Do I have capacity to determine capacity?

A Practical Approach for Family Physicians

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Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Define capacity and how it pertains to health care decisions (Scholar)
2. Recognize issues that influence capacity (Scholar, Medical Expert)
3. Better evaluate capacity in the clinical setting (Scholar, Communicator, Medical Expert)

This talk focuses on assessing capacity to make **medical decisions** due to cognitive impairment, delirium, and medical illness rather than primary psychiatric disorders

Case

84-year-old married male with cognitive impairment reported by his family; no diagnosis yet but history is compatible with mild stage dementia.

- HFrEF of 30%, 2 recent hospitalizations for exacerbation
- Losing weight, hardly any oral intake x 4 months, even when creatinine was normal
- Poor mobility and recurrent falls
- Creatinine now 500
- CT highly suspicious for locally advanced urothelial carcinoma (i.e., muscle invasive or greater) and bilateral hydroureter

- The patient was asked whether to proceed with bilateral nephrostomy tubes and biopsy of the mass
- Told, “without correction of hydroureter, time is short. The procedure is low risk.”
- When asked, the patient indicated that he wanted to have the procedure to live longer
- He was determined to have capacity by urology and geriatric medicine because he was “able to repeat information given to him about risks and benefits”

- Does this man have capacity to make this medical decision?
- Answer and comment in the chat

Assessment of Capacity

- Common
- Consequential
- Controversial

WHY CAPACITY ASSESSMENT MATTERS

Capacity assessment sits at the intersection of:

- patient autonomy
- the physician's duty to protect vulnerable patients

It is an inherent aspect of all clinician-patient interactions

Overestimating capacity may expose patients to harm

Underestimating capacity may inappropriately remove autonomy

CHALLENGES IN CAPACITY ASSESSMENT

The Challenge

Ethical standards presume that adults have decisional capacity unless there are reasonable grounds for concern

Why?

- Historically, individuals were too readily excluded from medical decision-making
- The standard of presumed capacity developed to protect patient autonomy, prevent paternalism, and avoid arbitrary removal of rights

Modern capacity assessment faces three evolving challenges

1. Medical decisions are increasingly cognitively demanding

- They require complex reasoning under uncertainty

- Patients are asked to decide about:
  - invasive procedures
  - uncertain benefits
  - competing risks
  - prolonged recovery
  - institutionalization
  - quality of life trade-offs

2. Cognitive concerns are common in older adults

- **30–40%** of hospitalized older adults have dementia or significant cognitive impairment
  - Sampson et al. Br J Psychiatry. 2009.

- **20–30 %** of adults over age 80 have dementia
  - Canadian Study of Health and Aging. CMAJ. 1994.
  - Lucca U et al. Journal of the Alzheimer's Association. 2015.

These conditions will affect capacity

Frailty and dementia impair the very abilities required for complex medical decisions:

- Executive reasoning
- Appreciation
- Future-oriented thinking
- Understanding uncertainty

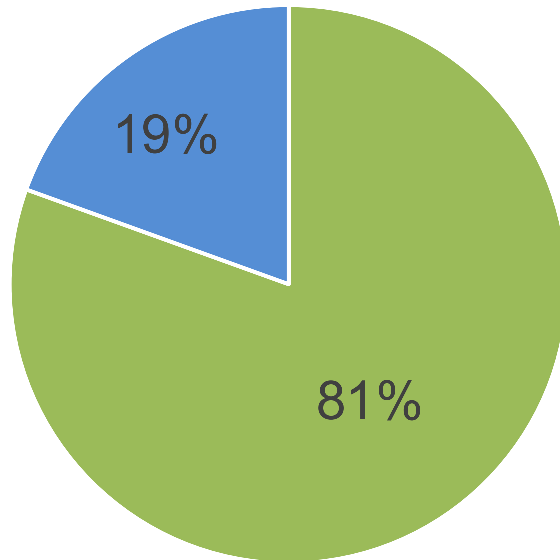
These impairments may not be obvious during routine conversation

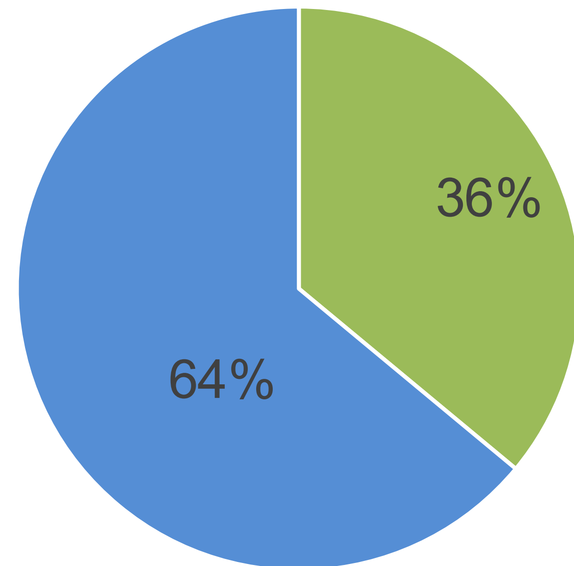
3. Cognitive impairment is overlooked in clinical practice

- ≈60% of dementia cases remain undiagnosed (Lang et al., BMJ Open, 2017)
- Clinicians frequently misidentify incapacity up to 56% of the time

- Marson et al., J Am Geriatr Soc, 1997
- Sessums LL et al. JAMA, 2011
- Raymont V et al. Lancet, 2004
- Appelbaum. NEJM, 2007

270 cardiology/cardiovascular surgery assessments





The Challenge: Variability in capacity determination

Experts assessing the same patient do not always reach the same conclusion regarding decisional capacity

Marson DC et al., Neurology, 1995
Marson DC et al., Arch Neurol, 1996
Raymont V et al., Lancet, 2004
Sessums LL et al., JAMA, 2011
Appelbaum PS, N Engl J Med, 2007
Grisso & Appelbaum, 1998

- Five experienced physicians reviewed video interviews of 29 patients with mild Alzheimer's disease
- The physicians agreed on capacity only about 56% of the time

Physician	Competent	Incompetent
1	3 (10%)	26 (90%)
2	14 (48%)	15 (52%)
3	22 (76%)	7 (24%)
4	25 (86%)	4 (14%)
5	29 (100%)	0 (0%)

Marson et al. J Am Geriatr Soc. 1997;45:453–457

Areas contributing to variability include:

- differing thresholds
- variability in interviewing technique
- different interpretation of appreciation and reasoning
- clinician values and biases
- executive dysfunction that is difficult to recognize

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Capacity Is Decision-Specific

Capacity is not:

- Global
- All-or-none
  - A patient may have capacity for some decisions but not others
    - different decisions require different levels of reasoning and appreciation

- Determined solely by diagnosis
- Determined by a cognitive test

- For example, a patient may be able to:
  - Choose what to eat
  - Consent to bloodwork

- While lacking capacity to:
  - Consent to high-risk surgery
  - Weigh chemotherapy risks and benefits
  - Understand complex discharge risks

Common Domains of Capacity

- Medical decision-making
- Personal care
- Finances
- Capacity to live independently
- Capacity to appoint a substitute decision-maker or power of attorney
- Capacity to drive
- Litigation/legal capacity
- Testamentary capacity (making a will)
- Capacity for research consent

Capacity Is Also Time-Specific

Capacity may fluctuate due to:

- Delirium
- Medication effects
- Fatigue
- Psychiatric illness

Capacity Is About Process, Not Outcome

- Patients may make decisions clinicians disagree with and still have capacity
- Focus on **how** decisions are made

The Four Core Elements of Capacity

1. **C**ommunicate a choice
2. **U**nderstand relevant information
3. **A**ppreciate the situation and consequences
4. **R**eason or weigh options

Element 1: Communicate a Choice

Can the patient:

- clearly express a treatment choice
- maintain a relatively stable decision

Element 2: Understand

Can the patient understand:

- their condition
- the proposed treatment
- risks and benefits
- alternatives
- likely prognosis

Element 3: Appreciate

Can the patient appreciate:

- that the information applies personally to them
- the likely consequences of the decision
- the seriousness of the situation

Element 4: Reason

Can the patient:

- compare options
- weigh risks and benefits
- explain why one option is preferred
- reason through uncertainty

The Sliding Scale Principle

Higher-risk decisions require greater certainty regarding capacity

Common Causes of Impaired Capacity

- Dementia
- Delirium
- Psychiatric illness
- Intoxication
- Medication effects

Mild stage dementia

- Conversational fluency may mask impaired decisional capacity
- The following does not necessarily indicate intact decisional capacity
  - Answering ”yes” or “no”
  - Repeating back information

Mild Stage Dementia

- Dementia impairs
  - abstract reasoning
  - appreciation
  - future-oriented thinking
  - understanding uncertainty

- Marson et al. Neurology. 1996;46:666–672.

Evidence From Dementia Research

- Marson and others demonstrated impairment in reasoning and appreciation in mild Alzheimer disease

- Marson et al., Neurology, 1996
- Kim et al., Am J Psychiatry, 2001
- Karlawish et al., Neurology, 2005
- Raymont et al., Lancet, 2004

Dementia

Our conclusion:

- Mild stage dementia almost always impairs the capacity to make complex medical decisions

Reason:

- Criteria for making a diagnosis of mild stage dementia requires impaired IADLs, i.e., simple tasks that people have been doing throughout their life
- Understanding and assessing medical complexity is much more difficult

Counterpoints in the literature

- Dementia does not automatically equal incapacity
- Patients may retain capacity for simpler or values-based decisions

Steps for capacity assessment

- Get a collateral history
  - helps clarify baseline cognition
- Perform cognitive testing
  - MMSE
  - Frontal Assessment Battery
  - Brief Cognitive Rating Scale
- Ask capacity related questions

Element 1: Communicate a Choice

Do you want to be resuscitated in the event of a cardiac event?

- Consistently saying, “I want the procedure and I understand the risks and benefits” does not on its own demonstrate capacity
- The following, by itself, does not establish capacity
  - The ability to state a preference
  - The ability to repeat back what was just said
  - Agreeing with physicians

Yes or no questions are useless in capacity assessments

Element 2: Understand

- "Can you tell me about your **medical conditions**?"
- "Can you tell me about the **prognosis** of each medical condition?"
- "What **treatment** has been recommended?"
- "What are the **risks and benefits**?"
- "**What could happen** if you refuse/accept treatment?"

Assessment must take into account whether individuals have been informed about their prognosis

Element 3: Appreciate

- “How do you think this problem affects you?”
- “Why do you think the team is recommending this?”
- “How do you think this decision will affect your future?”

Element 4: Reason

Compare options and explain why one choice is preferred

- “Can you walk me through how you made this decision?”
- “What are the pros and cons of each option?”
- “Why do you think this option is best for you?”
- “What matters most to you in making this decision?”

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Case: an incomplete assessment

1. Before determining capacity, there should be an assessment for possible dementia. Why?
   - Unmasking dementia usually changes who makes complex medical decisions.
2. Capacity assessment must be thorough for the following reasons:
   - The ability to repeat information ≠ demonstrate appreciation or reasoning
   - The patient must understand prognosis and future consequences of each medical problem and treatment options
   - Subtle impairments in appreciation and reasoning may be missed during routine clinical conversations.

Case: an incomplete assessment

3. The following information should be considered by the decision-maker in the context of dementia
   - Dementia increases vulnerability to treatment complications and poorer health outcomes
   - Dementia is a progressive illness. Life prolonging treatments, allows a person to live longer to progress through more advanced stages of dementia

Case: Questions to ask

- “Can you tell me about your medical conditions?”
  - The patient should know about the diagnosis of HFrEF and his 2 recent hospitalizations
- ”Can you tell me about the prognosis of each medical condition?”
  - This question will help clarify whether the patient understands and appreciates their current and future health
  - Dementia impairs the ability to understand future health states (i.e., future oriented thinking)

Case 1: Questions to ask

- “What treatment has been recommended and why?”
  - Diagnosis of muscle invasive diagnosis needs discussion, including the fact that the patient is not a candidate for curative treatment, which would be cystectomy
- “What could happen if you accept/refuse treatment?”
- “How do you think this decision will affect your future?”

How to Seek Additional Help

- Psychiatry to assess mental health
- Geriatric medicine to determine diagnosis of dementia
- Ethics
- Ask a colleague

Suggested Resources

Tool	Purpose	Free?	Limitation
ACE (Aid to Capacity Evaluation)	Brief structured clinical assessment	**Yes**	Less detailed than MacCAT-T
MacCAT-T	Assesses 4 domains ARUC	**No**	Time-consuming; requires training
HCAT (Hopkins Competency Assessment Test)	Screening	**No**	Limited assessment of appreciation and reasoning

Summary

- Capacity is often presumed but must be systematically assessed when there is cause of concern and universally for older adults
- Cognitive impairment is common and frequently unrecognized
- Capacity assessment evaluates 4 abilities: ARUC
- Patients with mild dementia may appear conversationally intact yet have significant impairment in appreciation, reasoning, and future oriented thinking
- Formal tools can support assessment, but capacity remains a clinical judgment—not a test score
- The greatest challenge is not identifying obvious incapacity—it is recognizing subtle incapacity in patients who appear capable at first glance

Questions

Thank You