

Contrary to Professor Holder's assumption, our model does not try to usurp the lawyer's function. She herself states: "We all agree that when a consent form is used... it should make sense to the person signing it..." We think our model makes clear to revisers of consent forms—people who are as legally knowledgeable and as sensitive to the needs of patients as Professor Holder—what they can do to make good on this agreement.

The Editor-in-Chief replies:

The topic of informed consent elicits strong reactions, as demonstrated by the response of Professor Angela Holder to the article by Kaufer, Steinberg, and Toney. Professor Holder's heated critique suggests that this article is somehow critically flawed and, therefore, that its conclusion is not credible. To the contrary, this article is important, using legitimate research on language use and comprehensibility to shed new light on the problems of drafting informed consent forms for hospitals. This article does not purport to be a learned exegesis on the law of informed consent. It offers something more modest, a model for revising forms so that they are understandable to the patient. It is the hospital's general counsel who evaluates the choice of issues covered in the light of the current law of informed consent in that jurisdiction (or federal law, as to research subjects). The authors begin with forms currently used by hospitals, typically badly written and poorly presented. They then provide suggestions for improvements, showing that the revised forms lead to a quicker and fuller comprehension by readers.

In the disclosure of medical information and the obtaining of informed consent, the focus is on the patient's comprehension. There is, however, a second side to this therapeutic relationship. The doctor must first be able to convey adequately, in understandable terms, the information relevant to the patient's decision. Professor Holder assumes an ideal hospital, in which a sensitive and compassionate doctor—well-informed and able to express himself in clear language—talks with the patient and family and then jots down a legible note on the chart to reflect that conference. Perhaps medical education will eventually

produce such a physician, but it does not do so at present. The course of medical education militates against it; the pressures of practice make it unlikely (except perhaps in exemplary teaching hospitals like Yale). A properly designed consent form will not guarantee adequate communication between doctor and patient; it will only facilitate its occurrence. As the authors write: "It is, however, at least an indication of good faith and a reflection of the physician's sincere attempt not only to enable the patient to understand but also to educate the patient..."

Some of Professor Holder's criticisms may benefit from analysis. In the difficult situation of an order not to resuscitate, having a form stuck under the nose of a family member is of course a chilling thought. Presumably, however, substantial discussion will take place, as implied by the form itself; the form can become a concrete focal point for the difficult issues discussed. Will a jury in a tort suit involving the issue of informed consent be suspicious of an institution which uses a form in such a situation? Or will a detailed form suggest that a caring hospital and staff have tried to take the family through an educative process in reaching a collaborative decision?

If we use such a form, is not a checklist preferable to a running together of alternatives, as older forms often do? A list with clearly delineated alternatives articulates choices rather than obscuring them. A separate checklist and glossary can be invaluable in helping a doctor to explain risks and alternatives in lay language, and it also reminds the doctor of the importance of doing so. "Extraordinary measures" may well depend on the patient, but certain categories can reoccur with sufficient frequency to justify definition and description in easy-to-understand language in many cases, e.g., use of artificial or mechanical organs.

Professor Holder contends: "In the best of all possible worlds, from the perspective of a hospital lawyer, there would be no consent forms... [S]uch forms should be eliminated." This is probably true if one could count on the staff to document satisfactorily the discussion between the patient and the doctor. However, forms are an excellent cross-check on the fact

of disclosure and its contents, ensuring at least minimal communication. We are not yet in this "best of all possible worlds," but the publication by Law, Medicine & Health Care of this important article may lay the cornerstones for improving patient-doctor communication—a goal which we all share.

Handicapped Infants and Their Families

Dear Editors:

If one were to find that families who beat children or own slaves had less marital discord and less reliance on psychiatry or tranquilizers than those who loved children and eschewed slavery, one might have one reason to endorse child abuse and slavery; but one would in no way have an adequate reason. It is this error that Carson Strong makes in *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, published in the September issue. One cannot kill a specific infant for the benefit of other people unless infants are held to be something quite different from the rest of the human race, since the sufferings of others that are caused by the mere existence of each of us cannot be allowed to count as justifying the killing of any one of us.

We must, as a society, decide what sort of thing we shall consider newborn infants to be. Are they to be a vehicle for the satisfaction of their parents, with their value based upon the degree to which those parents grant them value? Are they to be seen as bearers of rights and obligations just as are older children? When they have serious defects, are these to be seen as the parents' misfortune? Or, is the having of children to be seen as a community endeavor, with the community rejoicing in its future and sharing the burdens imposed when the endeavor goes awry?

I am neither able to solve nor interested in solving these puzzles for all time and all peoples; but, for this country at this time, the resolution must be to hold infants as being of the same moral status as older children or incompetent adults. This

requires that decisions regarding care are made so as to advance the infant's interests from his or her own perspective. Constraints upon pursuing the infant's interests are always present, but they must be equitable and just, and certainly cannot include the causing of the infant's death just because there is a statistical likelihood that a particular set of parents may be inconvenienced by the infant's life — even if that inconvenience is real emotional distress. Life was never promised to be easy, and those who join in having children were never promised perfect outcomes. Even healthy infants, after all, may become worthless adults or worse, but parents do not thereby gain authority to kill their children.

The alternative proffered by Strong raises serious conceptual and practical problems. To endorse this standard (that harms which may befall parents because of the existence of a particular child are burdensome enough to justify a course of treatment or nontreatment that is intended to have the child die) would require either (1) a claim that newborn infants are morally different from other persons, especially other children, or (2) an acceptance of these kinds of harms as a legitimate component of decisionmaking regarding the care of other incompetent persons. The first claim is not made by Strong, nor do I think that it is possible to defend it theoretically or to effectuate it practically. The alternative claim creates exceedingly great liability for abuse. Under this standard, many, if not most, patients with Alzheimer's dementia, severe retardation, cerebral palsy, strokes, and other diseases likely to cause severe dependency and reduced responsiveness would likely die from medical decisions designed to protect specific others from the annoyance of the patients' existence. In fact, healthy people who are troublesome to those in power — from criminals to revolutionaries to religious zealots — would be at risk of rather premature dying if they ever had to rely upon others to make medical decisions. Therefore, neither claim is at all in accord with strongly held moral values. And, if newborns

are to be treated as rights-bearers just as are other incompetents, and if all have a right to have decisions made in their best interests within the constraints of the equitable allocation of resources, then the putative harms that will befall some of the parents of handicapped newborns cannot justify an acceptance of parental decisions to have their children die.

Furthermore, exactly who it is that is harmed by raising a severely ill or handicapped child is quite uncertain. Many parents gain strength and insights. Many families are strengthened. While these benefits are perhaps even more uncertain, they are relevant. Our understanding and ability to predict the outcomes should give us pause before we allow parents to choose death for their children. One piece of data that even a convinced consequentialist would need is the rate and severity of serious burdens upon parents who have deliberately chosen to end the life of a child who could have survived. This information is completely unavailable and likely to remain so.

I do agree with Strong that the HHS procedures and the proposed rules on "Infant Doe" have many shortcomings, especially in their attempt to make very complex situations fit simple categories of good and evil. In fact, one of the most significant recommendations of the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research on this subject was that some cases are unavoidably ambiguous as to whether treatment is, from the infant's view, beneficial or burdensome, and that parental authority to decide should be protected in such cases.¹

I also agree that there has been entirely too little attention given to the potential and limitations of current arrangements designed to provide for handicapped children. In some areas, specially qualified adoptive parents are available for almost any newborn; in other areas, mere racial differences or cosmetic abnormality may make adoption unlikely. In some areas, early schooling and financial assistance are public responsibilities;

in others, it may still be difficult just to gain access to the public schools. Much could and should be done to improve opportunities for handicapped children and to support their care-givers.

However, if parents are to be allowed to kill their infants rather than bear the burden of raising them, the pressure upon society to help will be greatly diminished. In fact, it may well seem to some that parents who choose to raise the child will have brought the situation upon themselves since they could have chosen otherwise. This perception might well serve to weaken the present commitment to community support for such people.

Instead, society should provide reasonable alternatives, within legitimate, just, and publicly determined constraints of resources, to the overwhelming of parents with the burdens of raising a severely handicapped child. The President's Commission's chapter on this subject closes with these lines:

Public support for effective voluntary organizations and governmental programs is the inescapable extension of society's deep interest in sustaining life in neonatal intensive care units. Furthermore, to the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised.²

An adequate level of care is not the same as an ideal one, and the current level in the United States is merely adequate to support a public policy of defending the lives of newborn infants. This policy will leave some parents in unfortunate situations — sometimes nearly unbearable situations. However, there are better and worse responses available to the nation. It would be better to redouble our efforts to act as a community and to share the burdens. It would be worse to devalue the lives of newborns and to

allow them to be put to death rather than burden their parents.

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References

1. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS (U.S. Gov't Printing Off., Washington, D.C.) (1983) at 223.
2. *Id.* at 229.

Dear Editors:

One need but glance through the Stinsons' graphic and tragic account of *The Long Dying of Baby Andrew*¹ to learn of the devastating effects — financial, emotional, psychological, and marital — of caring for a profoundly compromised newborn. In the face of the physicians' repeated failures but constant refrain that not to do everything possible to save the life of such infants is murder, one fairly wants to scream: "In the name of God, stop the torture. Let the child die."

The issue, though, is the torture to whom. Both Robert and Peggy Stinson vividly present their own pain and suffering, but it is not that, but the futile pain and suffering of baby Andrew, which moves them to tears and pleas for mercy.

Their plaintive story reflects a markedly different approach from the plea of Carson Strong in the September issue. Strong argues that unless the government provides financial and institutional assistance to families of physically and mentally impaired children, families ought to be permitted to reject life-saving treatment for the child.

There is no denying that our society has seriously defaulted on its obligation to provide adequate assistance to the retarded, to the handicapped, and to their families. As Glick's recent report on pediatric nursing homes illustrates, even the more progressive programs fail to meet the practical needs of such families.² Moreover, those programs that do exist are now

falling victim to the Reagan Administration's cutbacks in the area of children's services. But neither of these facts justifies Strong's thesis that the state pays or the child dies.

Strong claims that his recommendation differs from previous proposals and guidelines inasmuch as it gives explicit attention to the potential hardships to families. It is, unfortunately, no novel theory; it is simply Raymond Duff's views writ long. In his famous (and surprisingly uncited) article, *Moral and Ethical Dilemmas in the Special Care Nursery*, Duff specifically stated that since it is the parents who bear the burden of the defective newborn, it is they who should decide if the infant lives or dies.³

It is that essay, more than anything subsequently written, which sets the stage for the Infant Doe regulations, and it is that view — that the infant's right to life is predicated on parental acceptance — which threatens to force a fearful society into demanding that *all* life, no matter how disabled or compromised, must be sustained if physically and technically possible.⁴

As one who has testified against the Infant Doe regulations before Senator Denton's sub-committee in April, and as one who has been subjected to virulent attacks for my writings on withdrawal of treatment from profoundly defective newborns, I wish to join those who raise their voice against the theory that children are to be accepted or rejected — to live or be killed — because of their burden on others.

One might well ask what limit there is to Strong's principle: "When interference with parental liberty would cause a grave burden to a family, we should consider such interference [the survival of the child] to be unwarranted." He applies it to both physical and mental impairments, to spina bifida as well as to retardation. He then justifies his position on the grounds that there is no discrimination against the disabled because it is not the impairment, but the burden on the family that is "the morally relevant factor." With such logic, whose right to existence is protected?

Nor can we take much consolation from Strong's reading of the common law. While acknowledging that "[t]he court will interfere with parental authority only when outweighed by considerations of great magnitude, such as death or other serious harm to the child," he seems to forget that it is precisely the *death of the child* that he balances against the financial and emotional harm to the family.

The fundamental error and inexcusable failure of Strong's essay is the deviation from the first principle of medical ethics: *Primum Non Nocere*. It is the interest of the patient, the good of the patient, and the harm to the patient which have been and ought to be the primary focus of medical ethics.⁵ To deviate from that norm is to distort if not destroy medicine's role in society.

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References

1. R. STINSON, P. STINSON, *THE LONG DYING OF BABY ANDREW* (Little, Brown & Co., Boston) (1983).
2. Glick, P.S., et al., *Pediatric Nursing Homes — Implications of the Massachusetts Experience for Residential Care of Multiply Handicapped Children*, *NEW ENGLAND JOURNAL OF MEDICINE* 309(11): 640, 641, 643 (September 15, 1983).
3. Duff, R.S., et al., *Moral and Ethical Dilemmas in the Special-Care Nursery*, *NEW ENGLAND JOURNAL OF MEDICINE* 289(17): 890, 894 (October 25, 1973).
4. See Angell, M., *Editorial: Handicapped Children: Baby Doe and Uncle Sam*, *NEW ENGLAND JOURNAL OF MEDICINE* 309(11): 659-60 (September 15, 1983).
5. See Paris, J.J., *Terminating Treatment for Newborns: A Theological Perspective*, *LAW, MEDICINE & HEALTH CARE* 10(3): 120, 124 (June 1982).

The author responds:

Dr. Lynn and Father Paris maintain that seriously impaired newborns should be treated aggressively, without consultation with parents, even when doing so is likely to result in great harm to — perhaps dissolution of — the family. However, none of the reasons they give in support of this opinion withstand critical scrutiny.

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