

Monograph 4

**Patient Self-Determination:
Informed Consent, Advance Directives, and Surrogate Decision
Making**

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In my outline "Basic Medical Ethics Principles" there are four basic general principles: respect for autonomy, beneficence, nonmaleficence, and justice. While these principles are not intended to imply a lexical or hierarchical ordering the respect for autonomy is pivotal. When put to the test the respect for autonomy has given us essential processes of patient self-determination for the ethical practice of medicine. Three of those processes are Informed Consent, Advance Directive, and Surrogate Decision Making.

1. Informed Consent is the authorization by a patient (or surrogate) for clinical management or for participation in human subject research
 - a. It is a process and NOT a singular event
 - b. Practitioners do NOT consent patients. Patients consent to procedures or research
 - i. The person performing the procedure or investigational trial should be the person(s) obtaining the consent
 - ii. The consent process may be performed via telephone or televideo but final consent must be obtained by signature and date of signing prior to the procedure
 - c. Informed consent is obligatory when there is the chance of any significant risk to a patient or when organizational policy requires informed consent
 - d. When risk is low simple consent rather than the process of informed consent is permissible ("I'm going to take your blood pressure and listen to your chest. Is that OK?")
 - e. Consent is implied in an emergency (imminent death can be avoided) and is a clinical decision

2. Informed consent is a process consisting of five parts that can take place over more than one conversation ending with a signed document affirming the process and its elements
 - a. Describe the diagnosis to the patient in language that can be understood by the layperson
 - b. Present the **medically reasonable** alternatives for managing the disease, impairment, disability or injury, including doing nothing, with all the clinical benefits and risks
 - c. Make sure the patient or surrogate understands each of the alternatives by engaging them in conversation
 - d. Support the patient (surrogate) decision based on their life and moral values and beliefs
 - e. Obtain the authorization or refusal of authorization
 - i. Prior consent is to be honored for a patient who becomes incapacitated **Unless** the medical condition and intervention has significantly changed.
3. Informed consent is **voluntary** and without restraint or undue influence, provides all the information needed to be **truly informed**, and is based on patient or surrogate **mental capacity to understand**. **All adults are presumed to have the capacity** to comply with informed consent unless proven otherwise through an examination by the physician or others authorized to do so.
 - a. Capacity and competence are two different concepts
 - i. **Competence is a legal term used by judges** to declare someone able or not to enter into contracts. Children, for instance are considered incompetent until they reach the age of majority or are emancipated minors.
 1. **An emancipated minor is one who is under the age of 18 but is married or a member of the armed forces or declared emancipated by a judge.**
 2. **A minor may request drug abuse information and treatment as well as birth control and reproductive counseling without the consent of a parent.**
 3. **In Georgia a minor may not request an abortion without parental knowledge and consent.**
 - ii. **Capacity is the medical term** denoting if a patient understands the material given for informed consent. It is a clinical decision and not a legal one and is legally sanctioned by law for use in informed consent

- a. A person with mental illness, diminished intellect, and other impairments may still be capacitated and able to make medical decisions especially those with less risk. Even children under the age of majority may be able to give informed assent though a parent would still have to give final consent and authorization or refusal.
 - i. **Informed consent or informed refusal are both morally and legally supported**
 - b. The basic test of capacity for informed consent is the ability to follow the process of informed consent as outlined above 2. a-e
 - b. Informed consent properly documented for covering all of its essential elements in the medical record is the best way to assure **legal liability**
- 4. Advance Directives have been in existence in some form for many years and recognized throughout the United States through the Patient Self-Determination Act (1990) that required all healthcare entities that used Medicare or Medicaid to inform patients of their right to have an Advance Directive and if not how to obtain one. **An advance directive is a legally binding document** executed by the patient and witnessed by two persons. It does need NOT to be notarized.
 - a. An advance directive can be in a variety of forms written by an attorney or found on the internet. "Five Wishes" is a popular form used by many people.
 - b. an advance directive is a document executed by a person who is capacitated for use in making medical decisions in the case that they cannot make decisions contemporaneously due to unconsciousness or other mental disability
 - c. an advance directive is often used to detail medical preferences due to acute illness and end of life
 - d. an advance directive often will use the formula "if.....then....." such as "if I am not able to feed myself and there is expectation of my recovery from my illness then I want to be fed artificially" or "if I am dependent on life support such as a ventilator and there is no reasonable expectation of my recovery then I want all life support to be stopped and I be kept as comfortable as possible"
 - e. an advance directive that is the most powerful is one that assigns a person to have healthcare power of attorney or healthcare agency

- i. advance directives of the living will variety are often hard to write (how is a healthy person writing a directive to know what they would want when critically ill?) but also hard to interpret due to general preferences applied to specific medical interventions
- ii. Advance directives assigning power of attorney or agency are so-called legal fictions that assign to the agent the same abilities the patient would have if they were present and capacitated. The agent becomes the patient and can make all informed decisions or refusals though an advance directive can limit those abilities if done so explicitly. Generally assigning agency, unless otherwise noted, assigns broad and unlimited powers.

5. The third avenue for patient self-determination is through **surrogate decision making**

- a. If a patient is unable to communicate and go through the process of informed consent and if the patient does not have an advance directive or has appointed a healthcare power of attorney an appropriate surrogate may speak for the patient
- b. According to Georgia law the following list are the identities of appropriate potential **surrogates in hierarchical order**
 - i. Legal guardian
 - ii. Spouse
 - iii. Adult children (all must agree or agree that one be the decision maker)
 - iv. Parent
 - v. Adult sibling
 - vi. Grandparent
 - vii. Adult grandchild
 - viii. Another close relative or close friend who is willing to serve
- c. Without an advance directive with stated preferences a surrogate must rely on one of two standards for decision making
 - i. **Substituted judgement**
 - 1. This is **the desired standard** in that the surrogate bases decisions on conversations, values, and previous statements made by the patient. The surrogate bases a judgment on the question “if the patient were able to assess and decide what to do in this situation, what would he or she do or say?”

ii. **Best interests**

1. This standard is **not as desirable** or as morally satisfying as substituted judgement. These standard asks “what would a reasonable person in this situation want or decide?” It is a standard that could lead to decision making through conversation between the physician and surrogate
- d. In Georgia surrogate powers can be restricted such as withdrawing life support when the patient is not diagnosed as end-stage or terminal. Check hospital policy.
 - e. Surrogates do not have financial obligations for the patient unless law provides that it does in the case of a spouse who shares all finances with the patient.