Assessment of Decision-Making Capacity

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Goals of talk: Audience will know...

- The distinction between “competency” and “decisional capacity”
- Prevalence of *incapacity* in clinical settings
- The four key elements in a capacity assessment
- The “sliding scale” on the burden of proof of capacity, risks of ‘pseudo-incapacity’
- Free, easy to use aid in capacity assessment
Global Competency vs. Decisional Capacity*

Competency Determination is all-encompassing
- Legal term;
- Determined by a judge only
- All-or-nothing: the incompetent person loses all rights to make autonomous decisions
- Invariably, a legal guardian is assigned by the judge to make decisions on their behalf

Decision-Making Capacity is more limited
- Pertains to a specific point in time and situation
- Typically determined by a physician
- Can be fleeting, and can be optimized

*Appelbaum (2007) argues that, in practice, these hard distinctions are not applied consistently in medical or legal literature
How common is *incapacity* in older adults?*

<table>
<thead>
<tr>
<th>Population</th>
<th>% Incapacitated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy elderly controls</td>
<td>2.8%</td>
</tr>
<tr>
<td>Medical inpatients</td>
<td>26%</td>
</tr>
<tr>
<td>Nursing Home Residents</td>
<td>44%</td>
</tr>
<tr>
<td>Alzheimer’s Disease Diagnosis</td>
<td>54%</td>
</tr>
</tbody>
</table>

• In pooled studies, physicians “missed” 58% of incapacitated patients

• However, *when they did deem someone incapacitated, they were usually right*

*Sessums LL, et al. JAMA 2011*
4 Major Elements to Decision-Making Capacity

1. Ability to communicate a CHOICE (and be consistent)
2. UNDERSTANDING of the facts relevant to the medical decision (risks, benefits, alternatives)
3. Appreciation of the treatment decision CONSEQUENCES (including non-treatment)
4. LOGICAL Manipulation of Information (not just ‘parroting back’)

Patient must demonstrate all four…
1. Communication of a Consistent Choice

• Barriers: Patient cannot communicate (examples: patient unconscious on ventilator, global aphasia; “locked in” syndrome)

• Patient refuses to state a preference or repeatedly reverses self (in the absence of new information)

• May require multiple assessments when patient is delirious (stability of decision)

• A given choice must be sufficiently stable that it can be acted on before the person changes his/her mind
2. Factual Understanding of the Issues

• Same standards as doctrine of informed consent

• Patient must understand their illness, the purpose of the intervention being discussed

• Risks, benefits, alternatives (*including non-treatment*)

• Example: What problem are you having now? Why are you in the hospital?
3. Appreciation of the facts and the consequences for them

• Example 1. “The tumor is invading my brain, but scientists say people only use 10% of their brains anyway. I’ll just use the other parts.”

• Example 2. “I understand I’ve caused three auto accidents in a week, and I get confused behind the wheel. But it’s fine, because I’ll be more careful from now on.”

• Example 3. “Refusing amputation will probably shorten my life. But I value quality not quantity. I’ve never understood why people pursue amputations just to extend their life by a year, maybe even less.”
4. Rational Manipulation of Information

- Logical “Chain of Reasoning” used to compare benefits and risks of various courses of action
- Outcome selected must be consistent with starting premises/values

- Example: “I value quality of life above quantity. Refusing surgery may shorten my life, but the bottom line is, being disfigured by an amputation is not an acceptable quality of life for me.” (intact logic)

- Example 2: “No matter what, I want to live, and I know I need the surgery to live. But the surgery will leave me scarred, and I simply can’t accept that.” (flawed logic?)
Making decisions according to the patient’s values is the ultimate goal

- Patients may employ flawed logic, but still arrive at a point that would be consistent with their values.

- “You call this a facial tumor, but I think it’s a bee sting. I don’t want surgery for a bee sting.”

- But the patient may have opted against surgery even if she understood it was a tumor.

- A surrogate decision-maker is identified to determine “what the patient would choose.”

- Attempts made to preserve autonomy whenever possible.
Be Wary of ‘Pseudo-Incapacity’

- A situation where the patient appears to lack capacity, but only because the situation has not been explained in a manner they can understand
  - Avoid technical medical jargon
  - Try to accommodate patient’s first language

Capacity exists on a continuum, and can be ‘optimized’
Who is the Surrogate?

- Obviously, legal guardian or power of attorney is first option
- After that, family and friends take precedence next, in the following order:*  
  - Spouse
  - Adult child
  - Parent
  - Sibling
  - Adult Grandchild
  - An adult with knowledge of individual’s preferences and values
  - Facility Director (in the absence of all above)
- NOTE: There may be situations where the logical decision-maker does NOT have the patient’s interests or values in mind, and this may require ethics consult or consultation with hospital attorney

*The Pennsylvania Code § 6000.1014
Aids in Assessment of Capacity

- **Aid to Capacity Evaluation (ACE)**
- Hopkins Competency Assessment Tool (HCAT)
- Understanding Treatment Disclosure (UTD)
- Ability to Consent Questionnaire (ACQ)
- Assessment of Capacity of Every Day Decision Making (ACED)
- Capacity to Consent to Treatment Instrument (CCTI)
- Cognitive Competency Test (CCT)
- Cognitive Questionnaire (CQ-M)
- Decision Making Rating Scale (DMRS)
- Fazel Questionnaire
- MacArthur Competency Assessment Test (MacCAT-T)
- Medical Decision Making Capacity Instrument (D.CAPCTY)
- Schmad Vignettes
- Specific Capacity Instrument
- Structured Interview for Competency/Incompetency Assessment Testing and Ranking Inventory (SICIATRI)
- Vellinga Vignettes
Not all questions are equal...

- Should I have a transurethral resection of my prostate?
- Do I want yogurt or cereal?
- Should I skip out on the conference this afternoon?
- Should I watch TV or read?
- Should I buy a new car?
The “Sliding Scale”

- The more potentially damaging (or peculiar) the decision, the more the patient must be able to demonstrate sound capacity to make decisions
- Example:
  - Yogurt vs. Cereal: very low threshold for accepting a patient has capacity
  - Life-saving transfusion vs. No transfusion: much higher threshold for accepting a patient has capacity
Important Points

• Adults presumed competent until proven otherwise

• Any physician with training can perform a capacity assessment; a psychiatry consultation can help in tricky cases

• Your hospital or practice may have an ethics committee or attorney
Four Elements Summary

• 4 Elements of Decision-Making Capacity
  – Understand the facts
  – Understand the consequences of those facts
  – Rational (logical) manipulation of information
  – Communicate a choice

• The goal is to ensure patients make decisions consistent with their own values

• Complex cases may require consultation with legal representatives, psychiatry or ethics consultation
Recommended References

• Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? JAMA 2011, 306:420-427

• Appelbaum PS. Assessment of patients’ competence to consent to treatment. NEJM 2007, 357: 1834-1840