Deciding for Persons (October 13)

The material we want to cover this week is to some extent an extension of, and to some extent an overlap with, the material we discussed last week. We talked then about informed consent, the right people have to decide for themselves what treatments to accept or refuse. We had two cases last week that we discussed at length. Mary Northern was a case where a (maybe) capable person refuses a treatment that others—the state, the caregivers—consider in her best interests. Dax, which we didn’t discuss at length, is a similar case: a severely burned patient wishes to discontinue a treatment that others consider in his best interest.

The other case we discussed at length was the Conroy case, and that falls more within the context of this week’s issue: it involves surrogate decision making, and raises the question of to what extent, and under which conditions, others can decide about treatments for people who are not capable of making treatment decisions for themselves. The Conroy case is very similar to a more recent case that we did not discuss at length, the Terri Schiavo case, which occurred 20 years later (but which resembles it closely). Differences between the two: the state in which it occurred; the time in the national history in which it occurred; and disagreement among interested parties.

So: if we want to allow surrogates to make decisions for other people, what conditions, what limits or guidelines, are appropriate for them to have in mind in doing so? We are willing to grant them the right to make those decisions if we have reason to believe they are acting in the stead of that person on behalf of that person’s best interests. What counts as evidence that they are doing so?

Something that is taken into consideration and considered relevant in cases affecting once-competent persons is something that is important for the decision-making standard called ‘substitute judgment’: It is important to know what the person would have wanted for themselves if they had anticipated being in the position they now find themselves. We saw that in the Conroy case—the nephew said she would have hated to be in this situation, and noone contested his claim. In the Conroy case, the judges decided that the surrogate had some grounds for thinking that if she were competent, Claire Conroy would also refuse the treatment. In the Schiavo case, the parents and the husband disagreed about whether Terri had ever expressed any relevant opinions; so the result was different.

I: Advance Directives: So: why not encourage people to make their wishes known? Thus advance directives—an attempt to institute as regular practice the convention of making your wishes (insofar as you know them) available to your surrogate, if you have one, or to your caregivers, if you don’t, what treatment you would like to refuse should you become incompetent at some point in the future.

On the website is a copy of the relevant California document, which has three parts. The first is a power of attorney for health care decisions, naming a surrogate
decision maker. The second is an abbreviated ‘advance directive’ form. The third addresses organ donation.

George Annas, in the readings for this week, is very down on the standard ‘Natural Death Act’ advance directive, as applicable only to the terminally ill and limiting the kind of treatment that can be refused. He also thinks it is a very bad idea to include any discussion of organ donation in the document. He thinks the ‘power of attorney for h/c’ is a very good idea, though.

Fagerlin and Schneider are less optimistic. They find difficulty not in the idea, but in the implementation: people don’t have them; they don’t know what treatment they want; so they can’t state their preferences clearly; people don’t carry them on them, so they aren’t available when needed—and the caregivers and/or family usually ignore them anyway, even if they see it. But they too approve of ‘power of attorney for h/c’ documents.

The main problem seems to be the distance—temporal and situational—between anticipated situations and what actually happens. The advantage of the power of attorney is that it authorizes someone who is in touch with what happens to make decisions on the ground and in real time—not in advance and in ignorance.

The attempt to universalize advance directives has not been particularly successful; despite 30 years of begging, most people do not have them, for many of the reasons that Fagerlin and Schneider discuss—and also because none of us really believe that we will be in a position to need them. But in addition to the various practical difficulties, there are some theoretical problems as well, and some of our readings discuss those.

II: Advance directives and prospective autonomy: The dilemma as Buchanan and Brock would put it is of having to choose between two equally defensible prima facie principles: an individual’s right of self determination, what we’ve grown use to calling the principle of autonomy—and the best interests of that individual, what we call the prima facie principle of beneficence.

Consider Cantor’s 5 Scenarios are about advance directives and what we call in the trade “Prospective autonomy.” (It’s interesting to think about how those situations would have worked out if there had been a ‘power of attorney for healthcare’ person named as decision maker.)

Scenario 1: senile (but apparently happy) JW develops bleeding ulcers and will live a few more years with transfusions. Should she be given blood?

Scenario 2: man who believes in the redemptive value of suffering requests all life-extending measures and NO pain relief. He then becomes incompetent and victim of an extremely painful cancer. Should he be given analgesics? Should the life-extending measures be discontinued?

Scenario 3: man who will need a heart transplant wishes to leave his estate to his
children wishes no transplant should he become incompetent. Sure enough, he later needs a transplant which would extend his life for 3-5 years, and will clean out his estate. Should he be transplanted?

Scenario 4: woman who wishes to do good asks that if she becomes incompetent she be used as an organ donor (kidney and bone marrow). Should her request be granted?

Scenario 5: woman who prides herself on her intellectual acuity wishes no life sustaining treatment should she become mentally incapacitated. In her present demented condition she seems to be enjoying the limited range of activities available to her, but must be sustained by artificial nutrition and hydration. Should it be withdrawn on the basis of her prior wishes?

The readings this week include a heated discussion between two of our authors about the appropriate standard for decision making for once capable but now incapacitated patients, a continuation of the discussion from last week.

*Dresser and Robertson think that for previously capable but nowincapable persons, the standard should be more like that for never-capable persons: the best interests of the present patient, rather than deferring to what they might have earlier imagined they wanted. (= minimize slavish obedience to advance directives.)*

*Rhoden on the other hand thinks that the presently demented person is the same person as the previously capable person, and as such deserves to have their wishes about how their life goes respected. She would prefer to use the substituted judgment standard, which requires one to consider what the person would choose if, counterfactually, s/he were still capable.*

The philosophical puzzle is a little bit different than the clinical puzzle. The philosophical puzzle about advance directives is fundamentally a puzzle about personal identity. And the question is: what makes me the person I am, and in this case—the same person? I suppose most of us know what makes us persons, and since the answer seems obvious, you will not be surprised to learn that there is a HUGE philosophical literature about it—five books that I know about, and more in the works. (The simpler the question, the larger the literature.) Is it physiological unity—the same body, from birth to death? Psychological continuity—memory of past, anticipation of present, some consistency of character or behavior? Narrative identity—being able to be the hero, the first-person narrator, in a story of my life?

The problem for personal identity arises when a person, a particular unique combination of memories, intentions, beliefs/goals/desires, and character, undergoes changes over time that alter or remove those psychological traits. Of course through the course of our lives we all undergo some changes; but is there a point at which we might hesitate to describe the physically continuous substrate as the ‘same person’? And when we consider the best interests of a person, are we thinking only of the interests of the
person immediately in front of us, or are we attempting to consider the person’s whole life, all the stages?

Suppose that a woman is in the earliest stages of Alzheimer’s disease, and she recognizes that there will come a point where she is in a demented state and will thus be incompetent to make autonomous or informed decisions about her treatment. Because she values her creativity and autonomy, she does not want that future demented self to be kept alive — her life under those circumstances, to her mind, will not be worth living.

So she signs an advance directive stipulating that no life-saving measures are to be used on that future demented self. Let’s say she gets pneumonia; but by that time, she is quite content in her intellectually diminished state and, when asked, says she wants to live. Should she be given antibiotics to cure her (easily curable) infection, that might otherwise be fatal?

Her advance directive suggests—demands—that she not be given that treatment. If her husband has authorized it for her anyway, has he been disrespectful to her, or respectful of her? Is she the same person, or not? If not, why not? If she’s not the same person, are her previous desires binding upon her present self? Should we, or her surrogate, consider the presently demented person the ‘same’ person as the previously competent one, whose previous intentions still hold; or rather, for treatment purposes, should she be considered a different person, with her own ‘interests’ which need to be respected?

Dresser/Robertson argue that prioritizing precedent autonomy runs the risk of doing damage to the present demented person. Rhoden counters by offering cases where not doing so runs the risk of producing unethical situations (eg by transfusing PG as soon as he loses consciousness).

David Shoemaker has an interesting article in the Stanford Encyclopedia on this question, in which he suggests that there are three standard answers to the question of what constitutes our ‘personhood’: psychological continuity; biological continuity (=being the same organism from birth to death); and narrative identity. Demented professor may not be the same person, psychologically; or narratively; but she is the same organism. Philosophy majors may wish to check out the first three articles in a recent issue of the APA Newsletter on philosophy and medicine. The URL is www.apaonline.org/documents/publications/v08n1_medicine.pdf

The question of who we are talking about is also a question about where ethical issues arise. I drew on the board a trajectory from sperm and egg through competent maturity to corpse. Ethical issues can be found at practically every stage of that progression (including, if we are to believe the Pentateuch, the question of whether we need respect sperm per se). Questions about the moral status of fertilized egg (in vivo or in vitro), blastomere, embryo at every stage of development from 4 days to birth, about the age at which children can be considered persons, and questions on the other end of the trajectory, about what constitutes appropriate treatment for people in the various states of comatose, minimally conscious, PVS, brain dead, and corpse. We will explore some of those questions in greater depth in the next few weeks.
III: *The never-capable patient:* If we are interested in decision making for never capable patients, there is no group of patients more complex than the **newborn**, and two of our readings for this week address that class.

We live in a pro-natalist society. *Children are particularly vulnerable*—the younger they are, the more vulnerable; and they represent the future of their families and their communities. Only puppies and the occasional kitten have more sentimental appeal.

Our society has established **legal protections that are extremely stringent** for them; and ethical disasters involving them have made for complicated laws and heated controversy.

There was a period in the 1980s when, in response to a few cases where imperiled newborns were allowed to die rather than being offered appropriate treatment—the federal government passed strict laws requiring treatment of disabled children—the “baby doe” laws. They were passed in 1982; and pretty much revoked in 1984, when a decision was made to put enforcement of the Child Abuse Protection Act in the hands of each state. The brief period in which they were in effect deprived both the physicians and the parents of decision making power, putting the power in the hands of judges who were neither knowledgeable about the probable life-course of the infants in question, nor responsible for their care—a basically undesirable, indeed, untenable situation which was not satisfactory to any of the major stakeholders in the cases.

But the people who are responsible have a uniquely difficult task because of the lability and the vitality of the subjects of their deliberation. Infants are remarkably adaptive, remarkably resilient—and extremely difficult to predict. You just don’t know what the prognosis will be. For that reason such things as brain death, for instance, cannot be determined in infants before a certain age.

The HHS rules (1984) (=the child abuse protection act) included the following provisions:

1. All disabled infants must receive nutrition, hydration and medication
2. All disabled infants must be given medically indicated treatments
3. There are three exceptions to these requirements (=circumstances in which treatment is not considered ‘medically indicated’):
   a. If the infant is [‘chronically and irreversibly’] comatose
   b. If treatment would merely prolong dying or be otherwise ‘futile’ in terms of the survival of the infant
   c. If the treatment would be inhumane
4. The physician’s ‘reasonable medical judgment’ must be relevant to the treatment possibilities with respect to the medical conditions involved, not based upon ‘quality of life’ judgments.
As you can quickly see, the exceptions are all subject to interpretation, about which honest and equally well-intended people can easily disagree. There’s probably no area of medicine where experience, wisdom and people-skills are more important.

And it is further complicated by the advances in technology that are spread all across medicine. The threshold of viability for premature infants, for instance moves back a week per decade. Current standards decree that infants less than 23 weeks of gestation or 500 grams at birth should not be recuscitated, “unless the parents request full support and the infant is potentially viable”—and age at birth for premature infants is hard to determine. Various handicaps and complications are common for premature infants—the language used is “mortality” for chance of survival, and “morbidity” for degree of eventual impediment.

So: Who gets to decide about the treatment of imperiled newborns? The physician knows the medical condition. The parent has the responsibility for the life, for the care, of the child. You can imagine the complications.

Some thumb rules:

- Parental right to make decisions about newborns is not absolute; it can be limited by the best interests of the infant, as interpreted by a court;
- All the professional organizations recommend that life-sustaining measures if the prognosis of the child is uncertain;
- There may be disagreement between obstetricians (who tend to take the view that the uncertainty of outcome and burden support parental right to make decisions for near-viable infants) and neonatologists (whose primary patient is the infant). Responsibility shifts from one to the other at birth.

The legal perspective: Parental rights can be limited by the infant’s best interest, if supported by a court. The physician’s role is medical advocate for the child, but treatment over parental objection creates a potential legal claim for battery.

There are four (or 5) cases that bring this problematic into focus: and you can find three of them on the “Court Cases of Interest” sheet: The Messinger case: which is very much like the Linares case, both concern whether parents have the right to refuse treatment for severely second, the Miller case, which our two articles address; and the third, on the Baby K.

Messenger and Linares respresent cases where the caregivers felt obliged by the conditions of the legal system to treat over parental objection. In those cases the parents took the situation into their own hands. Both were accused of murder but acquitted.

In the Miller case, the parents accepted the judgment of the law and caregivers, but 14 years later sued the then-owner of the hospital for the cost of care for their severely disabled child, who had survived.
The **Baby K** case is a little different: the question there (and in the **Sun Hudson** case, also on the “court cases” sheet) was whether parents could insist upon treatment when the caregivers did NOT think it appropriate. In Baby K, the courts said yes; in Sun Hudson, the courts said no. (We have a negative right, to refuse or withdraw treatments —but no positive right to obtain them. No “right” to health care.)