

Reading SAL Week 7

The readings for this week divide into two different issues. The first two readings address the role advance directives should play for once-capable patients, and raise questions about personal identity related to the priority of prior interests to present interests for a presently demented person. The third reading describes a legal case involving a never-capable woman in dire terminal suffering; and the last two address one specific category of never-capable patients, decision-making for an imperiled newborn.

The Conroy case, referred to in the readings, is described by our editors on pp. 331-3. Much of the discussion in the readings for this week arise in connection with court cases, which as our authors point out, don't always accord with our moral intuitions.

Dresser and Robertson: QoL and Non-treatment decision for Incompetent Patients: A critique of the orthodox approach (1989)

Quinlan has set precedent that is useful if

- a competent patient refuses LST, or
- a surrogate wishes to withdraw LST including ANH from a patient in PVS--

but there are still questions if the patient is neither competent nor in PVS, but conscious and demented.. Their resolution requires balancing the importance of life in such situations against the social and familial burdens of sustaining it. But the orthodox judicial approach is inadequate, because it is tied to the model of a competent person refusing treatment.

The orthodox approach: adopts a patient-centered approach and protects pt. autonomy (=via a substitute judgment "relying on prior expressed wishes or proxy inferred competent treatment preferences"). [p. 437]

Advantages:

- consistent with social value of personal autonomy
- extends it to situations of incompetency/incapacity
- protects incompetent patients from overzealous interventions
- denies others the power to override the incompetent's best interests for the sake of others
- recognizes a central role for family discretion
- allows decision makers to avoid confronting the question of weighing the value of debilitated life v. the burdens it places on families, physicians and society (= "others"). Can avoid [or pretend to avoid] quality of life choices or privileging others.

Disadvantages:

- may give excessive and unexamined power to family—or to cost considerations.
- is conceptually confused
- excludes patient's current interests
- allows other interests to take control

Three **erroneous** presuppositions of the orthodox approach:

- (1) that it is appropriate to treat incompetent persons as autonomous choosers (when actually choice is irrelevant to one incapable of choosing)
- (2) that prior choices are an accurate indicator of current (or future) interests
- (3) that personal autonomy includes the right to control the future.

One thing to notice: even if the argument from autonomy is accepted—it does *not* justify substituted judgment (although it *may* justify specific interventions explicitly discussed in an advance directive).

But even then—why should such advance directives be followed? They aren't like a contract or a will; they aren't legally binding, and they don't take effect only when one is dead (and thus has no present interests). Writing one may be a comfort to me when capable—but it can lead to undertreatment of an incapable person who still has current actual interests. Cf. *Evans v. Bellevue*.

[D-R consider the AD a 'comfort;' NR, as you will see below, considers it an obligation.]

Problems with advance directives:

- They are too imprecise: vague or general
- People may not realize that they authorize actions that may not be to their future well being!
- They solidify and institutionalize a conflict between prior wishes and present interests—and in such cases present interests, according to these authors, should always take precedence.

Dangers of the 'orthodox approach:'

Threatens incompetent patients with undertreatment (and substituted judgment is even worse, cuz not everyone has an advance directive, but many more have surrogate decision makers).

Prioritizing the kind of thing that leads capable people to imagine that they will not wish to be treated if debilitated or demented—like privacy or dignity—leads us to assign weight to things that are no longer relevant to the present demented patient, and thus allows family interest ‘to influence treatment decisions *sub silentio*.’ [p. 441]

Cf. *Spring, Hier and Brophy*. In both cases the court did not analyze the person’s present capacities and experiences in order to weigh them against the discomfort of tx. *Brophy* is particularly worrying because it does not restrict the judgment to unconscious patients, but could allow any medical treatment to be withheld from any conscious incompetent. Further—the orthodox position is also subject to abuse in the other direction: denying proxy requests for withdrawal that should be granted. Cf. *O’Connor* (1988)—where removal of ANH from an incompetent woman was denied because there was insufficient evidence that she would have rejected it if she were competent, and *Cruzan*, where removal was denied for the same reason. “In either case by focusing on the wrong question, the wishes of a past or hypothetical competent person, the interests of the incompetent patient as they now exist are ignored.” [p. 443]

Recommendation: a new standard: the incompetent patient’s current interests.—a variation of the ‘best interests’ standard. (1) It is respectful of the individual whose tx is in question. (2) it will allow non-treatment when it can be reasonably said that the person has no continued interest in living. (3) It acknowledges the role of costs, family stress or other third party interests in a direct rather than covert way. (4) It will force the society to confront the possible conflict of interests between patients and others. (5) It still permits the family to be the primary decision maker. And: it will allow the discontinuation of treatment for PVS or minimally conscious patients in a way that the current orthodox approach does not.

Difficulties: it is kinda hard to get reliable information about a patient’s subjective experiences. We can do assessment of behavior and physical condition; but who is to decide whether the result is a ‘life worth living’ for another? There is social consensus that PVS probably isn’t. The larger category of permanently unconscious individuals probably isn’t either. The “pleasantly senile” patient on the other hand can be argued to be having some benefit from his restricted life. But: at least the discussion in given cases will be explicitly about quality of life judgments, not covertly so.

Conclusion: the orthodox judicial approach which substitutes the fiction of a competent decision maker for the reality of an incompetent person is inadequate; an assessment that focuses on the quality of life and current interests of an incompetent person is preferable.

Rhoden: The limits of legal objectivity (1990)

[The position that Rhoden is addressing here under the Conroy decision’s vocabulary of “objective standard” is what Dresser and Robertson are recommending: a ‘best interests’ standard applied to the current patient. Rhoden is objecting to the position maintained in the previous reading.]

Of course *Conroy*’s ‘objective’ standard is intended only for those cases when there is no advance directives. But the presupposition that underlies it—that the prior and present person are two different people—undermines the premise of advance directives. And indeed D-R (see above) essentially reject them save where they reassure us in the judgment that we would make anyway. But: NR wants to argue for the value of advance directives as exercises of autonomy and thus owed respect. She answers D-R’s arguments and proposes a rights-based justification for honoring prior directives, using the vocabulary of respect for ‘precedent autonomy.’.

[NB: if she is offering a ‘rights based’ (deontological?) approach, what is Dresser’s approach?] Prior directives will bolster a decision to stop treatment for a patient who lacks present interests in living but it should not justify termination when the patient has such interests.

- (1) But: rejecting future oriented choices threatens present choices. Example: On Dresser’s position an incapacitated Christian Scientist (or Jehovah/s Witness) could be operated on (or transfused) as soon as he became incapable—even if he had written his advance directive yesterday. But that seems counterintuitive. The person who would be transfused is the person who would not want that.

The previously capable person h/s once was made decisions that currently restrict his choices. But: the capable person h/s once was was a moral agent: and [as Korsgaard, cited on p. 450, suggests] you are who you are NOW because of how you envisage your future. Who am I now, if I am not the person who

imagines my future self in a particular way? “When the person is viewed as a moral agent, no clear content can be given to the idea of a merely present self.” [p. 450, quoting Korsgaard]

- (2) Also: prior directives can reflect concern for others. Example: a woman with a terminal disease that is worsened by pregnancy refuses an abortion because she wishes to leave the legacy of a child; specifies this in an advance directive, then becomes incapacitated. Do not her prior values and choices have a moral primacy that forbids us to ignore them just because she is now incapable of the same choice?

Seen as an evidence of preferences, a living will will fail. But if viewed as an actual choice, it can function pretty well. In that sense it is closer to an actual will, and we have a *prima facie* duty to honor it.

- (3) There are reasons to overrule precedent autonomy: eg duties to or of other people; irrational choices—but we can set limits without overriding the basic principle. And we don’t want to pretend that anything like precedent autonomy applies to infants or the never-competent.
- (4) Earlier expressed preferences don’t have the same standing as advance directives—but they too are owed some respect—just not as unconditionally..

NR discusses several versions of philosophical theories of the “subject,” trying to justify what she calls our ‘moral intuition’ that we wrong someone when we do not honor their prior wishes. This leads to a discussion of what it is to have a right, and what it is to have a duty to the person who has a right.

Ouellette: Termination of Life-Support for a Never-Competent Patient: The Case of Sheila Pouliot

New York, Missouri and Michigan have laws in place that require *clear and convincing* evidence that removal of ANH is what the patient would have wanted. This is a very high bar for withdrawing or withholding treatment, in two respects. First, it does not apply to never-capable patients, since it presupposes a period of capacity when the person concerned could have made h/h wishes known. So surrogates cannot withdraw ANH on such people, even though (as in this case) all the people concerned might agree it to be the most humane course of action, thus in the best interests of the patient.

Second, the standard of evidence is much stricter than “the preponderance of evidence” used in some court cases. Thus there are constraints on withdrawing treatment even for once-capable patients, if they have not made their preferences clear. Thus inference from statements made under stress, or inference from religious beliefs, might not count as sufficiently ‘clear and convincing,’ although an advance directive would.

This case is about a 42 yo woman with severe mental retardation who had been institutionalized for 20 years and was an obvious candidate for DNR and palliative care. But state law did not allow for the removal of ANH, which would have provided the most humane death. The resulting conditions under which Sheila was sustained in suffering were sufficiently daunting that a judge trying the case (which was brought by NY state agency for mental retardation and developmental disabilities), after visiting the patient in the hospital, ordered the termination of the ANH, although state law narrowly interpreted would forbid it. Two years later a narrow law was passed in NY that allows surrogates to withdraw ANH from the mentally retarded in similar circumstances, justifying the judge’s decision *post facto*. The constraints (and higher standard of evidence) for other kinds of patients remain in place in NY.

In general, New York law is weighted ‘on the side of life.’ We will see next week that this is the case in determination of death, as well, where in New York (and New Jersey) determinations of death on the basis of neurological criteria is not always binding.

This reading and the following reading address the question of parental rights and caregivers obligations in respect to one category of never-capable patients: newborns. Who decides for the fetus on the threshold of viability? In the course of the commentaries, the troubled and still controversial history of Baby Doe laws is discussed. This is an area where law and ethics intersect with little resolution of conflicting imperatives.

Robertson: Extreme prematurity and parental rights after *Baby Doe* (2004)

Problem: three generally agreed upon principles of medical treatment may provide competing guidance in cases dealing with newborns. (a) disability should not disqualify individuals from treatment that would otherwise be medically appropriate; (b) some medically determinable conditions greatly reduce

the quality of life for affected individuals; (c) the parents should have a say in what treatment is appropriate for their children.

Historical background: Baby Doe Laws of the 1980s, and their unfortunate consequences; the resulting legal gray-areas; and some contemporary cases where the various imperatives conflict.

The Miller case in Texas (1996-2003) is the starting point for this article and the next. The question it raises for Robertson: Do parents have the right to have treatment withheld immediately at birth, prior to any resuscitation or evaluation of the child?

[The jury found for the parents that they had not consented to treatment. This verdict presupposes that their consent was essential to treatment. If their consent to treatment was essential, then they also have the right to refuse treatment. The Texas Supreme Court reversed that verdict, thus reaffirming the obligation of the hospital to treat all newborns alike regardless of expected disability.]

The eventual resolution of the case (after a jury trial and an appeal that took it to the Texas Supreme Court, where the initial judgment was overruled) had the effect of authorizing a physician to resuscitate an extremely premature infant over the objections of the parents.

Robertson approves of the eventual outcome, arguing that allowing the parents to decide upon tx before the condition of the child is evaluated and a reasonable prognosis is determined is not in the best interests of the child, and would “deprive some newborns who could have meaningful lives of treatments they need to survive.”

Paris, Schreiber and Elias-Jones: Resuscitation of the Preterm Infant Against Parental Wishes (2005)

The question this case raises for Paris et al is: who decides, and on what basis, when there is a conflict between parents and physicians? The article gives a good account of the details of both the medical case and the legal case(s).

An important factor in the case was the intervention of the institution: apparently the parents and the physicians had agreed not to resuscitate until a hospital policy requiring resuscitation of any infant over a certain weight was mis-stated in the care meeting, after which it was decided that it would be unwise not to override the parents’ decision if the child was of appropriate weight, regardless of its condition otherwise. Another matter for concern is that the condition of the child was not evaluated again later, after she had suffered a significant brain hemorrhage.

The authors of this article argue that consent in cases involving infants has until this case been the prerogative of parents. They contest the exemption for ‘emergent circumstances.’ The Texas Supreme Court’s decision raises the danger that if a physician’s judgment is allowed to override those of the parents, a physician’s values can be substituted for those of the parents, which they consider “a significant shift from present standards in neonatology” and “neither good policy nor good medicine.”

The Vocabulary of medical decision making: Rorty’s abbreviations in the notes

ANH: artificial nutrition and hydration; feeding tube (naso-gastric or gastrostomy)

EOL: end of life

LST: life sustaining treatment; typically ventilators, but also maybe ANH

Tx; Rorty’s abbreviation for ‘treatment’ (and also sometimes for ‘transplant’)

guardian *ad litem*: a court appointed conservator for a person judged incapacitated for whom decisions must be made

PVS: persistent [or permanent, after 6 months] vegetative state