

JOHN J. PARIS, MICHAEL D. SCHREIBER, and MICHAEL P. MORELAND

PARENTAL REFUSAL OF MEDICAL TREATMENT FOR A NEWBORN

ABSTRACT: When there is a conflict between parents and the physician over appropriate care due to an infant whose decision prevails? What standard, if any, should guide such decisions? This article traces the varying standards articulated over the past three decades from the proposal in Duff and Campbell's 1973 essay that these decisions are best left to the parents to the Baby Doe Regs of the 1980s which required every life that could be salvaged be continued. We conclude with support for the policy articulated in the 2007 guidelines of the American Academy of Pediatrics on non-intervention or withdrawal of intensive care for high-risk newborns

KEY WORDS: "Baby Doe" regulations, decision making, newborns, medically feasible, parental refusal, withdraw medical treatment, withhold medical treatment

INTRODUCTION

In a commentary on a recent Texas Supreme Court ruling on resuscitation of a very early gestational age newborn over parental objections George Annas observed, "One bioethical issue is as intractable today as it was 30 years ago, when it began to be publicly discussed: the extent of parental authority to refuse life-sustaining medical treatment for an extremely premature infant."¹ When there is a conflict between the parents and the physician over the appropriate care due to an infant whose decision prevails? What standard, if any, should guide such decisions?

EARLY CASES ON DECISION MAKING FOR INFANTS

The first of these issues to come to public attention is the now infamous 1963 Johns Hopkins' case² in which a child born with Down syndrome and duodenal atresia was left untreated and allowed to starve to death over a two-week period. The parents determined to

forgo the relatively easy corrective surgery because the child would be “a financial and emotional burden on the rest of the family.” The doctors at Hopkins accepted the parents’ decision. In the words of the treating physician, “In a situation in which the child has a known, serious abnormality ... I think it unlikely that a court would sustain an order to operate on the child against the parents’ wishes.” In fact, as the studies by Shaw et al.³ and Todres et al.⁴ demonstrate, an overwhelming majority of pediatricians and pediatric surgeons in the United States surveyed in 1977 agreed that in a case similar to that in the Johns Hopkins Hospital they would abide by a parental decision to omit surgery.

One of the first challenges to that approach was *Maine Medical Center v. Houle*,⁵ a 1974 case that involved a profoundly compromised newborn whose family and physician decided to forgo medical treatment. Other physicians in the hospital objected and the case was brought to court. Maine Superior Court Judge David Roberts began his analysis by stating, “The most basic right enjoyed by every human being is the right to life itself.” In his view, the issue before the court was the medical feasibility of the proposed treatment compared with the almost certain risk of death should surgical intervention be withheld. Judge Roberts ruled that regardless of the quality of life of the infant, if there was a medical need and a medically feasible response was available, it must be performed. The surgery was done, but the child died soon thereafter.

That stark “life-at-all-cost” stance occasioned a scathing criticism in a 1974 *JAMA* article by Richard McCormick entitled “To Save or Let Die.”⁶ McCormick noted there was no moral obligation to impose treatment on a patient who was dying or who was totally dependent on intensive measures to sustain life, nor was there an obligation to do so for a patient whose potential for relationships is nonexistent. That article, which was the first to attempt to establish practical norms or guidelines for seriously compromised newborns, has been quoted with approval by nearly every group that has subsequently tried to design standards for such decisions.

An even more frequently cited article published by Duff and Campbell⁷ a year earlier in *The New England Journal of Medicine* was the first to bring the topic of ethical dilemmas in the newborn nursery to the public’s attention. In their essay the authors revealed that decisions were regularly being made in major neonatal intensive care units to forgo treatment and let infants die. They reported that of 299 deaths in the special care nursery of the Yale-New Haven Hospital

between 1970 and 1972, 43 (14%) were associated with discontinuance of treatment. In cases of children born with multiple abnormalities, trisomy, cardiopulmonary crippling, or central nervous system disorders, no further treatment was provided if the parents and physicians concluded that the prognosis for “meaningful life” was extremely poor. In Duff and Campbell’s view the decision to withhold or withdraw treatment belonged to those who bore the responsibility for the consequences of treatment—the families.

In a subsequent essay Paris and McCormick had occasion to critique the Duff and Campbell position as “normless.”⁸ It provided no guidelines, no standards, no norms on which to base a decision to withhold or withdraw treatment. Under their schema a decision could equally be made on a concern for “family convenience” as on the best interests of the infant. What that approach failed to realize is that even good and caring parents—acting out of fear, ignorance, or a misreading of the clinical situation—can make decisions antithetical to the child’s interests.

Physicians, as illustrated in the well-known *Stinson* case, chronicled in Robert and Peggy Stinson’s *The Long Dying of Baby Andrew*,⁹ can also err in their judgments on the value of medical intervention for a seriously compromised newborn. The Stinson’s son, Andrew, was delivered 4 months prematurely as a “marginally viable” 800-g newborn. In the early 1980s, infants in his category had a survival rate of less than 5%. Recognizing that fact, his parents told the pediatrician not to attempt any “heroics.” The doctors at Community Hospital promised that they would follow their wishes.

The Stinsons kept a journal which reflected their initial joy at the baby’s successful delivery and their fear that he might he maintained “by science-fiction means in a state of pain or hopeless deterioration.” That fear was realized when Andrew developed problems in fluid adjustment and was transferred to a well-known pediatric hospital center (now acknowledged to be the Children’s Hospital of Philadelphia). There the commitment to care provided at Community Hospital was transformed into a “no stops, no exit, no appeal” stance. The family was informed that “[a] baby must be saved at all costs: anything less is illegal and immoral.”

When the parents asked the doctors not to use a ventilator, they were castigated for violating the sacredness of life and seeking a “return to the law of the jungle.” Brain death was the only criterion the doctors would recognize as a legitimate basis for stopping treatment. With such a standard, the parents helplessly stood by as the

doctors treated their child for brain hemorrhage, respiratory failure, necrosis of the right leg, gangrene, rickets, multiple bone fractures, retrolental fibroplasia, blindness, and finally pulmonary hypertension—a terminal disease occasioned by the ventilator. Through all of this, there was no hint of a willingness to accede to the parents' repeated requests to allow Andrew to die a natural death. Only when he accidentally pulled out his endotracheal tube and began breathing on his own did doctors allow "nontreatment"—that is, an inadequate oxygen supply—to bring Andrew's life to a close.

"BABY DOE" REGULATIONS

The attitude of the physicians in the *Stinson* case briefly became the standard of care for infants in what is now known as the "*Baby Doe*" regulations. Those federal regulations rose from the Reagan administration's disapproval of nontreatment in the *Bloomington Baby Doe* case.¹⁰ There an infant with Down syndrome and a tracheoesophageal fistula was allowed to die untreated when the attending obstetrician recommended, and the family agreed, to no surgical intervention. Although three courts, including the Indiana Supreme Court, upheld the parental decision, the subsequent public outcry led to federal involvement. Under the original regulations issued by the Department of Health and Human Services, physicians were required to provide life-sustaining medical interventions to every infant indifferent to the child's medical status or prognosis. As a highly critical editorial in *The New England Journal of Medicine* put it: "The Regulations are based on the premise that *all* life, no matter how miserable, should be maintained if technically possible."¹¹

Those regulations were struck down on administrative law grounds by the Supreme Court.¹² Their legacy, however, continues in the 1984 amendments to the Child Abuse Prevention and Treatment Act,¹³ the so-called "Baby Doe Regs," which mandate that state child protective agencies, as a condition for receiving federal funding, must have procedures in place for oversight of medical neglect. Despite the fact, as Alan Fleischman¹⁴ correctly observes, "[t]hese regulations ... do not mandate unnecessary or inappropriate treatments," more than one third of the neonatologist in a 1988 national survey stated that because of the Baby Doe regulations they provided medical interventions for seriously compromised infants that in their judgment were not medically indicated.¹⁵ In fact, the regulations not only

allow, but positively direct physicians to make treatment recommendations to the parents base on "reasonable medical judgment." But as the Committee on Bioethics of the American Academy of Pediatrics observed in 1996, "[M]any think that laws, regulations, and government policies have unduly constrained parents and physicians from exercising reasonable judgments about whether to forgo life-sustaining treatment."¹⁶

LINARES AND MESSENGER

The scope of those standards was tested in the late 1980s and 1990s in the *Linares*¹⁷ and *Messenger*¹⁸ cases, each a highly dramatic case in which a father was charged with homicide for turning off a ventilator used to sustain the life of his infant son. In the first case, Sammy Linares, a 1-year-old child who suffered massive anoxic damage when he ingested a balloon at a birthday party, was diagnosed as being in a persistent vegetative condition. Both the father and the treating physician agreed that given the child's physical status, it would be medically and morally appropriate to remove the respiratory support. The hospital attorney, however, informed the physician that "while Illinois law permits hospitals to withdraw life-support mechanisms from patients who have no brain activity, there is no precedent governing those who have minimal brain activity even if they have virtually no prospect of regaining consciousness." The attorney told the parents to seek a court order for the removal of the ventilator.

The father, rather than petitioning for a court injunction authorizing the withdrawal, entered the pediatric intensive care unit with a magnum .357, held it to the child's head, and threatened to kill his son if anyone approached. He then removed the infant from the ventilator. After waiting a half hour to be sure the child was dead, the father put down his weapon. The district attorney sought homicide charges. One of us (JJP) wrote an "op-ed" piece for the *Chicago Tribune* on the case entitled "A Desperate Act but Not Murder,"¹⁹ which argued that a patient in a well-diagnosed persistent vegetative state has no obligation to undergo life-sustaining interventions. The father's act, reprehensible though it might be as a way of proceeding in a medical case, was not murder. The grand jury in this case agreed; it refused to return a homicide indictment.

MESSENGER CASE

Homicide charges were likewise brought in a 1996 case against Dr. Gregory Messenger, a dermatologist from Lansing, Michigan, for removing his extremely premature infant son from a ventilator in Sparrow Hospital's neonatal intensive care unit. The newborn infant had been placed on mechanical life support despite the explicit instruction of the parents that they did not want aggressive or resuscitative measures used on their 780-g, 25-week gestational-age son.

The mother, who suffered from hypertension, went into pulmonary edema in week 25 of the pregnancy. Maternal complications led to delivery by cesarean section. Prior to delivery the parents had been told by the neonatologist that the child had a 30% to 50% possibility of survival and that if he did survive there was a 20% to 40% chance of severe intraventricular hemorrhage. The parents informed the neonatologist they did not want any extraordinary efforts undertaken, nor did they want any attempts at resuscitation. The neonatologist preferred a "wait and see" approach. She instructed her physician's assistant (PA) that if the child were "vigorous" at delivery and needed ventilatory support, she was to intubate. At birth the infant was hypotonic and hypoxic, purple-blue in color, "floppy," and "appearing lifeless." He did, however, have an umbilical cord pulse of 80 to 90 beats/min. The PA immediately intubated the infant.

The father informed the PA that he and the boy's mother did not want resuscitation. The PA told him that she was not authorized to withdraw treatment. The neonatologist returned to the hospital, saw the infant was pink and stable, and indicated she wanted to try surfactant to see how the child would respond before coming to any decision to remove the ventilator support.

Gregory Messenger asked to be left alone with his son, shut the door to the room and then he turned off the ventilator. Some 10 minutes later the father opened the door and indicated that his newborn son had died. The pathologist found the infant's condition was not terminal. He ruled the cause of death was respiratory failure due to the removal of ventilatory support. The district attorney claimed that the father had failed to provide proper medical treatment for his son and charged him with manslaughter.

One of us (JJP) testified at the trial that the focus in this case, as in all treatment decisions, must be centered on the patient. It is the patient's condition and the patient's desires—not the goals of the

physician—that ought to govern these treatment decisions. The issue here was how to discern what the infant patient would want. Although some, such as the Massachusetts Supreme Judicial Court, believe that through a process of “substituted judgment”²⁰ we can discern the mind of the never competent, including newborn infants,²¹ most commentators believe this admitted “legal fiction”²² is so farfetched as to be judicial fantasy.²³

The consensus in the literature seems to be that for the infants the “best interests” standard is the one that should be used. The question is: did the information given to the parents warrant a predelivery decision to withhold resuscitation and other aggressive medical interventions? Or, as the neonatologist wanted, must the parents authorize resuscitation and the use of aggressive life-sustaining measures until it becomes clear, if not certain, that the child will not survive?²⁴

Under any schema a 50% to 70% risk of mortality and a high risk of significant morbidity puts a newborn into that broad area of gray in which the degree of burden and the prospects of benefit are so suffused in ambiguity and uncertainty that a decision as to whether to continue treatment properly belongs to those who bear responsibility for the infant, in this case the parents.²⁵ That stance, as the Hastings Center Project on “Imperiled Newborns” notes, is contrary to the current practice in the United States where we respond to uncertain outcome in neonatal medicine by giving “a chance” to every infant who is even potentially viable.²⁶ Active treatment is then continued until it is nearly certain that the particular baby will either die or be so severely impaired that, under any substantive standard, parents could legitimately opt for termination of treatment.

That “wait and see” approach is appropriate when we face complete uncertainty, i.e., when decision makers have no knowledge at all about the probabilities of various outcomes. But, as the Hastings Center group put it, “It is not particularly well-suited to moral situations in which there are data on which to base predictions.”²⁷ The Messengers had such data. The jury in the Messenger case believed the data were sufficient to support the parents’ decision not to initiate ventilatory support and—once it had been initiated over their objection—the decision to terminate it. With minimal debate the jury unanimously found Gregory Messenger’s actions neither grossly negligent nor a breach of his legal duty to provide proper medical treatment for his son.

MILLER V. HCA

The apparent consensus that parents have the right to refuse unwanted medical interventions for seriously imperiled infants such as extremely premature newborns, where the risk of mortality and morbidity is significant and the prospects of benefit is suffused in ambiguity and uncertainty, has been challenged by the 2003 Texas Supreme Court's ruling in *Miller v. HCA*.²⁸ There the Texas Supreme Court carved out an "emergent [sic] circumstances" exception to the need for parental consent to treat an infant "so premature that despite advancements in neonatal care has a largely uncertain prognosis." This was the first court in the nation to authorize physician resuscitation of an extremely premature infant over parental objections.

The case arose when Kara Miller arrived at Woman's Hospital of Texas in premature labor. The ultrasound assessment was an estimated fetal weight of 629 g and a gestational age of 23 weeks. Tocolytics were administered to stop the labor, but were discontinued when it was learned that the mother had a life threatening infection. Labor inducing drugs were then begun. The attending obstetrician and a hospital neonatologist informed the parents that there was little chance of the infant being delivered alive. They also informed the parents that if the child were born alive, "it would most probably suffer severe impairments, including cerebral palsy, brain hemorrhaging, blindness, lung disease, pulmonary infections, and mental retardation."

With that background, the obstetrician and neonatologist asked the parents whether they wanted their infant daughter treated aggressively if, as anticipated, they would have to induce delivery. The parents informed the doctors that they did not want any attempts at treatment. The parents' decision was recorded in the medical record, and the obstetrician informed the medical staff that no neonatologist would be needed at the delivery.

After the parents' decision had been agreed to, someone on the nursing staff informed other hospital personnel that no neonatologist would be present for the delivery. At a meeting called to discuss objections to that decision, the administrator of the neonatal intensive care unit stated that hospital policy required resuscitation of any baby weighing > 500 g. Once that claim had been made, it was agreed by the staff that a neonatologist would be present at the delivery to assess the baby's age and weight. Kara Miller delivered a 23.1 week

gestational age infant girl weighing 615 g. The infant was immediately “bagged,” intubated, and placed on a ventilator. The Apgar scores were 3 at one minute and 6 at ten minutes. At some point during the first days of life, the infant suffered a significant brain hemorrhage which, in the Court’s words, “caused [her] to suffer severe physical and mental impairments,” such that seven years later she still required care twenty-four hours a day, a condition the court noted is not going to improve.

The Millers sued the hospital and its parent corporation Columbia/HCA Healthcare Corporation (HCA). A jury found that the hospital, without the consent of the parents, had resuscitated their infant. It also found that negligent action was the cause of their daughter’s injuries. The jury awarded actual and punitive damages of \$60 million. The jury verdict was overturned by the Texas Supreme Court.

TEXAS SUPREME COURT OPINION IN *MILLER V. HCA*

The Texas Supreme Court framed the issue posed in *Miller v. HCA* as “determin[ing] the respective roles that parents and health care providers play in deciding whether to treat an infant who is born alive but in distress and is so premature that despite advancements in neonatal care, has a largely uncertain prognosis.” Consent in cases involving markedly premature infants has till now been the prerogative of the parents. The state, acting as *parens patriae*, can and does intervene to protect children from neglect and abuse or to prevent parental choices that would produce such results.²⁹ But as long as parents choose from a professionally accepted option, the choice is rarely challenged or supervised. The Texas Supreme Court acknowledged that parental role, but in this instance the court ruled that when a doctor is confronted in a case where there are “emergent circumstances”—where death of a child is likely to result immediately unless treatment is administered—the physician may intervene even over parental objections.

The Texas court ruled that the infant “could only be properly evaluated when she was born.” Consequently, in the court’s view, “Any decision by the Millers before [the infant’s] birth would necessarily be based on speculation.” Further, the court opined, a pre-delivery decision would “not have been a fully informed one.” As the Texas Supreme Court saw it, the doctor present at the delivery

had to make “a split second decision on whether to provide life-sustaining treatment.” In that situation, it held, “there simply was no time to obtain [the parents’] consent to treatment or to institute legal proceedings to challenge their withholding of consent without jeopardizing [the infant’s] life.”

DISCUSSION

In an article on the *Miller* case John A. Robertson of the University of Texas Law School supported the Texas Supreme Court ruling authorizing physician treatment of newborns over parental objection and extended it to claim that under the federal Child Abuse Amendments (CAA) of 1984 (the “Baby Doe rules”), there is no room for physician discretion regarding resuscitation of infants, even those at the extreme margins of viability.³⁰ In his words, “[o]n their face, the CAA standards leave no room for discretion. All conscious viable premature newborns must be treated, even if they are likely to have severe physical and mental disabilities.”

Robertson would require the resuscitation of all infants indifferent to predelivery assessment of gestational age and weight. For him, as well as the Texas Supreme Court, a nontreatment decision made before birth would be based on “speculation” and thus not legitimate. However, as we noted in an earlier essay, “other than when presented with a stillborn, all decision-making about whether or not to provide potentially life-prolonging interventions for very low-birth weight early gestational age infants is necessarily based on speculation.”³¹

A helpful framework for decision making in these cases is found in an essay by Tyson and colleagues³² on viability of very low birth-weight neonates. Rather than an either/or designation of parent or doctor as the decision maker, the authors propose that the treatment options should be governed by the prospects for the individual infant. To make that assessment, the authors divide treatment decisions for newborns into four categories: mandatory, optional, investigational, and unreasonable. The classifications are explained as follows.

Mandatory—If the parents ask the physician to withhold or withdraw ventilatory support that has a very high likelihood of benefiting a child, the treating physician’s independent obligation to foster the best interests of the patient prohibits following the parents’ request. An example would be parents who ask the physician to remove ventilation from a full term newborn experiencing

respiratory distress unless the physician can guarantee that their child will be “normal.”³³

Optional—When the risks are very high and the benefits are at best uncertain or extremely low, the parents have the option of accepting or rejecting the proposed resuscitation. In this “grey zone” the parents’ decision to either accept or reject ventilatory support should be followed.

Investigational—For resuscitation for babies of very low birth weight, the outcome data are such that, in the words of Lantos *et al.*, “The best we can tell parents is that this intervention is so new or its effects on this class of patients so unproven that it is an ‘innovative’ or ‘experimental’ procedure.”³⁴ Such procedures, as the Nuremberg Code notes, require patient or proxy consent.³⁵

Unreasonable—If the parents are demanding aggressive medical interventions when in the physician’s best judgment there is no expectation of efficacy, e.g., on a child born with renal agenesis or one with Herlitz subtype of junctional epidermolysis bullosa, there is no obligation to provide the treatment. Such an action would be not care, but an abuse of the patient.³⁶

Partridge *et al.*³⁷ remind us, “[i]t is not clear which infants born at the margins of viability should be resuscitated and provided neonatal care.” In the face of that ambiguity, the President’s Commission report, *Deciding to Forego Life-Sustaining Treatment*, tells us that “great discretion is to be afforded to the parents.”³⁸ That position, which is the policy articulated in the 2007 guidelines issued by the American Academy of Pediatrics on non-intervention or withdrawal of intensive care for high-risk newborns,³⁹ holds that it is both legitimate and anticipated that parents will be the ones to make the decision on whether or not to use aggressive interventions for a markedly premature newborn. The substitution of the physician’s values for those of the parents for infants delivered at the extreme margins of viability would be a significant shift from present standards in neonatology. We believe such a change is neither good policy nor good medicine.

NOTES

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Boston College
Chestnut Hill, MA 02167
USA
E-mail: parisj@bc.edu

Department of Pediatrics, Sections of Neonatology and Pediatric
Critical Care
University of Chicago
Chicago, IL
USA

Villanova University School of Law
Villanova, PA 19085
USA