Decision Making Capacity:
Implications for Advance Care Planning Facilitators
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The Language, Ethics & Law of Self-Determination

- Legal and Clinical Terms
- Capacity/Incapacity
- Consent/Assent
- Authority of Surrogates
- Assessment of Decision Making Capacity
- Assessment of Capacity to Complete an Advance Directive
Assessment of Capacity: Why it’s Important

- Capable adults (not the advance directive) have a right to make any and all healthcare decisions
- Only capable adults have the right to complete a legally valid advance directive
- The advance directive (and authority of agent) only becomes “activated” when the patient is determined to have lost decision making capacity (DMC)

“Activation” of Advance Directive/Agent Authority

- Determined by state statute
- Documented via organizational standard of care
- Implications for healthcare providers to know who is the legally appointed decision maker
Legal and Clinical Terms

INCOMPETENCE
- Determined by a judge
- Clear & convincing evidence
- Standards for risk:
  - Unable to care for self
  - Unable to carry out important decisions
- Can override person’s decisions
- Relatively black/white

CAPACITY
- Determine by clinical evaluation, e.g., MD, psychologist
- Evidence that person does not understand or cannot evaluate needed medical information to make an informed decision
- Cannot override all decisions
- Many shades of gray

Legal/Ethical

Judicial duty is to protect constitutional rights of liberty unless clear, serious, and relatively imminent harm is evident.

Health professional duty is to protect the good of the patient and respect the patient’s self-determination.
Consent: An informed, voluntary decision by a capable and competent person to agree to or to refuse treatment no matter what the risk or expected outcome.

Assent: A decision to accept treatment even though the person is incapable or incompetent.

Legal/Ethical

Judicial
- Adversarial process
- Must be guided by clear evidence
- Clear procedure that must be adhered to
- Limited resolution options

Professional
- Collaborative process
- Should be guided by thoughtful assessment
- Follows certain rules of professional behavior
- May be creative in balancing conflicting values

Consent/Assent
1. Able to communicate
2. Able to understand relevant information (the elements of informed consent)
3. Able to appreciate the situation and its consequences (able to know there is a decision to be made)
4. Able to communicate a rationale for a decision (e.g., practical reasoning)
   • consistent with known values and goals, or explains deviation from known values and goals

Standards for Capacity

Applebaum, P.S.; Assessment of patients’ competence to consent to treatment. NEJM. 2007:357:1834-40

Capacity to make some decisions; but not others:

• Able to assess present quality of life
• Able to describe goals and values
• Able to select a proxy
• Able to make decisions about proposed medical treatments
• Able to make decisions about the future use of life-sustaining medical treatment

Decision-Specific Capacity
The notion that capacity is either fully supported or absent is not supported medically, legally, or ethically. Rather than an “on-off” switch, capacity is more like a dimmer control. Most... even those with profoundly reduced cognitive functioning... possess some ability to comprehend, form and express a preference.


No formal practice guidelines from professional organizations
Lacks standardization
Mini-Mental State Exam (helpful at high and low ends of capacity)
Formal Assessment Instruments
Psychiatric Consultation

Assessment of Capacity
Assessment of Capacity

ACP facilitators
- must recognize when DMC is in doubt; make a referral for assessment to qualified resources
- may gather data on the patient’s ability to participate in the planning process

Assessing DMC:
Implications for ACP Facilitators
Capacity/Incapacity

May vary over short periods of time, e.g., sun downer’s syndrome

Is decision specific: a person may be incapable of making complex decisions but capable of selecting a surrogate

Cannot be determined *only* on the basis of age, diagnoses, or intelligence

Exist together...individuals should be allowed to function with what capacity they have

When concerned about DMC

Assume capacity
Inform the person of the reasons for your concerns
Listen to the patient’s story for related values consistent/inconsistent with decision/behavior
Ask yourself, “Does the person understand?”
Optimize the Environment

- Assess for external factors (e.g., healthcare environment; family or caregiver pressure; provider bias)
- Assess for internal factors (e.g., medication, pain, stress, time of day)
- Correct communication barriers (e.g., language, hearing, vision impairment)
- Seek input from others

What level of capacity?

- Openly share concerns about incapacity
- Document your conclusions by giving specific justification
- Make a referral to a qualified person
- Determine if the person has adequate capacity to appoint a surrogate
Capacity to Complete an Advance Directive

Assessment guidelines for patients at the margins of cognitive abilities

- Understands the AD will determine future health care decisions
- Understands decisions will be honored when patient is no longer capable
- Understands the choices to select a proxy and other decisions as able
- Understands the choices can be changed at any time

What Understanding is Needed to Complete an AD?
Provide Information/Teach-back

- Provide information on each of the four areas of understanding
- Ask patient to tell you what is understood
- Look for gaps in understanding
- Look for consistency

Assessment of Capacity to Complete AD: Script 1

- Mrs. Smith, your son is interested in having you complete an advance directive. I will explain that to you in a minute. It is important that you understand what this includes. I will need to give you information and then see what you understand. I cannot help you complete the advance directive unless I am sure you understand what it means
We have a document called an advance directive that allows you to tell us how you would like healthcare decisions to be made for you in the future, for example if you become sicker and not able to communicate with us.

Tell me what I just said

What is an advance directive?

Will it include healthcare decisions that will be made for you now, or in the future if you cannot talk to us?

Assessment of Capacity to Complete AD: Script 2

One of the important choices you can make in this document is who you would want to make your healthcare decisions if you become sicker and not able to communicate. Who would you trust to make important life and death decisions for you?

Tell me what I just said

Who is a person you would trust to make healthcare decisions for you in the future?

Tell me why you have chosen that person.

Assessment of Capacity to Complete AD: Script 3
Assessment of Capacity to Complete AD: Script 4

- This advance directive is a legal document that is signed by you and witnesses. It will name the person you have chosen to make future healthcare decisions for you. You can change your mind about this person or this document at any time.

- Tell me what I just said
- Can you choose a different person whenever you want?
- Can you change your mind about this document whenever you want?

Patients who lack decision making capacity

How can they be included in the ACP discussion?
Questions?

Thank-you