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# 3 Informed Consent and Refusal

*Evolution of the doctrine of informed consent*
*Elements of informed consent and refusal*
*Capacity and consent*
*Disclosure of information*
*Voluntariness*
*The nature of informed consent*
*Informed consent as an interactive process*
*Sharing the burden of decision making*
*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 proxy 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 have to 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—most 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 exercise of autonomy is most fully realized in the doctrine of informed consent and refusal, 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—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 modified by its risk management function.



## ELEMENTS OF INFORMED CONSENT AND REFUSAL

The basic elements of informed consent and refusal include

- decisional capacity
- disclosure by physicians of sufficient information relevant to the decision in question
- understanding of the information disclosed
- 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 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, the relationship between consent and decisional capacity explains the informed consent and refusal process that is so central to the patient-physician interaction. 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 lends authenticity and validity to the consent and 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 thirty-one 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 the benefits, burdens, and risks of the therapeutic options. Accordingly, respecting the patient's rights of self-determination requires that he have access to relevant and sufficient information, which gives rise to the professional obligation of disclosure.

The challenge to the physician is determining *what* and *how much* information to provide. 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 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 somewhat paternalistic 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 is accepted in a minority of states, 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.

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 people who will have to use it to make important decisions. Finally, the patient is also entitled to the physician's judgment in the form of recommendations about the clinical options and their likely outcomes in light of the patient's goals and values.

Thus, the core information that physicians are obligated to disclose is generally held to include

- the facts about the proposed diagnostic or therapeutic intervention that patients typically consider relevant in deciding whether to consent
- information about the intervention and its purpose that the physician considers important to the patient's decision
- information about the consequences of nontreatment and alternatives to the proposed intervention
- the physician's recommendation about how the patient might consider the intervention's benefits and risks

III 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 percent 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.

### 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' 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' parents, wife, and sister pressure his brother to be tested. After forty-five 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' 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 autonomous decision making is both adequately informed and free of undue influence that corrupts the authenticity of the choice. 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 problematic from beneficial influences are the quality, intent, and manner of the attempt to alter the decision. Interactions that provide additional information, 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, it is likely to be controlling rather than supportive action. 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

By its nature, true informed consent is a process, not a moment in time, a perfunctory discussion, or a signed document. 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 or does to the patient—"You need to get consent from Mrs. Simon" or "I consented Mr. Thomas." 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. 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, that 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/or 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 meets 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
- regularly providing the patient and family with sufficient information to enable them to understand the progress and purpose of treatment, and appropriately revise care goals
- determining what elements of the care plan present genuine choices for patient and family decision making, and guiding and supporting those decisions

### 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 often complex medical information, as well as insight into the patient's personal goals and values. As discussed in chapter 6, decisions about end-of-life care, in particular, are emotionally wrenching and their memory is long-lasting. Both professionalism and compassion dictate that the burden of making them 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 *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 reject interventions that have no clinical indication.

When reversal of or improvement in the patient's condition is no longer possible, it is appropriate to limit the therapeutic options to those with likely benefit. 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 6. When specific treatments, such as dialysis, antibiotics, or vasopressors, are no longer effective, it is disingenuous to present them as options and hope that patients and families will be savvy enough to make the decisions that physicians already know they want. When there are *no real options,* physicians can and should determine *which interventions should be offered for consideration.* This does not mean disempowering patients and families. It means assuming the 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 can be seen as 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 demeans the capable adult and constricts the exercise of self-determination. Yet, patients 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 different 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 seriously suggest that surgery to stop bleeding wait until an unresponsive accident victim regains consciousness and is able to provide consent. In such circumstances, consent is presumed based on the assumption 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 unstable patients to suffer immediate, direct, and significant harm. *Only in these limited 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 comfort, that is being protected. As noted in the discussion 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 patient'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 affirmative declaration by a capacitated patient that he wishes not to be involved in treatment decisions. 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. The right not to receive information is further addressed in the discussion of truth telling and disclosure in chapter 4.

Thus, effective consent provides 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.

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 postarrest 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 receiving it. Because physicians are usually obligated to respect the wishes of capable patients, determining Mrs. Stack's decisional capacity and her wishes is of paramount 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 dialysis or on misunderstanding. Some have argued that a patient's decision to refuse treatment should be discounted if it is based on emotional, irrational, or false views. In general, however, coercing or disregarding otherwise decisionally capable patients should be avoided and efforts should focus on assisting them to make decisions based on accurate information 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 capacity. Mrs. Stack's refusal of dialysis has been consistent over time, an important factor 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 treatments. 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. Therefore, even if the son persuades his mother to change her mind, it does not necessarily invalidate her decision to accept dialysis. Caregivers 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.

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# 4 Truth Telling: Disclosure and Confidentiality

*Justifications*
*Disclosure*
- *Ethical obligation*
- *Arguments for disclosing information*
- *Conflicting obligations*
- *Arguments for not disclosing information*

*Disclosure of adverse outcomes and medical error*
- *Adverse outcomes and medical error*
- *Scope of disclosure*
- *Obligation of disclosure*
- *Barriers to disclosure*

*Confidentiality*
- *Justifications for protecting confidentiality*
- *Barriers to confidentiality*
- *Justifications for breaching confidentiality*

Arguably, the most valuable health care resource is information. Clinicians depend on its accuracy in making their diagnoses and prognoses. Patients rely on its adequacy in evaluating their options and arriving at their decisions about care. Families wait for news of their loved ones' changing conditions.

But beyond lab data and examination findings, clinical information defines the very nature of the therapeutic relationship, involving notions of self-image, privacy, autonomy, power, and trust. How clinical information is elicited, protected, and shared is a matter of ethical concern for professionals, especially when their obligations conflict.

The idea that care professionals should tell their patients the truth seems self-evident and uncontroversial. Previous chapters have devoted considerable space to the discussion of the importance of *informed* decision making and the trust that is so central to the therapeutic relationship. Like most other aspects of the clinical interaction, however,