Ethical issues have emerged in recent years as a significant component of care in the critically ill patient. Recently, the primary emphasis has been directed to care at the end-of-life. The factor that has been identified as the most important to patients and families and the one that is accomplished the least often is successful communication with the physicians. When communication does not take place or is inadequate physicians are left to try to determine what their patient’s wishes would have been regarding end-of-life decisions. This leads to tremendous potential for conflict between the physician and the family, as the patients are often incapable of participating in any discussion regarding end-of-life care. Advance planning on the part of the patient in terms of making their wishes known and education of the health care professionals is essential in promoting effective communication, thereby avoiding conflict in these difficult end-of-life decisions.

One report found 90% of deaths were preceded by recommendations to forgo life-sustaining treatment [5]. Another study reported that only 23% of patients who died received full ICU care including cardiopulmonary resuscitation (CPR), 22% received full care excluding CPR, 10% had life support withheld, and 38% had life support withdrawn, though there was wide variation ranging from 0 to 83% across all the groups [6]. A more recent report analyzed treatments provided when life support was or was not withheld or withdrawn [7]. The authors found that patients in whom life support was withheld or withdrawn were older and had significantly fewer technological and pharmacological supports. However, attending physicians were present during discussion regarding withdrawal of support only 54 to 96% of the time.

These issues have occasionally led to significant conflicts between physicians and patients and their families [8,9,10•,11•,12••]. Several authors have addressed causes of these conflicts and possible means of resolving them [10,13,14•,15••–17••,18•,19,20•,21•,22••,23,24].

Interest in end-of-life care has manifested itself in the appearance of major tracts related to this area at the annual symposia of two major professional societies devoted to the care of the critically ill. Additionally, many articles and even a book that comprehensively addresses ICU care at the end-of-life [25••] have been published. At the most recent annual meeting of the Society of Critical Care Medicine there were over 10 sessions devoted to compassionate end-of-life care in the ICU. These sessions were so well attended that the assigned room had to be changed to one that was twice the size.

This update will discuss some of the issues involved in end-of-life care, with emphasis on the needs for commu-
Advance planning

As expressed by Justice Benjamin Cardozo, a patient has long had the right “to determine what shall be done with his own body” [27]. This right also allows patients to forgo life-sustaining treatments based on their preferences and goals [8,28]. However, in one study only 3.4% of patients whose deaths were preceded by limitation of life support were judged to be competent throughout their ICU course to make treatment decisions [5]. Thus, we see that most decisions to limit therapy in the ICU are not made by the patients themselves.

Based on data collected from the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT) study, Teno found that fewer than 40% of patients and/or surrogates reported that their physicians had talked with them regarding their preferences regarding life-sustaining treatment [29], demonstrating a marked lack of communication between physicians and their patients regarding this issue. This lack of communication is common and will be discussed in more detail later. Wenger, also based on SUPPORT data, found that even when physicians communicated with their patients, they correctly understood their patients’ preferences to forgo CPR only 46% of the time [23].

Prendergast reviewed the need for advance care planning [16••]. Advance directives are one of two forms that take effect when a patient is incapable of making decisions. A living will provides written direction to a patient’s wishes. A durable power of attorney for health care provides for an agent to speak on behalf of the patient.

The Patient Self Determination Act (PSDA), enacted in 1990 in response to the case of Nancy Cruzan, provided a major impetus for promoting advance directives. She was a woman in a vegetative state after an automobile accident whose parents requested discontinuation of artificial nutrition. The US Supreme Court allowed the Missouri requirement of “clear and convincing evidence” of the patient’s wishes to stand, creating a burden of proof that surrogate decision-makers frequently are unable to meet. In an attempt to remedy this problem, the PSDA required hospitals to educate staff regarding advance directives, ask all patients admitted whether they had an advance directive and if not, provide them with information about their right to execute one.

Despite the PSDA, it has been shown that less than 40% of patients have advance directives [30–32]. In one report, only 5% of ICU admissions from the emergency room had advance directives [31].

The existence of advance directives does not ensure that the patients’ wishes will be carried out. In a study of 175 nursing home patients, 25% of the time end-of-life care did not follow the patients’ previously expressed wishes, in most cases being less aggressive than the patients wanted [33]. Schneiderman found no difference in any outcome variable between those patients who did and did not have an advance directive [34].

The SUPPORT trial attempted to improve end-of-life decision-making and reduce the prolonged process of dying [35]. The observational phase found poor end-of-life care, manifested by poor communication and decision-making [35,36]. The intervention phase had trained nurse facilitators who gave prognostic information to patients and physicians, elicited and documented patient and family preferences regarding end-of-life care, and facilitated communication between patients and physicians. Outcomes for the intervention phase were: the incidence and timing of do not resuscitate orders; patient-physician agreement on preferences for CPR; days in the ICU, in a coma or ventilated before death; presence of pain; and use of hospital resources.

An increase was found in the recording of advance directives in the medical record from 6% (pre-PSDA) to 35% (post-PSDA) to 78% (SUPPORT intervention) though the percentage of patients with an advance directive remained at 21% in all three groups [32]. Despite this, only 12% of patients with an advance directive discussed them with a physician when filling it out, and only 25% of physicians knew their patients had an advance directive.

The SUPPORT intervention group showed no difference in any of the outcome measures [35]. Teno also found that 10 of 22 patients who had advance directives that directed forgoing life-sustaining therapy received treatment that conflicted with the directive [37].

Lynn proposed several explanations for the ineffectiveness of the SUPPORT intervention, including bias against an effect of the intervention, lack of implementation of the intervention, and lack of appropriate outcome measures [38]. However, none of these or their other explanations was felt to be adequate to explain the failure of the intervention. Lynn continued in the same supplement to suggest that the underlying assumption was flawed, and that individual patient-level shared decision making may not be amenable to significant change [39•]. The authors felt that more attention may need to be made to system change and quality improvement. Specifically, they suggested that it may be better to focus
on improving communication rather than shared decision-making [36,39•].

One advance planning effort, the Respecting Your Choices model developed by Dr. Hamnies, has been successful [40]. It treats advance planning as an ongoing process, shifting the focus from document completion to facilitating discussion about values and preferences, changing the setting from the hospital into the community, and refocusing from autonomy toward personal relationships.

Communication
Communication with health care providers is consistently identified as the most important and least accomplished factor in end-of-life care in the ICU [17••]. Without adequate communication, the physician is left on his own to determine the aggressiveness of therapy at the end-of-life. Wenger found that more than 80% of patients who had decisions to withdraw dialysis had documentation of patient/family discussion regarding this decision, compared with no documentation of discussion of decisions to withhold dialysis in 40% of patients [41]. As previously mentioned, physician practice may conflict with the patient’s wishes between 25% and 45% of the time [8,33,37].

Curtis quantified the barriers that patients and clinicians erect and facilitators of patient-physician communication regarding end-of-life care [20•] and the interventions that could overcome them for patients with the acquired immunodeficiency syndrome. The most frequent patient barriers could be overcome with educational or counseling interventions (e.g., “I don’t like to talk about getting very sick” – counseling). The physicians also had barriers that would require educational or counseling interventions (e.g., “S/he isn’t ready to talk about the care s/he wants if s/he gets sick” – education). In addition 47% complained about having too little time to discuss everything they should (e.g., change in health care system). Facilitators that encouraged communication were: for a patient, if a friend or family member had died previously or, for the clinician, if the patient had been very sick in the past.

Even if communication does occur, the question is, does the patient/family understand it? Azoulay evaluated the ability of relatives of patients in an ICU in Paris to understand information regarding diagnosis, prognosis, and treatment of their relatives [18•]. He found that 54% did not understand the diagnosis, prognosis, or treatment; 20% did not understand the diagnosis, 43% the prognosis, and 40% the treatment. Factors associated with poor comprehension were relatives of patients who were younger (less than 50 years), unemployed, in a coma or in respiratory failure, relatives who did not speak French, had no personal ICU experience, had no healthcare professionals in the family, and were not the spouse of the patient. Poorer comprehension was also seen if no written brochure was given to the family.

If, as was found in the survey by Sjokvist [9], the public feels that the patient/family must have input into withdrawal of life support and other end-of-life decisions, then communication between the physician and the patient/family must be improved. Otherwise, as the accompanying editorial to Azoulay’s article was titled, the ICU will be known as the “Ineffective Communication Unit” [19]. Several authors have suggested various ways of improving end-of-life communication.

Larson discussed that the causes of failed communication may be related to the patient, physician, or the medical system [21•]. The patient may be embarrassed or afraid of the stigma associated with end-of-life conversations. The physician may fear bringing bad news, anticipate disagreement with the family, or feel threatened by such discussions. The medical care system does not allow time or reimbursement for these discussions. To overcome these barriers Larson recommends: focusing on the patient’s/family’s view of their disease (e.g., “There is a lot I can do for you by keeping you comfortable, etc.); improving physician interpersonal communication skills; focus on quality of life at the end-of-life; and implement these discussions earlier in the care process.

Von Gunten presented a seven-step approach for structuring communication [22••]. The first three steps prepare the participants for the discussion and after delivering the information the last three allow the physician to respond to the patient/family reactions. These steps are: prepare for the discussion; establish what the patient/family knows; determine how the information is to be handled; deliver the information; respond to emotions; establish goals for care and treatment priorities; establish a plan. He suggests the use of validated worksheets with a range of clinical scenarios to facilitate discussion between the physician and family.

Curtis suggests that the ICU family conference can play a large role in improving communication [15••]. It is important to properly prepare for the conference, reviewing the knowledge of the patient, family, and disease, resolving any clinical disagreements between specialists, identifying any areas of uncertainty, and making sure all appropriate staff members are present. During the conference discuss prognosis frankly in a way that is meaningful to the family, insure that the family knows that the physician is not withdrawing from caring for the patient, and after allowing time for family reaction, make specific recommendations. It can be useful to have the nurse talk to the family both before and after the conference, to
Palliative care

Until recently, end-of-life care was used when all attempts to save life were unsuccessful. However, ICU mortality is still high in many cases. Also, ICU physicians are unable to predict when patients are going to die. The predicted 2-month survival in the SUPPORT study was 50% one week prior to death and 20% one day prior to death [44]. 50% of patients in the SUPPORT study reported experiencing pain during their ICU stay [45]. Therefore, although good measures are lacking, palliative care would seem to be a goal from the outset of the ICU stay for most patients [13]. However, it is interesting to note that another article in the same supplement proposes that a shift to palliative care occur only when curative care is no longer a viable option [14].

Education

It is unsettling that a topic occurring so frequently and that generates such anxiety has no place in the medical school curricula. It would be unthinkable to send an intern to place a central line without ever having seen one done, yet that is what is done when it comes to communicating with families. Drs. Danis, Fins, and Mularski have proposed various educational schemes for members of the health care team to learn how to deal with end-of-life issues [2,14•,46]. Danis lists a number of principles, a knowledge base, attitudes, and skills that are essential to learn. She stresses that the goals of care determine the use of technology, that effective communication is essential to establish trusting relationships, that trust is crucial to good decision-making and care, and that the delivery of excellent palliative care is possible and effective when patients are dying in the ICU [2]. Fins’ course begins with a self-study of physicians facing death and progresses to cross cultural issues, withdrawal of life-sustaining therapy, brain death, pain management, and palliative care [46]. Mularski based his curriculum on that of Danis but extended it to a multidisciplinary approach to end-of-life care [14].

Futility

As can be seen from the above discussion and from Fins’ article [10•], if effective communication occurs, futility will not become an issue in most instances. Fetters studied the physician response if patients request nonbeneficial treatment or refuse beneficial treatment [12••]. The overwhelming majority negotiated and/or educated the patient/family. 33% acceded to requests for “benign, nonbeneficial” treatments. 35% either refused or did not offer such treatments.

Medical competence

Franklin proposed that in life-threatening situations where the risks of therapy are minimal and the patient refuses, the physician may override that refusal if it is “irrational, arbitrary, or capricious” [26•]. An editorial by Luce questions this premise, saying it ignores basic principles of autonomy and informed consent [47].

Conclusion

Clinicians in the ICU are confronted daily with ethical issues from every end of the spectrum. Learning how to communicate these issues to patients and their families and how to facilitate end-of-life decisions is a new and ongoing process for most intensivists. Education in this area needs to occur much earlier in the course of medical training.

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References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:
• Of special interest
** Of outstanding interest

5 A superb review of factors affecting end-of-life decision-making, especially in its discussion of cross cultural and national differences.
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17 Levy MM. End-of-life care in the intensive care unit: Can we do better? Crit Care Med 2001;29(Suppl):N65–N68. An excellent summary of the current state of end-of-life care in the ICU, with suggestions as to what constitutes good end-of-life care and how we may be able to achieve that goal.


22 Levy MM. End-of-life care in the intensive care unit: Can we do better? Crit Care Med 2001;29(Suppl):N65–N68. An excellent summary of the current state of end-of-life care in the ICU, with suggestions as to what constitutes good end-of-life care and how we may be able to achieve that goal.


24 American College of Chest Physicians/Society of Critical Care Medicine Consensus Panel. Ethical and moral guidelines for the initiation, continuation, and withdrawal of intensive care. Chest 1997;111:949–958. This article analyzed the bases for futility disputes. It proposed use of structured instruments to make judgments about appropriate goals of care, thereby minimizing futility disputes. This article, along with reference 20, identifies several factors that present barriers to patient/family lack of understanding of physician communication.