End-of-Life Decision Making in the ICU

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Twenty percent of deaths in the United States follow admission to an ICU, often in association with decisions to forego life support. In recent years, end-of-life decision making has become a key feature of critical care practice.

Unfortunately, numerous shortcomings afflict end-of-life care in the ICU. Patients unlikely to benefit are admitted frequently, leading to needless suffering and wasted resources. Inadequate treatment of pain and dyspnea are common. Patients’ relatives frequently develop psychiatric morbidity, which may be partly related to conflict with physicians and stress connected with end-of-life decisions.

End-of-life care varies dramatically among physicians, hospitals, and countries, and this variability fuels concern that factors besides a patient’s illness and preferences drive treatment. In one study, clinicians shown identical hypothetic cases suggested widely different treatments, ranging from aggressive care to palliation. Other studies have shown widely varying rates of decisions to forego life support, use of “do not resuscitate” (DNR) orders, and willingness to treat patients who are permanently unconscious or terminally ill. The reasons for this variability are unknown but probably include differences in practice style, access to care, and local cultural and religious traditions.

ICU management clearly improves survival for appropriately targeted patients. To some degree, end-of-life decisions determine if patients live or die. Careful decision making is essential to ensure that care provided is consistent with patients’ wishes. Given their expertise, intensivists are well positioned to provide outstanding end-of-life care and promote family satisfaction.

The remainder of this article is devoted to building a framework on which to guide end-of-life decision making in the ICU.

AN APPROACH TO END-OF-LIFE DECISION MAKING

The goal of end-of-life decision making is to meet patients’ wishes and needs by choosing appropriate treatments. In Western society, these choices occur within an ethical framework dominated by key precepts: respect for patient autonomy, the physician’s duty toward beneficence and nonmaleficence, and an obligation to ensure just distribution of resources.

These precepts sometimes pose internal conflicts. For example, patients may refuse treatment or request care physicians believe nonbeneficial. Alternatively, desired care may be unavailable, for example, if a shortage exists in ICU beds. Respect for autonomy generally allows patients to refuse recommended care, although most agree this does not require that physicians offer nonstandard interventions or care they believe harmful.

End-of-life choices fall into two broad categories, those that are constrained and those that are unconstrained. Unconstrained choices imply the opportunity to choose among multiple treatment options. In contrast, constraint occurs when options are limited, either because treatments are unavailable or because they cannot work. Specifically, under some circumstances, rationing and triage may be necessary when resources are limited. In other circumstances, medical futility may constrain treatment. In practice, most end-of-life choices are unconstrained,

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but constrained choices impose ethical and practical considerations that must be addressed.

**RATIONING AND TRIAGE**

Rationing is defined as "the allocation of health care resources in the face of limited availability." Rationing and triage are uncommon in American ICUs, where it is unusual to refuse admission, even to patients who have end-stage illness. Limitations have long affected care in countries with fewer resources. The need to triage will likely become more common in the United States with growing concern about pandemics, bioterrorism, and the expanding population of critically ill patients.

At first glance, the need to restrict services may strike some physicians as ethically troublesome. However, when resources are limited, rationing cannot be avoided and physicians are obligated to maximize benefit to the population and distribute services fairly. Policies must be designed to identify those patients most likely to benefit from the ICU, recognizing that triage has the potential to place patients refused admission at risk for worse outcomes.

Protocols using objective parameters can help guide decision making. Several models are available, as are reviews and position pieces that highlight essential principles. Institutions should prepare for shortages in advance and ensure that triage protocols are appropriately vetted, understood by affected clinicians, and ready to be implemented when needed. Good clinical practice should be promoted to minimize the need to triage. Examples include adhering to standard admission and discharge criteria; addressing end-of-life issues; expediting bed flow; expanding the capacity of acute care floors to manage seriously ill patients; and following practices that decrease length of stay, such as avoiding excess sedation and weaning in a timely manner. To avoid conflict of interest, triage physicians should be distinct from those providing patient care.

Objective, transparent principles of prioritization must be implemented that encompass two factors: the need for ICU care and the likelihood of benefit. Patients requiring interventions typically limited to the ICU, such as mechanical ventilation through an endotracheal tube, should generally take priority over patients admitted for monitoring only. Similarly, patients most likely to survive and resume a functional life should take priority over those unlikely to achieve an acceptable outcome. Examples of patients unlikely to benefit include those uninterested in aggressive care and those who have rapidly fatal illness.

**Box 1**

**Key triage principles**

- Triage is required when need (eg, for ICU beds) exceeds supply.
- The goal of triage is to provide the greatest good to a target population.
- Objective criteria are used to assign priority to one patient over another.
- Policies must be fair, transparent, and objective.
- Institutions should minimize the need to triage by
  - Expanding ICU bed capacity if possible
  - Improving their ability to care for patients outside the ICU
  - Encouraging efficient patient throughput
  - Promoting practices that decrease ICU length of stay
  - Addressing end-of-life issues
- Appropriate ICU bed use should be promoted before crises occur.
- Triage policy must be understood by all stakeholders.
- Triage responsibility must be separated from patient care responsibility.
- Oversight by experts in bioethics, legal affairs, and hospital administration must be provided for.
- One must remember that triage does not condone abandonment

*Data from Refs. 27,37,44–46,48*

**Box 2**

**An example of a triage scoring system**

- **Level I:** Requires ICU-only interventions/high likelihood of benefit
- **Level II:** No ICU-only interventions needed/high likelihood of benefit
- **Level III:** Requires ICU-only interventions/low likelihood of benefit
- **Level IV:** No ICU-only interventions needed/low likelihood of benefit
- **Level V:** Does not meet standard ICU admission criteria

*Adapted from Yale-New Haven Hospital ICU Triage Policy. March 5, 2008.*
advanced, irreversible cognitive impairment, or progressive multiple organ failure. Objective measures, such as severity of illness scores, clearly identified “ICU-only” interventions, and expert input should promote appropriate triage.

Even if denied ICU admission, critically ill patients merit treatment to the extent that resources are available. When implementing triage, institutions should consider whether prioritization should apply only within or also between individual ICUs (eg, to consider if a medical ICU patient should displace a patient who has lesser need from a surgical ICU). Similarly, policies should address whether candidates should be limited to those already within the institution or should include those hospitalized elsewhere (eg, those seeking transfer for specialty services). Finally, oversight and support should be provided by ethics committees, legal experts, and hospital administrators, to ensure that triage is implemented ethically, legally, and effectively.

FUTILITY

Few issues inspire more passion than medical futility.50–58 The definition of futility is hotly debated. However, any reasonable definition should recognize a condition as futile if no effective treatment exists. Futile care is inherently unethical, incurring cost and possible suffering without benefit.59 Identifying futility has critical implications for decision making. Many physicians and professional societies agree that physicians should not provide futile care, even if requested,53,55,60 although some dissent.56 Identifying futility may relieve physicians, patients, and families from difficult decisions when it is recognized that the outcome cannot be altered.

Disputes over the definition of futility make it difficult to determine its frequency. In a European study, 73% of ICUs frequently admitted patients without hope of survival.6 In a study from California, 4.8% of Medicare beneficiaries received “potentially ineffective care,” defined as expensive hospital care given shortly before death.61

Unfortunately, many physicians define futility loosely in practice.62 Quantitative and qualitative criteria have been promoted.50,53,60,63,64 A commonly cited quantitative definition denotes futility when treatments fail despite 100 attempts.53 Some object to using quantitative criteria if success remains possible, even if exceedingly unlikely.50 Others have suggested restricting futility designations to conditions meeting narrow physiologic criteria, such as recalcitrant hypotension or hypoxemia.84 In contrast, others support broader use, including states of permanent unconsciousness or inability to overcome dependence on intensive care.53,60 The more narrow the definition, the less commonly futility will be identified.

Citing futility as a rationale to limit care raises numerous concerns. For example, not all patients agree that futility should entitle physicians to withhold offers of mechanical ventilation.65 In addition, it is difficult for physicians and nurses to identify futile cases reliably.66 Several investigators have tried to identify clinical factors in specific populations that precluded survival,67 but survival estimates can become obsolete quickly as practice evolves and outcomes improve.68,69

Rigid notions of futility can create self-fulfilling prophecies.70 Clearly, concerns about causing needless suffering must be balanced with the imperative to seek better outcomes in our sickest patients.71 Many reasonable ethical concerns have been raised regarding the use of the futility rationale to justify decision making.56 In practice, it is difficult to cite in all but the most obvious cases. For these reasons, it is usually best to approach end-of-life decision making using the methods used in nonfutile, unconstrained, situations.

UNCONSTRAINED DECISION MAKING

Most end-of-life decisions are unconstrained by resource limitations or futility, and are restricted only by patient preference and practice standards. In North America (and, increasingly, elsewhere), respect for patient autonomy dominates decision making, empowering patients to choose among treatment options. In other places, paternalism often dominates, with physicians choosing treatments they think best for the patient, although this practice is becoming less frequent.23

Respect for autonomy parallels the principles of informed decision making. To make decisions, patients must understand their conditions and receive enough information to weigh the risks and benefits of treatment options. Physicians may, and often should, provide recommendations, although patients have the final say.

In the ICU, cognitive impairment due to factors such as delirium, sedation, and dementia prevent most patients from making decisions.72–75 Cognitive impairment can be subtle76 and mandates a thorough assessment to confirm decision-making capacity. In practice, most end-of-life decisions depend on surrogate decision makers, usually family members3,77–79 except under unusual circumstances when none are available.80

Surrogate Decision Making

Surrogates face special challenges, particularly because patients’ wishes are often unknown.
A hierarchy for surrogate decision making has been described. First, surrogates should report the patient’s specific preferences if known. Second, if this is not possible, surrogates should attempt substituted judgment, relying on available evidence to express what they believe the patient would choose if able. Finally, if preferences are completely unknown, surrogates should choose the treatment they believe to be in the patient’s best interest.

Surrogate decision making requires flexibility. Many patients would prefer their relatives to exercise discretion or make decisions for them rather than limit themselves to being spokespeople. Families from certain cultures may not recognize traditional Western views of autonomy. For example, some families may not be able to or want to consider patients’ interests as distinct from their own. Some families may not want to engage in decision making. It is reasonable to take a flexible approach to surrogate decision making as long as the patient’s wishes are not compromised.

**Advance Directives**

Physicians and families often do not know patients’ end-of-life preferences. To encourage accurate decision making, physicians should discuss preferences with patients preemptively, while they can still speak for themselves. Advance directives (ADs) have been proposed as a way to ensure patients’ wishes are respected if they become incapacitated. The most common ADs instruct physicians to forego life-sustaining treatment if patients become terminally ill or permanently unconscious. Unfortunately, few patients have ADs and little evidence exists that they aid decision making. As written, they generally apply to limited, specific circumstances, such as permanent unconsciousness and terminal illness. They often are unhelpful if incapacitation is temporary, the illness is not terminal, or the interventions in question are not specifically addressed. ADs do not improve surrogates’ abilities to represent patients’ preferences accurately. Patients frequently misunderstand their own ADs, which may also fail to reflect their wishes.

Discussion of preferences in advance can be helpful. Prior discussions can diminish the family’s burden when asked to make decisions. Outpatient discussions offer opportunities to consider treatment options, including hospice, should life-threatening illness develop. Patients who have advanced cancer who have end-of-life discussions appear to have a better quality of life before death and their family members experience fewer bereavement-related psychiatric disorders. Unfortunately, outpatient discussions occur inconsistently, even among patients who would benefit.

**Special Challenges Facing Surrogate Decision Makers**

Surrogate decision makers face enormous pressure. Many family members, especially spouses, experience anxiety, depression, and features of posttraumatic stress disorder. Participation in end-of-life decisions may contribute to psychiatric morbidity, although further work is needed to confirm this finding and to identify the mechanisms involved.

Decision making is especially difficult when patients’ preferences are unknown. In general, preferences are not consistently related to factors such as age, underlying illness, prognosis, presence of ADs, or quality of life. Physicians and family members often cannot predict preferences, although certain factors, such as level of surrogate and patient education and prior end-of-life discussions may improve accuracy.

Wishes expressed as outpatients may be unstable over time. Factors associated with instability include a long time between interviews, changes in health status and quality of life, not having children, absence of a living will, and previous desire for aggressive care. To some degree, changes in treatment preferences are understandable. Willingness to accept treatment may change if a patient’s condition or the likelihood of successful treatment evolves. Similarly, as illness progresses and quality of life deteriorates, some patients may be more willing to accept lower functional outcomes. Alternatively, they may be less willing to pursue highly burdensome therapies or risk severe disability.

Certain common observations are worth noting. A strong will to live will cause many patients to endure ICU care, even when prognosis is poor. Most survivors would return to the ICU even if the benefit was only 1 month of survival. In contrast, many outpatients who have chronic illness report little interest in aggressive therapy if the likely outcome is poor; many, but not all, would view survival with a poor quality of life or major functional or cognitive impairment as a fate worse than death.

**FAMILY MEETINGS**

Family meetings precede most end-of-life decisions in North America. Well-conducted meetings
promote appropriate decisions and family satisfaction and well-being. Meetings should occur shortly after ICU admission and not wait until decisions are urgent. As with any medical procedure, successful meetings include several components, including a clear description of the medical facts, a discussion of goals and treatment options, and decision making. Meetings should be held in a private, quiet place to minimize interruptions and should include all important members of the team, including attending physicians, medical trainees, nurses, social workers, and chaplains if possible. Caregivers should meet beforehand to achieve consensus regarding prognosis and treatment options.

**Discussing Prognosis**

Physicians leading meetings should review the patient’s course with the family, including ongoing and previous treatments attempted. Prognostic estimates are essential. Although precision may be difficult, decision making requires some prognostic quantification. Prognosis may vary depending on the outcome considered, whether it be survival, return of cognitive function, or quality of life. Severity of illness scores may help identify patients unlikely to survive, although population-based scores are often misleading when applied to individual cases.

A poor prognosis alone is unlikely to dictate treatment. Many families will support aggressive treatment as long as an acceptable outcome is possible. With appropriate support, families should be able to balance hope with realistic expectations. Patients can receive palliative care even as life-saving efforts continue; they are not mutually exclusive. One should not worry that an honest discussion regarding prognosis will destroy hope or cause psychologic harm; rather, honest discussions appear to improve end-of-life care for both patients and families.

**Making Decisions**

Agreement regarding treatment goals sets the stage for specific decisions. A clear identification of goals followed by an assessment of whether they can be achieved should help families and caregivers choose appropriate treatments. Goals can be grouped into three categories. On one end of the spectrum, the goal may be to cure or ameliorate the patient’s illness using all available therapies, without imposing limitations. On the other end, the goal may be to emphasize symptom management, sometimes to the point of providing “comfort measures only.” A midrange goal would be to attempt disease treatment while limiting those interventions and treatments considered overly burdensome. As distinct from treatments, goals should include outcomes expressed in nonmedical terms, such as a wish to return home, avoid disability, or be free of pain.

Once goals are established, decisions regarding specific interventions should follow logically. For example, if the decision is made to treat without limitations, it generally follows that all necessary interventions will be provided, including cardiopulmonary resuscitation (CPR) or mechanical ventilation. In contrast, if comfort is to be emphasized, these interventions would make little sense. A more nuanced discussion may be necessary if the decision is to provide limited treatment. Plans should be internally logical, recognizing that individual treatment decisions are not inherently independent. For example, it would be inappropriate to provide CPR to a patient who arrests after foregoing intubation for respiratory failure.

The implications of decisions made must be fully understood by clinicians and surrogates. By itself, a decision to make a patient DNR implies only that resuscitation would be withheld after cardiac arrest. DNR orders have no bearing on other decisions, and fully aggressive management may be provided otherwise. The distinction between therapies deemed heroic or not is arbitrary. Although it is common to draw certain “lines in the sand,” such as withholding vasopressors for shock, the rationale for imposing certain limitations and not others can be illogical. It is much more important to weigh the benefits and burdens of individual therapies to determine if they are consistent with the established treatment goals.

Pitfalls can result from mistaken assumptions. For example, patients who have metastatic cancer or dementia can vary widely in prognosis and functional status. ICU care may be appropriate for some but not others. Similarly, the fact that a patient has an AD or wants to be DNR says little about overall preferences. Finally, just because families and physicians agree does not ensure appropriate decision making. All decisions require careful deliberation to maximize the likelihood that they are appropriate.

Families should not be pressured to make decisions, and they should never simply be asked “what they want done.” It is the physician’s responsibility to determine if treatment preferences are achievable and to offer recommendations. Most families prefer to share decision making with physicians and should be allowed to do so.

Explicit language can reinforce the concept of surrogacy. For example, family members may be
asked what they believe the patient would say if present.4 Many families prefer to function as a group. It is important to strive for consensus among all present to avoid burdening any individual with sole decision-making responsibility.4,79 Families should be given sufficient time to speak and ask questions.111,124 Physicians should listen carefully, recognizing that concerns expressed may be subtle.77,111,113 Empathic statements foster family satisfaction.125 Finally, conferences should conclude with positive statements ensuring support for the patient and family, and, if the decision is made to forego life support, assurance that the patient will not suffer.126

OBSTACLES TO SUCCESSFUL FAMILY MEETINGS

Several factors pose challenges to reaching consensus with families. Real or perceived conflict between families and physicians is common.17,18 Physicians may be confounded by what they perceive to be a family’s illogical thinking,63 which should be taken as a sign that important issues need to be addressed. Inadequate or delayed communication is a common problem, contributing to misconceptions about prognosis and treatment options.112,127 Insufficient physician time to meet with families may also contribute.5 Insurmountable disagreements should be rare, however, and conflict should dissipate when communication improves, misunderstandings are corrected, and emotional and spiritual needs are met (Box 4).4,63,77,110,111,113 Significant shortcomings plague many family meetings. Many are led by unsupervised trainees.128 Discussions of prognosis, particularly likelihood of survival, occur inconsistently.128–130 Physicians often miss opportunities to share key concepts: the purpose of the meeting, surrogate decision making, shared decision making. Clearly describe the patient’s condition. Explain the disease process. Discuss what the patient is experiencing. Discuss ongoing and previous treatments attempted. Discuss prognosis. Allow time for questions, comments, and clarification. Discuss goals and treatment options. Focus on general goals, using lay language. Try to determine what the patient would want if possible. Consider the risks, benefits, and implications of specific treatment options. Focus on treatments designed to meet established goals. Explain why certain options are not available, if necessary. Determine the degree of shared decision making required. Provide recommendations as appropriate. Allow time for questions and deliberation. Make explicit treatment decisions. Ensure that decisions are consistent with treatment goals. Ensure the treatment plan is internally logical and consistent. Ensure consensus and comprehension. Wrap up. Provide explicit, empathic statements of support for the family. Ensure ongoing care for patient, including full efforts to meet the established goals management of symptoms as necessary. Provide opportunities for follow-up meetings if needed. A flexible approach is necessary to meet the needs of individual patients and families. Data from Refs.3,4,77,111,118,122

Box 3
Key components of successful family meetings

- Meet early in the hospitalization, before decision making is urgent.
- Prepare in advance.
  - Find an appropriate, private location.
  - Enlist all team members, including attending physicians, trainees, nurses, social workers, chaplains, and translators (if necessary).
  - Achieve team consensus regarding prognosis and treatment options.
- Introduce everyone present.
  - Sit in a circle if possible.
  - Clarify everyone’s roles or relationship to the patient.
  - Explain the purpose of the meeting.
- Explain key concepts:
  - The purpose of the meeting
  - Surrogate decision making
  - Shared decision making
- Clearly describe the patient’s condition.
  - Explain the disease process.
  - Discuss what the patient is experiencing.
  - Discuss ongoing and previous treatments attempted.
  - Discuss prognosis.
- Allow time for questions, comments, and clarification.
- Discuss goals and treatment options.
  - Focus on general goals, using lay language.
  - Try to determine what the patient would want if possible.
  - Consider the risks, benefits, and implications of specific treatment options.
    - Focus on treatments designed to meet established goals.
    - Explain why certain options are not available, if necessary.
  - Determine the degree of shared decision making required.
    - Provide recommendations as appropriate.
    - Allow time for questions and deliberation.
  - Make explicit treatment decisions.
    - Ensure that decisions are consistent with treatment goals.
    - Ensure the treatment plan is internally logical and consistent.
- Ensure consensus and comprehension.
- Wrap up.
  - Provide explicit, empathic statements of support for the family.
  - Ensure ongoing care for patient, including full efforts to meet the established goals management of symptoms as necessary.
  - Provide opportunities for follow-up meetings if needed.
- A flexible approach is necessary to meet the needs of individual patients and families.

Data from Refs.3,4,77,111,118,122
In one study, only a few meetings included efforts to confirm that families understood the decisions made. Misdirected focus can impose obstacles to consensus. No reason exists to ask families if they wish futile or unavailable therapy. Similarly, excessive time spent considering narrow issues such as “code status” (which addresses only how to respond to a cardiac arrest) might be better spent considering overriding goals such as whether to emphasize aggressive treatment or comfort.

The burden felt to make decisions may delay consensus. In addition to sharing in decision making, physicians may help families by placing decision making in appropriate perspective. Although some end-of-life decisions can influence outcome, the patient’s underlying illness almost certainly plays a bigger role in most cases. Fear that they are responsible for “pulling the plug” can make decision making difficult for some families and set the stage for subsequent misgivings. When prognosis is poor, it may be helpful to acknowledge that decisions are more likely to influence how, not whether, a patient dies.

Physicians may overestimate what families understand. Insufficient information may prevent families from making informed choices or trusting what physicians say. In one French study, half of families reported inadequate communication with physicians. In an American study, many families were not given enough information to make informed decisions regarding tracheotomy. Physicians may fail to distinguish between permanent and temporary conditions (eg, those related to cognitive impairment). Lacking understanding, many families may overestimate the likelihood of success of CPR, whereas accurate information may lead fewer to choose it. Similarly, some families may be concerned that a decision to choose intubation and mechanical ventilation commits patients to long-term life support, not recognizing that withdrawal of support is an option if treatments fail or preferences change.

Specific interventions should be described in an unbiased manner, addressing the risks and benefits in sufficient, but not overwhelming, detail.

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**Box 4**

Avoiding conflict and barriers to consensus

- Form supportive relationships with families.
  
  Meet early.
  
  Meet frequently.
  
  Ensure open visitation.
  
  Invite participation on rounds.
  
- Focus on overriding goals rather than narrow issues (such as code status).
  
- Allow families to express feelings and concerns.
  
- Be mindful of language and cultural barriers.
  
  Use professional translators.
  
  Avoid sloppy language and jargon.
  
  Consider cultural context and family’s background and past experiences.
  
  Explore common informal statements by family.
    
    “We’re hoping for a miracle.”
    
    “We want everything done.”
  
- Be aware of religious and spiritual concerns.
  
  Avoid assumptions about preferences.
  
  Enlist chaplain support.
  
- Address potential knowledge deficits:
  
  Nature of illness
  
  Risks and benefits of specific interventions
  
  Awareness of treatment options
  
  Assumptions about ADs and implications of DNR orders
  
- Ensure senior physician involvement.
  
- Do not place undue pressure on families to make decisions.
  
  Avoid placing the burden on individual family members.
  
  Place decisions in perspective (generally it’s not “if” but “how” death occurs).
  
  Share in decision making as requested.
  
- Do not rush families.
  
  Allow them time to consider new findings and recommendations.
  
  Allow time for treatment trials.
  
  Schedule follow-up meetings.
  
- Recognize stress and the potential for psychiatric morbidity in families.
  
  Be empathic.
  
  Be patient.

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Enlist support of social workers and mental health professionals.

*Data from Refs. 4, 5, 12–14, 63, 77, 82, 83, 110–113, 128, 134*
Families may not understand why physicians have concluded that a prognosis is poor or why recommendations are being made to limit life support. When patients are doing poorly, it may be especially helpful to recount the efforts made so families understand that deterioration has occurred despite treatment attempts.

Language may impose a significant barrier to communication. A growing number of residents of the United States are not comfortable with English. Inasmuch as possible, it is essential to use professional interpreters; family members and untrained hospital staff are not appropriate substitutes. Certain English terms do not translate easily. Allowing interpreters flexibility may be preferable to translating verbatim. Families may risk misunderstanding. Physicians may also misinterpret terms used by families, such as “letting nature take its course,” may soften language, for example with euphemisms such as “poor prognosis” or “unlikely to work” are prone to misinterpretation; more precise terms may help prevent misunderstanding. When impasse arises, it may be helpful to consider if key information is being “lost in translation.”

Even when everyone is speaking English, it is critical to ensure they are “speaking the same language.” Family members may misconstrue terms such as “DNR,” “CPR,” and “intubation” if not carefully defined. Imprecise phrases such as “poor prognosis” or “unlikely to work” are prone to misinterpretation; more precise terms may help prevent misunderstanding. Families may misinterpret intent when jargon such as “withdrawal of care” is used, as opposed to “withdrawal of life-sustaining treatment.” Attempts to soften language, for example with euphemisms such as “letting nature take its course,” may soften the blow when bad news is given, but may risk misunderstanding. Physicians may also misinterpret terms used by families, such as requests to “do everything,” which mean little if not explored and defined. Similarly, expressions of hope do not inherently imply that families are unrealistic.

In addition to language barriers, cultural differences may impose pitfalls. Families from many regions of the world may find the concept of patient autonomy alien. Some may consider it their responsibility to make decisions for their relatives, as opposed to trying to represent their preferences. Certain Western norms, such as truth telling, may be seen as cruel and some may be concerned that even talking about death may make it more likely. Some African Americans may view suffering as an obstacle to overcome rather than a rationale for palliative care, and some may be more willing than families from other backgrounds to accept life in a severely impaired state. Finally, negative experiences in other settings, for example in refugee camps or under conditions of racial discrimination, may make it difficult for families to trust physicians. While recognizing the existence of certain cultural traditions, it is also critical to avoid making assumptions about attitudes and wishes, which must be deliberately explored.

Physicians should be sensitive to religious and spiritual concerns. The relationship among religion, spirituality, and decision making is complex and not entirely predictable. Many families harbor non-Western beliefs regarding the cause of illness or the role God plays in outcomes. It is important not to assume that religious beliefs or belief in miracles preclude any particular treatment option. For example, hope for a miracle does not necessarily imply that physicians should offer nonstandard therapy or withhold recommendations to emphasize palliation or referral to hospice.

Many families report significant burdens placed on them when treatment decisions are made. According to families, helpful physician and nursing behaviors include timely communication, clarification of the family’s role, facilitating family consensus, and accommodating grief; in contrast, unhelpful behaviors include postponing end-of-life discussions, placing the decision-making burden on one person, withdrawing from the family, and defining death as a failure. Often, the burden of decision making may be lessened if physicians take a more active role.

**IF CONFLICT PERSISTS**

One of the greatest challenges facing intensivists is how best to address impasses created when families request potentially futile or inappropriate treatments. Although it is widely held that physicians are not obligated to provide futile care, it is rarely necessary to forego therapy over a family’s wishes. Conflict usually dissipates in response to empathic, comprehensive communication and patience. Impasses involving psychologic, spiritual, and social issues may require mediation and support from psychologists or psychiatrists, chaplains, or social workers. Some families may be more comfortable talking with nursing staff. Undue
pressure should not be placed on families to make decisions.15 A lack of trust may explain why some families fail to accept physicians’ recommendations.58 Families may need extra time to form working relationships with physicians they barely know.79 Many families simply need more time to grapple with and accept new findings. Treatment trials may help them come to terms with recommendations they initially resist.54,148

How to proceed when impasse persists remains an unsettled controversy. Some ethicists argue that physicians should defer to the wishes of families in these rare circumstances,56 although this is a minority view.53,55,60 If the decision is made to override a family’s wishes, due process must be followed to ensure that the patient’s and family’s rights are respected.149,150 Due process may include obtaining second opinions, providing opportunities to transfer care, and requesting oversight by an ethics committee. Institutional policies should ensure that decisions are fair and rational and eliminate the possibility that physicians would exert undue influence on patients and families.151

The American Medical Association has recommended a process-based approach to decision making under these circumstances,149 although it is not clear that this approach would be legally supported in all jurisdictions.54 To date, one state, Texas, has devised legislation to ensure due process when unilateral decisions are made.150 It must be emphasized, however, that unilateral decision making should only occur as a last resort.

SUMMARY

A large proportion of deaths, particularly in the developed world, follows admission to an ICU. For intensivists, managing death in the critically ill has become a key professional skill. Intensivists must be thoroughly familiar with the ethical framework that guides end-of-life decision making. Moreover, they must become skilled in the nuanced practice of working closely with family members serving as surrogate decision makers. A combination of rational thinking, empathy, and patience will almost always foster effective decision making and exceptional end-of-life care.

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