

February 1985

Review of Selective Nontreatment of Handicapped Newborns by Robert Weir

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Recommended Citation

Sharon Beckman. "Review of Selective Nontreatment of Handicapped Newborns by Robert Weir." *Michigan Law Review* 83, no.4 (1985): 894-899.

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SELECTIVE NONTREATMENT OF HANDICAPPED NEWBORNS. By Robert Weir. New York: Oxford University Press. 1984. Pp. viii, 292. \$27.95.

In April 1982, a Down's syndrome baby starved to death in a Bloomington, Indiana hospital when his parents refused consent to operate on his blocked esophagus.¹ Court battles and publicity focused nationwide attention on Bloomington's "Infant Doe," but his fate is not unique. Each year thousands of newborns are denied life-sustaining treatment — even food and water — because they are mentally or physically handicapped. Doctors today can save children who once would have died naturally at birth, but when life-saving treatment sustains a child with severe mental or physical burdens, doctors and parents wonder whether to let nature take its course. The nontreatment dilemma is one of a society whose scientific development has outgrown the boundaries of moral consensus. Recently it has become the subject of ethical, religious, medical, legal, and legislative debate.

Theologian Robert Weir's² *Selective Nontreatment of Handicapped Newborns* is a significant contribution to this debate. Weir surveys the views of pediatricians, lawyers, and ethicists on selective nontreatment and then proposes his own model for decisionmaking. The book's unique strength is its interdisciplinary approach — an approach which lays bare the complexities professionals and scholars must face when they peer outside their own disciplines at the broader social context. Ironically, Weir's proposed model ignores or evades many of these complexities, and that is the book's major flaw.

Selective Nontreatment of Handicapped Newborns surveys medical, legal, and ethical opinions in the nontreatment debate. In the medical area, Weir begins by describing the dynamics of the typical NICU (Newborn Intensive Care Unit) and explaining common birth defects in lay terms. By informing his readers from the outset of the gravity of newborn handicaps and the uncertainties of prognosis, Weir equips them to evaluate scholarly debate with common sense.

Weir goes on to compare the views of seven pediatricians who have written extensively on the question of selective nontreatment. Though the physicians surveyed all agree in principle to "do no harm," they disagree on the meaning of "harm." Physicians Raymond Duff,

1. *In re* Infant Doe, No. 608204-004A (Monroe County Cir., Apr. 12, 1982) (declaratory judgment), *affid.*, Ind. Sup. Ct. No. 4821540 (sealed), *cert. denied sub nom.* Infant Doe v. Bloomington Hosp., 104 S. Ct. 394 (1983); see generally Note, *Withholding Treatment from Defective Infants: "Infant Doe" Postmortem*, 59 NOTRE DAME L. REV. 224 (1983).

2. Robert F. Weir is Professor of Religious Studies at Oklahoma State University, where he teaches courses on biomedical ethics. He is the editor of *ETHICAL ISSUES IN DEATH AND DYING* (1977) and *DEATH IN LITERATURE* (1980).

Anthony Shaw, and John Lorber believe that "do no harm" implies nontreatment for newborns who lack the prospect of a "minimally acceptable quality of life." Doctors R.B. Zachary and Norman Frost think that doing no harm involves a detriment-benefit calculus: do not treat neonates for whom life's detriments outweigh its benefits. In contrast, Surgeon General C. Everett Koop maintains that doing no harm means treating all nondying infants, since death is the ultimate harm. Weir shows that even within the medical profession there is significant disagreement concerning who should make nontreatment decisions (physicians or parents) and what criteria they should use.

Weir does a superficial job of pointing out the ambiguities and inconsistencies in the legal response to the selective nontreatment problem. He briefly explores different views on the legal status of neonates, the distinction between ordinary and extraordinary means of maintaining life, and the significance of direct killing versus letting die. He recognizes the gap between the criminal law on the books and in practice: though those withholding treatment may be violating state homicide or neglect laws, no parent or physician has been successfully prosecuted for withholding medical treatment from a handicapped newborn.³ Weir presents the wide-ranging views of legal commentators advocating vigorous prosecution of nontreaters as murderers;⁴ retention of the current system of nonenforcement, with the law on the books as deterrent;⁵ interpretation of the current law to allow circumscribed areas of legal nontreatment;⁶ and legalization of nonvoluntary active euthanasia in certain cases.⁷

Weir also presents a scathing criticism of the Reagan administration's recent attempts to resolve the legal dispute. Though the book was written before the most recent Department of Health and Human Services regulations were released, Weir's criticism of the first set of "Baby Doe Regs" still applies: even if the new rules are less vague than the old ones, federal executive intervention and surveillance is

3. Weir points to the 1981 *Mueller* case (parents and attending physician were charged with conspiring to commit murder for withholding food from Siamese twin boys, but the charges were dropped for lack of evidence) and the 1975 *Edelin* case (Massachusetts obstetrician's murder conviction for failing to ventilate an aborted but possibly viable fetus overturned on appeal) as situations where the gap between legal theory and practice occasionally narrows (p. 101).

4. Horan, *Euthanasia as a Form of Medical Management*, in *DEATH, DYING, AND EUTHANASIA* 219 (D. Horan & D. Mall eds. 1977).

5. Burt, *Authorizing Death for Anomalous Newborns*, in *GENETICS AND THE LAW* 435, 447 (A. Milunsky & G. Annas eds. 1976).

6. A. HOLDER, *LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE* 114 (1977); Grad, *Legal Aspects of Informed Consent*, in *DECISION MAKING AND THE DEFECTIVE NEWBORN* 443 (C. Swinyard ed. 1978); MacMillan, *Birth-Defective Infants: A Standard for Nontreatment Decisions*, 30 *STAN. L. REV.* 620 (1978).

7. Morris, *Proposed Legislation*, in *INFANTICIDE AND THE VALUE OF LIFE* 221-27 (M. Kohl ed. 1978).

not the best way to handle medical care decisions for handicapped newborns.

Weir's legal analysis is limited, though, by his complete reliance on secondary sources. Unlike his medical survey, which is grounded in reality, Weir's legal discussion lacks any reference to the distinctions courts are actually making and applying. As a result, his characterizations of court decisions are often inaccurate, superficial, or unrealistic. His suggestion that most courts faced with nontreatment cases have ordered treatment (p. 266) is misleading — the majority of reported opinions uphold parental refusal of treatment for handicapped newborns.⁸ His statement that courts have so far protected the best interests of handicapped children (p. 140) does not explain how judges know what is best. Weir assumes that courts reach objective best interest determinations without making comparative quality of life projections: an examination of recent court opinions suggests not only that this characterization is untrue, but also that it may be impossible.⁹

Weir is at his best when surveying the attempts of ethicists and theologians to put together well-reasoned and consistent positions on selective nontreatment. In an effort to get beyond emotionalism, Weir presents the advantages and disadvantages of five ethical options: (1) treat all nondying neonates,¹⁰ (2) terminate the lives of selected "nonpersons,"¹¹ (3) defer to parental discretion,¹² (4) withhold treatment according to quality of life projections,¹³ and (5) withhold treatment not in the child's best interests.¹⁴ While recognizing the intuitive or practical appeal of these approaches, Weir also points out their vagaries, limitations and inherent subjectivities. Unfortunately, his preference for the "best interests" test leads him to overstate its advantages and to overlook its inherent problems: *Whose* objectivity? *How* is harm assessed if not relatively? *When* does the harm outweigh the benefits?

8. See *In re Infant Doe*, Ind. Sup. Ct. No. 4821540 (sealed), *cert. denied*, 104 S. Ct. 394 (1983) (upholding decision to withhold treatment, food, and water from Down's syndrome infant); *Weber v. Stony Brook Hosp.*, 467 N.Y.S.2d 685, *aff'd.*, 60 N.Y.2d 208, 469 N.Y.S.2d 63, 456 N.E.2d 1186, *cert. denied*, 104 S. Ct. 560 (1983) (upholding decision not to treat infant born with spina bifida and other complications); *In re Phillip B.*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (Cal. Ct. App. 1979) (upholding nontreatment of eleven-year-old Down's Syndrome boy with a correctible heart defect); see also *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *In re Custody of a Minor*, 385 Mass. 697 (1982).

9. See cases cited at note 8 *supra*.

10. P. RAMSEY, *ETHICS AT THE EDGES OF LIFE* 192 (1978).

11. Tooley, *A Defense of Abortion and Infanticide*, in *THE PROBLEM OF ABORTION* 51-91 (J. Feinberg ed. 1973).

12. Fletcher, *Choices of Life or Death in the Care of Defective Newborns*, in *SOCIAL RESPONSIBILITY: JOURNALISM, LAW, AND MEDICINE* 77 (L. Hodges ed. 1975).

13. McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J. A.M.A. 174 (1974).

14. Engelhardt, *Ethical Issues in Aiding the Death of Young Children*, in *BENEVOLENT EUTHANASIA* 185 (M. Kohl ed. 1975).

In short, Weir recognizes that physicians, lawyers, and ethicists have been talking past each other on the issue of selective nontreatment. His multidisciplinary approach challenges participants in the nontreatment debate to develop standards and procedures that are sensitive to the complexities of individual cases but can be clearly and consistently applied. Theories must be evaluated in terms of their applicability to actual nontreatment dilemmas. Weir recognizes this need, and concludes his book with a proposed model for further discussion. But Weir's model suffers from the same problems of vagueness, oversimplification, and rigidity which he warns against in the preceding chapters of the book.

Weir proposes that the standard for nontreatment decisions be "best interests of the child." He describes this standard as an objective balancing test which allows nontreatment only when the harm of treatment would outweigh the benefits to the child. His analysis is shallow, though, for in practice, the "best interests" test is as subjective as the "quality of life" projection he condemns. Harm can only be defined subjectively. The extent of harm is determined by comparing the handicapped child with a normal child — the quality of life comparison Weir himself criticizes. The harm/benefit balancing is also inherently subjective: to say that at a certain point the harm of continued existence outweighs the benefit is the same as saying that the life is not worth living.

Weir first argues that unlike the "quality of life" test, the "best interests" test focuses solely on the interests of the child. However, actual applications of this test in court have included considerations of the family's capabilities and interests¹⁵ — considerations which Weir himself recognizes as "tragically necessary" in some cases (p. 215). Weir also argues that the "best interests" test focuses on the infant's medical prognosis. In reality an infant's handicap may affect his or her strictly medical prognosis, and, as Weir demonstrates in his medical survey, physicians often incorporate quality of life judgments in their medical recommendations. Weir's "best interests" test, which allows but does not admit subjective quality of life comparisons, diverts debate from the fundamental questions of whether or how society should make such comparisons.

Second, Weir labels newborns as "potential persons" with lesser claims to life than adults. His use of this label to rationalize what the legal status of fetuses and newborns has been, however, does not answer the question of what their status *should* be. The concept of

15. See, e.g., *Weber v. Stony Brook Hosp.*, 60 N.Y.2d 208, 469 N.Y.S.2d 63, 456 N.E.2d 1186, cert. denied, 104 S. Ct. 560 (1983) (dismissing challenge to nontreatment decision to avoid subjecting parents to the invasion of privacy and expense of litigation brought by a third party); *In re Guardianship of Phillip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781, 792 (Cal. Ct. App. 1983) (earlier decision to withhold treatment from eleven-year-old Down's Syndrome boy may have been in the family's "combined best interests," but was not in the child's best interest).

nonpersonhood is no more than *post hoc* justification of nontreatment (They don't kill persons, do they?). The real question is not what to *call* neonates, but whether to *treat* them. A more helpful way to approach this question might be to think of a continuum of human life from fertilization to brain death and to ask where on that continuum nontreatment is justified.

Third, Weir makes a compelling argument that when treatment is not in the child's best interests there may be no moral difference between actively killing the child (*i.e.*, by injection) and passively letting the child die. Where nontreatment would result in prolonged suffering (*i.e.*, starvation) a lethal injection is more humane. Weir's argument is weakened by his suggestion that there is a causal difference between killing and letting die. Not all patients allowed to die do so,¹⁶ but not all attempts to kill are successful either. When death occurs, the responsibility for it is the same in either case. The fact that death is marginally more certain from active killing than from passive nontreatment should not be allowed to obscure the similar moral content of the choices. In addition, Weir suggests that death is only *intended* when life-prolonging treatment is withheld *against* the child's best interests. This analysis confuses intent with justification. Withholding life-prolonging treatment *in* the child's best interests *intentionally* causes death to mitigate harm. The appropriate argument is not that the killing is unintentional, but rather, that it is justified.

Fourth, Weir proposes that neonatal treatment decisions be made on the basis of diagnostic categories of diseases. Weir claims that congenital anomalies can be divided into three groups: (1) untreatable diseases (treatment is futile), (2) treatable diseases which should not be treated (treatment is *not* in the infant's best interests), and (3) treatable diseases which should be treated (treatment *is* in the infant's best interests). Weir concludes that this system can be objectively and consistently applied to nontreatment choices. He should know better.

Medical diagnoses and prognoses, as Weir warns in previous chapters, are tentative and complex. A disease like spina bifida spans the treatability range. Infants suffering from multiple anomalies may fall outside Weir's black and white categories. To answer, as he does, that treatment in "gray areas" is optional is to permit subjectivity and inconsistency, to risk maleficence in individual cases, and to leave the most interesting questions unanswered.

Weir lists examples of diseases which fall within each category, yet his alignment must change with technological advances. Ironically, he

16. In 1976 the New Jersey Supreme Court authorized doctors to remove Karen Ann Quinlan from a respirator despite medical predictions that she could not live without it. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976). The comatose woman survived for nine years without the respirator. *Karen Ann Quinlan, 31, Dies 9 Years After Coma Decision*, N.Y. Times, June 12, 1985, at 1, col. 2.

lists "hypoplastic left ventricle" as an untreatable disease. In 1984 doctors in Loma Linda, California kept an infant born with that condition alive for a month by replacing her heart with that of a baby baboon.¹⁷ Rigid adherence to Weir's categorical rules would have denied the infant, known as Baby Fae, even a chance for life. It would also have frozen medical science, by preventing physicians from ever learning how to treat what was considered to be an untreatable disease.

In addition to being overly rigid, Weir's categories are also subjective. Most writers agree that the agony of children suffering from Lesch Nyhan syndrome (a process of neurological and physiological deterioration characterized by severe mental deficiency and self-mutilation) should not be prolonged. There is wide disagreement, however, on the treatment of diseases like Down's syndrome and spina bifida. Weir admits that one basis for distinguishing between categories is the degree of mental ("neurological") deficiency — a subjective assessment of the projected quality of life.

Finally, Weir does a thorough job of discussing the strengths and weaknesses of doctors, parents, committees, and courts as nontreatment decisionmakers. Still, his proposed procedure ignores some practical problems. In Weir's model, parents are the primary decisionmakers. Considering that the parents' choice is heavily influenced by the physician's prognosis and recommendation, the independence of their decision is questionable. Furthermore, though Weir advocates the use of hospital committees, under his proposed procedure, committees will rarely review nontreatment decisions on which doctors and parents agree. Social workers and nurses rarely raise official appeals, and it is unlikely that people outside the hospitals will know to object. Weir's decisionmaking process could be alienating, time-consuming, and cumbersome (parents to doctors to committees to courts), and therefore inappropriate for NICU cases.

Despite the shortcomings of Weir's proposed model and standards, *Selective Nontreatment of Handicapped Newborns* is recommended reading for anyone concerned with the nationwide dilemma in the NICUs. Its pages are rich with medical, legal, ethical, and emotional complexity. And its very failings challenge readers to suggest a better way.

17. *Baby Girl 'Stable' With Baboon Heart*, Chicago Tribune, Oct. 28, 1984, § 1, at 14, col. 1; *Doctors Defend Baboon Heart For Baby*, Chicago Tribune, Oct. 29, 1984, § 1, at 1, col. 3.