

Lecture 7.2: Babies Doe and Decision Making for Imperiled Newborns

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’):

If the infant is [‘chronically and irreversibly’] comatose

If treatment would merely prolong dying or be otherwise ‘futile’
in terms of the survival of the infant

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 resuscitated, “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.

I’d like to discuss three cases: One, briefly, the Messinger case: which is very much like the Linares case; second, the Miller case, which our two articles address; and finally, if we have time, Baby K.