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A guide to assessing decision-making capacity

■ ABSTRACT

Many patients have uncertain capacity to make decisions about their care. Determining whether a patient possesses decision-making capacity challenges even the most seasoned of physicians. We illustrate an algorithm devised by Miller and Marin (*Emerg Med Clin North Am* 2000; 18:233–241) that assesses the patient's understanding of his or her condition, ability to process information, and stability of decision-making to determine whether he or she possesses adequate decision-making capacity. Although this algorithm is better than previous approaches, it has limitations and potential problems with its implementation.

■ KEY POINTS

Practicing physicians need an efficient way to determine and document a patient's decision-making capacity and the judgments upon which the determination is based.

Decision-making capacity must be assessed for a specific decision and cannot be inferred to be present or absent on the basis of the patient's diagnosis.

To demonstrate clearly that informed consent (or informed refusal) has been obtained, the physician should document in the patient record the process by which he or she has concluded that the patient has intact decision-making capacity.

PHYSICIANS must care for many patients whose decision-making capacity is questionable or uncertain, ie, who are neither fully capable nor totally incapable of understanding and expressing choices about their treatment. How then should one assess whether a patient has decision-making capacity?

Consider the following clinical scenarios:

Case 1: A patient admitted for sepsis needs a central line for intravenous access. He is confused about place and time. No family members are present. Does he have the capacity to assent to line placement?

Case 2: An older patient with Alzheimer disease and a Mini-Mental State Examination score of 23 of a possible 30 refuses elective cholecystectomy, but his daughter requests that the procedure be done. Does he have the capacity to refuse this treatment? How should his decision-making capacity be evaluated?

Case 3: A severely depressed patient refuses to be treated for acute pneumonia. Does she have intact decision-making capacity? If not, how should one proceed? What if the physician, patient, and family disagree?

■ NO ACCEPTED CLINICAL STANDARD

Patients have the fundamental right of self-determination in medical care. To proceed with a medical intervention that a patient has refused may constitute assault and battery. Conversely, however, to honor the refusal of treatment by a patient who lacks decision-making capacity may subject him or her to needless harm.

A patient's consent must be voluntary and informed, and he or she must have the capacity to give it. He or she must be able to

understand the nature and consequences of his or her decisions, which is the basis for autonomy in the medical setting. Specifically, a patient must possess:

- The capacity to understand and communicate,
- The ability to reason and deliberate, and
- A set of values and goals.¹

There is, however, no single clinically accepted standard of decision-making capacity.² Current medical textbooks provide very limited discussions of it and do not help internists with determining its presence or absence.^{3,4}

Most often, physicians question patients' decision-making capacity when patients disagree with the physician; however, agreement with the physician does not imply that this capacity is intact. Therefore, we should assess a patient's decision-making capacity *before* asking for consent, to avoid the situation in which disagreement with the physician is the reason for questioning the patient's capacity.

■ NOT THE SAME AS COMPETENCE

Physicians commonly confuse competence and decision-making capacity. Competence and incompetence are legal designations determined by courts and judges. Decision-making capacity is clinically determined by physician assessment.

In 1914, in the case of *Schlowndorff v. Society Hospital*, Judge Cardozo expressed the doctrine of informed consent: "Every human being of adult years and sound mind has a right to determine what should be done with his own body."⁵ All adults are presumed competent legally unless determined incompetent judicially.

An adult who possesses legal competence, however, may lack the capacity to make specific treatment decisions. Specific decision-making capacity should be determined by a physician's evaluation rather than by the courts.⁶

In 1982, The President's Commission for the Study of Ethical Problems in Medicine⁷ recommended that decision-making capacity be assessed at the bedside and that routine recourse to the legal system be avoided. It also specified that decision-making capacity should be specifically determined for the particular clinical situation.

■ CONSIDER THE URGENCY OF THE SITUATION

When a physician encounters a patient with questionable decision-making capacity, the urgency of the clinical situation determines how to proceed.

We generally assume that a reasonable person would not want to be denied life-saving treatment, and we thus institute standard medical interventions in life-threatening situations. For example, standard emergency care would include aggressive resuscitative measures for an unconscious patient presenting in respiratory distress even if no one were present to provide consent.

For the patient with sepsis in case 1 above, it would be correct to insert a central intravenous line, since the situation is life-threatening and the physician would appropriately assume that reasonable persons would desire life-saving treatment.

In nonemergent clinical situations, however, treatment decisions can be much more difficult because the physician must determine whether the patient has adequate decision-making capacity, and if not, then seek a substitute decision-maker. In addition, the balance of risk and benefit may require a different level of decision-making capacity. As discussed by Drane,⁸ a simple intervention with a low risk and high benefit (eg, drawing blood to measure the hematocrit) may require only simple assent; however, a procedure with substantial risk and uncertain benefit (eg, pneumonectomy for lung cancer in a patient with significant coronary artery disease) requires substantial reasoning and understanding by the patient.

This "sliding-scale" approach, whereby the relative balance of risk and benefit determines the degree of decision-making capacity required, contrasts with the following algorithm, which evaluates decision-making capacity without considering the risks and benefits of the treatment.

■ AN ALGORITHM FOR ASSESSING DECISION-MAKING CAPACITY

Miller and Marin² devised an algorithm for assessing decision-making capacity that consists of a series of questions:

Assess decision-making capacity before asking for consent



1. Do the history and physical examination confirm that the patient can communicate a choice?

- *If yes:* Proceed to the next question.
- *If no:* Defer to an advance directive or surrogate decision-maker for further direction or seek guardianship for decision-making.

Comment. Patients must be able to communicate their choices, and those choices must remain stable long enough to be implemented (see question 5, below). Either of these requirements may be affected by an impairment of consciousness, thought disorder, disruption in short-term memory, or degree of ambivalence so extreme that it produces repeated rapid alterations of choice.

2. Can the patient understand the essential elements of informed consent?

Ask the patient the following questions:

- What is your present medical condition?
- What is the treatment that is being recommended for you?
- What do you and your doctor think might happen to you if you decide to accept the recommended treatment?
- What do you and your doctor think might happen if you decide not to accept the recommended treatment?
- What are the alternatives available (including no treatment) and what are the probable consequences of accepting each?

If the physician deems that the patient is able to understand the essential elements of informed consent, then he or she proceeds to the next question. If not, however, then the physician must once again defer to an advance directive or surrogate decision-maker.

Comment. Relevant information must be understood. Patients who cannot understand what they have been told about a treatment cannot decide whether to accept or reject it. Understanding requires more than mere reception and recitation of information but also comprehension of the fundamental meaning of information about treatment. Deficits in attention span, intelligence, and memory may detract from these abilities.

Asking patients to paraphrase information that has been given can help assess their ability to understand relevant information.

Decision-making capacity also requires the ability to appreciate the medical situation that is being explained and the consequences of alternate forms of treatment. The patient must understand the diagnosis and the likelihood of various consequences of treatment or refusal. When these abilities are deficient, decision-making capacity is impaired.

Moreover, the patient must be able to compare the benefits and risks of various treatment options. Decision-making requires the ability to develop conclusions that are logically consistent with the starting premises, weighing risks and benefits of single as well as multiple options simultaneously in a way that reflects their importance. Thought disorders, delirium, dementia, extreme phobias, anxiety, euphoria, depression, and anger can affect this ability.

To assess this ability to manipulate information rationally, one must examine the patient's chain of reasoning. Patients should be able to indicate the major factors in their decisions and the importance assigned to them.⁶

3. Can the patient assign personal values to the risks and benefits of intervention?

- *If yes:* Proceed to the next question.
- *If no:* Defer to either the advance directive or the surrogate decision-maker.

4. Can the patient manipulate the information rationally and logically?

- *If yes:* Proceed to the next question.
- *If no:* Defer to an advance directive or surrogate decision-maker.

5. Is the patient's decision-making capacity stable over time?

The stability of the choice can be examined by repeating a question several minutes later.

- *If yes:* Honor and accept the patient's acceptance or refusal.
- *If no:* Defer to an advance directive or surrogate decision-maker.

Advantages of using the algorithm

There are several reasons for using a structured algorithm to assess capacity.

- This approach documents how decision-making capacity was evaluated. The patient's mental state at the time of this evaluation should also be documented in the record.

Encourage patients to complete advance directives before serious illnesses arise

Family and friends tend to overestimate patients' treatment preferences

- It avoids the tendency to devalue the capacity of chronically ill patients to decide for themselves.⁹

- It does not rely on surrogate decision-makers unnecessarily. In one study, 50 surrogates who had consented to feeding-tube placement in a family member or friend were contacted and completed a questionnaire.¹⁰ One of the questions was whether the surrogate thought that the patient would have agreed to the feeding tube. In 24% of cases, the answer was no, even though the surrogate had agreed to it!

- It does not assume that patients in certain settings lack decision-making capacity. Although the patient with sepsis in case 1 lacked decision-making capacity, in one study, 36% of patients admitted to an intensive care unit retained decision-making capacity at 24 hours.¹¹

- It does not rely solely on “expert” judgment or the MMSE. Agreements between “experts” on decision-making capacity have been poor. MMSE scores in the mid-20s lack sensitivity for cognitive impairment. Up to one third of cases of mental impairment in elderly patients may be missed by relying on expert judgment or the MMSE alone. In a study of 60 medically stable patients 65 years of age and older with MMSE scores of 23 to 30, specific cognitive and functional abilities showed evidence of impairment.¹²

- It does not determine decision-making capacity on the basis of the patient’s treatment decision. Instead, it examines the quality of the decision-making process.¹³

- It does not assume that decision-making capacity is static. Decision-making capacity may vary and be “transitory in duration, subject to waxing and waning, depending on factors such as the time when a person is asked for a decision, location and environment, medications, support systems available, and the effects of temporary, treatable physical ailments.”¹⁴

For example, the depressed patient with pneumonia in case 3 displays questionable decision-making capacity, but if her depression is treated successfully, she should regain appropriate decision-making capacity.

Limitations of the algorithm

- Poor English proficiency can limit the accuracy of decision-making determinations.

The questions may be difficult to translate into some languages owing to cultural differences and a lack of words with similar meanings, and some translators may be limited in their ability.¹⁵

- In some cultures, birth dates are not emphasized and may not be recalled; thus, a failure to know the birth date may be misinterpreted as reduced cognitive ability when it may indicate cultural diversity.^{15,16}

- Because certain Native American values include noncompetitiveness, downplaying achievements, and nonverbal communication, these patients may underachieve when tested for decision-making competence.¹⁶

- Some of the assessment questions, particularly questions 3 through 5, are subjective. For example, how does one evaluate the assignment of personal values (question 3)? What if the patient’s “manipulation of information is rational and logical” in his social or ethnic group but irrational to the physician (question 4)? What period of time constitutes stability of decision-making capacity (question 5)? The physician and patient may disagree on these questions—and so may different physicians.

Using an algorithm: Conclusions

Even though the algorithm has limitations, it provides an objective way to ascertain decision-making capacity for many patients. Until a validated method for documenting a patient’s decision-making capacity is available, it provides a tool for the physician to better determine and document a patient’s decision-making capacity.

A variation of this algorithm called the Capacity Assessment tool¹⁷ attempts to determine gradations of capacity using a numerical scale; however, pilot results are available for only a limited number of patients.

Just as a diagnosis alone is not proof of inadequate decision-making capacity, neither does bad judgment nor a lack of decision-making capacity in one area (eg, money management) mean that a patient lacks decision-making capacity for other decisions.¹⁰ An algorithm such as this one can help clinicians in determining a patient’s decision-making capacity for a specific decision.



■ WHEN SURROGATES MUST BE CONSULTED

In a nonemergent situation, if the patient lacks decision-making capacity, advanced directives or a surrogate decision-maker must be consulted, or a court may need to appoint a guardian for decision-making if there is no surrogate.

In case 2 described above, the patient was able to converse and answer questions; however, when asked to relate what he had been told about the cause of his abdominal pain, abnormal liver tests, and gallstones, he repeatedly answered "I don't know." Clearly, he did not have decision-making capacity. Since he was a widower, his only child served as an appropriate surrogate and agreed with cholecystectomy.

The appropriateness of decisions made by surrogates must also be examined. Surrogates sometimes project their own values and treatment preferences rather than try to determine what the patient's preferences would have been.^{18,19} In a prospective study, Seckler et al²⁰ found that friends and family tended to overestimate the patient's treatment preferences (in this case, believing that the patient would choose to receive cardiopulmonary resuscitation when in fact the patient did not) while physicians tended to underestimate them.

What about the patient with depression and pneumonia in case 3? She was so depressed that even though she understood the nature of her illness, the proposed treatment, and the outcome with and without treatment, she refused treatment and stated that life held insufficient meaning for her. Although the physician may understand how she reached this conclusion, most physicians would have serious doubts whether her decision was rational and logical (see question 4 above).

In this situation and in those in which the patient manifests hypomania, paranoia, or anorexia or gives idiosyncratic reasons for refusing treatment, a psychiatrist may help in determining whether the patient has intact decision-making capacity.²¹

Often, physicians and family members have conflicting interpretations of the best treatment for a patient, especially one lacking decision-making capacity. A formal ethics consultation from the hospital ethics committee can often help resolve conflicting suggestions and identify other options.²²

Because of the complexity of evaluating decision-making capacity, physicians should encourage patients to complete advance directives as part of routine care before serious illnesses and capacity questions arise. ■

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