Can the patient make treatment decisions? Evaluating decisional capacity

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ALMOST DAILY, PHYSICIANS EVALUATE whether a patient is capable of making decisions about his or her medical care. These evaluations are often made without explicit awareness of the different standards that apply for a patient's consent to or refusal of medical treatment or diagnosis in different clinical situations. Because these evaluations are so common in everyday practice, it is worthwhile to review the standards for evaluating decisional capacity.

The question about a patient's decisional capacity (or incapacity) arises most often when a patient refuses a diagnostic procedure or treatment that a physician believes is medically necessary or that promises to improve the patient's well being. Not surprising, a patient's consent to treatment is less likely to raise questions about decisional capacity, because there is a background presumption that a recommended diagnosis and treatment should be accepted by patients in most circumstances. This presumption is often based on the fact that patients themselves seek medical treatment.

Experienced clinicians, however, recognize that not all patients who come for medical care do so because they themselves want diagnosis and treatment. Some patients come because of family pressure or for other reasons that are not readily apparent. We need to distinguish consent and refusal, because in some clinical circumstances, such as emergencies, inadequately grounded refusal carries enormous risks for the patient. In such circumstances, knowing that the patient is fully aware of the consequences of refusing treatment is necessary. In other clinical circumstances, inadequately grounded consent, (eg, to procedures that are risky or experimental) threatens patient rights and welfare.

Thus, knowing what standards are ethically appropriate for assessing decisional capacity both for consent and refusal is an important everyday skill that all physicians should possess.

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OBSTACLES TO INFORMED DECISION-MAKING

When discussing risks, one size does not fit all

One obstacle to informed decision-making is itself a byproduct of common legal understandings of informed consent. Physicians have been sensitized over the years to their obligation to disclose risks and benefits of diagnosis and treatment as well as the alternatives available to the patient. As a result, some physicians overcompensate by making certain that their disclosure of information will satisfy an ideal legal review. They do so by aiming for a comprehensive enumeration of risks, side effects, and alternatives without regard for the particular patient's individual need for or comprehension of information. These physicians fail to recognize that comprehensive disclosure is not required. Instead, disclosure that adequately meets the patient's own particular need for information is a much better guideline. There is no simple "one size fits all" standard for the adequacy of information provided to patients.

Patients need the physician's advice not just the "facts"

Collaboration is not coercion

Another obstacle to adequate informed decision-making by patients is the belief that respecting patient autonomy requires that the physician be neutral with respect to whatever decision a patient makes, because nonneutrality will verge on coercion. Physicians need to be reassured that advice and not simply information is what physicians are obligated to pro-

vide their patients. Given the wide availability of medical information, not all of it accurate, patients increasingly seek professional assistance in interpreting the information that they already possess or think they possess.

Assisting a patient to make a decision undeniably involves some degree of influencing that decision, but influence is not coercion. Although physicians should not overtly or covertly pressure patients to make a particular decision that does not conform with a patient's own beliefs and values, they should remember that *shared* decision-making is the goal of informed consent. To think that one can simply present the facts and drop the entire medical decision into the patient's lap grossly misinterprets the obligations associated with informed consent.

In informed consent, different standards apply in different situations

Providing information may not be enough

A good rule of thumb is that the information provided should be appropriate to the patient's need for information and his or her ability to process information in making informed decisions. Information disclosure can clearly be overdone, and patients who are overwhelmed by too much information cannot be well-informed. Knowing the kind and amount of information that is appropriate for patient decision-making requires attention to the standards for assessing a patient's capacity to give an informed consent or to refuse a diagnostic procedure or treatment.

EVALUATING DECISIONAL CAPACITY

According to the 1982 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the key elements required for a patient to have legal decisional capacity are:

- Possession of a set of values and goals.
- Ability to communicate and understand information.
- Ability to reason and to deliberate about choices.

These elements express the basic conditions of autonomy. They require that patient treatment choices reflect the values and beliefs of the patient, values and beliefs that the patient should be able to identify and communicate under most, but not all circumstances.

These general elements of decisional capacity do not define a single standard. Instead, they point to a scale that varies across different clinical circumstances. Being able to recognize these circumstances and the different standards that they imply is prerequisite for physicians to traverse this obstacle-filled terrain.

Steps in evaluating decisional capacity

Can the patient comprehend his or her medical circumstances? This is the first question a physician should ask himself or herself when evaluating a patient's decisional capacity. This ability to comprehend the medical circumstances is different than the patient's capacity to make daily life decisions.

For example, a patient for whom a guardian has been appointed to handle financial affairs will often be quite capable of making his or her own health care decisions. Simply because a patient has developmental disabilities or has been diagnosed with early dementia does not automatically mean that he or she is incapable of medical decision-making. Each patient should be evaluated individually. Except for obvious situations such as patients in a coma or otherwise unresponsive, a patient's capacity for decision-making should not be based on status or diagnosis, but on a specific assessment of decisional ability. In many situations of serious illness, patients will exhibit depression, but depression alone does not invalidate a person's decisional capacity.

What are the consequences of the treatment? If a patient is aware of the medical circumstances, the next question that should be asked is: "How serious is the medical condition and how serious are the consequences of the intervention?"

Some practical guidelines for evaluating decisional capacity

These questions point toward practical standards that must be met for informed consent or refusal. Bioethicist James F. Drane has proposed a "sliding scale" of standards, from a minimum standard (called simple informed consent or refusal), to a midlevel standard (called ordinary informed consent or refusal) to the most rigorous standard (called reflective informed consent or refusal).

Simple informed consent or refusal is appropriate when a patient is aware of his illness and oriented to the medical situation. The patient might explicitly assent to treatment, saying, "Do whatever you have to do," or the assent might be implicit. For instance, the patient simply accepts a prescription or complies with the instructions given for a procedure. The absence of reticence or unwillingness can be accepted as assent in many everyday clinical situations. This assent can also be expressed by a spouse or another close family member on behalf of the patient. Disclosure of information about the procedure is still required, but one need not "test" for patient comprehension.

Patients with acute, reversible, common conditions, such as sinus infections, for which the benefits of treatment are high and the risks low, can be evaluated according to minimal standards for consent. This standard only requires evidence that the patient is aware of the medical condition and that the patient gives evidence of acceptance or rejection of the treatment. For example, the patient's assent or simple verbal expression of acceptance is sufficient to judge the patient capable of decision-making. No further information about the patient's personal beliefs and values is needed. This minimum threshold for accepting a patient's capacity to consent to treatment also applies to refusals of treatment in situations in which the treatment is experimental or offers only a small chance of success with significant risk. Unwillingness is an adequate standard for the capacity to refuse a risky and minimally beneficial treatment.

This minimum standard is applicable for consent when there is diagnostic certainty, when an effective treatment with a high benefit-to-risk ratio is proposed, and when there are limited treatment alternatives. In these common situations, one can safely make presumptions about a patient's personal values. If, however, there is evidence that the patient's acceptance of treatment is inconsistent with known patient values, inquiry is needed to clarify the reasons for this change.

In cases of refusal of treatment, this minimum standard applies in experimental settings or in situations in which the risks clearly outweigh the benefits for the patient. Thus, simple assent or refusal coupled with mere awareness of one's medical condition is all that is required in many common clinical situations by this standard.

The standard of ordinary informed consent or refusal requires more than a simple indication of acceptance or refusal by the patient. It additionally requires that the patient be aware of the nature of the illness and the implications of the proposed treatment. It requires patient education so that the decision can be based upon information about treatment outcomes. This imposes an obligation to provide more information and to communicatively assess the patient's comprehension.

This median standard is appropriate when a patient has a chronic illness in which effective case management requires an active collaboration of physician and patient. Also, in situations in which an effective treatment exists, but which imposes burdens on the particular patient, the patient needs to exhibit some evidence that he or she has reflected on the possible outcomes of treatment in light of his or her own personal values. In such situations, the physician need not have a detailed understanding of what motivates the patient, but an assessment that the consent or refusal of treatment expresses the patient's own values and beliefs is important. *Shared* decision-making is the focus here. Good clinicians naturally adopt cooperative attitudes that not only satisfy the need for information, but which help the patient to articulate reflectively their reasons for accepting or rejecting treatment.

Depression alone does not invalidate a person's decisional capacity

Reflective informed consent or refusal, the highest standard, requires a much greater degree of understanding on the part of the patient than either simple or ordinary informed consent or refusal. In fact, it is the obverse of simple informed consent in that it applies in situations in which a patient *refuses* a highly effective treatment for an acute illness or accepts an experimental or risky innovative procedure. Normally, we allow only very weighty reasons for refusal of such treatments. Honoring the informed and reflectively grounded refusal of blood products by an articulate, devout, practicing Jehovah's Witness is significantly different than honor-

ing a "refusal" inferred from a patient's confused resistance to placing an intravenous line.

When in doubt about the patient's decisional capacity

Advance directives. A physician who is still uncertain of a patient's decisional capacity or who judges the patient to be incapable of decision making after performing an evaluation can, in many situations, rely on prior consent or prior refusal of treatment. This is often overlooked, especially when referrals are involved. It is important that physicians convey their assessment of the patient's decisional ability or inability as well as whether there is actual consent to further investigation of disease or treatment.

If there is an advance directive, such as a power of attorney for health care, physicians should personally read the document carefully to see what specific situations it covers and whether the patient is expressing a refusal of treatment or a desire to receive treatment. Also, encouraging patients to articulate their wishes and the reasons for their choices regarding, for example, end-of-life care can significantly enhance patient autonomy.

Surrogates. Sometimes the physician can rely on a surrogate who knows the patient. This need not always be a person designated by a power of attorney. There is a longstanding practice of using family members to provide surrogate consent for treatment when the patient is unable to make decisions.

The standards enumerated above provide a gauge for judging when reliance on informal surrogate arrangements is acceptable. Seeking formal appointment of a legal guardian is another option, but it can delay medical decisions that should be made quickly. Although an ethics committee or ethics consultant can assist in the evaluation of decisional capacity, the responsibility to determine whether these conditions are met rests with the attending physician.

SUGGESTED READING

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