

Can the Patient Decide? Evaluating Patient Capacity in Practice

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Physicians assess the decision-making capacity of their patients at every clinical encounter. Patients with an abrupt change in mental status, who refuse recommended treatment, who consent too hastily to treatment or who have a known risk factor for impaired decision-making should be evaluated more carefully. In addition to performing a mental status examination (along with a physical examination and laboratory evaluation, if needed), four specific abilities should be assessed: the ability to understand information about treatment; the ability to appreciate how that information applies to their situation; the ability to reason with that information; and the ability to make a choice and express it. By using a directed clinical interview or a formal capacity assessment tool, primary care physicians are able to perform these evaluations in most cases. (*Am Fam Physician* 2001;64:299-306.)

Assessing a patient's medical decision-making capacity is part of every medical encounter. The process is generally spontaneous and straightforward: during the performance of routine inpatient and outpatient visits, physicians confirm the ability of their adult patients to understand their medical condition and options for care. For some patients, however, the assessment may not be straightforward. Consider the cases presented below.

Illustrative Cases

CASE 1

A 54-year-old woman with diabetes and schizophrenia has been hospitalized with unstable angina, bilateral heel ulcers, urinary retention caused by an acute urinary tract infection and anemia caused by a combination of gastritis and chronic renal failure. One year ago, she was hospitalized with diabetic ketoacidosis after reporting that "voices" told her to stop taking her insulin. Currently, she is improving but requires a urinary catheter and must keep her legs elevated at rest. She says she is now able to take care of herself and wants to return home. Does this patient have the capacity to make this decision?

CASE 2

A 78-year-old man has a recent diagnosis of metastatic cancer of unknown primary. He returned to the office today after having a

computed tomography (CT) scan showing a pancreatic lesion that may be the primary cancer and is the only lesion accessible for biopsy. He requires large doses of narcotics for pain control and his level of consciousness fluctuates greatly. It is not clear if he understands his prognosis or that a tissue diagnosis will probably not affect treatment or outcome. When he is more lucid, he wants "the test"—a CT-guided pancreas biopsy. Does this patient have the capacity to consent to this procedure?

When to Assess Capacity

Four clinical scenarios are described¹ that should alert physicians to assess a patient's decision-making capacity more carefully than usual. The first occurs when patients have an abrupt change in mental status. This change may be caused by hypoxia, infection, medication, metabolic disturbances, an acute neurologic or psychiatric process, or other medical problem. The second occurs when patients refuse recommended treatment, especially when they are not willing to discuss the refusal, when the reasons for the refusal are not clear or when the refusal is based on misinformation or irrational biases. The third occurs when patients consent to particularly risky or invasive treatment too hastily and without careful consideration of the risks and benefits. The last scenario occurs when patients have a known risk factor for impaired

Physicians are called on to make decisions about patients' capacity, not competency, which is a legal issue.

decision-making, such as a chronic neurologic or psychiatric condition, a significant cultural or language barrier, an education level concern, an acknowledged fear or discomfort with institutional health care settings or who are at an age at either end of the adult spectrum (adolescents younger than 18 years or adults older than 85 years).

Patients exemplifying one of these scenarios require careful assessment but may still be able to make their own decisions. Some abrupt mental status changes, for instance, are only temporary. Some patients refuse treatment for reasons that may be unusual or idiosyncratic but are not irrational when examined in more detail. Other patients consent to treatment without apparent consideration of risks and benefits because they have already decided to follow the recommendations of their physician. Many patients with neurologic or psychiatric conditions,^{2,3} or those who are younger than 18 or older than 85 years, are able to make decisions about some aspects of their medical care.

Decision-making capacity, medical or otherwise, is always specific to the task requiring the decision.^{1,4} Certain patients may be able to decide some aspects of their care, but not others. For example, a patient with mild-to-moderate Alzheimer's disease who experi-

ences chest pain may be able to understand the need for antibiotics to fight pneumonia but not the indications for, or the risks and benefits of, cardiac catheterization and angioplasty for coronary artery disease.

How to Assess Capacity

Once a patient has been identified as requiring a more careful assessment of capacity, the evaluation should proceed in a clear and organized manner.^{1,4-6} Physicians may use a directed clinical interview or a formal capacity assessment tool.

DIRECTED CLINICAL INTERVIEW

Ancillary tests may be needed, depending on the individual circumstances, including history from therapists or other caregivers, physical assessment, laboratory evaluation and possibly even neuroimaging studies. These tests may all help clarify whether the current level of functioning and, possibly capacity, is likely to improve. *Table 1*^{1,4-6} outlines specific patient abilities to be assessed along with suggested questions to assess each ability during a directed clinical interview. After these abilities are assessed, a general mental status examination also must be performed to determine whether any serious psychopathologic factors may be unduly influencing patient thinking. The clinician's final assessment of whether a patient has medical decision-making capacity depends on whether the clinician believes that the patient is free of significant psychopathologic-impaired thinking and possesses sufficient abilities to make the specific decision in question.

The lack of any one ability does not mean that a patient lacks the overall ability to make a decision.^{1,4} For example, patients with limited education, with diverse cultural backgrounds or with minimal prior experience in a medical setting may not completely understand all the alternatives to, or all the major risks of, a proposed treatment. However, they may still have enough understanding overall to make their own decisions.

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A judgment about capacity is precisely what clinicians are expected to render.⁷ Legally, such judgments are not made by physicians but are made by the courts according to the laws of the state in which the patient resides. Local authorities should be consulted for specific legal definitions and procedures.⁸ Practically, most cases never reach the courts and, when they do, the court's legal "determination of competency" usually agrees with the physician's overall "assessment of capacity." However, a legal determination of incapacity is generally limited to specified rights, whereas incompetency is (legally) associated with a loss of legal rights.⁹

Both legally and ethically, Western culture favors patient autonomy—an individual

patient's right to self determination—over the beneficent protection offered by others.¹⁰ Adults are believed to be "good enough" to make their own decisions—for better or worse—even though someone else might be a better decision-maker for them from a purely objective, academic or analytic point of view. Restricting autonomy requires a clear and convincing assessment that a patient's decision regarding care will result in unintended, irreparable harm. Unfortunately, harm is difficult to define because it varies from one person and circumstance to another. Therefore, many experts^{1,4,11} in capacity believe in a sliding-scale threshold, or variable level of certainty, for capacity that depends on the patient's decision and the specific risks and

TABLE 1

Patient Abilities to be Assessed in the Evaluation of Medical Decision-Making Capacity

1. Questions to determine the ability of the patient to understand about treatment and the proposed options for care:
 - What is your understanding of your condition?
 - What are the options for your situation?
 - What is your understanding of the benefits of treatment and what are the odds that the treatment will work for you?
 - What are the risks of treatment and what are the odds that you may have a side effect or bad outcome?
 - What is your understanding of what will happen if nothing is done?
2. Questions to determine the ability of the patient to appreciate how that information applies to their own situation:
 - Tell me what you really believe about your medical condition.
 - Why do you think your doctor has recommended (name of specific treatment or test) for you?
 - Do you think it (specific treatment/test) is the best treatment/test for you? Why or why not?
 - What do you think will actually happen to you if you accept this treatment? If you don't accept it?
3. Questions to determine the ability of the patient to reason with that information in a manner that is supported by the facts and the patient's own values:
 - What factors/issues are most important to you in deciding about your treatment? What are you thinking about as you consider your decision?
 - How are you balancing the pluses and minuses of the treatments?
 - Do you trust your doctor? Why or why not?
 - What do you think will happen to you now?
4. Questions to determine the ability of the patient to communicate and express a choice clearly:
 - You have been given a lot of information about your condition. Have you decided what medical option is best for you right now?
 - We have discussed several choices; what do you want to do?

Information from references 1 and 4 through 6.

Capacity Thresholds

STEP 1: CASE SPECIFICS

A. What is the risk-benefit analysis of the medical care option recommended to the patient?

Favorable: care option has high potential benefit and low risk

Intermediate: care option has intermediate or unclear benefit and risk

Unfavorable: care option has low potential benefit and risk

B. What is the patient decision? *Consent* or *Refusal*

STEP 2: THRESHOLD DETERMINATION

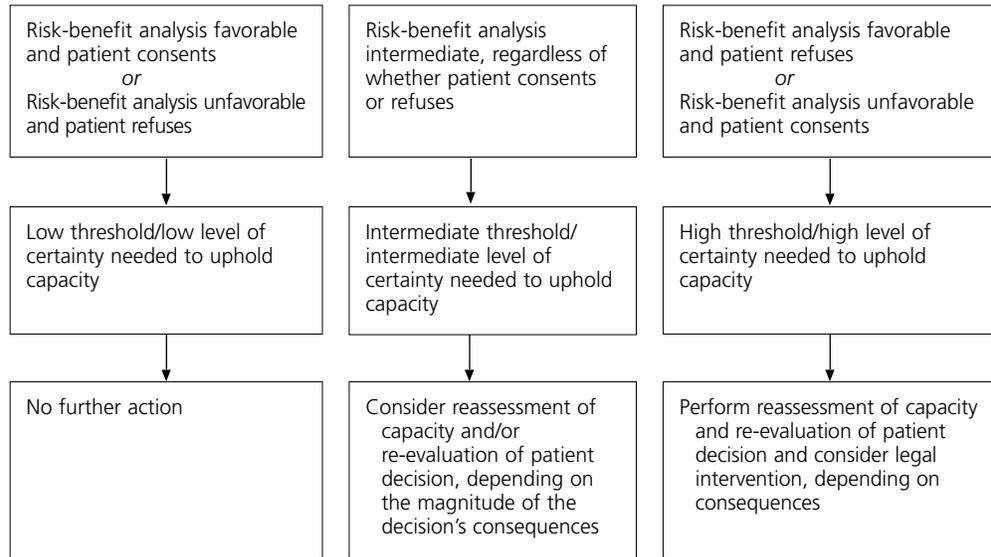


FIGURE 1. Capacity thresholds according to patient decision and risk-benefit analysis of care options.

Information from references 1, 4 and 11.

benefits of the proposed treatment as shown in *Figure 1*.^{1,4,11}

FORMAL ASSESSMENT TOOLS

In addition to or instead of a directed clinical interview, a formal, structured assessment tool can be used to evaluate capacity. Two such tools are the Aid to Capacity Evaluation (ACE)^{3,12} and the MacArthur Competence Assessment Tool (MacCAT).¹ Both use standardized questions and scoring systems to

achieve a more objective assessment of capacity than an interview. The abilities assessed, however, are the same as those assessed in a clinical interview and the scores still require interpretation by an evaluator. The MacCAT is a lengthy, comprehensive tool designed for patients with complex psychiatric or neurologic conditions whose capacity determination is especially difficult. The assessment can be administered and scored in approximately 30 minutes. The ACE (*Figure 2*) is a short,

Aid to capacity evaluation

Name of patient: _____

Record observations that support your score in each domain, including exact responses of the patient. Indicate your score for each domain with a check mark.

1. Able to understand medical problem

(Sample questions: What problem are you having right now? What problem is bothering you most? Why are you in the hospital? Do you have [name problem here]?)

- Yes
 Unsure
 No

Observations: _____

2. Able to understand proposed treatment

(Sample questions: What is the treatment for [your problem]? What else can we do to help you? Can you have [proposed treatment]?)

- Yes
 Unsure
 No

Observations: _____

3. Able to understand alternative to proposed treatment (if any)

(Sample questions: Are there any other [treatments]? What other options do you have? Can you have [alternative treatment]?)

- Yes
 Unsure
 No
 None disclosed

Observations: _____

4. Able to understand option of refusing proposed treatment (including withholding or withdrawing proposed treatment)

(Sample questions: Can you refuse [proposed treatment]? Can we stop [proposed treatment]?)

- Yes
 Unsure
 No

Observations: _____

5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment

(Sample questions: What could happen to you if you have [proposed treatment]? Can [proposed treatment] cause problems/side effects? Can [proposed treatment] help you live longer?)

- Yes
 Unsure
 No

Observations: _____

6. Able to appreciate reasonable foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment)

(Sample questions: What could happen if you don't have [proposed treatment]? Could you get sicker/die if you don't have [proposed treatment]? What could happen if you have [alternative treatment]? [If alternatives are available])

- Yes
 Unsure
 No

Observations: _____

NOTE: for questions 7a and 7b, a "yes" answer means the person's decision is affected by depression or psychosis.

7a. The person's decision is affected by depression.

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you feel that you're being punished? Do you think you're a bad person? Do you have any hope for the future? Do you deserve to be treated?)

- Yes
 Unsure
 No

Observations: _____

7b. The person's decision is affected by delusion/psychosis.

(Sample questions: Can you help me understand why you've decided to accept/refuse treatment? Do you think anyone is trying to hurt/harm you? Do you trust your doctor/nurse?)

- Yes
 Unsure
 No

Observations: _____

FIGURE 2. Aid to capacity evaluation.

(continued)

Aid to capacity evaluation (continued)

Overall impression

Definitely capable Probably capable Probably incapable Definitely incapable

Comments

(For example: need for psychiatric assessment, further disclosure and discussion with patient or consultation with family)

The initial ACE assessment is the first step in the capacity assessment process. If the ACE is definitely or probably incapable, considerable treatable or reversible causes of incapacity (e.g., drug toxicity). Repeat the capacity assessment once these factors have been addressed. If the ACE result is probably incapable or probably capable, then take further steps to clarify the situation. For example, if you are unsure about the person's ability to understand the proposed treatment, then a further interview that specifically focuses on this area would be helpful. Similarly, consultation with family, cultural and religious figure, and/or a psychiatrist may clarify some areas of uncertainty.

Never base a finding of incapacity solely on your interpretation of domain 7a and 7b. Even if you are sure that the decision is based on a delusion or depression, you should always get an independent assessment.

Time taken to administer ACE: Minutes: _____

Date: Day: _____ **Month:** _____ **Year:** _____ **Hour:** _____

Assessor: _____

Instructions for scoring

1. Domains 1-4 evaluate whether the person understands his or her current medical problems, the proposed treatment and other options (including withholding or withdrawing treatment). Domains 5 and 6 evaluate whether the person appreciates the consequences of their decision (see sample questions above).
2. For domains 1-6, if the person responds appropriately to open-ended questions, score yes. If the patient needs repeated prompting by close-ended questions, score unsure. If the patient cannot respond appropriately despite repeated prompting, score no.
3. For domain 7, if the person appears depressed or psychotic, then decide if the decision is being affected by the depression or psychosis. For domain 7a, if the person appears depressed, determine if the decision is affected by depression. Look for the cognitive signs of depression such as hopelessness, worthlessness, guilt and punishment. For domain 7b, if the person may be psychotic, determine if the decision is affected by delusion/psychosis.
4. Record observations that support your score in each domain, including exact responses of the patient.
5. Remember that people are presumed capable. Therefore, for your overall impression, if you are uncertain, then err on the side of calling a person capable.

University of Toronto Joint Centre for Bioethics Aid to Capacity Evaluation (ACE) Disclaimer

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FIGURE 2. Aid to capacity evaluation.

From the Aid to Capacity Evaluation (ACE). University of Toronto Joint Centre for Bioethics, Toronto, Ontario, Canada. Retrieved September 2000 from: http://www.utoronto.ca/jcbl_ace.

more clinically oriented tool that can be administered and scored in five to 10 minutes. The ACE can also be found on the Web site of the University of Toronto Joint Centre for Bioethics: http://www.utoronto.ca/jcb/_ace. General instructions are simple: clinicians are directed to address communication barriers, discuss treatment information and answer patient questions before administering the assessment.

Regardless of whether a directed clinical interview or a formal tool is used, the physician must clearly document the assessment and the final judgment about capacity in the patient record. If an interview is used, a brief summary of the questions asked and the answers provided should be documented; if a formal assessment tool is used, it should be included in the patient's record. In either case, the physician must also document the reasoning used to reach the final judgment.

Who Should Assess Capacity

Primary care physicians are qualified to perform capacity assessments. There are several reasons why a patient's primary care physician may be the best professional to assess capacity¹⁻⁷: (1) the primary physician already knows the patient's medical circumstances and the question to be decided; (2) the primary physician may have the best opportunity to know the patient's and their family's personal values and cultural and religious views; (3) the primary physician has the benefit of history, so that the assessment is not a one-visit snapshot of a patient but is a longitudinal and more thorough assessment based on multiple interactions; and (4) the primary physician, because of an ongoing medical relationship with the patient, is in the best position to re-evaluate capacity in the future.

Psychiatrists are more expert in evaluating patients with severe mental illness and may be legally required, in some locales, to assess patients referred to the courts. However, research comparing their judgments to those of other physicians shows that they are no better

Documentation regarding capacity determinations should include a summary of the questions asked by the physician and the answers provided by the patient. If a formal assessment tool is used, it should be included in the patient's medical record.

at assessing capacity in practice.¹³ At the same time, however, because psychiatrists perform capacity evaluations frequently, primary care physicians should feel comfortable consulting them in difficult cases. A bioethics panel may also help clarify or delineate the issues that need to be addressed with a specific patient.

Follow-up of Illustrative Cases

CASE 1

The 54-year-old woman with schizophrenia and multiple medical problems reported that she was not now hearing voices nor was she exhibiting any other psychotic symptoms. She had been very stable on her psychiatric medications for several months. The patient understood her medical situation, appreciated the consequences of care options, analyzed logically the information she was given and was able to express a clear choice. She was judged to have capacity. After learning self-catheterization, demonstrating knowledge of her medication regimen and agreeing to home health nursing care, she returned home and returned for follow-up visits as directed.

CASE 2

The 78-year-old man with metastatic cancer of unknown primary understood his medical condition and was able to express his choice, but he could not appreciate the fact that the biopsy would probably not affect treatment or outcome and he could not analyze the information given him. Even when he was lucid, he was convinced "the test" would cure him, despite repeated explanations. He was judged not to have capacity. He had a durable power-of-attorney for health care

naming his wife as his agent, and, after further discussion, she declined the biopsy. He died several weeks later without a tissue diagnosis but with full palliative care.

Final Comment

Physicians assess the decision-making capacity of their patients at every clinical encounter. Patients requiring careful assessment can be easily identified using standardized evaluations performed by means of a directed clinical interview or the use of a formal assessment tool such as the ACE^{3,12} or the MacCAT.¹

If the patient lacks the capacity for decision-making, a determination of surrogacy will be necessary. In the best-case scenario, the patient may have previously appointed an agent; in the worst-case scenario, the court may need to become involved. (The discussion of surrogacy is too broad for this article, but it has been well-covered elsewhere.)^{4,14} If the patient does not have an advance directive or health care proxy, the surrogate will need to make decisions based on principles of “substituted judgment” (what the patient would have decided) or “best interest” (what the surrogate judges to be best for the patient).

The author wishes to thank Janet Bruman and Dr. Stephen Saglio for their assistance in preparing the manuscript.

The authors indicate that they do not have any conflicts of interest. Sources of funding: none reported.

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