

Child Welfare Services for the Catastrophically Ill Newborn: Part II—A Guiding Ethical Paradigm

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Editor's note: Part I of this article—Child Welfare Services for the Catastrophically Ill Newborn: A Confusion of Responsibility—appeared in the last issue of CHILD WELFARE.

Each year, thousands of children are born suffering from a catastrophic illness and with a severe developmental disability [Lyon 1985; Driscoll 1982; Todres 1977]. For the majority of these children, formal decisions are made to provide treatment; for some, decisions are made to withhold treatment [Shaw 1973; Duff and Campbell 1973; Lorber 1971]. Yet, there is no consensus in our society about the proper locus of decision-making authority for these bioethical decisions, and there is no consensus regarding the proper ethical paradigm to guide this decision-making process—whether a child receives treatment may depend upon the place of birth, the parents, who attends the birth, or the local agency with responsibility to police these decisions. Without a consistent criterion with which to guide these bioethical treatment decisions, there are no assurances that these children will receive medical treatment in their best interests, or that they will not be unintentionally neglected or abused.

In passing the Child Abuse Amendments of 1985, Congress gave public child welfare agencies the responsibility to police bioethical decision-making

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for catastrophically ill neonates. These amendments, however, in spite of their intent, did not establish a consensus regarding what bioethical principles should guide the decision-making. As a result, child welfare agencies find themselves responsible for policing these decisions, but with no clear criteria to guide their actions.

Justice and Consistency

Since at least the time of Aristotle, the concept of justice has been an essential consideration in deciding the ethicality of an action. Justice, according to Aristotle, consisted of treating equals equally and unequals unequally, proportionate to their differences. The just application of standards and rules implies their consistent application—the right “to be treated alike . . .” Questions of justice, according to Hume, Mill, and other philosophers, presuppose conflicts of interest [Benn 1972]. A claim of medical benefit or a claim of treatment rights is a claim most often based upon rights justified by some standard or rule of justice. Most ethicists agree that justice necessitates consistency in bioethical decision-making and in the delivery of medical services, and that an important aspect of the concept of justice is the right to equal treatment.

The right to equal treatment appears to imply that individuals in similar circumstances require the same moral consideration. Consistency in bioethical decision-making, therefore, should be expected and demanded [Crossley 1987; Greenstein 1987]. For justice to be served, similar cases should receive similar consideration and similar medical treatment. Fost [1981] advocates the use of a standardized criterion in ethical decision-making for one essential reason—to facilitate consistency. Basson [1983] contends that traditional ethics insist on logical consistency in moral thinking, or else how could one decide between conflicting opinions or intuitions? Basson also questions how one can deal with a system that has no obligatory doctrine requiring that similar cases be treated similarly. He suggests that if this doctrine of justice is abandoned, the decision may as well be left to chance. Beauchamp and Childress [1983] suggest that an ethics system cannot be considered as such if it fosters inconsistent decisions, since it would not yield similar results when used by different persons, or even the same persons at different times. Brody [1981] suggests that inconsistency be the criterion for eliminating inadequate moral systems. He states that no one can claim ethical validity for a decision unless a rigorous and rational analysis proves that decision to be logically consistent.

Professional social workers with the responsibility to protect children should insist on the just and consistent application of bioethical decision-making guidelines in treatment decisions for developmentally disabled neonates with

life-threatening medical complications. To do so, the profession must adopt a guiding ethical paradigm as the standard. Until it does, consistency and justice will be beyond the scope of its activity, and "best interests of the child" may mean many different things to the many child welfare workers who must operationalize this concept. How does one know, then, that what is being done is in the best interests of the catastrophically ill neonate?

Guiding Paradigms

If consistency and justice in bioethical decision-making are a necessity, then a guiding set of principles must be established and used to inform the decision-making processes. The philosophical discipline of ethics provides such a set of principles [Popkin and Stroll 1956]. Ethics as a discipline can be simply defined as the study of deliberate actions in an attempt to determine which actions are "right or wrong" and or "good or bad." Child welfare agencies are, therefore, charged with the responsibility of making sure that treatment decisions for newborns are "right" and "good." The literature on bioethical decision-making suggests that two conflicting philosophical paradigms are most often used to guide ethical behavior in society—the utilitarian (a consequentialist ethic) and the deontological (a duty-based ethic).

The Utilitarian Paradigm

Utilitarianism is a teleological ethic that obliges us to consider the consequences or ends of actions to determine the morality of conduct. States of being that are free of pain and infused with pleasure are considered intrinsically good. Pain and distress are considered to be intrinsically negative states. The rightness of an action is derived from its consequences; "right" conduct produces net benefit over harm. Utilitarianism injects a strong social variable into the formula for ethical conduct. The morality of conduct depends not upon the consequences of action for any individual, but rather, the net effect for all. In moral decision-making, one must calculate the consequences of all discernible actions and inactions, and choose the one that will produce the maximum net social benefit over harm [Mill 1987].

The Deontological Paradigm

Deontological means literally "the study of duty." The deontological tradition in normative ethics defines right conduct as conduct consistent with duty—morally obligatory regardless of whether its consequences produce human weal or woe [Kant 1959]. The motto "Let justice be done though the heavens fall" conveys the spirit. Moral rules are believed by most deontologists to be

universally valid and admitting of no exceptions [Olson 1967]. Some deontologists may go so far as to suggest that one moral rule may conflict with another in the world of human affairs. With respect to these moral dilemmas, however, an assessment of an action's consequences is not a valid moral means of disengaging oneself from the dilemma's impaling horns.

The rules that deontologists hold in absolute regard may be derived from many sources: one's own personal communion with God, conscience, intuition, revelation, theological canon such as the Ten Commandments, and rational necessity, such as Kant's categorical imperatives [Kant 1959] or the discernible necessities of natural law.

Few deontologists refer to their guiding ethical paradigm as deontological. Instead their references are to "duty," "moral obligation," "normative rules," and "individual responsibility," all of which are often based upon obligatory rules of conduct and are, therefore, elements of deontological ethic.

Although the sources of moral guidance may vary, the defining characteristic of a deontological approach is the reliance upon immutable rules for guidance in the decision-making process. Rosner [1983] provides a good example of deontological ethics in his statement of reliance on the Torah for "eternally valid answers to even newly formulated queries." Rosner indicates that since "every moment of human life is also of infinite value," any life that can be prolonged should be prolonged.

A Comparison of Paradigms

Each of the two paradigms has its advocates. Battle [1987] argues strongly that physicians should take a utilitarian approach when deciding whether to treat seriously ill neonates. She contends that many physicians are driven to save some children by the "professional challenge and their own egoist pleasure of success which reaffirms (their) own omnipotence." As chief executive officer and medical director of the Hospital for Sick Children in Washington, DC, Battle each day walks among the consequences of technology and professional egoism that have "allowed us to create a new agony, an existence somewhere between life and death" with devastating repercussions for the families involved. She suggests that the child's potential quality of life and the impact of the child's survival on the child's family and upon society's limited resources should be considered in each decision to treat or to withhold treatment.

Taft [1987] examines this issue from the perspective of a hospital manager. She believes that the reality of limited resources may force a rationing system that should include utilitarian decision-making as the selection process. She states that some infants have medical bills totaling one million dollars, and

contends that if better cost control is not achieved, limitations in resources may require explicit ranking of cases based upon cost-benefit assessments.

Recent research on family dynamics related to the birth of severely disabled children concludes that a utilitarian approach to treatment decision-making should be used because of the potentially destructive effects such births can have on families [Simms 1986; Pahl and Quine 1984]. Kuhse and Singer [1987] state that the "principle of equal consideration of the interests of all those affected by a decision" is such a fundamental principle in ethics that it cannot be disregarded. They identify many factors that should be considered when deciding whether to provide treatment, including the interests of the parents and other children in the family. They claim that "the survival of a handicapped child is also the creation of a handicapped family." Lister [1986], in a straightforward argument for a utilitarian approach to decision-making, states that physicians must always consider the social costs involved in maintaining an infant's life. Although he would prohibit the interests of the child's family from overriding the infant's interests, he states that an infant "should only be treated if the costs are within established societal limits."

A strict utilitarian approach to treatment decision-making could require a decision not to begin treatment if (1) the net pain and suffering of the child's life would not be offset by the potential for positive human experience; (2) the net pain and suffering of others (parents and other family members) exceeded the benefits of treatment for the newborn; (3) more lives could be saved by using limited medical resources in a different and more efficient manner—for example, a utilitarian argument could be made to justify using the million dollars for saving the life of one catastrophically ill newborn to fund preventive medical strategies in prenatal care to save many lives; and (4) decisions to terminate treatment could be made as well as decisions not to begin treatment.

Many critics of utilitarian-based treatment decision-making, or any other selection process that could result in selective nontreatment of infants, argue that we must adhere to a deontological principle of sanctity of life. Although many would argue that sanctity of life standards are vague and therefore of little use in guiding decision-making [Annas 1989], general principles are discernible. Sanctity of life advocates embrace a deontological or duty-based ethic. Sanctity of life means literally that human life has intrinsic absolute value [Lyon 1985], and therefore must be viewed as its own end with transcending value. One has a duty, therefore, to value all human life equally, regardless of one's opinions of the relative worth or utility of a particular life. For sanctity of life advocates, all human life, regardless of its objective or subjective quality, must be considered as having transcendental value, requiring sustaining effort from all involved. The most obligatory, or deontologically

pure, form of the sanctity of life position is often referred to as "vitalism." Paris [1982] illustrates this position when he states that "life is the ultimate value . . . to be preserved regardless of prognosis, regardless of costs, and regardless of social considerations."

An Alternative Ethical Paradigm Based on Best Interests

In our pluralistic society, with its colliding and evolving cultural perspectives, and with the intellectual *rencontre* that is the hallmark and strength of a free society, the debate continues regarding the appropriate guiding ethical principles of treatment decision-making for catastrophically ill newborns with developmental disabilities. There is no consensus regarding appropriate guiding principles; in any case, a consensus would not prove validity.

Recent literature does suggest, however, that there are two principles that although not always clearly developed or delineated, do serve as guiding principles for many professionals with treatment and case management responsibilities for seriously ill newborns [Fleischman 1988; Kuhse and Singer 1989; Walters 1988; Singer and Kuhse 1988; Kinlaw 1990]. These principles are "quality of life" and "social transcendence." The quality of life principle can be described as the need to assess and consider the future quality of a person's life as an important variable in deciding whether to intervene to prolong life [Caplan and Cohen 1987; Brennan 1986]. A quality of life perspective assumes that some life situations can be worse than death, and in such situations, it may be unethical to support or prolong life [Caplan and Cohen 1987]. The principle of social transcendence can be defined as the requirement that decisions not be based upon the potential relative social utility of a person's life. It requires that treatment not be withheld on the basis of assessments of a child's future potential to contribute to society or upon the priorities of social utility. Individual treatment decisions should transcend considerations of social utility. Quality of life and social transcendence are concordant with the intent of the historical child welfare principle of best interests of the child.

In recent years, many health care, social service, and bioethical organizations have begun to identify and delineate these principles as appropriate decision-making criteria. The Bioethics Committee of the Canadian Paediatric Society [1986] states that both quality of life (referred to as the best interests of the child) and social transcendence principles should be used in treatment decision-making. The society states that careful consideration must be given to all potential outcomes of both treatment and nontreatment, and defines best interests of the child as the sum of the potential benefit minus the harm that can be derived from potential treatment. Adherence to social transcendence is

apparent in their statement that no outside interest of parents, family, or other care providers can override the interests of the child or be considered a reason to withhold treatment. For example, they suggest analgesics be used to control severe pain in severely ill infants, even if they hasten death, and even when contrary to the parents' requests.

For the Infant Bioethical Review Committee of the Albert Einstein College of Medicine, the overriding principle is that care should be provided that is "reasonably thought to be in the infant's best interests" [Fleischman 1986]. The principles indicate that parents have the right and responsibility to make the decision in most cases, but they cannot be allowed to choose an action contrary to the infant's best interests. These guidelines indicate that a determination of the child's best interests should be the sum of the benefit minus the harm of any treatment considered. The guidelines also indicate that treatment should be withheld or withdrawn if it imposes a burden without compensating benefits for the infant.

A report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Deciding to Forego Life-Sustaining Treatment," presented specific recommendations and conclusions regarding how decisions should be made and who should make them [President's Commission 1983]. The commission established the infant's best interests as the criterion for treatment decision-making. Although the words "quality of life" do not appear in the recommendations, the commission's position on treatment is clearly concordant with a general quality of life criterion [Ross et al. 1986]. The commission report appears equivocal on social utility as a medical decision-making criterion. While it strongly affirms the developmentally disabled infant's best interests as the appropriate standard for treatment decisions, other sections of this same report suggest that social decisions regarding limited availability of treatment may supersede patients' autonomous choice for vigorous treatment [Ross et al. 1986].

In December 1987, the Hastings Center undertook a comprehensive effort to articulate a decision-making criterion based upon principles of quality of life and social transcendence. The center sought to determine whether a broader consensus regarding the ethics of neonatal care existed than was apparent from public debate. After assembling a group of "knowledgeable participants" to "grapple with the controversy of existing ethical paradigms," they concluded that "a child-centered best interest standard" was most appropriate, and that quality of life judgments were ethically proper and in a practical sense, inevitable. The report asserted that quality of life should not refer to the social worth of a person's existence as determined by a utilitarian criterion—"measured by balancing the burdens and benefits to others, especially to family members."

Rather, quality of life referred to "the present and future characteristics of the infant, judged by standards of the infant's own well-being and not in terms of social utility." Further, the center indicated that a consensus existed to equate quality of life with the best interests standard, and concluded that this standard should be used to determine if continued life would be in the infant's best interests; that certain states of life, marked by severe and intractable pain and suffering, can be viewed as worse than death; and that an infant's best interest could possibly lie in withholding or withdrawing medical treatments, resulting in death [Caplan and Cohen 1987].

This author suggests that although there continues to be considerable contention regarding the appropriate guiding principles for decision-making and considerable opposition among various groups to one or both of the principles of quality of life and social transcendence, these basic principles should be considered in the formulation of a guiding ethical paradigm for child protective service workers and agencies with the responsibility to police treatment decision-making for catastrophically ill newborns.

Vicarious Egoism

If the child welfare profession adopts standards for case investigation of catastrophically ill newborns based upon the combined principles of social transcendence and quality of life, neither a utilitarian nor a deontological paradigm would be appropriate. Utilitarianism is based upon social utility, a concept that social transcendence repudiates. And a deontological paradigm would not consider the concept of quality of life an appropriate value base. Instead of either of these paradigms, a philosophical paradigm based upon the principle of ethical egoism would appear more appropriate.

Ethical egoism is one of the oldest ethical traditions. Its roots lie in Greek philosophy's earliest attempts to describe human motivation and behavior. Its fundamental proposition is that all human motivation and behavior are derivations of calculated efforts to achieve satisfaction and contentment and to avoid pain. This elegantly simple moral philosophy is often assailed for its fundamental reliance upon self-interest as the basis for human conduct. Many biologists, sociologists, and anthropologists, however, tell us that the most complicated altruistic behavior and the most exalted moral motivation can be traced to the collective attempts of individuals within a social milieu to achieve their individual and shared self-interests. In any case, regardless of the validity of ethical egoism as a moral paradigm for general humanity, it is an imminently attractive alternative for the catastrophically ill neonate. These infants are born into a world of competing interests, with no power, little means of communica-

tion, and compelling needs; their existential situation demands that we develop consistent and just criteria to champion their best interests.

To apply an egoistic ethical paradigm to a situation in which a person is incompetent, such as in the case of a catastrophically ill newborn, the guiding ethical paradigm would have to be applied by either a competent person, a group of persons, or an advocacy agency charged with the responsibility of acting in the child's best interests. A paradigm of ethical egoism, when applied with vicarious consideration of a catastrophically ill neonate's present condition and future possibilities, would provide a basis for determining whether treat or no-treat decisions were in a child's best interests, and would require that treatment decisions be made utilizing the guiding principles of quality of life and social transcendence.

Case examples can help us to compare and contrast the potential outcomes of treat/no-treat decisions using utilitarian, deontological, and vicarious egoism paradigms to guide decision-making. The following are actual cases of neonates referred to infant care ethics committees for guidance in treatment decision-making.

Case # 1: Bobby

Bobby is nine months old. Born to a drug-addicted mother, Bobby was two months' premature, of low birth weight, and showed evidence of drug toxicity. He remained in the hospital's intensive neonatal care unit for several weeks; ventilation was required to assist his breathing. As a result, Bobby's lungs were badly scarred and he developed a condition called bronchopulmonary dysplasia. He now needs the ventilator for an indefinite amount of time, perhaps permanently, at a cost of \$3,000 per day.

Bobby's mother abandoned him in the hospital shortly after he was born. His father is unknown. Bobby was placed in a specialized foster home when he was released from the hospital.

Bobby is restricted to his crib. His physical development is delayed, as he is essentially bedridden because of his dependence upon the ventilator. He appears to be socially and emotionally responsive, smiling and responding to conversation and social contact. He has not learned to vocalize, as the throat tube of the ventilator has prevented development of verbal expression.

Without treatment, Bobby would die within hours. With treatment, Bobby's life can be prolonged indefinitely, although lung disease could be reasonably expected to cause death in the first two decades. Although Bobby is not in pain, he will probably remain bedridden

and on the respirator throughout his life, and he will need continuous nursing care. Although his social and cognitive development are delayed due to environmental deprivation, a normal potential probably exists. There is no locatable family.

If the treat/no-treat decision were made based upon the deontological ethic of sanctity of life, the decision would certainly be to continue treatment. A decision based on a utilitarian ethic would be questionable. Considering the net benefit to everyone concerned, a utilitarian ethic could advocate the discontinuance of treatment based on the cost alone. The cost of ventilator treatment at \$3,000 a day totals over one million dollars a year. If Bobby lives an expected 20 years, the total cost to society would be in excess of \$20 million. Utilitarian ethics would consider that this money could, in a limited resource economy, potentially be used instead to save the lives of many other children for whom there is a better prognosis for a happy and successful life. Since Bobby has no family, family foster care or residential care would be an additional cost to the state.

Vicarious egoists would almost certainly advocate that continued treatment would be in Bobby's best interests. He is in no pain, he is alert, socially involved, and expected to be cognitively normal. He has the capacity to experience pleasure, to be cognitively productive, and to derive enjoyment and meaning from life.

Case 2: Baby Bill

Baby Bill, a newborn, was born four weeks postmature. He has been diagnosed as anencephalic, a condition in which significant portions of the brain, including the cerebral cortex, have not developed. Baby Bill responds to stimulation in a gross manner. His medical condition is stable. He has many reflexes, including a partial sucking reflex. No other organ deficiencies were noted. His level of comfort or pain is difficult to determine, but he appears to be in considerable distress. He is an otherwise healthy baby.

Without treatment, Baby Bill will die within a week, due to his inability to eat. With extensive intervention, including continuous life support and hyperalimentation, Baby Bill's life could be maintained for several years. He would remain profoundly mentally retarded and physically disabled, and would be expected to have no social interaction and a life of considerable discomfort.

Baby Bill was born to an indigent 32-year-old psychotic woman. She is unable to make an informed decision.

Most deontologists would probably choose to treat: sanctity of life is often operationalized as "life is sacred, no matter what, even for a moment, and all things should be done at all times to preserve it." An alternative sanctity of life interpretation, however, is that the sacredness of life means life should be beyond the humanistic meddlings of overintrusive science. Preventing the natural course of life and death through the artificial interference of excessive and extraordinary medical treatment could be interpreted as inappropriate within a deontological ethic. In this case, this could mean withholding heroic treatment and allowing the child to die a natural death.

Utilitarians, by contrast, might advocate treatment to maintain the child's life for the purposes of research. This could enable scientists to better understand the principles of brain development and to determine the causes of anencephaly, which in the long run might lead to prevention of the same condition in other infants. The infant could also be kept alive to harvest his other vital organs for transplant, which could, in effect, save the lives of infants whose lives are at risk because of organ failure. These benefits would have to be balanced against the costs of maintaining the child's life. There are no countervailing family interests.

Vicarious egoists would advocate not to treat. It would not be in this child's best interests to prolong life when the infant has no possibility of any positive cognitive or emotional experience of life, when pain is his only awareness, and when the extraordinary medical interventions necessary to maintain life or research activities would potentially be experienced as additionally painful.

Case # 3: Katie

Katie has just turned three years old. She has been hospitalized for six weeks. She has AIDS and is in the terminal stages of the illness. She weighs 18 pounds and is extremely ill with a host of infections, including pneumonia. She shows increasing signs of cerebral neuropathy, and is in extreme and continuous discomfort. Katie has no chance of recovery. If antibiotic therapy is not increased, Katie will die within hours. With more heroic intervention, including drugs increased to the level of effective relief of pain, Katie could live for several weeks, but with increasing discomfort.

Katie is in the custody of a child welfare agency and in family foster care. Her mother died of AIDS last year. Her father, a recovering alcoholic, has recently expressed the desire to reestablish custody of Katie. Based upon his religious beliefs, he is advocating continued heroic treatment and threatens a lawsuit if treatment is not forthcoming. Katie's father says his religious beliefs require that every effort

be made to maintain Katie's life, regardless of the consequences for her, him, or anyone else, because "It's the right thing to do."

Katie's father's guiding ethical perspective appears to be deontological. He is advocating heroic treatment irrespective of the consequences.

A utilitarian approach would weigh everyone's interest. If Katie's physical pain and suffering could be relieved with pharmacological intervention, then a decision to treat could be made in the interests of Katie's father's religious beliefs and emotional well-being. If Katie's suffering could not be alleviated, or if the high cost of continued treatment could not be justified given scarce resources and the almost certain lack of efficacy of such treatment, then treatment would be discontinued.

Vicarious egoism would consider only Katie's best interest. If there were no hope of recovery and no good means of alleviating Katie's suffering, treatment would be discontinued. If Katie's suffering and pain could be controlled, and if there was some slight chance of arresting the disease, treatment would be continued.

Conclusion

The above case examples illustrate the complex issues in treatment decision-making for catastrophically ill newborns and young children. They are meant to illustrate the differences associated with using various ethical paradigms to guide decision-making. Others may arrive at different case decisions even within the same ethical paradigm. It is this author's contention, however, that more consistent and just bioethical treatment decisions will be forthcoming if the child welfare profession adopts vicarious egoism as a guide.

Treat/no-treat decisions for catastrophically ill neonates are being made inconsistently throughout this country, depending upon whether a utilitarian, deontological, or some other poorly defined or personal criterion is used. Decision makers frequently do not consciously select an agreed-upon and consistent paradigm to guide their decisions. Many decision makers are not trained in or lack knowledge of principles of ethical decision-making. The criteria they use are often subjective. Many of those making decisions consider principles of quality of life and social transcendence only tangentially, if at all. As a result, treatment decisions for children with similar conditions and in comparable circumstances vary widely.

The Child Abuse Amendments of 1985 require states to assign their state child welfare systems the responsibility to assure that treatment decisions for catastrophically ill newborns do not result in abuse or neglect. As with any

other case of potential child abuse or neglect, it is the responsibility of the child welfare system to investigate reports or allegations of abuse and neglect. Few investigations have taken place. The reasons for this lack of activity are many and complex: (1) child welfare responsibilities are perceived to overlap with the responsibilities of others; (2) the treatment decisions are medically difficult; and (3) there are no clear decision-making criteria.

In this shadowy arena of converging responsibilities and feelings, of questionable prognoses and questionable treatment efficacies, and of uncertain personal and professional ethical guidelines, social workers cannot help but be hesitant and unsure if called upon to provide protective services for catastrophically ill newborns. Although the government has assigned them the responsibility to police life and death bioethical decisions, it has not provided a consensus bioethical paradigm to guide their actions. If we are to achieve consistency and justice in moral decision-making for catastrophically ill newborns, the child welfare system must be given a consensus-guiding ethical paradigm. The two most often championed ethical systems, the utilitarian and the deontological ethical paradigms, are potentially incompatible with the guiding principles of best interests of the child. The author would recommend the integrated principles of social transcendence and quality of life. If such standards are used, an egoist ethical paradigm applied with a vicarious consideration of the neonate's present condition and future possibilities can produce case management decisions in the child's best interests. ◆

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