Medical decision-making, as an extension of the physician–patient relationship, is grounded in ethical principles of autonomy and self-determination. From a legal perspective, it can be a matter of contractual obligation or civil duty. A basic assumption governing the shared responsibility is a “meeting of the minds” in the process of consultation and informed decision-making. Decisions made at the end of life, however, often lack clear direction and are fraught by mitigating medical and legal circumstances, leaving lingering doubt as to the final disposition of a patient’s concern. It is in these areas that an often-reluctant judiciary has developed a growing body of case law guiding their role in the finality of life.

A corollary to the right to consent to medical treatment is a patient’s right to not consent (to refuse) medical treatment. In January 1908, Mary Schloendorff was admitted to New York Hospital to evaluate and treat a stomach disorder. During her stay at the hospital, she was diagnosed as having a fibroid tumor. The physician recommended surgery, which Schloendorff adamantly declined, although she did consent to an examination under ether anesthesia. During the procedure, the doctors performed surgery to remove the tumor. Afterwards, Schloendorff developed gangrene in the left arm, ultimately leading to the amputation of some fingers. Schloendorff blamed the surgery, and filed suit. Justice Benjamin Cardozo wrote the Court’s opinion, in which he stated, “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body… [T]he doctrine of informed consent—a doctrine borne of the common-law right to be free from nonconsensual physical invasions—permits an individual to refuse medical treatment” (1).

Until recently, there were relatively few cases involving a patient’s right to refuse care (2). However, technologic advances in medicine have made it possible to sustain life—or, alternatively stated, prolong dying—through artificial means (3). Generally speaking, it is the exercise of this “fundamental” right to refuse treatment that is at the center of most judicial intervention in treatment decisions. In particular, judicial intervention has been often sought out where there is disagreement between the desires of patients, surrogates, family, and/or providers regarding the terminal disposition of medical care.
Prolonging Life or Accelerating Death

The Case of Karen Ann Quinlan

In 1975, 22-year-old Karen Ann Quinlan went to a party at a friend’s house and proceeded to consume a combination of diazepam and alcohol. Reportedly, she had been on a crash diet and had not eaten in the previous 2 days. Shortly afterwards she felt faint, and was quickly taken home and put to bed. When friends checked on her about 15 minutes later, they found she was not breathing. Paramedics were called and during the resuscitation, she regained a pulse but did not regain consciousness. Three days after admission, she was diagnosed as comatose and required a mechanical ventilator to assist her breathing; the coma was followed by a persistent vegetative state. At the time that the New Jersey Supreme Court considered the case, which was less than 1 year after her anoxic event, Quinlan had lost at least 40 pounds, and was in a permanent fetal-like position with her joints severely rigid and deformed.

Joseph and Julia Quinlan, believing that their daughter would not want to continue to live in this condition, requested the withdrawal of life support. Her physician refused, believing that the standard of care at that time prohibited withdrawal. After the physicians refused the request of her parents to disconnect Quinlan’s ventilator, which they believed constituted extraordinary means of prolonging her life, her parents filed suit to force discontinuation from her ventilator. Complicating matters, hospital officials, too, faced threats of homicide charges if they complied with the parent’s request.

The Quinlans filed a suit on September 12, 1975, to request that the extraordinary means prolonging Quinlan’s life be terminated. The Quinlans’ lawyer argued that Quinlan’s right to make a private decision about her fate superseded the state’s right to keep her alive, while Quinlan’s court-appointed guardian argued that disconnecting her ventilator would be homicide. The suit was denied by New Jersey Superior Court Judge Robert Muir Jr. in November 1975, stating that Quinlan’s doctors did not support removing her from the ventilator, that whether or not to do so was a medical, rather than a judicial, decision, and that doing so would violate New Jersey homicide statutes.

The Quinlans appealed the decision to the New Jersey Supreme Court. On March 31, 1976, the court granted their appeal, citing that the right to privacy was broad enough to encompass the right to keep her alive, while Quinlan’s court-appointed guardian argued that disconnecting her ventilator would be homicide. The court issued its order on July 9, 1976; Saikewicz died 2½ years old, was a resident of the Belchertown State School in Belchertown, MA. In April 1976—1 month after the Quinlan decision—Saikewicz was diagnosed with acute myeloblastic monocytic leukemia. A guardian ad litem was appointed by the State to provide direction for Saikewicz’s medical care.

When she was taken off the ventilator, Quinlan surprised many by continuing to breathe unaided, and was fed by artificial nutrition for 9 more years, until her death from respiratory failure in 1985.

The State Interest Test

Joseph Saikewicz, a 67-year-old man with the mental age of a 2½ years old, was a resident of the Belchertown State School in Belchertown, MA. In April 1976—1 month after the Quinlan decision—Saikewicz was diagnosed with acute myeloblastic monocytic leukemia. A guardian ad litem was appointed by the State to provide direction for Saikewicz’s medical care. After reviewing the recommendation of Saikewicz’s attending physicians which stated that the patient should not receive chemotherapy, the guardian ad litem recommended that Saikewicz go untreated, letting his disease run its natural course.

The Saikewicz court was presented with expert testimony indicating that acute myeloblastic monocytic leukemia was, at that time, incurable and inevitably fatal. Regardless, most incapacitated patients chose to have chemotherapy, enduring its significantly unpleasant side effects even though the potential for remission was only 30% to 50% and, when it did occur, remission typically lasted for only 2 to 13 months. Thus, while chemotherapy was the normal medically indicated course of treatment, it could only provide the possibility of some uncertain and limited extension of life. Given Saikewicz’s age and condition, the court was informed that left untreated, he would live for a matter of weeks or, at most, several months. Further, given his mental age, Saikewicz would not likely be able to comprehend the reasons to endure the treatment, nor appreciate its potential benefit and likely require restraint, which would cause him mental and physical anguish.

The court issued its order on July 9, 1976; Saikewicz died on September 4, due to bronchial pneumonia. On November 28, 1977, the Saikewicz court issued an opinion intended to provide comprehensive guidance in the review of cases related to the withholding of critical care in end-of-life situations, both for capacitated and incapacitated patients.

In its opinion, the Saikewicz court developed a four-pronged test to evaluate the “state’s interest” and has been widely adopted by the courts in determining when an individual patient’s ability to exercise her or his constitutional right to refuse treatment can be circumscribed:

1. The preservation of life
2. The protection of the interests of innocent third parties
3. The prevention of suicide
4. Maintaining the ethical integrity of the medical profession

When she was taken off the ventilator, Quinlan surprised many by continuing to breathe unaided, and was fed by artificial nutrition for 9 more years, until her death from respiratory failure in 1985.
Substituted Judgment

In addition to articulating the four state interests to be used in determining when a patient’s fundamental right to refuse life-prolonging medical treatment may be denied, the Saikewicz court addresses the important question regarding the rights of an incompetent patient to forgo such treatment. The Saikewicz court believed that the “substituted judgment” standard would best preserve respect for the integrity and autonomy of the patient. In other words, the decision-maker’s role would be to put himself/herself in Saikewicz’s position and make the treatment decision the patient most likely would make were he competent. In this case, the court believed Saikewicz would have refused treatment.

“Clear and Convincing” Standard

In 1981, two cases involving the guardians of terminally ill, incapacitated patients objecting to the continued use of life-prolonging treatments further delineated the boundaries of “substituted judgment.”

The first case was the 83-year-old Brother Joseph Fox; this patient suffered cardiac arrest and substantial brain damage; he was placed on a ventilator, and remained in a persistent vegetative state. Father Philip Eichner, a close friend, and leader of the Catholic order, acted as Fox’s surrogate for medical decision-making. He reflected that in private conversations with Father Eichner, Fox had previously made it known that he would not have wanted to be maintained on a respirator in his present condition; the Court agreed.

In the second case, John Storar, a 52-year old man, profoundly mentally disabled since birth was diagnosed with terminal cancer of the bladder. With a prognosis for a very limited lifespan, palliative blood transfusions would be required frequently to maintain his daily activities; the Court refused to permit the withdrawal of treatment.

The key distinction between these cases according to the Court was the question of competence. The case of Brother Fox involved a man who was, at one time, competent for medical decision-making; this is as opposed to Storar who, at no time, had such capacity. The Court identified four key points that continue to provide us with guidance today:

1. A patient’s common-law right to determine the course of his own medical treatment is paramount to the doctor’s obligation to provide needed medical care.
2. Clear and convincing proof is required in cases where it is claimed that a person, now incompetent, left instructions to terminate life-sustaining procedures when there is no hope of recovery.
3. An individual who was never competent at any time in his life is considered still a child and a parent may not deprive a child of life-saving treatment, however, well intentioned.
4. Neither the common law nor the existing state statutes require persons to seek prior court approval in cases involving discontinuance of life-sustaining treatment for incompetent.

The Right to Die

The Case of Nancy Cruzan

On January 11, 1983, Nancy Cruzan lost control of her car and was thrown from the vehicle landing face down in a water-filled ditch. Paramedics found her with no vital signs, but they resuscitated her. After 3 weeks in a coma, she was diagnosed as being in a persistent vegetative state (8); surgeons inserted a feeding tube for her long-term care.

Rehabilitative efforts failed, and when it became apparent in 1988 that she had no medically reasonable chance of recovery, her parents—who were her court-appointed guardians—requested that the hospital terminates artificial nutrition and hydration measures. The hospital refused to do so without a court order, since the removal of the tube would cause Cruzan’s death.

The Cruzans filed for, and received, a court order for the feeding tube to be removed. The trial court ruled that, constitutionally, there is a “fundamental natural right … to refuse or direct the withholding or withdrawal of artificial death prolonging procedures when the person has no more cognitive brain function … and there is no hope of further recovery” (9). The Court specifically noted that Nancy had effectively “directed” the withdrawal of life support by telling a friend earlier that year that if she were sick or injured, “she would not wish to continue her life unless she could live at least halfway normally” (9).

The State of Missouri appealed this decision. In a 4 to 3 decision, the Supreme Court of Missouri reversed the trial court’s decision. It ruled that no one may refuse treatment for another person, absent an adequate living will “or the clear and convincing, inherently reliable evidence absent here” (10). The Cruzans appealed, and in 1989, the Supreme Court of the United States agreed to hear the case (11).

The legal question in this case was whether the State of Missouri had the right to require “clear and convincing evidence” in order for the Cruzans to remove their daughter from life support. Specifically, the Supreme Court considered whether Missouri was violating the Due Process Clause of the Fourteenth Amendment, which “protects individuals, conscious or unconscious, from such invasion by the state, without any particularized interest for that invasion” (12).

In a split 5 to 4 decision, the Court found in favor of the Missouri Department of Health. Upholding the Missouri Supreme Court’s ruling, the United States Supreme Court ruled that nothing in the Constitution prevents the state of Missouri from requiring “clear and convincing evidence” before terminating life-supporting treatment (13).

The Court did rule that competent individuals have the right to refuse medical treatment under the Due Process Clause. However, with incompetent individuals, the Court upheld the state of Missouri’s higher standard for evidence of what the person would want if they were able to make their own decisions. This higher evidentiary standard was constitutional, the Court ruled, because family members might not always make decisions that the incompetent person would have agreed with, and those decisions might lead to actions (like withdrawing life support) that would be irreversible (13). The Cruzan case:

1. Recognized a “right to die” but carefully noted that this was not guaranteed by the Constitution
2. Set out rules for what was required in order for a third party to refuse treatment on behalf of an incompetent person
3. Established that, absent a living will or clear and convincing evidence of what the incompetent person would have wanted, the state’s interests in preserving life outweigh the individual’s rights to refuse treatment
4. Left it to the states to determine their own right to die standards, rather than creating a uniform national standard (14)
Ongoing Challenges to the Right to Die

In February 1990, at the age of 27, Terri Schiavo suffered a cardiac arrest. She was resuscitated by paramedics, but never regained consciousness. Almost 9 years later, her husband, Michael Schiavo, petitioned the court to authorize removal of her feeding tube, arguing that Terri would not have wanted prolonged artificial life support without the prospect of recovery, and elected to remove her feeding tube. Schiavo's parents argued in favor of continuing artificial nutrition and hydration, and challenged Schiavo's medical diagnosis (15). The highly publicized and prolonged series of legal challenges presented by her parents, which ultimately involved state and federal politicians up to the level of President George W. Bush, caused a 7-year delay before Schiavo's feeding tube was ultimately removed.

In all, the Schiavo case involved 14 appeals and numerous motions, petitions, and hearings in the Florida courts; 5 suits in federal district court; extensive political intervention at the levels of the Florida state legislature, then-governor Jeb Bush, the US Congress, and President George W. Bush; and 4 denials of certiorari from the Supreme Court of the United States (16).

The Schiavo case did not change the landscape of legal authority surrounding the “right to die” as established by Quinlan and Cruzan. The courts recognized Schiavo as a permanently incapacitated patient and authorized her guardians to withdraw life-sustaining treatment—ventilator support and feeding tube—as compelled by “clear and convincing” evidence balanced against the four-pronged test of the State’s interest. However, the prolonged nature of the case and its involvement of all three branches of government act as a testament to the ongoing controversy, emotion, and debate surrounding the withdrawal of life-sustaining treatment from a permanently incapacitated patient.

Conclusion

Decisions at the end of life have been made significantly more difficult with the advancement of technology that keeps physiologic functions intact in the absence of cognition. The cases reviewed here reflect the case of law authority that guides judicial involvement when conflict arises. Ultimately categorized as “right to die” cases, as illustrated by the Schiavo case, legal precedent does not eliminate controversy. What is clear, however, is that the individual power of medical decision-making to accept or refuse treatment is protected by the penumbra of the Due Process Clause of the Constitution of the United States. This individual right is balanced against the State’s interest in the preservation of life and is more easily defended when one’s wishes are made clear through legal instruments such as an advanced directive. In the case of incapacity, the courts struggle with their role in adjudicating these decisions and have established a standard of clear and convincing evidence to support the substituted judgment where incapacity exists.

INFORMED CONSENT

Informed consent is the process of providing patients with information about the risks, benefits, and potential alternatives to the care they are offered. Informed consent is an essential part of the therapeutic discussion and is central to the relationship created between patient and physician (17–20).

While the roots of the informed consent doctrine can be traced as far back as the Magna Carta, its practical basis was established in the early 20th century in the 1914 New York case Schloendorff v. New York Hospital, as noted above (1).

While Schloendorff is nearly synonymous with patient autonomy and informed consent today, at the time there was no specific mention of informed consent as an actual principle. The case did not address issues such as what amount or type of information is necessary for a patient to make appropriate care decisions, nor did it result in damage recovery.

The process of informed consent did not become an established part of American medical practice until the late 20th century. Two historical tragedies proved instrumental in the creation of the informed consent doctrine as we know it today. The first event was the Nuremberg Code (1946 to 1949), which was developed as a result of the notorious Nazi medical experiments at Dachau during World War II (21). This code provided that “voluntary consent of the human subject is absolutely essential” and “the person involved...should have sufficient knowledge and comprehension of the elements of the subject matter as to enable him to make an understanding and enlightened decision” (22).

The Tuskegee Syphilis Study (1932 to 1972), conducted under the direction of the United States government, marked the second event. The study resulted in the deliberate withholding of syphilis treatment from several hundred rural African-American males so that investigators could gain information regarding the serious complications of late-stage syphilis. When the facts surrounding this experiment finally became public, it raised the consciousness about the rights of patients and research subjects regarding what information doctors must disclose (23).

Unfortunately, a wide gap persists between the idealized elements of informed consent and current clinical practices. Too often, “informed consent” is simply another shopworn phrase of internal contradictions along the lines of “rush hour,” “United Nations,” or “reliable software.” Simply put, when a harried medical student, nurse, or ward clerk hurries into a patient’s room with a boilerplate form, the patient is expected to sign immediately; informed consent is thus often neither informed nor consent. A signed informed consent form is not the same as getting informed consent (24).

In this section, we discuss the current status of informed consent in the intensive care unit (ICU), stressing the principles of sharing information, making good faith attempts to understand patient values and decision-making processes, and finally, avoiding manipulation and coercion of the vulnerable ICU patient.

ETHICAL FOUNDATIONS OF INFORMED CONSENT

The ethical foundations of informed consent encompass the classic principles of autonomy, beneficence, and justice. These three virtues provide the moral framework for informed consent and present guidelines for appropriate clinical action (25).

Autonomy

Autonomy, from the Greek words for self (auto) and rule (nomos), refers to the capacity for self-governing and the
patient’s right to self-determination. This includes the right to select a course of medical therapy that best reflects individual values and preferences. A prerequisite of autonomy is that an individual maintains the right to hold certain beliefs and to exercise independent thought. From these principles arise the ability to choose a specific course of action, to act according to this preference, and to accept the consequences of that decision. This necessarily presumes an individual has access to relevant information and also possesses freedom from both internal and external constraints.

Practically speaking, before patients can reasonably form opinions regarding available therapeutic options, they must first appreciate the nature of their medical condition, recognize the range of possible interventions, and understand the possible risks, benefits, and consequences associated with each option. This is essentially the mental checklist the physician should perform when speaking with the patient. It is the physician’s duty to ensure that the patient understands the medical diagnosis, the details of the proposed therapy, the available alternatives, and the consequences of refusal. Although the responsibility to provide this information lies with the physician, it is the patient who must ultimately integrate the facts and determine the most appropriate course of action.

Generally, autonomous action requires that individuals enter into the physician–patient relationship voluntarily and remain free to accept or refuse treatment without feeling coerced or intimidated; this is often not the case in the ICU. Patients frequently arrive in the ICU in a vulnerable condition, and are often admitted without their consent or knowledge; the additional stresses of critical illness leave them susceptible to fear, pain, or anxiety. With these factors in mind, the intensivist must maintain a balance between talking to the patient and making prompt therapeutic decisions. Given the emergent nature of developments in the ICU, it may be impractical to engage in extensive discussion about every procedure or therapy, but whenever possible, it is essential to provide patients with sufficient information to let them guide the overall course of their care. The balance between acting and letting the patient act characterizes the essence of informed consent in the ICU (26).

**Beneficence**

Beneficence—doing good—and its associated principle, nonmaleficence—not doing harm—embody the physician’s obligation to provide benefit while refraining from committing harm. Beneficence requires the physician to treat illness, provide other appropriate care, and relieve pain; nonmaleficence compels the physician to avoid causing pain and refrain from committing unnecessary harm. It is unreasonable to expect physicians to completely avoid risk when treating patients, as many ICU therapies and interventions pose considerable risk to the patient and may also cause pain. The therapeutic relationship in the ICU represents a working relationship between physician and patient, balancing potential benefits against harms whenever possible. Physicians are not neutral observers and, as long as they avoid coercive techniques, it is certainly acceptable—and some would argue mandatory—for them to provide their professional recommendation based on their clinical experience (27).

**Justice**

The third principle, justice, is rarely a source of conflict between the individual physician and patient in matters of informed consent. Ideally, the rules of informed consent serve to motivate the social virtue of justice; when conflicts do occur, they relate more commonly to societal versus individual claims and, thus, do not involve the physician–patient relationship. An exception is organ transplantation, a situation in which the transplant surgeon’s primary duty is directed to the proper allocation of organs rather than to a specific patient (28). Implicit in the relationship of justice to informed consent is the specific involvement of society’s instrument of justice: the court.

**LEGAL FOUNDATIONS OF INFORMED CONSENT**

The development of legal opinions during the past century illustrates the evolution of the currently recommended standards of informed consent. The first use of the term informed consent was in 1957 by an unheralded attorney named Paul Gebhard, drawing on his experience in labor law negotiations (29). In Salgo v. Leland Stanford Jr. University, Gebhard used the term in a friend-of-the-court brief on behalf of the American College of Surgeons to refer to the requirement that physicians must disclose the relevant risks and benefits of a procedure to patients (30).

**CURRENT ETHICAL MODELS OF THE PHYSICIAN–PATIENT RELATIONSHIP**

Models of informed consent that propose strategies for presenting information to patients and discussing alternatives emanated from the paternalistic Hippocratic tradition. In the physician-centered model—alternatively known as the paternalist, parental, or priestly model—the physician is the authority figure and guardian (31). In prioritizing the principle of beneficence—doing good—the physician engages the patient in decision-making simply to provide relevant information and encourage acceptance of the proposed therapy. Historically, Hippocrates advocated “concealing most things from the patient while you are attending to him. . . .” Similarly, in 1871, Oliver Wendell Holmes asserted, “Your patient has no more right to all the truth you know than he has to all the medicine in your saddlebags. . . He should get only just so much as is good for him” (32).

In time, greater emphasis on patient self-determination emerged, along with a higher priority on patient autonomy. Consequently, the informative model—also known as the scientific, engineering, consumer, or independent choice model—emerged as an alternative patient-centered strategy. It minimized physician bias and value judgment, while acknowledging the physician as technician and source of information. This provided the patient with options regarding the range of medical choices, along with the risks and benefits of potential alternatives. In contrast to the physician-centered model, the informative model asserts the physician’s duty to provide facts and medical knowledge without expressing bias toward
any particular treatment strategy. Ultimately, only the patient determines which course of action best suits his/her values and goals.

By minimizing physician input, this departure from paternalism represented an attempt to achieve complete patient autonomy. Nevertheless, this remained an unsatisfactory strategy for achieving informed consent, as true informed consent requires an interactive process between physician and patient. In clinical practice, the physician–patient relationship is collaborative with both sides sharing responsibility for participation, with a common goal of enhanced understanding. Clearly, the physician must be more than a technical adviser; the ICU is where the physician’s training, knowledge, and experience are most important in providing interpretive guidance about diagnosis and treatment. This means the patient may, on occasion, request and receive a great deal of information; other times, circumstances will dictate the physician as the primary decision-maker alone.

Two current models of shared decision-making propose mutual understanding through an interactive process. The first, the interpretive model, focuses on clarifying the patient’s values and determining preferences regarding the goals of therapy. By serving as a counselor providing information and engaging the patient in a joint process to achieve understanding, the physician may help the patient recognize and express their preferences. A discussion of treatment options permits the patient to identify their own priorities and determine which option best realizes these values. Thus, physician guidance allows the patient to demonstrate autonomy and self-understanding.

The second model of shared decision-making, the deliberative model, requires the physician to provide clinical information and then elicit information from the patient regarding their understanding and goals. In representing an idealized interaction between physician and patient, the physician integrates medical information with the patient’s values. In this model, the physician should express opinions and preferences regarding appropriate therapy. Patient autonomy is preserved through the patient’s moral understanding and action.

These idealized models of the physician–patient relationship acknowledge that informed consent is a process of shared decision-making. Examining the values of both patient and physician contributes to decisions regarding treatment benefits or risks (33). The optimal model for the physician–patient relationship is one that achieves a level of interactive and shared decision-making, thereby prioritizing patient autonomy while still engaging the participation of a concerned physician (34).

CURRENT LEGAL STANDARDS OF INFORMED CONSENT

Considerable uncertainty and debate remain regarding the level of information a physician should reasonably provide for a patient to adequately appreciate the risks associated with any particular therapeutic intervention (35). The perpetual dilemma of informed consent in the ICU is that, in extreme situations of both benefit and risk, greater obligation lies on the physician to adhere strictly to the guiding principles of informed consent. At the same time, ICU patients, because of their weakened condition, may be less able to comprehend and make decisions. In any discussion of possible risks, a physician should routinely disclose to the patient the complications that would occur most commonly; a reasonable figure would be a complication with a probability of at least 1% to 5%. If the potential risk is particularly serious or potentially fatal, it seems obvious that even rare complications with less than a 1% probability should be mentioned (e.g., the vascular complications of routine central venous catheter placement). However, some might argue that the occasional one-in-a-million fatal complication is not the appropriate standard for disclosure (not to mention that some physicians may be unaware of such rare complications). Because opinions differ, no uniform legal standard exists that defines how much information is required to meet the standard of adequate disclosure (36). Consequently, three standards of disclosure have been developed and currently exist: the professional community standard, the reasonable patient standard, and the individual patient standard (37,38).

Standards of Disclosure

The Professional Community Standard

For decades, the professional community standard was the traditional standard for informed consent. According to this standard, a physician should provide the level of information that physicians in the community would communicate to patients in comparable situations. Courts would assess physician disclosure based on the standard practices of other physicians with similar training and experience, working under similar circumstances. Because of the imprecise definition of “professional community,” the professional standard was used to justify a broad range of interpretation, albeit without solid grounding in clinical criteria. The “community” could range from very specific practice locations to a broad geographic region, or otherwise refer to a level of specialized training or experience. In some circumstances, even the opinions of a “respectable minority” of physicians would constitute an appropriate practice standard. As such, the expectation of what the physician should tell the patient was notoriously imprecise. It was difficult to define which specific surgical or procedure risks a physician should disclose to a patient. Furthermore, physicians often invoked the concept of “therapeutic privilege,” which permitted them to withhold all information if they thought it would be harmful to the patient. This doctrine has fallen out of favor, both clinically and legally (25).

Critics cited not only the imprecision, but also the paternalistic nature of the professional community standard. According to this standard, the physician ultimately determined the threshold of risk that should be disclosed to the patient. The obvious problem with this model was that if the community standard did not include the disclosure of a potential complication or other information that a patient might reasonably want to know, the physician was not obligated to disclose it. For example, physicians might prescribe penicillin, and, while a potentially lethal anaphylactic reaction to the drug was possible, because it was rare, it would not necessarily merit mention as a complication. Although physicians could not be expected to divulge every possible complication of a procedure or adverse reaction to a drug, many still felt it unacceptable that the standard for providing information rested solely in the hands of the physician.
The Reasonable Patient Standard

In response to the paternalistic standard, and in concert with the trend toward greater emphasis on the patient’s right to self-determination, American courts began recognizing an alternative reasonable patient standard to judge the adequacy of risk disclosure. Since it was unreasonable to expect a physician to disclose every potential risk associated with a particular treatment, the reasonable patient standard required the physician to disclose all information a reasonable person would need to make an informed decision. This new standard dictated that even rare complications should be explained to the patient if the consequences (death, severe injury) were such that a reasonable person would want to know them.

However, there are also problems with this model. For one, the physician must divine what a reasonable person would want to know. (Would a reasonable person want to know about anaphylactic responses to penicillin?) Second, the ICU, a setting where life and death decisions are commonplace, may not lend itself to the enforced neutrality of the reasonable person standard. The physician would be performing a grave disservice simply by reciting potential complications of endotracheal intubation to a patient in respiratory distress. Consequently, another standard was needed.

The Individual Patient Standard

In the ICU, the physician’s input is critical to good decision-making, which is why the optimal model for physician–patient relationships is one of interactive and shared decision-making; the individual patient standard addresses this relationship. Based on interaction with the patient and understanding of their beliefs, the physician should disclose specific information, so the patient can reach a decision consistent with his or her principles. The distinction between the different standards is subtle but significant. Under the professional community standard, the physician asks, “What should I tell the patient?” Under the reasonable person standard, the physician asks, “What does a reasonable person want to know?” Under the individual person standard, the physician asks, “What does this patient want to know?” Obviously, the most idealized standard of disclosure, the individual person standard, is ultimately the most difficult to achieve. Courts may not require such an idealized standard in all cases, but when questions of informed consent arise, this is the standard courts are most likely to favor.

Adjustments of Standards

In discussing these legal standards, a note of caution is in order: These models represent guidelines for medical encounters where both parties—patient and physician—can interact. In the ICU, situations are constantly changing, life and death decisions are commonplace, and emergencies sometimes make the search for an ideal physician–patient relationship impractical. The long-term relationship between the patient and the primary physician does not apply; the intensivist is often meeting the patient for the first time under conditions of duress (39). For the patient, admission to the ICU is virtually always a stressful, and potentially overwhelming, situation where critical illness creates an unusual dependence and power imbalance. The patient may be unable to comprehend or express their wishes (see below, Competence and Decision-Making Capacity). Other times, when acute care is required, an autonomous patient may choose to relinquish medical decision-making at the physician’s discretion (40).

When explaining the risks and benefits of any intervention, it is also important for physicians to use language patients can understand. This includes adequate translation non-English speaking patients and also making explanations as nontechnical as possible. Even in the best case, patients may have difficulty extracting important information from discussions with physicians. When physicians lapse into technical jargon, the anxious, frightened patient may have little or no opportunity to process what is being said. It is important that, when appropriate, physicians make use of translators, family members, and other intermediaries.

An extensive discussion regarding the risks and benefits of care are the desired standard, but in the ICU, sometimes less is more. In emergencies, the need to keep patients informed sometimes becomes a luxury that time and circumstance may not permit. Emergency circumstances, where a patient lacks decisional capacity and no proxy decision-maker is identifiable, do not realistically allow for voluntary consent. In truly emergent situations, if the patient lacks capacity, no proxy decision-maker is available, and the potentially life-saving intervention must be administered immediately, the “emergency exception” to informed consent permits the physician to intervene without obtaining formal informed consent. In these situations, the intensivist should document the emergent nature of the situation and the difficulty in obtaining informed consent.

COMPETENCE AND DECISION-MAKING CAPACITY

Hospitalized patients, especially those critically ill, often suffer from an impaired ability to comprehend, process, or analyze information. Under the influence of pain medication, sedation, or the physical and mental stresses of illness, even the healthiest ICU patient may not fully appreciate or be able to actively participate in health care decisions, as the emotional stresses of critical illness may temporarily compromise their decisional capacity (41). As one study noted, for very sick patients, the ability to perform simple cognitive tasks is impaired to the point an adult patient may temporarily function at the level of a 10-year-old (42). This presents unique challenges for critical care practitioners when discussing medically complex issues.

Definition of Terms: Competence Versus Capacity

Both “competence” and “capacity” refer to the patient’s ability to make decisions. Although the terms are often used interchangeably, there is a distinction between their legal and medical definitions. Strictly speaking, competence refers to a legal determination, and does not refer specifically to the patient’s ability to make appropriate health care decisions (43). A court decides whether or not a person is legally competent, and generally, when “competence” is used as a legal term, it refers to patients’ ability or inability to conduct their personal affairs, but not necessarily to make health care decisions. It is unusual, but not unheard of, for petitioners to ask the court specifically to declare a patient incompetent to make medical decisions.

In the ICU, situations are constantly changing, life and death decisions are commonplace, and emergencies sometimes make the search for an ideal physician–patient relationship impractical. The long-term relationship between the patient and the primary physician does not apply; the intensivist is often meeting the patient for the first time under conditions of duress (39). For the patient, admission to the ICU is virtually always a stressful, and potentially overwhelming, situation where critical illness creates an unusual dependence and power imbalance. The patient may be unable to comprehend or express their wishes (see below, Competence and Decision-Making Capacity). Other times, when acute care is required, an autonomous patient may choose to relinquish medical decision-making at the physician’s discretion (40).

When explaining the risks and benefits of any intervention, it is also important for physicians to use language patients can understand. This includes adequate translation non-English speaking patients and also making explanations as nontechnical as possible. Even in the best case, patients may have difficulty extracting important information from discussions with physicians. When physicians lapse into technical jargon, the anxious, frightened patient may have little or no opportunity to process what is being said. It is important that, when appropriate, physicians make use of translators, family members, and other intermediaries.

An extensive discussion regarding the risks and benefits of care are the desired standard, but in the ICU, sometimes less is more. In emergencies, the need to keep patients informed sometimes becomes a luxury that time and circumstance may not permit. Emergency circumstances, where a patient lacks decisional capacity and no proxy decision-maker is identifiable, do not realistically allow for voluntary consent. In truly emergent situations, if the patient lacks capacity, no proxy decision-maker is available, and the potentially life-saving intervention must be administered immediately, the “emergency exception” to informed consent permits the physician to intervene without obtaining formal informed consent. In these situations, the intensivist should document the emergent nature of the situation and the difficulty in obtaining informed consent.

COMPETENCE AND DECISION-MAKING CAPACITY

Hospitalized patients, especially those critically ill, often suffer from an impaired ability to comprehend, process, or analyze information. Under the influence of pain medication, sedation, or the physical and mental stresses of illness, even the healthiest ICU patient may not fully appreciate or be able to actively participate in health care decisions, as the emotional stresses of critical illness may temporarily compromise their decisional capacity (41). As one study noted, for very sick patients, the ability to perform simple cognitive tasks is impaired to the point an adult patient may temporarily function at the level of a 10-year-old (42). This presents unique challenges for critical care practitioners when discussing medically complex issues.

Definition of Terms: Competence Versus Capacity

Both “competence” and “capacity” refer to the patient’s ability to make decisions. Although the terms are often used interchangeably, there is a distinction between their legal and medical definitions. Strictly speaking, competence refers to a legal determination, and does not refer specifically to the patient’s ability to make appropriate health care decisions (43). A court decides whether or not a person is legally competent, and generally, when “competence” is used as a legal term, it refers to patients’ ability or inability to conduct their personal affairs, but not necessarily to make health care decisions. It is unusual, but not unheard of, for petitioners to ask the court specifically to declare a patient incompetent to make medical
Care decisions. More often than not, this legal determination regarding who decides care for a patient remains in limbo and is left to the patient’s family and doctors.

If courts are not involved with a patient’s ability to make decisions, health care providers commonly invoke the term “medical competence,” but they are really referring to the patient’s capacity. In contrast to legal competence, decision-making capacity is a clinical judgment, which specifically describes the patient’s ability to make medical decisions. The physician’s need to assess capacity arises when there is reason to question whether a patient can make decisions about care. When assessing the patient’s capacity, i.e., what most observers refer to imprecisely as whether the patient is competent to consent to care, the examining physician must determine whether the patient understands the five basic elements of capacity (Table 4.1) (45). During an interview, if a patient demonstrates satisfactory understanding of these five facts, it can reasonably be inferred the patient possesses adequate decision-making capacity.

### Informal Assessments

Informal assessments of a patient’s cognitive abilities typically occur throughout physician–patient interactions. In the critically ill patient, mental status may fluctuate during the course of hospitalization or even during the course of the day. Unless presented with evidence to suspect otherwise, the treating physician should assume the default position that the patient remains capable of independent choice. If this ability is in question, the health care provider is obliged to demonstrate that the patient cannot make medical decisions. When the clinical situation suggests the patient is incapable of independent choice, a more formal evaluation may be initiated (46).

Physicians may be more likely to question the patient’s mental capacity if the patient’s choices appear unreasonable or contradict the physician’s personal values. The patient who refuses a relatively low-risk, high-benefit intervention, or a terminally ill patient who insists on pursuing a painful intervention with little proven benefit, are both scenarios that may prompt a physician to question the patient’s decision-making capacity. In these situations, the physician must first attempt to decipher whether the patient’s seemingly illogical behavior is actually part of a rational thought process. A critically hemorrhaging patient who refuses a blood transfusion may be medically frustrating to care for, but this refusal becomes understandable once it is revealed the patient is a Jehovah’s Witness. Similarly, the patient with end-stage metastatic cancer who has failed multiple rounds of chemotherapy may appear irrational for insisting on pursuing invasive experimental procedures. This seemingly irrational insistence may become more understandable in the context of an upcoming family event, anniversary, or graduation.

### External and Emotional Factors

In the ICU, external factors, including sundowning, sedation, pain medication, or altered sleep patterns, may contribute to transient, reversible episodes of incapacity. Whenever possible, attempts should be made to minimize the impact of these influences and optimize the patient’s cognitive status prior to making a capacity assessment. The patient’s judgment is often compromised by emotional factors—anger, fear, denial, depression, or pain—this is especially true in both the ICU and in the emergency department. The common scenario of the 50-year-old executive with crushing substernal chest pain who denies he is having a heart attack and wants to sign out of the hospital is an example of how denial may compromise a patient’s judgment.

Health care providers should recognize that the patient’s decisions under those conditions may not be the same ones they would choose in a less stressful environment. The physician must attempt to ensure that external factors do not unduly influence the patient. True informed consent requires the patient’s unhindered judgment; when that judgment appears to be unduly compromised, the physician should use appropriate measures such as family intervention, psychiatric consultation, or medication aimed at treating the specific problem. The frightened patient who refuses necessary medical care is often grateful if, after appropriate intervention, proper care is provided.

For particularly high-risk interventions or close-call scenarios, a second physician, generally someone with expertise in this area such as a psychiatrist or neurologist, may be consulted to evaluate the patient. In such cases, the physician should inform the consultant in advance about the situation so the consultant can conduct a focused interview and provide the necessary information.

### Legal Interventions

In rare circumstances, questioning a patient’s capacity means seeking a court determination of legal incompetence. In practice, resorting to court is rarely necessary. Rather than deferring to the court system, most states recognize the authority of a spouse, family member, or friend to make decisions in the best interest of the patient. However, when family members and health care providers cannot agree about the most appropriate course of action after attempts at resolution, a legal opinion may be the only option. Courts are generally reluctant to get involved in health care decisions, so this should generally be the last option.

### SURROGATE DECISION-MAKING

#### Signing out of the Hospital Against Medical Advice

One of the most difficult situations for the ICU staff is the extremely uncooperative, combative patient. In most cases, these patients are reacting to fear, pain, illicit drug ingestion, or alcohol withdrawal. Usually, after appropriate sedation or analgesia, care can be rendered although occasionally a patient must be physically restrained. The indication for physical restraint is when patients present a risk to themselves or to others. In rare circumstances, despite the best efforts of the

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**TABLE 4.1 The Five Elements Patients Must Understand to Determine Their Capacity**

1. The diagnosis
2. The proposed therapy
3. The risks and benefits of the proposed therapy
4. The alternative options
5. The risks and benefits of refusal

staff, a patient may refuse all treatments and demand to leave the hospital. The staff is then forced to reconcile the conflict between respecting the patient’s rights and their duty to care for, and protect the patient from harm; there may be no easy resolution of this problem.

The right to leave the hospital against medical advice is the prerogative of the competent patient. If the patient meets the general test of medical competence as described in the five basic elements of capacity (see Table 4.1) (45), the patient must be permitted to leave the hospital, even if the staff disagrees with the decision or the decision seems irrational. However, all decisions by patients to leave against medical advice should be scrutinized by senior staff to ensure the patient truly is competent. Those decisions that appear irrational should be scrutinized with even more care. A classic example is the aforementioned 50-year-old male with an acute myocardial infarction, otherwise competent but who, in a fit of denial, demands to sign out of the hospital. All avenues should be used to get the patient to stay, including a detailed discussion of the situation and an appeal to family or friends who accompany the patient to the hospital. Ultimately, however, if the patient refuses to listen, because he is competent he must be permitted to leave. In such situations—very trying ones, indeed—heath care providers must attempt to provide any appropriate care or workup before the patient leaves. Staff should avoid recriminations, and the patient should also be reassured he or she can return for care at any time.

Other situations are not so clear-cut. In many cases, the patient’s competence is in question. Possible physiologic causes for the patient’s condition, e.g., hypoxemia, electrolyte disturbances, sepsis, should be identified. If the patient cannot be deemed competent, staff may decide to institute treatment over the objection of the patient, which might even entail physical restraint. Failure to restrain when indicated carries a significant risk to both patient and health care providers. The classic counterpart to the aforementioned myocardial infarction patient is the patient in a motor vehicle accident who appears intoxicated but wants to sign out of the hospital. If the physician suspects that the patient is intoxicated, based on clinical observation even before confirmation of blood alcohol concentration, the patient should not be allowed to leave until appropriate radiologic assessment of the head and neck have been performed.

Some health care providers are overly concerned with the liability they may incur by treating a patient against his or her wishes. When competence cannot be established with certainty, if the staff decides to restrain the patient, they may theoretically open themselves to charges of battery. Such an outcome, however, is extremely unlikely, and almost certainly less likely than the alternative of being charged with negligent discharge. The consequences of being responsible for the negligent death of unrestrained patients are far more serious than the responsibility for holding patients against their will for several hours. When the staff’s actions are medically reasonable, they are acting in good faith, and they document their decision (see below, Documentation), the likelihood of successful litigation against them is remote.

**Documentation**

Every situation of implied consent, or a decision to leave the hospital against medical advice, requires *scrupulous* and *detailed* documentation. The information that should be included in the medical record is listed in Table 4.2. Specialty consultations with neurology or psychiatry are not mandatory but may be useful in assessing the patient and documenting the situation. In difficult cases, it may be necessary to involve a representative of the hospital’s administration or legal counsel.

### TABLE 4.2 Documentation of Patients Who Leave the Hospital Against Medical Advice

| 1. Description of the patient’s condition |
| 2. The basic questions used to assess the patient’s competence |
| 3. Risks, benefits, and alternatives of treatment |
| 4. Urgency of the situation |
| 5. Any attempts to contact family members or other potential surrogates (detail who, when, and what interaction occurred) |

There is no medical or legal consensus regarding which procedures require formal consent. As a general guideline, the greater the risk of the procedure, the greater need to discuss the risks and benefits more formally (34). This standard results in consent policies that vary significantly from hospital to hospital. One survey of informed consent practices found that while over 90% of hospitals surveyed required formal consent for gastrointestinal endoscopy, fiberoptic bronchoscopy, or medical research, fewer than 10% required consent for nasogastric intubation or bladder catheterization (47). Of note, requirements for consent varied between medical and surgical services, even within the same institution.

Achieving satisfactory informed consent may not always be possible, even when physicians explain the procedures to patients. In one study of patients who consented to moderately invasive bedside procedures (thoracentesis, paracentesis, bone marrow aspirate, or lumbar puncture), 90% of the patients surveyed reported the physician had informed them of the risks of the procedure, although only 70% could correctly recall the reason for the procedure. Although 86% of patients reported the physician had informed them of the risks of the procedure, only 57% could later name any of the risks (48). This raises the question of how effectively information is communicated to patients and how accurately patients understand and recall information presented to them.

To anticipate patients’ needs and to simplify the consent process, many institutions use standardized consent forms that include essential information regarding particular procedures or interventions. The use of a standardized ICU admission consent package, describing and requesting consent for the most commonly performed procedures, can enhance the informed consent process (49). Standardized forms, however, do not necessarily guarantee clear communication. As a response to defensive medicine concerns, standardized consent forms may describe every possible adverse consequence instead of actually trying to inform the patient (50). Moreover, standardized lists of complications may fail to communicate the risks most relevant to any particular patient, especially in the ICU, where a patient’s changing medical condition can present a dynamic series of risks and benefits. The risk of an iatrogenic...
pneumothorax from central venous catheter placement during mechanical ventilation carries different implications than the same complication when the catheter is simply placed for fluid replacement.

Despite these caveats, standardized consent forms for common procedures may be useful in initiating dialogue between patient and physician. Standardized consent forms may also be necessary for especially complex ICU surgical procedures such as organ transplantation or experimental surgery. In these situations, a detailed informational document provides patient and health care providers with a ready reference. The language of such forms should be reviewed periodically to ensure simplicity and reader-friendly, understandable language. Even when standardized forms are used, health care providers should enter a note in the patient’s medical record detailing the conversation between the patient and physician.

**RESEARCH CONSENT IN THE ICU**

Like every specialty, critical care medicine has achieved progress through research involving the participation of volunteers (51). Critically ill patients represent a particularly vulnerable population, which raises concerns about their ability to give voluntary, autonomous consent to participate in clinical research (52). Ongoing critical care research recognizes a corresponding obligation to protect this vulnerable population. Requesting consent for voluntary participation in research differs fundamentally from discussing informed consent for therapeutic interventions. When discussing the risks, benefits, and alternatives of any therapeutic or diagnostic intervention, both the clinician and patient seek a course of action that would maximally benefit the patient. In contrast, the goal of research is to generate information that may benefit future patients but does not necessarily benefit the individual research participant (53). This creates a potential conflict of interest between researcher and patient, and thus, researchers must exercise particular caution in protecting patients’ rights (54). Federal regulations, known as “the common rule,” have been designed to protect this vulnerable population of research participants (55).

Patients participating in clinical research may misunderstand or overestimate the individual benefits of participation; alternatively, they may not fully recognize the potential risks (56). Although the possibility for personal benefit does exist, a patient might be randomized to a nontreatment arm of a study or may alternatively receive experimental therapy with expected, hazardous side effects (57). Researchers are obligated to ensure that research participants recognize the additional risks and benefits of participation. Occasionally, this means a researcher may ask a research participant to accept a disproportionate share of risk with no prospect of additional individual gain. The precise limits of risk a vulnerable patient may be asked to accept have not been specifically defined (58).

The research consent process should clearly delineate the nature of the research and structure of the trial, specifically including details on any randomization process (59). In contrast to therapeutic interventions, informed consent for research represents a process that continues throughout the course of a clinical study. Consequently, routine updates for the patient may be necessary. Standardized consent forms may be helpful in communicating the relevant information, and the physician should ensure that information is clearly explained. During the study, clinical research consent forms may be used as reference documents. Because of concerns regarding literacy and language comprehension, the complexity of language should generally target comprehension for no higher than a sixth-grade reading level.

Since few patients are likely to have voiced their previous preferences regarding research participation, proxy decision-makers are left to infer the most appropriate actions in certain situations for patients without decision-making capacity. Emergency situations where patients cannot consent, and surrogates cannot be located, raise concerns about the ethics of conducting research in these cases. Although regulations have sought to protect potential research subjects, those regulations acknowledge that denying research participation to patients who cannot give consent may also deny them potentially beneficial therapy. A 1996 amendment to the Code of Federal Regulations for the Protection of Human Subjects permits emergency research with certain provisions if consent cannot be obtained (54,60). Clinical trials describe waivers of consent based on implied consent (61). Delayed consent is another mechanism that has been employed for clinical trials comparing two clinically acceptable therapies (62).

**The Emancipated Minor Exception**

Emancipated minors are children younger than 18 years of age (or whatever the age of majority is in the state of residence) who can decide their own medical care. The specific criteria for emancipated minors vary from state to state, but generally pertain to minors who are either married, pregnant, a parent, in the military, financially independent and living apart from their parents, or those who have been legally declared emancipated by the court. Pediatric critical care practitioners should be familiar with laws concerning the age of majority and emancipated minors in the state where they practice.

**When the Parents or Surrogate and Health Care Team Disagree on the Care of a Critically Ill Child**

This situation arises most commonly in end-of-life situations regarding the propriety and timing of providing care (63,64). These are obviously emotionally wrenching circumstances when health care professionals and parents or surrogates disagree. Health care providers may anticipate the termination of ventilatory support in a severely brain-injured patient or a terminal cancer patient days, or even weeks, before parents or surrogates reach an understanding that this is the proper decision. Parents or surrogates may hold out unreasonable hope, however understandable, in the face of a child’s impending death. Patience is usually the best approach, as time and reasoned discussion generally resolve these issues. This strategy requires the understanding that those involved may be at different stages of acceptance. Collegial communication eventually brings the concerned parties to an acceptable conclusion. It is imperative that critical care practitioners offer parents or surrogates sufficient opportunity to discuss their feelings and emotions. A distant, emotionally detached approach by the critical care provider is inappropriate and complicates the delivery of care.
When there is neither common ground nor hope of agreement between the critical care provider and parents or surrogates, the final resort is to resort to the courts. Practitioners should not undertake formal legal action lightly. Experience has shown that in most cases, attorneys, courts, and judges, rather than hearing such cases, prefer resolution outside the courtroom. Besides being expensive, the legal process requires time and energy, both physical and emotional, on the part of everyone involved. In this adversarial process between the critical care provider and parents or surrogates involving end-of-life decisions, medical professionals should keep in mind that, in some cases, courts have ruled against the medical team who originally instituted the proceedings (65). Whenever pediatric critical care practitioners consider going to court for resolution, they should consult the hospital’s legal staff and ethics committee to explore other options and coordinate an optimal strategy for all parties involved. They should remember that the best interests of the pediatric patient are their paramount concern.

Key Points

- Rooted in principles of autonomy and self-determination, the courts have long upheld that one’s body may not be violated without proper approval.
- A corollary to the right to consent to medical treatment is a patient’s right to not consent (to refuse) medical treatment.
- The Saikewicz court developed a four-pronged test to evaluate the “state’s interest” and has been widely adopted by the courts in determining when an individual patient’s ability to exercise her or his constitutional right to refuse treatment can be circumscribed:
  - The preservation of life
  - The protection of the interests of innocent third parties
  - The prevention of suicide
  - Maintaining the ethical integrity of the medical profession
- In a patient who at no time had capacity, the Court identified four key points that continue to provide us with guidance today:
  - A patient’s common-law right to determine the course of his own medical treatment is paramount to the doctor’s obligation to provide needed medical care.
  - Clear and convincing proof is required in cases where it is claimed that a person, now incompetent, left instructions to terminate life-sustaining procedures when there is no hope of recovery.
  - An individual who was never competent at any time in his life is considered still a child and a parent may not deprive a child of life-saving treatment, however, well intentioned.
  - Neither the common law nor existing state statutes require persons to seek prior court approval in cases involving discontinuance of life-sustaining treatment for incompetent.
- In the Cruzan “right to die” case, the Court:
  - Recognized a “right to die” but carefully noted that this was not guaranteed by the Constitution
  - Set out rules for what was required in order for a third party to refuse treatment on behalf of an incompetent person
  - Established that, absent a living will or clear and convincing evidence of what the incompetent person would have wanted, the state’s interests in preserving life outweigh the individual’s rights to refuse treatment
  - Left it to the states to determine their own right to die standards, rather than creating a uniform national standard
- The roots of informed consent are to be found in the case of Schloendorf v New York Hospital, the Nuremberg Code, and the Tuskegee Syphilis Study.
- The ethical foundations of informed consent encompass the classic principles of autonomy, beneficence, and justice.
- The standards for informed consent vary.
  - Under the professional community standard, the physician asks, “What should I tell the patient?”
  - Under the reasonable person standard, the physician asks, “What does a reasonable person want to know?”
  - Under the individual person standard, the physician asks, “What does this patient want to know?”
- Emancipated minors are children younger than 18 years of age (or whatever the age of majority is in the state of residence) who can decide their own medical care. Specific criteria include minors who are married, pregnant, a parent, in the military, financially independent and living apart from their parents, or those who have been legally declared emancipated by the court.

References

3. In 1987, the Arizona Supreme Court wrote: “Not long ago the realms of life and death were delineated by a bright line. Now this line is blurred by wondrous advances in medical technology—advances that until recent years were only ideas conceivable by such science-fiction visionaries as Jules Verne and H.G. Wells. Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues.” As the Arizona court notes, the rub is that “[s]ome patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity”. Rasmussen v. Fleming, 154 Ariz. 207, 216 (1987).
4. In the Matter of Karen Quinlan. 355 A.2d 647, 655 (N.J. 1976). “It seemed to be the consensus not only of the treating physicians but also of the several qualified experts who testified in the case, that removal from the respirator would not conform to medical practices, standards and traditions.”
7. Cruzan’s condition was described as “oblivious to her environment except for reflexive responses to sound and perhaps painful stimuli. . . .[having] a massive enlargement of the ventricles filling with cerebrospinal fluid in the area where the brain has degenerated and [her] cerebral cortical atrophy is irreversible, permanent, progressive and ongoing. . . .her highest cognitive brain function is exhibited by her grimacing perhaps in recognition of ordinarily painful stimuli, indicating the experience of pain and apparent response to sound. . . .her four extremities are contracted with irreversible muscular and tendon damage to all extremities.” Cruzan v. Harmon. 760 S.W. 2d 408, 411 (Mo. 1989).