

Ten Myths About Decision-Making Capacity

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As a matter of practical reality, what role patients will play in decisions about their health care is determined by whether their clinicians judge them to have decision-making capacity. Because so much hinges on assessments of capacity, clinicians who work with patients have an ethical obligation to understand this concept. This article, based on a report prepared by the National Ethics Committee (NEC) of the Veterans Health Administration (VHA), seeks to provide clinicians with practical information about decision-making capacity and how it is assessed. A study of clinicians and ethics committee chairs carried out under the auspices of the NEC identified the following 10 common myths clinicians hold about decision-making capacity: (1) decision-making capacity and competency are the same; (2) lack of decision-making capacity can be presumed when patients go against medical advice; (3) there is no need to assess decision-making capacity unless patients go against medical advice; (4) decision-

making capacity is an "all or nothing" phenomenon; (5) cognitive impairment equals lack of decision-making capacity; (6) lack of decision-making capacity is a permanent condition; (7) patients who have not been given relevant and consistent information about their treatment lack decision-making capacity; (8) all patients with certain psychiatric disorders lack decision-making capacity; (9) patients who are involuntarily committed lack decision-making capacity; and (10) only mental health experts can assess decision-making capacity. By describing and debunking these common misconceptions, this article attempts to prevent potential errors in the clinical assessment of decision-making capacity, thereby supporting patients' right to make choices about their own health care. (*J Am Med Dir Assoc* 2004; 5: 263-267)

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Clinicians have both an ethical and a legal obligation to ensure that patients are informed about and allowed to participate, to the degree they desire, in choices regarding their own health care, which derives from the principle of respect for autonomy. Respect for autonomy requires, at a minimum,

acknowledgment of an individual's right to have opinions, to make choices, and to take actions based on personal goals and values.

Autonomous choices have three central characteristics: they are adequately informed; they are voluntary, not coerced; and they are based on reasoning. Patients who are unable to make autonomous choices are said to lack "decision-making capacity."¹ The concept of decision-making capacity is pivotal, because, as a practical matter, assessments of decision-making capacity determine whether patients are empowered to make their own healthcare decisions or whether someone else should be empowered to make decisions for them.²

Patients are presumed to have decision-making capacity, and for many patients, decision-making capacity is never in doubt. Some patients (eg, those in a coma) are clearly not capable of making contemporaneous decisions about their care, whereas other patients are unquestionably capable. In routine clinical practice, decision-making capacity is often assessed informally or inconsistently,^{2,3} and misconceptions about decision-making capacity and its assessment are surprisingly common.

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We identified 10 “common myths” about decision-making capacity based on a survey of members of the Academy for Psychosomatic Medicine, geriatrician and psychologist members of the Gerontological Society of America, and chairs of ethics committees in VA Medical Centers.⁴

MYTH 1: DECISION-MAKING CAPACITY AND COMPETENCY ARE THE SAME

Although decision-making capacity and competency both describe patients’ ability to make decisions, they are not synonymous. Decision-making capacity is a clinical assessment of a patient’s ability to make specific healthcare decisions, whereas competency is a legal determination of the patient’s ability to make his or her own decisions in general.

Clinicians routinely assess decision-making capacity as part of clinical care. It can be defined as the ability “to understand and appreciate the nature and consequences of health decisions” and “to formulate and communicate decisions concerning health care.”⁵ Clinicians have the *de facto*, even if not the *de jure*, power to determine whether a patient is incapable of making healthcare decisions and, if so, to identify a surrogate decision-maker to act on the patient’s behalf.³

In contrast, courts, not clinicians, determine competency. To say that a person is incompetent indicates that a court has ruled that the person is not able to make valid decisions and has appointed a guardian to make decisions for the person.⁶ Competency proceedings, typically long, expensive, and emotionally charged, are generally the last resort, often triggered when there is a dispute about decision-making capacity (or about who should be surrogate), and typically reserved for people who are presumed to be highly and permanently impaired.⁷

Some patients who are legally incompetent could still have the capacity to make particular types of healthcare decisions. A clinician who believes he or she has such a case, should immediately seek advice from an ethics committee and/or legal counsel.

MYTH 2: LACK OF DECISION-MAKING CAPACITY CAN BE PRESUMED WHEN PATIENTS GO AGAINST MEDICAL ADVICE

Clinicians should *not* conclude that patients lack decision-making capacity just because they make a decision contrary to medical advice. Determining decision-making capacity involves assessing the process the patient uses to arrive at a decision, not whether the decision he or she arrives at is the one preferred or recommended by the healthcare practitioner.^{3,8} Sound decision-making requires that one be able to⁹:

1. Communicate choices;
2. Understand relevant information;
3. Appreciate the situation and its consequences; and
4. Manipulate information rationally.

At the same time, clinicians should not accept, without question, a decision that is consistent with medical advice if it markedly deviates from the patient’s own previously stated values and goals. Although the concept of patient autonomy requires that patients be permitted to make even idiosyncratic

decisions, it remains the responsibility of the clinician to assure that no decision is the result of a problem with decision-making capacity or some misunderstanding that needs to be resolved.³

MYTH 3: THERE IS NO NEED TO ASSESS DECISION-MAKING CAPACITY UNLESS PATIENTS GO AGAINST MEDICAL ADVICE

Just as clinicians should not presume incapacity in patients who make decisions that are contrary to medical advice, neither should they overlook incapacity in patients who go along with whatever clinicians recommend.¹⁰ A patient could assent to an intervention without understanding the risks and benefits or alternatives sufficiently to appreciate the consequences of that decision. Although it is unrealistic to expect clinicians to formally assess decision-making capacity with every patient decision, assessment is imperative for patients who, because of their medical conditions, are at risk of cognitive impairment. Assessment is also essential whenever the risks of a proposed medical intervention are relatively high in comparison to its expected benefits.

MYTH 4: DECISION-MAKING CAPACITY IS AN ‘ALL OR NOTHING’ PHENOMENON

A patient who lacks the capacity to make one decision does *not* necessarily lack the ability to make all decisions. In addition to assessing a patient’s capacity to make healthcare decisions, a clinician could also be asked to assess a patient’s ability to make choices about living independently, handling funds, or participating in research.⁴ Each type of decision requires different skills and therefore calls for a separate, independent assessment. Patients should be empowered to make their own decisions, except those for which they lack specific capacity.^{3,9,10}

Decisions about health care vary in their risks, benefits, and complexities, and patients might be able to make some decisions but not others.^{2,11} For example, a mildly demented patient might be able to decide that she wants antibiotic treatment for a urinary tract infection because the treatment allows her to pursue important goals such as feeling well or staying out of the hospital, and its burdens and risks are low. On the other hand, the same patient might be unable to weigh the multiple risks and benefits of a complex neurosurgical procedure with uncertain tradeoffs between quality and quantity of life. Therefore, when evaluating a patient’s capacity to make healthcare decisions, clinicians must assess each decision separately.

Finally, lack of capacity should not be taken to mean that patients cannot participate in decision-making at all. Even patients who are legally incompetent should be allowed to participate in decision-making to the extent that they are able. For example, when a guardian has been appointed because a patient’s capacity fluctuates as a result of mental illness such as bipolar disorder or schizophrenia, the clinician should, if possible, discuss proposed treatments with both the guardian and the patient. In the rare situation in which the patient is confronted by a treatment decision for which he or she has capacity and disagrees with the decision made by the guard-

ian, the clinician should not disregard the patient's opinion, but attempt to resolve the disagreement and, if necessary, seek advice from an ethics committee and/or legal counsel.

MYTH 5: COGNITIVE IMPAIRMENT EQUALS LACK OF DECISION-MAKING CAPACITY

Decision-making capacity and cognitive ability are related, but they are *not* the same thing. Whereas decision-making capacity refers to the patient's ability to make a particular healthcare decision, cognitive ability encompasses a broad range of processes, including attention, comprehension, memory, and problem-solving. Although cognitive ability and decision-making capacity are correlated, cognitive tests should not be used as a substitute for a specific capacity assessment.^{3,11,12} Some patients who lack decision-making capacity could have high scores on cognitive tests.¹³ Others who perform poorly on the same tests could nonetheless be capable of making some healthcare decisions.^{2,11}

Unfortunately, there is no single, universally accepted test for determining decision-making capacity. In complex cases, experts could disagree in their capacity assessments of the same patient.¹² In recent years, several instruments have been developed that increase the reliability of clinical assessments,^{13,14} but none are in common use.

On a practical level, one commonsense approach physicians might take to assess decision-making capacity is to ask a patient with doubtful capacity questions of the sort suggested in Figure 1.

Appelbaum PS, Crisso T. (unpublished)

Model Questions for Assessing Capacity

Ability to choose

1. Have you made a decision about the treatment options we discussed?

Ability to understand relevant information

2. Please tell me in your own words what I've told you about
 - the nature of your condition
 - the treatment or diagnostic test recommended
 - the possible benefits from the treatment /diagnostic test
 - the possible risks (or discomforts) of the treatment /diagnostic test
 - any other possible treatments that could be used, and their benefits and risks
 - the possible benefits and risks of no treatment at all
3. We've talked about the chance that x might happen with this treatment? In your own words, can you tell me how likely to you think it is that x will happen?
4. What do you think will happen if you decide not have treatment ?

Ability to appreciate the situation and its consequences

5. What do you believe is wrong with your health now?
6. Do you believe it's possible that this treatment /diagnostic test could benefit you?
7. Do you believe it's possible that this treatment /diagnostic test could harm you?
8. We talked about other possible treatments for you—can you tell me, in your own words, what they are?
9. What do you believe would happen to you if you decided you didn't want to have this treatment /diagnostic test?

Ability to reason

10. Tell me how you reached your decision to have [not have] the treatment /diagnostic test?
11. What things were important to you in making the decision you did?
12. How would you balance those things?

Fig. 1 Model questions for assessing capacity.

MYTH 6: LACK OF DECISION-MAKING CAPACITY IS A PERMANENT CONDITION

Lack of decision-making capacity is *not* always permanent and is often only short-lived. Patients' capacity to make healthcare decisions could wax and wane over time, especially in patients with evolving medical or mental health disorders.³ Patients could be temporarily incapacitated, for example, as a result of general anesthesia or delirium, a transient mental syndrome characterized by global impairments in cognition (especially inattention) that develops in the context of severe medical or surgical illness. In patients with delirium, capacity could fluctuate substantially over hours to days or between one hospital admission and another.¹⁵ In such patients, decision-making capacity must be regularly reassessed. In patients who are only intermittently incapacitated, important discussions should be timed to correspond to periods when the patient is capable of making decisions. Under such circumstances, conversations might need to be repeated to assure that any decisions made are an authentic reflection of the patient's values and goals.

Whenever loss of decision-making capacity is expected to be only temporary, important decisions should be delayed, if possible, while efforts are made to treat the underlying illness so that capacity can be restored. If delay is not possible, a surrogate should be selected to make decisions on the patient's behalf. Decisions made under these circumstances should not be considered immutable, however. As soon as patients recover capacity, authority for decision-making should return to them.¹⁶

MYTH 7: PATIENTS WHO HAVE NOT BEEN GIVEN RELEVANT AND CONSISTENT INFORMATION ABOUT THEIR TREATMENT LACK DECISION-MAKING CAPACITY

A patient who has not received appropriate information, or who has received inconsistent information, cannot be expected to make an informed decision. Lack of adequate information should *not* be mistaken for lack of decision-making capacity.

In many medical settings, especially teaching hospitals, patients receive information from many different sources, including their inpatient treatment team, consultant specialists, primary care providers, and trainees at various levels. Not surprisingly, the information is not always uniform. In addition, some clinicians could be more conscientious than others in providing information or more skilled at communicating in a way that patients can easily understand. Regardless of who has previously communicated with the patient, it is the responsibility of the clinician recommending a particular treatment or procedure to assure that the patient is adequately informed about the expected benefits and known risks of the recommended intervention, as well as the risks and benefits of all reasonable alternatives, including no intervention.^{4,8}

In addition to providing adequate information, clinicians should also assure that the information they provide is understood. Some patients could be capable of making healthcare decisions only if their clinicians make special efforts to help

them. In some cases, all that is required is patience and repetition, or allowing extra time for patients to digest information or to consult with family and friends. Other strategies that could improve patient understanding include communicating both orally and in writing, presenting information at the appropriate reading level, use of personnel specially trained to bridge language or cultural barriers, and enlisting the patient's own support system to convey information.^{3,11,16} It remains to be seen how HIPAA will affect clinicians' ability to enlist the support of a patient's friends and family in communicating health information to him or her.

MYTH 8: ALL PATIENTS WITH CERTAIN PSYCHIATRIC DISORDERS LACK DECISION-MAKING CAPACITY

The fact that a patient has a particular psychiatric or neurologic diagnosis does not necessarily mean that he or she lacks the capacity to make healthcare decisions; in fact, even patients with serious disorders such as dementia or schizophrenia often retain decision-making capacity.^{3,11,17} Frequently, however, clinicians assume otherwise. In a survey of physicians in Massachusetts, for example, less than one third of respondents thought it possible that a person with dementia or psychosis could have decision-making capacity.¹⁸ Although a particular psychiatric diagnosis does not necessarily imply incapacity, the most common causes of incapacity include psychiatric disorders such as delirium and dementia. Therefore, the presence of such syndromes should alert clinicians to assess decision-making capacity with special care.^{2,3,9}

MYTH 9: PATIENTS WHO HAVE BEEN INVOLUNTARILY COMMITTED LACK DECISION-MAKING CAPACITY

In most states, patients can be involuntarily committed for mental illness because they are a danger to themselves or others or are unable to take care of themselves. Although patients who have been committed involuntarily often lack the capacity to make healthcare decisions, this is not always the case. Even with involuntarily committed patients, incapacity should never be presumed, but must be assessed.

Like all other patients, those who are involuntarily committed should be allowed to make healthcare decisions, except decisions for which they lack specific capacity, and they should be allowed to participate in all decisions to the extent that they are able. In addition, involuntarily committed patients could be entitled to extra protections under federal regulations and state law.⁷

MYTH 10: ONLY MENTAL HEALTH EXPERTS CAN ASSESS DECISION-MAKING CAPACITY

Mental health experts are not the only clinicians who can assess decision-making capacity. All clinicians who are responsible for the care of patients should be able to perform routine capacity assessments. Although psychiatrists and psychologists have specific expertise in diagnosing and treating many of the disorders that cause incapacity, for many routine cases, decision-making capacity is best assessed by the clinician who is responsible for the patient's care.¹⁹

Assessment by the primary clinician could be advantageous for several reasons. Mental health professionals who are asked to evaluate decision-making capacity often must base their capacity assessments on only one or two encounters with the patient. A clinician who has a longer-term relationship with the patient, however, could be in a better position than a consultant to understand the patient as a person, and to assess whether the patient's decision is consistent with his or her goals and values.^{3,9} Furthermore, whether primary care provider or specialist, the clinician who recommends a given intervention has the advantage of being more familiar with the risks and benefits, as well as its alternatives.²⁰

On the other hand, consultations from mental health professionals could be invaluable, especially when assessing capacity is particularly challenging. For example, primary clinicians might need help from mental health consultants in assessing the capacity of patients with major mental disorders such as schizophrenia or severe personality disorders in whom distinguishing poor judgment from lack of decision-making capacity can be difficult.²¹ Whether a mental health consultant renders an opinion about capacity, the final responsibility for determining capacity rests with the treating clinician.⁹ When clinicians cannot reach agreement about a patient's decision-making capacity, their first recourse should be to consult an ethics committee.

CONCLUSION

All clinicians have an ethical responsibility to respect patients' autonomous choices and to support patients' participation, to the greatest degree possible, in making decisions about their health care when patients desire to participate. To determine whether a patient is able to make an autonomous choice, clinicians must have an accurate understanding of decision-making capacity and how it is assessed. We intend this report to serve as a catalyst for education and discussion about the assessment of decision-making capacity, thereby promoting ethical healthcare practices essential to quality patient care.

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