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e-Ethics, 2000 November

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Daisy's Dilemma: Assessing Decisional Capacity

Daisy is a fifty-eight-year-old diabetic with complications, including amputated forefeet. A dialysis patient for five years, she also has coronary artery disease. Daisy is now an inpatient because of a gangrenous left foot. Surgical and infectious disease consultants recommend a below-knee amputation. In her first conversation with the surgeon, Daisy refuses the operation. She recognizes that death may ensue but asserts her belief that God will perform a miracle, a perspective her only daughter supports. In a subsequent conversation, Daisy appears disoriented, repeatedly asking why she is in the hospital. But later that same day she lucidly discusses the risks of foregoing surgery with her nurse, reiterating that she is "in God's hands."

Advocate's commitment to equality (respecting the integrity and dignity of all people) affirms the fundamental moral principle that patients have a right to accept or refuse treatment. However, consent and refusal are meaningful only if they reflect considered choice by patients who understand their options and can assert their preferences freely. Therefore, Daisy's physician should evaluate whether she is capable of making this decision.

Generally, all patients eighteen and above are presumed to have capacity to opt for or against med-

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ical therapy. In Illinois, when a patient's decisional faculties are questioned, it is the attending physician's responsibility to evaluate capacity and appropriately document that assessment in the medical record. Psychiatric or psychological consultations may be helpful in particular cases but are not required to render medical judgments about decision-making capability.

Capacity includes the patient's ability to assert goals and values, understand information, communicate, and weigh options before making a decision. Incapacity means that the patient is too impaired in one or all of these qualities to make a meaningful choice.

Decisional capacity differs from legal competence, a judicial determination primarily concerned with property and legal rights. In health care, capacity relates to the patient's medical condition and the necessary treatment decisions. Therefore, the fact that Daisy cannot manage her finances does not

necessarily mean she cannot decide whether to undergo surgery. However, the complexity of treatment options is relevant, since a patient may be able to make some medical choices (such as whether to have a sonogram) but not others (undergoing bypass surgery).

Daisy's refusal of the amputation may well be questioned. Caregivers, however, should not automatically equate noncompliance with impaired decisional ability. Capacity should not be judged according to what most patients choose, what a patient's family wants, or what health providers think is right. Some patients with capacity will exercise personal or idiosyncratic beliefs to make decisions that go against family preferences or medical advice.

The ability to make decisions may be compromised by deliberate or unintentional coercion. A patient may be cognitively intact but unduly influenced by circumstances, family desires, or the values of the health care team. Patients who appear to have some cognitive impairment, like Daisy, may be particularly susceptible to manipulation. For example, a patient may refuse a procedure he wants in order to avoid burdening family, or he may consent to surgery he does not desire in order to be a good patient. During the informed consent process,

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associates should therefore attend not only to patients' intellectual understanding, but also to their particular reasons for refusing or consenting to treatment.

In the process of making medical recommendations, health professionals should verify that patients understand their options, including potential outcomes of acting against medical advice. Reasonable attempts to persuade a capable patient to comply with recommended treatments are acceptable, but information should not be distorted or withheld in order to influence that patient's decision. And while refusal of medical procedures may limit treatment options, it is unethical to abandon patients who reject advice or to provide less than quality care in other aspects of therapy.

In Daisy's first conversation with the surgeon and the later discussion with her nurse, it appears that she understands the gravity of refusing surgery, including the possible risk of death, and that she has made a deliberate choice to trust God for a miracle. The daughter's support for Daisy's choice may also signify that this decision is consistent with Daisy's values and beliefs, rather than the product of delusion.

However, Daisy's second conversation with the surgeon illustrates that decisional capacity may not be stable over time. Underlying disease,

treatment side effects, emotional stress, and other factors may cause fluctuations. Thus, in assessing capacity physicians should consider whether losses are temporary or permanent and whether decisional skills can be improved or restored by altering medications or other aspects of treatment. It may also be important to reassess capacity periodically, particularly when new and more complex decisions must be made.

Given the discrepancy between Daisy's conversations with the surgeon and her nurse, the physician primarily responsible for her care should confirm that her statements seem reasonably consistent with her values, and assess Daisy's understanding of her condition, treatment options, and predictable outcomes. In nonemergency cases, it may be helpful to observe and converse with patients over time as a way of assessing the consistency of their statements. If Daisy is decisionally capable, her rejection of surgery should be respected. Moreover, Daisy's refusal should be considered if she loses capacity in the future, since it will be the responsibility of her agent or surrogate decision maker to choose treatment consistent with what Daisy would want.

Calendar of Events November

Ethics for Lunch

November 17
Christ Hospital

e-Ethics provides discussion of important ethical issues in clinical care and organizational life. In specific cases, fuller ethical analysis may be required. The discussions in e-Ethics should not be construed as legal advice and do not necessarily represent official positions of Advocate Health Care.

To list an event in the e-Ethics calendar, contact Mary Ann Clemens at (312) 266-2222 ext. 240 or mac@prchfe.org.

