Lecture 6.1: Deciding for others

We discussed capacity last week, and pointed out that the capacity of the patient is a pre-condition for informed consent to, or refusal of, treatments offered by the health care system. Each patient falls somewhere on a continuum of capacity between being completely or ideally capable, and being completely incapable. Incapacity may be permanent or temporary; and a presently incapable patient may have been previously capable, or never capable.

Capable patients are given the privilege (and responsibility) of deciding for themselves whether to accept or refuse proposed treatments. Decision making for incapable patients is much more complicated. Some of the variables were discussed last week. It depends on whether the decision in question is one of accepting treatments, or refusing them—as well as varying depending upon how serious the consequences of each are.

Capable patients must give informed consent to proposed treatments. Valid **informed consent** requires:

(Threshold conditions)
1. capacity (to understand and decide, as defined last week)
2. voluntariness (freedom from coercion, persuasion and manipulation)

(information elements)
3. disclosure (of relevant information)
4. recommendation of a proposed care plan
5. understanding (of disclosure and recommendation)

(consent elements)
6. decision (in favor of one proposed alternative)
7. authorization (eg., by signature)

The **incapable** patient needs to be represented by someone else to make decisions for them. Decision making for a previously capable patient should be made by a surrogate decision maker who takes into consideration the values and goals of the person when capable (=*substituted judgment*), advised by previously expressed wishes, if available. (This is the role of the advance directive and h/c proxy)

Decision making for a never-capable patient should be made taking into consideration what is in the *best interests* of the present patient (including future interests, if the incapacity is developmental, as for children).

In the cases that are discussed in these readings, there are several complicating issues that require discussion: prospective autonomy vs. present best interests; PVS; whether ANH is a medical treatment on the same footing as other medical treatments; sanctity of life v. relief of suffering.

"Prospective autonomy:" The five cases in Cantor raise the question of the priority in different circumstances between what the person, when capable, wishes for his incapable future, and the best interests of that same person should they become incapable. (See the questions at the end of 'reading SAL')

The idea of 'present interests' becomes problematic in cases of coma, vegetative state or permanent unconsciousness: is perception of pain the only kind of suffering? Is there a sense in which an unconscious person has 'interests'? Is there an obligation that we owe to fellow human beings to respect and preserve their life even when there is reason to believe they do not experience it? [Why do we eat cattle, but not corpses?] What is more 'respectful'—to preserve life or to minimize suffering?

The Conroy case is very rich for discussion (and is very similar to the Schiavo case). The contrast between the initial court decision and the appellate court decision is in part a function of what the appellate courts are allowed to pay attention to: namely, procedural issues.

Some of the most important things in this case are the things that are NOT considered relevant to the final decision but are discussed at some length:

--the distinction between *withholding treatment and withdrawing it* after it has been started. Withdrawing treatment may be psychologically more difficult for the agents concerned, but in the mind of the court and in general agreement there is no ethically relevant difference between the two; one is not worse or better than the other.

--the distinction between ventilation and artificial nutrition and hydration: the courts consider artificial nutrition and hydration 'medical treatments' for purposes of considering withholding or withdrawing: that is, they are both equally artificial, equally 'extraordinary' in terms of their 'naturalness.' [The US catholic bishops disagree.]

--broadening the notion of suffering beyond pain [but the degree of consciousness might be relevant there too—does fMRI tell us anything about whether people suffer?]

--is there ever a morally relevant difference between acts and omissions?

As if the question of informed consent was not complicated enough, there are also many specified, legally exempted, good-excuse cases where it is NOT required. HIV status is a good case in point: the rules governing when you cant tell and when you must tell leave virtually no room for discretion, and require careful navigation skills!

Exceptions to the requirement for informed consent:

1. emergency treatment: sometimes you can't ask, or can't get an answer.
2. incapacity (but then the demand moves to consent of surrogate decision maker)
3. patient waiver: the patient says "I don't want to know!" (problematic! You'd better have a witness to the request, or put it in writing.)
4. 'therapeutic privilege:" when disclosing poses dangers to the patient (also problematic, since others can contest your claim that it is dangerous)
5. national or state waivers: there are things the state says you can do without consent.

Eg. vaccination programs, newborn genetic screening…

Points to remember: The emphasis on informed consent is so great because the task is so difficult. We have seven hard and fast conditions that are required for informed consent, but all our readings are designed to suggest that there are few hard and fast answers.