

Decision-making For Impaired Infants

by Christine Mitchell

Some infants are so premature and underweight, so profoundly impaired, so hopelessly diseased, or so severely asphyxiated that their fore-shortened lives are full of misery for them and those around them.

For infants who are so impaired that medical therapies are futile or for whom therapies would only prolong suffering, invasive medical procedures and surgery are morally as well as medically inappropriate. This is not to say that care is withheld or withdrawn. Rather, care is redirected to other goals. Instead of aiming first to cure disease, correct defects, or save life, we seek primarily to provide comfort, relieve suffering, and help a grieving family. Nursing care remains intensive intimate, and complex.

The greatest moral difficulty arises when we are uncertain how to weigh hope against hurt, especially when we don't know whether our hopes are justified or how much and how long it will hurt.

Still, a decision must be made. And one of the thorniest questions in the current debate among clinicians, philosophers, clergy, the courts, parents, organizations for the handicapped, legislators, and the federal government is who should decide about the goals of care for so-called "impaired" infants.

Most nurses and philosophers suggest that parents should decide because it is their child. Parents, presumably, know their child best and care most about his or her well-being. Moreover, parents live longest with the results of the decisions made in caring for their baby.

However, most physicians and some nurses argue that parents should not be the ones to decide because parents cannot comprehend the complexity of their child's medical problems and long-term care needs, and because parents are so traumatized by the birth of a "defective" baby that they cannot make life-and-death decisions rationally. Also, some parents tell us they don't want to decide or they can't. They rely on professional

recommendations and judgment. So, it is suggested that physicians should decide because of their special knowledge and objectivity, relieving the parents of the burden and guilt of decision-making.

There are clear drawbacks to leaving the decision to either parents alone or physicians alone. Since newborns are indeed new, it is hard to hold that any person can be routinely counted upon to know and care about the baby most. Often—but not always—it is the parents.

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Yet, the very fact that parents must bear the emotional and economic burdens associated with the decision leaves open the possibility for conflicts between the child's interests and the parents' interest. On the other hand, when physicians decide, the person who makes the decision is not the person who lives with it daily. There is, moreover, no reason to assume that physicians are moral as well as medical experts. But, as one physician wrote, physicians are in a position to decide, for "... who... is in a similarly pivotal position to make sure that the proper medical consultation has been obtained in ascertaining the hopeless condition of the patient, that the parents receive sympathetic and thorough explanation, and that they are exposed to broadly based advice? Who else can lead all those involved to a decision, and who else is more responsible for consoling after a decision has been reached?*" Although he was referring to the child's physician, his description fits the primary nurse as well as — if not better than, in some cases — the physician.

Criteria

All of this debate and disagreement serves to point out some important considerations in determining who should decide. I suggest the following three equally important criteria:

First, those who bear the burden of both care and conscience should participate in the decision. Usually, this is the parents, but it includes the nurses, who day after day have to provide difficult care for some severely impaired and suffering infants, and the physicians.

Second, those with special knowledge should participate in the decision. The physician clearly has the most relevant medical assessment. The nurse and parents often have the best understanding of daily care routines and infant interaction capability. This other way of "knowing," by touching, holding, rocking, and feeding over time, is equally important. Only the parents know how they experience and respond to their newborn, and only they can gauge the relative weights of their own values and moral convictions. Thus, I see special knowledge as including both expert technical knowledge that physicians and nurses have, and experiential knowledge that parents and nurses accrue in interaction with the infant.

Third, those health professionals with the most continuous, committed, and trusting relationship with the parents should have primary responsibility in the health care domain for deciding and for coordinating care around that decision. Although we cannot be assured that parents and health professionals together will always come to a consensus comfortable to all, that outcome is most likely when parents have a close, continuous, and trusting relationship with their child's care-givers.

No one should make this kind of decision alone. Nurses, parents, and physicians are each morally troubled by the birth and care of some children and are morally

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responsible for their decisions and actions in providing what they believe to be best for the child.

What we must ensure above all is that we exchange our expert and experiential knowledge about a child's condition and future in a caring and candid manner, and reason together respectfully to arrive at a decision.

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Drug Screening

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operator errors such as equipment contamination or sample mislabeling. Still another factor leading to false positives is the presence of endogenous substances in the urine or serum that might confound the test (Panner and Christakis, Hastings Center Report, Dec. 1986.) The reported occurrence of false positives varies greatly from one authority to another. However, whether the rate is 5% or 20% makes no difference. It is irrefutable that false positives do occur.

Therefore, some people who have done no wrong are bound to be placed in a position to prove their innocence by being subjected to the humiliation of further testing. Not only is this contrary to our legal notion of just, but it is also a violation of the principle of justice from an ethical point of view. Regardless of the reason why, false positives, even in the most controlled environment, will occur, and in my opinion, because the false accusations stem from a "scientific test", they will be exceptionally dangerous and extremely difficult to disprove for two reasons. First, because we bestow special significance to "scientific" data, once accused false positives will

leave lingering doubts. Second, if we admit some positive results may be inaccurate, do we retest, and if there are contradictory results do we use a best two out of three criteria?

In addition to concerns about the special credence given to science and to scientists (i.e., physicians), we ought to be concerned about asking health care professionals to participate in an activity which I believe is contrary to the role society has prescribed for them. The Hippocratic Oath charges physicians first "to do no harm" which is sometimes called the principle of non-maleficence. Many argue that this principle is even stronger than is the principle of beneficence (i.e., to do good.) It appears to me that the priority of the principle of non-maleficence is especially true for health care providers. To add a policeman-like role to physicians duties is inappropriate.

In this time of cost containment and discussion about rationing of health care, what about the cost of drug testing? In the Midwest the least expensive drug screening I have heard of is \$20, and the average cost appears to be around \$100. To test all entering students would be a significant expenditure for colleges and universities. In times of declining student enrollments and increasing costs for education, is this an appropriate allocation of funds for our universities, or would the financial burden also be placed on the student? Furthermore, is drug screening for college admission an appropriate use of health care resources?

As to what is appropriate, I have one more question about mandatory drug screening for college students — why only students? What is it about this category of people, who are even for the most part legally adults, that would allow us to discriminate against them by singling them out for drug screening? There is a universalizability principle in ethics which asserts that for any act to be ethical we must be able to will it to become a universal maxim (i.e., we would willingly apply it to every person.) I do not believe we

are yet willing to impose mandatory drug screening on our entire society, nor do I believe that administrators of most universities would push for mandatory drug screening of students if it were also required for faculty, staff and administrators.

I am opposed to any mandatory drug screening of college students. I do believe, however, that voluntary drug screening should be made available to students. I agree with the reasoning which supports mandatory drug screening — that we must protect our children and our society from the inherent dangers of illegal drug use. However, I believe we cannot wait until our children have reached college age to try to stop this problem. The money we would spend to screen college students, in my opinion, would be spent better to provide education to students in preschool and elementary school when children are developing values and a self image they will hold to for the rest of their lives. To paraphrase William James, "we ought to teach students to admire what is admirable and to disfavor what is cheap and trashy."

"I won't . . . in a bottle unless
Nancy Reagan holds it"
a line from a song by
Mojo Nixon and Skid
Roper, a rock and roll
duo popular with college
students.

*Stands for enzyme multiplied immunoassay technique.

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