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Special Care: Medical Decisions at the Beginning of Life

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SPECIAL CARE: MEDICAL DECISIONS AT THE BEGINNING OF LIFE. By *Fred M. Frohock.* Chicago: University of Chicago Press. 1986. Pp. xiii, 263. $19.95.

Special Care is an examination of the ethical issues that confront society over the treatment of profoundly ill infants. If treated, these infants might survive only in perpetual pain, or in a state of unconsciousness, or as prisoners to life support mechanisms. When should doctors withhold treatment even though they might have the means to prolong life? Here technology outpaces moral philosophy; the questions posed are not only exceedingly difficult, but divisive as well.

Recently, there have been several well-publicized "Baby Doe" cases, where parents decided not to pursue treatment for their seriously ill infants.[1] These decisions not to treat the infants have "galva-

1. The two most celebrated cases of parents wishing to withhold treatment from seriously ill infants were known as "Baby Doe" cases. The first occurred in Bloomington, Indiana in 1982.

nized American social reformers"[2] and have caused the right-to-life movement to embark on what has been referred to as a "crusade" to prevent doctors and parents from withholding treatment from severely ill children.[3] The Reagan administration sided with the right-to-life movement and forced hospitals to post notices stating that the failure to feed and care for handicapped infants is prohibited by federal law and providing phone numbers for anyone with information about violations.[4]

Special Care was written within the context of the Baby Doe controversy.[5] Professor Frohock[6] spent four months in the neonatal intensive care nursery of a well-respected hospital (which he declined to identify) to gather information on this subject. The hospital displayed one of the notices required by federal law (p. 27). Frohock had complete access to the ward and to those who worked there.

Frohock disagrees with the position of the right-to-life movement, and this disagreement pervades his impressions. Moreover, Frohock mistrusts the intrusion of the legal system into the decisions of when to terminate treatment, and uses a right-to-life attorney as an example of the problems of legal intervention in these issues. In his conclusion, Frohock not only expresses his dissatisfaction with the concept of a right to life, but with the concept of rights altogether.

On the whole, though, *Special Care* is not a polemic. Throughout most of the book, Professor Frohock presents the issues through the cases of actual infants. Ten of *Special Care's* eleven chapters consist of the author's observations, interspersed with fragments of interviews with the doctors, nurses, and the parents whose infants depend on the care of the nursery. Only the last chapter approaches the dilemma of terminating treatment theoretically.

Professor Frohock is a passive but not dispassionate observer. His impressions are written in a journal format and are organized chronologically. Rather than presenting a succession of case studies with problems posed and the manner of solution announced within a few pages, the author describes the infants as he saw them. They are char-

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See, e.g., Comment, *The Legacy of Infant Doe*, 34 BAYLOR L. REV. 699 (1982); Comment, *Defective Newborns: Inconsistent Application of Legal Principles Emphasized by the Infant Doe Case*, 14 TEXAS TECH L. REV. 569 (1983). The following year a similar case, referred to as the Baby Jane Doe case, arose on Long Island. *See* Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983); Kerr, *Reporting the Case of Baby Jane Doe*, 14 HASTING CENTER REP., Aug. 1984, at 7. For a general discussion and comparison of the two cases, see J. LYON, PLAYING GOD IN THE NURSERY 22-58 (1985).

2. *See* J. LYON, *supra* note 1, at 39.

3. *Id.*

4. *See* Fost, *Putting Hospitals on Notice*, 12 HASTINGS CENTER REP., Aug. 1982, at 5.

5. In the past year, several books have been written about this same issue. *See, e.g.*, J. LYON, *supra* note 1; E. SHELP, BORN TO DIE (1986).

6. Professor Frohock is the chairman of the political science department at Syracuse University. He has written books on political theory, public policy, and law and morals.

acters in the drama of life, not mere case studies, and Frohock succeeds in making them real enough so that all but the most callous reader will care about them as well.

For example, the infant Stephanie is a girl with an incurable disease that causes the skin to blister constantly.[7] She can not eat because the skin in her mouth and esophagus also blisters. Few children suffering from the disease Stephanie has live past their second year. Stephanie lives in constant pain, yet she also responds affectionately to love, as all babies do. The reader, by becoming familiar with the case of Stephanie, as well as those of the other infants, can begin to appreciate the conflict between the desire to keep human beings alive and the desire to spare these infants from unceasing, excruciating pain.

Special Care differs from most scholarly works[8] in that the author invites his emotions to form his judgment. Frohock is willing to admit that no purely rational response to these infants is possible. Illustrative of this is a discussion concerning a decision by parents to end treatment:

> Yet no one can say — morally, rationally — that enough is enough, for no alternative to what is being done for [the infant] makes any better sense. Her doctors and her parents are simply deciding without guidance. There do not appear to be any right answers. . . . [T]he pain of the choices and the pain that [she] feels, are not touched by more rational procedures in medical decisions. [p. 137]

Contrasted with a sympathetic view of perplexed parents is Frohock's mistrust of the legal system. He criticizes Lawrence Washburn, a right-to-life attorney who initiated the Baby Jane Doe case,[9] for his legal approach to these life and death issues:

> Washburn's proposals introduce the logic of law into medical practice — disinterestedness, adversarial proceedings, conclusive decisions, objective interests, and even rights. It is not easy to see how a legal hearing can remain consistent with the special commitments, consultative and cooperative actions, serial and tentative decisions, and particularized interests of neonatology. Reform by its nature intends to change the object of its attention to something better. But it is important to understand how much of medical practice will be changed if therapy decisions are governed by judicial review. [p. 124]

Frohock finds the doctors' approach to these issues far more appealing than the lawyers' approach, preferring the "cooperative" nature of

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7. The disease is known as epidermolysis bullosa. *See* A. RUDOLPH, PEDIATRICS 827-29 (17th ed. 1982).

8. For example, J. LYON, *supra* note 1, contains several case studies, but also a far more abstract discussion of the issue, and a collection of the the views of many experts. E. SHELP, *supra* note 5, is similar.

9. *See* Weber v. Stony Brook Hosp., 60 N.Y.2d 208, 456 N.E.2d 1186, 469 N.Y.S.2d 63 (1983); Levine, Gallo & Steinbock, *The Case of Baby Jane Doe,* 14 HASTINGS CENTER REP., Feb. 1984, at 10.

medicine to the "adversarial" nature of the legal system.[10] He also sees legal decisions as inappropriate to medical cases. Medical decisions are "serial and remedial" (p. 123) and can be changed as new information becomes available. Legal decisions, on the other hand, are "singular and decisive" (p. 123).

Frohock's distaste for the legal system, while understandable in the context of his disagreement with certain decisions, is misplaced. While the goals of medicine might be cooperative in contrast to the adversity of a lawsuit, it must be remembered that the Baby Doe case in Indiana was brought to court by one doctor who disagreed with the decision of another.[11] Conflicts are often undesirable, especially in health care, but they are also inevitable; and the judicial system must resolve them. One observer has noted that the courts are the proper arbiters of this issue if "interests other than those of the infant and in the sanctity of life [are to] be considered."[12]

Frohock's criticism of the "singular and decisive" nature of legal decisions is also inappropriate. While decisions in our common law culture take on the effect of law, they are not absolute and are interpreted and amended as factual situations change. Similarly, medical decisions, while made on a case-by-case basis, still create guidelines and precedents which doctors tend to follow.[13]

Surprisingly, Frohock pays little attention to the greatest drawback of the legal system in these cases, the time factor. Litigation is very time consuming, and the lives of these infants are often very brief.[14] Not only does this extremely abbreviated time span for judicial decisions and appellate review result in the absurdities of on-again/off-again treatment, but neither the attorneys nor the courts have the time to develop their arguments and decisions to the necessary degree of complexity this issue deserves.

The last chapter of *Special Care,* entitled "Languages of Evaluation," abandons the journal format for a more traditional essay. Frohock discusses the ethical dilemmas of extreme neonatal care without using "rights language," but instead using the concept of "harm."

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10. P. 123. For other discussions on this topic, see Robertson, *Legal Norms and Procedures for Withholding Care from Incompetent Patients: The Role of Law in Passive Euthanasia,* in FRONTIERS IN MEDICAL ETHICS: APPLICATIONS IN A MEDICAL SETTING 99 (V. Abernathy ed. 1980); LAW AND ETHICS IN HEALTH CARE (J. McKinlay ed. 1982); Comment, *Withholding Treatment from Defective Newborns: Substituted Judgment, Informed Consent, and the* Quinlan *Decision,* 13 GONZAGA L. REV. 781 (1978).

11. J. LYON, *supra* note 1, at 28.

12. Longino, *Withholding Treatment from Defective Newborns: Who Decides and on What Criteria?,* 31 KAN. L. REV. 377, 403 (1983).

13. One alternative to the legal system is a hospital ethics committee to set guidelines. While this is extra-judicial, the decisions are no more rigid, or less inflexible, than legal decisions. *See generally* American Academy of Pediatrics, *A Proposal for an Ethics Committee,* 13 HASTINGS CENTER REP., Dec. 1983, at 6-7; Longino, *supra* note 12, at 402-03.

14. *See, e.g.,* J. LYON, *supra* note 1, at 74; Longino, supra note 12, at 381 n.30.

While he admits that rights are important, in this context he sees them both as an impediment and as an incorrect way of thinking about the issue. Frohock views rights as "a shield insulating the individual from regulation by others without . . . obligating the individual to any action" (p. 203). By keeping people alive without any other reason than a concept of a right, he feels that the "right to life has been transformed into an obligation to live — which is not a right at all" (p. 204).

Frohock accuses the rights concept of obfuscating the interests of babies by ignoring the fact that health, not simply the maintenance of life, is the primary goal of medicine. "A right is a blocking device, a term that sets the individual off from the community. What is needed in neonatal nurseries is a clear statement on how individual interests occur within communities" (p. 214). Earlier, Frohock states,

> [I]t is important to remember that rights are the instruments to represent deeper values, the conclusions of a hypothetical dialogue on the meaning and importance of individual life, not items valuable in themselves or simplistic trump cards to stop discourse on values. Seen in this way, a discussion of rights can admit the question — are there alternative instruments to realize the values we want to protect? [p. 204]

Frohock believes there is an alternative way to look at these issues. He prefers to use the language of harm, as in the Hippocratic oath's injunction to "do no harm."[15] This language would allow doctors to withhold treatment in cases in which treating the patient would do him more "harm" than would allowing him to die.

> A harm principle may be the more basic consideration in life-and-death issues. Maintaining life seems justified on the thought that death harms individuals in the worst possible way. . . . But if death can be merciful on occasion, then the principle justifying life may require that death be sought as a way to avoid harm. The best we may be able to do in critical situations within the constraints of primary goods and life forms is to recognize the deeper interests of the individual in avoiding harm. This recognition, painful and imperfect as it often is, reconstructs the conditions of an individual's life to determine how harm can be avoided. [p. 209]

Frohock's view really does not solve the complex dilemma. His hostility to the right-to-life position leads him to criticize rights, rather than simply that position's expression of rights. The concept of harm, in the hands of absolutists, would treat death as the worst possible harm, and thus not be all that different. Rights, and even the right to life, need not be absolute. It is a rare right that does not, at some

15. P. 204. The author lists three types of harm: physical pain, emotional pain, and deprivation. Physical pain is allowable for therapeutic value, as is emotional pain. Otherwise, they should be avoided. Deprivation, meaning deprivation of some measurable time of life, is the most complicated aspect. There is no readily accepted answer as to when death is preferable to continued treatment. For example, those who advocate the right-to-life position feel that the answer is never. Pp. 206-09.

point, conflict with another one. Is not the concept of "harm" another name for the "right" to be free from the infliction of unnecessary pain? One can fully accept both the language of rights and the proposition that care may be terminated at some point. The values necessary in a harm evaluation are no simpler to calculate[16] than the point at which one right takes over from another.

While Frohock has not succeeded in providing a convincing framework in which to solve the dilemma, that is more a function of the nature of the issue than the shortcomings of the author. The book is a fascinating look inside the nursery, one which can give minds predisposed to legal methods insight into the perceptions of those intimately involved with these life-and-death dilemmas. Frohock adds a human element to a debate which often gets lost in abstractions.

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16. In Frohock's argument in favor of the harm principle, he includes a discussion of "Bayesian decision-rules" and equations to calculate rational decisions of when it is uncertain to continue treatment. Pp. 209-10. While his assertion that there are points at which "even the best life is equal in value to death when the treatment is highly likely to produce a permanent comatose condition," p. 211, may well be true, it is still impossible to fill in the variables of the equation with purely rational rules.