

Learning Objectives:

- Be able to define decisional capacity.
- Be able to identify patients at risk for impaired decisional capacity.
- Know when and how to assess decisional capacity at the bedside.

Case:

A 49 year old male with ESRD, hypertension and diabetes is admitted to my medicine service with a necrotic left foot with maggots in the wound. He had presented 5 months earlier with a foot ulcer which was not healing; numerous attempts were made to do vascular studies in preparation for revascularization or amputation but he either directly refuses or eats right before the procedure; he was discharged with PO antibiotics. He then went to live with family in another state; the ulcer progressed and he was admitted to a hospital there. He was told that he needed bilateral LE amputations. He refused amputation multiple times, got on a bus to Seattle and presented to the HMC ER.

The Vascular Surgery service is consulted for amputation. I made the patient NPO after midnight expecting surgery the next day, but the next morning I found the following note from the Surgery intern:

ASSESSMENT / PLAN

_49 yo M patient with ESRD on HD and with dry gangrene on left foot

refuse consent for a left leg open guillotine amputation x2 saying "in a couple of days ". I explained to the patient the risk that he is taking if he doesn't have the surgery. He appear to understand.

I examined the patient. His mental status exam was notable for a flat affect. When I asked him a question, he often responded by closing his eyes and turning away from you.

He carried no psychiatric diagnosis in our records, but when I asked his sister she said "he's never been right in the head" and thought he was diagnosed with schizophrenia at some point in the past.

Discussion:

Decisional capacity is the ability to consent to or refuse care. It is closely related to competence, which can only be determined in a court of law. [1, 2] The assessment of a patient's decisional capacity is an essential part of the ethical practice of medicine and research because an individual must have decisional capacity in order to participate in the informed consent process.[3] Knowing which of our patients have decisional capacity allows us to strike the proper balance between the ethical principles of autonomy and beneficence; allowing patients to make their own decisions whenever possible, but protecting those with cognitive impairment. [1]

The question of a hospitalized patient's capacity to make decisions, particularly about surgery or discharge planning, arises frequently. It is easy to assume either that a patient with cognitive impairment is unable to make their own medical decisions or that a patient who seems relatively intact in a brief interaction is competent, but either of these assumptions can be problematic. In general, clinicians probably overestimate their patients' decisional capacity. For example, one study assessed 302 consecutive medical inpatients with a formal assessment tool and found that about 40% lacked decisional capacity. They also asked the senior resident on the team and the patient's relative and correlation between those opinions and the results of the formal assessment was very poor; for example in 76% of the patients found to lack capacity, their clinical team

thought they possessed it. Not surprisingly, increasing age and cognitive impairment were associated with lack of decisional capacity. More surprisingly, psychiatric illness did not correlate with lack of decisional capacity. [4] Other studies have shown that patients with schizophrenia are more likely to lack decision-making capacity than those with depression. Among patients with psychiatric illness, lack of insight into their disease is thought to be a strong predictor of lack of decision making capacity. [5] Of note, even patients with mild to moderate dementia may retain decisional capacity for many decisions, and should be assessed individually. [6]

Anytime you are obtaining informed consent you should be assessing decisional capacity; in practice, we often don't do it formally unless the patient has evidence of impairment. We are also probably more likely to formally assess capacity when the patient doesn't agree with us. Ideally, however, all internists should become skilled and efficient at bedside evaluation of decisional capacity and assess decisional capacity before obtaining informed consent. Psychiatry consultation is not necessary in every case but can be helpful when the situation is complicated, especially when there are psychiatric comorbidities such as delirium, dementia or schizophrenia.

Bedside evaluation of decisional capacity should be based on the four elements related to decisional capacity first described by Appelbaum and Grisso in a landmark article in the New England Journal of Medicine in 1988: [7]

- a. The ability to communicate a choice.
- b. The ability to understand the relevant information
- c. The ability to appreciate a situation and its consequences
- d. The ability to reason rationally.

In practice, you should first assess whether your patient is delirious, as this assessment should not occur if the patient is experiencing delirium. If at all possible, you should look for and treat causes of delirium before assessing decisional capacity. Then, you should have a conversation with your patient in which you present information related to the specific choice and assess whether they possess the four abilities above. It is important to ask the patient to repeat information back to you in their own words. Note that patients with dementia can retain elements of conversation that make us assume they are understanding us when that may not be the case, so it is particularly helpful if patients can actually paraphrase information rather than just giving yes or no answers. [8] Of note, decisional capacity is decision-specific. A patient may be competent to choose a DPOA or decide where he will live, but not to make a complicated decision about the best kind of surgery.

If the patient lacks capacity, you then turn to the hierarchy of decisionmakers for the state of Washington:

- a. Legal guardian with health care decision-making authority
- b. Individual given durable power of attorney for health care decisions
- c. Spouse
- d. Adult children of patient (all in agreement)
- e. Parents of patient
- f. Adult siblings of patient (all in agreement)

Remember that even if a patient lacks decisional capacity you still want to discuss medical decisions with them. You should try to get *assent* from a patient even if someone else is going to get *consent*. Even if someone cannot legally refuse a procedure, everything goes more smoothly if they understand what you are doing and agree.

Case continued:

I attempted to engage the patient in a conversation to assess his decisional capacity several times. He was very difficult to engage at all, and at one point stated "there's nothing wrong with my leg," which demonstrated a

lack of understanding and appreciation. Psychiatry agreed that he did not possess decisional capacity either to consent to surgery or to appoint a DPOA. He had no legal guardian, DPOA, living spouse or children but had 9 living siblings. The surgery team had to attempt to contact all of them and document this carefully, and surgery was performed. Luckily with discussion with his family he was providing assent to the surgery, although he was not providing his own consent; surgery was uneventful and he was discharged.

About a year later he was readmitted with an ulcer on the remaining foot. His family provided consent for a BKA of the remaining leg; reportedly he also provided assent. Postoperatively he developed sepsis was intubated in the ICU and an AKA on that leg was performed urgently. At the end of that hospitalization Palliative Care was consulted for a goals of care conversation; the consultant assessed decisional capacity and felt the patient had capacity to name a DPOA and to set his own goals of care. The patient wished to focus on comfort and not to pursue aggressive measures unless they were likely to return him to a quality of life where he could be mobile in his wheelchair and not be in the hospital. He was discharged to a SNF, but died about a week later.

Questions:

- 1) What is decisional capacity?
- 2) What percentage of medical inpatients lack decisional capacity? What are some risk factors?
- 3) Do you need to assess this patient's decisional capacity? Which patients need formal assessment?
- 4) How do you assess decisional capacity? What elements are involved?
- 5) Once you have decided that a patient lacks decisional capacity for a particular decision, does he necessarily lack it for all decisions?
- 6) If the patient lacks decisional capacity, what do you do next?

Resources:

Appelbaum, P.S., *Clinical practice. Assessment of patients' competence to consent to treatment.* N Engl J Med, 2007. **357**(18): p. 1834-40.

Table 1 in this article is especially helpful; it lists the four elements related to decisional capacity with sample questions to use in assessment.

References:

1. Appelbaum, P.S., *Clinical practice. Assessment of patients' competence to consent to treatment.* N Engl J Med, 2007. **357**(18): p. 1834-40.
2. Moye, J. and D.C. Marson, *Assessment of decision-making capacity in older adults: an emerging area of practice and research.* J Gerontol B Psychol Sci Soc Sci, 2007. **62**(1): p. P3-P11.
3. Jonsen Albert R, S.M., and Winslade William J., *Decisional Capacity*, in *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* 2002, McGraw-Hill: New York. p. 55-60.
4. Raymond, V., et al., *Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study.* Lancet, 2004. **364**(9443): p. 1421-7.
5. Grisso, T. and P.S. Appelbaum, *The MacArthur Treatment Competence Study. III: Abilities of patients to consent to psychiatric and medical treatments.* Law Hum Behav, 1995. **19**(2): p. 149-74.

6. Karlawish, J.H., et al., *The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment*. *Neurology*, 2005. **64**(9): p. 1514-9.
7. Appelbaum, P.S. and T. Grisso, *Assessing patients' capacities to consent to treatment*. *N Engl J Med*, 1988. **319**(25): p. 1635-8.
8. Brauner, D.J. and S.E. Merel, *How a model based on linguistic theory can improve the assessment of decision-making capacity for persons with dementia*. *J Clin Ethics*, 2006. **17**(2): p. 139-48.