LESSON 1: INFORMED CONSENT AND THE RIGHT TO REFUSE

Summary

Aims

1. To appreciate the moral importance of informed consent in medical practice.
2. To understand when consent is valid.
3. To become familiar with informed consent as a legal requirement.

The Moral Importance of Consent

There are two ethical justifications for the claim that doctors should get consent from patients for tests or treatments. The first is based on the moral (and ethical) principle of autonomy, according to which a person has a right to determine the course of her own life and to be free (within limits that must themselves be justified) from interference by others. A central aspect of this right is a person’s right to bodily integrity. It is impermissible for any person (including a doctor) to invade or manipulate the body of another without permission. The second is based on the ethical principle of beneficence, according to which doctors should act out of compassion or concern for their patients and aim at doing what will be best for them. Patients are typically the best source of information about what will make their lives go better.

In addition to the ethical bases for informed consent, the legal concept of assault has been used as justification for the medical notion of informed consent when surgery was done without a patient’s permission. (Schloendorff, 1914)

Sometimes, there is a conflict between the physician’s duty to respect patient autonomy and her duty to aim at what would in fact be best for the patient. There is significant consensus that, in such cases, the duty to respect patient autonomy takes precedence.

The Criteria for Valid Consent

Consent from a patient is generally considered to be valid if (and only if) the following criteria are satisfied:

1. The patient has decision-making capacity.
   - Capacity-determinations are specific to the particular decision that must be made; they are not judgments about the patient’s decision-making ability in general.
   - The patient with decision-making capacity is able to understand and retain treatment information relevant to the choice at issue. She believes in the validity of the information given. She is able to use the information to make a choice consistent with her own beliefs and values.
• While the concept of decision-making capacity, like the legal concept of competence, is a status concept (a patient either has capacity or she hasn’t), decision-making ability is really more of a spectrum concept (the ability to make decisions comes in degrees). It is widely thought that, when confronted with a treatment refusal from a patient whose decision-making ability is in question, we must strike a balance between the degree of decision-making ability and the risk and degree of harm from not treating. That is, whether or not a patient will be determined to have capacity (a status) may depend, in part, on the seriousness of the decision she must make.

2. The patient has been adequately informed. There are three ‘standards of disclosure’ for adequate informing.
   i. Professional Practice Standard. The amount of information disclosed is determined by the traditional practice of a professional community, such as a community of physicians or clinical psychologists.
   ii. ‘Reasonable Person’ Standard. The pertinence of a piece of information is measured by the significance a hypothetical reasonable person would attach to it in deciding whether to undergo a procedure. The physician must disclose all information the reasonable person would judge relevant.
   iii. Subjective Standard. Adequacy of information is judged by reference to the specific beliefs, desires, fears of the individual patient.

   Typically, it is expected that a physician will meet (ii) and, where she has (or should have) information about a particular patient that would shed light on the desirability for that patient of additional information, (iii) as well.

3. The patient has not been coerced. The patient must consent to treatment voluntarily. If she is forced to agree or threatened with grave consequences if she refuses, her consent is not valid.

Surrogate Decision-making

When a patient does not have decision-making capacity, someone else must make health care decisions for him. When the patient is an adult who has had but who no longer has the ability to make decisions, the physician’s obligation to respect the decisions of a surrogate decision-maker is seen as an extension of her duty to respect patient autonomy. In such cases, the principle of substituted judgment is given priority. This principle states that the decisions of a surrogate should reflect what the particular patient would decide were he able. The principle of substituted judgment is, however, inapplicable to some cases involving adult patients and never applies to cases involving infants or very young children. In such cases, a best interest standard is applied, i.e., a surrogate is expected to decide among treatment options by aiming at the “best interest” of—what would be best for—the patient.
Informed Consent, Surrogate Decision Makers, and the Law

Physicians have not only a moral but also a legal responsibility to obtain the informed consent of competent patients for testing and treatment. See Berg, et al. In *Cruzan v. Director, Missouri Dept. of Health* (1990), the Supreme Court granted the right to refuse treatment to every patient, even when the treatment at issue is necessary to sustain life, and gave states the authority to construct criteria for surrogate decisions. In every state, competent individuals have the right to determine who will make decisions about their care should they lose decision-making capacity. In Georgia, this is done through the execution of a durable power of attorney for healthcare. Georgia law also specifies who can make decisions for patients without decision-making capacity and without a durable power of attorney, and provides guidelines on how surrogate decision makers should reach decisions. For adult patients without decision-making capacity, surrogates are identified through the application of Article 31 (Georgia Medical Consent Law), Chapter 9 (specifically, Title 2, Section a, 1.1-6). If the patient has no durable power of attorney for healthcare, physicians are to look to relatives, in rank order specified in the law. The decisions of surrogates are to be guided by the principle of “substituted judgment” (31-9-2b). The cumulative effect of such statutes as Georgia’s Living Will (31-32), Durable Power of Attorney for Healthcare (31-36), and Do Not Resuscitate (31-39) laws is to make clear that each adult patient or appropriate surrogate has the right to refuse treatment, even “life-sustaining” treatment.

Discussion Case

Mr. Smith

References:


LESSON 1: DISCUSSION CASE

Mr. Smith

Mr. Smith, a vigorous 75-year-old man with no significant prior medical history, was found at home by his wife to be aphasic and hemiplegic. He was brought to the hospital and diagnosed with a large ischemic cerebrovascular event. Four days after admission, the patient had made no improvement and developed aspiration pneumonia. He was awake, in no distress, tracked with his eyes, and was able to grimace nonspecifically, but remained aphasic, had a dense right hemiparesis, and had little interaction with his family. He was no longer able to express his preferences. His wife requested that her husband be made “comfort measures only.” However, the following day, after discussion with her family, Mrs. Smith requested more aggressive care, stating that the children had difficulty coming to grips with the decision to institute comfort measures only. The palliative care team was consulted.

Mr. Smith was an avid sportsman, coaching football and playing golf seven days a week. He was very proud of his children’s athletic accomplishments. His loving family included a wife of 53 years and three children. His wife described him as a very impatient man who had little tolerance for disability. As an example, she told the story of a close friend and golfing partner who suffered a stroke that left him with residual hemiplegia. When the friend returned to the golf course, Mr. Smith would “turn around and leave” as he couldn’t bear to see his friend in that condition.” Prior to the palliative care consultation, Mrs. Smith had again talked to her family and was now clear that the entire family agreed that comfort measures were Mr. Smith’s wishes. Mr. Smith had repeatedly told her that he didn’t want to live if he had any disability and would in fact be “angry” with her if she were not to follow these wishes. The patient had a living will stating that he did not want his life prolonged in case of an “irreversible” medical condition. The living will did not specifically address the issue of a large cerebrovascular event. The palliative care team was in agreement with the wife’s request for comfort measures.

However, the primary team taking care of Mr. Smith had difficulty accepting these requests because 1) they had seen many similar patients make partial recovery; 2) Mr. Smith had no underlying terminal condition and 3) the team thought that withholding artificial nutrition would “actively” hasten Mr. Smith’s death.