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2

Decision Making and Decisional Capacity in Adults

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III Mrs. Klein is an 89-year-old woman admitted from home five days ago with cellulitis of the legs. Despite her discomfort, she has cooperated with her diagnostic work-up and treatment and consented to all interventions related to the cellulitis. She was able to provide accurate information about her medical history, which was corroborated by her niece. According to both women, Mrs. Klein has been very healthy and self-sufficient all her life, a state she attributes largely to “keeping my distance from doctors and hospitals.” Her goal, expressed repeatedly since admission, is “to go home and take care of my cats.”

Mrs. Klein's admission blood tests revealed anemia that suggests slow internal bleeding. Despite repeated attempts to explain the dangers of unchecked bleeding and the importance of identifying the source, she has consistently refused consent for a GI series. When asked why she is opposed to a diagnostic work-up, she replies, “Darling, you look, you'll find. No more tests or treatments. Just get me back on my feet so I can go home to my cats.”

After several days, the attending physician requests a psychiatric consult to do a capacity

assessment, suggesting that the patient is not capable of making decisions in her best interest and cannot be discharged under these circumstances.

Why does no one question Mrs. Klein's capacity to consent to treatment, only her capacity to refuse?

We now embark on a discussion of the issues most frequently brought to ethics committee attention—how and by whom health care decisions are made. Ethical principles require that decisions about care and treatment be made by the decisionally capable patient (the subject of this chapter), following adequate discussion of the benefits, burdens, and risks of the therapeutic options (the subject of the following chapter). When the patient is not able to participate in this process, the responsibility for making care decisions must be assumed by others.

The quality of the decision-making process and the validity of the resulting consent or refusal are directly related to the clarity of physician-patient communications; the patient's understanding of the information presented; the physician's attention to patient values and preferences; and the patient's trust in the physician that encourages questions and full discussion. Although decisional capacity and consent are thus inextricably linked, for logistical purposes they are discussed separately in this curriculum. This chapter examines decision making and capacity, while chapter 3 sets out the ethical basis and significance of the consent process.

HEALTH CARE DECISIONS AND DECISION MAKING

Health care in general and bioethics in particular deal with decisions requiring attention to patient needs and preferences in the context of medicine's capabilities and limitations. These decisions involve deeply personal ideas about life and death; the meaning of health, illness, and disability; and the importance of self-image, self-determination, and trust. While the patient has the greatest stake in these decisions, others, including family members and care professionals, bring their perceptions and concerns to the discussion. Indeed, it is the value- and interest-based nature of care decisions that makes them so complex and often difficult to negotiate.

DECISION-MAKING CAPACITY

It is tempting to suggest that, like obscenity, decisional capacity is something that cannot be precisely defined but we know it when we see it. While we may sense that a patient is or is not able to make decisions, intuition is not enough to guide an evaluation with such important implications. In the health care setting, the exercise of autonomy is promoted or hindered by the assessment of decisional capacity, which effectively includes or excludes patients from making decisions about their care. Determining the patient's ability to understand the issues, consider the consequences of different op-

tions, and communicate these thoughts to professionals is key to supporting autonomy. Without this set of cognitive capacities, patients will need assistance in making and articulating choices. Indeed, as noted below, even capable patients can benefit from assistance in making autonomous decisions. Excluding a decisionally capable patient from making choices violates autonomy; treating an incapacitated patient "as if" she were capable makes her vulnerable to the consequences of deficient decision making. Thus, the clinical assessment of decisional capacity is critical to determining whether the patient can participate in care decisions and provide informed consent and refusal.

Capacity and Competence

Although the terms *capacity* and *competence* are often used interchangeably, in the health care setting there are important distinctions that go beyond semantics. Competence is a *legal* presumption that a person who has reached the age of majority has the requisite cognition and judgment to negotiate most *legal* tasks, such as entering into a contract, making a will, or standing for trial. Incompetence is a functional assessment and determination by a court that, because the individual lacks this ability, she should be deprived of the opportunity to do certain things. Because the legal system is and should be rarely involved in medical decisions, it is customary to refer to the patient's decisional capacity, a *clinical* determination about the ability to make decisions about *treatment or health care*.

Elements of Decisional Capacity

Decisional capacity refers to the patient's ability to perform a set of cognitive tasks, including

- understanding and processing information about diagnosis, prognosis, and treatment options
- weighing the relative benefits, burdens, and risks of the therapeutic options
- applying a set of values to the analysis
- arriving at a decision that is consistent over time
- communicating the decision

Decisional capacity thus encompasses several skills, including understanding, assessing, valuing, reasoning, and articulating the factors relevant to a choice. Capacity can be seen as an index of a person's *ability* to exercise autonomy by making decisions that reflect personal preferences, values, and judgments at a given time. This is not the same, however, as the person's *willingness* to make autonomous decisions. Having capacity *enables* but does not *obligate* patients to act independently. Despite our good intentions, we cannot drag people kicking and screaming into self-determination and, in many instances, insisting that patients make decisions abandons them to their own autonomy.

Frequently, capacitated patients look to family, friends, and trusted others to help

them exercise autonomous decision making. Patients demonstrate *supported* autonomy when they rely on others for advice in making choices (“I want my son to help make the decision”). Some patients, especially those who are elderly or from cultures in which self-determination is not a central value, demonstrate *delegated* autonomy. These patients often entrust to others the authority to make decisions on their behalf (“Talk to my daughter and do whatever she thinks is right”). Here, autonomy is expressed in the voluntary choice to delegate rather than independently exercise decision-making authority. Patients with capacity who benefit from the advice, guidance, and support of clinicians and trusted others can be said to demonstrate *assisted* autonomy. The ethics committee can perform a useful service by clarifying for the care team—through clinical consultations, in-service presentations, or informal conversations—the several ways in which patients can make authentic decisions.

Decision-specific and Fluctuating Capacity

Capacity is not global, but decision-specific, referring to the ability to make *particular* decisions. A patient may have the ability to decide what to have for lunch but may be incapable of weighing the pros and cons of surgery. For this reason, nothing is less helpful than a chart note that says, “Patient lacks capacity to make decisions.” The misleading implication is that the patient lacks the capacity to make *all* decisions, effectively excluding her from making *any* decisions.

In fact, many patients have the capacity to make some decisions and not others. For example, a lower level of capacity is required to appoint a health care proxy agent (appreciation of the likelihood that someone will have to make decisions on her behalf and consistent designation of the same person) than to make the often complex decisions the proxy agent will eventually make. Thus, the appropriate response to the question, “Does this patient have capacity?” is “For what decision?” Likewise, a request for a capacity assessment is most helpful when it specifies the decision(s) at issue, such as “Please evaluate the patient’s capacity to make decisions about discharge.” Distinguishing among the specific decisions facing the patient and assessing her capacity to make them offers her the opportunity to make the widest range of choices within her ability.

Just as capacity is not global in its application to all decisions, it is not always constant. Depending on their age, cognitive abilities, clinical condition, and treatment regimen, patients may exhibit fluctuating capacity, demonstrating greater ability to make decisions at some times than others. For example, elderly patients, who are especially prone to “sundowning,” often exhibit greater alertness, sharper reasoning, and clearer communication earlier in the day. Recognizing this tendency allows care providers to approach patients for discussion and decisions when they are at their most capacitated, thereby increasing their opportunities for autonomous action.

To return to the case of Mrs. Klein, the 89-year-old patient with cellulitis of the legs, a

critical threshold question is whether, in making a decision to refuse the diagnostic work-up and return to her home, the patient is exercising decisional capacity. If her decision is an informed and voluntary one that appreciates the implications and accepts the consequences, it should be honored, despite the caregivers’ concerns that it is not in her best interest. Nevertheless, efforts to persuade her to reconsider and consent to suggested treatments are still appropriate, especially if the potential risks of nontreatment and the benefits of treatment are significant.

Disagreement with medical recommendations is not by itself evidence of a lack of decisional capacity. Mrs. Klein’s decision may be foolish and ill advised, but it is not necessarily the product of a misperception or delusion. Continued discussion will be necessary to confirm her understanding and the consistency of her decision with characteristic behavior and prior choices. She has led an independent life that she attributes partly to avoiding doctors and hospitals. Her present decision to refuse the work-up, therefore, conforms to a pattern of life choices that, until now, have served her relatively well.

Care providers, including health care institutions, have an ethical and legal obligation to arrange for a safe discharge for their patients. Ethical concerns arise when capable patients make decisions that run counter to their best medical interests. Here, clinicians’ obligations to respect patient autonomy may be in tension with their obligation to promote Mrs. Klein’s well-being and protect her from harm.

One way to address these conflicting obligations is to ensure that, when capable patients are discharged, especially under less-than-optimal circumstances, they are encouraged to accept appropriate nursing and other home care services. In contrast, allowing patients who lack capacity to elect an unsafe discharge is a form of patient abandonment. Whatever the patient’s level of decisional capacity, involved family should be encouraged to participate in discharge planning, follow-up care, and advance care planning for future health care decision making.

Intervention by the bioethics consultation service or committee is often requested in cases of uncertain patient capacity, usually when questions arise about consent for or refusal of recommended treatment. These issues and the role of ethics intervention in resolving them are discussed further in chapter 3.

ASSESSMENT AND DETERMINATION OF CAPACITY

III Mr. Herbert is back again. He is a 38-year-old man who is confined to a wheelchair because of bilateral amputations resulting from untreated leg ulcers. Mr. Herbert has had multiple admissions to treat his repeatedly infected areas of skin breakdown. Once the wounds have been cleaned and repaired and the infection is under control, he signs himself out against medical advice (AMA) to return to his fifth-floor walk-up apartment, where he has a thriving business dealing street drugs. He insists that, with his buddies to carry him up and down and

his girlfriend to help him with meals and activities of daily living (ADLs), he can manage just fine. He acknowledges that his recovery might be better if he remained in the hospital longer or if he came to the clinic regularly, but, if he is not home, his business will be picked up by other dealers. He insists that he is willing to risk future infections, although he is confident that "you guys will always get me back on my game." Nevertheless, each time he returns, he is in worse shape and it is harder to resolve his medical problems.

The Importance of Determining Capacity

Decisional capacity requires more than the ability to articulate choices. As discussed in chapter 5, young children can be very vocal and sincere in expressing their wishes, but their choices would not be considered thoughtful judgments. The obligation to respect autonomy and the integrity of the informed consent process depend on the patient's ability to understand the facts and appreciate the consequences of treatment options. The presumption is that adult patients have the requisite capacity and, absent contrary evidence, decisions about treatment and nontreatment defer to patient wishes. Moreover, this deference usually extends to all capacitated decisions, including those that providers may think reflect poor judgment or are not in the patient's best interest. Yet troubling and potentially harmful decisions, such as patient rejection of recommended care, must be carefully explored because they may well reflect misunderstanding and lack of trust, rather than informed and considered choices.

III Mrs. Rodriguez is a 69-year-old woman transferred from a nursing home in a semicomatose state and respiratory failure. She was admitted to the intensive care unit (ICU) and intubated to provide ventilatory support. Her multiple medical problems include congestive heart failure, non-insulin-dependent diabetes, and several prior episodes of pneumonia.

After several weeks, the care team recognized that Mrs. Rodriguez would not be able to breathe without ventilatory assistance and recommended that a tracheotomy be done to promote safety and comfort. Because she was still unresponsive, the procedure was explained to her daughter, who provided consent. The next day, Mrs. Rodriguez unexpectedly became more alert and responsive. The critical care resident expressed concern because he believed the patient was indicating opposition to the tracheotomy.

The ear nose and throat (ENT) attending argued that the endotracheal tube made it impossible to determine what, if anything, the patient was trying to communicate and, in any event, she did not have the capacity to make decisions about her care. He insisted that the trach, which would be in the patient's best interest, be performed in accordance with the daughter's consent. The critical care attending asked Mrs. Rodriguez a series of yes-no questions that she could answer by nodding or shaking her head. Her nonverbal but consistent responses, which indicated that she understood the purpose of the tracheotomy and agreed that it should be performed, were considered a ratification of the consent provided by her daughter.

Would Mrs. Rodriguez's capacity have been considered sufficient for her to consent to the tracheotomy without her daughter's involvement? Why might a higher level of capacity be required for her to refuse the procedure?

One useful strategy for approaching decisional capacity is a sliding scale, which assesses the required level of capacity according to the seriousness of the decision. As the risks associated with a decision increase, the level of capacity needed to consent to or refuse the intervention should also increase. For example, a decision about whether to go to physical therapy before or after lunch carries a low risk of harm. This decision could safely be made by a patient with diminished capacity because the consequences of either choice are relatively benign. In contrast, a decision about whether to undergo a life-saving amputation or enroll in an experimental trial of chemotherapy requires the ability to understand and weigh the significant benefits, burdens, and risks of the proposed intervention. Asking a patient with uncertain capacity to take responsibility for a choice this serious would abandon her to the consequences of her deficient decisional ability. Clinically, the sliding scale provides heightened scrutiny when the potential outcomes of decisions require clinicians to be confident that patients fully appreciate the implications of their choices. Mrs. Rodriguez's low level of capacity was considered sufficient to ratify her daughter's consent because she concurred with the plan her care professionals and family agreed would benefit her. If she had refused the recommended procedure, however, it is likely that further assessment of her decisional capacity would have been indicated.

The danger in the sliding scale approach is that of paternalism, the tendency to treat otherwise capable adults as though they were children in need of others to make decisions for them. While it is not necessary that the family and care team agree with the patient's decision, choices considered irrational or harmful to the patient are likely to be challenged or at least closely scrutinized to protect incapable and, therefore, vulnerable patients from making decisions not in their best interest. The fact is, we only question the capacity of people who do not agree with us. Think about it—when was the last time you saw a capacity consult called to evaluate a patient who had just agreed with the doctor?

Capacity assessments, therefore, require a conscious effort to look beyond the decision we would make for ourselves or even recommend for the patient. If we focus exclusively on the *content* or the *outcome* of the decision rather than the decision-making *process*, we risk disempowering people who make risky or idiosyncratic choices. An important safeguard is assessing the decision in terms of *how* it is made, evaluating the patient's ability to manage the several skills required for capable decision making. Likewise, it is necessary to distinguish *questioning capacity* and *finding incapacity*. While treatment refusals or other questionable decisions may *trigger* a capacity assessment, they do not automatically *confirm* incapacity.

Who Assesses Decisional Capacity?

Given the importance of assessing decision-making capacity, the desire for a precise method of measurement is understandable. Unfortunately, it's not that simple. Decisional capacity is an index of patient ability to make decisions and, therefore, involves cognitive processes. Nevertheless, its assessment requires more than a test of mental acuity or a psychiatric exam. The Mini Mental Status Exam (MMSE), often used to evaluate cognitive ability, is useful in gauging "orientation of the subject to person, place, and time, attention span, immediate recall, short-term and long-term memory, ability to perform simple calculations, and language skills" (Lo, 2000, pp. 84–85). The MMSE is less helpful, however, in assessing an individual's ability to understand, weigh alternatives, and appreciate consequences—the skills required for capacitated decision making. This evaluation is more effectively done through one or more discussions that reveal the patient's grasp of the decision's context and implications.

Likewise, simply calling a psych consult does not get the job done. While psychiatric consultation may be helpful in assessing decisional capacity, it is not always necessary or sufficient. To be sure, psychiatric intervention can be invaluable in engaging patients in discussion, eliciting and interpreting their concerns, and identifying mental illness, cognitive impairments, and interpersonal conflicts that can mask or interfere with decisional capacity. Even a skillful psychiatric consultation, however, captures only a snapshot of the patient's thinking at a specific moment rather than over time. Ultimately, the clinicians who observe and interact with the patient day to day—especially nurses, residents, and medical students—may be better positioned to evaluate the quality and consistency of the patient's decision-making ability. For this reason, assessing decisional capacity should be considered part of the clinical skill set of care professionals and the responsibility of the medical team. Reinforcing this aspect of the caregiver role can be a valuable ethics committee function.

DECIDING FOR PATIENTS WITHOUT CAPACITY

Usually, health care decisions are made by capable patients with the advice and support of their caregivers and families. Frequently, however, treatment decisions must be made for patients who lack the capacity to make decisions for themselves. These may be persons who were formerly but are no longer capacitated or individuals, such as newborns or the severely retarded, who never had an opportunity to form values or preferences.

Making medical decisions for others raises a series of questions involving the patient's clinical needs and treatment options, what is known of the patient's care wishes, and the appropriate delegation of decision-making authority. Answering these difficult questions is often complicated by disagreements between and among the patient's family and care providers. Mediating these conflicts and facilitating decision making

for incapacitated patients are among the most frequent and effective interventions by the ethics committee. The theory and skills important to clinical consultation are discussed at greater length in part II.

Standards of Decision Making

The standards of health care decision making rely on the patient's voice as the central and most authentic source. When that voice is temporarily or permanently unavailable, those who act on behalf of the patient have only indirect access to her wishes and values. Three standards are customarily invoked in an attempt to get as close as possible to what would be the patient's decision, each concentric circle drawing on less direct information from the patient.

- Prior explicit articulation is the previous expression of a capacitated person's wishes, the most reliable information about her preferences. "*What do we know about this person's wishes based on what she has said or written?*"
- Substituted judgment is a decision by others based on the formerly capacitated person's inferred wishes. "*Knowing what we know about this person's behavior, values, and prior decisions, what do we think she would want in these circumstances?*"
- Best interest standard is used to arrive at a judgment based on what a reasonable person in the patient's situation would want. This standard is used when the incapacitated person never had or made known treatment wishes and her preferences cannot be inferred. Others weigh the benefits and burdens to the patient of a proposed intervention or care plan. "*What do we believe would best promote this person's well-being in these circumstances?*"

Decision Making for the Formerly Capacitated

The notion that only the explicit statement of a capable patient can inform treatment decisions has proved to be double-edged—both a protection of the patient's right to consent or refuse and a barrier to decision making when the patient's wishes are unknown or inaccessible. Among the clinical setting's greatest challenges is the patient who was formerly but is no longer capable and/or communicative, making it difficult to determine or honor her wishes. In this category are the elderly demented and patients of any age with terminal illness or irreversible injury that has impaired their decision-making ability. In response to the needs of the formerly capacitated, two approaches that invoke the three decision-making standards have developed—advance directives and surrogate decision making.

Advance Directives

III Mrs. Stern is a 74-year-old woman admitted from home for surgical repair of a hip fracture. Although she is in the early stages of dementia and has mild coronary artery disease, she has

been healthy and fairly independent until her recent fall. She has lived alone since her husband's death three years ago, but her daughter, Mrs. Keller, lives nearby and they either visit or speak daily.

On admission, despite her considerable discomfort, Mrs. Stern was alert, understood her medical condition, and was able to provide consent for the surgery. During the postoperative period, however, she has been increasingly agitated and confused. When recent blood tests indicated anemia, she was unable to discuss the need for a transfusion. She asked that the doctors talk to her daughter, who provided the necessary consent.

Mrs. Stern is scheduled to be discharged to a nursing home for rehabilitation in preparation for her eventual return home. She is expected to make a good recovery from her surgery and should be able to resume her normal activities with some assistance. Her doctors anticipate that, once she is in familiar surroundings, she will be less agitated and confused. Because her dementia is likely to progress, however, she will find it increasingly difficult to make independent decisions, including those related to her health care. For that reason, the care team is encouraging the execution of an advance directive that will enable care decisions to be made on her behalf when she is no longer able to make them herself.

If Mrs. Stern is determined to lack the capacity to make care decisions, is she capable of executing an advance directive? Would different levels of capacity be required to execute a living will and appoint a health care proxy agent?

Advance directives are legal instruments intended to secure an individual's ability to set out prospective instructions regarding health care. Conceived during the 1970s, they responded to the concern that patients who were unable to speak for themselves might be subjected to unwanted medical interventions, especially at the end of life. The 1990 federal Patient Self-Determination Act (PSDA) requires any health care facility receiving federal funds to offer patients the opportunity to execute advance directives and assistance in doing so. Although all fifty states have statutory and/or case law governing advance directives and all states honor them, their standards and restrictions differ. While advance directives are helpful whenever substitute decision making is required, they are most often invoked in making decisions at the end of life. For that reason, they are discussed further in chapter 6.

Advance directives commonly come in two varieties—living wills and health care proxy appointments. In different ways, they provide direct expression of the patient's wishes, enabling caregivers to rely on the most immediate of the decision-making standards. The living will is a written set of value-neutral instructions about the particular medical, surgical, or diagnostic interventions the individual *does* or *does not* want under particular circumstances, usually at the end of life. The structure of the document generally has a trigger phrase, such as, "If I am in an irreversible coma, . . ." or "If I am unable to recognize or relate to my loved ones and my doctors say that I will not recover, . . ." followed by the list of instructions related to the specified circumstances.

Patient wishes may also be communicated orally when the patient is unable to

execute a written document. In these instances, the patient's verbally expressed instructions can be documented by a health care provider or other individual. If properly documented and witnessed, these statements are considered formal advance directives in several states.

Because the living will presents the explicit articulation of the patient's prior capacitated wishes, it can provide helpful guidance to family and clinicians about what she would want in the current circumstances. It is significantly limited by the fact that it is a static piece of paper written when the person could not accurately anticipate her future medical condition. In addition, these documents do not always mean what they say. The person whose living will says, "I don't ever want to be on a respirator" probably does not mean, "I don't want to be on a respirator for four hours if it gives me ten more years on the tennis court." What she probably means is, "I don't want to live out the rest of my life on a respirator." But living wills typically do not provide for that kind of nuance. Finally, this type of advance directive usually refers only to end-of-life care. The result is a set of instructions that reflect what the patient *believed* and *tried to communicate* at a particular time about what she *thought she would want* under different circumstances at a later time. Because of their limitations, living wills are most useful for someone who does not have trusted friends or family to make decisions in the event of her incapacity.

The preferred advance directive is the health care proxy, sometimes called a durable power of attorney for health care decision making. This document enables a capable individual to legally appoint another person—an agent—to make health care decisions on her behalf after capacity has been lost. The agent is authorized to make any and all health care decisions the individual would make, not just those about end-of-life treatment.

The health care proxy is recommended over the living will because it authorizes decision making in the event of temporary or permanent incapacity and permits greater flexibility in responding to unanticipated or rapidly changing medical conditions. The agent is generally required to honor the patient's previously expressed wishes in making care decisions. If those instructions do not apply to or are inconsistent with the patient's current health needs, however, the agent is empowered to use his knowledge of the patient's wishes, values, and decision history to exercise substituted judgment in making choices that promote the patient's best interest. This scope of authority presupposes a patient-proxy relationship characterized by trust, familiarity with the patient's wishes and values, and the agent's willingness to exercise judgment and make hard decisions in the patient's interest.

Mrs. Stern is a good example of a patient who lacks the capacity to make health care decisions, yet is capable of appointing a trusted person to make decisions for her. Her current illness and hospitalization have exacerbated the agitation and confusion of her early-stage dementia, making it difficult or impossible for her to understand and decide about her medical treatment adequately. Moreover, she does not want to assume this responsibility, preferring to delegate decision-making authority to her daughter.

Thus, while she may not have the capacity to make decisions about her current treatment or articulate instructions about future care in a living will, she does understand the notion that someone will have to make decisions for her and she consistently designates the same trusted person for that task, meeting the criteria for health care proxy appointment.

Deciding for Patients without Capacity or Advance Directives

Advance directives appear to provide all the authorization and safeguards necessary to communicate and implement prior care wishes effectively. You might reasonably think that every capable person would have one. Unfortunately, you would be wrong. Even though people are encouraged to express their health care preferences prospectively through the designation of a health care agent or the execution of a living will, only 15 to 25 percent of adults in the United States have an advance directive. Thus, decisions for most patients who lack capacity are made by unofficial surrogates—people who assume the decision-making role without specific legal appointment or the guidance of documented patient wishes. In some states, a surrogate's authority to make health care decisions for someone else may be based on statutory or case law. More often, an informal surrogate is asked by the medical team to participate in making treatment decisions. The people who fill this void and act on behalf of incapacitated patients include family, close friends, trusted others. In their absence, care providers and courts, who are essentially strangers to the patients, may assume this responsibility.

Without the patient's explicit instructions in an advance directive, health care decisions made by surrogates are necessarily based on the remaining two decision-making standards—either substituted judgment (when the patient's wishes can be inferred) or the best interest standard (when the patient did not have or did not articulate treatment preferences). Clinicians and families of patients unable to participate in care discussions or decisions work to determine a course that meets medical, legal, and ethical imperatives. Goals and plans of care are considered in light of the patient's condition and prognosis, the benefits, burdens, and risks of the therapeutic options, and what is known about her wishes or best interests. Depending on the laws of the state in which the patient is treated, family and trusted others may have greater or lesser latitude in drawing on their knowledge of and concern for the patient in making decisions on her behalf. In helping to guide substitute decision making, ethics committee consultants need to be familiar with the scope of authority that their states accord to informal surrogates.

Decision Making for Patients Who Never Had Capacity

Those who never had the opportunity or ability to form values or preferences include newborns and severely retarded adults. As discussed in chapter 5, decisions for the endangered or profoundly disabled newborn are almost always made by the parents who are presumed, by tradition and law, to act in the best interests of their child.

However, courts tend to override parental refusals of specific life-saving interventions, especially if the child can be returned to reasonable health.

Mentally retarded adults, like infants and young children, are considered to need decision making by others because they are and have always been incapable of reasoned judgment. As in the case of salvageable newborns, courts tend to overrule requests to withhold or terminate beneficial treatment.

Addressing the needs of never-capacitated patients does not raise the question, "What does or did this person want?" Because there is no way of knowing what these individuals would have wanted and there is no history of past decision making to use as a guide, the best interest standard is invoked to inform care decisions on their behalf. In these instances, the analysis is based on the objective assessment of what would be most likely to benefit or promote the well-being of a hypothetical patient in the same circumstances, similar to the legal reasonable person standard discussed in chapter 3. In the clinical setting, the best interest standard might consider mitigating pain and suffering, prolonging life, restoring and enhancing comfort, and maximizing the potential for independent functioning.

Sometimes, in an attempt to represent the patient's interests, care providers and surrogates create what amounts to a fiction of substituted judgment. For example, they might ask, "What would this imperiled newborn or profoundly retarded adult want if he could want anything?" Careful review of the decision-making standards reveals the fallacy in this approach. Precisely because this patient has no history that would permit inference about his wishes, substituted judgments cannot be made. Rather, decisions on his behalf must be based on the best interest standard, drawing on what *others* believe would be best for him.

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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

III 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