THE ETHICS AND PRACTICE OF ASSESSING CAPACITY

Nathan R. Harmon, DO
Maine Dartmouth Geriatric Medicine

Maine Association of Physician Assistants CME Conference 2019

Disclosures

- No financial disclosures
- No discussion of off-label use of medications

Objectives

Participants will be able to:

- State the definition and criteria for decision making capacity for health care decisions
- Explore the ethical considerations that arise for clinical cases in which capacity is questionable.
- Discuss risk factors for diminished medical decision making capacity

Case 1: Locked-In Syndrome

- 33 year old man with a pontine stroke, resulted in locked in syndrome.
- Communication via looking up with left eye. Difficult to interpret movements. Patient tired after about 5 questions.
- Wife wanted to move to hospice care.
- Parents wanted continued treatment.
- Does the patient have decisional capacity?
- If not, who should make the decision?

Case 2: Outpatient Dementia

- 70 year old male with moderate dementia
- Wife, who had been handling finances, driving, managing medication, dies of pancreatic cancer
  - Patient is home alone, no other family, only neighbors/friends
- MPOA/FPOA, friend of family, for patient did not want to continue acting in those roles
- PP505 is requested by patient's attorney
- When to consider a PP505?
- When to consider guardianship?

DECISION MAKING CAPACITY

Definition and Evaluation

Ten Myths About Capacity

1. Decision-making capacity = competency.
2. Against medical advice = lack of decision-making capacity.
3. There's no need to assess decision-making capacity unless a patient goes against medical advice.
4. Decision-making capacity is all or nothing.
5. Cognitive impairment = no decision- making capacity.
6. Lack of decision-making capacity is permanent.
7. Patients who have not been given relevant information about their condition can lack decision-making capacity.
8. All patients with certain psychiatric disorders lack decision-making capacity.
9. All institutionalized patients lack decision-making capacity.
10. Only psychiatrists and psychologists can assess decision-making capacity.

Source: Ganzini L, Volicer L, Nelson WA, Fox E, Derse AR. Ten myths about decisionmaking capacity. J Am Med Dir Assoc. *2004;5(4):263-267.*

Epidemiology

- Lack of capacity to make medical decisions is often under-recognized in the hospital setting
  - Study: 302 inpatients, 48% deemed to lack decisional capacity, medical team only recognized one half of these patients
- Healthy Elderly Controls – 2.8%
- Medical Inpatients – 26%
- Nursing Home Residents – 44%
- Alzheimer's Disease – 54%

Capacity vs. Competence

- Capacity is a medical determination.
- Competence is a judicial determination.

These can come out of sync: a patient can regain decision capacity but still be declared incompetent under a court order.

- Capacity can be evaluated by any physician. A psychiatrist has specialized training to make determinations in tough cases.
- That a patient has a mental illness (such as depression, schizophrenia, etc.) does not entail that the patient lacks capacity.

Determining Capacity

- Maine State Law (18§5-101)

"Incapacitated person" means any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause except minority to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person.

Determining Capacity

- Appelbaum and Grisso (*NEJM*, 1988) necessary and jointly sufficient conditions for decisional capacity:
  - the ability to communicate choices;
  - the ability to understand relevant information;
  - the ability to rationally manipulate information; and
  - the ability to appreciate the situation and its consequences.

- Capacity determinations are made for a particular time and indexed to a particular question.
  - A patient can lack capacity today and have it tomorrow.
  - A patient can have capacity to appoint a POA, but lack capacity to consent to cardiac surgery.

Communicate a Choice

- Patient's role
  - Clearly indicates preferred tx option
  - Settings of altered communication (Aphasia, Intubated)
- Questions for Assessment
  - Have you decided?
  - What is making it hard for you to decide?
- Frequent reversals or ambivalence may indicate lack of capacity

Understanding

- Grasps the fundamental meaning of information provided
- Patient is encouraged to paraphrase the information (their own words)
  - This shows the patient is not just reciting information
  - “Please tell me in your own words what your doctor told you”
- Understands nature of condition, nature and purpose of treatment, benefits/risks of tx/no tx

Appreciation of the Situation

- Acknowledgement of the condition as it pertains to them (the patient)
- Patient's views of conditions
- "What do you **believe** is wrong with your health?"
- "Do you **believe** you need treatment"
- "What do you **believe** will happen if you are/are not treated"
- Lack of acknowledgement/insight, delusions, pathologic levels of distortion

Rational Manipulation of Information

- Patient is asked to compare treatment options and offer reasons for choice (s)
- Chain of Reasoning
- “How did you decide to accept/reject the treatment?”
- How treatments correspond to their Values
- Focus is on the process by which decision is made, not the outcome
- Patient’s have right to make “unreasonable choices”

Decisions consistent with values

- What does the patient value?
  - Quality of life, Quantity of life
- Do we have outside surrogates who can speak to the patient's values if the patient cannot
  - Would the patient want treatment?
- Attempts to preserve Autonomy whenever possible

Pseudo-Incapacity

- Patient appears to lack capacity, but only b/c the situation has not been explained in a manner they can understand
  - Avoid medical jargon
  - Ask about baseline education, reading/writing difficulties, illiteracy
- Capacity exists as a continuum, and can be optimized

Assessment

- Am I qualified to do the assessment?
  - Most cases yes
  - Physician or Psychologist only can sign PP505 (Maine)
- Start with functional status (IADLs/ADLs)
  - Good clues to baseline function in community
- Rule out Delirium, reversible causes
  - Capacity may be regained
  - Urgency of decisions?
- Difficult situations → consultation
    - Not just medical capacity sought (see PP505)
    - Underlying psychiatric/neurologic conditions

Assessment Tools

- Medical Decision Capacity
  - Most studied in elderly, mild/moderate Dementia
- MMSE
  - >24 good NPV for lack of capacity, <16 good PPV
  - Unreliable if delirium present
- No one tool will give a definitive “yes” or “no” answer, requires clinical application
- “Yes” or “No” is desired, in truth may be more of a “sliding scale”

Aid for Capacity Evaluation (ACE)

- Free
- Online
- Validated
- Uses patient's own clinical situation

WHO MAKES DECISIONS IF YOUR PATIENT CAN'T?

Review

Substituted Judgment

- Determine what the patient would have wanted were they able to understand relevant information and make a choice.
- Search for ***evidence***
  - POA
  - Family
  - Living Will
  - Medical Record
  - Other providers (PCP)
  - Patient behaviors/values
- If sufficient evidence from these sources of evidence is not available, move to best interest standard

Maine Statutes: Who makes decisions for a patient who lacks capacity?

In order of priority:

1. Power of attorney (unless revoked)
2. Court appointed guardian
3. Family member acting as surrogate.
4. Others who know the patient

Maine Health Care Advance Directive

Taking Charge of Your Health Care

Maine Medical Center
MaineHealth

centered around you

YOUR ADVANCE DIRECTIVE BEGINS HERE

Choosing an agent: Fill in your name and the name of the person you choose to be your agent to make health care decisions for you here:

My name_____

My agent's name_____

Title or relationship to me_____

My agent's address_____

My agent's home phone (___)_____ My agent's work phone (___)_____

If the agent I have named above is not willing, reasonably available or able to make decisions for me, I choose the following person to be my agent:

Choice # 2 to be my agent

Name_____

Title or Relationship to me_____

Address_____

_____

Home Phone (___)_____

Work Phone (___)_____

If the person I have named as Choice # 2 is not willing, reasonably available or able to make decisions for me, I choose the following person to be my agent:

Choice # 3 to be my agent

Name_____

Title or Relationship to me_____

Address_____

_____

Home Phone (___)_____

Work Phone (___)_____

You may change your mind later about who you want to be your agent. If you want to stop the agent you have named from making decisions for you, you must tell your primary physician or fill in these blanks:

I do **not** want _____ to be my agent. _____
My signature

Date you filled out and signed this section _____

Any time you cancel, replace or change this form you should give copies of the changed or new form to everyone who has a copy of your original form.

STATE OF MAINE

WALDO COUNTY PROBATE COURT[1] DOCKET NO. _____

IN RE: _____ PHYSICIAN'S /PSYCHOLOGIST'S GUARDIAN /CONSERVATOR PROCEEDING[2]

I, _____, am a physician/psychologist licensed to practice in Maine, having an office at _____.

My professional relationship with the above-named person is as follows:

I examined her/him on _____.

I found the following:

1. History pertinent to current condition:

2. Diagnosis:

3. Prognosis

PP-505 (Rev. 10.15.00)

4. If the appointment of a guardian is sought (answer either A **OR** B):[3]

___ A. It is my opinion that the mental and functional condition of the above-named person to care for himself/herself and/or to make, communicate or implement decisions about her/his well-being is limited., and s/he is incapable of performing ANY of the tasks listed in 4(B). **OR**

___ B. I have checked below all things I believe the patient does possess sufficient mental and physical capacity to perform, and I have indicated when appropriate, whether such functions can be performed only with assistance:

- ___ (1) Establish his/her place of abode.
- ___ (2) Place himself/herself in any hospital or any other institution
- ___ (3) Make provisions for his /her care, comfort and maintenance.
- ___ (4) Give or withhold consents or approvals related to medical or other professional care, counsel, treatment or service.
- ___ (5) To manage, protect, and expend assets and income consistent with 18-A M.R.S.A. § 5-312.

5. If the appointment of a conservator is sought (answer either A **OR** B):[4]

___ A. It is my opinion that the mental and functional condition of the above-named person to manage his/her property and financial affairs is limited and that s/he is incapable of performing any of the tasks listed in 5(B). **OR**

___ B. I have checked below all things I believe the patient does possess sufficient mental and physical capacity to perform, and I have indicated when appropriate, whether such functions can be performed only with assistance.

- ___ (1) Receive money and tangible property and apply the money and property for his/her support, care and education.
- ___ (2) Collect, hold and retain assets (including real estate).
- ___ (3) Deposit and withdraw funds.
- ___ (4) Invest and reinvest his/her assets.
- ___ (5) Dispose of assets.
- ___ (6) Pay bills.
- ___ (7) Establish and use credit and borrow money.
- ___ (8) Pay, settle, prosecute or contest any claim.
- ___ (9) Sell or exercise stock subscription or conversion rights.
- ___ (10) Enter into any contract, financial commitment or lease.
- ___ (11) participate in the operation of any business enterprise.
- ___ (12) Vote a security, in person or by general or limited proxy.
- ___ (13) Make ordinary or extraordinary repairs or alterations to or in buildings or other structures belonging to him/her.
- ___ (14) Employ persons, including attorneys, auditors, investment advisors or agents, to advise or assist her/him.

Dated: _____ _____
Physician/Psychologist

---

[1] *See* M.R.Prob.P. 84 (Official form may serve as guide.); *see also* Mitchell and Hunt, *Maine Probate Procedure: Guide to Official and Recommended Forms* § 1.01 (These Waldo County's revised forms are non-mandatory, simply preferred for the uniform citation(s) and formatting for interactive use online.).

[2] *See* 18-A M.R.S.A. §§5-303 and 5-407 (Report due to court and parties 10 days before hearing.).

[3] *See* 18-A M.R.S.A. §5-304(a) (The development of maximum self-reliance and independence of the patient must be encouraged whenever possible.).

[4] *See* 18-A M.R.S.A. §5-408.

Maine Law: Surrogacy (Title 18A §5-805)

Priority of surrogates

(1) The spouse, unless legally separated;

(1-A) An adult who shares an emotional, physical and financial relationship with the patient similar to that of a spouse;

(2) An adult child;

(3) A parent;

(4) An adult brother or sister;

(5) An adult grandchild;

(6) An adult niece or nephew, related by blood or adoption;

(7) An adult aunt or uncle, related by blood or adoption; or

(8) Another adult relative of the patient, related by blood or adoption, who is familiar with the patient's personal values and is reasonably available for consultation.

(c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably available, an adult who has exhibited special concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate.

Maine Law: Surrogacy (Title 18A §5-805)

On what basis should surrogates make decision

A surrogate shall make a health-care decision in accordance with the patient's individual instructions, if any, and other wishes to the extent known to the surrogate. Otherwise, the surrogate shall make the decision in accordance with the surrogate's determination of the patient's best interest and in good faith. In determining the patient's best interest, the surrogate shall consider the patient's personal **values** to the extent known to the surrogate. A consent is not valid if it conflicts with the intention of the patient previously expressed to the surrogate.

Emergency Situations

- In Emergencies, physicians can provide appropriate care under the presumption that a reasonable person would have consented to such treatment.

Case 1: Follow Up

- “Basic” preferences elicited from patient
  - I do not want my wife to be my guardian
  - I do want continued LST at this time
- Family dispute deepens: Who gets the money from the community fund-raiser?; Mom’s stepson (patient’s son) take to live with parents/uncle.
- Legal proceedings: Custody; Suit filed by parents to request guardianship.
- Patient eventually discharged to hospice (~6 months after stroke). Patient transferred from hospice to NF. Died ~12 months after stroke.

Case 2: Follow-Up

- PP505 completed by Family physician after several cognitive exams, outside neuropsychiatric evaluation
- Physician asked to testify at guardianship hearing
- State guardian appointed

Ethics Consultation

- For Difficult cases – refer to the processes at each of your institutions

Criterion	Patient's Task	Physician's Assessment	Questions	Comments
Communicate a choice	Clearly indicates preference	Ask pt to indicate a tx choice	Can you tell me what your decision is? What is making it hard to decide	Frequent reversals of choice may indicate lack of capacity
Understand relevant information	Grasp meaning of information	Encourage pt to paraphrase information	Please tell me in your own words about: Condition, Tx options, benefits/risks	Demonstrate understanding of condition, tx, risks/benefits
Appreciate situation	Acknowledge condition, tx options as it pertains to them	Ask pt to describe their views, beliefs about tx	What to you believe is the problem? What is tx likely to do for you	Lack of insight can indicate lack of capacity
Reasoning	Rational process of information	Compare tx options, offer reasons for decisions	How did you decide? What makes this choice better?	Focus on the process by which a decision is reached, not the outcome… flawed logic?

Documentation of Appelbaum Criteria

- Based on the Appelbaum criterion for capacity, I (DO or DO NOT) believe this patient has the capacity to make decision (X).
- She (IS/IS NOT) able to explain a factual understanding of the issues (AS EVIDENCED BY STATEMENTS SUCH AS….)
- She (IS/IS NOT) able to appreciate the consequences (AS EVIDENCED BY…) and
- She (IS/IS NOT) able to manipulate the information rationally (AS EVIDENCED BY…)
- She (IS/IS NOT) making a clear and consistent choice (AS EVIDENCED BY…)

- See handout

Summary

- The lack of capacity often goes unrecognized in the acute care setting
  - We often don’t assess for capacity if the patient agrees with our recommendations
- Capacity should be evaluated
  - Acute mental status change
  - When patients refuse treatment without “good” reason
  - Patients hastily consent
  - Known risk factor for impaired capacity

Summary

- Determination Medical Decision making capacity is a learned skill
- Application of Appelbaum's criterion provides a useful framework
  - Able to communicate a choice
  - Understands medical issues
  - Appreciates issues and choices
  - Rational manipulation of information
- Use of Aid to Capacity Evaluation provides a good framework
- Specialty consultation for difficult cases

Questions

References

- Appelbaum, P. Assessing Patients' Capacities to Consent to Treatment. NEJM 1988;319:1635-8.
- Appelbaum, P. Assessment of Patients' Competence to Consent to Treatment. NEJM 2007;357:1834-40
- Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologist. American Psychological Association 2008.
- Dastidar, J. How Do I Determine if My patient has Decision-Making Capacity? The Hospitalist, August, 2011.
- Moye,J. Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research. J of Gerontol 2007; 62B:3-11.
- Moye, J. Capacity to Consent to Treatment: Empirical Comparison of Three Instruments in Older Adults With and Without Dementia. Geront 2003;44:166-75.
- Tunzi, M. Can the Patient Decide? Evaluating Patient Capacity in Practice. Am Fam Phys 2001;64:299-306.