Decision-Making Capacity

At the end of the session, participants will be able to:
• Know the definition of decision-making capacity;
• Understand the distinction between decision-making capacity and competency;
• Know the four elements of decision-making capacity;
• Understand the factors that influence assessment of decision-making capacity;
• Recognize which factors are not in and of themselves reasons to determine a patient incapacitated but are rather reasons only to question capacity;
• Know the efforts that healthcare professionals should make to maximize decision-making capacity;
• Know what procedures to follow after a person has been determined to be incapacitated;
• Recognize questions that may be asked to help determine decision-making capacity.

Introduction

One of the cornerstones of the Catholic tradition is respect for human dignity. This dignity has been respected in the Catholic tradition largely, though not exclusively, by respecting patients, residents and client choices (hereafter this group will be referred to as patients). From a theological perspective, patients can be understood to participate in God’s own creativity in the world as they make choices and determine their future with God’s help. Respect for patient choices allows patients to interpret the benefits and burdens of medical treatment in terms of their own life circumstances and those of their loved ones. This does not mean that Catholic institutions abide by patient wishes in all cases, however. Healthcare organizations at times may limit treatment choices available to patients in terms of clinical quality, legal and patient safety, and the like. Catholic organizations follow Catholic principles, such as the tenets of Catholic Social Teaching and the Ethical and Religious Directives for Catholic Health Care Services, and at times these principles may conflict with patient choices. The nuances of such conflicts will be discussed in other essays.

Today respect for patient choices reaches beyond Catholic health care to other healthcare institutions through the doctrine of informed consent—patients must be told the nature and purpose of the proposed treatment, its benefits and risks and alternatives. The doctrine of informed consent is similar to the respect for patient choices in the Catholic tradition, which in turn stems from respect for human persons. In both cases a pivotal element of patient choice is a patient’s decision-making capacity. Decision-making capacity is the patient’s decision-specific ability to make a choice about medical treatment. Patients without decision-making capacity cannot make fully informed choices, and may
make choices that create more harm than benefit. It is the presumption in the law, but not always in practice, that out of respect for human dignity, physicians should presume at all times that patients have decision-making capacity unless it is demonstrated otherwise. This essay will address the determination of decision-making capacity of patients for healthcare decisions.

**Besides assuming that patients have decision-making capacity unless demonstrated otherwise, another important point that needs to be made from the beginning is the difference between decision-making capacity and competency.** The two terms are often used interchangeably, but in fact they denote different things. Competency is a legal determination made by a judge to determine a person’s ability to handle his or her own affairs, including financial and property issues, as well as healthcare decisions. That a patient possesses decision-making capacity, on the other hand, is a determination usually made by a physician to determine a patient’s ability to make a specific healthcare decision. (In a few states, other healthcare professionals, such as social workers, are allowed to make this determination. Persons involved with ethics case consultations should be familiar with the laws of their particular state. For the sake of simplicity, in this essay it is assumed that the physician is the one responsible for assessing decision-making capacity.) Although there is a relation between competency and decision-making capacity, a patient may be declared legally incompetent but still may have the decision-making capacity to make certain healthcare decisions.

**The Elements of Decision-Making Capacity**

The elements of decision-making capacity are those components necessary for the patient to process and respond to the information presented by the physician for a particular healthcare decision. These general components are:

- The ability to **understand** the relevant information to make a treatment decision.

- The ability to **appreciate** the importance of that information to one’s personal situation, including risks and benefits of options.

- The ability to **reason** about options consistently with one’s beliefs, values, etc.

- The ability to **express** a choice, either verbally or via another means.

The New York State Task Force on Life and Law, a public bioethics commission, defines decision-making capacity as the ability to understand and appreciate the nature and consequences of a healthcare decision, including the benefits and risks of treatments, alternatives to any proposed health care, and to reach an informed decision.
Precise interpretation of these abilities, however, is difficult to ascertain. Patients may exhibit varying degrees of each, depending upon level of education, intelligence, diagnosis, and medications. No specific level of education, diagnosis, or medical condition \textit{in and of itself} is sufficient cause to make a determination about EITHER the presence OR absence of decision-making capacity. There is no objective level of understanding, appreciation, reasoning, or expression of choice that can be used as a measure to declare a patient capacitated or incapacitated. Rather, decision-making capacity is better understood as the patient’s ability to meet the demands of a specific healthcare decision. \textit{In other words, physicians do not want simply to ask whether a patient has general decision-making capacity; they want to ask whether the patient has the sufficient ability to make a meaningful, capable, and specific healthcare decision given the particular circumstances the patient faces.}

For example, a young patient who is declared legally incompetent may have been diagnosed with a rare heart disease that happens to be one of the leading causes of sudden death in young athletes. Discerning among the many treatment options, which depends upon prognostic information, and includes lifestyle modifications, may be too complicated for this patient to handle. The patient may be able to understand and appreciate that he or she has a heart problem, but may be unable to appreciate the differences in risks and benefits of each particular treatment. Hence, a physician might declare that this patient does not have the capacity to make a treatment decision because of the complexity of the decision in relation to the patient’s mental abilities. However, the patient may still have the capacity to make a decision about a trusted family member to serve as a proxy; and further, the patient likely has the capacity to exercise certain lifestyle choices that might inform the treatment decisions, aided by the proxy.

\textbf{Factors that Influence Assessment of Decision-Making Capacity}

At all times, physicians should be aware of factors that may influence their assessment of a patient’s decision-making capacity, including a patient’s religious and cultural beliefs, their reasoning and communication style, and their psychological characteristics, to make sure that such factors are not unfairly affecting their assessment. Patients may have a different set of cultural or religious values that might appear strange to some physicians, or patients may be making a decision for personal reasons that they have not communicated. When questions exist about a patient’s capacity under these circumstances, further communication should be initiated with the patient. Patients should be given the opportunity to clearly and adequately explain the reasons for their decisions. Physicians should look for consistency in patients’ reasoning, beliefs, and values during this explanation.

Physicians’ personal beliefs should not be the basis for evaluating a patient’s decision-making capacity. During this evaluation, patients may be asked to communicate the nature and magnitude of treatment, including the risks
and benefits of both accepting and rejecting treatment. Such an explanation from the patient, or lack thereof, may help guide physicians in determining the patient’s capacity. Questions should be open-ended and should take into account that the scale for determining capacity is correlated to the gravity of the situation.

In addition to cultural or religious differences, sometimes physicians may question a patient’s decision-making capacity because the decision may seem to be medically unsound. For instance, a patient may refuse life-sustaining treatment or even routine medical care that is considered ordinary care and standard medical procedure. Such decisions could indicate a reason to question the patient’s capacity, but should not be used as a reason to declare a patient incapacitated. The simple fact that one or many physicians involved in a patient’s care disagree with the patient’s proposed medical decision does not in and of itself indicate that the patient is incapacitated to make such a decision.

Healthcare professionals and loved ones often have questions about the patient’s psychological characteristics and how those may affect his/her capacity. Depression is frequently cited as a reason why the patient does not have the capacity to make healthcare decisions. For example, a patient who was normally a happy person makes statements that he or she wants to stop treatment and die naturally and is thus labeled incapacitated to make decisions. At times even a psychiatrist may be consulted. It is important to keep in mind, however, that even if this patient is diagnosed with major depression, the patient may still have the capacity to make a decision to forego life-sustaining treatment. The patient may understandably exhibit symptoms of depression because they are in pain and at the end of their life, and yet his/her decision may still reflect sound reasoning that is consistent with his/her life values.

Further, patients’ diagnoses, their age, or medication may be reasons to question their capacity, but not sufficient reasons in and of themselves to declare patients incapacitated. Patients exhibiting symptoms of sundown syndrome, for example, may be capacitated to make certain decisions earlier in the day, but they may be incapacitated to make the same decisions as evening approaches. Or, patients who are incapacitated due to high levels of pain medications may later be able to make the decision when the effects of the medications have worn off. It is also very important for physicians to be aware of pressures from family members or others that may coerce or manipulate patients to make certain decisions. Although these influences might not directly affect patients’ capacity to make a decision, they still may affect patients’ willingness to express their true wishes or concerns.
Examples that may be indications to question and thus assess patients’ decision-making capacity, but are not by themselves reasons to declare patients incapacitated, may include:

- Patients who refuse treatment, especially treatment that offers a reasonable hope of benefit without imposing too much burden, or treatment that seems routine
- Patients who frequently change their minds
- Patients who consent to questionable procedures that are very risky and invasive
- Patients who disagree with their physicians

Furthermore, it is crucial to remember that not all patients with cognitive impairments are necessarily incapacitated. Cognitive impairments include dementia, delirium, or more focal cognitive syndromes as defined in the DSM-IV (or V, as of May 2013). Below is a list of certain conditions that are reported in the medical literature to have higher rates of cognitive impairment associated with them. However, in and of itself, none of these conditions is sufficient reason to determine a patient incapacitated, but only perhaps to question and then assess his/her capacity:

- Dementia
- Delirium
- Alzheimer disease
- Brain disease
- Certain psychiatric conditions
- Hospitalized patients with CHF (congestive heart failure)
- AIDS
- Acutely ill ER patients
- IC patients
- Nursing home residents
- Assisted living residents
- Individuals of very advanced age

Assessing a Patient's Decision-making Capacity

Decision-making capacity is decision-specific; it is not static and must be re-evaluated for each healthcare decision, regardless of the factors mentioned above. A patient’s healthcare decision-making capacity is specific to the quality and complexity of the decision. A patient may be able to make a simple healthcare decision, such as appointing a relative to make healthcare decisions,
but simultaneously unable to make a more complicated healthcare decision, such as accepting or refusing a respirator.

Efforts should be made by health professionals at all times to maximize patients’ decision-making abilities. Efforts may include delaying decisions to certain times of days or adjusting medications as just mentioned. Other techniques may include, but are not limited to: 1) varying how information is presented (verbal, written, use of diagrams, etc.) to aid in the access and comprehension of information; 2) providing proper situational supports (presence of trusted social support, comfortable surroundings to the extent possible, etc.); 3) addressing psychodynamic issues (alleviating anxiety, providing pharmacological support if necessary, etc.)

Possibly the most important step to maximize patients’ performance in decisions is to delay final judgments about their decision-making capacity as much as possible. Emergency situations arise, but delays in making final judgments (hours or even days) can be helpful to distinguish between time-limited impairments and permanent impairments. If a patient has periods of decision making capacity, then in fairness to the patient the physician should wait, if possible, until the patient can make the decision. Most importantly, patients are presumed at all times to have decision-making capacity unless they demonstrate otherwise. A common mistake is the unwarranted assumption that a patient is incapacitated for decision making because he or she is elderly or has some form of physical incapacity, or because there is a relative who insists that the patient cannot make healthcare decisions. **This is why delays in making final judgments are helpful, assessments should be frequent, and an assessment should be made for each treatment decision.**

If the attending physician determines to a reasonable degree that a patient lacks the capacity to make a healthcare decision, the physician is required by law in all states to place an entry on a chart describing the nature, etiology, and likely duration of the incapacity. If the patient can understand the physician’s determination, the physician must inform the patient orally or in writing of the determination of incapacity. If the patient objects to the physician’s determination, the physician may elicit help from family members. Sometimes conversations with trusted family members may help alleviate the patient’s concerns and objections. Oftentimes trusted family members may talk with the patient and persuade him or her to allow a proxy to help make decisions. However, if the patient continues to object, a court order is required before a proxy can be appointed.

In cases in which a proxy has been appointed for a decision to withdraw or withhold life-sustaining treatment, most states require that a second physician confirm the determination of incapacity in the medical chart. Additionally, after the initial incapacity determination is made, the attending physician must confirm
that the patient still lacks capacity in the medical chart before complying with new
decisions by the proxy.

Decision-making capacity for minors is made according to the same
criteria as adults, with additional attention given to the general age and maturity
of the minor. Adolescents, for example, may react more fervently to a medical
illness than an adult because of social concerns, worries about appearances, etc.
Their lack of maturity may lead to rash decision-making. At the same time, an
adolescent who has experienced great suffering in life due to past medical
illnesses or personal tragedy may be more mature than some adults. Such
considerations should also factor into the determination of a minor’s decision-
making capacity. And of course, minors may not have the legal authority to
override their parents’ decisions.

Overall, the following questions may be asked to help determine a patient’s
capacity:

- Does the patient understand what is wrong and what the proposed
treatments are?
- Does the patient understand the benefits and risks of different proposed
treatments or no treatment?
- Can the patient reason about the medical information and relate this
information to his or her personal values and beliefs?
- Can the patient communicate in some fashion why he or she has made a
certain decision?

Learning a patient’s narrative is crucial during this process. Patients’ life
experiences, including their experiences of illness and past medical treatments,
greatly influence their values and understanding of the situation at hand. For
example, a 15-year-old diagnosed with leukemia may have a completely different
set of values and reasoning mechanisms than a previously healthy 50-year-old
also diagnosed with the same form of leukemia. Each person will likely
comprehend and answer the above questions in different ways.

Therefore, besides the questions above, it is very important to understand
the person’s history and how that history may affect their current decisions. Such
questions to assess this history may include:

- How has this illness/diagnosis affected you, personally, spiritually?
- What reasons are important to you in accepting or refusing treatment?
What are your sources of strength, such as loved ones, friends, or faith, and how have these influenced your decision?

Crucial elements of the person’s history include their beliefs, relationships, and values, not simply the physical pains and burdens of their illness and treatment options. Physicians should listen to how the illness/diagnosis and treatment options relate to the person’s lifestyle choices, wishes, and aspirations. It is easy to mistakenly declare a patient incapacitated in cases in which a physician does not fully appreciate or discuss with the patient his/her social and spiritual history. Patients may make decisions that seem irrational when they are actually consistent in light of their personal values and past experiences.

Summary

In summary, decision-making capacity—distinct from competence—is the patient’s ability to make a specific healthcare decision. This ability typically includes a patient’s ability to understand and appreciate the nature and consequences of a healthcare decision, including its benefits, risks, and alternatives; and his or her ability to reach an informed decision. For this reason, decision-making capacity is decision-specific and should be measured for each decision. Although many factors, such as age, diagnosis, or refusal of treatment, may be reasons to assess a patient’s decision-making capacity, none of these reasons are sufficient by themselves to declare patients incapacitated. Rather, patients are presumed to have decision-making capacity unless they demonstrate otherwise.

Declaring patients incapacitated entails determining to a reasonable degree of medical certainty that they do not have the ability to make a particular healthcare decision. The determination of incapacity should be entered into the medical chart, including its nature, etiology, and probable duration. Physicians at all times should try to maximize patients’ capacity as outlined in this essay, as well as be aware of how their own personal values and beliefs might unfairly affect their interpretation of patients’ decisions. If a patient is found to be incapacitated despite repeated assessments and efforts to maximize his/her capacity, and if the patient continues to object to this determination, a court order is required to turn decision-making over to a healthcare proxy.
Sources:


http://www.health.state.ny.us/regulations/task_force/health_care_proxy/guidebook/

Endnotes

1 This list is taken from Alzheimer’s Association, “Research Consent for Cognitively Impaired Adults: Recommendations for IRBs and Investigators,” Alzheimer Disease and Associated Disorders 2004 Jul-Sep;18(3):171-5.