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LEGAL ISSUES IN MEDICINE

Extremely Preterm Birth and Parental Authority to Refuse Treatment — The Case of Sidney Miller

George J. Annas, J.D., M.P.H.

Disputes between physicians and patients over medical care have tended toward resolution in both the courts and ethics committees, with each of these bodies ultimately deciding that the informed, competent patient must be the final decision maker. Parents, too, have the authority to make medical decisions for their children, but these decisions can be challenged if physicians do not believe they are medically reasonable. One bioethical issue, however, 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. Who decides for the newborn, and on what basis, when there is conflict between the parents and the physician? In his 1984 book on this topic, Robert Weir put it simply and accurately: “Without doubt, decision making is difficult in cases involving birth-defective newborns.”¹ This remains true today, with virtually no change in either the substantive criteria to apply to the decision or the procedures to follow, and decision making is even more complex with extremely preterm infants.

Advances in neonatology have far outpaced decision-making practices in the neonatal intensive care unit (NICU), a situation well illustrated in *Miller v. HCA*.² This case, which was decided in the fall of 2003 by the Supreme Court of Texas, involved the 1990 treatment of Sidney Miller, an extremely premature neonate, at Women’s Hospital of Texas in Houston. Even though the birth at issue took place more than 13 years ago, nothing has changed in the practice of neonatal medicine since then that would prevent repetition today. The facts of the case, as described here, are taken from the court’s opinion.

THE BIRTH OF SIDNEY MILLER

Karla Miller, the mother of the infant Sidney, went into premature labor at approximately 23 weeks of

gestation. On ultrasonography, her fetus was found to weigh about 629 g, and attempts were made to stop labor by using drugs. Subsequently, an infection developed that Miller’s medical team thought could endanger her life if delivery were further postponed. Her obstetrician, Dr. Mark Jacobs, and a neonatologist, Dr. Donald Kelley, informed her and her husband, Mark Miller, that the fetus had little chance of being born alive and that if it did survive, it would probably suffer severe impairments, including brain hemorrhage, blindness, lung disease, and mental retardation. Mark Miller later testified that the physicians also told him that they had “never had such a premature infant live and that anything they did to sustain the infant’s life would be guesswork.”²

Jacobs and Kelley then asked the Millers to decide whether or not the infant should be treated at birth. The Millers told the physicians that they wanted no heroic measures performed. Kelley recorded this decision in the medical record of Karla Miller, and Jacobs informed the medical staff of the hospital that no neonatologist would be needed at the delivery. Mark Miller then left the hospital to make funeral arrangements.

While Miller was away, the nursing staff informed other medical personnel about the instruction not to have a neonatologist present at the birth. Meetings were held with various hospital administrators and physicians, who then met with Miller on his return to the hospital. Miller later testified that a hospital administrator in charge of the neonatal intensive care unit, Anna Summerfield, told him that the hospital had a policy that required the resuscitation of any baby who was born weighing more than 500 g. Jacobs recalls the decision then made in this way:

What we finally decided that everyone wanted to do was not to make the call prior to the time we actually saw the baby. Deliver the baby, be-

cause you see there was this [question,] is the baby really 23 weeks, or is the baby further along, how big is the baby, what are we dealing with. We decided to let the neonatologist make the call by looking directly at the baby at birth.²

The neonatologist who attended the birth, Dr. Eduardo Otero, was not at the meeting, but he agreed with Jacobs that he would have to see the newborn to decide what treatment, if any, was appropriate. Mark Miller testified that, after the meeting, the hospital administrators asked him to sign a consent form that would allow resuscitation, but he refused. When he asked the administrators how he could prevent resuscitation, he was told that he would have to remove his wife from the hospital.

Later that evening, Karla Miller's condition worsened, and it was determined that labor should be augmented (rather than stopped as it had been) before further complications developed. When Sidney was born, she weighed 615 g and had a heartbeat. Otero noted that she gasped for air, cried spontaneously, and had no unusual dysmorphic features. Accordingly, he immediately manually ventilated and intubated her and placed her on a ventilator. He did this, in his words,

because this baby is alive and this is a baby that has a reasonable chance of living. And again, this is a baby that is not necessarily going to have problems later on. There are babies that survive at this gestational age — with this weight — that later on go on and do well.²

THE LAWSUIT

Neither parent objected to the treatment of Sidney after her birth, and therefore, decision making in the NICU was not explored at trial. Sidney seemed to do well at first — the score on her Apgar test, which, on a scale of 1 to 10, reflects the condition of a newborn immediately after birth, improved from a 3 at one minute to a 6 at five minutes — but a few days later, she suffered a brain hemorrhage that caused severe physical and mental impairment. At the time of the trial, she was seven years old and “could not walk, talk, feed herself, or sit up on her own . . . [.] was legally blind, suffered from severe mental retardation, cerebral palsy, seizures, and spastic quadriplegia in her limbs . . . [.] could not be toilet-trained, required a shunt in her

brain to drain fluids, and needed care twenty-four hours a day.”² No improvement in her condition was expected.

The parents did not sue any of the physicians involved but, instead, sued the hospital and its parent company, HCA, for battery and negligence. Mark Miller explained to the press that he did not blame the physicians, because he and his wife “thought the doctors just did what they were told” to do by hospital officials.³

The physicians were involved in the trial because the lawsuit alleged that they acted as the agents of the hospital, and so the hospital was legally responsible for their actions. The jury concluded that the resuscitation had been performed without consent and that the negligence of the hospital and HCA “proximately caused the occurrence in question.” Moreover, the jury concluded that both HCA and the hospital were grossly negligent, that the hospital itself acted with malice, and that Otero was the hospital's agent in the resuscitation of Sidney. The jury awarded the Millers \$29,400,000 for medical expenses, \$17,503,066 in interest on these expenses, and \$13,500,000 in punitive damages.³

THE APPEAL

The Texas Court of Appeals reversed the jury verdict and ordered that the Millers get nothing.⁴ The court reasoned that, in Texas, parents could withhold medical treatment from a child only after the child's medical condition had been certified as “terminal” under the Texas Natural Death Act. The appeals court also noted that a court order is usually required to override a parental refusal of treatment, but it ruled that if the need for treatment by a child who is not terminally ill is urgent, a court order is unnecessary. The court thus agreed with HCA that it owed no duty to the Millers to refrain from resuscitating Sidney or to have a policy prohibiting resuscitation of patients like Sidney without parental consent. A dissenting judge believed that the Texas Natural Death Act was not applicable, that a court order was required to overcome parental refusal of treatment, and that a reviewing court would have to determine which action was in the best interests of the child.⁴

THE TEXAS SUPREME COURT

The Texas Supreme Court summarized the case precisely as requiring it “to determine the respective

roles that parents and healthcare 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 intensive care, [he or she] has a largely uncertain prognosis.”² This was the first time a case that raised this question had come to the Texas Supreme Court, and the court began by summarizing existing law: “Generally speaking, the custody, care, and nurture of an infant resides in the first instance with the parents.”² This includes, the court stated, the presumption that the parents have the right to consent to their infant’s medical treatment as well as to refuse such treatment. The real question relates to the limits of the parents’ right to refuse. In this regard, the court noted that the state punishes parents only for what amounts to child abuse or child neglect and that “as long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court.”² In other words, in the absence of child neglect, parents have the right to give or withhold consent for medical treatment for their children.

The ultimate question the court confronted was this: Is there an emergency exception to this general rule that permits physicians to treat neonates without parental consent? The court relied exclusively on dicta from a 1920 case that involved a tonsillectomy in a child, to which an older sister had consented. The child died as a result of the anesthesia, and the father sued the surgeon for failure to obtain his consent for the surgery.⁵ In that case the court determined that parental consent was legally required, because although “there was an absolute necessity for a prompt operation,” the situation was “not emergent in the sense that death would likely result immediately upon failure to perform it.”⁵ The 1920 case, according to the court, “implicitly acknowledges” that a physician may perform an operation “under emergent circumstances — i.e., when death is likely to result immediately upon failure to perform it.”² In its application of the reasoning of this pre-NICU case to *Miller v. HCA*, the court ruled, “We hold that a physician, who is confronted with emergent circumstances and provides life-sustaining treatment to a minor child, is not liable for first obtaining consent from the parents.”²

This is a reasonable rule when parents are not available for consultation and consent, but what if the parents are present and refuse? The court concludes that parental presence (and refusal to give consent) simply does not matter in extreme cases,

because the exception that allows treatment in emergency circumstances is not based on the concept of implied consent. The physician is privileged by law to treat in emergency circumstances because he or she is trying to prevent a harm (death) that outweighs any harm from treatment. Other courts have ruled that consent is “implied” in emergencies; however, the Texas court correctly saw this formulation as wrong (no one implies anything simply by having a medical emergency, and if this were the correct rule, contemporaneous explicit refusal of treatment by the Millers would have to have been honored).

The court’s conclusion is another way of saying that physicians in emergencies are permitted to err on the side of the preservation of life. But, as this case illustrates, in situations that involve extremely premature neonates, the choice is never so clear-cut. It is not life or death alone, but the chance of survival in a severely disabled condition such as Sidney’s, that makes these decisions so difficult. Nonetheless, after the determination that treatment was necessary to save the child’s life had been reached, the only remaining issue for the court was procedural: Is a physician obligated to seek court approval before he or she proceeds with emergency treatment when the parents object to it?

The Millers contended that there was plenty of time to seek a court order because they had objected to treatment 11 hours before the birth and that physicians should not be permitted to delay a decision in such a case until the situation becomes an emergency. The court agreed that the “physician cannot create emergent circumstances from his or her own delay or inaction and escape liability for proceeding without consent.”² Nonetheless, the court concluded that the circumstances of extreme prematurity were unique because a decision about resuscitation could not reasonably be made before birth. In the court’s words:

The evidence established that Sidney could only be properly evaluated when she was born. Any decision the Millers made before Sidney’s birth concerning her treatment at or after her birth would necessarily be based on speculation. [A decision made before the birth] could not control whether the circumstances facing Dr. Otero were emergent because it would not have been a fully informed one according to the evidence in this case.²

The only remaining question was whether Otero himself was negligent in making the decision to resuscitate Sidney without either parental consent or a court order. The court decided he was not negligent because of the nature of the decision itself: “Dr. Otero had to make a split-second decision and [even though] the Millers were both present in the delivery room, there was simply no time to obtain their consent to treatment or to institute legal proceedings . . . without jeopardizing Sidney’s life.”² Moreover, since the circumstances that required this “split-second decision” resulted from the inability to evaluate Sidney until she was born, not from any delay or inaction on the part of the hospital or physicians, neither the hospital nor the physician could be held responsible for the emergency situation. The court, while stressing that the best practice is to obtain parental consent before birth to make an evaluation and render “warranted medical treatment,” concluded, “We decline to impose liability [for either battery or negligence] on a physician solely for providing life-sustaining treatment under emergent circumstances to a new-born infant without that consent.”²

DECISIONS AT BIRTH

The conclusion of the court — that an informed decision about resuscitating an extremely premature infant can be made only by actually examining the infant at birth — is perfectly reasonable and is in accord with good medical practice. There is no clinical test or objective indicator that can accurately predict outcome (the hospital denied that it had a rule about the resuscitation of infants who weigh at least 500 g, and even if it had such an arbitrary rule, this would have been no substitute for a more comprehensive evaluation of the infant at birth). The court did not have to say more to decide the case in front of it, but more can and probably should be said. Many observers had hoped that this case would help to clarify the legal rules about decision making for extremely premature infants and help physicians and hospitals to develop better procedures for making treatment decisions in this area of great and inherent medical uncertainty.^{3,6} More specific guidelines were probably too much to hope for, and the ultimate court decision was a very narrow one. For example, although the ruling permits a neonatologist to make decisions about resuscitation immediately after birth in the case of extreme prematurity,

nothing in the decision requires the presence of a neonatologist at the delivery.

More troubling, the court implies that life is always preferable to death for a newborn and thus could be interpreted in the future to support the neonatologist who always resuscitates newborns, no matter how premature or how unlikely their survival is without severe disabilities. This interpretation, however, seems problematic, because such a neonatologist is not exercising any medical judgment or making a “split-second” decision. In these circumstances, the decision to attempt resuscitation has been made at a time during which the court believes it cannot reasonably be made: before the birth. All-or-nothing responses, nonetheless, seem to be common in neonatology. As Cole has observed, “In the absence of biologically reliable predictors of outcome, decisions on care for extremely premature infants have historically fallen between the inflexible extremes of mandated nontreatment and mandated full treatment by relying on individual evaluation by parents and physicians.”⁷

Given the inherent uncertainty in outcomes, trials of therapy that can be ended when reasonable clinical goals cannot be achieved seem more consistent with legal principles and good medical practice. More data are unlikely to provide a yes-or-no answer to whether resuscitation should be attempted at birth. In one major prospective study of extremely premature infants, about half of the survivors had substantial disability, with approximately one quarter having severe disability, and no clear predictors of outcome were identified.⁸ The authors concluded, “The prevention or amelioration of disability in survivors of extreme prematurity remains one of the most important challenges in medicine.”⁸ Life is not always preferable to death, as was made clear by the exceptions to the old Baby Doe regulations (which pertained to refusals of treatment for disabled, not premature, newborns) and by the entire series of so-called right-to-die cases.⁹

DECISIONS IN THE NICU

The decision to resuscitate Sidney triggered a new series of decisions about her continued treatment. Although these decisions were not the subject of the lawsuit, the Texas Supreme Court has made it clear that the parents had the legal authority to make all of these subsequent decisions. If the parents disagreed with the physicians about, for example,

whether to continue ventilation, the obligation of the physicians was either to follow the wishes of the parents nonetheless or to seek court authorization to ignore them. It seems unlikely, for instance, that anyone would have questioned the Millers' decision to cease the provision of aggressive care after Sidney had the intracranial bleeding that drastically decreased her chances of living anything but a severely disabled life. Giving parents the right to make treatment decisions for their extremely premature newborns in the NICU not only is consistent with basic legal principles but also accords with good medical practice.⁷ Treatment in the high-technology NICU, however, takes on a life of its own, and although there is no ethical or legal difference between starting and stopping an intervention such as ventilation, stopping it is much more emotionally and psychologically difficult for both parents and physicians. This is just one reason why trials of therapy should be discussed before they are initiated and why such trials should be evaluated at regular intervals to reevaluate the child's condition to see if their therapeutic goals remain reasonable or achievable.

Reasonable people may disagree about what the therapeutic goals should be. Defining a therapeutic goal depends on a combination of the medical prognosis, the family's circumstances, and the quality of life of the child, and no one-size-fits-all legal or medical rule is possible. Even the standard of the best interests of the child raises questions. The phrase "best interests" is often translated into the unhelpful slogan "better off dead" — that is, the infant should be treated aggressively unless all agree that he or she would be better off dead. A standard of benefit or burden would be preferable, but of course such a standard cannot definitively determine difficult cases. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research observed in 1983:

Permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant. Though inevitably somewhat subjective and imprecise in actual application . . . net benefit is absent only if the burdens imposed on the patient by the disability or its treatment would lead a competent decision maker to choose to forgo the treatment.¹⁰

The application of a benefit–burden standard would not have prevented Sidney from being resuscitated in the first place, but it could have led to a more thoughtful examination of the aggressiveness of continued treatment after her cranial hemorrhage. The decision to treat at this point would have remained with the parents.

When I began working in health law and bioethics in 1972, decision making that involved neonates with intracranial bleeding was seen as so difficult, and the outcomes so uncertain, that there could be no substantive rules, just a procedural one. That basic procedural rule was that it is acceptable to withdraw treatment if both the physician and the parents agree. Implementing this rule led to a backlash, which gave rise to the Baby Doe regulations, which were drafted in response to a 1981 case in which parents refused to consent to a surgical repair of a tracheal-esophageal fistula that would have enabled the child to eat. The baby died during the court proceedings. The Baby Doe regulations were based on the assumption (never demonstrated, and almost certainly wrong) that many physicians were terminating treatment because of "quality-of-life" assessments that devalued disability.^{9,11} The standard of the best interests of the child returned to prominence, and child neglect became a relevant factor in treatment decisions for neonates.^{9,12}

When asked about the Miller case, Dr. C. Everett Koop, the former surgeon general of the United States and main promoter of the Baby Doe regulations, was quoted as saying, "I don't think parents should have the discretion to kill their children. I'm a great believer in the slippery slope. You get into the terrible quagmire of having only perfect children, and nobody can guarantee that."⁶ Koop is, of course, correct about guarantees, but it is the very inability of physicians to predict outcomes that leads most commentators to insist that parents, with physicians' input, be the ones to make the ultimate decisions about treatment for their children, at least when there exists a range of reasonable medical options, including termination of treatment.^{1,7} In addition, although the court did not deal with the issue, many of the interventions in the NICU, including resuscitation, can reasonably be classified as experimental.¹³

IMPLICATIONS OF THE DECISION

The Texas Supreme Court's decision limits physicians' discretion to the moments immediately after

birth. The court does not require the neonatologist or obstetrician to treat or resuscitate a newborn, only to decide whether or not to treat or resuscitate newborns at birth. The standard to be applied in making this determination is never well articulated, since both the best interests of the child and the contention that the treatment is “warranted” are vague and can often be used to justify a decision either to treat or not to treat. The Texas Supreme Court has made clear that after the initial “emergency” assessment, when many more treatment decisions must be made in the NICU, parental consent is legally required; if such consent is not forthcoming, a court order must be obtained before treatment proceeds. More important are the ethical issues that pertain to decision making in the NICU, and these require, at the least, clear, regular, and honest discussions with the parents about the health of and prognosis for their child, as well as trials of therapy that have realistic stopping points. Because clear rules seem to be impossible to formulate in this arena, adherence to reasonable procedures in making treatment decisions may be the best we can do.

The narrow decision of the Texas Supreme Court was reasonable but nonetheless unfortunate for the Millers. The result to Sidney was not entirely predictable, but the financial consequences of a lifetime of medical care — the cost will total in the tens of millions of dollars — were foreseeable. Public funding of Sidney’s care would certainly help the Millers, and such funding could have made this

lawsuit unnecessary. To the extent that society insists on treatment, public support may be morally obligatory, so that, as the President’s Commission noted more than 20 years ago, “these children, once rescued [in NICUs], are not then left to drown in a sea of indifference and unresponsiveness.”¹⁰

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