Determining Decision-making Capacity

View online at http://pier.acponline.org/physicians/ethical_legal/el578/el578.html

Module Updated: 2012-07-20
CME Expiration: 2015-07-20

Author
Herbert S. Diamond, MD, MACP

Table of Contents
1. Background ............................................................................................................................................. 2
2. Indications ............................................................................................................................................... 4
3. Implementation ....................................................................................................................................... 6
4. Complications ......................................................................................................................................... 8
5. Patient Education ................................................................................................................................... 9
6. Follow-up ............................................................................................................................................... 10
References ................................................................................................................................................ 11
Glossary ..................................................................................................................................................... 14
Tables ......................................................................................................................................................... 15

Quality Ratings: The preponderance of data supporting guidance statements are derived from:

A level 1 studies, which meet all of the evidence criteria for that study type;
B level 2 studies, which meet at least one of the evidence criteria for that study type; or
C level 3 studies, which meet none of the evidence criteria for that study type or are derived from expert opinion, commentary, or consensus.

Study types and criteria are defined at http://smartmedicine.acponline.org/criteria.html

Disclaimer: The information included herein should never be used as a substitute for clinical judgement and does not represent an official position of the American College of Physicians. Because all PIER modules are updated regularly, printed web pages or PDFs may rapidly become obsolete. Therefore, PIER users should compare the module updated date on the official web site with any printout to ensure that the information is the most current available.

CME Statement: The American College of Physicians is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing education for physicians. The American College of Physicians designates this enduring material for a maximum of 1 AMA PRA Category 1 Credit™. Physicians should claim only credit commensurate with the extent of their participation in the activity. Purpose: This activity has been developed for internists to facilitate the highest quality professional work in clinical applications, teaching, consultation, or research. Upon completion of the CME activity, participants should be able to demonstrate an increase in the skills and knowledge required to maintain competence, strengthen their habits of critical inquiry and balanced judgement, and to contribute to better patient care. Disclosures: Herbert S. Diamond, MD, MACP, current author of this module, has no financial relationships with pharmaceutical companies, biomedical device manufacturers, or health-care related organizations. Deborah Korenstein, MD, FACP, Co-Editor, PIER, has no financial relationships with pharmaceutical companies, biomedical device manufacturers, or health-care related organizations. Richard B. Lynn, MD, FACP, Co-Editor, PIER, has no financial relationships with pharmaceutical companies, biomedical device manufacturers, or health-care related organizations.

PIER is copyrighted ©2013 by the American College of Physicians. 190 N. Independence Mall West, Philadelphia, PA 19106, USA.
1. Background

- Brief description:
  - Patients have the right to decide which medical treatments and procedures they undergo and which they forgo; however, impairments caused by medical illness, psychiatric illness, or denial may hinder a patient’s ability to make his or her own medical decisions.
  - When a physician is concerned about a patient’s ability to make medical decisions, that physician should assess the patient’s decision-making abilities in order to decide whether a surrogate decision-maker should be enlisted.

- Ethical and legal foundation:
  - The principles of autonomy and self-determination empower patients to participate in their medical decisions. Legal cases from the early 1900s established patients’ rights to determine what is done to their bodies (1).
  - Subjecting a patient to a procedure or treatment without his or her consent is an infringement on that patient's liberty and can be considered battery. “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages” (2).
  - Physicians honor patient autonomy by respecting the patient’s choices. When patients no longer have the capacity to make their own decisions, physicians honor their autonomy by respecting their previous preferences and by asking a surrogate to interpret their previous preferences.
  - In 1982, the U.S. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended that, to make their own decisions, patients need:
    - A set of values and goals
    - Ability to communicate and understand information
    - Ability to reason and deliberate about options (3)

- Legal considerations:
  - Physicians assess decision-making capacity as a part of routine clinical care. Any physician, not just a psychiatrist, has the authority to determine if a patient has decision-making capacity for a specific medical decision.
  - In contrast, “competence” is a legal term. Only the courts can determine if a patient is competent to make one or more decisions. Physicians do not determine if patients are competent but often testify at competency hearings (4).
  - When courts determine competency, they rely on state laws that define incapacity, which differ slightly across states:
    - The New York state law, for example, uses general terms, and incapacity is determined based on “clear and convincing evidence that a person is likely to suffer harm because: 1. The person is unable to provide for personal needs and/or property management; and 2. The person cannot adequately understand and appreciate the nature and consequences of such inability” (5)
    - In Washington state more specific terms are used, and according to Washington law, individuals may be incapacitated if they fall into one of four categories:
      1. “Has a significant risk of personal harm based upon a demonstrated inability to adequately provide for nutrition, health, housing or physical safety”
      2. “Is at significant risk of financial harm based upon a demonstrated inability to adequately manage property or financial affairs”
      3. “Is under the age of majority”; or
      4. “Is incompetent by reason of mental illness, developmental disability, senility, habitual drunkenness, excessive use of drugs, or other mental incapacity” (6)
  - Minors who are not considered emancipated (i.e., those who are not living independently of their parents, not married, or not in the armed forces) cannot legally make their own decisions, even if they have the cognitive skills to do so.
Once a patient is determined to be incapable of making a medical decision, a surrogate decision-maker is identified to make medical decisions on his or her behalf. Thirty-one states have laws listing a legal hierarchy of surrogate decision-makers (7). The order in Washington state, for example, is as follows: court-appointed guardian, DPOA for healthcare, spouse, adult children, parents, and adult siblings. If a patient is married, his spouse becomes his legal surrogate, unless he has completed a DPOA for healthcare, or a legal guardian has been appointed by the courts.

Once identified, surrogates can use one of three standards—known risks, substituted judgment, and best interests—when making medical decisions for others. When the patient's explicit wishes are known, the surrogate is expected to apply them. When using the substituted judgment standard, the surrogate makes the decision that he or she believes the patient would have made. When using the best interests standard, the surrogate selects the medical treatment that he or she personally feels is best for the patient. Ethicists and others have debated the pros and cons of applying each of these standards to a given case (8; 9; 10).

Many patients prefer that their surrogates make decisions based on the actual clinical situation, including both medical and nonmedical concerns, rather than adhering to this sequential decision-making process (11).
2. Indications

2.1 Determine a patient's decisional capacity whenever his or her ability to make medical decisions is in question.

- Patients are presumed to be capable of making their own decisions and giving informed consent unless there is evidence to the contrary.
- Patients must have decision-making capacity in order to:
  - Consent to or refuse a treatment or procedure (13; 14; 15; 16; 17)
  - Complete an advance directive (18)
  - Consent to be a research study participant (19; 20)
  - Leave the hospital against medical advice (15)
  - Return to independent living
- It is especially important to thoroughly assess a patient's capacity to make a decision that will result in an irreversible condition, such as withdrawal of life support that would result in death.
- Any time a physician obtains informed consent from a patient, he or she is informally assessing that patient's decision-making capacity. For example, a physician does not need to do a formal evaluation of a patient's capacity before obtaining a urine sample from that patient to exclude a urinary tract infection.
- A physician will obtain a more formal evaluation of a patient's capacity when the consequences of a decision could be more serious for the patient. For example, a physician should do a more thorough evaluation of a patient's capacity before letting that patient make a decision to undergo a risky surgery.
- Some experts have advocated a sliding scale of decisional capacity. That is, as the complexity of a decision and the risk to a patient increases, more stringent criteria should be employed in determining whether that patient has capacity (21; 22; 23).
- Because higher rates of incapacity are seen in the following groups of patients, physicians should pay particular attention to whether their patients from these categories are capable of making their own decisions (23):
  - Patients who refuse beneficial and low-risk treatments (24)
  - Patients who quickly consent to risky treatments
  - Residents of nursing homes or assisted living facilities (25; 26; 27)
  - Patients who are hospitalized (28; 29)
  - Patients with psychiatric illness (such as depression with suicidal ideation or schizophrenia) (14; 30; 31)
  - Patients with fluctuating mental status (32; 33)
  - Patients who are demented (14; 33; 34)
  - Patients who have had strokes (33)
  - Patients with mild cognitive impairment (35)
  - The types of patients listed above should not automatically be considered incapable of making their own decisions. Many patients who refuse beneficial procedures or who have diagnoses of dementia, delirium, or schizophrenia are capable of making their own decisions (14; 34).
  - Conversely, if a patient agrees to a treatment recommended by a physician, this does not automatically mean she is capable of making her own decisions.
  - Although non-emancipated minors cannot legally make their own medical decisions, they should be presented with age-appropriate information. Lack of competence does not exclude them from the minor's right to have a say (36; 37).
  - A patient with questionable decisional capacity who is not permanently incapacitated should have his or her capacity assessed before each subsequent medical decision.
  - When a patient decides to pursue a treatment with unfavorable outcomes or high risk, his or her physician may want to document an assessment of the patient's capacity (38). If the patient...
sustains a poor outcome, the physician can then explain why the patient opted to undergo that treatment to the patient's family.
3. Implementation

3.1 In determining whether a patient can make his or her own medical decisions, examine the four decision-making abilities: understanding, appreciating, reasoning, and choosing.

- Capacity is determined with respect to making a specific decision. Patients may be capable of making some decisions but not others. Global incapacity, as in the case of coma, is less common than limited capacity. For example, a patient may not be able to decide whether or not to undergo a round of risky chemotherapy but may be able to choose whom he would like to make that decision on his behalf.
- The following steps can be used to assess a patient's decision-making capacity (39):
  - Have a conversation in which you find out what the patient already knows. Find out if the patient wants to make his own medical decisions. Patients with decisional capacity can defer decision-making to a surrogate decision-maker.
  - As you talk to the patient about what he or she knows, you may need to present the medical information to the patient. You should not assume that the patient already knows the pertinent medical information or that others have adequately informed the patient about this information.
  - During this conversation, mention the risks and benefits of the treatment. Include a discussion of any risk of death and of “states worse than death” (40).
  - Consider the patient’s overall cognitive status during this conversation. Is the patient tangential, inappropriate, or factually incorrect? A sample question is “Can you tell me what you know about your (illness or condition)?”
  - Next, determine what the patient understands about her diagnosis or treatment options. The patient should not repeat back what has been discussed verbatim but should put the information into her own words. A sample question is “Can you tell me what we have discussed about how to treat your (illness or condition)?”
  - Assess whether the patient appreciates that the treatment options apply to his situation. For example, a patient who is in denial about a new diagnosis may be able to understand the diagnosis and treatment options but may not appreciate that he has the illness and needs treatment. A sample question is “Which option makes the most sense for you?”
    - Patients should appreciate that they have the right to refuse treatment.
    - In the case of consenting to participate in research, patients must appreciate that their consent is entirely voluntary.
  - Ask the patient to explain the reasoning behind her choice. The patient should be able to explain why she has made a certain choice, and this choice should be consistent with previous decisions and her values. The physician should focus more on the process of coming to the decision than on the actual decision. Sample questions are “Why did you pick that option? What might happen if you don't receive any treatment?”
  - Patients may exhibit one or two different types of reasoning. If a patient can assess the risks and benefits of different treatments, he has comparative reasoning. If he can imagine the consequences of undergoing different treatments, he has consequential reasoning.
  - Determine if the patient consistently maintains that choice over time. A sample question is “Having thought about the treatment options we discussed the other day, what do you think is the best option for you today?”
  - The physician may find it useful to get additional information about the patient's care preferences and values from family members, friends, and other individuals who know the patient well (such as caregivers from the patient's nursing home).
  - There are no specific guidelines about how to make a decision about capacity based on the assessment. Instruments such as the MacArthur Competence Assessment Tool provide information that may be helpful to the physician who is determining decisional capacity but leave the final decision about capacity up to the physician (41). Other validated instruments are available for
assessment of competence for specific tasks, such as competence to sign a consent for participation in research (42).

- The strongest correlate of capacity with focus on understanding and appreciation of disclosed information is cognitive ability (43).

- A patient does not have to have each ability entirely intact and does not even have to possess all four abilities to be deemed capable of making a given decision. The most important options that the patient should understand are 1) what will happen with and without treatment and 2) why the physician is recommending a certain treatment. Ultimately, the decision about the patient's capacity is up to the physician.

- Consider use of decision aids to maximize a patient's decision-making capacity. Decision aids prepare individuals to participate in decisions that involve weighing benefits, harms, and scientific uncertainty (44; 45).
4. Complications

4.1 Be alert to complications and conflicts that may arise in the process of determining whether a patient has decision-making capacity.

- If a patient has fluctuating mental status and does not remember a previous discussion but comes to the same conclusion about a treatment, that choice is likely valid. Because decision-making capacity may fluctuate, physicians should aim to assess a patient's capacity when that patient is doing his or her best (32).
- Patients may wish to participate in health care decisions even when decisional capacity is impaired. Thorough analysis of decisional capacity and use of decisional aids may help in resolving the resulting ethical and practical issues (46).
- Over time a patient may change his or her mind about a treatment and has the right to do so. If this happens, the physician may want to evaluate the patient's reasons for the change.
- A belief that is rational and coincides with the patient's previous statements but results from psychosis (a “fixed false belief”) cannot serve as evidence that the patient has decision-making capacity.
- If a patient refuses a capacity evaluation, the following steps have been proposed (47):
  - If the physician is unable to engage the patient in a discussion about the reasoning for his choice, the physician should ask the patient to identify someone with whom he would feel comfortable having a discussion.
  - If the patient cannot identify anyone, the physician should assess the risks to the patient if his choice is honored.
  - If the risks are high, the case should be handled as if the patient were incapacitated. At this point, the patient should be informed that he will be treated as if he were incapacitated and that this is done in order to protect patients who refuse evaluations and who truly are unable of making their own decisions.
  - Psychiatrists and some psychologists can be consulted to offer a second opinion about a patient's decision-making capacity. If a patient refuses to talk to a psychiatrist, some members of hospital ethics committees also may be capable of making determinations of decisional capacity (4).
  - If the surrogate disagrees with the physician's assessment of the patient's capacity, the physician may want to repeat the evaluation with the surrogate present (48).
5. Patient Education

5.1 Inform patients about aspects of decisional capacity and incapacity while they are still capable of making their own decisions and advise families about these issues before and after a patient becomes incapacitated.

- Tell patients that they have the right to refuse recommended treatments and that refusals do not equal incapacity.
- Inform patients about their right to have their care preferences honored in the future if they become incapable of making decisions and about the ways to do this.
- Patients with decisional capacity should understand that they can defer decision-making to someone else. For example, older patients and patients from certain ethnic backgrounds are more apt to delegate decision-making than younger patients (49; 50; 51).
- Patients should learn who their future legal surrogate would be. If they do not believe this is the best person to make future decisions for them, they should be encouraged to fill out a DPOA for health care to give their preferred surrogate legal standing as a decision-maker. For example, if a patient does not have a DPOA or a spouse, his adult children together would be the surrogate decision-makers. If a patient does not believe that those children would be able to reach consensus, he might want to designate one of them as his DPOA.
- Once patients complete a DPOA, they should be urged to give copies of this legal document to their physician(s), health care facilities, and family members, and discuss their care preferences and goals of care with their physician(s), identified future surrogates, and, if possible, with the rest of the family.
- Patients and their families should be informed that a patient's preferences are easier to honor if these preferences are written down and discussed with a surrogate decision-maker before decisional capacity is diminished or lost.
- Patients with decisional capacity should be made aware that they can revoke a DPOA but cannot revoke a guardianship.
  - A DPOA is a legal document designating the person a patient has selected to make future decisions on his behalf.
  - A legal guardian is selected by the courts after a patient is deemed incapable of making a given decision.
- Families should be encouraged to inform the physician if they have any concerns about a patient's ability to make his or her own decisions.
- Families should understand the concept of limited capacity, i.e., their loved one may be incapable of making some medical decisions but still be capable of making others.
6. Follow-up

6.1 Continue to assess decisional capacity and work with appropriate surrogates to guide care.

- Patients who are not permanently incapacitated should have their decision-making capacity reexamined as new treatment decisions arise.
- After a patient has been found to lack decision-making capacity, medical decisions for that patient should be made by the legal surrogate, who can usually be identified by determining if the patient had previously completed a DPOA for healthcare and by consulting the state law's legal hierarchy of surrogates.
  - If the patient has not designated a surrogate and is widowed, her adult children together act as the surrogate decision-makers.
  - If an incapacitated patient has no family, friends, or designated surrogate, a guardian should be appointed by the courts to make medical decisions on her behalf.
  - In an emergency, if the patient's surrogate cannot be located, the physician can invoke the best-interests standard to make decisions and should err on the side of providing treatment.
- Once the legal surrogate has been identified, the physician may find that the surrogate also is incapacitated. If this happens or if the physician does not believe that the legal surrogate is acting with the patient's best interests in mind, the physician can petition the courts to appoint a guardian.
- In working with surrogates to make medical decisions, follow specific steps to elicit their input and to provide them with information needed to help them make the decision (52). Although surrogates sometimes make decisions that may not seem to match patients' past preferences, studies have shown that patients want their loved ones to use leeway when interpreting their preferences (53; 54).
  - If discussion with multiple surrogates, such as an incapacitated patient's adult children, does not result in a consensus, encourage them to take sufficient time to make a decision if possible, provide them with information about options, avoid a power struggle, and remain true to the fundamental values of all concerned (52).
- See table Steps to Providing Palliative Care to Patients Who Lack Decision-making Capacity.
- See table What to Do If No Consensus Emerges.
Determining Decision-making Capacity

References

5. New York Mental Hygiene Law sec. 81.02.
37. John T, Hope T, Savulescu J, Stein A, Pollard AJ. Children's consent and paediatric research: is it appropriate for healthy children to be the decision-makers in clinical research? Arch Dis Child. 2008;93:379-83. (PMID: 18089635)
43. Palmer BW, Jeste DV. Relationship of individual cognitive abilities to specific components of decisional capacity among middle-aged and older patients with schizophrenia. Schizophr Bull. 2006;32:98-106. (PMID: 16192412)

Determining Decision-making Capacity

Glossary

DPOA
durable power of attorney

Terms

Advance care planning
A method of implementing patient preferences about care in the event that the patient is ever unable to participate in health care decision-making. It can take the form of written directives, conversations between the patient and family, or discussions between the patient and physician that are documented in the medical record.

Competence
Determined by the courts, not physicians

Decision-making capacity
An individual's ability to process information and formulate a coherent decision

Durable Power of Attorney for Healthcare (DPOA)
A legal document that identifies a patient's preferred surrogate decision-maker if that patient becomes incapacitated in the future

Guardianship
The appointment or sanctioning by the court of a person responsible for making decisions on behalf of a patient. The scope of a guardianship can vary from case to case.

Surrogate decision-maker
A person who makes medical decisions for someone else
# Tables

## Steps to Providing Palliative Care to Patients Who Lack Decision-making Capacity

<table>
<thead>
<tr>
<th>Step</th>
<th>Representative Quote to Achieve Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Identify the main participants in the decision-making</td>
<td>&quot;We need to make some decisions about the care of your wife. Is everyone here who could help us think through what we should do?&quot;</td>
</tr>
<tr>
<td>2A. Allow the participants to narrate how the patient has come to this stage of illness</td>
<td>&quot;Can you tell me how she's changed, how things have gone for all of you?&quot;</td>
</tr>
<tr>
<td>2B. In cases where the physician has an extended relationship with the patient and family</td>
<td>&quot;I know I've been caring for your wife for many years, but it helps me if you can tell me how she's changed, how things have gone for each of you.&quot;</td>
</tr>
<tr>
<td>3. Teach the decision-makers about the expected clinical course of the patient's disease</td>
<td>&quot;Your wife has an incurable, progressive, and ultimately fatal disease. I can't say for sure when she'll die of her Alzheimer disease, but given its severity, we shouldn't be surprised when she does.&quot;</td>
</tr>
<tr>
<td>4. Advocate for the patient's quality of life and dignity</td>
<td>&quot;We ought to care for her in a way that makes us confident that after she's gone, we can say she was treated with dignity and respect.&quot;</td>
</tr>
<tr>
<td>5. Provide guidance on the basis of existing data and clinical experience</td>
<td>&quot;For patients like Mrs. B, feeding with a tube does not significantly reduce the risk for pneumonia. On the basis of my experience, a speech therapist can give us some useful hints on ways to feed her that will allow her to continue to eat by mouth.&quot;</td>
</tr>
</tbody>
</table>

Reprinted with permission from [52].
What to Do If No Consensus Emerges

<table>
<thead>
<tr>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postpone the decision-making and recommend that the participants take time to think about and discuss key issues</td>
</tr>
<tr>
<td>Understand and separate from each person's perspective the goals of medical care and the treatment choices to achieve these goals</td>
</tr>
<tr>
<td>Invent new solutions (for example, a time-limited trial rather than an all-or-nothing solution)</td>
</tr>
<tr>
<td>Avoid power struggles or personalizing the conflict</td>
</tr>
<tr>
<td>Call in a third party (for example, trusted clergy, ethics consult, or palliative care consult)</td>
</tr>
<tr>
<td>Don't violate fundamental values of the patient, family, or physician</td>
</tr>
</tbody>
</table>

Reprinted with permission from 52.