LIFE AND DEATH IN THE ICU: ETHICAL CONSIDERATIONS

DAVID B. WAISEL

“Death in the ICU is not always preventable and should neither be unduly hastened nor delayed” (1).

Approximately 20% of all deaths in the United States—roughly 500,000 patients annually—occur in, or after a stay in, the intensive care unit (ICU) (2). The principles guiding end-of-life care center on the desire to have patients receive appropriate, carefully chosen, intensive therapy with comfort, dignity, security from fear, and the chance to be with loved ones. Doing this in a technology-driven and death-denying health care system requires incorporating the principles of palliative care throughout the intensive care practice (3–5).

A BRIEF HISTORY OF END-OF-LIFE CARE

The modern history of end-of-life care began with demands of patients to refuse treatments. In 1974, the American Medical Association asserted that “the purpose of cardiopulmonary resuscitation is the prevention of sudden unexpected death. Car-
surrogate’s view of what is best for the patient. A gate must rely on the able adult, substituted judgment is impossible, and the surrogate must choose or interpret the patient’s preferences. These standards care. While these are two distinct categories, both levels require know the patient’s attitudes and beliefs, may be used to direct the decision-making process for the once competent patient’s previously expressed preferences for end-of-life care should be followed as is best possible. When the patient’s declared preferences are not known, substituted judgment, the surrogate’s intimate knowledge of the patient’s attitudes and beliefs, may be used to direct care. While these are two distinct categories, both levels require the surrogate to sufficiently know the patient to appropriately choose or interpret the patient’s preferences. These standards put significant burdens on decision makers who may have legitimate doubts about the appropriateness of their decisions. When a surrogate has to make decisions for a patient who has never been competent, such as a young child or a mentally disabled adult, substituted judgment is impossible, and the surrogate must rely on the best interests standard. The best-interests standard requires the surrogate to make decisions based on the surrogate’s view of what is best for the patient.

**ADVANCED CARE PLANNING**

Advanced care planning permits patients to declare preferences for medical treatment if they become incapacitated. Respecting these preferences is how physicians honor the ethical principle of respect for autonomy, in which patients have the right to make substantially informed decisions about medical therapy and the resultant trajectory of their lives.

Advanced directives are designed to minimize the likelihood of undesired overtreatment and undertreatment of the patient. Partially as a result of Quinlan, the Patient Self-Determination Act (PSDA) was introduced in 1991 to increase the use of advance directives. The PSDA requires health care institutions—hospitals, nursing homes, and hospice programs—to notify individuals about their rights regarding advanced directives. The two types of advanced directives are living wills and health care proxies; the latter are also known as a durable power of attorney for health care decisions.

When a surrogate has to make decisions for a patient who has become unable to make such decisions for themselves. If the patient does not assign surrogacy, most jurisdictions have a hierarchy for doing so. Surrogacy is not always effective, particularly for patients who do not make their preferences clearly known to the surrogates. In 1990, the Supreme Court of Missouri mandated continued care because Cruzan’s evidentiary standard of “clear and convincing evidence” of a patient’s wish to terminate potentially life-sustaining care. The case was appealed to the United States Supreme Court, but unlike Quinlan and Bartling, the Supreme Court grounded the right of a competent patient to refuse treatment in the more powerful liberty interest of the Fourteenth Amendment, which states, “No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty or property . . . “ The decision upheld the rights of states to determine the standards for the level of certainty required, permitting Missouri to use the “clear and convincing evidence” standard, but also permitting other states to use different standards (12–14).

Intensive care unit practices may also lead surrogates to demand care for their loved ones. An archetypical case involves Helga Wanglie, an 86-year-old patient in a persistent vegetative state who was receiving mechanical ventilation. The medical center believed that further therapy would be futile for Mrs. Wanglie and wanted to withdraw mechanical ventilation. When Mr. Wanglie refused the medical center request to stop mechanical ventilation, the medical center sought appointment of an independent guardian to supplant Mr. Wanglie as her guardian. The Court declared that Mr. Wanglie was best able to be Mrs. Wanglie’s surrogate (15,16).

Competent patients have a right to refuse potentially life-sustaining medical treatment (17). The modifier “potentially” is used before life-sustaining medical treatment to acknowledge that although physicians may believe that a therapy is life sustaining, there is rarely certainty that the intervention will be life sustaining. For the incompetent patient, three hierarchically levels of judgment direct the decision-making process for end-of-life care. The once competent patient’s previously expressed preferences for end-of-life care should be followed as is best possible. When the patient’s declared preferences are not known, the surrogate’s intimate knowledge of the patient’s attitudes and beliefs, may be used to direct care. While these are two distinct categories, both levels require the surrogate to sufficiently know the patient to appropriately choose or interpret the patient’s preferences. These standards put significant burdens on decision makers who may have legitimate doubts about the appropriateness of their decisions. When a surrogate has to make decisions for a patient who has never been competent, such as a young child or a mentally disabled adult, substituted judgment is impossible, and the surrogate must rely on the best interests standard. The best-interests standard requires the surrogate to make decisions based on the surrogate’s view of what is best for the patient.
WHY ADVANCED DIRECTIVES FAIL

- Not done
  - Patients radically overestimate their 6-month survival and thus avoid advanced care planning or favor more aggressive care than if they had known their true likelihood of survival.
  - People defer advanced care planning because they think they are too young to need it or because they do not want to contemplate it.

- Inauthentic preferences
  - Default responses ("Please check ‘no’ if you do not want intubation") tend to be chosen more frequently than if the question is phrased neutrally and requires a forced choice ("Please check ‘yes’ if you want intubation or check ‘no’ if you do not want intubation").
  - Patients may not know their “authentic” preferences and, even if they do, a one-time assessment may not reveal them.
  - Physicians may be inadequately trained or have insufficient time to successfully elicit values or attitudes about end-of-life care.

- Advanced directives rarely cover specific situations, and few patients successfully communicate their treatment preferences to their families.

- Unavailable documents
  - Because the term advanced directive is unfamiliar, people may not realize what clinicians are requesting when clinicians ask if the patient has such a document. People are more familiar with the terms health care proxy, DNR (do not resuscitate), and living will.
  - Patients falsely assume that doctors and hospitals have copies of their advanced directives.
  - There is inadequate communication and sharing of documents among health care providers (although there is a rising presence of Web-based national systems).

- Inadequate application
  - Surrogates correctly predicted patients’ preferences for treatment 68% of the time. Prior discussion did not necessarily improve the correct rate of prediction.
  - Advanced directives may be ignored when they defy the physician’s goals.
  - Physician–patient discussion of treatment preferences did not improve physicians’ understanding of the patient preferences.


inherent uncertainties of prognostication in medicine and the value of speaking in likelihoods.

While competent patients may modify their previously declared preferences, demented patients who previously made an informed choice to limit certain therapy may express an interest in receiving that therapy (33). If a patient manifests evidence of decision-making capacity, such as being able to provide internally coherent reasoning, their wishes to receive therapy should be honored. However, the process of resolving this situation in a patient without decision-making capacity, and with almost no likelihood of regaining decision-making capacity, is more complex. It would be quite easy to simply provide therapy, however, that is unlikely to reflect their true desires if they had the capacity. In this situation, it is better to choose therapy based on multiple sources, including significant others, documentation, and the best interests standard.

FUTILITY

The concept of futile care has undergone several changes over the past decade (34). Previously, attempts were made to define futile care based on a specific percentage of the likelihood of achieving a certain outcome; for example, cardiopulmonary resuscitation is futile when the likelihood of a patient with this disease process being discharged from the hospital is less than 1% with 95% confidence. This approach failed, in large part because it was difficult to know the likelihood of success in the individual patient. Policies based on this approach inappropriately de-emphasized the importance of individual values and preferences such as the willingness to trypically undertake expensive burdens for relatively minor or highly unlikely benefits (35).

A clearer way to think about futility is to delineate treatments that will not accomplish their intended goals from treatments that have a very low likelihood of accomplishing their goals. Thus, in this sense, therapy may be labeled futile when it cannot accomplish its intended specific goal, for example, when mechanical ventilation cannot accomplish pulmonary gas exchange. In this sense, questions about futile care are infrequent.

The ability to resolve differences of opinions about applying treatments with low likelihoods of success is important. Such treatments may be considered inadvisable because of the burden to the patient, cost, or uncertain benefit, but they are not futile. As discussed above, policies based on definitional approaches are hard to apply and do not respect individual values. A policy based on a procedural approach, in which the process for resolving conflict is described, is more practical. Good policies are public, reflect the moral values of the community, and include processes for identifying stakeholders, initiating and conducting the policy, commencing appellate mechanisms, and determining relevant information (35). Discussions about advisory treatment should bear in mind qualitative and quantitative considerations. The qualitative aspects define the goals of the treatment, and the quantitative aspects state the likelihood of achieving a defined result. When offering likelihoods of a result, physicians should be clear whether the information used to form the estimation is from intuition, clinical experience, or rigorous scientific studies. Scoring systems useful for population-level predictions should be considered as contributory but not determinative for decision making for individuals.
Recently, Texas has enacted a legislative approach to resolving disputes about appropriate care. Physicians are permitted to unilaterally withhold or withdraw treatments they regard as futile, provided they obtain the agreement of the hospital ethics committee. The impact of this questionable strategy for conflict resolution is being closely monitored (36–38).

**CARE OF THE DYING PATIENT**

“End-of-life care seems too early until it is too late—too often” (39).

Management of symptoms, pain, dyspnea, sleep, and other distressing physical and psychological symptoms, including depression and discomfort from catheters and suctioning, needs to be integrated into the routine of intensive care (40–42). The goal is to provide patients and families the best of intensive therapy and palliative care, because physicians cannot predict which path the patient’s course will take. By aggressively providing medical, emotional, psychological, and spiritual care, the patient is more able to focus on decision making and related matters. Poor-quality end-of-life care harms more than just the patient. One third of family members who had relatives die in the intensive care unit had posttraumatic stress syndrome (43).

Good end-of-life care requires successful communication between nurses and physicians to improve patient care and minimize the stress of clinical practice (44). Dissimilar training and experiences of nurses and physicians lead to differences that can hinder communication and collaboration. By virtue of their profession, nurses spend more time with patients and families, take a more holistic view, and may feel more frustrated by conflicting opinions. In the ICU, nurses tend to feel ignored and that their opinions are not respected (45). While physicians tend to think that nurses have a great deal of influence, many nurses would like a more active role in end-of-life decisions (46). Physicians in the United States lag behind those in European countries in terms of involving nurses in end-of-life decision-making. Nurses involved in providing such aspects of care felt greater satisfaction and were more committed to a successful operating unit (47).

Good-quality end-of-life care also requires effective communication among families and clinicians. In one study, 10% of family members in the ICU believed they received contradictory information, and more than half of family members did not know the roles for each clinician (48). Factors that improve communication among the clinicians and between the clinicians and family include minimizing hierarchy, implementing protocols for multidisciplinary communication, and using team training to improve communication skills and diminish the effects of differences in training (45,49–52). Extensive communication involving a weekly team meeting, which included a physician leader, a nurse, a chaplain, and a social worker, decreased discord and length of ICU stay, but it did not affect mortality rate (53). Implementing daily medical updates by the intensivist and adding physician support personnel, such as a social worker and a clinical nurse specialist to elaborate and provide further information, decreased length of stay, mortality, and costs (54). Daily goal worksheets requiring active acknowledgment from providers improved understanding of the goals of the interventions and tasks, decreased length of ICU stay, and improved workflow (52). A “proactive end-of-life conference and a brochure” with a focused communication strategy improved the response to bereavement (55). The communication strategy with family members was based on the mnemonic VALUE: “to Value and appreciate what the family members said, to Acknowledge the family members’ emotions, to Listen, to ask questions that would allow the caregiver to Understand who the patient was as a person, and to Elicit questions from the family members” (55). Given the variety of successes, it would not be unreasonable to suggest that communication can be improved by simply having a reasonable protocol.

Self-imposed attitudinal barriers affect end-of-life care (Table 2.2) (45,56,57). In Western society, individuals tend to assume immortality while intensive care physicians tend to view death as a failure rather than as a natural end to life (39). Prognostic uncertainty fosters this death-denying attitude. Thus, the most commonly adopted attitude is to hold out for the most beneficial possibility—no matter how unlikely—rather than critically analyzing likely outcomes (39). This view may push physicians to wait for proof of failure of therapy, rather than to instigate timely escalation of palliative care. The “siloing”

### TABLE 2.2

**BARRIERS TO END-OF-LIFE CARE**

<table>
<thead>
<tr>
<th>Cultural □</th>
<th>Denial of death □</th>
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<tr>
<td>□</td>
<td>Prognostic uncertainty □</td>
</tr>
<tr>
<td>□</td>
<td>Slowing of professional activity □</td>
</tr>
<tr>
<td>□</td>
<td>Emotional overtones of withdrawal of therapy, particularly mechanical ventilation □</td>
</tr>
<tr>
<td>□</td>
<td>Unrealistic patient, family, and/or clinician expectations about prognosis or effectiveness of therapy □</td>
</tr>
<tr>
<td>□</td>
<td>Disagreement among physicians and nurses about prognoses, which may slow initiation of good end-of-life care; these disagreements were greater in sicker patients and patients with longer intensive care unit stays □</td>
</tr>
<tr>
<td>□</td>
<td>Communication □</td>
</tr>
<tr>
<td>□</td>
<td>Perception of inadequate communication between nurses and physicians □</td>
</tr>
<tr>
<td>□</td>
<td>Perception of inadequate communication between training physicians and attending physicians □</td>
</tr>
<tr>
<td>□</td>
<td>Lack of multidisciplinary approach to communication □</td>
</tr>
<tr>
<td>□</td>
<td>Inadequate financing and insurance coverage for palliative care □</td>
</tr>
</tbody>
</table>

of surgeons, internists, subspecialty consultants, nurses, and specialty nurses, often with relevant prognostic and treatment information, results in poor communication, to the patient’s detriment (39,58).

Race is a barrier to good end-of-life care. Difficulties associated with race include inadequate access to care secondary to finances, geography, and language differences. Family members of African Americans were more likely to report financial hardships than whites (39). In addition, due to historical abuses, some African Americans and members of other minority groups may mistrust the health care establishment. This mistrust may lead to family/surrogate decisions, such as the desire to attempt every therapy and to forgo palliative care, that are not necessarily in the best interests of the patient because of the fear that the motivation for suggesting that the patient forego certain therapies is not made in the patient’s best interests.

Critical care medicine can improve practices surrounding end-of-life care by viewing it as a clinical state to be studied, with emphasis on legitimizing research, assessing the needs of families of dying patients, providing guidelines-based professional support for withdrawal of care, assessing interventions, and modeling of good end-of-life care (1,60). One of the most influential studies of end-of-life care was the SUPPORT study (61).

What is defined as good care is often determined by what is measured. The information in this section needs to be tempered with the knowledge that there are issues with measurements used to define quality care. Process measurements, based on whether a task is performed—such as occurrence of multidisciplinary discussions, the frequency of caregiver/family meetings, chaplaincy visits, attendance at unit educational programs, and so forth—are easy to measure and collect (62,63). However, isolated process measurements are, at best, indirect measures of improvements in care, even when there is evidence of a process-to-outcome link. Outcome measurements are patient-related results, such as length of stay, patient or family member symptoms, or satisfaction of care (63). Outcome measurements can be misunderstood or too indirect. For example, having fewer days per admission due to inappropriate transfer of patients to the ward is not the same as having fewer days per admission due to improved care. Some outcome measurements—for example, pain management—are hard to characterize and may be reduced to using less reliable surrogate characteristics for interpretation, such as behavioral cues for pain management.

The SUPPORT study was a multimillion dollar, 9,100-patient two-phased study designed to assess end-of-life care. In the observational phase, individuals followed patients near the end of life to identify problems in their care. They asked patients about preferences for interventions such as mechanical ventilation and pain medication and the importance of various outcomes, such as being able to interact with others. In the following intervention phase, these trained individuals sought to improve communication of patient preferences to the clinicians. The study found many of the problems discussed in this chapter, such as insufficient use of documented preferences, inadequate pain management, inconsistent communication among clinicians, and an overestimation of medicine’s ability to deny death. Although the intervention phase of the study did not improve end-of-life care, the knowledge gained from the SUPPORT study’s many analyses and publications has shaped nearly all subsequent research in end-of-life care.

### WITHDRAWAL OF CARE

While ethically equivalent, there is an emotional difference between withdrawing care and withholding care (60). But in fact because withdrawal of therapy permits a trial of the therapy in question, it is superior to the withholding of therapy, because if therapy is withheld, the patient will never know if the therapy could be applied with an acceptable benefit-to-burden ratio. Intensivists are more likely to fulfill a patient’s wishes by implementing a trial of therapy and reviewing it at specific intervals for appropriateness (64). A physician’s willingness to withdraw therapy is affected by a prediction of poorer cognitive function, a prediction of a less than 10% chance of survival, and patient preferences (1,65).

Practices of withdrawal of mechanical ventilation vary in hope of maximizing patient comfort during this process. Some intensivists prefer a slow terminal wean while others prefer more rapid extubation (66). Either way, neuromuscular blockade should not be initiated after the decision to withdraw life support has been made. Neuromuscular blockade does not provide sedation or pain relief for the patient and impairs the ability of the intensivist to assess the comfort of the patient. Although some may argue that neuromuscular blockade minimizes the trauma to the family witnessing the withdrawal of life support, that argument does not outweigh the potential harm to the patient (67). Explaining to the family the reasons to avoid neuromuscular blockade may make it more tolerable for them to be present through the dying process.

Physicians should aggressively treat discomfort when withdrawing therapy, even if treatment may hasten death. The doctrine of double effect emphasizes the intention of the clinician in cases in which actions may have both good and bad effects. Consider the intensivist seeking to provide comfort to terminally ill patients. Although two possible effects of the opioids are recognized and foreseen—relief of pain followed by respiratory depression—only the good effect, pain relief, is intended, and thus the intensivist is not held morally culpable if respiratory depression and a sooner death should occur (68). If the intensivist uses far more opioids than necessary to make the patient comfortable, or if the intensivist chooses an agent without pain-relieving properties—for example, intravenous potassium—then the intensivist can no longer plausibly claim that the intention was solely to relieve pain and suffering. The doctrine of double effect oversimplifies the concept of intentionality, particularly by assuming that clinical intentions are unambiguous and recognizable to the actor. More important, it centers the justification of the action on the physician’s intent rather than on the patient’s authorization.

Withdrawal of implantable cardiac defibrillator shock therapy presents an interesting problem for clinicians (69). Painful defibrillations prolong life. In a patient near the end of life, the discomfort of the shocks may no longer be worth the benefit. The continuation of implantable cardiac defibrillator therapy should be based on the benefits and burdens. In one study comparing patients in which one group had the defibrillator turned off and the other group did not, continuing defibrillator therapy did not extend life, suggesting little benefit in exchange for the discomfort of continued defibrillation (69).
Introduction/General Concepts

DISTRIBUTIVE JUSTICE AND RATIONING IN THE ICU

Distributive justice refers to an equitable allocation of resources. Distributive justice can be viewed as a substantive request, such as determining a fundamental and inviolable level of health care for all members of a society. Distributive justice can also be viewed as a process for achieving justice, using approaches including queuing and potential benefit to determine valid distribution. These approaches belie simplicity; consider the different interpretations of benefit, such as quality-adjusted life years, functional status, or the fair innings approach, which aims to level the playing field for characteristics such as gender that are not under control of the individual (3,70,71).

Because critical care services account for more than 1% of the gross domestic product in the United States, hospitals, intensive care units, and critical care physicians are under pressure to control costs (72). An argument sometimes made for invoking futility as a reason not to perform a therapy is that futile care is a waste of health care dollars. This statement implies rationing, in that money is a scarce resource that could be better used elsewhere. The Task Force on Values, Ethics, and Rationing in Critical Care defined rationing as the “allocation of healthcare resources in the face of limited availability, which necessarily means that beneficial interventions are withheld from some individuals” (72). Rationing may be viewed more optimistically as a means of using resources wisely to minimize inequities and maximize population health (70).

It is helpful to consider three taxonomic categories of rationing (72). The first is the limited availability due to external constraints, such as not giving a medication that is not on a formulary or diverting ambulances from an emergency department of an overfull hospital. This form of rationing is beyond the physician's control.

A second category of rationing occurs from following clinical guidelines. For example, local hospital policies may define pathways for evaluation of certain diseases, such as requiring a specific radiologic study before proceeding to a more costly study. Rationing from clinical guidelines may also, for example, limit the use of certain antibiotics to control emergence of resistant organisms. Deviations from clinical guidelines should be based on patient characteristics and scientific literature, not on personal idiosyncrasies.

The third category of rationing is based on clinical judgment. Clinical judgment is imperfect. Decisions about therapy are influenced by a patient’s race, pre-illness employment status, the intensity of interest in rationing, and the political power of clinical services (73–76).

For rationing policies to be fair, there should be public access to decision-making policies and rationale, a framework for principled decision making as a means for resolving dispute, and an appeals process (3). When considering rationing, one should recognize the difference between the statistical patient and the individual, or identifiable, patient. Clinical guidelines are developed in reference to the statistical patient, which is the ideal and abstract future patient. It is easier and more proper to discuss rationing for the statistical patient, such as whether society should spend dollars on preventive care, primary care, or tertiary care. When participating in those debates on a macro level, physicians may wish to consider their obligation to their patient community as well as to society as a whole.

Clinical judgment refers to the known individual patient. When faced with an identifiable patient whose situation does not align precisely with guidelines or studies, it is improper for a physician to determine and implement rationing based on distributive justice at the bedside (3). When caring for the individual patient, physicians are required to maximize use of resources while ensuring that care remains focused on patients (3).

Triaging is a special consideration of distributive justice. The utility principle encourages actions that maximize “the greatest good for the greatest number” and is at the heart of permitting unequal outcomes as long as overall health is maximized. It is by this principle that, for example, physicians in the midst of a mass casualty will choose to provide discrete, rapid, and potentially life-saving care—chest tubes, tracheal intubation, and so forth—to many patients before devoting these resources to the treatment of a single resource-intensive head injury (77). Implicit in the utility principle is that like patients are treated similarly, without regard to other factors, such as socioeconomic status. The utility principle is suitable for a mass casualty situation in which all patients are equally unknown and no prior relationship with the patient has been established. It may, however, be less suitable for considering distribution of an absolute scarce resource, such as ECMO (extracorporeal membrane oxygenation). In this case, many would suggest that the presence of a patient-physician relationship, current use of the resource, the appropriateness of the claim to the resource, and the idea that every person should have an equal chance to potentially life-saving care—chest tubes, tracheal intubation, and so forth—to many patients before devoting these resources to the treatment of a single resource-intensive head injury (77). Implicit in the utility principle is that like patients are treated similarly, without regard to other factors, such as socioeconomic status. The utility principle is suitable for a mass casualty situation in which all patients are equally unknown and no prior relationship with the patient has been established. It may, however, be less suitable for considering distribution of an absolute scarce resource, such as ECMO (extracorporeal membrane oxygenation). In this case, many would suggest that the presence of a patient-physician relationship, current use of the resource, the appropriateness of the claim to the resource, and the idea that every person should have an equal chance to potentially life-saving care—chest tubes, tracheal intubation, and so forth—to many patients before devoting these resources to the treatment of a single resource-intensive head injury (77).

PHYSICIAN-ASSISTED SUICIDE, VOLUNTARY EUTHANASIA, AND PHYSICIAN AID IN DYING

The term physician-assisted suicide means that the physician makes a lethal dose of medicine available to the patient, but that the patient must perform the act of ingestion. The term voluntary euthanasia means that the physician administers the medication directly on a patient's request (78). While there may be a distinction between making the medication available and actually administering it, the distinction may not be ethically significant, as both require effort and contribution from the physician. Similarly, while requiring the patient to perform the final act may protect against abuses, psychological pressure may defeat safeguards inherent in requiring the patient to self-ingest. For purposes of this discussion, unless otherwise specified, voluntary euthanasia and physician-assisted suicide will be considered together and the term physician aid in dying (PAD) will be used to denote both. Nonvoluntary euthanasia is distinct from PAD and means that the physician administers the medication, but there has been no formal request by the patient. Arguments surrounding PAD center on the interpretations of the principles of respect for autonomy and beneficence, as well as the possible ramifications of legalization (Table 2.3) (79).
Chapter 2: Life and Death in the ICU: Ethical Considerations

### TABLE 2.3
**PAD: ARGUMENTS FOR AND AGAINST LEGALIZING PHYSICIAN AID IN DYING**

<table>
<thead>
<tr>
<th>For</th>
<th>Against</th>
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<tr>
<td><strong>AUTONOMY</strong>&lt;br&gt;Individuals have the right to make informed choices about their lives.</td>
<td>Requests for PAD are false expressions of autonomy because inadequate control of suffering—including pain, discomfort, loss of dignity, depression, the feeling of being a personal and financial burden, and “tiredness of life”—lead to poorly informed and forced choices.</td>
</tr>
<tr>
<td><strong>BENEFICENCE</strong>&lt;br&gt;The obligation to do good for our patients.</td>
<td>Doing good means physicians are obligated to help patients have a good death (as defined by the patient).</td>
</tr>
<tr>
<td>Nonmalfeasance&lt;br&gt;The obligation to “do no harm.”</td>
<td>Doing good means doing a better job of maintaining patients' comfort and dignity.</td>
</tr>
<tr>
<td><strong>LEGALIZATION</strong></td>
<td>Physicians do not cause death.</td>
</tr>
<tr>
<td>Legal safeguards and public oversight (such as the yearly reporting by the Oregon Department of Human Services on the Death with Dignity Act) will prevent abuses.</td>
<td>There will be concerns that clinicians may offer, feel pressure to offer, or be perceived to offer PAD for inappropriate reasons (e.g., race/gender/socioeconomic status).</td>
</tr>
<tr>
<td>Permitting PAD will discourage physicians from aggressively addressing the problems surrounding end-of-life care.</td>
<td>Permitting PAD will devalue the sanctity of life, thus further nudging society down the psychological slippery slope toward nonvoluntary euthanasia.</td>
</tr>
</tbody>
</table>

In European countries that have not decriminalized PAD, surveys indicate that voluntary euthanasia accounted for 0.05% to 0.46% of deaths and nonvoluntary euthanasia accounted for 0.11% to 2.26% of all deaths (80). Patients wished to hasten death when they considered themselves a burden to others, when they worried about suffering and receiving a substandard quality of care in the future, and when they were depressed, hopeless, and without adequate social support (81–83).

Some countries have legalized PAD. Although the Dutch had been practicing PAD for several decades, in 1993 the Dutch parliament granted physicians immunity from prosecution, provided that proper procedures were followed (Table 2.4) (84,85). In 2002, PAD was explicitly legalized in the Netherlands. Four nationwide investigations (in 1990, 1995, 2001, and 2005) have been conducted into the Dutch practice of PAD and nonvoluntary euthanasia (86–88). The 1990 Remmelink study found that 1.7% of all deaths were as a result of euthanasia. The 1995 and 2001 studies showed an increase in euthanasia as a percent of all deaths to 2.4% and 2.6%, respectively, and in the 2005 study the rate returned to 1.7%. Deaths from assisted suicide decreased from 0.2% of all deaths for the first three studies to 0.1% for the 2005 study. The decreases in the 2005 study may be from epidemiologic changes or the use of other techniques to alleviate symptoms, such as terminal sedation. Deaths from nonvoluntary euthanasia decreased from 0.8% of all deaths in 1990 to 0.4% in 2005. Reporting improved from less than 20% of PAD cases in 1990 to nearly 80% in 2005. In 2005, physicians chose not to report because they did not believe they were ending life (76% of nonreports), because they were concerned about whether criteria had been met (9.7% of nonreports), and because they viewed euthanasia as a private matter between the patient and physician. Nearly all the patients who received PAD appeared to have had a short life expectancy, with approximately 45% of granted requests for euthanasia or assisted suicide having a life expectancy of 1 week.

### Table 2.4
**COMMON CRITERIA FOR PATIENT ELIGIBILITY FOR PAD**

1. The patient must clearly, voluntarily, and repeatedly request to die.
2. The patient's judgment must not be distorted.
3. The patient must have an incurable condition associated with severe, unrelenting, and intolerable suffering.
4. The physician is obligated to ensure the request is not made out of inadequate comfort care.
5. PAD should be done in context of a physician–patient relationship.
6. Consultation with other experts should be made to review and verify the facts about prognosis and current comfort management.
7. Document above and fulfill reporting requirements.

### TABLE 2.5
QUALITY END-OF-LIFE CARE

<table>
<thead>
<tr>
<th>Honor patient wishes.</th>
<th>Address needs of clinicians.</th>
<th>Address needs of the family.</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Have a system for continually evaluating and communicating end-of-life preferences.</td>
<td>■ Commit to a multidisciplinary practice that leads to respectful and productive collaboration and communication.</td>
<td>■ Have a presentable senior team member inform family of bad news in private using non-technical language.</td>
</tr>
<tr>
<td>■ Review therapies at specified intervals to assess whether they are legitimate and consistent with the patient’s desires.</td>
<td>■ Provide ongoing education about palliative care and cultural beliefs.</td>
<td>■ Help families find meaning in the death of their loved one.</td>
</tr>
<tr>
<td>■ Treat iatrogenic events by outcome and not by etiology.</td>
<td>■ Provide opportunities for bereavement, debriefing, and psychological support.</td>
<td>■ Accept, support, and comfort the family.</td>
</tr>
<tr>
<td>■ Consider whether care guidelines apply to the specific patient.</td>
<td>■ Provide time and space for professional conversations and personal reflections.</td>
<td>■ Assure family of patient comfort.</td>
</tr>
<tr>
<td>■ Reassess advanced care planning continuously and by focusing on the patient.</td>
<td>■ Identify objectives.</td>
<td>■ Enable family to be with and help the patient.</td>
</tr>
<tr>
<td>■ Initiate end-of-life discussions early.</td>
<td>■ Review medical facts and options for treatment.</td>
<td>■ Clarify roles of clinicians to family.</td>
</tr>
<tr>
<td>■ Withdraw ventilatory therapy in a manner that permits recognition of distress; aggressively treat discomfort with opioids and sedatives.</td>
<td>■ Agree on a care plan and on criteria to define success or failure of a plan.</td>
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<tr>
<td>■ Incorporate palliative care into intensive care.</td>
<td>■ Understand and respect the narratives and perspectives of others.</td>
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<tr>
<td>■ Reassess advanced care planning continuously and by focusing on the patient.</td>
<td>■ Seek out perspectives on dying, dependence, and loss of function.</td>
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<tr>
<td>■ Have a presentable senior team member inform family of bad news in private using non-technical language.</td>
<td>■ Use multidisciplinary approach to keep family informed.</td>
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<tr>
<td>■ Help families find meaning in the death of their loved one.</td>
<td>■ Provide sufficient time for questions.</td>
<td></td>
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<tr>
<td>■ Accept, support, and comfort the family.</td>
<td>■ Perform end-of-life research.</td>
<td></td>
</tr>
<tr>
<td>■ Assure family of patient comfort.</td>
<td>■ Measure and assess end-of-life care.</td>
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<tr>
<td>■ Enable family to be with and help the patient.</td>
<td>■ Promote a change in attitude toward end-of-life care.</td>
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<td>■ Clarify roles of clinicians to family.</td>
<td>■ Maintain knowledge of end-of-life law.</td>
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<tr>
<td></td>
<td>■ Maintain knowledge of end-of-life guidelines and care.</td>
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Quality End-of-Life Care

- Hold regular meetings with family and team to clarify intermediate and long-term goals.
- Work to improve end-of-life care.
Chapter 2: Life and Death in the ICU: Ethical Considerations

In 1997, the State of Oregon in the United States legalized Oregon Death with Dignity Act, which permitted terminally ill patients to receive prescriptions in lethal quantities for the purpose of self-administration. It does not permit any other forms of PAD, such as another person administering the medication. From 1998 through 2006, 292 patients used 456 prescriptions authorized by this law. The most common diseases for patients choosing to ingest a lethal dose of medication were malignant neoplasms (81% of patients), amyotrophic lateral sclerosis (8% of patients), and chronic lower respiratory tract diseases (4% of patients) (89). Of the 23 patients receiving prescriptions in 1998, 21 had used the prescriptions and 2 were alive in 1999 (90). In 2006, 40 physicians wrote 65 prescriptions. Of those 63 patients, 35 used the prescriptions, 19 died of their underlying disease, and 15 lived throughout the year (89). The financial and educational status of patients did not seem to play a role in the request for PAD.

In 2003, Belgium passed a law permitting euthanasia (85). In the first 15 months after passage of the law, euthanasia represented 0.2% of all deaths. This appeared to be a decrease in euthanasia when compared with studies performed in 1998 and 2001 (91). Interpretation of this information is not straightforward. The consistency of the data from the Netherlands and Oregon indicate that these two societies are not sliding down a slippery slope to increased misuse (92). Another view, however, is that not enough time has passed to see if this slide will occur (93).

**Doc, Will You Help Me Die?**

In a national survey of U.S. physicians, 18% reported receiving a request for assistance with suicide and 11% received a request for euthanasia (94). The majority of both sets of physicians received multiple requests (94). About 6.4% of physicians honored at least one request for PAD, with their last case split between physician-assisted suicide and euthanasia. In the survey, 4.7% of all physicians had performed lethal injection and 3.3% had participated in physician-assisted suicide (94). For these reasons, it is important for physicians to have a practiced approach to managing patient requests for PAD (95) (Table 2.5).

Depression should be assessed to determine (a) if the patient is able to make rational decisions, (b) whether the depression is treatable, and (c) whether treating the depression would change the circumstances (95). Physicians should explore what patients mean by requesting aid in dying and should overtly focus on patient dignity and comfort. Because patients may request PAD as prevention against future abandonment and suffering, physicians should emphasize that they will be actively involved throughout the end-of-life period (95). Given that survey data indicate that some physicians honor requests for PAD, physicians should clarify their position on participating in PAD for themselves and to their patients.

**ETHICS CONSULTATION IN THE ICU**

The goals of ethics consultation services are to “protect patient rights, diffuse real or imagined conflicts and cause a change in patient care that improves quality” (96). Ethics consultation can help address treatment conflicts, reduce costs without diminishing quality, and limit inappropriate nonbeneficial or unwanted interventions (97). In a randomized controlled trial, individuals who received ethics consultation in the ICU were not more likely to die than individuals who did not receive consultation (98). ICU ethics consultations proved to be valuable across a range of populations (99).

Much of the information about ethics consultation services in the United States comes from a 2000 survey. Most ethics consultation services use a small group, typically about three people, to perform consults, although some use the full ethics committee or a single individual to perform consults. Various individuals performed ethics consultation, including physicians, nurses, social workers, chaplains, administrators, and lay people. Most ethics consultation services have been practicing between 5 and 10 years. Three common characteristics of ethics consultation services were that they

1. permitted anyone to request an ethics consultation,
2. required notification—not permission—of the patient, surrogate, and attending physician prior to performing a consult, and
3. made recommendations that are wholly voluntary.

**PEERS**

- Treat patients and families in the manner you would want you and your family to be treated—that is, with respect for personal values, feelings, and preferences.
- Know common approaches and formats for advance directives in your jurisdiction.
- Intensivists should focus end-of-life discussions with surrogate decision makers on what the patient would have wanted, not what they would want for the patient.
- Know local policies regarding dispute resolution.
- End-of-life decision making is a dynamic process requiring frequent reconsideration of therapy and goals and communication among the clinicians, the patient surrogates, and, if available, the patient.
- Attitudes on the unit are infectious.
- Actively root out personal presumptions and biases in health care, and challenge them so they do not affect the care provided.
- Recognize the benefits of trials of therapy in terms of maximizing the likelihood of fulfilling the patient's desires for end-of-life care. It is one thing to presume that the burdens of therapy are not worth the benefits; it is more ethically stout to test that assumption and then withdraw therapy when it is shown that the burdens outweigh the benefits.
- Withdrawing potentially life-sustaining therapy requires active clinical assessment and treatment to minimize harm to the patient and family.
- Just as intensivists seek consultation for diagnosing and treating subspecialty medical problems, intensivists should seek consultation for diagnosing and treating intricate ethical dilemmas.

**References**

Section 1: Introduction/General Concepts


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166x365


59. woman DB, Teague RD. The end-of-life sequence. Anesthesiology. 1997;87:674–676.
Meanwhile, demanding, “entitled,” or rudely behaving patients and families are troubling—even infuriating—to many physicians, nurses, and ICU staff. Occasionally, these difficult staff-patient exchanges arise from problems with the care providers themselves; factors such as depression, anxiety, overwork, sleep deprivation, longstanding interpersonal rigidity, and the cumulative effects of stress (1,2) may cause some physicians and nurses to fail to adequately address the emotional needs of their patients and patients’ families (3,4). At other times, patients and families with markedly impaired abilities to negotiate interpersonal relationships become overwhelmed and subsequently act in ways that are extremely problematic. The judgment of these families and patients may become clouded by longing, shame, rage, and despair, making reasoning with them almost impossible. In this chapter, we endeavor to relieve the critical care practitioner of some of the fury that problematic patient and difficult family member encounters engender, offer some reason where none seems to exist, and provide suggestions for less alarming, routine ICU interactions. Herein, we pose—and offer practical answers to—the following questions:

- What is the psychological impact of critical illness and ICU treatment on patients and families?
- Why are some patients and families so taxing to deal with and others so easily treated, soothed, and able to be active team members?
- How should one approach problematic interactions with patients?
- What are some tips for enhancing communication between staff and family members?
- What are some ways to handle family requests for children to visit the ICU?

### INITIAL STEPS

The psychological impact of critical illness and ICU treatment on patients and their families can be very powerful. Although problematic patient-doctor interactions are often due to emotional or relationship factors, there are many steps (Table 3.1) that can be taken before focusing on these factors. First, when ever one encounters a problematic patient, the initial questions should be: “Do I feel safe?” and “Are the other patients and staff feeling safe?” Physicians are taught to override their sense of danger. As medical students and interns, they begin placing catheters and doing lumbar punctures, charging through the fears. This sometimes translates to physicians overriding their inner sense of “danger” when managing potentially violent patients, a situation possibly leading to injury. It is thus important for physicians and nurses to “tune in” (5) to their sense of alarm and, when necessary, to call on security personnel, administer calming medications, or apply temporary physical restraint. The principal also applies to angry or threatening family members. If one feels in imminent danger, then contacting security—before examining the roots of the conflict and attempting to reason with family members—is key.

Next, medical causes of disruptive behavior should be ruled out. ICU patients acting in a bizarre or agitated manner often do so as part of a delirium. This may entail suffering persecutory delusions that staff members are torturing them or hallucinations that are arrestingly frightening. Since delirium can be lethal (6), it is very important to first discover and treat the underlying causes of delirium and to administer treatment for agitation, which may include a bedside restraint or use of calming pharmacotherapy, including neuroleptics. A full discussion of delirium is provided in Chapter 150 of this textbook.

In addition, a number of patients come to the ICU with established psychiatric diagnoses, including major depression, anxiety disorders, substance abuse, and schizophrenia. Occasionally, discontinuation of a patient’s outpatient psychopharmacologic medication is performed purposefully (7). In other instances, admitting physicians fail to review the outpatient medication lists, and unintended disruptions (8) in the proper treatment of a patient’s psychiatric illness ensue. This can lead to some patients suffering panic attacks, and cause others psychiatric exacerbation with paranoia and hallucinations. Some patients experience discontinuation phenomena, such as fatigue and myalgias associated with abrupt cessation of sero tonin reuptake inhibitors (SRIs), or outright withdrawal syndromes specifically related to sudden discontinuation of alcohol, stimulants, narcotics, or sedative medications. Hence, on admission, it is important to learn about a patient’s psychiatric and substance abuse history, and to find out what medications, if any, have been useful in the past in treating their illness or
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can occur even in a delirious patient. For example, one 80-year-
most prominent concern early in their ICU stays involves how they feel
physically. Pain, hunger, restless exhaustion, the irritation of
tubes and catheters, and isolation are the predominate focus
of the acutely ill individual; it is usually not until the conva-
lescent or subacute period in the patient’s hospital course that
larger, existential crises and psychological problems come to
the forefront (15).

Critical illness raises many existential concerns for patients
and loved ones. Looting the minds of patients and family
members of ICU patients is the prospect of death, with criti-
ically ill individuals often reflecting on their lives. Confronting
death may fill them with guilt, regret, and wishes that they
could have accomplished more. In others, this may be a time of
contentment and reflecting on lives well lived. Amazingly, this
can occur even in a delirious patient. For example, one 80-year-
old gentleman who had undergone emergency cardiac bypass
surgery happily shared that, amid his postoperative delirious
days, he “went on a train trip in my head, with stops along the
way involving each stage of my life. My marriage, the birth of
my children, the child we lost, the different businesses I had run, everything was in there.” Family members also reflect
on the lives of their ill loved ones and their relationships with
them. For many, fond memories and experiences will abound;
for others, traumatic memories may arise, leading to some sur-
prising interactions with staff that may seem to come from out of
the blue.

Thoughts about not only the past, but also the future, arise in
critically ill patients and their family members. Patients of-
ten worry about how they will function once discharged from
the ICU and hospital. Depending on the nature of their in-
jury, patients may ponder such questions as: Will I ever have
to live in a nursing home? Will I ever be free of dialysis? Will
I ever walk unassisted again, or visit Paris? Although excited
that their loved ones will survive, friends and family must often
confront concerns about the future. Loved ones wonder how
they will financially and emotionally shoulder the often heavy
burden of caring for their mother, father, husband, wife, part-
ner, or friend after hospitalization. Ambivalence and tension
between, on the one hand, being excited that the ICU patient
has survived and, on the other hand, concern about his or her
quality of life and how to handle extreme medical problems in
the long term cause many patients and family members psy-
chological suffering.

There are pressing concerns about the present as well. Most
patients are treated in the ICU because their bodies fail to
handle the most fundamental tasks of life. Whether involving
breathing on their own, feeding themselves, or handling secre-
tions, urination, and bowel movements, ICU patients are often
dependent on others. This leads many patients to feel loath-
somely dependent. Still others may long for exceeding amounts
of attention, reacting to the loss of autonomy with complete
resignation. Loved ones, particularly those who are caretakers
of chronically ill individuals, also feel the sting of this loss of
autonomy. For example, one woman who, for several years,
had taken care of her husband suffering end-stage Parkinson
disease tenderly commented: “It’s not just that my husband’s sick; it’s that I have to trust you doctors and nurses to take care of
him. That’s my job.”

**EXISTENTIAL CONCERNS OF PATIENTS AND FAMILIES IN THE INTENSIVE CARE UNIT**

Being an ICU patient, or having a loved one who is critically ill,
is intensely stressful (11,12). Studies indicate that 3 months af-
after patients are treated in the ICU, approximately one third of
caregivers and family members are at risk for depression (13)
and posttraumatic stress disorder (14). Patients’ most promi-
nent concern early in their ICU stays involves how they feel
physically. Pain, hunger, restless exhaustion, the irritation of
tubes and catheters, and isolation are the predominate focus
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disease tenderly commented: “It’s not just that my husband’s sick; it’s that I have to trust you doctors and nurses to take care of
him. That’s my job.”

**COPING IN THE INTENSIVE CARE UNIT**

It is difficult to bear the intense feelings of pain, love, loss,
regret, and hope that being treated in the ICU, or having a
loved one treated for critical illness, engenders. Families and
patients vary in their ability to tolerate these emotions. To an
amazing extent, most families and patients are able to muster
inner strength, gain security from each other or draw on out-
side resources, and cope well in times of adversity. While such
families and patients may continue to suffer stress and depres-
sive symptoms, their mature psychological coping mechanisms
(Table 3.2) allow them to work smoothly with ICU staff.

On the other hand, some families and patients are extremely
difficult to manage in the ICU. Such individuals typically fall
into two categories: (a) those with personality disorders, whose
personal and professional lives were replete with problems be-
fore they entered the ICU; and (b) those who have simply re-
gressed, utilizing primitive coping mechanisms that, outside the
ICU, would be less apparent.

Personality disorders refer to severe, pervasive exaggera-
tions of normal personality traits—styles of dealing with the
world (15). As the focus of intensive care medicine is on the
here and now, and major psychosocial investigations of a pa-
tient or family member’s life outside the unit are inappropriate,
distinguishing between the two categories is unnecessary in this
chapter. Also, for the sake of convenience, we refer only to the
“personality-disordered patient”; however, please note that the
descriptions provided may also characterize family members.
Note also that these descriptions also encompass the more rare,
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<table>
<thead>
<tr>
<th>Defense</th>
<th>Description</th>
<th>ICU-relevant examples</th>
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<tbody>
<tr>
<td><strong>NARCISSISTIC DEFENSES</strong></td>
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<tr>
<td>Denial</td>
<td>Failing to be aware of some aspect of reality in order to avoid the painful consequences of this, despite otherwise intact reality testing</td>
<td>A patient denies that she has cancer, refusing to talk about hospital aftercare, convinced that: “It’s just a cough. I’m fine.”</td>
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<tr>
<td>Distortion</td>
<td>Molding reality to fit one’s need to feel superior, attractive, or powerful</td>
<td>A patient protects against feeling ill and romantically unappealing by convincing himself that: “My doctor always smiles at me seductively. I bet on the outside we’d go out on a date.”</td>
</tr>
<tr>
<td>Projection</td>
<td>Placing one’s unacceptable inner urges and affects outside the self, often projecting them (like a movie projector) onto the screen of another individual</td>
<td>A patient with many regrets says: “I bet my wife and kids wish they had treated me more nicely.”</td>
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<tr>
<td><strong>IMMATURE DEFENSES</strong></td>
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<td>Acting out</td>
<td>Giving into an impulse to relieve inner tension, gratifying this wish without regard for the consequences</td>
<td>An anxious son lights up a cigarette at his father’s bedside, sending the ICU into a panic.</td>
</tr>
<tr>
<td>Passive-aggressive action</td>
<td>The use of procrastination, failing to do something, and other devices that cause disruption to either the individual or others but appear benign</td>
<td>A 24-year-old college senior admitted after a motor vehicle collision feels that her friends, family, and she are quite vulnerable. She thus cuddles a teddy bear and uses “baby talk,” eliciting paternal/maternal responses from the ICU staff and bringing to mind the security she felt as a child.</td>
</tr>
<tr>
<td>Regression</td>
<td>Reverting to an earlier developmental stage using the strategies from that developmental era to tackle a stressful event or set of emotions</td>
<td>After hip replacement, a patient who “can’t stand” her physical therapist refuses to get out of bed for this treat - er because her leg legitimately throbs with pain whenever the therapist enters the room.</td>
</tr>
<tr>
<td>Somatization</td>
<td>Converting psychological stress into physical symptoms</td>
<td>A physician is very anxious about her husband’s spine imaging studies.</td>
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<tr>
<td><strong>NEUROTIC DEFENSES</strong></td>
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<tr>
<td>Controlling</td>
<td>Scheduling or managing aspects of a painful event or problem in order to alleviate anxiety</td>
<td>A patient’s daughter routinely demands a review of his medication, medication doses, lab test results, and imaging studies.</td>
</tr>
<tr>
<td>Displacement</td>
<td>Transferring overwhelming emotions and thoughts related to one entity to another, which shares similar features</td>
<td>A woman whose husband has emphysema is disappointed with him for not quitting cigarettes; in displacement, she yells at her adult son who is eating a cheeseburger and fries in the hospital cafeteria, saying: “You need to lose weight and eat more healthy foods!”</td>
</tr>
<tr>
<td>Intellectualization</td>
<td>Much like controlling, involves excessive focus on the intellectual aspects of illness or hospitalization</td>
<td>A patient whom the day before she admitted she found “totally obnoxious.”</td>
</tr>
<tr>
<td><strong>MATURE DEFENSES</strong></td>
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<tr>
<td>Anticipation</td>
<td>Realistically looking at the future and making management plans for upcoming challenges</td>
<td>A father, whose wife is dying in the ICU, asks the patient’s social worker for a referral to a grief support network for her daughter and himself, saying: “Right now I can’t even think straight, but I know this is going to be hard and we’ll need help.”</td>
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<tr>
<td>Humor</td>
<td>Utilizing comedy to help oneself and others acknowledge and tolerate painful aspects of reality</td>
<td>While rolling to the operating room for leg amputation, an elderly woman drolly comments to the medical student: “You think my pedicures will be half-price?”</td>
</tr>
<tr>
<td>Sublimation</td>
<td>Accepting that one’s impulse is socially unacceptable, adapting it into one that is useful and gratifying</td>
<td>A college student visiting a friend hates how emotionally sterile the ICU environment is and would like to scream at the doctors and nurses. Instead, she becomes determined to go to medical school and become a warm, empathic physician.</td>
</tr>
<tr>
<td>Suppression</td>
<td>Conciously delaying focusing on a painful topic or aspect of reality, saving it for later</td>
<td>A family who desperately wanted their grandmother to be part of a wedding service is concerned that she will not survive a subdural bleed. Wisely, the bride’s mother counsels: “This is upsetting, but let’s just cross that bridge when we come to it. For now, let’s work on taking good care of grandma.”</td>
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The Narcissistic Patient

Patients in the ICU lose autonomy. In almost every way, they are at the mercy of ICU staff and visitors, leading many patients to feel infantilized. For most patients, then, regaining a sense of control over their lives is important. Meanwhile, for the narcissistic patient, this need takes on an overwhelming, life-or-death urgency. Narcissistic patients approach the world in a grandiose fashion with an exaggerated sense of self-importance. They typically believe they are special and unique, requiring excessive admiration. They have significant problems with empathy and feel a strong sense of entitlement for care, concern, or special treatment (17). If they fail to receive these "entitlements," they attack, sometimes ruthlessly. It should be noted that these traits often are responses to underlying feelings of insecurity, low self-esteem, ineffectiveness, and profound feelings of deprivation—typically stemming from neglectful interactions in their childhood. Despite their overt demonstrations of strength and power, in reality they feel weak and fragile; it is crucial to recognize that they are not in touch with these underlying feelings, and that if confronted, they will fiercely deny and reject that they have them.

Occasionally, as the example above demonstrates, the narcissist's need for control and special care may take the form of scathing critique concerning the health care staff. These patients often deride nurses ("That's the wrong bandage!"), be little housestaff ("You must be new at this, Doogie"), and drop names ("Dr. Thompson, the world famous nephrologist, is a buddy of mine from college; he never allows patients to be treated like this") to demonstrate their "connections." Staff reactions to such patients include rage and revulsion when they are the subject of derision, or, more commonly in more junior house officers, nurses, or staff, feelings of inadequacy or inferiority when a patient presents as an entitled, very important person (VIP). Insofar as possible, it is best to collaborate with—rather than confront—this type of patient. To avoid caustic exchanges ending in both the patient and physician feeling hurt or enraged, one must choose to have a different relationship with the patient, which can be accomplished by avoiding authoritar- isation condensation and antagonism. Remember, when narcissistic patients examine their surroundings in the ICU, all they see are their inadequacy, inability, and incapacity. The nasogastric tube attached to the churning ventilator brings to mind that they cannot breathe on their own; the bedpan is a glaring reminder that they cannot even use a toilet. Insofar as possible, it is best to collaborate with—rather than confront—the self-described "VIP." Narcissistic patients appreciate gaining as much control as possible. Hence, even controlling their light switch and TV, using patient-controlled analgesia, or being able to choose to "go first" or "go last" when the phlebotomist performs rounds helps patients feel like more of a collaborator in their care. Finally, avoiding power struggles with narcissistic patients is of the utmost importance. For example, a psychologically minded ICU nurse who was typically well liked by staff and patients was being bossed around by a VIP, who eventually asked for a different nurse. Rather than be offended, the nurse simply exchanged patients with a colleague. She offered: "Hey, when I was young I would have been offended and told him 'I am your nurse and you are stuck with me.' But he's not in the ICU any more. A VIP is a VIP."
for me to be his nurse. He’s here because he’s sick and needs help. So I just found another nurse to take care of him.”

The Dependent Patient

Dependent patients are hypersensitive to being alone and suffer intense anxiety. These individuals feel empty and isolated, often because they came from families that never provided adequate caretaking. They cling tenaciously to clinicians or family members, often engendering feelings of disdain and aversion. Clinicians are typically idealized and considered endowed with superhuman powers. Such patients have an inability to hold onto the comforting feelings they receive from ICU staff, friends, or relatives when those people are not actively helping them. In psychiatric terms, we would state that, similar to the early toddler, the dependent patient has poor object permanence, unable to conjure a mental image of his mother when she’s out of sight (18). Thus, these patients demand urgent assistance with nearly every aspect of ICU life. Often these entreaties are the same as one would expect any hospitalized person would want. Better food, more analgesia, softer pillows, more frequent visits and doctor reports, enhanced light, nicer views, gentler exams, and food, more analgesia, softer pillows, more frequent visits and doctor reports, enhanced light, nicer views, gentler exams, and doctor reports, enhanced light, nicer views, gentler exams, and fewer tubes and catheters. However, for the dependent patient, these concerns take on an overwhelming urgency, often driving ICU staff to distraction.

Addressing—as opposed to avoiding—the relationship needs of the dependent patient involves frequent visits and keeping the patient informed. Nurses and doctors should let such patients know when they plan to come back into the room, when rounds might take place in the morning, when transfer to another ward will happen, and when tests will take place. For many dependent patients, this basic information will not be enough to soothe their demands for instant anxiety relief. In these situations, the nurse-patient or physician-patient relationship can be transformed by (a) validating that the patient’s concerns are real, (b) communicating to the patient that his or her request is understood, and (c) explaining to the patient that the staff will do everything in their power to help, but that it may not be possible to provide everything the patient demands.
These three tasks are accomplished through statements that include two words: “I wish.” For example, an exceedingly dependent patient in the ICU whispered to her young house officer: “Doctor, I’m so scared. Please, please keep checking on me!” The savvy resident responded: “Mrs. D, your illness is severe and I am certain very frightening. While I wish I could stop by every hour, I have a lot to do in the hospital today. I promise, though, to check in with you this evening around 5 p.m.” With the woman’s fear and anxiety validated—believing that her physician would keep her and her problems in mind throughout the day and actually stop in for a visit (which the resident did with all of her patients)—this patient felt comforted and acted less demanding.

The Obsessive Patient

Obsessive individuals are emotionally constricted and rigid. They tend to focus on minute details and lose the big picture. They are compelled to make the “right” or “perfect” decision based on “facts” and never feel that they—or their caregivers—have all the information to provide optimal treatment. Consequently, they are intensely frustrating to providers, who feel assaulted by endless questions and devalued, as the provider never has the patient’s confidence in treatment decisions (15). Caring for the patient or family member who pays obsessive attention to detail and routine can be very taxing. By clinging to the “rules of medicine” as a 7- to 10-year-old child might adhere to the rules of a board game, the obsessive patient can irritate physicians and nurses. In contrast to narcissistic patients, who regain control over their surroundings via denial, distortion, and bullying behavior, obsessive individuals defend against feelings of helplessness by focusing on medical minutiae. The obsessive logic goes: “a place for each thing and each thing in its place” (19). Of course, everything in the ICU is out of place; patients do not know what their radiographs show right away; their labs are a mystery to them for several hours, even days; and the meaning of the blips and bleeps of monitors buzzing around them is not understood. So, with very rudimentary medical knowledge, the obsessive patient or family member works hard to gain mastery over these details. Losing the forest for the trees, the obsessive patient asks incessant questions. For example, one woman with Guillem-Barré syndrome demanded to know why she was not being transfused when she saw an “L” marked next to her “HCT” of 32.3%. When her nurse sat down next to her bed, summarized her lab report, and explained the team’s management rationale, the patient felt knowledgeable and was soothed. Again, dealing with this type of difficult patient interaction takes extra time and a firm decision on the practitioner’s part to have a different relationship with the patient. Obsessive patients cannot stand the paternalistic, authoritarian approach, and the practitioner who is not flexible will get into fruitless standoffs with these patients. Statements such as “you just rest and let us take care of you” are intensely irritating to the obsessive patient. Instead, offering the obsessive individual a set amount of information, with a satisfying but not overwhelming amount of detail, can be key. This may mean showing the obsessive patient or family member a chest radiograph or reviewing their “lytes” at bedside. Second, the obsessive patient, like all patients, appreciates routine. Announcing and, insofar as possible, keeping to a schedule in which nurses and physicians will visit is important. Finally, scientifically, deductive reasoning (“if your labs show X, then we’ll respond by doing Y”) curbs the obsessive patient’s anxiety.

The Dramatic Patient

Linked to many instances in early childhood trauma and because they have intense difficulty identifying their own affective state, in distinguishing how they think and feel from how others think and feel (20), dramatic patients fail to recognize subtlety. They thus engage in highly volatile relationships. In the hospital, these patients—many of whom suffer borderline personality disorder in the official psychiatric nomenclature (17)—engage their physicians and nurses in relationships that are intensely intimate or staggeringly confrontational. The dramatic patient often seduces some staff members and alienates others. This leaves ICU personnel at odds, with some having had a very positive experience with the patient, using phrases like “lovely,” “charming,” and “delightful” to describe the patient, and others considering the patient obstreperous or toxic. When clinicians who have such divergent experiences with a dramatic patient converge, there is often a conflict over how to manage the patient’s demands. This experience is dubbed “splitting” and can create tremendous tension. The deleterious effects of splitting, which include mistrusting the patient and high staff tension, are minimized when physicians and nurses acknowledge that they have had much different emotional experiences with a patient. Once this is done, limits can be set in a manner that both soothes the patient and settles the staff (Table 3.4).

Dramatic patients are also notorious for their hypersensitivity to physical pain and perceived slight and threat of abandonment by physicians and nurses. Similar to the dependent

| TABLE 3.4 |
| PRINCIPLES OF EFFECTIVE LIMIT SETTING IN THE INTENSIVE CARE UNIT (ICU) |

- Validate: Acknowledge the patient’s real struggles.
- Explain: Provide limits in a clear and concise manner and avoid overly euphemistic statements such as: “Refrain from unsafe behavior.” Instead, say: “Please stop throwing things!”
- Be flexible: Before speaking with the patient, discuss as a team what the patient may ask for and what the ICU team can be flexible in offering. For example, can a patient begging for a cigarette be administered nicotine gum or a transdermal patch?
- Determine consequences: Know in advance how to handle transgression of limits; these do not necessarily need to be shared with the patient or his or her family, but can give the ICU team a sense of security.
- Avoid arguments: Long, drawn-out battles of will or reason are rarely useful. Leaving the patient’s bedside in order to cool down, think of a new strategy, or consult a colleague is better than acting impulsively.

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Patient, validating the very dramatic patient's feelings is key. Although the clinical staff may believe that dramatic patients are "exaggerating" or "faking" their symptoms, even if these assessments may be accurate, it is futile to believe that these concerns can be managed by approaches that entail feelings such as "I hope that they will just go away or stop if I ignore them." One must have an explicit plan to improve the relationship with a patient. As one of our ICU senior residents at Walter-Reed Army Medical Center once intoned, "Sir, hope is not a course of action!" It can be immensely soothing to dramatic patients if you convey your understanding of their struggles and let them know that you are aware of many of the problems they are facing. Furthermore, asking, "Are there some problems that I've missed that we need to make certain we are helping with?", can lead to further improvement in your relationship.

COMMUNICATING WITH FAMILIES IN THE INTENSIVE CARE UNIT

The car says more
Than any tongue.
W.S. Graham, "The Hill of Intrusion"

Family members and friends are not mere visitors to the ICU (21). They are often charged, sometimes reluctantly (22), with understanding a patient's diagnosis, prognosis, and treatment options, in addition to making informed decisions when their loved one is unable to express his or her own medical care preferences. Family members also play an integral role in encouraging critically ill spouses, siblings, aunts, and uncles. In addition, they may help nurses provide care, and often spend much time on the phone or e-mailing, communicating progress and problems to relatives and friends of the patient who cannot visit the ICU. A study by Pochard et al. found that the prevalence of depression in family members of intensive care unit patients was 69%, while 35% suffered marked anxiety (12). These symptoms may make it very hard for family members to function in their roles as caretakers, nurturers, communicators, and decision makers while on the unit; moreover, it impacts their abilities as mothers, fathers, and employees outside the unit. Quality communication between ICU staff and family members of ICU patients is central to:

- Reducing family stress and dissatisfaction (23)
- Minimizing conflict surrounding end-of-life decisions (24)
- Decreasing futile interventions (25)
- Reducing friction between ICU staff and families (26)

Again, while some families may utilize maladaptive coping strategies or appear very similar to the personality profiles listed in Table 3.3, ICU staff committed to communicating with families stand the best chance of promoting patient and family security and alleviating suffering.

While each family and critical care situation is unique, following some general guidelines (Table 3.5) for interacting with families can be helpful. These include being clear and concise when explaining the medical information; asking to make certain the data are understood; scheduling appointments for family meetings; listening more and talking less; tuning in to those things that make the patient and family special (27); and providing early diagnostic and prognostic information, even if this involves admitting uncertainty (28). Keep in mind that most families rate the clinician's ability to communicate above their clinical prowess (29).

Despite early, open dialogue between ICU clinicians and patients' families, problems nevertheless will arise. Owing to stress, depression, and anxiety, some families may not want to participate in the decision-making process regarding their loved one's care (22). Referral to unit support staff, including social workers who are able to assess the needs of family members, can be very helpful. At times, the family members' judgment may be clouded by anger toward the patient. For example, the relatives of a patient who is being treated in the ICU following a suicide attempt may be upset at the patient for "wanting to leave them behind," and hence may make decisions out of anger, frustration, and disappointment (30). If one senses that this is the case, bringing these feelings out into the open—what psychotherapists term "making the implicit explicit"—can help families consider treatment decisions more thoughtfully.

Breakdowns in understanding and communication between clinicians and families occur when, wrought with guilt or a profound sense of duty, family members demand that staff "do everything possible' for the patient, even when aggressive care is futile. One scenario in which this occurs involves the distant son or daughter who has played a minimal role in his or her parent's life and feels overwhelming guilt. Alternatively, family members may feel they "need" a relative so badly that losing him or her would be psychologically devastating. This may impair their reasoning to the point that they overinterpret subtle cues as signs that their loved ones can hear them, appreciate their presence, or "want to keep on fighting." Sometimes these

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**TABLE 3.5**

CORE PRINCIPLES OF COMMUNICATION WITH FAMILIES IN THE INTENSIVE CARE UNIT (ICU)

<table>
<thead>
<tr>
<th>CLEAR</th>
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</thead>
<tbody>
<tr>
<td>Provide family members and loved ones with clear, concise descriptions of the patient's condition and avoid jargon. Frequently ask if there are any questions and provide more detail as necessary.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ON TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schedule appointments for family meetings or treatment updates. Try, as best as possible, to be on time. If you will be late or unavailable, send a representative.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RESPECT THE PATIENT'S UNIQUENESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>These appointments are as much about what you say as how well you listen. Focus carefully on what makes the patient special and try to learn the names of the people who are important to the patient.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EARLY DIAGNOSIS AND PROGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Even if it means saying, &quot;I'm not sure,&quot; try to inform the family early in the ICU stay.</td>
</tr>
</tbody>
</table>

wishful perceptions cause family members to make decisions counter to what the patient requested before he or she was incapacitated. In these cases, it can be transformative when the clinician conveys an understanding of what the patient means to his or her family members and also offers a solution that preserves the family members’ views of themselves and of the patient.

For example, after a prolonged battle with cancer, a war veteran was admitted to an ICU in respiratory failure. The patient's daughter was made aware that this man had had little chance of making a meaningful recovery; yet in family meetings, she foreclosed any discussion of withdrawing ventilator support. "He's a fighter; he's made it this far and he's gonna keep fighting," she protested. In response, a very empathetic intensivist explored how much this woman's father meant to her, learning that this patient being a “fighter” inspired his daughter to battle with her own illness. The ICU physician described back to this woman what an inspirational life her father had lived, conveying an understanding of what “being a fighter” meant in their family. Upon hearing these words—that the physician “got it” and was still recommending a full discussion of treatment options—the patient's daughter relaxed her stance and was willing to discuss end-of-life care options with the ICU team and the rest of her family.

A family’s spoken language and cultural understanding of health, illness, and dying play crucial roles in their ability to meaningfully communicate with ICU staff members. Both literally and figuratively, it is important for families to sense that ICU physicians and staff members are working hard to “speak the family’s language.” Translated literally, this means that ICU staff must ensure that families can understand the content of what the staff are conveying. For families who may not enjoy a medically rich vocabulary, this means avoiding the use of technical terms and medical jargon, and frequently asking if there are questions. Meanwhile, for families for whom English is not their first language, offering and utilizing medical interpreters is extremely important (31). Family members should not be used as interpreters, as it places a major burden on these individuals to remain intellectually engaged in understanding and conveying material and to emotionally cope with the information they are processing. Family members who become the “go-to” person in times of interpreting may also emphasize certain facts to loved ones in order to influence their decisions or can reluctantly become primary decision makers based solely on their fluency, but not out of a desire to lead the family in making medical decisions.

All families hold explanations for illness embedded in a cultural identity. To physicians steeped in the Western allopathic medical tradition, some culturally bound beliefs—often stemming from a family or individual’s religious, spiritual, ethnic identity—may seem strange such that a meaningful dialogue about a patient's medical condition seems impossible. As one puzzled intern intoned after a troubling family meeting, "I was talking about heart failure, while his wife kept talking about spirits. It was weird, I was like, ‘Are we having the same conversation?’" In order to prevent such Socratic dialogue, physicians can benefit from being openly curious about the way a family member will integrate the information he or she has to share. Thus, it may be helpful to open a family meeting by asking family members what their understanding of the situation is and, perhaps, why they believe their loved one is experiencing the problems he or she is. This helps set the stage for a more fruitful conversation, by establishing that the physician hopes to offer information that will be integrated into, but not supplant, a family’s perspective. One can also suggest to families that they invite a trusted friend, priest, shaman, or other culturally esteemed individual to family meetings with medical staff, or offer to review the information with that person.

Of course, despite the best efforts of clinicians and family members, standstills sometimes occur. In those situations where family members linger at odds with each other or with ICU staff regarding medical decisions, an ethics consultation is helpful.

**Chapter 3: Understanding Reactions of Patients and Families**

If the behavior of ICU patients and their family members and loved ones can be perplexing and irritating to critical care physicians and nurses, then understanding the reactions of children visiting the ICU can be downright bewildering. Still, parents often ask if their son or daughter should visit a parent or loved one in the ICU and, if so, how to facilitate these visits. Thus, it behooves the physician or nurse interested in practicing whole-family care to keep in mind a few developmental principles.

The first issues to consider when a family asks about a child visiting in the ICU are whether it is appropriate for the developmental level of the child and whether the child could visit the unit and feel safe, as well as whether the child may understand the content of the visit. It is thus most important to ask: Whose idea is it for the child to visit, and why? Occasionally, when the staff inquires who the child's visit is for, revelations about the individual's own experience are revealed. For example, one man who was quite emotionally distraught wanted his 4-year-old son to visit his grandmother, who was on a ventilator and likely to pass away. This preschool-aged boy had experienced little contact with his grandmother prior to her illness and had clearly stated he did not want to go. Yet, his father explained to the ICU social worker: “Well, I just think he ought to see grandma. I always wanted to see my grandma and regret it, so I think my son should see his.” Having made that statement, the man realized that his desire to have his son come to the ICU was a projection of his own wishes to relieve guilty feelings about failing to visit his own grandmother. With the help of the unit social worker, the gentleman and his wife instead opted to have their son stay at home, but were able to learn some simple phrases to explain to this youngster what was going on with his grandmother.

Meanwhile, there are very good reasons for children to visit loved ones in the ICU. To promote attachment and understanding: to reduce fears, hopelessness, and guilt; and to fulfill a mutual desire on the part of the patient and child to see one another (32). For example, when a child's parent is hospitalized but likely to recover, the child's fears of his mother or father dying or going through inhumane torment may be assuaged by visiting. The visit may have a dual positive purpose—it may buoy the spirits of the hospitalized parent.

In addition to gauging emotional factors when helping families decide whether a child should visit the ICU, safety factors must also be considered. For example, the child who becomes overwhelmingly anxious, even dangerously hyperactive, is not...
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Preschoolers (3- to 6-year-olds)

There are three features of preschool-aged children that are central to their visiting the ICU. The fact that they are egocentric, they employ magical thinking, and they are keenly focused on body integrity; they love bandages, catheters, blood-smeared intravenous sites, or wounds, they can become tremendously fearful. They may also reason that these things are what is keeping the patient in the ICU and making him or her ill, as opposed to thinking that the ICU is keeping the patient there to provide loved ones the necessary care to keep him or her alive. Providing children with pictures of what they will see in the ICU—such as showing them an IV pole, a stretcher, a monitor, and a puppet play about what the ICU will be like before they visit—can be key to helping them gain a sense of mastery over their ICU visit. For example, after taking a tour of an empty ICU room and being told what to expect, one proud 6-year-old commented: “My dad was connected to this bag (IV fluids) on this pole and this machine, ‘cuz his lither and his kid knees aren’t working, but it was okay, these machines were helping.”

School-aged Children (7- to 11-year-olds)

Around the age of 7, children begin developing a more sophisticated world view based on logic. They have a voracious appetite for knowledge and understanding the “rules” of a system. For example, first-graders love board games. However, their desire for understanding is balanced with not wanting to look “dumb,” so school-aged children will often not ask questions. The key to preparing children of this age for visits with critically ill relatives and family friends is to provide basic details about illness and frequently ask if they have any questions. Too much information can overwhelm children of this age, who may still find the internal organs “goings on” of an ill individual quite mysterious. Helping children gain a sense of mastery by buying books and using diagrams or models to explain what is happening to a relative may be very helpful. Finally, giving children something to do, such as filling a water pitcher or vase, opening cards, or presenting a gift, can help alleviate boredom and promote a sense of accomplishment—they will feel like they have been helpful to the loved one. One last note on children of this age is that early in the school-age developmental era, children gain a sense that death is permanent. This may bring about a profound anxiety. Exploring children’s thoughts on the matter and reassuring them that their life routines and schedules will continue despite the possible loss of a loved one can be very reassuring.

Preteens and Adolescents (12+ Years)

Teenagers have a much stronger sense of medical reality and, with this understanding, more robust, emotional responses. Some adolescents may throw themselves into the caretaker role, wanting to operate on the level of adult family members that are visiting. Others may choose to avoid the hospital, finding the experience too overwhelming. Helpful measures can be taken such as being nonjudgmental, laying out the pros and cons of visiting relatives, and avoiding “guilt trips” such as “this may be the last time you ever get to see your uncle so you’d better go.” Also, when providing adolescents with information before they come to the hospital, they may be quite offended when they are “spoken down to”; hence, a very nonauthoritarian, open discussion of what is happening to their relative or loved one is the best approach. Finally, it is helpful when communicating with anxious teenagers to ask, in an open-ended manner, if there is anything they are worried about. Most teenagers louther comments such as “I can see you’re worried. Just admit it,” which can lead to painful arguments during the drive to and from the hospital. Particularly with teenagers, but also with younger children, in family conferences, it is important for doctors and nurses to look them in the eye, shake their hand, and ask if they have any questions—treating them as full members of the family.

SUMMARY

Mindful practitioners attend in a non-judgmental way to their own physical and mental processes during ordinary, everyday tasks. This critical self-reflection enables physicians to listen attentively to patients’ distress, recognize their own errors, refine their technical skills, make evidence-based decisions, and clarify their values so that they can act with compassion, technical competence, presence and insight.

Ronald Epstein (33)

Care in the ICU requires highly specialized knowledge and skill on the part of all health professionals. However, the technical skills required for optimal care may be severely compromised by the emotional reactions of patients and families. Physicians in the ICU should see themselves not only in a capacity to cure or stabilize illness, but also in a unique position to heal. Healing involves more than applying current scientific knowledge, diagnostic procedures, and therapeutic technique. Beyond these critical factors, it requires providing comfort, reassurance, open and honest communication, respect, and empathy (34). Too often, care is compromised by the interference of the patient and/or families in the therapeutic process. When
the clinician can appreciate the types of personalities and re-
actions of patients and families in crisis situations, understand the
underlying psychological processes that engender them, and main-
tain an acute awareness of his or her own responses to
them, he or she will be fully able to provide the best possible
care in the ICU.

Working in the ICU is, of necessity, a multidisciplinary team-
based enterprise. As such, there is no substitute for discussion
by team members of both the medical aspects of their patients’
conditions and their emotional reactions, especially as they im-
 pact individual clinician and team functioning. Being mindful
pertain not only to the individual, but also to the team, and
taking some time for distance from the patient, communication,
and reflection is often clarifying and rejuvenating. Moreover,
the ICU staff should welcome the assistance of consultants and
mentors with extensive experience in their management of dif-
ficult patients and families.

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