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Objectives
- To learn what decision-making capacity is
- To describe how to assess decision-making capacity
- To elaborate how to use capacity when providing patient care

Decision-making Capacity
Decisional capacity may be defined as the mental ability to understand the nature and effects of one’s actions.

Is the presence or absence of decision-making capacity that important?

Clinical / Ethical Significance
Why is it important to determine decision-making capacity (DMC)?
- Lack of DMC often goes unrecognized (748%)
- Prevalence of impaired DMC makes it imperative that physicians learn how to assess this
- Lack of capacity is often what triggers the use of advance directives
- We try to practice in an ethical manner
Ethical Principles and Duties

- Autonomy
- Beneficence
- Non-Maleficence
- Justice
- Veracity
- Confidentiality
- Respect for Life
- Respect for Culture
- Family Integrity
- Responsible Stewardship
- Professional Integrity

Autonomy

- Patients are deemed to be the best judges of their own well-being
- Patients must be given the appropriate information (informed consent), assuming they have sufficient capacity and can give consent freely and without coercion
- There is a need to strike a balance between patient autonomy and protecting those with cognitive impairment

Decision-Making Capacity

- Current context of shared decision-making and “partnership” in the patient-clinician relationship.
- Expertise of the ...
  - Physician/clinician – provides medical knowledge and experience and consultancy
  - Patient:
    - Values, preferences, goals, quality of life, meaningful ADLs.

Right Language

- “Competence”:
  - Legal term. Determined by a court/judge or law.
  - A patient is presumed to be competent until deemed otherwise
- “Decision-Making Capacity”:
  - Clinical term. Determined by clinical assessment.
- Interconnection:
  - Formal assessment of DMC.
  - “Statement of Expert Evaluation.”
Assessing Decision-Making Capacity

When do we assess?
- When it is obvious we need to do so or when the right decision is not obvious
- When there is conflict or indecision
- When the proposed intervention presents a significant burden

Dorothy
- 86 years old. Widowed. Two adult sons and two daughters.
- Type 2 DM, HTN, and PVD. Not feeling well. Lost 8 lbs.
- Two cm painless nodule in the pancreas on CT scan.
- Surgical consult: Possible surgical intervention but patient refuses. Patient elects hospice care.
- Dorothy stops eating.
  - “I’m just not that hungry.” She asks how long she might live if she is not eating.
  - Her children wonder whether she is depressed or might have very early dementia. “Should we consider a PEG?”

Guidelines for Assessment?

“There are currently no formal practice guidelines from professional societies for the assessment of a patient’s capacity to consent to treatment.”

Paul S Appelbaum
N Eng J Med 2007

Assessing Decision-Making Capacity

Two key features:
1. Assessment is for a specific decision regarding a specific treatment, test or research protocol. Task-specific.
2. Preceded by a process of information-disclosure about the specific treatment, test or research protocol.
Assessing Decision-Making Capacity

1. Ability to understand the relevant information... (about a specific decision)
2. Ability to appreciate the situation and its consequences...
3. Ability to reason with the relevant information...
4. Ability to express a choice...

Not easy...! Much physician inconsistency.

Risk Factors for Impaired DM

- Dementias.
- Mental disorders (e.g., schizophrenia).
- Perceived irrational thinking & expressions.
- Mental retardation.
- Denial, depression, delusion.
- Frontal lobe dysfunction.
- Co-morbidities that alter mentation.
- Medications and polypharmacy.
- ICU admission.
- Fear, anxiety, dependency, regression.
- Other?

Assessing Decision-Making Capacity

Who do we assess?
A person’s list of medical diagnoses alone does not determine his decision-making capacity. It must be assessed.

"Forget informed consent. Just give us your uninformed consent."
Clinical Triggers for Assessment

- Abrupt changes in mental status or mood.
- Refusals of recommended treatment, especially when unwilling to discuss refusal or reasons are unclear.
- Treatment that will be especially invasive or risky and consent is given too hastily.
- Displaying one or more risk factors for impaired decision-making.

How Do We Assess Capacity...

1. Does the patient understand the medical condition and relevant factors?
   - What do you know about your illness?
   - Why are you in the hospital?
   - What have your doctors told you about your illness?
   - How severe is your illness?

2. Does the patient understand the possible treatments and the benefits and burdens?
   - What do you know about the test (procedure)?
   - Are there any other tests or therapies for your illness?
   - Why has your doctor recommended this? What are the expected benefits or side effects?
   - What do you expect will happen if you decide to follow this recommendation? or not follow it?

Assessing Capacity...

3. Is the patient able to apply the information to his situation and decide based on his values?
   - Can you tell me about your decision?
   - How did you reach your decision to agree to (or refuse) the recommended test or treatment?
   - Can you help me to understand why you decided to accept/refuse the recommended therapy?
   - What factors were important in helping you decide the way you did?
...Assessing Capacity

4. Is the patient able to communicate personal preferences?
   - Consider repeating a question or two to check for the stability of a patient’s choices
   - Rephrase the question in both a negative and positive way to check for consistency
   - Have the patient state their preference to a family member or to a third party

Caveats

- Communication may be severely limited in some patients (stroke, ventilator, etc.)
- Language can be a barrier – try to use a professional interpreter
- Decisions made near the end of life may be more difficult: loss of health, loss of independence, severity of illness, more significant consequences to one’s decisions

Capacity Determinations

Lack of decision-making capacity should be presumed when patients go against medical advice.

True or False?

Capacity Determinations...

There is no need to assess decision-making capacity if the patient is not going against medical advice.

True or False?
Frank
92 y/o veteran with CLL and mild cognitive impairment. He also has HTN, gout, and osteoarthritis. He is widowed for three years, has a son in Utah, and lives alone in a small first floor apartment. He is now in the hospital being treated for a UTI. He is a 1 person assist, and insists that he can continue to live independently although the SW and RN feel this is not safe. He refuses efforts to place him in an assisted living facility.

Capacity Determinations
Lack of decision-making capacity is a permanent condition.

True or False?

Capacity Determinations…
• Cognitive impairment equates to lack of decision-making capacity.

True or False?

Mary
78 y/o widow with colon cancer metastatic to her liver. She also has early stage Alzheimer’s dementia. She was admitted to the hospice IPU b/o RUQ pain responding only slightly to morphine. Bedtime methadone is quite helpful. Her daughter subsequently demands that methadone be stopped b/o what she read on the internet. She says she is her mother’s DPOA-HC, and she wants only MS used. The pt is interviewed separately, but she defers to her daughter’s demands.
Sliding Scale Capacity...
- Various medical conditions have varying levels of severity
- Might not there be varying levels of decisional capacity?
- The level of impairment that renders a patient incompetent to make treatment decisions should reflect a balance between respecting a patient’s autonomy and protecting the patient from the consequences of a bad decision

Sliding Scale Capacity
- The stringency of the test applied varies directly with the seriousness of the likely consequences of the patient’s decision
- This “sliding scale” often reflects how courts actually deal with competency cases
- Gradation or continuum.
- Not “all or nothing” but “more or less.”

Sliding-Scale Model
- Variable “standard” determined by...
  - Risk-benefit ratio of a specific decision.
  - Whether patient consents or refuses.
  - High benefit, low risk, patient consents.
  - High benefit, low risk, patient refuses.
  - High risk, low benefit, patient refuses.
  - High risk, low benefit, patient consents.

Sliding-Scale Model
- How high or low we place the bar for DMC for a specific decision can vary.
- This variable “standard” for DMC is determined by...
  - Risk-benefit ratio of a specific decision.
  - Whether patient consents or refuses.
Sliding-Scale Model for DMC

At a given time, a patient may have decision-making capacity for one decision and not another.

Mini-Mental State Exam

- 11-question measure by which a patient scores 0-30 total points related to:
  - Orientation.
  - Registration.
  - Attention and calculation.
  - Recall.
  - Language.

Mini-Mental State Exam

What value? How helpful?

Limited “global” screening tool.

“MMSE scores of less than 19 are highly likely to be associated with (a lack of DMC).”

PS Appelbaum

DMC -- Who Should Assess?

- Primary Physician.
  - Ultimate responsibility.
- Assistance/information from ...
  - Psychiatry; Neurology; Palliative Care
  - Nursing, Social Work, Chaplain
  - Family
  - Ethics committee
Clinical Challenges and Contingencies

- Mental status can “wax and wane”:
  - DMC for a specific decision can be intermittent or temporary, not absolute or permanent.
- Consistency and stability over time.
- Conflicting opinions by “assessors.”
- Potentially reversible factors (e.g., infection, electrolyte imbalance, medication effect).
- Communication barriers (e.g., intubation, dysarthria).
- Urgent decisions.

What Happens if the Patient is Determined not to Have DMC?

- Look for reversible factors
- Consider delaying any decision if that would not harm the patient
- Look for guidance from advance directives
- Find surrogate decision-makers – hierarchy
- Substituted judgment – two physicians

What if the Patient Has Capacity and Clearly Makes a “Bad” Decision

- Consider repeating capacity steps
- Discuss with family members or others close to the patient (cultural factors?)
- Review possible community support
- Respect autonomy
- Humility on part of clinician
- Learning opportunity

“We can be knowledgeable with other men’s knowledge, but we can’t be wise with other men’s wisdom.”

- Montaigne
Influential Literature


