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# **PERSONAL REFLECTIONS ON EXTREMELY PREMATURE NEWBORNS: VITALISM, TREATMENT DECISIONS, AND ETHICAL PERMISSIBILITY**

**William J. Winslade\***

## INTRODUCTION

In 1976, I was one of three panelists at a meeting of the American Academy of Pediatrics on the topic: *The 1500-gram newborn: Is it worth it?* At that phase in the evolution of neonatology, it was reasonable to ask whether life-saving medical technologies (LST) used to rescue and treat imperiled premature newborns was likely to cause more harm than benefit. Our panel concluded that aggressive attempts to save the lives of such premature newborns were rarely successful, and even if they were, the complications and disabilities caused by the interventions themselves were often severe. Yet I could understand why neonatologists, urged by anxious parents to save their premature baby, sought to develop new technologies to push back the threshold of viability. Even in the absence of LST, some 1500-gram infants survive. For example, in 1976 I had just begun seeing patients as part of my training to become a psychoanalyst. One of my first analysands, a clinical psychologist, related to me the circumstances of her birth. She was the third daughter born to her mother (a nurse) and her father (a family physician). Born in 1950, she weighed slightly less than three pounds—approximately 1500 grams. Her parents initially believed that she was so premature and small that she had virtually no chance to survive. They wrapped her in a blanket to keep her warm and placed her in the open top drawer

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of a dresser fully expecting her to die soon. But she survived and thrived without any disabilities. Her parents were surprised but delighted; she felt both special and lucky.

Another personal experience in 1976 made a deep impression on me. I was teaching a course on medical ethics to medical students, residents, and fellows at UCLA, and I asked my students to write a paper about a case that raised ethical problems for them. One post-doctoral fellow, who had interned at Johns Hopkins in 1970, narrated his experience as the primary physician assigned to care for an infant with Down Syndrome whose parents refused surgery for his duodenal atresia.<sup>1</sup> The student described his emotional agony of standing helplessly, ordered to do nothing to save the life of a newborn when that could have been achieved by a simple surgical intervention. The young physician wrote passionately not only about saving life but also about life's intrinsic value. He was still deeply troubled about what he had not done.

Still another event in 1976 raised profound questions about the value of life: the Karen Quinlan case.<sup>2</sup> The New Jersey Supreme Court ruled that it was legally permissible for Karen's father to tell the doctors to remove her from the ventilator based on Karen's right to privacy and a prognosis that she was permanently unconscious.<sup>3</sup> Many observers assumed that she would promptly die. But after the doctors slowly weaned her from the ventilator, she continued to breathe on her own. Supported by artificial nutrition and hydration, she lived for nearly ten more years. Karen's parents objected to the intrusiveness of the technological machinery necessary to support her respiration but not the other forms of life-sustaining interventions. They did not question, even in her persistent vegetative state, the value of her life. As we all know from *Cruzan v. Director, Missouri Dep't of Health*<sup>4</sup> and especially the many controversies about the

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1. See generally James Gustafson, *Mongolism, Parental Desires and the Right to Life*, PERSP. ON BIOLOGY & MED., Summer 1973, at 529.

2. See generally *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

3. *Id.* at 662-64.

4. See generally *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

Terri Schiavo case,<sup>5</sup> vitalism<sup>6</sup>—the belief in the sanctity or, at least, the intrinsic value of, human life (even without consciousness)—is often reinforced by powerful emotions, fervent advocates, medical practices, legal rules, and religious doctrines.

Some vitalists base their beliefs upon religious doctrines, such as the position taken by Pope John Paul II that all persons—from an unborn fetus to an adult in a vegetative state—have “the inviolable right of every innocent human being to life.”<sup>7</sup> Right-to-life advocates, whether religious or secular, often echo the value of life expressed by the late Pope. Others turn to the law for support. Legislation<sup>8</sup> such as the Child Abuse Prevention and Treatment Act (CAPTA)<sup>8</sup> and the Born-Alive Infants Protection Act (BAIPA)<sup>9</sup> clearly endorse vitalism. Some judicial decisions, such as the Missouri Supreme Court’s decision in the *Cruzan* case, assert that “[l]ife is precious and worthy of preservation without regard to its quality.”<sup>10</sup> The claim that the right to life is inalienable also expresses a vitalist idea. Secular versions of vitalism include the notions that human life itself has an intrinsic and ultimate value regardless of its quality, and that it should be preserved regardless of costs and consequences. Some medical practices, such as the use of medical technology to prolong life, even if it is the only goal of medicine that can be achieved in a particular case, qualify as a form of vitalism. The strong resistance to termination of LST by health professionals, as well as patients or their families, also reflects explicit or implicit vitalist sentiments. One

5. See generally Leslie P. Francis & Anita Silvers, *(Mis)Framing Schiavo As Discrimination Against Persons with Disabilities*, 61 U. MIAMI L. REV. 789 (2007).

6. See Vitalism – AMERICAN HERITAGE DICTIONARY 1352 (2d ed. 1985).

7. Joseph Card. Ratzinger, *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation* (Feb. 22, 1987) available at [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19870222\\_respect-for-human-life\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html). See also Pope John Paul II, *Address of John Paul II to the Participants in the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas”* (Mar. 20, 2004), available at [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march/documents/hf\\_jp-ii\\_spe\\_20040320\\_congress-fiamc\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html).

8. See generally Child Abuse Prevention and Treatment Act (CAPTA), 42 U.S.C. §§ 5101–5107, 5118 (2006).

9. See generally Born-Alive Infants Protection Act of 2002 (BAIPA), Pub. L. No. 107-207, 116 Stat. 926 (2002).

10. *Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988).

might even consider that psychological forces, such as fear or denial of death, contribute to deeply rooted and pervasive vitalist tendencies in American culture.<sup>11</sup> It is safe to say that in America vitalism is not dead.

I will argue in this essay that although uncompromising or absolute vitalism is not ethically obligatory, vitalism is a relevant and ethically permissible value to consider in treatment decisions for extremely premature newborns (EPNs).<sup>12</sup> Both health professionals and parents may be vitalists or appeal to vitalist values in reaching treatment decisions. I interpret vitalism as a defensible value, one that has ethical significance but which may be overridden by other ethical values such as preventing excessive pain and suffering or reducing serious psychological or economic costs. I will also argue that treatment decisions for EPNs should take into consideration the responsible recommendations of both health professionals and the informed choices of parents, ideally resulting in a collaborative consensus. Such treatment decisions should ordinarily be individualized and contextualized on the basis of specific ethical values rather than prescribed by legal rules. Legal regulation should be invoked only to prevent arbitrary or abusive practices. If conflicts arise between health professionals and parents over treatment decisions for EPNs, attempts should be made to resolve them through clear communication and non-adversarial negotiation or mediation. If intractable value conflicts remain, then it may be necessary as a last resort to turn to the courts for a ruling. However, it is my contention that balancing ethical values rather than applying legal rules provides a better way to reach sound, sensitive, and humane treatment decisions.

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11. See Stacey A. Tovino & William J. Winslade, *A Primer on the Law and Ethics of Treatment, Research, and Public Policy in the Context of Severe Traumatic Brain Injury*, 14 ANNALS HEALTH L. 1, 26–27 (2004); WILLIAM J. WINSLADE, CONFRONTING TRAUMATIC BRAIN INJURY: DEVASTATION, HOPE AND HEALING 117 (1998).

12. See Craig Conway, *Baby Doe and Beyond: Examining the Practical and Philosophical Influences Impacting Medical Decisions Making on Behalf of Marginally-Viable Newborns* 16 (Dec. 12, 2008) (unpublished Ph.D., dissertation, University of Houston Law Center) (on file with author) (defining EPNs as those generally less than twenty-seven weeks gestation and weighing less than 1000 grams).

To support my claims I will discuss three cases in which I played a peripheral role as an ethics consultant. These three cases will illustrate why individualized, contextualized treatment decisions that are ethically permissible (rather than obligatory) provide sound guidance and sufficient justification for treatment decisions for EPNs. I am in general agreement with the carefully reasoned position of Loretta Kopelman.<sup>13</sup> However, I prefer to characterize EPN treatment decisions as being based not only on the best interests of the child but also, at least to some degree, on the best interests of other relevant parties—including parents and their families, health professionals, hospitals, government agencies, and even local communities.

### I. EXTREMELY PREMATURE NEWBORNS

The plight of the EPN continues to provoke much medical, ethical, and legal controversy.<sup>14</sup> Survival alone is uncertain since EPNs sometimes die quickly and approximately one-half die within a few months. Of those who do survive, a spectrum of physical and mental disabilities with varying degrees of severity are probable.<sup>15</sup> Few EPNs are unaffected. Medical professionals and their practice patterns, as well as hospital policies, are variable with regard to the use of aggressive interventions versus comfort care only.

Some physicians are more or less inclined toward vitalism. Some physicians and neonatal teams allocate more and others less authority to parental preferences. Some physicians are more or less deferential to hospital policies or CAPTA directives. Similarly, some parents explicitly or implicitly endorse vitalism; others do not. Some parents defer to physicians recommendations; others challenge them.

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13. See generally Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J. L. MED. & ETHICS 187 (2007); Loretta M. Kopelman, *Baby Doe Rules: In Reply*, 116 PEDIATRICS 1602 (2005); Loretta M. Kopelman, *Are the 21-Year Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797 (2005).

14. See generally Sadath A. Sayeed, *The Marginally Viable Newborn: Legal Challenges, Conceptual Inadequacies, and Reasonableness*, 34 J. L. MED. & ETHICS 600 (2006).

15. Georgie J. Annas, *Extremely Preterm Birth and Parental Authority to Refuse Treatment—The Case of Sidney Miller*, 351 NEW ENG. J. MED. 2118, 2121 (2004).

Hospitals vary in the degree of oversight or influence they exert through their administrative or relevant committees on clinical decisions. Multiple ethical issues arise regarding EPNs. Even in the face of uncertainty of outcomes and variable values and practices of interested parties, questions arise about the use of life-saving resuscitation and continuation of life-sustaining treatment. Quality of life criteria and sanctity of life values may come into conflict among health professionals or between health professionals and parents or even between parents themselves. Uncertainties are abundant about the disabilities experienced by EPNs from the side effects of procedures such as supplemental oxygen or the vulnerabilities of premature organs. The psychological and economic burdens on parents as well as caregivers of EPNs are profound. The influence of hospital policies, guidelines from professional organizations, legal regulations, and the fear of litigation contribute to the complexity and compound the uncertainty of single treatment decisions as well as ongoing treatment plans. This is only a partial list of the issues that arise in the context of treatment decisions for EPNs.

Finally, before turning to the cases themselves, I have a few comments about my role in the three cases. The first case deals with the highly controversial, publicly debated, and judicially reviewed case of Sidney Miller.<sup>16</sup> In that situation I served as a paid consultant to the parents of Sidney Miller during the litigation and jury trial of *Miller v. Hospital Corporation of America (HCA)*. I met and talked with the Millers and their attorney, read the medical records and other relevant documents, formulated opinions about ethical issues, and was prepared to testify at the trial. Although I was present at the court on the day I was expected to testify, a technical problem with my designation as an expert precluded my participation. I did not serve as an expert for the two subsequent cases decided by the Fourteenth Court of Appeals of Texas<sup>17</sup> and the Texas Supreme Court.<sup>18</sup> In the second case I was an ethics consultant to the parents of an EPN. In

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16. See *infra* Part III.

17. *HCA, Inc. v. Miller*, 36 S.W.3d 187 (Tex. App. 2000).

18. *Miller v. HCA, Inc.*, 118 S.W.3d 758 (Tex. 2003).

that role I counseled the parents, met as their representative with several health professionals, negotiated obtaining a second opinion, arranged a transfer of the infant from one hospital to another, and helped to coordinate comfort care only.<sup>19</sup> In the third case I was an ethics consultant to a utilization review company that advised an insurance carrier about whether the medical care and the charges by the physicians and the hospital were justified.<sup>20</sup> This case involved an ethics review of treatment decisions for an EPN who died after approximately eight months of treatment. I reviewed all the medical records in the case, read an expert report from a consulting neonatologist physician, and wrote an opinion about ethical issues that arose about the treatment decisions. In addition, I attended a somewhat unusual, but intriguing, informal meeting and discussion with representatives from the hospital staff and administration, the external physician consultant, and representatives from the insurance carrier (who observed but, except for brief comments, did not participate in the discussion).

In each of the cases, I was a paid consultant to parties with specific interests in the case. My perception, analysis, and evaluation of the ethical issues were no doubt influenced by the role I was asked to assume, but I tried to remain as objective as possible. This was easier to do in the first and third cases. When I actually served in a representative capacity for the parents, I also was their advocate and agent as well as their counselor. Nevertheless, I attempted to serve as an objective advisor with the responsibility to offer observations, interpretations, and, in some instances, recommendations.

## II. THE SIDNEY MILLER CASE

My references to “the Sidney Miller case”<sup>21</sup> include all the circumstances leading up to and including Sidney’s birth, resuscitation, subsequent hospital treatment, court decisions, and

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19. See *infra* Part IV.

20. See *infra* Part V.

21. See Conway, *supra* note 12, at 51–60.



Sidney's life situation now, almost twenty years after her birth. The case also refers to three judicial proceedings—the jury trial for damages against the Hospital Corporation of America, a Texas Court of Appeals decision, and the Texas Supreme Court decision.

Today, Sidney Miller is eighteen, yet she cannot walk, talk, feed herself, or sit up on her own. She is legally blind in one eye, and has a range of vision of only a few feet in the other. She suffers from cerebral palsy, seizures, and spastic quad paresis in her limbs. She has severe mental retardation and will have the mental capacity of an infant for the remainder of her life. She has a surgically implanted shunt in her skull to drain fluid leaking from her brain. She periodically requires hospitalization to clean or replace the shunt. And her family provides twenty-four hour care to change her diapers, feed and clothe her, and take care of her needs. Sidney's condition will never improve.

### *A. Sidney's Birth*

On August 17, 1990, Karla Miller, accompanied by her husband, Mark, was admitted to Woman's Hospital of Texas in Houston while experiencing symptoms of premature labor. It was four months before her scheduled due date. Physicians immediately administered a drug to Karla to stop labor. Although her premature labor ceased, physicians subsequently discovered that Karla had an infection threatening to take her life and the life of her unborn daughter. Karla's obstetrician, Mark Jacobs, M.D., and a neonatology resident, Donald Kelley, M.D., informed Karla and Mark that the child would need to be delivered soon to save the lives of both mother and child. The physicians informed the couple that, even if born alive, the infant would most likely suffer severe impairments including brain hemorrhaging, blindness, lung disease, pulmonary infections, and mental retardation.

After their discussion, Drs. Jacobs and Kelley asked the Millers to decide whether the newborn should be aggressively treated upon delivery. After deliberating, the Millers informed the physicians at noon that "no heroic measures" were to be performed on the infant

and that the doctors should let “nature take its course.” Dr. Kelley recorded the Millers’ request in the medical record, and Dr. Jacobs informed other medical staff that no neonatologist would be needed at delivery. Mark then left the hospital to make funeral arrangements for the infant; he purchased a gown, a casket, and a burial plot.

Alarmed by the notation in the medical record, the nursing staff notified other hospital personnel and administrators. An afternoon of meetings ensued to discuss what should be done. An ultrasound revealed that Karla’s fetus weighed approximately 629 grams, or slightly more than one pound, and had a gestational age of about twenty-three weeks. Around 4:30 p.m. that afternoon, Mark was advised by Anna Summerfield, administrative director of the neonatal intensive care unit, that a hospital policy, as well as state and federal law, required the hospital to resuscitate any infant born weighing more than 500 grams. When a copy of the policy was requested by Mark, he learned that it was an “unwritten” policy. When asked by the Millers how they could prevent resuscitation and other measures from being taken on the newborn, hospital officials informed them that they would need to transfer Karla to another facility. However, Karla’s obstetrician had made it clear that transfer was not a viable option given Karla’s infection and worsening condition.

What concerned the physicians, as well as the hospital administrators, was the ethical dilemma of not providing any medical treatment without first observing the newborn’s condition. As Dr. Jacobs testified:

[W]hat we [an ad hoc hospital committee] finally decided that everyone wanted to do was to not make the call prior to the time we actually saw the baby. Deliver the baby, because 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.<sup>22</sup>

Dr. Jacobs reversed the earlier medical record and wrote that a plan of evaluation would begin upon the birth of the newborn. The Millers, however, still refused to consent to resuscitation or other medical treatment to be provided to the infant at birth.

That evening, Karla's amniotic sac broke and physicians determined that labor would need to be induced to prevent further complications. At 11:30 p.m. that night, Karla delivered a premature female infant weighing 615 grams, whom the Millers named Sidney. Sidney's gestational age was twenty-three and one-seventh weeks. The neonatologist, Eduardo Otero, M.D., noted that Sidney had a heart beat, "was blue in color and limp, gasped for air, spontaneously cried, and grimaced."<sup>23</sup> The physician also noted that Sidney displayed no dysmorphic features other than being premature; he immediately "bagged" and "intubated" Sidney and placed her on ventilation.<sup>24</sup> When asked at trial why, the physician responded:

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, that—with this birth weight, that later on go on and do well.<sup>25</sup>

Otero's testimony obviously conflicted with the medical opinions previously given to the Millers before Sidney's birth. Yet neither Karla nor Mark objected further at the time the treatment was administered by Otero. They felt they had already expressed their refusal and had no other realistic options.

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22. *Miller*, 118 S.W.3d at 762.

23. *Id.* at 763.

24. *Id.*

25. *Id.*

Sidney initially responded well to treatment, but within the first few days after birth, she suffered a serious brain hemorrhage—a common occurrence in extremely premature infants. It was unclear whether the hemorrhage resulted from the medical treatment provided or in spite of it. But as originally predicted by her physicians, Sidney suffered all the severe physical and mental impairments that remain with her today.

### *B. The Lawsuit*

Karla and Mark Miller sued The Woman's Hospital of Texas and its parent company, HCA, and subsidiaries, asserting claims of negligence, gross negligence, battery, intentional infliction of emotional distress, and the tort of wrongful birth. The Millers decided not to pursue legal action against any of the physicians, including neonatologist Eduardo Otero, who performed the life-sustaining treatment despite Mark Miller's objections. When asked by the media why they chose not to bring suit against the physicians, Mark Miller responded that he and Karla believed "the doctors just did what they were told" to do by hospital officials. The physicians were involved in the litigation to the extent that it was alleged they acted as the agents of the hospital, so the hospital was legally responsible for their actions.

After approximately a one-month trial, the jury found that resuscitation had been performed on Sidney without the consent of the Millers and that the negligence of the hospital and HCA "proximately caused the occurrence in question." Additionally, the jury concluded that both HCA and the hospital were grossly negligent, that the hospital acted with malice, and that Dr. Otero was the hospital's agent in the resuscitation of Sidney. The jury awarded the Millers \$29,400,000 in actual damages, \$17,503,066 in prejudgment interest, and \$13,500,000 in punitive damages.

### C. *The Appeal and Opinion of the Texas Supreme Court*

A Texas Court of Appeals reversed the jury's award and ordered the Millers to take nothing. The three-judge court concluded that, pursuant to state law, parents could withhold medical treatment from a child only if the child's condition was deemed "terminal."<sup>26</sup> But in Sidney's case, the court noted there was no authority allowing a parent to "withhold [urgently-needed life-sustaining medical] treatment from a non-terminally ill child."<sup>27</sup> Thus, according to the majority opinion, HCA and the hospital were under no duty to follow the Millers' instruction to withhold resuscitation or to have a policy prohibiting resuscitation of newborns like Sidney without parental consent. One dissenting justice disagreed and stated that a court order was required to override the Millers' refusal and to determine what was in Sidney's best interests.

The Texas Supreme Court limited its role in the matter 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, has a largely uncertain prognosis."<sup>28</sup> After summarizing existing law allowing parents the authority to make health care decisions on behalf of their children, the court noted that such parental autonomy has its limits.<sup>29</sup> 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."<sup>30</sup> Thus, absent evidence of abuse or neglect, a parent has the right to give or withhold consent for medical treatment for a child.<sup>31</sup>

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26. *HCA*, 36 S.W.3d at 193.

27. *Id.* at 194.

28. *Miller*, 118 S.W.3d at 766.

29. *Id.*

30. *Id.* at 767.

31. *Id.* at 766 (citing *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 627 n.13 (1986)).

However, the court went on to acknowledge that there are exceptions.<sup>32</sup> In those circumstances, the court held:

[A] physician, who is confronted with emergent circumstances and provides life-sustaining treatment to a minor child, is not liable for not first obtaining consent from the parents. . . . [This is] an exception to the general rule that a physician commits a battery by providing medical treatment without consent. As such, the exception is narrowly circumscribed and arises only in emergent circumstances when there is no time to consult the parents or seek court intervention . . . .<sup>33</sup>

In other words, physicians will not be legally liable for erring on the side of preservation of life in emergencies. In disagreeing with the Millers' contention that Sidney's birth was not an "emergent circumstance" and that there was plenty of time to seek a court order, the court concluded that the circumstances were unique, in that a decision about resuscitation could not reasonably be made before birth.<sup>34</sup> The court noted:

[T]he 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 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.<sup>35</sup>

The court held that the actions of Dr. Otero were not negligent because he was required to "make a split-second decision . . . [and

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32. *Id.* at 767.

33. *Miller*, 118 S.W.3d at 767–68.

34. *Id.* at 769.

35. *Id.*

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 . . . .”<sup>36</sup>

Throughout the legal proceedings, HCA had consistently argued that the federal Baby Doe Rules<sup>37</sup> forbade any denial of medical treatment based on quality of life considerations. The healthcare corporation argued that the rules were “scrupulously followed” and “faithful adherence to the public policy established by the regulations should not be thwarted through civil liability in damages.”<sup>38</sup> Although the court agreed in spirit, it went on to note that the rules required Texas to “provide a mechanism by which the child protective services system [could] initiate legal proceedings to prevent the withholding of medical treatment from infants.”<sup>39</sup> But it was clear that neither the hospital nor HCA requested child protective services to initiate legal proceedings to override the Millers’ decision to withhold treatment. The court affirmed the appellate court’s judgment, declining to impose liability for battery or negligence on a physician acting on behalf of the hospital for providing life-sustaining treatment under emergent circumstances to an infant without parental consent.

#### *D. Discussion*

Recall that Drs. Jacobs and Kelley first requested the Millers decide whether to attempt resuscitation if Sidney was born alive. Given the fact that Dr. Jacobs told the Millers that Sidney’s birth should be viewed as a “tragic miscarriage,”<sup>40</sup> it is not surprising that Mark left to make funeral arrangements. In 1990, more so than it is now, mortality for a twenty-three week fetus was highly probable at birth or soon thereafter even with resuscitation and LST. In fact, at

36. *Id.*

37. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101–5106 (2006) and implemented in relevant part by 45 C.F.R. § 1340.15).

38. *Miller*, 118 S.W.3d at 771.

39. *Id.*

40. Kathryn Casey, *Born Too Soon*, LADIES HOME J., Aug. 1998, at 53.

the jury trial, a physician from Johns Hopkins testified that the resuscitation and subsequent treatment was experimental and beyond the standard of care for such an EPN. Not only did the Millers not consent to resuscitation, they were not even informed that any of the treatment of Sidney might be classified as experimental. The jury accepted the expert's opinion and, in part on that basis, awarded the Millers punitive damages.

Quite apart from the experimentation issue, it was my opinion then, as it is now, that it was ethically permissible for the Millers, on the basis of the information provided by their physicians, to choose not to have a neonatologist present and not to attempt resuscitation or LST. I think it was also ethically permissible for the physicians to accept the Millers' decision. The Millers did not want to put their unborn child at risk for the predicted disabilities, pain, and suffering that did in fact ensue. They relied in good faith on what indeed was reliable information and a prediction about outcomes. Given the uncertainty of survival and the probability of severe disability, it was reasonable and responsible for the Millers to opt for no resuscitation which they understood to be "heroic measures."

However, if the Millers had listened carefully to their physicians and then after deliberation said, "Well, if our baby is born alive, we want you to resuscitate her at birth," that would also have been ethically permissible. The Millers might have based such a decision on vitalism, religious faith, hope, or gambling against the odds that she would not suffer severe impairments. If the Millers had chosen resuscitation at birth, it would have been medically and ethically obligatory for a neonatologist to be present.

Another ethical issue arose after Sidney suffered a grade IV intracranial brain bleed that probably caused her other severe disabilities. It was noted in the Texas Supreme Court decision that the Millers did not object to subsequent treatment.<sup>41</sup> However, there is more to the story. First, the Millers told me that they were never offered an option to limit aggressive care and initiate comfort care

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41. *Miller*, 118 S.W.3d at 763.



only. In fact, on the fourth day after her birth, the Millers asked if Sidney could be taken off of life support. "The doctors told us it would be incredibly painful for Sidney," Karla recalls, "and then it could take a long time for her to die."<sup>42</sup> The Millers claim they were told by the doctors that they had no choice about whether to terminate the life support. In addition, the Millers say they were led to believe that subsequent treatment would reduce Sidney's pain and suffering. It would have been ethically permissible to shift from aggressive LST to comfort care only.

After Sidney's prolonged hospitalization and devastating disabilities made her prognosis so grim, the Millers took Sidney home. Immense burdens were imposed on the Millers to care for her. At great personal and economic sacrifice, the Millers changed their life to fulfill her needs. Although Sidney has major physical disabilities and minimal mental capacities, she is conscious and does respond to her parents. The large jury award for medical expenses was no doubt influenced by the enormous financial burdens the Millers initially incurred and the continuing costs of her care. Some families might not have been willing or able to endure the emotional costs of twenty-four hour care of a severely handicapped child with no prospect of improvement.<sup>43</sup> The Millers have devoted themselves

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42. Casey, *supra* note 40, at 53.

43. About five years ago, I was asked to intervene as a consultant to a private hospital in a western state. An infant was unexpectedly born prematurely, suffering from multiple genetic anomalies. The infant's mother was devastated; her husband and family were so disturbed that they refused to come to the hospital to see the baby. The attending neonatologist was sympathetic to the mother's distress. The neonatologist, without consultation with anyone else, responded to the mother's distress by giving the infant, at the mother's request, a lethal injection that the physician documented in the medical record. A nurse who read the note the next morning reported it to the hospital administration. The hospital reported it to the medical board and the district attorney investigated the incident. The neonatologist, who had an excellent reputation in the community, initially believed that his decision was justified and was shocked that his action was called into question. After negotiations with the medical board and the district attorney, the hospital administration reached an agreement to provide a comprehensive education program for the staff and a special tutorial for the neonatologist. Upon completion of both phases, the state agencies agreed that no further action would be taken. It was my assignment to provide the education program and the special tutorial. It was difficult as an outside consultant to address the many emotional issues, the political undertones, the ethical conflicts, and the legal issues. Because the hospital-wide education program was mandated rather than voluntary, passive and active resistance to my presence was no surprise to me. The neonatologist was also a reluctant, but contrite, participant because he knew that euthanasia was illegal. He also realized that his impulsive response to the mother's

to providing extraordinary care for Sidney in their home when some parents might have placed such a child in a state institution.

Turning to the neonatal physicians that cared for Sidney after her resuscitation, what obligations did they have to Sidney or her parents? At the very least, the physicians had a duty to fully inform the Millers about the consequences of continuing the LST. The Millers should have had an opportunity to consider comfort care only, but that option was never offered to them. Perhaps the physicians marginalized the Millers because of their attempt to refuse resuscitation. Neonatal intensive care in 1990 often marginalized, if not excluded, parents from participating in ongoing treatment decisions other than to routinely sign consent forms. The Millers, in retrospect, realized that they were denied *informed* consent. Perhaps also the neonatologists were motivated by what I call technological vitalism—using LST to keep an infant alive even if this is the only realistic goal of medicine that can be achieved. It would have been ethically permissible for the physicians, with the Millers' informed consent, to provide less aggressive or even comfort care only when Sidney's prognosis greatly worsened. In fact, I suggested to the Millers' attorney that he consider including the failure to inform the Millers about their ethical option to refuse continued aggressive LST in the lawsuit. Although he agreed with my ethical analysis, the lawsuit was limited to the parents' explicit refusal of resuscitation, the hospital's unwritten resuscitation policy, and its failure to get third-party authorization to override the parents' refusal.

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distress was unwise, but he was not easily convinced that it was unethical. He also resented the involuntary tutorial. My own reaction to the situation was concern that so many health professionals failed to appreciate the complexity and ambiguity of the entire sequence of events. The participants retreated into oversimplification, and polarization of the issues made it virtually impossible for me to engage the participants in a meaningful dialogue, or effective education. I did my best to overcome their resistances, but the circumstances made the task extremely difficult. Although the hospital administration was relieved and the state agencies signed off, I was dubious about whether my efforts were effective or merely tolerated as a pragmatic necessity. It came as no surprise when I later learned that the neonatologist had resigned and moved away. I recommended to the hospital administration that an involuntary "education" intervention should be followed by a more reflective and systematic approach to continuing professional education. I wondered whether my recommendation would be taken seriously. I have no reason to believe or evidence that it was. I hope I am wrong.

The hospital policy invoked in the *Miller* case was problematic for another reason. The resuscitation of any EPN who weighs more than 500 grams may save a newborn's life only to condemn it to a quality of life diminished by devastating disabilities. Such an unwavering commitment to resuscitation may shield an institution and its physicians from allegations that they did not do enough to save a life. But it is also an unwarranted pursuit of vitalism—attempting to save lives regardless of excessive emotional and economic costs with often disastrous consequences for the patients and their families. Vitalism motivated by fear of litigation is a bad reason for action and a dangerous policy. It is likely that this factor contributed to the decision of the ad hoc hospital committee to disregard what the physicians originally told the Millers and the Millers' refusal of resuscitation.

The dissenting judge in the Court of Appeals agreed with the Millers that HCA and the hospital had the time and an obligation to seek a court order to overrule the parents' refusal of resuscitation.<sup>44</sup> This was especially important because the physicians initially offered the Millers the option to refuse. The hospital's later unilateral decision to resuscitate Sidney at birth if she was born alive, even though ruled legal by the Texas Supreme Court, was, I believe, arrogant and unethical. William Silverman, who is one of the founders of modern neonatology, once said that his colleagues in neonatology are driven not only by arrogance but also by a "rescue fantasy" that fails to consider the costs or consequences for the family of the premature infants.<sup>45</sup> George Annas points out that the Texas Supreme Court's opinion in the *Miller* case authorizes only the hospital's unilateral resuscitation.<sup>46</sup> Annas correctly observes that the court made no ruling about what the physicians are permitted or required to do after the emergency resuscitation.<sup>47</sup> John Robertson, in

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44. *HCA*, 36 S.W.3d at 198 (Amidei, J., dissenting).

45. William A. Silverman, *Mismatched Attitudes About Neonatal Death*, 11 HASTINGS CENTER REP. 6, 15–16 (Dec. 1981).

46. Annas, *supra* note 15, at 2120.

47. *Id.* at 2123.

a comprehensive review of CAPTA and a detailed discussion of the Miller case, recommends that any aggressive treatment after emergency resuscitation should respect the parents' "presumptive right" to make treatment decisions for their child's welfare.<sup>48</sup> If physicians desire to continue to treat and the parents object, the burden of proof should be on physicians to obtain legal authorization to override parental refusal.<sup>49</sup> True, CAPTA endorses a nearly unqualified vitalism limited only by infants who are dying or lack consciousness. But for the physicians and the hospital to act unilaterally under the dubious authority of an unwritten and belatedly disclosed hospital policy only pays lip service to CAPTA. Even if one agrees with CAPTA (which I do not), oversight from the state child abuse agency was meant to apply to physicians and hospitals as well as parents.

### III. THE BABY C CASE

Shortly after the jury trial in the Miller case, I was approached by a colleague who knew that I had been a consultant for the Millers. My colleague mentioned that he knew a young couple who had an EPN who was born and in treatment at the same hospital as Sidney Miller. He asked me if I would meet and talk with the parents. Although ordinarily I serve as an ethics consultant only to health professionals or hospitals, I agreed to talk with his friends. I was distressed to learn from them that they had an EPN born at twenty-five weeks weighing less than 1000 grams who suffered a grade IV brain bleed and vulnerable to the same disabilities as Sidney. However, this couple had an older child, then eighteen months, who was born less prematurely (thirty-one weeks) and successfully treated at the same hospital. The parents initially assumed that the neonatal course of treatment for their second son, where he had been hospitalized for about two months, would not pose any problems. A pediatric

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48. John A. Robertson, *Extreme Prematurity and Parental Rights After Baby Doe*, 34 HASTINGS CENTER REP. 32, 38 (2004).

49. *Id.*

neurologist explained to the parents all the severe disabilities likely to result from the brain bleeds. At that point the parents were concerned; the husband talked with his two sisters from the East Coast, one of whom was an adult neurologist and the other a general internist. The sisters expressed alarm about the report from the pediatric neurologist. They also inquired about neonatal practices in their community where neonatal teams continually reassessed treatment plans, discussed them with the parents, and made joint decisions. They were surprised to learn that their brother and his wife, both school teachers, had so little knowledge, involvement, or participation in the treatment discussions.

When the parents met with me, they asked if I would serve as their representative to find out what was going on with their son. Although they had visited the neonatal nursery, they were intimidated and felt hesitant to raise questions. In particular, they did not want to create conflicts at the hospital where their older son received medical care. They authorized and asked me to speak to the neonatal staff on their behalf. With the assistance and intervention of a colleague, I was able to talk with a nurse and a resident who were specifically involved with their son's care. I also met with the physician who was the Chief of Neonatology. The nurse and the resident painted a grim picture of the infant's future; it sounded eerily similar to Sidney Miller. But the Chief of Neonatology tried to assure me that the infant was stable. I asked specifically if the infant was terminally ill or on a dying trajectory. The Chief adamantly denied that this was the case. After what I had been told by the nurse and the resident, however, I was dubious.

As it happened, I personally knew the hospital risk manager who was also an attorney. I explained the situation to him and indicated that the parents wanted to obtain a second opinion. I made it clear that the parents did not want to disrupt their relationship with the hospital or to cause trouble. The risk manager complied by sending the medical records to a neonatologist who I knew well as a conservative, vitalist-leaning physician. When she reviewed the records, she was convinced that the infant had a very poor prognosis

if not a terminal condition. Of course, given the uncertainty of predictions of mortality, she qualified her opinion; she was more certain of the prognosis of severe morbidities. After further discussion with the consulting neonatologist and a pediatric intensivist who directed a pediatric hospice, a decision was made to offer the parents the option of transferring their son to the pediatric hospice for comfort care only. Although the parents were stunned and ambivalent after talking with the husband's physician-sisters, they decided to request a transfer. With the cooperation of the treating hospital's risk manager, a transfer was made to the pediatric hospice.

The infant, who was still on a ventilator, barely survived the transport of about fifty miles. Gathered together in the pediatric hospice were the infant, his parents, the husband's two sisters, physicians and nurses from the hospice, clergy, and at my suggestion, the eighteen-month-old son. After introductions and some preliminary discussion, a decision was made to remove the ventilator that had been sustaining Baby C's respiration. It was the first time that Baby C's parents had seen his face unencumbered by the ventilator. The parents took pictures for their family history and to capture the brief time that he was able to breathe on his own. Twenty minutes later, he died. Although his death was sad and difficult, because it was not unexpected the family was prepared and able to cope with it. When I visited with them on the anniversary of Baby C's death, they remained sad but relieved that he had a peaceful, though untimely, death.

If Baby C had remained at the first hospital, he may have survived and suffered a fate similar to Sidney Miller. Or, contrary to the assertion of the Chief of Neonatology, he may have passed away in spite of LST. If the parents had been told about and appreciated their option to continue LST, it would not have been unethical for the physicians to do so. But, it was clear to me that the parents had not really been adequately informed about, much less understood, their son's precarious and fragile condition. They had been kept in the dark by peremptory reassurances that everything was stable. Because the parents were not assertive or probing, they at first accepted the

reassurances at face value. Although the report from the pediatric neurologist startled and frightened them, they were more fortunate than many parents to have access to helpful family members and my consultation. My personal contacts in the hospital gave me not only access to information but also an ability to negotiate on behalf of the parents. In the end they were able to make a difficult and painful—but well-informed—decision to seek comfort care only rather than aggressive LST. The outcome of the treatment decisions for Baby C obviously differed from the results in the Miller case. In my opinion, it was ethically and legally appropriate to seek and rely on a second professional opinion and alternative treatment plan in view of the uncertain prognosis. Once the parents were fully informed about their son's prognosis, it was ethically permissible for them to opt for comfort care only and discontinue ventilator support. Although disagreements arose between the parents and the original neonatology treatment team, they were resolved without resorting to litigation or legal rulings.

#### IV. BABY V

In this case, my role as an ethics consultant was unusual in that I was engaged by a company that provides utilization review for a large medical insurance group. I was asked to examine the complete medical records of a male neonate born in November 2005 at a gestational age of almost twenty-six weeks at a birth weight of 760 grams. In addition, a clinical assessment of his treatment from a consulting neonatologist hired by the company was provided to me. My responsibilities were to identify and evaluate ethical issues manifested in the medical records and brought out by the expert report from the neonatologist. I organized the ethics review in terms of the heuristic framework of *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*.<sup>50</sup> This framework

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50. See generally A.R. JONSEN, M. SIEGLER & W.J. WINSLADE, *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* (6th ed. 2006).

considers medical indications and the goals of medicine, patient (here parental) preferences, quality of life, and contextual features.

### *A. Medical Indications*

The consulting neonatologist described in detail the many medical problems faced by this premature infant—infections, renal insufficiency, brain bleeds, chronic lung disease, and cystic fibrosis. The parents of Baby V, after a month of neonatal intensive care at his birth hospital, were advised of V's dire prognosis. They then transferred him to a tertiary care hospital well equipped and willing to treat seriously compromised infants. Despite an aggressive treatment plan that used state-of-the-art medical technology, V remained critically ill, suffering from chronic lung disease. During nearly eight months of treatment, he remained ventilator-dependent—except for approximately two weeks from late February to early March 2006. After continued complex, aggressive treatment, by mid-April an attending physician informed the parents that Baby V's chronic lung condition was irreversible and that it was highly probable, if he survived, that he would remain ventilator-dependent. At that point, the attending physician recommended a Do Not Resuscitate order (DNR) in the event of respirator or cardiac arrest. After prolonged deliberation, the parents refused and requested continued aggressive care. Finally, a few days before Baby V died—approximately three months later—the parents accepted some limits on aggressive treatments. Even so, it was noted in the records that Baby V's father inquired about a lung transplant shortly before V died. It was unclear whether the father's remark was a serious request or only a hope for a miracle. From the moment of birth, this premature infant had an extremely poor prognosis. This was reiterated after two months by the physicians and the hospital where he was born. Like others who evaluated this case, I believed that the prolonged treatment of Baby V was excessive.



*B. Parents' Preferences*

It is clear from the medical records that V's parents requested continued life-prolonging procedures, and it was repeatedly noted that they remained "hopeful" and "optimistic" about V's long-term survival. The records do not describe the details of the conversations of the physicians with the parents, nor do the records describe whether the parents understood or accepted V's extremely poor prognosis for long-term survival. There is no mention in the records of any use of ethics consultation or ethics committees to evaluate the circumstances of this case. It seems to me that some such consultation was at least desirable, if not necessary, to determine if the parents were adequately informed and able to appreciate the situation. It was the ethical responsibility of physicians not only to fully disclose V's diagnoses and prognosis to the parents, but also to educate them about whether their hopes and optimism were realistic or unrealistic. It is always difficult to communicate to the parents of a critically ill infant that life-prolonging procedures may not be providing any other therapeutic benefits and may only be postponing the death of an infant on a dying trajectory. However difficult that may be to confront, physicians have a responsibility to disclose in a sensitive manner what may be a painful truth to the parents. The parents do not have the right to demand the impossible and the physicians have no duty to attempt it. It is unclear from the records in their case whether the physicians continued the aggressive and excessive treatment merely because the parents requested it or whether the physicians believed in good faith that the treatment was medically indicated and potentially beneficial to V. Whenever the parents were approached about limiting treatment, they resisted it until shortly before V's death. However, it is the ethical responsibility of the physicians to recommend and advise the parents that if no therapeutic benefits other than life-prolongation can be achieved, comfort care only is a medically appropriate option. It is questionable whether the many other interventions, especially after April 11, 2006, provided any significant therapeutic benefits. One of the grave dangers of the prolonged administration of life support technologies

in cases of critically ill premature infants is that it may create or reinforce false hopes and unwarranted optimism on the part of the parents. Physicians have a duty to sensitively but candidly dispel mistaken beliefs and resist unwarranted requests. It is not clear that the physicians in this case adequately explained, advised, or recommended to the parents that, although continued aggressive treatment of V was permissible, it was also unlikely to achieve long-term survival.

### *C. Quality of Life*

There was scant evidence in this case that V's quality of life was improved or enhanced by the treatments he received. Although sedation reduced V's pain and suffering, there is little evidence of significant therapeutic benefits. The enormous economic costs, the physical burdens on V, and the emotional burdens on the parents and the health professionals outweighed any benefits that V received other than a brief extension of his life. It would have been ethically permissible to limit or even withdraw life support long before V died.

### *D. Contextual Features*

Several contextual features of this case raise serious ethical questions. Why did the parents insist that aggressive, or even excessive, treatment be given to V? Were they in denial or captivated by irrational beliefs? Why did the physicians continue aggressive care even though it resulted in no significant improvement in V's condition? Why were so many expensive and invasive treatments given when they provided so few therapeutic benefits? Did the physicians merely capitulate to the parents' demands without challenging them? Was the treatment in this case an appropriate use of limited medical resources? Was the treatment continued only because it was anticipated that the cost of care would be covered by third-party payments? To what extent did the physicians attempt to persuade or negotiate with the parents about limiting treatment? Although I cannot fully answer these questions—because only

cryptic notes were made regarding these questions—I strongly suspect that the extensive, expensive, and aggressive treatment, at least after April 11, 2006, was not medically required, indicated, or therapeutically useful (except to prolong the dying process of V). It is, of course, impossible to discern the motives of the parents or the physicians merely from the documents provided. It is my opinion that from a clinical ethical perspective, the sustained course of aggressive life-sustaining treatment, with so few therapeutic benefits, was neither ethically required nor ethically justified. But it was ethically permissible if the parents, after being adequately informed, espoused vitalist values and were willing to deal with possible consequences such as permanent ventilator dependence as well as economic and emotional burdens. If the physicians believed that it was medically appropriate and agreed with the parents about continuing LST, then it is ethically permissible even if others would disagree.

### *E. Resolution of the Case*

Although I wondered what, if anything, was happening with regard to this case, several months went by before I received any further communications. Then I received copies of two letters, one from a physician and another from a hospital administrator that disputed my opinions as well as those of the neonatologist consultant. I wrote a response to those letters and I assumed that my role in this case was finished.

Much to my surprise, I later received a call asking me whether I would be willing to participate, along with the neonatologist consultant, in an informal meeting with physicians and the hospital administrator to clarify a number of issues and to better understand the treatment of Baby V. I also understood that representatives from the benefits administration company and others from the hospital might attend the meeting as observers. But no lawyers from either side were to be present and no transcript of the meeting would be made.

The underlying issue in this case was whether the full \$2.8 million that had been billed to the parents' insurance carrier was fully

justified. The benefits administrators wondered whether certain treatments were appropriate, whether the hospital had followed its own protocol once a disagreement arose between the attending physician and the parents with regard to the DNR order, and whether the LST had been excessive and inappropriate. I was fascinated by the idea of the informal meeting and certainly willing to participate.

When the meeting was held at the hospital in question, one of the first things I noticed, as I was walking down the hall to the meeting was a familiar name on one of the office doors. It was a physician ethics consultant that I have known for many years. What a coincidence, I thought. When I entered the room for the meeting, I was surprised to see the ethics consultant because his name had never appeared in any of the records I reviewed.

The meeting was very cordial but everyone was cautious and chose their words carefully. The hospital physicians explained their rationale for aggressive LST. The palliative care physician told us how he could work to reduce pain and suffering while the neonatologists continued the aggressive LST. I asked the ethics consultant if he had been involved with this case. He said that no formal consultation had been requested; he just knew about the case through the hospital grapevine. I wondered why he was attending the meeting, but the question was not addressed. In any event, I did ask whether there was further information about the parents' preferences or the basis for their hope and optimism. But no new information was provided. I asked why the physician who recommended the DNR order was not at the meeting with us. The curious response was that he was just unable to be there. I thought it odd that such a key person, who could have shed light on a number of the ethical issues raised in my letter, was not present.

I did learn at the meeting that the hospital policy and apparently the law in the state was that LST for infants may not be terminated upon a physician's recommendation unless the parents give their informed consent. Since the parents did not agree to the DNR or any other limits on treatment until shortly before Baby V died, as far as the hospital and the physicians were concerned that was the end of

the matter. I felt, however, that information about what the parents were told or not told about Baby V's condition and his prognosis was essential to an assessment of the issue of informed consent.

As I mentioned previously, the underlying issue and subtext of the informal meeting was whether the full \$2.8 million billed to the insurance company was warranted. The billing issues were not discussed in our informal meeting. However, it did seem to me that the unanswered questions relevant to informed consent—the parents' understanding of Baby V's prognosis, and what I would call therapeutic extravagance—might have a bearing on subsequent negotiations. Perhaps ethically permissible aggressive treatment was provided by the physicians and accepted by the parents during the eight months of care. But it is not clear, given all the unanswered questions, incomplete data, and conflicting values that the treatment was ethically justified on rational grounds. In addition, it is difficult to justify the extraordinary economic costs and other burdens of the prolonged treatment. I subsequently learned that the dispute between the hospital and the insurance company was settled informally without litigation.

### CONCLUSION

In this essay I have argued that vitalism is an ethically relevant value that may support the use of aggressive LST in EPNs. But I have also argued that it is ethically permissible in some circumstances to withhold or withdraw aggressive LST and to override vitalist values. The three cases I have presented illustrate a variety of different issues. I believe that treatment decisions concerning EPNs ideally should seek a proper balance of medical indications, parents' preferences, quality of life, and contextual features considered in the light of the nuances of particular cases.