

40. Daley L: The perceived immediate needs of families with relatives in the intensive care setting. *Heart Lung* 1984; 13:231–237

41. Rodgers CD: Needs of relatives of cardiac surgery patients during the critical care phase. *Focus Crit Care* 1983; 10:50–55

42. Maguire PA, Faulkner A: Helping cancer patients disclose their concerns. *Eur J Cancer* 1996; 32A:78–81

43. Asch DA: The role of critical care nurses in euthanasia and assisted suicide. *N Engl J Med* 1996; 334:1374–1379

44. Asch DA, Shea JA, Jedrziewski MK, et al: The limits of suffering: Critical care nurses' views of hospital care at the end of life. *Soc Sci Med* 1997; 45:1661–1668

45. Campbell ML: Breaking bad news to patients. *JAMA* 1994; 271:1052

46. Buckman R: Breaking bad news: Why is it still so difficult? *Br Med J* 1984; 288:1597–1599

47. Buckman R. How to Break Bad News. Baltimore, MD, Johns Hopkins University Press, 1992

48. Quill TE, Townsend P: Bad news: delivery, dialogue, and dilemmas. *Arch Intern Med* 1991; 151:463–468

49. Lo B, Quill T, Tulsky JA, for the ACP-ASIM End-of-Life Care Consensus Panel: Discussing palliative care with patients. *Ann Intern Med* 1999; 130:744–749

50. Curtis JR, Patrick DL: How to discuss dying and death in the ICU. *In:* Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort. Curtis JR, Rubenfeld GD (Eds). New York, Oxford University Press, 2000, pp 85–102

51. Block SD: Helping the clinician cope with death in the ICU. *In:* Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort. Curtis JR, Rubenfeld GD (Eds). New York, Oxford University Press, 2000, pp 183–192

52. Curtis JR, Wenrich MD, Carline JD, et al: Understanding physicians' skills at providing end-of-life care: Perspectives of patients, families, and health care workers. *J Gen Intern Med*, In Press

53. Foley K: Managing pain and other symptoms in dying patients in the ICU. *In:* Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort. Curtis JR, Rubenfeld GD (Eds). New York, Oxford University Press, 2000, pp 103–126

54. Rubenfeld GD, Crawford S: Principles and practice of withdrawing life-sustaining treatments in the ICU. *In:* Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort. Curtis JR, Rubenfeld GD (Eds). New York, Oxford University Press, 2000, pp 127–148

55. Emanuel LL, von Gunten CF, Ferris FD: The Education for Physicians on End-of-Life Care (EPEC) Curriculum. Chicago, IL, American Medical Association, 1999

56. Curtis JR, Rubenfeld GD: Managing Death in the ICU: The Transition From Cure to Comfort. New York, Oxford University Press, 2000

57. Campbell ML. Forgoing Life-Sustaining Therapy: How to Care for the Patient Who Is Near Death. Aliso Viejo, CA, AACN Critical Care, 1998

58. Matzo M, Sherman D. Palliative Care Nursing: Quality to the End of Life. New York, Springer, 2001

59. Ferrell B, Coyle N: The Textbook of Palliative Nursing. New York, Oxford University Press, 2001

60. Rubenfeld GD, Curtis JR, for the End-of-Life in the ICU Workgroup: End of life care in the intensive care: A research agenda. *Crit Care Med*, In Press