

Ten Myths About Decision-Making Capacity



*A Report by the National Ethics Committee
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Founded in 1986, the National Ethics Committee (NEC) of the Veterans Health Administration (VHA) is an interdisciplinary group authorized by the Under Secretary for Health through the National Center for Ethics. The NEC produces reports on timely topics that are of significant concern to practicing health care professionals. Each report describes an ethical issue, summarizes its historical context, discusses its relevance to VHA, reviews current controversies, and outlines practical recommendations. Previous reports have been useful to VHA professionals as resources for educational programs, guides for patient care practices, and catalysts for health policy reform. Scholarly yet practical, these reports are intended to heighten awareness of ethical issues and to improve the quality of health care, both within and beyond VHA.

Executive Summary

Assessment of decision-making capacity is critical, since it determines whether a patient's health care decisions will be sought and accepted. Because so much hinges on decision-making capacity, clinicians who care for patients have an ethical obligation to understand this concept.

This report by the National Ethics Committee of the Veterans Health Administration (VHA) provides clinicians with practical information about decision-making capacity and how it is assessed. As background for this report, we conducted an empirical study of clinicians and ethics committee chairs. Drawing from the results of this study, we identified ten common myths about decision-making capacity, which are explained in this report:

- Myth 1. Decision-making capacity and legal competency are the same.
- Myth 2. Lack of decision-making capacity can be presumed when patients go against medical advice.
- Myth 3. There is no need to assess decision-making capacity unless patients go against medical advice.
- Myth 4. Decision-making capacity is an "all or nothing" phenomenon.
- Myth 5. Cognitive impairment equals lack of decision-making capacity.
- Myth 6. Lack of decision-making capacity is a permanent condition.
- Myth 7. Patients who have not been given relevant and consistent information about their treatment lack decision-making capacity.
- Myth 8. Patients with certain psychiatric disorders lack decision-making capacity.
- Myth 9. Patients who are involuntarily committed lack decision-making capacity.
- Myth 10. Only mental health experts can assess decision-making capacity.

By describing and debunking these common misconceptions the report aims to prevent potential errors in the clinical assessment of decision-making capacity, thereby supporting patients' right to make autonomous choices about their own health care.

Introduction

Clinicians have both an ethical and a legal obligation to ensure that patients are informed about and allowed to participate in choices regarding their own health care. This obligation is rooted in 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.¹

Autonomous choices have three central characteristics: they are adequately informed, they are voluntary instead of coerced, and they are rational.² Patients who are unable to make autonomous choices are said to lack "decision-making capacity" (President's Commission, 1982).³ The concept of decision-making capacity is pivotal, since assessments of decision-making capacity determine whether patients are empowered to make their own health care decisions, or whether someone else is empowered to make decisions for them. Without decision-making capacity, patients are considered unable to make autonomous choices.

For many patients, decision-making capacity is never in doubt. Some patients (e.g., those in a coma) are clearly incapable of making decisions about their care, while other patients are unquestionably capable. In routine clinical practice, decision-making capacity is often assessed informally or inconsistently.⁴⁻⁵ But when decision-making capacity is questionable and important clinical decisions must be made, the process for assessing decision-making capacity should become more formal and explicit.

Responsibility for assessing decision-making capacity belongs with the clinician who is in charge of the patient's care. Because so much hinges on capacity assessments, all clinicians who care for patients have an ethical obligation to understand decision-making capacity and how it is assessed.

Misconceptions about decision-making capacity and its assessment are surprisingly common. As background for this report, we surveyed members of the Academy for Psychosomatic Medicine (most of whom are consultation liaison psychiatrists), geriatrician and psychologist members of the Gerontological Society of America, and chairs of ethics committees in VA Medical Centers. We asked respondents to rate, in their experience, the frequency and importance of 23 potential pitfalls in capacity assessment. Based on over 900 survey responses, we identified ten items that were rated as "common" by over 50% of survey respondents and "important" by over 70%. These ten "common myths" form the basis for this report. (The empirical study will be described in more detail in a separate manuscript.)

Myth 1. Decision-making capacity and legal competency are the same.

Although decision-making capacity and competency both describe patients' ability to make decisions, they are *not* synonymous. Whereas competency is determined by a court of law, decision-making capacity is a clinical assessment.

Competency is a legal term – to say a person is incompetent indicates that a court has ruled the person unable to make valid decisions and has appointed a guardian to make decisions for the person.⁶⁻⁸ Sometimes courts restrict the guardian's decision-making authority to particular domains in which the patient has a specific lack of capacity, such as financial decisions or health care decisions.⁷ Though the legal process of determining incompetence varies from state to state, it is often lengthy, expensive, and emotionally draining.⁶⁻⁷ For this reason, the legal process is typically reserved for people who are very impaired, not expected to recover, and making decisions that adversely affect their well-being.

In contrast to legal competency, decision-making capacity is assessed by clinicians as an everyday part of clinical care. Decision-making capacity is defined as the ability "to understand and appreciate the nature and consequences of health decisions and to formulate and communicate decisions concerning health care".⁹ Although clinicians do not have the power to determine whether patients

are incompetent as a matter of law, they do have the *de facto* power to determine that a patient is incapable of making health care decisions and to identify a surrogate decision maker to act on the patients' behalf. Moreover, legal challenges to clinician's capacity assessments are rare.

VA policy specifies that patients who have been judicially determined to be incompetent should be considered to lack decision-making capacity as well.⁹ If a clinician believes that a patient who is legally incompetent does in fact have the capacity to make a particular health care decision, the clinician should immediately seek advice from an ethics committee and/or legal counsel.

The word "incompetent" also has another meaning unique to the Department of Veterans Affairs: it is the term used to describe an official determination of a veteran's capacity to manage VA funds. A decision that a veteran is incompetent in this sense, however, does not imply that the veteran is legally incompetent or lacks decision-making capacity for health care.

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 that seems ill advised. Determining decision-making capacity involves assessing the process the patient uses to make a decision, not whether the final decision is correct or wise.^{5,10} Sound decision-making requires the following four elements:¹¹

1. Capacity to communicate choices;
2. Capacity to understand relevant information;
3. Capacity to appreciate the situation and its consequences;
4. Capacity to manipulate information rationally.

Clinicians should not automatically assume that a patient who makes an apparently unwise decision lacks decision-making capacity, nor should they accept without question a decision that markedly deviates from the patient's own previously stated values and goals. While the concept of patient autonomy requires that patients be permitted to make even idiosyncratic decisions, it is the responsibility of the clinician to assure that an idiosyncratic decision is not due either to a problem with decision-making capacity or to a misunderstanding that needs to be resolved.

Myth 3. There is no need to assess decision-making capacity unless patients go against medical advice.

While clinicians should not presume incapacity in patients who make decisions that are contrary to medical advice, nor should they overlook incapacity in patients who go along with whatever clinicians recommend.¹² The fact that a patient is agreeable and cooperative should *not* be interpreted as evidence that the patient is capable of making an informed decision. A patient may 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. Instead, patients often have decision-making capacity with regard to some decisions but not others. In addition to assessing a patient's capacity to make health care decisions, a clinician may also be asked to assess a patients' ability to make choices about living independently, handling funds, or participating in research.^{8,13} Each type of decision requires different skills and therefore requires a separate, independent assessment. Patients should be empowered to make their own decisions, except those for which they lack specific capacity.^{5,9-10,12,14}

Even within the realm of health care decisions, capacity is not an “all or nothing” concept. Rather, because health care decisions vary in their risks, benefits and complexities, patients may be able to make some decisions but not others.^{4,11,14-16} For example, a mildly demented patient may 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 may 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 health care decisions, clinicians must assess each decision separately.

Finally, capacity is not “all or nothing” in the sense that patients who lack decision-making capacity may still have wishes that should not be entirely ignored. Incapacitated patients, including those who are legally incompetent, should be allowed to participate in decision-making to the extent that they are able. For example, a patient may have a guardian appointed because of fluctuating capacity stemming from mental illness such as bipolar disorder or schizophrenia. In such a case, 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 guardian, 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 health care decision, cognitive ability encompasses a broad range of processes including attention, memory, and problem solving. Perhaps the simplest and most common cognitive test assesses “orientation to person, place, and time” by asking patients for their name, their location, and the date. Another widely used test called the Folstein Mini-Mental State Examination (MMSE), which takes about 5 minutes to administer, measures attention, concentration and memory.¹⁷⁻¹⁸

While cognitive ability and decision-making capacity are correlated, cognitive tests should not be used as a substitute for a specific capacity assessment.¹⁹⁻²¹ Some patients who lack decision-making capacity may have high scores on the MMSE,^{20,22} while patients who perform poorly on the MMSE may be capable of making some health care decisions.^{4,13,23}

Unfortunately, there is no single gold standard test for determining decision-making capacity that is universally accepted. In fact, in complex cases, experts may disagree in their capacity assessments of the same patient.^{8,24} In recent years, several instruments have been developed that increase the reliability of clinical assessments,²⁴⁻²⁷ but none of these are in common use.

On a practical level, how should decision-making capacity be assessed? The model questions listed in Table 1 represent one common sense approach.

Myth 6. Lack of decision-making capacity is a permanent condition.

Lack of decision-making capacity is *not* always permanent; in fact, it is often only short-lived. Patients' capacity to make health care decisions may wax and wane over time, especially in patients with evolving medical or mental health disorders.⁵ Patients may be temporarily incapacitated, for example, as a result of general anesthesia. Another common cause of temporary incapacity is delirium: a transient mental syndrome characterized by global impairments in cognition, especially inattention, that most often affects hospitalized patients. Delirium develops in the context of severe medical or surgical illness. In patients with delirium, capacity may fluctuate substantially over hours to days, or between one hospital admission and another.²⁸ In such patients, decision-making capacity

Table 1: Model Questions for the Assessment of Psycholegal Capacities²⁹

Ability to render a choice

1. Have you decided whether to go along with your doctor's suggestions for treatment? Can you tell me what your decision is? (Can be repeated to assess stability of choice.)

Ability to understand relevant information

1. Please tell me in your own words what your doctor told you about:
 - a) the nature of your condition
 - b) the recommended treatment (or diagnostic test)
 - c) the possible benefits from the treatment
 - d) the possible risks (or discomforts) of the treatment
 - e) any other possible treatments that could be used, and their risks and benefits
 - f) the possible risks and benefits of no treatment at all
2. You mentioned that your doctor told you of a (percentage) chance the (named risk) might occur with treatment. In your own words, how likely do you think the occurrence of (named risk) might be?
3. Why is your doctor giving you all this information? What role does he/she expect you to play in deciding whether you receive treatment? What will happen if you decide not to go along with your doctor's recommendation?

Ability to appreciate the situation and its consequences

1. Please explain to me what you really believe is wrong with your health now.
2. Do you believe you need some kind of treatment? What is treatment likely to do for you?
3. What do you believe will happen if you are not treated?
4. Why do you think your doctor has recommended (specific treatment) for you?

Ability for rational manipulation of information

1. Tell me how you reached the decision to accept (reject) the recommended treatment.
2. What were the factors that were important to you in reaching the decision?
3. How did you balance those factors?

needs to 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 decision-making. Under such circumstances, conversations may 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 may 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 be able to make an informed decision. Therefore, 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 may be more conscientious than others in providing information, or more skilled at communicating in a way that is easily understandable to patients. 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.⁵

The clinician must inform the patient of the expected benefits and known risks of the recommended intervention, as well as the risks and benefits of all reasonable alternatives, including no intervention. The legal standard for how much information a clinician is required to provide varies depending on the jurisdiction. In approximately half of the states, and in the Department of Veterans Affairs, the clinician must disclose what a “reasonable person” would want to know in order to make the decision.^{6,9,30}

In addition to providing adequate information, clinicians should also assure that the information they provide is understood. Some patients may be capable of making health care decisions, but 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 may improve patient understanding include communicating both verbally and in writing, presenting information at the appropriate reading level, use of personnel specially trained to bridge language or cultural barriers, and enlistment of the patient’s support system to convey information.^{5,13,31-32}

Myth 8. 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 the patient lacks the capacity to make health care decisions—in fact, patients with serious disorders such as Alzheimer’s disease or schizophrenia often retain decision-making capacity.^{5,13,33-36} 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 with psychosis could be competent.³⁷

Although a particular psychiatric diagnosis does not necessarily imply incapacity, the most common causes of incapacity include delirium and dementia. Therefore, the presence of such syndromes should alert clinicians to assess decision-making capacity with special care.^{4,5,10}

Myth 9. Patients who are 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 unable to take care of themselves. Although involuntarily committed patients often lack the capacity to make health care 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 health care decisions, except decisions for which they lack specific capacity, and should be allowed to participate in all decisions to the extent that they are able. In addition, involuntarily committed patients may be entitled to extra protections under federal regulations and state law.⁷ For example, a

VA clinician who wishes to administer a psychotropic medication against the will of an involuntarily committed patient is legally obligated to follow special due process requirements.⁹

Myth 10. Only mental health experts can assess decision-making capacity.

Although assessments of decision-making capacity are often conducted by mental health professionals, especially psychologists and psychiatrists, mental health experts are *not* the only clinicians who can assess decision-making capacity. Rather, all clinicians who are responsible for the care of patients should be able to perform routine capacity assessments. Psychiatrists and psychologists have specific expertise in the diagnosis and treatment of many of the disorders that cause incapacity; however, for many routine cases, decision-making capacity is best assessed by the clinician who is responsible for the patient's care.³⁸

Assessment by the primary clinician may be advantageous for several reasons. First, while 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, the primary clinician has the advantage of multiple encounters over time. Second, a clinician who has a longitudinal relationship with the patient may 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.^{5,10} Finally, the clinician who is responsible for the patient's care has the benefit of familiarity with the risks and benefits of the recommended intervention and its alternatives.

On the other hand, consultations from mental health professionals may be invaluable, especially in cases where capacity assessment is particularly challenging. For example, primary clinicians may need help from mental health consultants in assessing the capacity of patients with severe personality disorders, in whom distinguishing poor judgment from lack of decision-making capacity can be difficult.³⁹ Moreover, for many patients with impaired decision-making capacity, mental health professionals can provide useful recommendations for further evaluation and treatment of an underlying mental disorder. Recognizing this, VA policy requires consultation with a psychiatrist or psychologist for all patients whose lack of capacity results from mental illness such as schizophrenia or a mood disorder.⁹

Whether or not a mental health consultant renders an opinion about capacity, the final responsibility for capacity determination rests with the primary clinician.¹⁰ In cases where professionals cannot reach agreement about a patient's decision-making capacity, an ethics committee should be consulted.

Conclusion

All clinicians have an ethical responsibility to support and respect patients' autonomous choices. 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. This report is intended to serve as a catalyst for education and discussion about the assessment of decision-making capacity, thereby promoting ethical health care practices essential to quality patient care.

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Report Authors: Linda Ganzini, MD; Ladislav Volicer, MD, PhD; William Nelson, PhD; Ellen Fox, MD; Arthur Derse, MD, JD.

Committee Members: Arthur Derse, MD, JD (Chair); Michael D. Cantor, MD, JD; Jeni Cook, DMin; Sharon P. Douglas, MD; Linda K. Ganzini, MD; Ginny Miller Hamm, JD; Kathleen A. Heaphy, JD; Joanne D. Joyner, DNSc, RN, CS; Gerald J. Mozdierz, PhD; Judy Ozuna, ARNP, MN, CNRN; Peter Nim Kwok Poon, JD, MA; Paul J. Reitemeier, PhD; Randy Taylor, PhD; Ladislav Volicer, MD, PhD; Ginger Schafer Wlody, RN, EdD, FCCM.

Consultant to the Committee: Michael J. O'Rourke

Steering Committee Members: Joan E. Cummings, MD; Thomas V. Holohan, MD.

Director, National Center for Ethics in Health Care: Ellen Fox, MD.