Competence, Capacity, and Surrogate Decision-Making

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Author: Robert D. Orr
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Generally speaking, patients should make their own treatment decisions based on their understanding of the facts, the recommendations of their physicians, and their own personal values which likely are influenced by their cultural and religious beliefs. But what happens when an individual's ability to understand information or to make decisions becomes impaired? Who decides what medical interventions should and should not be employed? And how does that surrogate decision-maker know what the patient would want?

Competence and Capacity

We often use the terms "competence" and "capacity" (short for "decision-making capacity") interchangeably. However, they are not exactly the same. Competence is a legal term. Competence is presumed unless a court has determined that an individual is incompetent. A judicial declaration of incompetence may be global, or it may be limited (e.g., to financial matters, personal care, or medical decisions).

Decision-making capacity, on the other hand, is a clinical term that is task-specific. A physician may determine that a patient does not have the capacity to make a decision for or against surgery for a hip fracture, but she may have the capacity to decide if she wants a sleeping pill or a laxative.

How does a physician make a determination of capacity? We say, only half facetiously, that a generation ago a patient had capacity if he agreed with the doctor and lacked capacity if he disagreed. Today we recognize that this "standard" was incorrect. But we also recognize that there is no easy test to determine capacity.

In order to make valid treatment decisions, a person must be able to (a) recognize there is a decision to be made, (b) understand the needed information, (c) understand the treatment options, (d) understand the likely consequences of each option (i.e. risks, burdens, and benefits),
and (e) rationally manipulate the information to come up with a decision consistent with his or her values.

**Surrogate Decision-Making**

How do we make treatment decisions for a person who has lost capacity either permanently (e.g., from dementia, stroke, head injury) or temporarily (e.g., from acute illness or injury)? In some instances our goal should be to restore their decision-making capacity. When we are unable to do so, or unable to do it quickly enough to make critical decisions, we must rely on a surrogate. Proxy decision-making raises ethical issues Traditionally, we have relied on the "next of kin" to make surrogate treatment decisions. This ambiguous designation has allowed health care professionals some latitude in choosing between a spouse, adult children, siblings, companions, etc. In the last 10-12 years, over 35 states have eliminated this latitude by passing surrogate decision-making laws, which set up a rigid hierarchy of who should be the designated relative to act as surrogate if a patient has not left written instructions. This can often be very helpful when there is disagreement between family members. However, it may not always be helpful because appropriate surrogacy is not automatically established by biologic or legal relationship. The appropriate surrogate is one who knows the patient and knows her abilities, wishes, and values.

Once a surrogate is chosen, either by statute or by tradition, what standard does he or she use in making treatment decisions for the patient who has lost the capacity to do so?

**Standards for Surrogate Decision-Making**

When possible, a surrogate should make a treatment decision using what is called "substituted judgment." That is, they should make the decision the patient would make if he or she were able. This is the ethically correct thing to do; we should not do something to a patient that he would not want to have done. In addition, this process often relieves the surrogate of the perception that she is making a life or death decision. It is really the patient who is making the decision; the surrogate is merely speaking on his behalf.

How do we know what the patient would want? Sometimes a patient has left written instructions in an advance directive (see below). If not, perhaps she has said to her loved ones what she would want or not want in specific circumstances, or what values are important to her. However, we must cautiously consider the context of such statements; some comments have more moral significance than others. Absent a written advance directive or a meaningful conversation, perhaps those who know the patient best have some understanding of his values and can judge what she would find acceptable in a given situation.

When it is impossible to make a "substituted judgment" because there is no surrogate or no knowledge of wishes or values, we drop to the lower "best interests" standard. While this may sound like "just do whatever you think is right," it is not quite that simple. In fact, it is not simple at all. A best interest treatment decision is a difficult attempt to define "what would most people choose in this situation," and it should often involve second or third opinions, and perhaps an ethics consultation as well, in an effort to balance potential benefits and burdens while assessing the patient's current and future quality of life.
Making decisions regarding medical treatment is often difficult, and such is especially true when
the patient's ability to weigh in on such matters is questionable or even impossible. In such
cases, we must carefully seek to assess the patient's competence and decision-making capacity
and, if necessary, empower a suitable surrogate to act on his or her behalf. Though not ideal,
hopefully the treatment administered will be as compatible as possible with what the patient
would have chosen, had he or she been able to articulate his or her desires.

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