Lecture 5.1: Capacity and the capable patient

This week and the next week are about informed consent. Because it presupposes, for its validity, that the patient is capable, it represents an irresistible obligation confronting immovable obstacles. What **constitutes** adequate capacity?—considering that many patients are frightened, angry, ill with capacity reduced by fever or disease, unable to take in what they are being told, under great pressure from family loyalties or other competing values, and many, even before their current health crisis, are demented, legal minors, developmentally retarded, children or infants. The various cases and articles last week and next are designed to point out what kinds of considerations decision makers have to take into account in determining their course of action in complicated situations.

People who are conscious and able to communicate their wishes are not necessarily automatically judged competent. In DAX's case, the pain of the burns and the treatments was considered sufficient to count as disruptions in his capacity to decide his care. In Mary Northern's case her decision was so visibly against others' view of her best interests that they were inclined to override her decision.

If a competent person wishes to have a say in the interventions that will be available to h/h in case of future incompetence, there are several possibilities. The advance directive and the health care proxy are two alternatives. Issues and values that complicate accepting a conscious apparently capable person's decisions are no less weighty when they are introduced second-hand by a surrogate's attempts to interpret those instruments.

I: *Language*: Rorty tends to use the term "capacity" in medical contexts to distinguish a functional determination that a person is in/capable of medical decision making in a given context from a legal decision that a person falls into a certain category. **But**: in our readings, Buchanan and Brock (pp 368-378) use the language of "competence."

A: Legal competence: to declare a person wholly or partially legally incapable of making decisions, a court hearing is held, in which clear and convincing evidence must be presented that a person is wholly or partially incapable of taking care of h/hself or estate. [Competence is always presumed; the burden of proof rests on the person who challenges it.] The court appoints a guardian with appropriate powers to act on the individual's behalf.

Some people who are legally incompetent are nonetheless capable of medical decision making. [Eg: in *Rogers v. Okin* (1979), mental patients who had been legally committed were judged to be capable of choosing to refuse psychotropic drugs.] Some persons who are legally competent can be situationally or medically incapable of some decisions regarding their health care.

B: Capacity: the functional in/ability of an individual at a given moment to take part in decision making. It is relative to the abilities of the person, to the task in hand, in

light of probable consequences. The determination of capacity may be decision-specific; it may be made by the treating physician; and it need not become a legal decision.

The degree of functional ability required for capable decision making is a function of the seriousness of the consequences of the decision. "Consent to a low risk life-preserving treatment should require a minimal level of [capacity], but refusal of that treatment…should require the highest level of [capacity]." (B&B, p. 375)

II: *Determining capacity:* It is important to determine capacity in order to inform the patient about care options and get informed consent or refusal to any proposed treatment.

Ethical guidelines: respect for self-determination, and promotion of the well-being of the person concerned.

A person is functionally able to make health care decisions when s/he can:

- **Understand the information relevant to the decision,**
- **Reason about alternatives and consequences, and**
- **Communicate with caregivers about the decision.**

Incapacity can be *developmental* (eg, children below the age of consent, developmentally retarded individuals; or the very old) or *pathological*, and either temporary or permanent. There are some clear-cut cases of an incapable patient: someone in a coma or vegetative state, a pre-verbal infants, the severely retarded or severely mentally ill, or someone who is heavily intoxicated.

If the person is capable, then informed consent is required for any recommended interventions. If the person is not capable, then a surrogate decision maker must be found for relevant decisions.

Adolescents represent a special category of legally incompetent but possibly capable decision makers. One speaks of '**assent**' for teenagers, suggesting that even if they are not the legal decision makers they should be informed, consulted, and have their preferences taken into consideration.

There are some legal categories [eg. 'emancipated minor'] which allow legally incompetent people to make their own decisions, often around reproductive issues.

III: *Decision making for the incapable patient*:

There may be a designated proxy.

The family may be both knowledgable and concerned

There is a *legally defined hierarchy* of surrogate decision makers to be identified in a case where a person is judged incapable of [medical] decision making. [specified in the Patient Self determination Act of 1991]

Order of surrogates:

- Legal guardian [in cases of legal incompetence]
- Person named in a h/c decision document
- Spouse
- Adult children
- Parents
- Siblings
- Other relatives, in descending order of blood relationship

The courts are the last resort. (Judges don't want to make medical decisions.)

Standards for decision making:

Substituted judgment (for a person who has lost decision making capacity)

Best interests (for a person who never had it)

IV: *Capacity and informed consent*: Capacity is a precondition for informed consent, which is itself a legal requirement for medical interventions. In order to be able to give informed consent (or refusal) to a proposed treatment, a person must be *capable* and free from *coercion*. The line between coercion and persuasion is hard to draw; and there has been considerable discussion of the extent to which we are supposed to consider the patient's own values—h/h desire to save precious economic resources for the future welfare of the surviving family, a priority of religious values over self-preservation—a kind of compulsion.

Most of the class was devoted to a careful discussion of the *Mary Northern* case.