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Assessment of decision-making capacity in adults

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INTRODUCTION

The capacity to make one's own decisions is fundamental to the ethical principle of respect for autonomy and is a key component of informed consent to medical treatment. Determining whether an individual has adequate capacity to make decisions is therefore an inherent aspect of all clinician-patient interactions.

The main determinant of capacity is cognition, and any condition or treatment that affects cognition may potentially impair decision-making capacity. In the presence of cognitive impairment from any cause, determining whether a patient has adequate capacity is critical to striking the proper balance between respecting patient autonomy and acting in a patient's best interest. A skillful capacity assessment can also help determine the severity of a patient's cognitive impairments and improve the effectiveness of conversations with patients and their families.

These skills are especially important in the care of adult patients who have diseases that impair cognition. Patients with traumatic brain injury (TBI), psychiatric illnesses (eg, schizophrenia, bipolar disorder, and unipolar major depression), and neurodegenerative diseases (eg, Alzheimer disease [AD] and Parkinson disease [PD]) are at risk for impaired capacity. Hospitalized patients and older adults are also at risk due to cognitive impairment from chronic diseases, cognitive aging, and delirium [1].

This topic reviews the definition of capacity, predictors of impaired capacity, when and how to assess capacity, and how to incorporate an assessment of capacity into clinical judgments about

the ability of patients to choose their treatment. Informed consent, advance care planning, advance directives, and medical decision-making at the end of life are discussed separately. (See ["Informed procedural consent"](#) and ["Advance care planning and advance directives"](#) and ["Ethical issues in palliative care"](#) and ["Legal aspects in palliative and end-of-life care in the United States"](#).)

DEFINITIONS

Capacity and competency — Capacity describes a person's ability to make a decision. In a medical context, capacity refers to the ability to utilize information about an illness and proposed treatment options to make a choice that is congruent with one's own values and preferences. Capacity is defined around a specific medical decision; individuals may have capacity in one clinical context but not in another and vice versa.

The law and ethics have settled on four decision-making abilities that constitute capacity: understanding, expressing a choice, appreciation, and reasoning ([table 1](#)) [2]. A formal assessment of an individual's decision-making abilities in the context of a specific medical decision constitutes an assessment of capacity; the capacity assessment focuses on a person's ability to transact a decision about a particular set of options. (See ["How to assess capacity"](#) below.)

The terms "capacity" and "competence" are sometimes used interchangeably, but historically they have held separate although overlapping meanings. Capacity is most often used to denote an individual's decision-making abilities in the context of a specific choice, such as medical treatment. Clinicians assess capacity in order to decide whether patients can make their own decisions. By contrast, competence refers to a legal judgment, informed by an assessment of capacity, relating to whether individuals have the legal right to make their own decisions [3].

Informed consent — The term "informed consent" is the process by which competent adults make voluntary decisions following adequate disclosure of the relevant information [4]. Informed consent allows a clinician to achieve a balance between respecting patient autonomy versus exercising beneficence on behalf of a patient. In order for consent to be valid, the patient must have adequate capacity to make decisions. The decisions of patients who provide valid informed consent or dissent should be respected. Conversely, patients who lack capacity cannot provide informed consent (or dissent), and clinicians must turn to someone else to decide for the patient, even if the patient agrees with the recommended treatment.

Additional information about informed consent is discussed separately. (See ["Informed procedural consent"](#).)

How capacity differs from cognition and function — Capacity is related to but distinct from cognition. Cognition is a more general concept that describes the various functions of the brain. Capacity is also conceptually distinct from functional status, which includes activities such as the ability to manage medications [5]. It is possible that a person who is unable to perform a functional task is capable of deciding how someone else can assist them to manage the task.

There is an ethical reason to distinguish capacity from cognition and function. Questions such as "Can you tell me in your own words how you might benefit from having your medications set up in a pill box?" (a question that assesses appreciation of benefit) ask patients to express values about the risks they are willing to take to live their lives and the benefits that are important. Clinicians should ask patients who can communicate these kinds of questions out of a moral and professional obligation to learn the patient's values and thereby respect the patient as a person, regardless of their diagnosis or the severity of their cognitive or functional impairments.

FACTORS ASSOCIATED WITH IMPAIRED CAPACITY

General principles — Any illness or treatment that compromises cognition may be associated with reduced capacity. The likelihood of diminished capacity is related to the severity of cognitive impairment, although brief measures of overall cognition such as the Mini-Mental State Examination (MMSE) are not a substitute for an assessment of capacity. While low scores (eg, <16 out of 30 points) in patients with dementia due to Alzheimer disease (AD) are highly correlated with impaired capacity, higher scores may or may not correlate with full capacity to make decisions. (See ["Neurodegenerative disease"](#) below.)

Additional general principles include the following:

- Diagnostic labels such as AD or mental illness cannot substitute for an assessment of capacity. (See ["High-risk groups"](#) below.)
- Performance on measures of capacity has limited association with the severity of mood and other neuropsychiatric symptoms. (See ["Psychiatric disorders"](#) below.)
- Among individuals without neurologic or psychiatric symptoms or disorders, a small proportion nonetheless have impairments in capacity. In a study of treatment consent

capacity among 82 inpatients with ischemic heart disease, impaired understanding was present in 7 percent [6]. (See '[Hospitalized adults](#)' below.)

- Decision-making capacity is not static. To the extent that cognition is impaired by reversible factors such as delirium or medication side effects, treatment of the underlying condition can improve decision-making capacity. This is particularly relevant in hospitalized patients.

High-risk groups

Neurodegenerative disease — Dementia is the most common cause of impaired capacity in adults in the outpatient setting.

- **Alzheimer disease** – Among various forms of dementia, AD dementia is the most prevalent and widely studied with respect to decisional capacity. Numerous studies in patients with AD have examined the capacity to make a variety of decisions, such as completing an advance directive, enrolling in research, taking a treatment, voting, and managing functional problems [7-11].

A review of 32 studies of capacity in patients with AD identified the following key points [12]:

- The MMSE score can assist in stratifying the risk that an individual with AD lacks capacity. Scores in the moderate to severe range (<16) are highly correlated with an inability to understand and appreciate, while scores in the mildly affected range (>24) correlate with retained decision-making abilities. Scores between these values show variable sensitivity and specificity, indicating the need to perform a decision-specific capacity assessment. (See '[How to assess capacity](#)' below.)
- The abilities to express a choice and to provide some reasoning about that choice are often preserved in patients with AD, even among those with severe-stage dementia. If a capacity assessment is restricted to just these two abilities, as it may be for certain low-risk decisions, even patients with severe-stage dementia are likely to be judged to have adequate capacity. (See '[How the capacity assessment informs clinical judgment](#)' below.)

Among patients with mild- to moderate-stage dementia, verbal reasoning and verbal memory are the two cognitive domains that explain most of the performance on measures of capacity to consent [13]. Verbal reasoning and conceptualization are associated with measures of executive function (eg, setting goals and planning), semantic

memory (general facts and meanings that are common knowledge), and attention, whereas verbal memory correlates with immediate and delayed verbal recall. These findings make intuitive sense, since a capacity interview requires a person to attend to information, encode it, and integrate it.

Measures of insight on formal neuropsychiatric testing have also been shown to correlate with decision-making capacity [10,11]. In a cohort of patients with mild to moderate AD (n = 48) who were assessed with the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), the following measures of insight were independently associated with being judged capable of consent to treatment [11]:

- Do you have problems with your memory and thinking?
 - Will those problems get worse?
 - Do you have AD or dementia?
- **Parkinson disease** – Patients with Parkinson disease (PD) are also at risk for impaired capacity. Compared with age-matched, cognitively normal controls, patients with PD dementia as well as those with milder cognitive impairment are more likely to have impairments in their decisional abilities [14-17].

In a study of research consent capacity in 90 patients with PD whose cognitive function ranged from normal to dementia, only 3 percent of those with PD dementia were able to consent to a neurosurgical trial and only 17 percent were able to consent to a drug trial [14]. Even among the 30 patients with only borderline cognitive impairment, capacity impairments were still present: 57 percent were judged able to consent to the surgical trial and 67 percent to the drug trial. Almost all patients with normal cognition were judged capable of providing their own informed consent for both the surgery and drug trials (83 and 97 percent, respectively).

As in patients with AD, brief tests of cognitive function in patients with PD can be useful in predicting the likelihood of impaired capacity. Scores on both the MMSE and the Montreal Cognitive Assessment (MoCA) have been shown to correlate with capacity to consent to complex research studies. In one study, a MoCA score ≤ 22 had a sensitivity of 90 percent for detecting individuals incapable of providing their own consent [14].

Psychiatric disorders

- **Schizophrenia** – Among psychiatric patients, those with schizophrenia are at particularly high risk for impairments in capacity. A review of 12 studies found that impaired performance on at least one measure of decisional ability was present in 10 to 52 percent

of patients with schizophrenia, compared with 0 to 18 percent of controls [18]. Capacity impairments were more common among hospitalized patients compared with community-dwelling patients, schizophrenic patients with more severe cognitive impairment, and those with negative symptoms (eg, paucity of speech, lack of initiative, and flat affect).

Patients with other psychotic disorders (eg, schizoaffective disorder) as well as bipolar mood episodes with psychotic features and unipolar major depression with psychotic features may also be at risk for impaired capacity, but there are fewer studies in these patients.

- **Depression** – Depression appears to have less impact on decision-making abilities than has been assumed, suggesting that the label of mental illness is not sufficient to raise concerns about capacity impairment. In a study of treatment consent capacity in 92 patients hospitalized for depression, impaired understanding was present in 5 percent, impaired reasoning in 8 percent, and impaired appreciation in 12 percent [19]. Another study found that outpatients with depression typically performed well on all four decision-making abilities [20].
- **Substance abuse** – Substance abuse may be one of the more common reasons for clinicians to question decisional capacity, particularly in the general medical inpatient setting. In one study of over 300 consecutive psychiatric consultations for decisional capacity at an urban hospital, 41 percent of patients had substance use disorder. Of these, 37 percent were found to have impaired decisional capacity [21]. In comparison, capacity was impaired in 17 percent of those with mood disorder and 54 percent of those with cognitive disorder.

Traumatic brain injury — Patients with traumatic brain injury (TBI) across a range of severities are at risk for impairments in capacity that may improve over time. The severity of the injury generally correlates with the severity of impairment in decision-making capacity.

In a cross-sectional study that included 86 patients with TBI evaluated at one month after injury, impairments in decision-making abilities were present in less than 30 percent of those with mild TBI, 50 percent of those with complicated mild TBI, and more than 50 percent of those with moderate or severe TBI [22]. At 6 and 12 months of follow-up, all three groups showed recovery in performance, although some patients with moderate to severe TBI continued to have impairments [23,24]. Recovery of capacity has been associated with baseline measures of executive function and working (short-term) memory [25,26].

Hospitalized adults — Impaired capacity is common among adults hospitalized for medical illness. In a study that assessed capacity in randomly selected inpatients (n = 159) with a standardized instrument, capacity was impaired in 31 percent [27]. Decisional ability impairments were associated with increasing age and the overall severity of cognitive impairment as measured by the MMSE. Impairments were not associated with the severity of other psychiatric symptoms as measured by the Brief Psychiatric Rating Scale.

End of life — Diminished decision-making capacity at the end of life is common. A study of adults age 60 years or older (n >3700) who died found that decisions about treatment in the final days of life were necessary for 42 percent, but that capacity was impaired in 70 percent [28]. Of those lacking decision-making capacity, approximately one-third did not have advance planning directives. (See "[Advance care planning and advance directives](#)" and "[Legal aspects in palliative and end-of-life care in the United States](#)".)

WHEN TO ASSESS CAPACITY

The assessment of capacity to make decisions is an intrinsic aspect of every clinician-patient interaction, since capacity is required for valid informed consent [29]. In the absence of a reason to question an individual's decision-making, adults are generally assumed to have adequate capacity.

The presence of cognitive impairment from any cause should prompt one to consider a formal assessment of capacity. Cognitive impairment is the main determinant of impaired capacity in clinical practice, recognizing that there are varying degrees of cognitive impairment, and that no single condition invariably predicts impaired capacity. Commonly encountered conditions that often have a clinically significant impact on cognition and thereby decision-making capacity include moderate to severe dementia, delirium, and schizophrenia. (See '[Factors associated with impaired capacity](#)' above.)

In addition to cognition, certain factors related to the decision itself also warrant assessing capacity. These include decisions with high risks, decisions with extreme differences in the magnitudes of risks and benefits, and circumstances in which a patient's decision is inconsistent with prior decisions. In such cases, an individual may be held to a higher standard of decision-making capacity than if the decision were associated with low risk. (See '[How the capacity assessment informs clinical judgment](#)' below.)

HOW TO ASSESS CAPACITY

Capacity is best determined by a face-to-face interview using a series of open-ended questions that relate to the medical decision at hand. The goal of the interview is to evaluate at least one of the four decision-making abilities: understanding, expressing a choice, appreciation, and reasoning. The decision of which ability or abilities to assess is based on factors specific to the decision. A clinician assesses these abilities to inform a judgment about whether an individual has adequate capacity to make the decision in question. (See '[How the capacity assessment informs clinical judgment](#)' below.)

Prior to the interview, the clinician must be versed in the facts of the specific decision. In addition, a review of the patient's medical record should identify conditions that raise the likelihood of impaired capacity. The more a clinician knows the patient as a person (eg, where they live, their family, how they spend a typical day), the better the clinician can respect the patient's autonomy and identity.

Capacity reflects a spectrum of decision-making ability; thus, adults are typically described as having adequate decisional capacity, marginal capacity, or inadequate capacity ([table 1](#) and [table 2](#)). Capacity assessments begin with the presumption that a person has adequate capacity to make decisions.

The decision-making abilities — There are four generally accepted decision-making abilities that constitute capacity ([table 1](#)):

- Understanding
- Expressing a choice
- Appreciation
- Reasoning

The following case exemplifies these components. An 80-year-old man declines his clinician's prescription for [metformin](#) for the treatment of his diabetes, explaining, "No, don't bother, doc. I take too many pills." In this brief dialogue, the patient demonstrates two of the four decision-making abilities. He expresses a choice ("No, don't bother") and he engages briefly in a bit of consequential reasoning ("I take too many pills"). If the standard for judging capacity were based on only these two abilities, then the patient would likely be judged as having adequate capacity to make the decision whether to take metformin. However, an assessment of his understanding and appreciation of the facts with respect to his own situation may show impairments in capacity.

Understanding — In both ethical theory and the law, the ability to understand (that is, to know the meaning of information) is a key decisional ability. In the case of the man who declines to take [metformin](#), his prescribing clinician would want to know whether he knows

what diabetes is, why metformin is indicated, and the benefits and risks of metformin for the treatment of diabetes.

Expressing a choice — Individuals should be able to clearly communicate a choice when presented with multiple treatment options. In the case above, the patient expresses a choice: "No, don't bother." Frequent reversals of choice in the setting of neurologic or psychiatric conditions may indicate lack of capacity [29]. Set against the cognitive skills needed for the other three decisional abilities, expressing a choice seems quite simple. It is, however, best viewed as ethically essential. Regardless of how a patient performs on the other decisional abilities, clinicians ought to aspire to seek a patient's assent. The more ethically challenging circumstance is whether to respect a dissent from a patient whose performance on the other decisional abilities is marginal. (See '[Patient dissents from recommended treatment and has marginal performance on other decisional abilities](#)' below.)

Appreciation — Knowing facts is essential to making a decision, but applying those facts to one's own life is essential to making the decision authentic. The ability to appreciate facts refers to people's ability to recognize how facts are relevant to themselves. Individuals who do not acknowledge their illness due to impaired insight or delusional beliefs may lack capacity on the basis of failed appreciation for the facts.

Patients who can explain diabetes in general terms show understanding of the disease. Stating that they have diabetes and how it affects them now and could affect them in the future shows that they appreciate their diagnosis and prognosis. By contrast, patients who deny they have diabetes do not appreciate their diagnosis, even if they can explain the disease in general terms.

Reasoning — The ability to reason is the ability to compare options (ie, comparative reasoning) and to infer consequences of a choice (ie, consequential reasoning). Like appreciation, reasoning draws on a patient's values and beliefs. A person may, for example, decline a risky and time-consuming hospital-based treatment for a disease because they value being at home with family. The question "How is not having the in-hospital treatment better than having it?" will likely elicit these values, as this question requires patients to compare the consequences of what they want to do with what they do not want to do.

In the case above (see '[The decision-making abilities](#)' above), the patient engaged briefly in a bit of consequential reasoning ("I take too many pills"), as his statement implies that the consequence of one more pill is now having too many pills to take.

Semi-structured patient interview — We suggest assessing capacity with a semi-structured interview ([table 1](#)). Before beginning, it is important to ensure that patients have received

adequate information relevant to making an informed decision about their treatment. This typically includes the diagnosis, the nature and purpose of the proposed treatment, and the risks and benefits of the proposed and alternative treatments, including the option of no treatment at all. (See ["Informed procedural consent", section on 'Informed decision-making'](#).)

The use of a systematic approach with open-ended questions to assess each of the four decision-making abilities improves interrater agreement [30-32]. Samples of open-ended questions to assess all four decision-making abilities and examples of adequate, marginal, and inadequate responses are provided in the tables ([table 1](#) and [table 2](#)). The interview starts with assessing understanding and correcting any factual mistakes. Next, individuals are asked for a choice. The interview then moves to an assessment of appreciation and reasoning about that choice, and finally a reassessment of the choice.

Performance on measures of each decision-making ability may be influenced by baseline cognition and life experience. This can be assessed indirectly by asking about educational and occupational attainment.

The capacity assessment interview provides data that must be integrated with other information about the risks of the treatment decision itself to inform a judgment of whether the patient has sufficient ability to make the decision at hand. (See ['How the capacity assessment informs clinical judgment'](#) below.)

Validated instruments — A variety of instruments exist to measure capacity [12,33]. The advantage of instruments is that they provide a structured interview that produces good interrater reliability. Although validated instruments are not used in routine care, they are useful in complicated cases, those associated with disagreement among various parties, or cases that are likely to be reviewed in court. They are also useful to help clinicians develop and train their skills in capacity assessment.

- **MacArthur Competence Assessment Tool for Treatment** – Among the available instruments, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) [34] is perhaps the most clinically applicable. The instrument and a training video are available for purchase from the publisher. The MacCAT-T provides a structured set of questions to guide an interview to assess capacity to make a treatment decision. The instrument incorporates the particular facts of a patient's treatment decision into the interview questions. It takes between 15 and 20 minutes to administer. Quantitative scores are generated for each of the four decision-making abilities; as with a structured clinical interview, the results must be integrated with other data, particularly the risks and benefits of the decision, to reach a clinical judgment.

- **Assessment of Capacity for Everyday Decisions** – The Assessment of Capacity for Everyday Decision-Making (ACED) is similar in design and structure to the MacCAT-T and exists in the public domain [10]. It assesses the capacity to consent to an intervention to manage a functional problem such as managing finances or medications. The patient-centered and decision-specific format of the ACED is an ethically important feature that assures the clinician performs a decision-specific assessment of a patient's capacity. For each answer, the interviewer scores the patient's answer as adequate (2 points), marginal (1 point), or inadequate (0 points) ([table 2](#)). A summary score is then generated for each decisional ability. As with other instruments, the ACED does not specify an adequate score for each ability; rather, the clinician must interpret the score in the context of the risks and benefits the patient faces. (See '[How the capacity assessment informs clinical judgment](#)' below.)
- **Capacity to Consent to Treatment Interview** – The Capacity to Consent to Treatment Instrument (CCTI) is not as useful for a clinical assessment of capacity compared with decision-specific instruments such as the MacCAT-T or ACED. The CCTI presents a patient a vignette of a hypothetical treatment decision and then asks the patient structured questions that assess each of the decisional abilities [35]. Scoring criteria are then applied to generate summary scores for each of the decisional abilities. The advantage of this vignette-based method is that scores are comparable across patients and disease states. The disadvantage is that the information is not specific to the patient. While scores provide insight into a patient's decisional abilities, they do not measure the patient's ability to make the decision at hand.

Challenges

Patient dissents from recommended treatment and has marginal performance on other decisional abilities — Among the most ethically challenging and emotionally charged challenges is the patient who refuses the indicated treatment and shows only marginal but not entirely impaired performance on other decisional abilities. This is especially problematic when the intervention presents clear benefits and the refusal presents notable risks to the patient's health and well-being.

Such cases warrant consultation with an expert in capacity assessment. That expert, commonly a psychiatrist, may identify remediable barriers such as failures to communicate and mistrust. Still, a patient may persist in dissent. In such cases, a pragmatic resolution is possible. The key is learning from the clinical team the decision they will make if the patient persists in dissenting. If the team intends to treat the patient despite refusal and will use methods such as restraints or involuntary hospitalization, then the capacity assessment and the patient's dissent are

effectively moot. Neither will change what will happen to the patient, though they will exemplify how ethically fraught the patient's care has become. Conversely, if the treating team has no intention to overrule the patient's dissent, then the dissent ought to be respected [36].

Patient refuses a capacity assessment — Patients may decline to participate in a capacity assessment. At times, patient refusal indicates a lack of trust in the clinician or the medical system more generally. Individuals may feel that they are not being treated with respect when their decision-making abilities are being questioned. An approach that focuses on building trust and respect and that addresses interpersonal communication issues can therefore be the most constructive. It can be useful to explain that one of the main goals of a capacity assessment is to better understand the patient's own values and preferences.

When patients persist in refusing assessment, the clinician should explain that a judgment will still need to be made based on the available information so that care can proceed, and that an assessment is an essential source of information. It may help to involve collateral informants such as family members and caretakers to obtain more information. Depending upon the urgency and risks associated with the decision, it may be possible to defer the assessment and revisit on another occasion.

Family does not agree with clinician's assessment — Lack of agreement between a patient's family and the clinician as to whether a patient has capacity is relatively common. Such disagreement is a source of breakdown in the foundation of ethical decision-making and may well be one of the causes of clinical stereotypes such as the "demanding" or "difficult" family. Treatment consent capacity studies in medical inpatients have found only modest agreement between the expert capacity assessors' judgments and the capacity judgments of the patients' relatives, as well as the patients' clinicians [27].

Capacity puts into practice the value of respect for autonomy and concepts of identity and rationality. The priorities placed on these values and concepts may differ according to social and cultural norms and among family members and clinicians. For example, clinicians may prioritize "rationality" and "reasonableness." While such concepts are essential for accord in professional relationships, they are less useful when trying to respect a person's autonomy. Disagreement may also reflect that the family is applying a different standard to assess capacity than what the clinician has used.

In our experience caring for patients with Alzheimer disease (AD) and related dementias, families may rely more upon the patient's expressed choice and reasons for that choice (a standard that would classify most moderate- to severe-stage patients with retained conversational skills as capable), and less upon the patient's understanding and appreciation.

Explaining the results of the assessment of the patient's ability to understand and appreciate can often settle disagreements over whether the patient has capacity to make a decision.

HOW THE CAPACITY ASSESSMENT INFORMS CLINICAL JUDGMENT

The capacity assessment must be integrated with additional patient- and decision-specific data to inform a judgment about whether the patient has sufficient ability to make the decision at hand. Such judgments are decision specific and risk specific. They must respect the patient's values, which are typically evident in answers to questions that assess appreciation and reasoning.

In most cases, this judgment is made by the evaluating clinician. In complex or controversial cases, this judgment may require consultation with an expert in capacity assessment. In rare cases, judicial review and legal designation of competency are required.

In practice, the stringency of the capacity assessment varies directly with the seriousness of the likely consequences of the decision [29]. The clinician must therefore reflect on the risks and benefits of the decision at hand. It is generally accepted that decisions associated with a high risk of negative consequences require a higher standard of decision-making capacity than low-risk decisions.

Similarly, not all four components of the capacity assessment must carry equal weight. The law may guide how to weigh them, as for some decisions, such as involuntary commitment, the law prescribes which decisional abilities must be assessed and not assessed [37]. Whether an ability is assessed and, if it is, the weight given to it is also guided by clinical considerations such as the severity of the risks of the decision.

For example, a patient who declines to take a low-risk and highly beneficial intervention may warrant assessing all four decisional abilities with equal weight, whereas a patient who accepts it may only require adequate demonstration of understanding and choice. Performance will span a spectrum, from clearly capable to clearly not capable. In between are cases of marginal capacity. Settling these may require repeated assessment and careful probing into the questions that yielded marginal performance.

The influence of the risks and benefits of a decision on judgments of capacity has been verified experimentally:

- In one study, expert raters reviewed one of two videos of a patient engaged in a standardized capacity interview for enrollment in either a high-risk neurosurgical research

study (n = 47) or a lower-risk medication study (n = 52) [38]. Experts were more likely to judge that the patient lacked capacity to consent for the high-risk study compared with the lower-risk study (60 versus 30 percent).

- Similar findings were reported in a study of patients with Alzheimer disease (AD; n = 182) who were presented with three distinct decisions: appointing a proxy to consent for research, enrollment in a low-risk medication study, and enrollment in a high-risk neurosurgical study [7]. Independent expert reviewers were much more likely to judge the patients capable of appointing a proxy (62 percent) than of giving their own consent for the medication study (41 percent) or the neurosurgical study (16 percent).

WHAT TO DO WHEN A PATIENT LACKS CAPACITY

The degree and urgency with which to act on findings of impaired capacity depend on multiple factors, including the expected duration of impairment, the severity of the impairment, and the seriousness of the decision.

Unless the urgency of a patient's medical condition requires that a substituted decision be made immediately, efforts should be made to identify and correct any reversible causes of the impairment [29]. This is particularly relevant in hospitalized patients with impaired capacity due to delirium. Treatment of the underlying causes of delirium may restore decision-making capacity.

Patients with mild to moderate cognitive impairment that is not expected to fluctuate may benefit from more intensive efforts at education to improve understanding of the relevant facts, followed by reassessment of decision-making abilities. A randomized trial found that a memory and organizational aid given to patients with mild-stage Alzheimer disease (AD) dementia (n = 80) improved performance on understanding, which in turn increased the likelihood of being judged capable of providing informed consent to enroll in a clinical trial [39]. This enhancement was also effective in a randomized trial with middle-aged and older adults with schizophrenia [40].

For patients whose impairments are severe enough that they are judged to lack the capacity to make a decision, there is a clear ethical obligation to seek out a substitute decision maker. Substitute or surrogate decision makers should ideally have been chosen by the patient in advance. In the absence of a designated surrogate, laws may vary in terms of which people can serve in this proxy role and their hierarchy; in general, the order is the spouse, adult children,

parents, siblings, and other relatives. (See "[Legal aspects in palliative and end-of-life care in the United States](#)", section on 'Surrogate decision makers'.)

When making a substituted decision, the proxy should take into consideration the patient's preferences or, lacking knowledge of these, decide based on what is in the patient's best interests [41]. Studies suggest that proxies may prefer to blend these two standards [42].

Formal guardianship is rarely necessary. A guardian is assigned by a judge in a court of law based upon a legal determination that the patient is decisionally incompetent. In most cases, guardianship proceedings are initiated when a clinician is faced with a major treatment dilemma in a patient who is incapable of making decisions and has no health care surrogate or next of kin. Guardianship is also occasionally necessary if there are multiple first-degree relatives who cannot agree on an approach to medical care despite mediation by the health care team, or if the next of kin is clearly acting in self-interest rather than the best interest of the patient.

Patients with marginal capacity but who still retain the ability to make the decision at hand require planning and follow-up. Advance care planning is crucial at this stage, so that a surrogate has been designated in the event that the patient later loses capacity. Repeated assessments should also be done in follow-up to determine whether capacity has become further impaired.

SUMMARY

- The capacity to make one's own decisions is fundamental to the ethical principle of respect for autonomy and a key component of informed consent to medical treatment. In the presence of cognitive impairment, determining whether a patient has adequate capacity is critical to striking the proper balance between respecting patient autonomy and acting in a patient's best interest. (See '[Introduction](#)' above.)
- "Capacity" describes a person's ability to make a decision. In a medical context, "capacity" refers to the ability to utilize information regarding a proposed treatment option to make a choice that is congruent with one's own values and preferences. The four principal decision-making abilities are understanding, expressing a choice, appreciation, and reasoning ([table 1](#)). (See '[Capacity and competency](#)' above.)
- Any diagnosis or treatment that compromises cognition may impair capacity, and the likelihood of diminished capacity is related to the severity of cognitive impairment. Although impairments in capacity are common in patients with moderate to severe

dementia, certain psychiatric disorders, and delirium, a diagnostic label or brief assessment of overall cognition cannot substitute for an assessment of capacity. (See ['Factors associated with impaired capacity'](#) above.)

- The presence of cognitive impairment from any cause should prompt one to formally assess capacity when a patient is faced with an important decision, recognizing that there are varying degrees of cognitive impairment, and that no single condition invariably predicts impaired capacity. Certain factors related to the decision itself may also warrant assessing capacity, including decisions with high risks or circumstances in which a patient's decision is inconsistent with prior decisions. (See ['When to assess capacity'](#) above.)
- Capacity is best determined by a face-to-face interview using a series of open-ended questions that relate to the medical decision at hand. The goal of the interview is to evaluate at least one of the four decision-making abilities: understanding, expressing a choice, appreciation, and reasoning. All four abilities do not need to be assessed in every interview; the selection of which ability or abilities to assess is based on factors specific to the decision being made. Any clinician can assess a patient's capacity by applying the skills of a semi-structured interview at the bedside or in the clinic ([table 1](#) and [table 2](#)). (See ['The decision-making abilities'](#) above and ['Semi-structured patient interview'](#) above.)
- The capacity assessment must be integrated with additional patient- and decision-specific data to inform a judgment about whether the patient has sufficient ability to make the decision at hand. Such judgments are decision specific and risk specific. In practice, the stringency of the capacity assessment varies directly with the seriousness of the likely consequences of the decision. (See ['How the capacity assessment informs clinical judgment'](#) above.)
- The degree and urgency with which to act on findings of impaired capacity depend on multiple factors, including the expected duration of impairment, the severity of the impairment, and the seriousness of the decision. For patients whose impairments are severe enough that they are judged to lack the capacity to make a decision, there is a clear ethical obligation to seek out a substitute decision maker. (See ['What to do when a patient lacks capacity'](#) above.)

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