

Baby Doe

This resolution was adopted following the decision of the Indiana Supreme Court in the case of a Down's Syndrome neonate in Bloomington, Indiana:

RESOLVED that the Christian Medical Society strongly opposes the decision allowing for the death of "Baby Doe" and urges that this Court decision not be seen as either legal or moral precedent for the future. The right of privacy does not allow for parents to decide the death of such infants.

*Approved by the House of Delegates
Passed with a vote of 41 for and 12 opposed
May 7, 1982. Dallas, Texas.*

Explanation

Background

On April 9, 1982, an infant was born in Bloomington, IN with both Down syndrome and a tracheoesophageal fistula. Although closure of the fairly small fistula had a better than 90% chance of success, the parents chose to decline consent for the corrective surgery for "Baby Doe". This choice was made based on a gloomy prognosis for the Down syndrome presented to them by one of the physicians involved. Other physicians and hospital administrators went to court to challenge the parents' right to make such a decision. The judge upheld the parents right, and two appeals of the court decision failed. The infant died on April 15. In retrospect, most commentators believe this was a poor decision from a medical, legal, and ethical perspective.

Intense public discussion led quickly to federal government intervention to prevent such decisions in the future. The establishment of mandatory signs posted in hospital nurseries warning about discrimination against handicapped newborns, a hot-line to report suspected abuse to Washington, and responding investigative teams created an adversarial atmosphere. Procedural skirmishes and legal challenges to the federal regulations did little to ease the tension. Subsequent compromises between the government and professional bodies led to the current "Baby Doe" regulations which were implemented in 1984 as an amendment to the Child Abuse and Treatment Act. These regulations specify that treatment may not be withheld from children unless (a) they are chronically and irreversibly comatose, (b) treatment would merely prolong dying or otherwise be futile, or (c) treatment would be virtually futile in terms of survival and would be inhumane. Debate continues about the interpretation, applicability, and enforceability of the regulations.

CMDS Position

The CMDS responded quickly to the Bloomington, Indiana judicial decision with strong opposition. They have not visited the issue of handicapped newborns further.

Abstracts

"Baby Doe and the Concept of Grace" by Tom Elkins and Douglas Brown - Christian Medical Society Journal Vol XVIII, no 3; Summer 1987, pp 5-9

After a review of the controversy surrounding the "Baby Doe Regulations", the authors explore the possibility of growth through the various phases of the grief process which follows the birth of an infant with severe handicaps. They then discuss the universal handicaps of human limitations. Our response

should be one of grace which leads to hope, and from hope to joy, and from joy to love of others as Christ loved us. However, the authors contend that we have trouble understanding the concept of grace. They encourage us to minister to "the least of these", all vulnerable and disenfranchised patients, including handicapped newborns.

"Life and Death and the Handicapped Newborn" by C. Everett Koop - Ethics & Medicine 1987;3(3):39-44

The Surgeon General tells of his experience as a pediatric surgeon in caring for children who were born with severe handicaps. He includes quotations from several after they had grown to adulthood about the joys of life, even with their residual disabilities. He criticizes the British "Lorber criteria" for treatment/non-treatment decisions in children born with spina bifida. After a detailed narration of the Bloomington, IN "Baby Doe" case, he tells of his own growing role in advocacy for handicapped newborns. He concludes by stating that "...all aspects of medical ethics are dwarfed by the question: 'How are we to care for those who cannot---in one way or every way---care for themselves?'"

"Protecting Handicapped Newborns: Who's In Charge and Who Pays?" by James F. Childress in Genetics and the Law III, Milunsky A and Annas G, eds. New York: Plenum Press, 1985:271-281

Drawing on John Rawls, the author argues that decisions about the care of handicapped infants, at best, represent imperfect procedural justice, based on two claims. First, there is an independent standard of just/right outcome: the infant's best interests. He asserts that life is a primary good and a precondition for other goods and, therefore, there should be a rebuttable presumption in favor of treatment. This presumption may be rebutted if the infant will not survive, be unable to interact, or be overwhelmed by pain and suffering. Second, there is no procedure that can guarantee a just/right outcome. Childress argues that the best possible procedure involved a lexical ordering of proxy decision-makers: parents, physicians and other professionals, ethics committees, and the courts. Proxies should be disqualified if they act contrary to the child's best interests. He believes it may prudent to require ethics committees to review each non-treatment decision. He also argues for increasing societal financial support for the care of handicapped children.

Bibliography

Gustafson JM. Mongolism, parental desires, and the right to life. Perspectives in Biology and Medicine 1973; 16(4):529-557

The author sympathetically criticizes the decision of parents and physicians not to treat a newborn with Down syndrome and duodenal atresia by redescribing the dilemma they faced in a manner that places greater emphasis on moral obligations, relative independence from immediate desires, and on respect for human life.

McCormick RA. To save or let die: the dilemma of modern medicine. JAMA 1974;229(2):172-176

The author argues that the Judeo-Christian tradition's affirmation that life is a basic good to be preserved as the condition for human relationships suggests the following guidelines for the treatment of handicapped newborns: if an infant does not possess the potential for human relationships or if that potential "would be, because of the condition of the individual, totally subordinated to the mere effort for survival" the infant need not be treated.

Ramsey P. The benign neglect of defective infants. Chapter 5 in Ethics at the Edges of Life: Medical and Legal Intersections. New Haven: Yale University Press, 1978:189-227

After proposing in an earlier chapter his "medical indications policy" (in contrast to Robert Veatch's "reasonable man standard and Richard McCormick's personal intersubjectivity/ minimal personal relatedness standard), Ramsey argues that withholding medical care from handicapped newborns is a species of injustice. He concludes by considering whether there are exceptions to the duty to treat nondying incompetent patients. He argues that we must always treat them, but there are exceptions once they are dying.

Meilander G. If this baby could choose... Linacre Quarterly 1982;49(2):313-321

The author argues for the superiority of a medical indications policy to a reasonable person standard or a substituted judgment standard for making decisions about the care of defective newborns, but he is concerned about the possibility of restricting medical indications to physiologic criteria.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Seriously ill newborns. In Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions. Washington, DC: U.S. Government Printing Office, 1983: 197-229

After reviewing the context in which treatment decisions are made, the Commission advances an ethical framework for decision-making that focuses on an evaluation of the benefits and burdens from the infant's own perspective and on internal hospital review of non-treatment decisions. This chapter is a rich bibliographic resource.

Singer P, Kuhse H. The future of Baby Doe. New York Review of Books 1984;31(3):17-22

The authors argue that the justifications that the Reagan administration advances for the "Baby Doe Guidelines," the sanctity of human life and justice, are inconsistent and incoherent. They suggest that all human life is not of equal worth, a view that is more fully developed in their chapter "Should the Baby Live?: The Problem of Handicapped Infants" in *Studies in Bioethics*, (Peter Singer, ed.); Oxford University Press, 1985.

Gerry MH. The civil rights of handicapped infants: an Oklahoma 'experiment'. Issues in Law & Medicine 1985;1(1):15-66

The inaugural issue of this journal has four sections which (1) explores the ethical and moral issues that surround the withholding of medically indicated treatment from handicapped infants and addresses the legitimacy of approaching these issues from a traditional civil rights analysis, (2) describes a f-year experiment at the University of Oklahoma involving non-treatment of some infants with spina bifida, (3) discusses the applicability of two federal statutes to the withholding of treatment from handicapped infants, and (4) gives an overview of the legislative action amending the Child Abuse Act.

Bopp J, Nimz M. A legal analysis of the Child Abuse Amendments of 1984. In Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns, Caplan AL, Blank RH, Merrick JC, eds. Totowa, NJ: Humana Press, 1992

The authors offer an interpretation of the Child Abuse Amendments of 1984 and a criticism of its enforcement mechanisms while describing the Amendment's development and interpretation.