CHAPTER 3

Informed Consent and Refusal

Evolution of the doctrine of informed consent
Elements of informed consent and refusal
The nature of informed consent
Exceptions to the consent requirement

Mrs. Stack is a 67-year-old woman admitted with rectal bleeding, chronic renal insufficiency, diabetes, and blindness. On admission, she was alert and capacitated. Two weeks later, she suffered a cardiopulmonary arrest, was resuscitated and intubated, and was transferred to the medical intensive care unit (MICU) in an unresponsive and unstable state. Consent for emergency dialysis was obtained from her son, who is also her health care agent. Dialysis was repeated two days later.

During the past several years, Mrs. Stack has consistently stated to her family and her primary care doctor that she would never want to be on chronic dialysis and she has refused it numerous times when it was recommended. The physician, who has known and treated Mrs. Stack for many years, also treated her daughter who had been on chronic dialysis for some time and had died after suffering a heart attack. According to the physician and the patient’s family, Mrs. Stack’s refusal of dialysis has been based on her conviction that her daughter died as a result of the dialysis treatments.

Mrs. Stack’s mental status has cleared considerably and, despite the ventilator, she is able to communicate nonverbally. Although she appears to understand the benefits of dialysis and the consequences of refusing it, including deterioration and eventual death, she has consistently and vehemently refused further treatments. Her capacity to make this decision is not now in question. Her son, however, wants her to undergo dialysis and insists, “She’s feisty and I just have to be tough with her. It’s for her own good.” He has told his mother, “If you don’t have dialysis, I’ll put you in a nursing home.” Finally, after several extended interactions with her son, the patient reluctantly agrees to undergo dialysis. How should her consent be interpreted?

What are the care team’s obligations?

Let’s face it—many clinicians and administrators are less interested than you are in the principle of autonomy or the concept of decisional capacity. What concerns them is the fact that, unless the patient or a surrogate can authorize treatment, the clinical process comes to a screeching halt. Ethics committee involvement is
frequently requested in the hope that clarifying and allocating decisional authority will get the process moving again. This brings us to the practical application of this authority.

In the clinical setting, the doctrine of informed consent is generally justified by appeal to the principle of respect for patient autonomy; as such, it is the legal and ethical embodiment of the right to self-determination in health care. Indeed, the right to determine what is done to one’s body, including the right to consent to and refuse medical treatment, is considered so fundamental that it is protected by the U.S. Constitution and state constitutions, and supported by decisions of the U.S. Supreme Court. In the informed consent process, a decisionally capable individual who understands the benefits, burdens, and risks of a proposed treatment grants explicit permission for or rejects a particular intervention.

**EVOLUTION OF THE DOCTRINE OF INFORMED CONSENT**

The legal doctrine of informed consent was initially based on the law of battery, holding that any unconsented-to touching, even to promote the patient’s well-being, constituted an unlawful act. In time, courts came to reject the rather crude notion that consent either did or did not occur. Considered more useful was the standard of negligence, which permits a more nuanced examination of whether a physician-patient discussion revealed the risks and benefits material to the patient’s decision about treatment.

By the latter part of the twentieth century, the new dynamic of more robust patient participation had introduced a somewhat adversarial tone. Some patients came to see informed consent as their offensive security against physician overreaching, while some physicians saw it as their defensive protection against charges that they provided inadequate information and an opportunity to secure liability waivers—the medical equivalent of a prenuptial agreement. As a result of liability concerns, the critical role of informed consent as the expression and protection of patient self-determination in health care decision making has been somewhat modified by its risk management function.

**ELEMENTS OF INFORMED CONSENT AND REFUSAL**

The basic elements of informed consent and refusal include

- patient decisional capacity;
- disclosure by physician(s) of sufficient information relevant to the decision in question;
- understanding of the disclosed information;
- voluntariness (in acting without compulsion or coercion), and, on the basis of these;
- communication of consent to or refusal of the proposed medical intervention.

Each of these elements is essential to the integrity of the process. For example, disclosing information about the proposed treatment is necessary but not sufficient
Informed Consent and Refusal

35

unless the information is both adequate and understood. Likewise, consent that is informed but coerced is invalid.

These elements come together in the following definition: “One can confidently presume that an act is an informed consent if a patient or subject agrees to an intervention on the basis of an understanding of relevant information, the consent is not controlled by influences that engineer the outcome, and the consent given was intended to be a consent and therefore qualified as a permission for an intervention” (Beauchamp 1997, p. 185). A more elaborated formulation includes recommendation, the physician’s obligation to go beyond mere disclosure, and authorization, the patient’s active ratification of the consent or refusal (Beauchamp and Childress 2001, p. 80). Indeed, it may be helpful and more accurate to think in terms of assisted or advised consent as the dynamic that links the physician’s disclosure and guidance with the patient’s understanding and decision making.

Capacity and Consent

As discussed in chapter 2, meaningful informed consent can only be provided by patients who are capable of making a decision about accepting or refusing the proposed intervention. Consent is more than permission to treat; it can be seen as the compact by which a capable patient voluntarily entrusts his care to a clinical professional. Capacity is the set of cognitive, volitional, and affective patient abilities that makes authentic and valid consent possible, and consent authorizes the professional to enter into and maintain the care-providing compact.

Disclosure of Information

Mr. Porter is a 52-year-old man whose advanced diabetes has resulted in decreased peripheral circulation and gangrene in his lower extremities, particularly severe in his left foot. He has worked as a mail carrier for 31 years and, he says proudly, “never missed a day.” According to his family, he has resisted seeking medical attention because of his fear that amputation would be recommended, a course he would unquestionably refuse.

It is clear to the surgeon that only amputation of Mr. Porter’s left foot will save his life, but that aggressive deep debridement (removal of dead or diseased tissue) of his right foot might possibly prevent the spread of gangrene on that side. When she approaches the patient for consent to surgery, she says, “Mr. Porter, we need to take you to the operating room to clean away all the dead tissue on your feet. If we don’t do this, the infection will continue to spread and you could die. Don’t worry, we do this all the time in cases like yours.”

What is the nature of the interaction? Has the surgeon met her professional obligation? What would be the quality of Mr. Porter’s consent?

True informed consent is impossible unless the patient can adequately evaluate his condition and has received relevant and sufficient information about the purpose of the proposed treatment; its potential benefits, burdens, and risks; treatment alternatives; and the benefits and risks of the therapeutic options. This informational imperative gives rise to the professional obligation of disclosure. The challenge to
the physician is determining what and how much information to provide, as well as how to communicate that information so that the patient understands it.

In assessing the quality of disclosure for purposes of informed consent, the courts have defined two standards—professional practice and reasonable person. A third standard—subjective—has also been advocated. These standards reflect both the legal criteria for disclosure and the underlying ethical distinctions about who determines the relevance and sufficiency of the information to be disclosed.

The traditional professional practice standard bases adequate disclosure on what the customary practice of professionals in the physician’s community would deem appropriate. This standard presumes that the physician, acting in the patient’s best interest, is in the best position to determine what information to provide. Because the determination lies with the physician, this standard, also known as the reasonable doctor standard, risks undercutting the patient’s autonomous decision making.

In contrast, the reasonable person standard holds that disclosure should be based on what a reasonable person would consider material in making this decision. This standard, which has gained acceptance in more than half of the states in the United States (Beauchamp and Childress 2009), shifts the determination of what is pertinent from the physician to the patient. In so doing, it supports patient autonomy and elevates the physician’s ethical obligation to respect it even over the obligations of beneficence.

The subjective standard looks at what this specific patient would consider material in making this decision. It is also possible to combine the reasonable person standard with the subjective standard by disclosing what a reasonable person would consider material to the decision, and then providing opportunity for this patient to ask questions of particular importance to his situation.

The core information that physicians are obligated to disclose is generally held to include:

(a) the facts about the proposed diagnostic or therapeutic intervention that patients typically consider relevant in decision making, including information about the intervention and its purpose;
(b) information about the consequences of alternatives to the proposed intervention, including nontreatment; and
(c) the physician’s recommendation about how the patient might consider the intervention’s benefits and risks.

The point of the disclosure requirement for informed consent is that the patient’s beliefs about the therapeutic interventions and their possible outcomes should be well founded. There is no simple or single formula, however, for what is necessary to make this happen in all informed consent interactions. For example, less demanding standards of disclosure may be reasonable in the context of a close and trusting doctor-patient relationship than in a relationship in which the patient and physician know little about each other (Kihlborn 2008).

Mr. Silver is a 39-year-old man with prostate cancer. Although the disease is confined to his prostate, Dr. Binder knows that, in a patient this young, the cancer is virulent and should be treated aggressively. For this reason, he strongly recommends that Mr. Silver undergo a radical prostatectomy. Mr. Silver has heard about the potential...
side effects of the surgery, including impotence and incontinence, and he insists that he prefers radiation.

Dr. Binder has explained that the chances of a long-term cure are 30% to 40% better with the prostatectomy and that any resulting problems can be surgically corrected later. Mr. Silver is adamant, however, saying, “Unless you can tell me that the odds are overwhelming that I will not be impotent or incontinent, I’ll take my chances with the radiation.” His wife has told Dr. Binder privately, “I don’t care about the side effects and he’ll get used to whatever happens. I just want him alive. We could have many good years ahead of us if he has the surgery.”

What would be the quality of Mr. Silver’s consent to the prostatectomy if he did not fully appreciate the risks? Does the physician have an obligation to Mrs. Silver that is in conflict with his obligation to his patient?

The notion of patient best interest is far from clear in this case. The conflicting potential outcomes appear to be surviving cancer with sexual and urinary dysfunction versus maintaining those functions at an increased risk of dying from cancer. Depending on their personalities, values, and notions of an acceptable quality of life, reasonable patients, families, and professionals may disagree about which option is preferable.

This case illustrates the tension between the physician’s obligation to respect patient autonomy and the obligation to promote patient best interest. Because Mr. and Mrs. Silver define best interest differently, the information Dr. Binder provides will greatly influence how they think about treatment. Mrs. Silver has very real concerns about her husband’s welfare and his decision will have a significant impact on her life, affecting the most intimate aspects of their relationship. She is hoping to influence her husband to make the choice that she believes will be better for both of them.

While Dr. Binder can and should try to convince his patient to choose the most beneficial option, he should not manipulate the decision process by withholding critical information. Ultimately, his obligation is to his patient, who, as a capable person, is in the best position to assess the facts and consequences according to his own values, beliefs, and goals, as long as he has the necessary information and recommendation. He can and should, however, encourage Mr. Silver to engage his wife in a thorough discussion of her concerns and the short- and long-term implications of his decision on his health and their relationship.

Understanding of Information

Because the content and process of informed consent should enhance the patient’s capacity to make decisions, limiting the professional obligation to mere disclosure of facts is inadequate. In addition to the provision of appropriate information by the physician, informed consent requires that it be understood by the patient or surrogate decider. Thus, the obligation has not been met unless the information is presented in ways that are educationally, linguistically, and culturally accessible to the recipients, who demonstrate that they can use it to make important decisions.

Meeting this obligation requires that the physician actively determine that the patient has understood the disclosed information. Asking the patient to repeat, even in his own words, what has been said is insufficient because it tests memory...
alone. In contrast, “Please tell me why you have decided to (or not to) have this treatment” requires the patient to explain the reasoning behind his decision, revealing misunderstandings and unrealistic expectations that can be corrected. Finally, the patient is also entitled to the physician’s clinical reasoning in the form of recommendations about the treatment options and their likely outcomes in light of the patient’s goals and values.

As discussed further in chapter 4, the patient’s understanding of the disclosed information is greatly enhanced if the discussion is conducted in his preferred language. Even patients who speak more than one language are likely to achieve greater understanding and security if they can use the language with which they are most comfortable. In these situations, it is important to secure the services of a trained interpreter, either in person or through a telephone language line, rather than relying on the patient’s family or friends. First, those close to the patient may, consciously or unconsciously, edit or soften the information in an effort to protect the patient from distressing news or for other, less compassionate reasons. Second, it is difficult to accurately translate medical terms and concepts from English to English; the process is even more formidable when the information must traverse two languages. Lest informal translators become offended, explain that both Joint Commission standards and the policies of most care-providing institutions require the use of certified or trained interpreters to ensure completeness and accuracy.

In addition, recent work in cognitive psychology and neuroscience has shown that an individual’s emotional states can affect how the information that he is given is received and processed. For example, how individuals perceive and evaluate risks associated with a particular course of action is strongly influenced by their affective reactions to the information they are given and to the person providing the information. In order to improve the quality of patient understanding, those who seek informed consent should be sensitive to the intertwined role of emotion and cognition. They should not manipulate patient emotions since this would undercut the patient’s autonomy, but should take account of how emotions can enhance, as well as diminish, his decision-making capacities (Braude and Kimmelman 2012).

Voluntariness

Mr. Jenkins is a 28-year-old man with chronic renal disease who has been on hemodialysis for several years. Despite scrupulous attention to his medication, diet, and dialysis regimen, multiple complications have led to his deteriorating condition. Peritoneal dialysis has been ruled out because prior surgeries have left abdominal adhesions. At this point, his doctors believe his only chance for improvement or even survival is a kidney transplant.

Mr. Jenkins’s immediate family consists of his pregnant wife and their 3-year-old son, his parents, his 26-year-old sister, and his 19-year-old brother. His parents and sister have been tissue typed and found to be incompatible as donors. His brother has said that, as much as he cares about the patient, he does not want to give up his football scholarship to college, which would be required if he had only one kidney.

At a family meeting, called to discuss options, Mr. Jenkins’s parents, wife, and sister pressure his brother to be tested. After 45 minutes of “How can you be so heartless?” “What is your career compared to your brother’s life?” “You’re no better than...
a murderer!” he agrees to be typed. When he is found to be a suitable donor, he says to the physician, “Now I have no choice. I have to donate or I’ll be killing my brother and my family will hate me.”

Is Mr. Jenkins’s consent the product of altruism, family persuasion, or coercion? Does the physician have obligations to Mr. Jenkins that are in conflict with his obligations to the patient? How might the ethical dilemma be resolved, and what might be the role of the ethics committee?

But wait, there’s more to consent and refusal. Genuinely voluntary decision making is both adequately informed and free of undue influence that prevents the individual’s choice from being an authentic expression of his own values and beliefs. Voluntariness refers to the individual’s independence in making decisions that are the product of information, analysis, and personal values, not influenced by threat, force, or manipulation. Independent decision making, however, is not the same as isolated decision making, which would deprive the patient of physician and family recommendations and support. Problematic influences are those that subvert autonomous action by distorting individual choice through coercion or deception.

Influences with detrimental impact on the informed consent process can come from the patient’s physician, family, or others in a position to exert compelling pressure. Voluntariness can be overtly sabotaged by relentless badgering, threats of family disruption, or emotional manipulation. An example would be, “Undergoing this treatment is the only way to save our marriage.” Voluntariness can also be undermined when the physician says, “I won’t continue to care for you if you don’t do what I say.”

What distinguishes morally problematic from morally acceptable influences is the manner in which the influence is exercised. As discussed in chapter 2, patients often turn to trusted others for assistance in making decisions, especially those with significant consequences. Interactions that provide additional information, insights, encouragement, and support may modify the patient’s choice by enhancing his decision-making powers. If, however, the influence is the product of deception that withholds or distorts information, if it denies or diminishes choice, if it appeals to fear rather than reason, even if this is not the intent, it compromises the patient’s autonomy. Continual attention to the purpose, process, and impact of external influences is necessary to preserve the integrity of the consent process.

THE NATURE OF INFORMED CONSENT
Informed Consent as an Interactive Process

The move in recent years to make consent documents more detailed and explicit is intended to make the patient better informed and avoid litigation. But their complexity often has the opposite effect, leaving patients confused, poorly informed, and alienated from the informed consent process. When it functions well, informed consent is not an event, a moment in time, a perfunctory discussion, or a signed document, but a process. Meaningful consent is voluntarily and knowledgeably given by the patient, not secured or imposed by the staff as part of an assignment. Consent is not something the physician extracts from—“You need to get consent from
Mrs. Simon”—or does to—“I consented Mr. Thomas”—the patient. This attitude violates the autonomy of the patient and makes the signed consent form a trophy rather than the documentation of a process of communication, education, understanding, and trust.

The physician should begin the process by determining what the patient knows and whether he wants to participate in decisions about his care. As noted above, language differences that may be barriers to communication should be identified and, as far as possible, corrected through the use of certified interpreters (Schenker et al. 2011; Clark et al. 2011). Lack of medical background should not be used as an excuse for withholding information from the patient but should lead to new approaches for conveying it. Ongoing discussion should confirm his decisional capacity, his preferences and values, his appreciation of his condition, and the implications of his choices. Unless and until the patient is found to lack the ability to make his own decisions or he makes a capacitated and voluntary delegation of his decision-making authority to someone else, the patient is the person with whom the physician communicates.

The informed consent process, thus, assumes greater significance than simple physician disclosure of information and patient permission for treatment. It is an interaction between patient and physician, often including the family or trusted others, which promotes the exchange of relevant information and the provision of guidance and support that facilitates effective decision making. While this process is necessary each time consent is required for an intervention, these discussions are not isolated events. As this chapter and the ones that follow demonstrate, the collaborative nature of the therapeutic relationship requires ongoing physician engagement in the decision-making process, including

- working with the patient and family to determine the goals of care based on the patient’s condition, prognosis, and health care wishes;
- developing a plan of care based on the goals that meet the patient’s medical needs and is consistent with the patient’s known wishes or the family’s informed understanding of what is best for the incapacitated patient;
- providing care that benefits the patient without imposing unnecessary suffering or prolonging the dying process, and discontinuing interventions that have not demonstrated clinical effectiveness and benefit;
- regularly providing the patient and family with sufficient information to enable them to understand the progress and purpose of treatment, and appropriately affirm or revise care goals in light of the patient’s evolving condition; and
- determining what elements of the care plan present genuine choices for patient and family decision making, and guiding and supporting those decisions.

The informed consent process as described above is a time- and labor-intensive enterprise that may strike many physicians as unnecessarily burdensome, especially in the light of growing pressures in our health care system to increase physician productivity and limit the time spent on each individual patient. No doubt, having a patient simply read and sign a document is much less time consuming than engaging in the educational and communicative process that informed consent re-
Informed Consent and Refusal

quires. An important function of your ethics committee is to reinforce the notion of authentic informed consent as a process of physician-patient engagement in pursuit of collaborative decision making.

Sharing the Burden of Decision Making

The prevailing emphasis on patient autonomy risks diminishing the importance of the caregiver role in making difficult decisions. Treatment decisions require a grasp of medical information that is often complex, as well as insight into the patient’s personal goals and values. As discussed in chapter 9, decisions about end-of-life care, in particular, are emotionally wrenching and may leave painful memories for those who make them. Both professionalism and compassion dictate that the burden of these decisions should be shared by those responsible for the care.

The suggestion is sometimes made that the full disclosure necessary for informed consent requires that physicians offer all possible treatment options for consideration. We argue that respecting patient or surrogate choice also recognizes that some care decisions, namely those that involve false choices, do not require and should not impose the burden of patient or family consent. Presenting patients and families with false choices diminishes the exercise of their autonomy and abdicates the professional’s responsibility to exercise clinical judgment. False choices are offered when patients and families are asked to approve interventions for which there are no medical alternatives or to reject interventions that have no clinical indication. For example, asking family members for consent to stop dialysis treatments for an unconscious patient who is imminently dying inappropriately shifts responsibility for clinical decision making from the treating team to the family.

Especially when reversal of or improvement in the patient’s condition is no longer possible, it is appropriate to limit the therapeutic options to those that are likely to benefit the patient. Interventions that are physiologically impossible or outside the standards of medical practice should not be proposed. These distinctions are addressed further in the discussion of medical futility in chapter 9. When specific treatments, such as dialysis, antibiotics, or vasopressors, are no longer effective, it is disingenuous and possibly cruel to present them as options and hope that patients and families will be savvy enough to refuse them, thereby making the decisions that physicians want them to make. When there are no real (i.e., medically appropriate) options, physicians can and should determine which interventions ought to be offered for consideration. This does not mean disempowering patients and families. It means assuming responsibility for making the judgments only physicians can make and then promoting the authentic choices reserved for patients and families.

Reflecting the tension between respecting patient autonomy and promoting patient well-being, physicians walk a fine line between supporting and usurping health care decision making. Patients and families depend on professional guidance in making care decisions and depriving them of clinical judgment, advice, and support is a form of abandonment. Even real choices should not be presented as value-neutral when one approach is clearly better, and physicians should be encouraged to clearly recommend what they believe to be the most appropriate course.
Guiding patient decisions should not be confused with paternalism, which de-
means the capable adult and constricts the exercise of self-determination. Yet, pa-
tients and their surrogates have different levels of comfort assuming responsibility
for treatment choices and caring physicians provide more or less structure as needed.
Recognizing this delicate balance, commentators have suggested various approaches
to providing information and decision-making support. For example, Emanuel and
Emanuel (1992) offer four models of physician-patient interaction, representing dif-
ferent degrees of control and collaboration. Ultimately, providing genuine choices
and thoughtful recommendations enhances patients’ capacity to act in ways that
promote both their autonomy and their well-being.

**EXCEPTIONS TO THE CONSENT REQUIREMENT**

The requirement for informed consent before treatment may be suspended in three
narrow circumstances.

1. *Emergency Care*—Informed consent is not required when patients are unable
to participate in care decisions, information about their wishes is not available, and
delaying treatment would place their lives or health in peril. No one would seri-
ously suggest that surgery to stop bleeding wait until an unresponsive accident vic-
tim regains consciousness and is able to provide consent or a surrogate decision
maker is located. In such circumstances, consent is presumed based on the assump-
tion that patients would want emergency treatment.

2. *Therapeutic Exception*—In very rare instances, physicians may believe that the
disclosure of information about diagnoses or prognoses will cause clinically un-
stable patients to suffer *imminent, direct, and significant harm*. *Only in these lim-
ited and extreme circumstances* are physicians justified in withholding potentially
harmful information from patients until such time as their clinical condition
permits disclosure. The reasons for withholding the information must be detailed
in the medical record and, whenever possible, the information must be disclosed to
the patient’s family or other trusted surrogate. Justifications for nondisclosure on
this basis must be carefully scrutinized to ensure that it is the patient’s well-being,
not the physician’s or family’s comfort, that is being protected. As noted in the dis-
cussion of truth telling in chapter 4, inappropriately invoking this exception to the
disclosure obligation must be avoided because it threatens the trust so essential to
the therapeutic relationship.

3. *Waiver of Consent*—Corresponding to the right of informed consent is the pa-
tient’s right not to be burdened with unwanted information or the pressure to make
decisions if he understands the consequences of giving up the opportunity to make
decisions about care. Electing not to know and delegating decisional authority to
another person can be an authentic exercise of autonomy. But there must be an af-
firmative declaration by a capacitated patient that he wishes not to be involved in
treatment decisions, such as “Talk to my daughter and do whatever she thinks is
right. She makes all my decisions for me.” The fact that he asks few questions or
says, “Don’t bother me with this now” is not the same as explicitly saying that he
does not want to know or decide. Delegation of decision-making authority is not
something that should be inferred, but something that must be confirmed. Patterns
of decision making that have been established over time may continue in the hos-
pital setting, and in some cases physicians may know enough about the patient and
his family to feel confident that the patient’s delegation is not an aberration. Even
then, clinicians should be encouraged to periodically ask capable patients, “Do you
have any questions?” leaving the door open to patient involvement in her care, how-
ever limited it might be. The right not to receive information is further addressed
in the discussion of truth telling and disclosure in chapter 4.

Returning to the case of Mrs. Stack, the 67-year-old woman with chronic renal
insufficiency, a critical element in the ethical analysis is the assessment of decisional
capacity. In her immediate post-arrest and intubated state, she clearly lacked the
ability to make decisions. Nevertheless, she was known to have had this capacity
prior to admission and, during her hospitalization, she was found to have regained
it sufficiently to understand the benefits of dialysis and the consequences of not re-
ceiving it. Because physicians are usually obligated to respect the wishes of capable
patients, determining Mrs. Stack’s decisional capacity and her wishes is of para-
mount importance.

In this case, Mrs. Stack’s primary physician and family believe that her repeated
refusal of dialysis has been based on her belief that her daughter died because of
the treatments. Thus, it may legitimately be asked whether Mrs. Stack’s reasons for
refusing are based on an adequate comprehension of the risks and benefits of di-
alysis or on misunderstanding. Some have argued that a patient’s decision to re-
fuse treatment should be discounted if it is based on irrational or false beliefs. Even
so, coercing or disregarding otherwise decisionally capable patients should be avoided
and efforts should focus on assisting them to make decisions based on accurate in-
formation and comprehension of the medical risks and benefits.

When the patient’s ability to understand her medical condition and make choices
is uncertain, consistency and durability of decisions can often substitute for capac-
ity. Mrs. Stack’s refusal of dialysis has been consistent over time, an important fac-
tor in assessing the quality of her decision making. While her refusal may be based
on a misunderstanding, this durability indicates that she is comfortable with her
position and speaks in favor of respecting her choice.

The patient’s son threatens her with nursing home placement if she refuses
dialysis—an odd ploy because she is not likely to survive for long without the treat-
ments. Despite the possibility that he has pressured her into accepting treatment,
some types of influence are ethically acceptable because they do not rise to the level
of coercion, or objectionable manipulation. Therefore, even if the son persuades his
mother to change her mind, it does not necessarily invalidate her decision to ac-
tcept dialysis unless his strategy appears to be more threat than persuasion. Care-
givers should confirm the patient’s change of mind and satisfy themselves that it is
truly informed and voluntary. One approach is to observe discussions between the
patient and her son, if they do not object. Another safeguard is to review Mrs. Stack’s
decision with her when her son is not present.

This chapter has discussed informed consent and its rationale in providing
ethical as well as legal authorization for the physician to treat. In contrast, assent, a
notion with particular relevance in pediatrics, reflects the patient’s agreement with
a treatment plan rather than *authorization* of it. Only when the conditions of informational disclosure, understanding, and voluntariness have been met in the context of decisional capacity can the patient’s consent or refusal be considered truly informed and authentic.

**REFERENCES**


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