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# ETHICAL DILEMMAS IN THE TREATMENT OF CRITICALLY ILL NEWBORNS

*Benjy F. Brooks\**

Tragic choices are often involved in the management of a newborn with serious birth defects. Historically, these choices have been made by parents, physicians, and frequently members of the clergy. Before recent advances in the technology of medicine, there were often no decisions to be made. For example, thirty years ago no attempt was made to produce an anatomical diagnosis of heart defects since there was no surgical treatment. The pediatric surgeon has played a significant role in the development of life saving procedures for neonates born with defects incompatible with life. The majority of infants have only a single defect and, if it is corrected, can look forward to long and productive lives.

I have had the extraordinary privilege of working in the field of pediatric surgery for thirty years and have participated in the surgical care of approximately twenty thousand infants and children. For the past two years I have engaged in the study of bioethics,<sup>1</sup> beginning these studies with a sabbatical year spent at Cambridge University in England. It is in the light of this background that I make the following observations and suggestions.

## *Infanticide*

The first observation is that infanticide has always been more widely practiced in the United States than has been appreciated, and that incidences of its occurrence vary with geography. It is to be hoped that the amendment to the Child Abuse Act will protect this group, and that we will have a more consistent policy in dealing with disabled newborns.<sup>2</sup> It is also interesting to

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1. See generally A. NADAS, *A PEDIATRIC CARDIOLOGY* (2d ed. 1964); Kelsey, *Which Infants Shall Live? An Interview with Raymond Duff*, *HASTINGS CENTER REP.* 5 (Oct. 1975); Pasternak & Volpe, *Full Recovery from Prolonged Brainstem Failure Following Intraventricular Hemorrhage*, 95 *J. PEDIATRICS* 1046 (1979); Robertson, *Dilemma in Danville*, *HASTINGS CENTER REP.* 5 (Oct. 1981); Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A Nationwide Survey of Pediatricians and Pediatric Surgeons*, 60 *PEDIATRICS* 558 (1977); *Optimum Care for Hopelessly Ill Patients: A Report of the Critical Care Committee of the Massachusetts General Hospital*, 295 *NEW ENG. J. MED.* 362 (1976).

2. 42 U.S.C. § 5101 (1984).

note the difference in the definition of infanticide in the United States and in Great Britain. In Britain the definition of infanticide is the killing of an infant by his mother, while in the United States it is the killing of an infant by direct means or by withholding something necessary for his survival.<sup>3</sup>

The second consideration deals with communication. The correct information for those involved in the decision making process is essential. A physician can go before the parents or the hospital's ethics committee, and present the case in such a way that the outcome is predictable. One example of this is an actual case in which the parents of a child born with Down's syndrome were told that all mongoloids are hopelessly mentally retarded; in reality, most of them have IQ's of fifty to seventy and are trainable. They were also told that the mortality rate for surgical repair of a tracheo-esophageal fistula with esophageal atresia is fifty per cent (this is a condition where the esophagus ends blindly with a fistula into the trachea, where all saliva and food ends up in the lungs, a situation incompatible with life). The actual survival rate of these children is ninety-five per cent.<sup>4</sup> On this very false information the parents were asked to make decisions regarding the infant's life.

Good ethical decisions are based on true facts. When presenting a patient to the review committee, the bias of a physician will often become apparent. The use of the words "hopeless," and "terminally ill" could certainly sway the decision of the committee, since death is no longer defined as a cardio-pulmonary failure. In actuality, there are few conditions which are hopeless or terminal.

The third consideration is that the great majority of people in the United States believe that life is preferable to death. Most people are in favor of preserving life even if it is accompanied by pain and suffering. I will start with the assumption that life should be preserved. The burden of proof should be on the person who supports a course of action intended to result in death.

### *Justifications for Allowing Critically Ill Newborns to Die*

There have been major disagreements among physicians, some believing that infants born with defects incompatible with life should be allowed to die, and others who would save life at any cost. I will review the common justifications for allowing a critically ill infant to die and show that they are

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3. W. LANGER, *INFANTICIDE: A HISTORICAL SURVEY* 353 (1974). See generally M. TOOLEY, *ABORTION AND INFANTICIDE* 1 (1983).

4. M. RAVITCH, K. WELCH, C. BENSON, E. ABERDEEN & J. RANDOLPH, 1 *PEDIATRIC SURGERY* 464-65 (3d ed.). See Gustafson, *Mongolism, Parental Desires and the Right to Life*, 16 *PERSP. IN BIOLOGICAL MED.* 529 (1973).

seriously flawed. The first justification is the choice of words used to describe the critically ill newborn. These words often have powerful effects on the decision making process. Some of these words are "hopeless," "non-viable," and "terminally ill." I have observed changes in the meaning of these vague terms over the past thirty years. With the development of high technology, mortality rates for infants with congenital defects have been significantly reduced.<sup>5</sup> Today, very few conditions are hopeless. Infants weighing less than eight-hundred grams are often viable, and terminally ill is not a predictable condition. All of us who have worked in a newborn intensive care unit will recall a patient whose prognosis seemed hopeless, yet grew to be a normal child.

I will give two examples from my own experience. The first was a short-gut infant who lost seventy per cent of his small bowel due to volvulus. He was in the hospital for the first five months of his life. Since he was treated prior to the days of hyperalimentation, his outlook was indeed poor. Recently he was asked to come to my office as part of a long term follow up study. His family arrived, including his brother, who is two years older than the patient. Because the family had moved out of town, I had not seen this patient since he was three years old. I approached the shorter of the two brothers, who was 5'8" tall. The taller one, at 6'1", looked down at me and said, "I am your baby". The prognosis of this infant was by no stretch of the imagination predictable.

Another infant had continuous seizures with an abnormal encephalogram and pneumothorax. The pneumothorax was easily treated with a chest tube. The neonatologist had a sign over the child's crib which said "Do Not Resuscitate". The infant survived and is now a perfectly normal six year old.

Not only is the defective newborn dependent upon the geographical location of his birth, but also upon attitudes and decisions of those around him. The language in which the patient is presented could influence the decision of the courts. There are several ways to offset the fact that decision making will always be done with imperfect data. Consultation with an Infant Care Review Committee could reduce this uncertainty. It has been suggested in the model guidelines of the Child Abuse Amendments of 1984 that this Infant Care Review Committee should consist of the following: a practicing physician (pediatrician, pediatric surgeon, or neonatologist), a practicing nurse, a hospital administrator, a social worker, a representative of the legal profession, a representative of a disability group, and a lay community member.<sup>6</sup> It has also been suggested that a member of the facility's organized

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5. *Id.*

6. 49 Fed. Reg. 48,170-71 (1984).

hospital staff could serve as a chairperson.<sup>7</sup> An ad hoc committee composed of the clergy could also be included.<sup>8</sup> It has been suggested by Firth and others that decisions regarding the treatment of incompetent patients be approached from an ideal proxy standpoint.<sup>9</sup> It is thought that the proxy should be empathetic, detached, with no personal interest, dispassionate, and informed of all facts pertaining to the patient at the time of the decision. Clearly parents could not fill these criteria. Most of the time parents are emotionally distraught and hear very little of what is said to them. Physicians and parents have a deep vested interest which makes them less than an ideal proxy. It is doubtful that a committee could be constructed of the proxies conceived of in the model guidelines. We can only hope that a decision made for the infant would be the right one.

Physicians should try to define ordinary care versus extraordinary care. Everyone would agree that ordinary care would be defined as care all patients should receive. Some controversies exist, however, as to what ordinary care would mean in regard to a disabled infant. In the treatment of a disabled infant ordinary care could be defined as appropriate nutrition, hydration, and medication. Extraordinary care could be defined as going beyond our duty, once the physician's duty to the patient has been established. What is considered extraordinary care today will be considered ordinary care tomorrow.

The surgical repair of a duodenal atresia in a normal infant is considered to be ordinary care, and no one would question this decision. However, some would consider the surgical repair of a duodenal atresia in a mongoloid infant to be extraordinary. Extraordinary treatment would therefore be defined as an ordinary operation on a normal infant, but when performed on an infant apt to be mentally retarded it would be extraordinary. This thinking is flawed; either the treatment is ordinary or extraordinary. It cannot be both when a human life is at stake.

#### *Parental Wishes and Desires*

One of the most common reasons for withholding treatment is based on the wishes and desires of the child's parents. In other words, one person's life is subject to another person's desires. Until recently, the child's relationship to his parents was one of ownership. Well into the 19th century infanticide was tolerated and widely practiced in France and England.<sup>10</sup> Only

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7. *Id.*

8. *Id.*

9. Firth, *Ethical Absolutism and the Ideal Observer*, 12 J. PHILOS. PHENOMENA 317 (1952).

10. *Supra* note 2.

recently have child abuse laws reflected the state's right to intervene when a child's life or safety is threatened by his parents.<sup>11</sup> Some have regarded the parent-child relationship in a trustee context.<sup>12</sup> This acknowledges the parent's authority over a child's education, both academic and religious, and places the behavior of the child as a responsibility of the parent. The state, however, has a duty to intervene when the child's life is in danger as a result of parental decisions.<sup>13</sup>

Alternatively, it is conceded that parents and children could have equal rights, where the child's right to life would take precedence over any inconvenience, sacrifice, social, or financial burden to the parents. In this context it would not be permissible to let someone die to ease the burden of another. However, the equal rights relationship would not necessarily lead to the conclusion that all infants or children should be kept alive.

#### *Death in the Best Interest of the Child*

Another reason for withholding treatment from a critically ill newborn is when euthanasia is in the best interest of the infant. To put it bluntly, the infant would be better off dead. Most of us would agree that it is not acceptable to suppose that everyone should live in this world forever. We can all imagine a life not worth living. We think of this usually within the confines of our own life values. Extreme suffering and pain has been used as a reason for "letting an infant die". The severely burned patient could be visualized to fit this category, perhaps more than an infant, where pain and suffering would include endless future treatment. In considering the neonate, no one would presumably argue that an anencephalic baby with the absence of kidneys should be treated. One pre-eminent moral theologian has suggested that a criterion for discontinuing the care of a brain-damaged newborn would be a lack of potential for human relationships.<sup>14</sup> This would possibly apply to anencephalic infants, or those with irreversible coma and brain damage but would not be justified for babies with Down's syndrome, meningomyelocoele, or prematures with intraventricular hemorrhage.

Several surveys have revealed that physicians would rely upon parental decisions concerning the treatment of a child. Indeed, it has been suggested that the parents should have the authority to withhold treatment from their

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11. B. SALES, B. POWELL & R. VAN DUIZEND, *DISABLED PERSONS AND THE LAW: STATE LEGISLATIVE ISSUES 89-98* (1982).

12. *Id.* See also Kuzma, *The Legislative Response to Infant Doe*, 59 *IND. L. J.* 376 (1984).

13. *Id.*

14. McCormick, *To Save or Let Die: The Modern Dilemma of Modern Medicine*, 229 *J.A.M.A.* 172 (1974).

children.<sup>15</sup>

To what degree state interference is appropriate in the protection of a disabled infant has been the subject of long and far reaching discussion since the guidelines for the care of defective newborns were issued in March, 1983, by the United States Department of Health and Human Services (known in the popular press as the "Baby Doe Regulations.")<sup>16</sup> The state's obligation to intervene to protect over one million abused children in the United States has not been challenged. There has been intense controversy, however, as to the state's obligation to an infant whose parents desire that the infant die. Regretably, there has been a failure to distinguish between the two examples of state interference.

#### *Allocation of Scarce Resources*

A common justification for the withholding of treatment from disabled newborns is the allocation of scarce resources.<sup>17</sup> Since there is no coherent public policy on the allocation of so-called scarce resources, there is some question as to what extent scarce resources exist. The lack of an identifiable policy and a morally compelling reason for favoring one allocation of resource over another makes it difficult for a physician to allow a disabled child to die for some future unknown child. Under the present system there is no guarantee that funds saved by allowing a disabled infant to die would remain in the health care system and not be used in other ways, such as the defense budget or the construction of roads. When we talk of the "bottom-line" in the treatment of disabled newborns, for most individuals the question will be one of economics. We are being bombarded with all kinds of propaganda regarding the cost of the handicapped to society. Before we make any lasting policies concerning the allocation of scarce resources we should study the cost of the morally handicapped to society. None of the disabled infants in my experience has grown up to commit crimes, none of them is in prison, none is part of the drug scene, and none has committed suicide. Would it be just to compare the cost of treating disabled newborns to other circumstances which are a financial burden to society? For example, alcoholism, driving while intoxicated, drug addiction, and violent crimes all take a tremendous toll on our financial resources. Even within the area of health care there are arguments as to how money should be spent. The dis-

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15. J. GOLDSTEIN, A. FREUD & J. SOLNIT, *BEFORE THE BEST INTEREST OF THE CHILD* (1971).

16. 48 Fed. Reg. 9,630 (1983).

17. See Smith, *Triage: Endgame Realities*, 1 J. CONTEMP. HEALTH L. & POL'Y. (1985).

tribution of money to prevent disease in research is competing with crisis intervention types of medicine.

### *Defective Newborns and the Law*

The law and the courts have not been helpful in determining justice for the disabled newborn. Physicians and others who have appealed to the judicial system for guidance have received mixed messages. There have been some decisions that indicate that the infant does have a right to life, and other cases where the parental decisions have been upheld by the courts. Parents, along with many physicians, would find it helpful if a structured, pragmatic medical standard for decision making was published.<sup>18</sup> In our experience, predicting the outcome of a seriously ill newborn is impossible. The future of defective or any other newborn is unpredictable. The courts have used such terms as: "reasonable choice," "fulfilling and useful life," "happy life," or "in the kindest interest of the child," in handing down their decisions. These terms are absolutely meaningless as far as newborns are concerned. The above terms would be very useful in making decisions about the older child, for example, a child who had been brain damaged, or a near-drowning victim, or one who had been severely burned. Much could be said about the absence of rights of children in our society and our legal system. Today, the value of life is made relative to intelligence in our society. There are many individuals who believe that neither the state nor physicians have any right to interfere with the freedom of choice of a family. Every child is a financial and an emotional burden to his family at times, yet many physicians have felt no obligation to save the life of a child if the parents did not want the child for many reasons, including those besides the original defect.

First, it is questionable if a child has a legal right to life. Second, it is felt that the infant's legal right is conditioned by his parents' desires.<sup>19</sup> Third, the physicians did not believe that the court would order surgery, for example, on a baby with Down's syndrome, and the parental rights would override legal rights in these cases. Fourth, if the infant's life was saved, it would be doubtful if the parents would accept such a child, and probable that they would not love the child. The assumption is that the parents would not change their minds about caring for the child at a later date. Physicians have distinguished between not saving a life and taking a life. For example, feeding has been withheld to hasten death by starvation, but there has been a

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18. Smith, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 NEB. L. REV. 709 (1984).

19. See Dickens, *The Modern Function and Limits of Parental Rights*, 97 L. Q. REV. 462 (1981).



reluctance to give medicine to hasten death, so that doctors will stay free of any legal censure.<sup>20</sup>

One very important member of the health care team has been largely overlooked in the discussion of letting a newborn die. Nurses have a great sense of the relief of suffering and a need to preserve life. Most have a profound belief in the sanctity of life. In the past they had no recourse but to follow the doctor's orders. Nurses have feelings of frustration and anger that they are now beginning to express. With the new guidelines established by the Child Abuse Act, a nurse will no longer have to see a baby starve to death, or carry moist cotton balls concealed in her uniform to moisten an infant's eyes (he had no tears) or mouth (he had no saliva). When a parental decision has been made to allow an infant to die, there has been very little thought of imposing this judgment on the nurses, who have had to stand by until the child dies.

We are entering an era of increasing involvement in decisions concerning the defective newborn. This intervention will lead to a loss of control by physicians and parents. However, it will eventually bring a much needed standardization of treatment for defective newborns in the United States. Under the present *Interim Model Guidelines Concerning Services and Treatment for Disabled Infants for Health Care Providers to Establish Infant Care Review Committees*<sup>21</sup> that effectuate Section 124 (b) of The Child Abuse Amendments of 1984, the basic policy of the legislation is stated as being that of developing institutional policies and guidelines to prevent acts which withhold medically indicated treatment from disabled infants with life threatening conditions.<sup>22</sup> Treatment may be withheld from an infant, however, only when, in the reasonable medical judgment of the treating physician or physicians: the infant is chronically and irreversibly comatose; the treatment would merely prolong dying; the treatment would be ineffective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the infant's survival; or finally, such treatment would be virtually futile in terms of the infant's survival and treatment and be considered inhumane.<sup>23</sup> Infant Care Review Committees are encouraged to be established in over seven thousand health care providers who receive federal monies.<sup>24</sup> These committees are to provide counseling and are also

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20. See Robertson & Fost, *Passive Euthanasia of Defective Newborns—Legal Considerations*, 88 J. PEDIATRICS 883 (1976).

21. 49 Fed. Reg. 48,170 (1984). The final rule implementing The Child Abuse Prevention Act was issued April 15, 1985. See 50 Fed. Reg. 14879 (1985).

22. *Id.* at 48,171.

23. *Id.*

24. *Id.* at 48,170.

charged with developing and recommending institutional policies for withdrawal or withholding of medical treatment from infants with life threatening conditions.<sup>25</sup>

#### *Conclusion*

In the past children have been treated horribly. The protection and nurturing of children is really a new idea that has made great strides in the 20th century. National attention has been focused on the abused and battered child. It is interesting to remember that the single most important accomplishment of the first White House Conference on Children called by President Herbert Hoover was the removal of the child from the sweat shops. This happened only sixty years ago. At this first meeting, President Hoover observed that the nation's children are the greatest national resource this country possesses.<sup>26</sup>

Ethical considerations and dilemmas in the treatment of the very young will remain in controversy for many years to come. The nation's consciousness has been raised by Baby Doe and other cases, so the plight of the defective newborn is now better known, but a final consensus or resolution is many years away.

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25. *Id.*

26. See PROCEEDINGS FROM THE WHITE HOUSE CONFERENCE ON CHILDREN (1970).

