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WITHDRAWING OR WITHHOLDING MEDICAL CARE FROM PREMATURE INFANTS: WHO SHOULD DECIDE, AND HOW?

I. INTRODUCTION

A young woman arrives at a hospital in labor.¹ She is at approximately twenty-six weeks gestation.² She is poor and has had no prenatal care.³ She has a history of cocaine use.⁴ The infant is born weighing less than 750 grams.⁵ A neonatologist takes over.⁶ She wonders if the infant is viable.⁷ The child has difficulty breathing, and his heart rate is too fast.⁸ The doctor is not optimistic, but she wants to give the infant a chance. She inserts a breathing tube in the infant's airway and begins artificial ventilation. The infant is transported to a tertiary care facility and admit-

1. This case is hypothetical.

2. Premature births are those occurring before 37 weeks gestation. *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 1585 (17th ed. 1993). The normal human gestation period is 40 weeks. *Id.*

3. Poverty and lack of prenatal care are risk factors for premature delivery. RASA GUSTAITIS & ERNLE W.D. YOUNG, *A TIME TO BE BORN, A TIME TO DIE* 41 (1986).

4. Cocaine abuse is associated with premature delivery. William W. Hurd et al., *Cocaine selectively inhibits beta-adrenergic receptor binding in pregnant human myometrium*, 169 *AM. J. OBSTETRICS & GYNECOLOGY* 644, 648 (1993). Other risk factors related to the mother include smoking, young age, manual labor, and emotional stress. GUSTAITIS & YOUNG, *supra* note 3, at 41.

5. Infants weighing less than 2500 grams at birth are classified as low birth weight infants. *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 1585 (17th ed. 1993). This benchmark is accepted as the clinical indicator of prematurity, although the low birth weight category includes infants who are not premature. *Id.* Infants weighing less than 1000 grams are classified as extremely-low-birth-weight [hereinafter ELBW] infants, with gestational ages usually ranging from 22 weeks to 28 weeks. Richard M. Cowett, *Introduction*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH I* (Richard M. Cowett & William W. Hay, Jr. eds., 1989).

6. A neonatologist is a physician specializing in neonatology, "[t]he medical study of the first 60 days of an infant's life." *WEBSTER'S II NEW RIVERSIDE DICTIONARY* 472 (1984).

7. See *infra* notes 32-35 and accompanying text (discussing the physician's difficulty in assessing a premature infant's viability).

8. These are signs of respiratory distress syndrome, a frequent problem among very premature infants. GUSTAITIS & YOUNG, *supra* note 3, at 50. The authors compare a normal birth and a premature birth, explaining the premature infant's inability to breathe independently:

Until [birth], oxygen has come through the placenta. . . . A fetal artery called the ductus arteriosus allowed most of the flow to bypass the lungs, which were still developing. . . . Normally, labor prepares the baby to start breathing. . . . As the baby emerges, air rushes in with the first breath, filling the alveoli, the tiny air sacs in the lungs. The blood vessels of the lungs expand and suddenly become the route of least resistance for the blood. A coating, called a surfactant, appears in the lungs, preventing their total collapse during exhalation. . . .

The heart adapts to the new circulation pattern. . . . The ductus arteriosus closes.

. . . But premature infants are not yet ready for this awesome process. For them the stresses that would later have been beneficial are harsh and dangerous. Contractions may asphyxiate these babies. The alveoli, lacking the surfactant, tend to collapse during exhalation and are then held shut by surface tension. Each breath becomes harder. . . .

The failure of the lungs to stay expanded allows the carbon dioxide-laden blood to continue flowing through the fetal ductus arteriosus and from there through the baby's body. This means that the infant gets too little oxygen—he gasps, his chest heaves and retracts, the heart beats too fast.

ted to a neonatal intensive care unit [hereinafter NICU], where he is placed on a respirator.⁹

Six weeks later, the infant remains in the NICU. Because he is still dependant on the respirator, he has developed a chronic lung disease.¹⁰ A heart defect related to prematurity has failed to correct itself, which has exacerbated the lung problem.¹¹ The infant also exhibits signs of considerable brain damage due to his prematurity.¹² In addition, he has developed a severe bowel infection common among premature infants.¹³

The infant's prognosis is uncertain.¹⁴ Surgery will be necessary to assess the damage to his digestive tract.¹⁵ Dead bowel tissue must be removed, and if too much is removed for the infant to digest food, he will never be able to eat orally and will die within a few years.¹⁶ In addition, he may live with severe neurosensory handicaps due to brain damage.¹⁷

9. Tertiary care is "[a] level of medical care . . . available only in large . . . institutions. [It] include[s] . . . techniques and methods of therapy and diagnosis involving equipment and personnel that would not be economically feasible to have in a smaller institution because of the lack of utilization." *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 1966 (17th ed. 1993). A respirator is "[a] machine for prolonged artificial respiration." *Id.* at 1703.

10. This disease is called bronchopulmonary dysplasia. See *GUSTAFS & YOUNG supra* note 3, at 38 (explaining that with bronchopulmonary dysplasia, the "lung tissue [becomes] scarred, impeding the passage of air and interfering with the exchange of oxygen and carbon dioxide"); see also Richard J. Martin, *Chronic Lung Disease in the Extremely-Low-Birth-Weight Infant: Is It Avoidable?*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH* 36 (Richard M. Cowett & William W. Hay, Jr. eds., 1989) (discussing causal factors of bronchopulmonary dysplasia).

11. This refers to the problem of a persistent patent (open) ductus arteriosus. See *supra* note 8; Robert B. Cotton, *Persistent Patent Ductus Arteriosus in the Extremely-Low-Birth-Weight Infant* in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH* 44 (Richard M. Cowett & William W. Hay, Jr. eds., 1989).

12. Brain damage may be caused by asphyxia before or during birth. See *supra* note 8 (referring to asphyxia due to contractions). Asphyxia results in an insufficient supply of oxygen to the brain. See *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 160 (17th ed. 1993). Brain damage also may be caused by a moderate or severe hemorrhage of the immature blood vessels in the brain and a resulting fluid buildup known as hydrocephalus. See Lu-Ann Papile, *Periventricular-Intraventricular Hemorrhage in the Extremely-Low-Birth-Weight Infant*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE ROSS CONFERENCE ON PEDIATRIC RESEARCH* 145, 146-47 (Richard M. Cowett & William W. Hay, Jr. eds., 1989) (explaining that infants with birth weights under 1000 grams are more likely to have moderate (Grade III) or severe (Grade IV) hemorrhages and that "[p]osthemorrhagic hydrocephalus develops in approximately 50% of ELBW infants who have a moderate or severe [hemorrhage]").

13. This infection, called necrotizing enterocolitis, can cause parts of the bowel tissue to die. FRED M. FROHOCK, *SPECIAL CARE: MEDICAL DECISIONS AT THE BEGINNING OF LIFE* 42 (1986). While the exact cause of this disorder is unknown, prematurity is the greatest risk factor. Robert M. Kliegman, *Necrotizing Enterocolitis: A Consequence of Enteral Feeding*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH* 122, 123 (Richard M. Cowett & William W. Hay, Jr. eds., 1989).

14. See David K. Stevenson et al., *The 'Baby Doe' Rule*, 255 *JAMA* 1909, 1911 (1986) (describing the uncertainty of diagnosis and treatment decisions for premature infants).

15. FROHOCK, *supra* note 13, at 42-43.

16. *Id.*

17. See Maureen Hack, *Follow-Up of Extremely-Low-Birth-Weight Infants*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH* 154, 159 (Richard M. Cowett & William W. Hay, Jr. eds., 1989) (stating that up to one third of infants with birth weights under 750 grams "have moderate to severe neurosensory handicaps" two years later).

He may remain hospitalized and dependent on life-support machines for the rest of his life.¹⁸ Or, he may die very soon as a result of the bowel condition,¹⁹ the severe brain damage,²⁰ or the lung disease.²¹ Meanwhile, he is isolated, dependent on machines for his basic functions, and regularly subjected to invasive procedures which may cause him pain.²² His mother has decided that she wants aggressive medical treatment to be withdrawn and resuscitative measures to be withheld. What now? This hypothetical case illustrates some of the medical difficulties encountered with premature infants and some of the reasons that medical decision-making in such cases is difficult.

The care of very premature infants has become one the major frontiers of medicine.²³ By the 1920s, physicians realized that the birth process merited medical attention,²⁴ and hospital births gradually became standard.²⁵ The problems of premature births received little attention, however, until the 1960s.²⁶ During and after that decade, breakthroughs came about in ventilation and nutrition for premature infants, NICUs multiplied, and many more doctors specialized in neonatal practice and research.²⁷ In recent years, slightly less than two percent of all births in the United States have been very premature (under 32 weeks gestation).²⁸ "Prematurity is the leading cause of death in the neonatal period" and

18. See FROHOCK, *supra* note 13, at 37.

19. See Kliegman, *supra* note 13, at 123 (stating that infants with birth weights under 750 grams have a mortality of 40% to 65% from this disorder).

20. See Papile, *supra* note 12, at 146 (stating that infants with birth weights under 1000 grams have an approximate mortality rate of 40% from intraventricular hemorrhage); see *id.* at 153-54 (indicating that the mortality rate is very high for infants under 1000 grams with Grade IV hemorrhages and hydrocephalus).

21. See Maureen Hack and Avroy A. Fanaroff, *Changes in the Delivery Room Care of the Extremely Small Infant (<750 g)*, 314 *NEW ENG. J. MED.* 660, 662-63 (1986) (indicating that death may result from immature lung development or from complications of respiratory distress syndrome).

22. See Allen F. Fischer and David K. Stevenson, *The Consequences of Uncertainty: An Empirical Approach to Medical Decision Making in Neonatal Intensive Care*, 258 *JAMA* 1929, 1929 (1987) ("In any setting other than an intensive care unit, a daily routine that involved restraining neonates in bed, placing plastic tubes (endotracheal and gavage) into various body orifices, and pricking the feet with needles (phlebotomy) would be considered torture."); K.J.S. Anand and P.R. Hickey, *Pain and Its Effects in the Human Neonate and Fetus*, 317 *NEW ENG. J. MED.* 1321, 1326 (1987) (stating that premature newborns respond to painful stimuli by means of physiologic and behavior changes).

23. *E.g.*, Cowett, *supra* note 5, at 1.

24. GUSTAITIS & YOUNG, *supra* note 3, at 30.

25. *Id.* at 31.

26. *Id.* at 32. Several events fueled this increased interest in premature newborns. These events included the death of President and Mrs. Kennedy's premature baby, the provision of research funding by the March of Dimes, the beginning of Medicare funding, and the movement to lower the United States' high infant mortality rate. *Id.* at 32-34.

27. *Id.* at 36-37.

28. See NATIONAL CENTER FOR HEALTH STATISTICS, *VITAL STATISTICS OF THE UNITED STATES*, 1988, VOL. 1, NATALITY 261 (1990) (giving national statistics).

complications related to prematurity "vary in direct proportion to the degree of immaturity present."²⁹

Ethical dilemmas in the treatment of these infants are first confronted at the time of delivery because "no clear guidelines dictate the initial delivery room care of the extremely immature infant (<750 g)."³⁰ The physician must decide whether, and how aggressively, to treat the infant. This decision is complicated by the immediacy of the situation and by the presence of other persons under stress.³¹ It is further complicated by the difficult assessment of whether or not the infant is viable.³² In practice, more and more doctors are initially providing aggressive treatment in all but the worst cases.³³ While doctors do not want to begin treatment that will prove futile, they are even more wary of a delay in treatment that will harm an infant who does survive.³⁴ Because of the enormous uncertainty about prognosis at delivery, doctors also want to buy time with which to gather more information.³⁵

For the parents and doctors of premature infants who survive but do not improve, uncertainty may be prolonged considerably.³⁶ The situation is further complicated by the fact that the very treatments which such

29. *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 1585-86 (17th ed. 1993). Mortality for infants with birth weights under 2500 grams is 17 times higher than for infants weighing more than 2500 grams at birth. *Id.* at 1585. In addition, very premature infants are likely to be the largest group of patients in an NICU at any given time because they stay there so long. Cowett, *supra* note 5, at 1.

30. Hack & Faranoff, *supra* note 21, at 660.

31. See FROHOCK, *supra* note 13, at 63 (quoting a physician: "The decision, in order for it to be a good one, has to be one which is made under optimum conditions: least emotional tumult, greatest information and maximum participation of all people involved. . . . That's frequently not the case at the outset of a baby's life . . ."); see *id.* at 44 (quoting a physician: "[The resident is] sweating his brains out because he has a kid and an obstetrician's screaming and the parents are fainting and he is supposed to be a doctor and taking care of this . . .").

32. See Alan D. Bedrick, *Driving Home at 5 AM*, 146 *AM. J. DISEASES CHILDREN* 281 (1992) (describing a neonatologist's delivery-room uncertainty about viability). "Viable" means "capable of life. This term is applied to a newly-born infant, and especially to one prematurely born, which is not only born alive, but in such a state of organic development as to make possible the continuance of its life." *BLACK'S LAW DICTIONARY* 1566 (6th ed. 1990). The medical boundaries of viability are uncertain and changing. First, the definition of viability has changed over time. At the time of the *Roe v. Wade* decision, 410 U.S. 113 (1973), the accepted medical limits of viability were 28 weeks gestation and 1000 grams birth weight. Nancy K. Rhoden, *Trimesters and Technology: Revamping Roe v. Wade*, 95 *YALE L.J.* 639, 660 (1986). One 1990 medical dictionary retained this definition. *MOSBY'S MEDICAL NURSING DICTIONARY* 1234 (1990). One 1993 medical dictionary, however, defined the limits of viability as 24 weeks gestation and 500 grams birth weight. *TABER'S CYCLOPEDIA MEDICAL DICTIONARY* 2131 (17th ed. 1993). Second, the age and weight limits of viability may depend upon the resources of the medical center in which the infant is born. Roderic H. Phibbs, *Delivery-Room Management of the Extremely-Low-Birth-Weight Infant*, in *THE MICROPREMIE: THE NEXT FRONTIER, REPORT OF THE NINETY-NINTH ROSS CONFERENCE ON PEDIATRIC RESEARCH* 13 (Richard M. Cowett & William W. Hay, Jr. eds., 1989). A doctor's personal viewpoints about viability and prognosis also influence the delivery-room decision. *E.g.*, Hack & Faranoff, *supra* note 21, at 660.

33. Phibbs, *supra* note 32, at 13.

34. *Id.*

35. FROHOCK, *supra* note 13, at 61-64.

36. See Stevenson et al., *supra* note 14, at 1911 (discussing uncertainty in diagnosis and treatment decisions for premature infants).

infants need to survive may also be harmful.³⁷ Parents and doctors in such cases may contemplate withdrawal of certain treatments or withholding of resuscitative measures.³⁸ The ethical and legal issues are difficult and unique.³⁹

This Note will examine the issues of who should decide to withhold or withdraw medical treatment from premature infants and how these decisions should be made. Part II will examine the background and development of federal law and regulations relating to medical care of handicapped and disabled infants. While prematurity may not be a handicap or disability in itself, it is frequently associated with complications which may be handicaps or disabilities.⁴⁰ Part III will analyze the federal decision-making standards as well as alternative standards that courts have used in cases of infants and incompetent adults. Part IV will discuss the roles of various parties in the decision-making process. Part V will conclude that parents and doctors should make such decisions with the limited involvement of a hospital ethics committee, that judicial intervention should rarely be necessary, and that quality of life considerations must be part of a realistic benefits and burdens analysis.

II. BACKGROUND AND DEVELOPMENT OF FEDERAL LAW

A. EARLY ATTENTION TO NEONATAL TREATMENT DECISION-MAKING AND THE FIRST FEDERAL EFFORT TO REGULATE THIS AREA

In the early 1970s, commentary began to appear in medical and legal literature about the practice of "passive euthanasia" of very ill or handicapped newborns.⁴¹ This attention coincided with the United States

37. One three-year study of infants with birth weights under 750 grams showed that as the infants lived longer, more deaths were treatment-related. Hack & Faranoff, *supra* note 21, at 662. One doctor describes an example of this phenomenon:

I can't think of one infant under 1000 [grams] with grade IV [periventricular-intraventricular hemorrhage] and hydrocephalus who has left our nursery. The infants have lived for several months, even with hydrocephalus, but they have died of the complications of our therapy as well as their disorders. Everything we do to treat hydrocephalus just becomes more and more complex and produces more complications.

Papile, *supra* note 12, at 153-54. Treatments also may cause permanent disability, pain, and suffering. Amnon Goldworth and David K. Stevenson, *The Real Challenge of "Baby Doe": Considering the Sanctity and Quality of Life*, 28 CLINICAL PEDIATRICS 119 (1989).

38. Stevenson et al., *supra* note 14, at 1909.

39. Some formulations of ethical guidelines for the withholding or withdrawal of life-sustaining care specifically exclude newborns from their application. American Thoracic Society, *Withholding and Withdrawing Life-Sustaining Therapy*, 144 AM. REV. RESPIRATORY DISEASES 726 (1991); HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING 7 (David H. Smith & Robert M. Veatch eds., 1987).

40. *Supra* notes 10-18 and accompanying text.

41. See generally John Lantos, *Baby Doe Five Years Later: Implications for Child Health*, 317 NEW ENG. J. MED. 444 (1987).

Supreme Court decision upholding the legality of abortion⁴² and drew the interest of right-to-life activists.⁴³ Public interest in the medical treatment of newborns was heightened in response to the 1982 Bloomington, Indiana, "Baby Doe" case in which a state court upheld a parental decision to refuse surgery for an infant with Down's syndrome.⁴⁴ The Reagan Administration responded by ordering the Department of Health and Human Services to enforce section 504 of the Rehabilitation Act of 1973⁴⁵ against hospitals receiving federal funds to prevent withholding of medical services on the basis of handicap.⁴⁶ The Department of Health and Human Services promulgated regulations to ensure that handicapped infants received "medically beneficial treatment" in such facilities.⁴⁷ The regulations required that hospitals post notices entitled "Principles of Treatment of Disabled Infants"⁴⁸ and encouraged hospitals to form Infant Care Review Committees to be guided by principles set forth in the regulations.⁴⁹ In addition, they required enforcement by state child protective agencies and established a 24-hour hotline to the Department of Health and Human Services which anyone could call to report suspected non-compliance.⁵⁰ "Interpretive guidelines" accompanying the regulations

42. *Roe v. Wade*, 410 U.S. 113 (1973).

43. Lantos, *supra* note 41, at 444-45.

44. *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1587 (citing *In re Infant Doe*, No. GU 8204-004A (Ind. Cir. Ct. Apr. 12, 1982), *cert. denied*, 464 U.S. 961 (1983), *reprinted in Declaratory Judgment in the Infant Doe Case*, 2 ISSUES L. & MED. 77 (1986)) [hereinafter *Developments*]. For a detailed account of the facts of the case and the media's response, see HELGA KUHSE & PETER SINGER, *SHOULD THE BABY LIVE?* 11-16 (1985).

45. 29 U.S.C. § 794 (a) (1998). The statute provides that "[n]o otherwise qualified individual with handicaps . . . shall, solely by reason of her or his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ." *Id.* The statute formerly used the words "handicapped individual" instead of the current term, "individual with handicaps." 29 U.S.C. § 794(a) (1985), *amended by* 29 U.S.C. § 794(a) (1986).

"Individual with handicaps" is defined as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C. § 706(8)(B) (Supp. 1991).

The regulations implementing section 504 define "major life activities" as "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working." 45 C.F.R. § 84.3(j)(2)(ii) (1992).

The Supreme Court has defined an "otherwise qualified" person under section 504 as "one who is able to meet all of a program's requirements in spite of his handicap." *Southeastern Community College v. Davis*, 442 U.S. 397, 406 (1979).

46. KUHSE & SINGER, *supra* note 44, at 14, 21.

47. 45 C.F.R. § 84.55 & app. C (1992). According to at least one commentator, these executive actions were politically beneficial to the Reagan Administration because they appealed to right-to-life activists and advocates for the handicapped as well as civil libertarians, thereby "winning friends and dividing opponents . . . with only a small expenditure of regulatory and legal resources." Lantos, *supra* note 41, at 445-46.

48. 45 C.F.R. § 84.55(b)(2) (1992). These notices to be posted "at location(s) where nurses and other medical professionals . . . will see [them]" and were required to state that "nourishment and medically beneficial treatment . . . should not be withheld from handicapped infants solely on the basis of their present or anticipated mental or physical impairments." *Id.* at (b)(4).

49. 45 C.F.R. § 84.55(a)-(b), (f) (1992).

50. *Id.* § 84.55(b)-(e).

explained that “[f]utile treatment or treatment that will do no more than temporarily prolong the act of dying” was not required⁵¹ and left such determinations to “reasonable medical judgment.”⁵² They explained that while the regulations were not applicable to parents, health care providers must turn to child protective agencies or the courts if parents withheld consent for “medically beneficial treatment or nourishment.”⁵³ The guidelines also included the statement that “[w]ithholding of certain potential treatments from a severely premature and low birth weight infant on the grounds of reasonable medical judgments concerning the improbability of success or risks of potential harm to the infant would not violate section 504.”⁵⁴

The 1983 “Baby Jane Doe” case⁵⁵ in which a New York court upheld a parental refusal of surgery for an infant with spina bifida prompted the first challenge to these regulations.⁵⁶ A federal district court refused the Department of Health and Human Services access to the child’s records, reasoning that the hospital had not violated section 504 because it was not required to perform surgery when the parents had reasonably decided to refuse consent.⁵⁷ The Court of Appeals for the Second Circuit affirmed, finding that section 504 did not apply to treatment decisions involving defective newborns⁵⁸ because although handicapped, they were not “otherwise qualified” for services as section 504 required.⁵⁹

The regulations were later invalidated by the Supreme Court because the Department of Health and Human Services had failed to show any evidence of discrimination by hospitals which would necessitate the regulations.⁶⁰ A plurality of the Court also indicated that the regula-

51. *Id.* at pt. 84 app. C at (a)(2).

52. *Id.* at (a)(3).

53. *Id.* at (a)(4).

54. 45 C.F.R. pt. 84 app. C at (a)(5)(iv) (1992).

55. *Weber v. Stony Brook Hosp.*, 467 N.Y.S.2d 685, 687, *aff’d per curiam on other grounds*, 456 N.E.2d 1186, 469 N.Y.S.2d 63, *cert. denied*, 464 U.S. 1026 (1983).

56. *United States v. University Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff’d*, 729 F.2d 144 (2d Cir. 1984).

57. *University Hosp.*, 575 F. Supp. at 614-15.

58. *United States v. University Hosp.*, 729 F.2d 144, 161 (2d Cir. 1984).

59. *Id.* at 156. The court explained that:

section 504 prohibits discrimination against a handicapped individual only where the individual’s handicap is unrelated to, and thus improper to consideration of, the services in question. . . . [H]owever, where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to, the need for services.

. . . [T]he phrase “otherwise qualified” is geared toward relatively static programs or activities such as education, employment, and transportation systems. As a result, the phrase cannot be applied in the comparatively fluid context of medical treatment decisions without distorting its plain meaning.

Id. (citations omitted). The court went on to explain that the legislative history of section 504 did not reflect any intention on the part of Congress that the statute would apply to medical treatment decisions involving newborns. *Id.* at 157-61.

60. *Bowen v. American Hosp. Ass’n*, 476 U.S. 610, 631-39 (1986) (plurality opinion).

tions intruded on state authority by imposing enforcement requirements on state child protective agencies.⁶¹ However, the Court left open the question of whether section 504 could ever apply to neonatal treatment decisions.⁶²

B. THE SECOND FEDERAL EFFORT TO REGULATE NEONATAL TREATMENT DECISION-MAKING

After taking testimony from various right-to-life and disability groups and professional medical organizations,⁶³ Congress passed the Child Abuse Amendments of 1984 to pick up where the first federal effort had failed.⁶⁴ The 1984 provisions amended the Child Abuse Prevention and Treatment Act⁶⁵ [hereinafter CAPTA] to prevent "medical neglect," which included the "withholding of medically indicated treatment from disabled infants with life-threatening conditions."⁶⁶ Federal funding under CAPTA was conditioned upon enforcement by state child-protective agencies.⁶⁷ "Withholding of medically indicated treatment" was defined as the failure to provide treatment most likely to correct life-threatening conditions, with limited exceptions based upon an infant's potential for survival.⁶⁸ "[A]ppropriate nutrition, hydration, and medication" were to be provided in all cases regardless of survivability.⁶⁹

Again the Department of Health and Human Services promulgated regulations to implement the law.⁷⁰ The regulations defined an "infant" as "an infant less than one year of age."⁷¹ However, they included a refer-

61. *Id.* at 639-42.

62. *Id.* at 624.

63. See Stephen A. Newman, *Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants*, 15 AM. J. LAW & MED. 1, 6-7 (1989) (noting that no true consensus was reached among the professional medical groups, as the American Medical Association and the Association of Medical Colleges, representing most of the tertiary care facilities for newborns in the country, opposed the law).

64. 42 U.S.C. §§ 5106a-5106b, 5106g (1988).

65. 42 U.S.C. §§ 5101-5106h (1988).

66. 42 U.S.C. § 5106a(b)(10) (1988).

67. *Id.* But cf. Newman, *supra* note 63, at 6 (noting that funding under CAPTA is relatively low in comparison to other federal programs, so that a state may not be losing much money if it does not comply with the law).

68. 42 U.S.C. § 5106g(10) (1988). The exceptions to the treatment requirement are as follows:

- (A) the infant is chronically and irreversibly comatose;
- (B) the provision of such treatment would—
 - (i) merely prolong dying;
 - (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or
 - (iii) otherwise be futile in terms of the survival of the infant; or
- (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id.

69. *Id.*

70. 45 C.F.R. § 1340.15 (1992).

71. *Id.* § 1340.15 (b)(3)(i).

ence to premature infants quite different from that in the former set of regulations:⁷² "In addition to their applicability to infants less than one year of age, the standards set forth in . . . this section should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant . . . who was born extremely prematurely"⁷³

Interpretive guidelines which accompanied the regulations made clear the Department's emphasis on survivability as the key factor in determining whether treatment was beneficial.⁷⁴ The guidelines emphatically rejected "quality of life" considerations.⁷⁵

The federal attempts to regulate neonatal treatment decision-making under section 504 and under CAPTA have been criticized extensively.⁷⁶ They have caused confusion for judges⁷⁷ and physicians⁷⁸ about what standards should be used in deciding to withdraw medical treatment from newborns. Uncertainty is heightened with regard to premature infants because it is unclear whether the current federal regulations are even applicable in these cases.⁷⁹ It is useful to examine the substantive differences among the federal standards and alternative decision-making standards which have been proposed by courts and commentators for making decisions to withdraw medical treatment from infants.

III. DECISION-MAKING STANDARDS

A. THE NONDISCRIMINATION STANDARD

The federal regulations which were promulgated under section 504 of the Rehabilitation Act and subsequently invalidated⁸⁰ employed a non-

72. See *supra* note 54 and accompanying text (quoting the reference to premature infants found in the first set of federal regulations).

73. 45 C.F.R. § 1340.15(b)(3)(i).

74. 45 C.F.R. pt. 1340 app.

75. *Id.* at (9). The guidelines also provided definitions for terms used in the statutory exceptions to the treatment requirement, stating that "virtually futile" meant "highly unlikely to prevent death in the near future" and that "inhumane" treatment would only include treatment that was medically contraindicated or that would cause "significant pain and suffering . . . for an infant highly unlikely to survive." *Id.* at (8) & (9). The guidelines also stated that if parents refused consent for a treatment that would not in itself improve all life-threatening conditions but which was recommended as part of an overall treatment plan, child protective services should take action. *Id.* at (4).

76. See *infra* parts III.A-B.

77. The few state courts to address the federal laws and regulations have accorded them little weight. See *In re Guardianship of Barry*, 445 So.2d 365, 372 n.4 (Fla. Dist. Ct. App. 1984) (upholding the parents' decision to withdraw life support from a terminally ill infant, but only referring to federal requirements in a footnote which stated: "Of course, all medical and hospital personnel will have to abide by any state or federal regulations in this area."); see also *In re C.A.*, 603 N.E.2d 1171, 1185 n.1 (Ill. App. Ct. 1992) (McMorrow, J., dissenting) *cert. denied*, 610 N.E.2d 1264 (Ill. 1993) (noting that the federal law regarding nutrition, hydration, and medication did not apply in a case involving a "Do Not Resuscitate" order for a terminally ill infant).

78. E.g., *Developments, supra* note 44, at 1591.

79. See *supra* notes 72-73 and accompanying text (comparing the references to premature infants in the two sets of federal regulations).

80. See *supra* notes 48-62 and accompanying text.

discrimination approach to medical decision-making for handicapped infants.⁸¹ While this simple approach may work well in certain cases when the handicap is unrelated to the life-threatening condition, such cases are rare.⁸² This approach is especially ineffective with premature infants because of the number and complexity of their medical problems which often give rise to serious disabilities if the infants survive.⁸³ Commentators have also criticized this approach because it ignores the infant's future incapacities, no matter how severe they may be.⁸⁴

Despite these criticisms, the nondiscrimination standard has received renewed attention in recent court cases.⁸⁵ A federal district court in Virginia found in a 1993 case⁸⁶ that a hospital's withholding of ventilator treatment from an infant with anencephaly would violate the Rehabilitation Act because, unlike the parents in the *University Hospital*⁸⁷ and *Johnson*⁸⁸ cases, the infant's mother had requested that the treatment continue.⁸⁹ The hospital had conceded that the infant's anencephaly, which the court found to be a handicap under the Act, was

81. 45 C.F.R. § 84.55 & app. C (1992). See also Dolores M. Coulter, *The "Baby Doe" Dilemma: Withholding Treatment from Disabled Infants*, 60 MICH. B. J. 40, 44 (Jan. 1987) (explaining that the federal regulations required that handicap should not be relevant to a treatment decision).

82. See Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1299 (1985). As one physician explains,

In most cases, it is impossible to distinguish neatly medical conditions that need treatment from "handicaps." The further one gets from the Baby Doe paradigm of a baby with an underlying condition like Down's syndrome and a medical problem, such as esophageal atresia, that is easily separable from the underlying condition, the harder it is to distinguish discrimination from medical judgment, and the more inappropriate it is to use the Rehabilitation Act.

Lantos, *supra* note 41, at 445-46.

83. See Coulter, *supra* note 81, at 44.

84. E.g., Rhoden, *supra* note 82, at 1299-1302.

85. A federal district court in Pennsylvania found in a 1988 case that parents of an infant with cystic fibrosis had failed to state a claim under section 504 of the Rehabilitation Act for discrimination because infancy could not be characterized as a handicap. *Gerben v. Holsclaw*, 692 F. Supp. 557, 563-64 (E.D. Pa. 1988). The parents had alleged discrimination in the form of aggressive medical treatment that would not have been provided if the infant had "been a conscious adult able to speak for herself." *Id.* at 560. Thus, while the treatment was related to the handicapping condition (i.e., the cystic fibrosis), the basis of the asserted discrimination claim (i.e., the patient's age) did not fall within the Rehabilitation Act. See *id.*

In 1992, the Court of Appeals for the Tenth Circuit found that no claim existed under section 504 for failure to treat infants with spina bifida due to socioeconomic discrimination. *Johnson by Johnson v. Thompson*, 971 F.2d 1487, 1493 (10th Cir. 1992), *cert. denied*, 113 S. Ct. 1255 (1993). The court explained that section 504 did not apply to "discrimination among similarly handicapped persons" on the basis of socioeconomic status, but only to discrimination based upon the handicap itself. *Id.* The court also stated that no claim existed under section 504 for discrimination based upon anticipated handicap because the infants were not "otherwise qualified" for treatment under section 504. *Id.* Like the court in *University Hospital*, 729 F.2d 144, 161 (2d Cir. 1984), *supra* notes 58-59 and accompanying text, the *Johnson* court was unable to distinguish the handicap from the medical condition that would qualify the infant for treatment. *Johnson*, 971 F.2d at 1493.

86. *In re Baby K*, 832 F. Supp. 1022, 1027 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

87. *United States v. University Hosp.*, 729 F.2d 144, 161 (2d Cir. 1984).

88. *Johnson by Johnson v. Thompson*, 971 F.2d 1487, 1491 (10th Cir. 1992), *cert. denied*, 113 S. Ct. 1255 (1993).

89. *Baby K*, 832 F. Supp. at 1028. Anencephaly is a congenital defect in which most or all of the brain is missing. *Id.* at 1025.

the sole reason for withholding treatment.⁹⁰ The court also found that withholding ventilator treatment from the infant would violate the Americans with Disabilities Act (ADA),⁹¹ which prohibits discrimination by "public accommodations,"⁹² including hospitals,⁹³ against an individual with a disability.⁹⁴ "Disability" is defined as "a physical or mental impairment that substantially limits one or more of the major life activities."⁹⁵ Furthermore, the court noted that unlike the Rehabilitation Act, the ADA does not require the handicapped individual to be "otherwise qualified" for services.⁹⁶

Because an infant need not be "otherwise qualified" for services under the ADA, it is possible that a court may uphold a discrimination claim for withholding medical treatment even when parents have not consented to the treatment.⁹⁷ While the ADA may revive the nondiscrimination standard of decision-making for infants, a standard of decision-making based solely upon a nondiscrimination principle nevertheless may be inadequate in many cases.⁹⁸

B. THE SURVIVABILITY STANDARD OF THE CHILD ABUSE AMENDMENTS

The Child Abuse Amendments of 1984⁹⁹ and associated federal regulations¹⁰⁰ seem to require that medical decisions be based only upon an infant's potential for survival and that treatment be provided unless the infant is highly unlikely to survive.¹⁰¹ Only the exception for an infant who is "chronically and irreversibly comatose" is clearly not based upon survivability.¹⁰² Physicians and commentators have criticized this narrow federal standard.¹⁰³ First, the exception for the "chronically and irreversibly comatose" infant has been criticized for being too narrow.¹⁰⁴ As one

90. *Id.* at 1027.

91. *Id.* at 1029.

92. *Id.* at 1028 (quoting 42 U.S.C. § 12182).

93. *Id.* (citing 42 U.S.C. § 12181(7)).

94. *Baby K*, 832 F. Supp. at 1028 (quoting 42 U.S.C. § 12102(2)).

95. *Id.* (quoting 42 U.S.C. § 12102(2)).

96. *Id.* at 1028.

97. *Cf. id.* (relying in part upon a parental request for treatment in ordering continued treatment).

98. See *supra* notes 82-84 and accompanying text (discussing criticisms of the nondiscrimination standard).

99. 42 U.S.C. §§ 5106a-5106b, 5106g (1991).

100. 45 C.F.R. § 1340.15 (1992).

101. See *supra* notes 72-79 and accompanying text.

102. 42 U.S.C. § 5106g(10)(A) (1991). *But cf.* Rhoden, *supra* note 82, at 1313-17 (arguing that the exceptions to the treatment requirement implicitly recognize quality of life considerations); *Developments, supra* note 44, at 1602-03 (asserting that the exceptions allow "quality-of-life considerations [to] enter the decisionmaking process unacknowledged and unexamined").

103. *E.g.*, Loretta M. Kopelman et al., *Neonatologists Judge the "Baby Doe" Regulations*, 318 *NEW ENGL. J. MED.* 677, 681 (1988).

104. *Id.*

physician explains, "[d]etermining which of several states of permanent unconsciousness the infant is in may be a difficult, technical decision, and it is not clear why distinguishing between them is relevant in deciding whether nontreatment is justified."¹⁰⁵ For example, a persistent vegetative state is unlike a coma in that it involves a sleep-wake cycle, some eye movement, and some reflexive action; yet, it is nevertheless a state of permanent unconsciousness in which the patient has no awareness.¹⁰⁶ Other exceptions to the treatment requirement also have been criticized. The exception for treatment that would "merely prolong dying,"¹⁰⁷ for instance, may be vague in some cases, especially when advanced life-support technology is available.¹⁰⁸ The exception for treatment that would be both virtually futile *and* inhumane seems to require physicians to provide inhumane treatment unless it is also virtually futile, or virtually futile treatment unless it is also inhumane.¹⁰⁹ This standard could lead to an illogical course of treatment for a premature infant.¹¹⁰ The law's requirement for "appropriate nutrition, hydration, and medication"¹¹¹ regardless of prognosis also has been criticized for allowing potentially inconsistent

105. *Id.*

106. Newman, *supra* note 63, at 24-25. A Florida court, in a decision made before the current federal law was passed, allowed withdrawal of life-support systems from an infant in a persistent vegetative state who was terminally ill but who could have lived more than two years with the life-support systems. *In re Guardianship of Barry*, 445 So. 2d 365, 367-68, 372 (Fla. Dist. Ct. App. 1984). See also *In re L.H.R.*, 321 S.E.2d 716, 723 (Ga. 1984) (affirming a parental decision to withdraw life-support systems from an infant in a "chronic vegetative state," but providing no estimate of life expectancy with continued treatment). Such decisions made for incompetent adults also have been respected. Newman, *supra* note 63, at 25. See also *In re Quinlan*, 355 A.2d 647, 655, 671 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (allowing withdrawal of life-support systems from a 22-year-old woman while characterizing her condition as both "comatose" and a "persistent 'vegetative' state" but stating that she did exhibit eye movement and reaction to light and sound).

107. 42 U.S.C. § 5106g(10)(i) (1991).

108. Kopelman et al., *supra* note 103, at 682.

109. Newman, *supra* note 63, at 27.

110. Rhoden, *supra* note 82, at 1315.

[The standard] could thus justify, for example, withholding dialysis or cardiac surgery from the extremely premature infant who has suffered severe lung damage, brain hemorrhages and other calamities, and who now experiences heart disease or kidney failure. Given the pain and invasion of cardiac surgery or renal dialysis and the infant's slim chance of survival, doctors could view such treatments as "inhumane."

It would appear, however, that if such an infant developed an infection responsive to antibiotics, antibiotic treatment would be required because, while virtually futile, such treatment itself is not painful. But why not allow decision-makers to ask whether simply extending such an infant's life would itself be inhumane . . . ?

Id.

111. 42 U.S.C. § 5106g(10) (1988).

actions¹¹² and for the vagueness of the term "appropriate."¹¹³ In practice, courts have used alternative legal standards.¹¹⁴

C. "SUBSTITUTED JUDGMENT" VS. "BEST INTERESTS"

A competent patient is able to provide informed consent for medical care, including the withholding or withdrawal of treatment.¹¹⁵ An incompetent patient is unable to make such decisions.¹¹⁶ A surrogate decision-maker must decide whether to accept or reject medical treatment on behalf of the incompetent person.¹¹⁷ In doing so, the decision-maker "must seek to respect simultaneously both aspects of the patient's right to self-determination—the right to live, and the right, in some cases, to die of natural causes without medical intervention."¹¹⁸ Courts have described two related standards for making such decisions on behalf of incompetent persons: the "substituted judgment" standard¹¹⁹ and the "best interests" standard.¹²⁰

The substituted judgment standard requires the decision-maker "to ascertain the incompetent person's actual interests and preferences" and to attempt to make the decision which that particular incompetent person would make if he or she were competent.¹²¹ Some courts have attempted to use this standard when dealing with infants.¹²² A Florida court purported to employ the substituted judgment approach in allowing the with-

112. Newman, *supra* note 63, at 28-31. For a more detailed discussion of the criteria to be considered in making decisions about specific medical procedures or treatments, see *infra* part III.D.2.

113. See Kopelman et al., *supra* note 103, at 682 (explaining that the term "appropriate" may mean appropriate for a medical condition considered alone or appropriate for an individual patient with that condition and noting that "traditional medical judgment" considers the latter).

114. See *infra* parts III.C-E (discussing decision-making standards that courts have used in resolving medical treatment questions for infants and other incompetent patients).

115. See BLACK'S LAW DICTIONARY 779 (6th ed. 1990) (citing ZeBarth Swedish Hosp. Ctr., 499 P.2d 1, 8 (Wa. 1972), and defining "informed consent" as the principle of disclosure which allows the "patient . . . faced with a choice of undergoing the proposed treatment, or alternative treatment, or none at all, [to] intelligently exercise his judgment . . ."); see also *In re Conroy*, 486 A.2d 1209, 1222 (N.J. 1985). The *Conroy* court stated that

[t]he doctrine of informed consent presupposes that the patient has the information necessary to evaluate the risks and benefits of all the available options and is competent to do so. . . .

The patient's ability to control his bodily integrity through informed consent is significant only when one recognizes that this right also encompasses a right to informed refusal.

Id. (citing Note, *Informed Consent and the Dying Patient*, 83 YALE L.J. 1632, 1648 (1974)).

116. *E.g.*, *Conroy*, 486 A.2d at 1209, 1227.

117. *Id.*

118. *Id.*

119. *E.g.*, Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 431 (Mass. 1977).

120. *E.g.*, *In re Guardianship of Hamlin*, 689 P.2d 1372, 1375 (Wash. 1984).

121. *Saikewicz*, 370 N.E.2d 417, 431. For an account of the historical development of the substituted judgment standard, see *id.*

122. *E.g.*, *In re Guardianship of Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984).

drawal of life-support systems from a ten-month-old child but recognized that the doctrine was "difficult to apply to children" and that the court was actually "guided primarily by the judgment of the parents."¹²³ Because of the impossibility of ascertaining an infant's preferences or wishes about life-sustaining treatment, other courts have specifically rejected the substituted judgment standard in cases involving infants.¹²⁴

In cases involving incompetent patients whose preferences about life-sustaining treatment are not known, courts have used a best interests of the patient standard.¹²⁵ Unlike the subjective approach of the substituted judgment doctrine, the best interests standard is objective in that a decision is based upon the patient's best interests as determined by a surrogate decision-maker.¹²⁶ "Objective societally shared criteria" may be used.¹²⁷ However, the individual patient's best interests are determined with regard to his or her unique situation.¹²⁸ Courts have used this standard in cases involving minors whose preferences about life-sustaining treatment are unknown.¹²⁹ Physicians also have relied upon a best interests standard in making medical decisions for children.¹³⁰

123. *Id.* at 371.

124. *See In re Rosebush*, 491 N.W.2d 633, 639 (Mich. Ct. App. 1992) (noting that "as applied to immature minors and other never-competent patients, the substituted judgment standard is inappropriate because it cannot be ascertained what choice the patient would have made if competent"); *In re C.A.*, 603 N.E.2d 1171, 1180 (Ill. App. Ct. 1992) *cert. denied*, 610 N.E. 2d 1264 (Ill. 1993) (observing that "[t]he substituted judgment test is of limited relevance in the case of immature minors" and that "[i]f anyone's judgment is being substituted, it is that of the parents or some other person with a close interest in the child's welfare").

125. *E.g.*, *In re Guardianship of Hamlin*, 689 P.2d 1372, 1375 (Wash. 1984). *Cf. In re Conroy*, 486 A.2d 1209, 1229-33 (N.J. 1985) (proposing a three-tiered test based upon the degree of knowledge about the incompetent patient's preferences, so that a subjective standard is used when the patient's preferences are known, a "limited-objective test" is used when "some trustworthy evidence" exists about the patient's preferences, and a "pure-objective test" is used when no evidence about the patient's preferences is available).

126. *See Custody of a Minor*, 379 N.E.2d 1053, 1065 (Mass. 1978) (comparing the substituted judgment and best interests standards).

127. *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713, 721 (Conn. Super. Ct. 1984) (determining the criteria to be used in deciding the best interests of an incompetent patient when no expression has been made about treatment preferences). *See also Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (referring to objective criteria such as "relief of suffering, the preservation or restoration of functioning and the quality as well as the extent of life sustained").

128. *E.g.*, *Hamlin*, 689 P.2d at 1372, 1375 (emphasizing that such "decisions must be made on a case-by-case basis with particularized consideration of the best interests and rights of the specific individual").

129. *E.g.*, *In re Rosebush*, 491 N.W.2d 633, 635, 639 (Mich. Ct. App. 1992) (using a best interests standard for a ten-year-old girl in a persistent vegetative state because she was an "immature minor" whose choice could not be ascertained).

130. *Kopelman et al.*, *supra* note 103, at 683 ("There is a longstanding, well-accepted medical . . . tradition of basing medical care for children on a determination of their best interests (known as the 'best-interest standard' of medical care).").

D. BALANCING BENEFITS AND BURDENS

In ascertaining the patient's best interests, courts have balanced the benefits and burdens of treatment.¹³¹ The federal standard has been criticized for ignoring this aspect of the decision-making process by assuming that treatment will always be a benefit unless the infant is highly unlikely to survive.¹³² Realistically, it has been argued that the present and future burdens of the patient's medical disorders and treatments must be weighed against the present and future benefits of those treatments.¹³³ Physicians have endorsed this standard.¹³⁴ Likewise, courts have employed a benefits and burdens balancing standard in deciding whether life-sustaining treatment should be withdrawn from incompetent patients.¹³⁵

Questions may arise under the benefits and burdens analysis as to what factors should be considered.¹³⁶ These questions include: 1) whether and how "quality of life" considerations should influence a treatment decision;¹³⁷ 2) whether a treatment decision should turn on the nature of the particular treatment technology,¹³⁸ and 3) whether burdens on people other than the patient should receive consideration.¹³⁹

131. *E.g.*, *In re Conroy*, 486 A.2d 1209, 1231-32 (N.J. 1985).

132. *E.g.*, Newman, *supra* note 63, at 37.

133. *See id.* at 37-41 (arguing that burdens of medical disorders and treatments should be considered).

134. *See, e.g.*, Task Force on Ethics of the Society of Critical Care Medicine, 18 CRITICAL CARE MED. 1435, 1435 (1990) (stating that "[a]ny treatment derives its medical justification from the benefits that [it is] hope[d] to achieve" and that "[f]oregoing therapy should be discussed . . . [w]hen the burdens of therapy outweigh the benefits").

135. *See Conroy*, 486 A.2d at 1209, 1232 (employing a "pure-objective test" when no evidence of the patient's preferences exists, under which treatment may be withheld if "the net burdens of the patient's life with the treatment . . . clearly and markedly outweigh the benefits that the patient derives from life," and if the degree of pain and suffering would make the treatment inhumane); *see also Barber v. Superior Court*, 195 Cal. Rptr. 484, 491 (Cal. Ct. App. 1983) (using a benefits and burdens balancing test in permitting the withdrawal of life-support systems from an adult in a persistent vegetative state). The *Barber* court explained that

proportionate treatment is that which . . . has at least a reasonable chance of providing benefits to the patient, which benefits outweigh the burdens attendant to the treatment. Thus, even if a proposed course of treatment might be extremely painful or intrusive, it would still be proportionate treatment if the prognosis was for a complete cure or significant improvement in the patient's condition. On the other hand, a treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition.

Id.

136. *See infra* parts III.D.1-3 (discussing possible considerations in a benefits and burdens analysis).

137. *See infra* part III.D.1.

138. *See infra* part III.D.2.

139. *See infra* part III.D.3.

1. "Quality of Life" Considerations

The meaning of "quality of life" has been a source of confusion in treatment decisions for incompetent patients.¹⁴⁰ One court, for example, rejected "assessments of the personal worth or social utility of another's life" as improper "quality of life" judgments.¹⁴¹ However, the same court employed a benefits and burdens analysis which involved other quality of life considerations in weighing pain and suffering against "possible enjoyment" of life.¹⁴² These quality of life considerations focus on the quality of the individual's life to that individual.¹⁴³

Rejecting quality of life judgments would require maximum treatment to preserve biological life in all cases.¹⁴⁴ This approach would violate widely-accepted moral and religious beliefs about the nature of personhood,¹⁴⁵ beliefs which give value to "pleasure, thought, emotion, and recognition of and interaction with others."¹⁴⁶ It would also run counter to views expressed by many adults about when they would want treatment withdrawn from themselves.¹⁴⁷ Many of those who take care of the sickest infants on a daily basis reject this absolutist view as well.¹⁴⁸ At least one court upholding a decision to withdraw life-support systems from an adult also explicitly rejected this view.¹⁴⁹

140. *E.g.*, *In re Conroy*, 486 A.2d 1209, 1232-33 (N.J. 1985) (stating that pain, suffering, and a dim prognosis "[do] not mean that [the patient] is not enjoying what remains of his life"); *but see* Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 432 (Mass. 1977) (stating that continuing pain and suffering should be considered when placing a value on the "quality of life").

141. *Conroy*, 486 A.2d at 1232-33.

142. *Id.*

143. In attempting to evaluate the subjective quality of life of an individual who has never been competent, reference is made to objective criteria. *See supra* notes 126-28 and accompanying text (discussing cases in which courts referred to objective criteria in determining the best interests of incompetent patients). However, this evaluation differs from a quality of life analysis which looks only at the individual's worth to others and does not consider the experiences of the individual. *See Rhoden, supra* note 82, at 1334-38 (discussing the *Saikewicz* and *Conroy* decisions and the interpretation of "quality of life").

144. *Developments, supra* note 44, at 1603.

145. *See id.* (comparing mainstream religious views of human life with those of the right-to-life movement).

146. Rhoden, *supra* note 82, at 1320.

147. *See* Goldworth & Stevenson, *supra* note 37, at 121 (noting that many adults have expressed a preference for death over medical intervention that would produce continued pain and suffering and that treatment which saves an infant's life "may produce the very state that much of the public has accepted as justifying adult individuals in preferring death to life").

148. *See* FROHOCK, *supra* note 13, at 29. Frohock describes a discussion with NICU nurses:

They tell me it is impossible for anyone who is a strict right-to-lifer to work in the nursery. If you are one, you will change your views after being there a short while. All the nurses talking to me believe that the quality of life is important in deciding whether a life is worth living and a baby worth saving.

Id.

149. *In re Quinlan*, 355 A.2d 647, 669 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (stating that "the focal point of decision should be the prognosis as to the reasonable possibility of return to a cognitive and sapient life, as distinguished from the forced continuance of that biological vegetative existence to which Karen seems to be doomed").

Quite a number of specific criteria may be relevant to quality of life considerations in a benefits and burdens analysis.¹⁵⁰ One commentator has proposed a standard which would guide decision-making with reference to the relative weight of medical criteria.¹⁵¹ This quality of life standard would permit withdrawal of aggressive treatment if an infant faces any one of the following outcomes: certain death during infancy, permanent unconsciousness, unceasing pain, dependence on invasive and restrictive technology such as a respirator, or an incapacity for human interaction.¹⁵² However, this standard may be helpful only in the rare cases in which prognosis is relatively certain.¹⁵³ In practice, physicians constantly reevaluate and balance medical criteria and quality of life factors when determining treatment in uncertain cases.¹⁵⁴

2. *Distinctions Among Specific Medical Procedures*

When it is determined that certain treatments are no longer in the infant's best interests and should be withdrawn, questions may arise as to whether other, less aggressive, treatments should be continued.¹⁵⁵ The federal standard requires that "appropriate nutrition, hydration, and medication" should be maintained in all cases, regardless of survivability or the status of other treatment.¹⁵⁶ Commentators have criticized this distinction between nutrition, hydration, and medication as opposed to other treatments, noting that such a standard can lead to inconsistent treatment and may needlessly prolong suffering.¹⁵⁷ Physicians' organizations have

150. One commentator suggests that the following factors should be weighed:

medical diagnosis; clinical course of medical conditions since birth; length of life expectancy; survival chances with and without treatment; expected neurological, physical and mental impairment; developmental potential; availability of corrective treatment; extent of treatment benefits if cure is not possible; pain and suffering associated with medical condition; pain and suffering associated with treatment; invasiveness, stressfulness, and duration of treatment; need for repeated medical interventions; need for lengthy hospitalization or institutionalization; risks associated with treatment; and the proven, experimental, or untested nature of treatment.

Newman, *supra* note 63, at 50.

151. Rhoden, *supra* note 82, at 1322-23.

152. *Id.*

153. *Id.* at 1323.

154. See Fischer & Stevenson, *supra* note 22, at 1930-31 (explaining that a "wait until certainty" approach, when used in all cases, prolongs suffering for very disabled infants, while an "individualized prognostic strategy" allows reexamination of a treatment plan over time based upon statistical estimates and the individual infant's response to treatment; for example, for infants with birth weights of 500 to 800 grams who are dependant on ventilators after 28 days and who have a poor clinical history as well as a poor statistical mortality estimate, withdrawal of aggressive support is discussed with parents).

155. E.g., Rhoden, *supra* note 82, at 1325.

156. 42 U.S.C. § 5106g(10) (1988).

157. See Rhoden, *supra* note 82, at 1325 (noting that when prolonged life has been found not to be in the child's best interests, further "treatments inconsistent with this recognition" should not be provided); *Developments*, *supra* note 44, at 1601 ("Continued provision of food and water . . . may render the original decision to withhold treatment both meaningless and cruel."); Newman, *supra* note 63, at 29 ("Does the permanently vegetative infant, whose damaged brain can support vital signs

specifically disagreed with the federal requirement to provide nutrition, hydration and medication to infants in all cases,¹⁵⁸ and ethical standards developed by a variety of experts have rejected the view that such treatments are always advisable.¹⁵⁹

Some courts also have refused to employ distinctions between types of treatment.¹⁶⁰ A California court, for instance, found no ethical or legal difference between a respirator and intravenous feedings.¹⁶¹ While recognizing that nourishment carried "emotional symbolism," the court explained that "medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration" and stated that "[t]heir benefits and burdens ought to be evaluated in the same manner as any other medical procedure."¹⁶² In agreeing with this reasoning, a New Jersey court explained that "artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoonfeeding—they are medical procedures with inherent risks and possible side effects"¹⁶³ Like respirators, they "prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own."¹⁶⁴

3. *Burdens on Others*

Family members of an infant with severe incapacities face burdens of their own.¹⁶⁵ The financial cost of long-term neonatal intensive care is enormous.¹⁶⁶ An anencephalic infant who was the subject of a 1993 court decision¹⁶⁷ had so far spent approximately 120 days in a Virginia hospital

but not consciousness, truly benefit from feeding tubes that may prolong a vegetative existence for years?").

158. *E.g.*, Task Force on Ethics of the Society of Critical Care Medicine, *supra* note 134, at 1439 (stating that the federal standard is "overly restrictive" and that nutrition, hydration, and medication "may be ethically unjustified" when the physician feels that they "are harmful to the patient's interests").

159. *E.g.*, HASTINGS CENTER, *supra* note 39, at 60 (noting that although nutrition and hydration usually are beneficial, their use should be evaluated in each individual's case); *id.* at 65 (explaining that medication may be burdensome in certain cases, as when it must be injected repeatedly or when it causes complications).

160. *E.g.*, Barber v. Superior Court, 195 Cal. Rptr. 484, 490 (Cal. Ct. App. 1983).

161. *Id.*

162. *Id.* The Barber court also refused to distinguish between "disconnecting" life-support machines and withholding "manually administered" treatments, explaining that discontinuing machines should be viewed as an omission rather than an affirmative act. *Id.*

163. *In re Conroy*, 486 A.2d 1209, 1236 (N.J. 1985).

164. *Id.* See also *In re Hier*, 464 N.E.2d 959, 964 (Mass. App. Ct. 1984) (characterizing nutrition as a medical treatment and refusing to order surgical implantation of a feeding tube for an incompetent adult due to the invasiveness of the procedure and other risk factors).

165. *E.g.*, FROHOCK, *supra* note 13, at 138 (discussing financial burdens on families).

166. See, e.g., *id.* at 138 (noting that at one hospital, the average daily cost of an NICU patient was approximately one-third greater than the hospital average and exceeded only by the cost of adult intensive care).

167. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *affd.*, 16 F.3d 590 (4th Cir. 1994).

"at a minimum cost of \$1,450 a day."¹⁶⁸ Very premature infants, when they survive, usually remain in intensive care for many weeks.¹⁶⁹ If they remain incapacitated and dependant upon life-support machines, they may stay in a hospital indefinitely.¹⁷⁰ It is almost always impossible for families to pay for this type of long-term hospital care themselves, and insurance or governmental assistance will not always make up the difference.¹⁷¹ Families also suffer severe emotional strain in such situations.¹⁷² The financial and emotional impact can have a harmful effect on siblings,¹⁷³ as well as on the parents' marriage.¹⁷⁴ When a severely impaired infant is able to leave the hospital, these factors may combine to make it impossible for parents to provide adequate care for the infant at home.¹⁷⁵ The family may find it necessary to place the child in an institution, which in itself may affect the child's quality of life.¹⁷⁶

Some commentators argue that family considerations (such as the availability of long-term home care or institutionalization) are not relevant in a benefits and burdens analysis.¹⁷⁷ At the other end of the spectrum, one physician has proposed a quality of life standard that would accord such factors as much weight as the infant's long-term medical prognosis.¹⁷⁸ Few courts have dealt directly with these issues.¹⁷⁹

168. *Mom fights for Baby's Life*, MINNEAPOLIS STAR TRIBUNE, Sept. 25, 1993, at 5A.

169. See Cowett, *supra* note 5, at 1 (stating that most extremely-low-birth-weight infants (weighing under 1000 grams at birth) "stay in the nursery until at least the time they were due to be born at term").

170. Frohock, *supra* note 13, at 37.

171. *Id.* at 138 (explaining that Medicaid, the principal source of funds for intensive care, pays a maximum daily rate which falls considerably short of the average daily cost of neonatal intensive care). See also Newman, *supra* note 63, at 52 (posing the question: "[i]f [the government] will not itself pay these astronomical bills, should it tell a family to take the risk of going bankrupt for a chance, perhaps slim, that an infant will survive, but with a lifelong, incurable major impairment?").

172. *Developments*, *supra* note 44, at 1605.

173. Newman, *supra* note 63, at 52.

174. GUSTAITIS & YOUNG, *supra* note 3, at 239.

175. See Newman, *supra* note 63, at 53 (explaining that such children may need constant supervision and assistance with basic functions).

176. See GUSTAITIS & YOUNG, *supra* note 3, at 238-39 (discussing the chronological progression from therapy programs to foster homes or pediatric facilities and, finally, to state hospitals or adult programs where a patient shares one caretaker with many other patients); Newman, *supra* note 63, at 53-54 (discussing the poor quality of some pediatric nursing homes).

177. See Rhoden, *supra* note 82, at 1322 (arguing that "social factors" should not be considered in medical decision-making because social problems can be changed and because child custody can be resolved separately from medical treatment issues).

178. See GUSTAITIS & YOUNG, *supra* note 3, at 192 (describing a formula of "QOL = NE x (H + S)," in which QOL is quality of life, NE is natural endowment, and H and S are the contributions from home and society, respectively, so that a child with a higher natural endowment might still have a very poor quality of life if no contribution can be expected from home or society).

179. *But see* Barber v. Superior Court, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (applying a best interests analysis to approve withdrawal of life-support systems from an adult and giving weight to "the impact of the decision on those people closest to the patient" because "most people are concerned about the well-being of their loved ones"). Cf. Foody v. Manchester Memorial Hosp., 482 A.2d 713, 717 (Conn. Super. Ct. 1984) (noting that the family of an adult patient "ha[d] no financial interest in the outcome of [the] proceeding" to terminate life-support systems, as expenses were covered). See also *In re Guardianship of Barry*, 445 So.2d 365, 371 (Fla. Dist. Ct. App. 1984) (allowing withdrawal of life-support systems from an infant in a persistent vegetative state and noting

E. BALANCING RIGHTS AND INTERESTS

In making treatment decisions for incompetent patients, many courts have used a second balancing test in conjunction with the benefits and burdens analysis under which they weigh the rights of the patient against the interests of the state.¹⁸⁰ Courts have found that an incompetent adult possesses the same right to reject life-sustaining treatment as a competent patient and that a surrogate decision-maker may exercise this right on behalf of the patient.¹⁸¹ This right to reject life-sustaining treatment stems in part from the common law right to control one's own body.¹⁸² It also may stem from federal constitutional protections of privacy.¹⁸³ Finally, a right to refuse medical treatment may stem from state constitutional guarantees of privacy and from state statutes specifically granting such a right.¹⁸⁴

The state's interest in the preservation of life is the most significant interest which may be balanced against the right of an individual to refuse medical treatment.¹⁸⁵ This interest may be seen as encompassing both an interest in the individual patient's life and "an interest in preserving the sanctity of all life."¹⁸⁶ Other state interests include prevention of suicide, protection of third parties, and protection of the integrity of the medical profession.¹⁸⁷ In the case of a competent adult, these state interests usu-

that the parents' decision "was not motivated by any financial strain" because insurance was covering the infant's medical bills).

180. *E.g.*, *In re Conroy*, 486 A.2d 1209, 1221-27 (N.J. 1985).

181. *E.g.*, *id.* See also *Foody* 482 A.2d at 717-20 (reasoning that "[t]o deny the exercise because the patient is unconscious or incompetent would be to deny the right. . . . It is incumbent upon the state to afford an incompetent the same panoply of rights and choices it recognizes in competent persons"). *But see* *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 279-80 (1990) (refusing to decide the question of whether an incompetent person had the same right to refuse treatment as a competent person and stating that "[a]n incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right").

182. See *Conroy*, 486 A.2d at 1221 (explaining that the doctrine of informed consent protects a patient's control over his or her body and includes "a right to informed refusal"); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 424 (Mass. 1977) (expressing this concept as the right to be "free from nonconsensual invasion of . . . bodily integrity").

183. The *Quinlan* court first articulated this concept, citing Supreme Court decisions which had granted constitutional protection to certain privacy interests. See *In re Quinlan*, 355 A.2d 647, 663 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (citing *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Stanley v. Georgia*, 394 U.S. 557 (1969); *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973)). The Supreme Court, while not explicitly affirming a constitutional privacy right to refuse life-sustaining treatment, agreed in a 1990 case that this right could "be inferred from [its] prior decisions." *Cruzan*, 497 U.S. at 278. The Court assumed "for purposes of [the] case . . . that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition." *Id.* at 279.

184. See *In re Rosebush*, 491 N.W.2d 633, 635 (Mich. Ct. App. 1992) (noting that this right may be derived from a statute); *In re Guardianship of Barry*, 445 So.2d 365, 370 (Fla. Dist. Ct. App. 1984) (noting that the state constitution expressly guaranteed a right of privacy). See generally Newman, *supra* note 63 (discussing state constitutional barriers to federal regulation of neonatal treatment decisions).

185. *E.g.*, *Conroy*, 486 A.2d at 1223.

186. *Id.*

187. *E.g.*, *id.* at 1224-25.

ally are readily outweighed by the individual's rights of self-determination and privacy.¹⁸⁸ Courts also have found that an incompetent patient's rights outweigh these state interests.¹⁸⁹

The right to forego life-sustaining treatment has been extended to incompetent minors as well as adults.¹⁹⁰ When minors are involved, three sets of rights or interests must be balanced; in addition to the rights of the patient and the interests of the state, parental rights must be considered.¹⁹¹ Protection of parental decision-making authority stems from United States Supreme Court cases such as *Parham v. J.R.*,¹⁹² *Wisconsin v. Yoder*,¹⁹³ *Pierce v. Society of Sisters*,¹⁹⁴ and *Meyer v. Nebraska*.¹⁹⁵ This protected parental authority has been found to include decisions about medical treatment for children.¹⁹⁶ In several cases upholding a parental refusal of life-saving or life-sustaining treatment for a child on nonreligious grounds, courts have accorded considerable weight to parental rights.¹⁹⁷ However, most of these described the parental right not simply

188. See *id.* at 1224-26 (explaining that certain state interests were inapplicable to a competent person's decision to refuse life-sustaining treatment because withdrawing treatment was not suicide, the medical profession did not require treatment in all cases, and third party interests were significant only in cases where public health or potential abandonment of children was involved). See also *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 426 (Mass. 1976). The *Saikewicz* court explained:

The constitutional right to privacy . . . is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice.

Id.

189. See *e.g.*, *In re Quinlan*, 355 A.2d 647, 663-64 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (explaining that "the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims" and that "[u]ltimately there comes a point at which the individual's rights overcome the State interest").

190. *E.g.*, *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984); *In re Rosebush*, 491 N.W.2d 633, 636 (Mich. Ct. App. 1992); *In re Guardianship of Barry*, 445 So.2d 365, 370 (Fla. Dist. Ct. App. 1984).

191. *Custody of a Minor*, 379 N.E.2d 1053, 1061-62 (Mass. 1978). See also *Developments, supra* note 44, at 1594-1600 (discussing parental and individual rights, state interests, and the merits of rights and obligations theories in the context of medical decision-making for children).

192. 442 U.S. 584, 602-603 (1979). The *Parham* court explained that:

[t]he law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions. More important, historically it has been recognized that natural bonds of affection lead parents to act in the best interests of their children.

Id. at 602.

193. 406 U.S. 205, 232 (1972) (recognizing a parental right stemming from the right of free exercise of religion to determine a child's religious and educational upbringing).

194. 268 U.S. 510, 534-35 (1925) (recognizing a parental right to determine a child's education).

195. 262 U.S. 390, 399 (1923) (recognizing parental child-raising rights).

196. See, *e.g.*, *Custody of a Minor*, 379 N.E.2d 1053, 1062 (Mass. 1978) (stating that courts have been reluctant to override parental refusals of medical treatment when "the child's condition is not life-threatening, and [when] the proposed treatment [involves] great risk"). See also Robyn S. Shapiro & Richard Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827, 828-32 (1986) (discussing cases involving parental decisions about medical treatment for older children).

197. See *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) (upholding a parental decision to withdraw life-support systems from an infant in a chronic vegetative state); *In re Rosebush*, 491 N.W.2d 633, 636-37 (Mich. Ct. App. 1992) (upholding a parental decision to withdraw life-support

as an independent right of control over the child but as a capacity to determine the child's best interests and "speak for" the child, in effect, exercising the child's right on behalf of the child.¹⁹⁸ Courts in other cases, however, found that the parental right to withhold treatment was outweighed by the interests of the child and the state when life-saving treatment was promising.¹⁹⁹

The practice of balancing rights and interests in making treatment decisions for minors has been criticized.²⁰⁰ One commentator asserts that the focus on parental rights is unwise because traditional rights theories involve individuals vis-a-vis the state, and that this approach breaks down when children's rights are also involved.²⁰¹ A right-to-life standard as applied to seriously ill and incapacitated infants also has been criticized because it "ignores the fact that *health* is the primary goal of medicine, not simply the maintenance of life."²⁰²

IV. PARTIES IN THE DECISION-MAKING PROCESS

A. PARENTS

Physicians have recognized the importance of the parental role in making treatment decisions for infants, particularly premature infants whose cases are often uncertain.²⁰³ Courts also have recognized the

systems from a minor in a persistent vegetative state); *In re Phillip B.*, 156 Cal. Rptr. 48, 50-51 (Cal. Ct. App. 1979) (upholding a parental refusal of corrective heart surgery for twelve-year-old child with Down's syndrome).

198. See *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) ("In any discussion of who will exercise the incompetent patient's constitutional right to refuse treatment, we must recognize the importance of the family The right of the parent to speak for the minor child is . . . embedded in our tradition and common law"); *In re Rosebush*, 491 N.W.2d 633, 636-37 (Mich. Ct. App. 1992) ("It is well established that parents speak for their minor children in matters of medical treatment. . . . Because medical treatment includes the decision to decline lifesaving intervention, it follows that parents are empowered to make decisions regarding withdrawal or withholding of lifesaving or life-prolonging measures on behalf of their children." (citation omitted)).

199. See, e.g., *Custody of a Minor*, 379 N.E.2d 1053, 1056, 1063 (Mass. 1978) (ordering chemotherapy for a minor child when the treatment offered a "chance for a cure and a normal life," there was no alternative treatment, and the child would die without the treatment); *Application of Cicero*, 421 N.Y.S.2d 965, 966-68 (1979) (ordering corrective surgery for an infant's spinal disorder when the infant would die without the treatment but would have moderate handicaps with the treatment). In a unique 1993 case, a Virginia court strongly affirmed parental rights but also relied upon a child's "constitutional right to life" in ruling that a hospital could not refuse a mother's request for continued ventilator treatment for an infant with anencephaly. *In re Baby K*, 832 F. Supp. 1022, 1028 (E.D. Va. 1993).

200. E.g., Carl. E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 CAL. L. REV. 151, 157-58.

201. *Id.* Schneider also argues that the basis of parental rights is tenuous and that a focus on parental rights influences parents to place their own concerns first. *Id.* at 158-64.

202. FROHOCK, *supra* note 13, at 214.

203. E.g., Fischer & Stevenson, *supra* note 22, at 1931; Stevenson et al., *supra* note 14, at 1911. Ethical guidelines on the termination of life-sustaining treatment developed by the Society of Critical Care Medicine explain that "[t]he unique interdependence between the child and family justifies the family's participation in treatment-related decisions. Within the family unit, there is a strong presumption in favor of parents as primary decision-makers for their children." Task Force on Ethics of the Society of Critical Care Medicine, *supra* note 134, at 1438.

advisability of giving parents the primary role in decisions to withhold or withdraw care from infants.²⁰⁴ However, commentators have argued for limits to parental discretion.²⁰⁵ Emotional distress at the premature birth of a child may be overwhelming, and parental ability to make sound decisions may initially be impaired.²⁰⁶ Fear of raising an impaired child may influence decisions,²⁰⁷ as may individual biases of parents about such children.²⁰⁸ Finally, some parents may harbor "idiosyncratic" views such as a fear of technology or a moral bias against blood transfusions.²⁰⁹ All of these factors may interfere with a parent's ability to determine a child's best interests.²¹⁰

B. PHYSICIANS

Physicians may have biases of their own which may interfere with an objective best interests analysis in some cases.²¹¹ A bias toward nontreatment in marginal cases may cause a physician not to recommend aggressive treatments.²¹² On the other hand, some doctors may have a bias toward aggressive treatment for a number of reasons.²¹³ As one observer of an NICU relates, "[m]any of the sickest babies in the nursery appeal to the doctors' self-image as crisis managers."²¹⁴ Doctors also may favor aggressive treatment in order to obtain research funding, practice treatment techniques, or instruct junior physicians.²¹⁵ They may wish to further the reputation of the hospital as a research center or a facility with high survival statistics for very premature infants.²¹⁶ They also may be influenced by personal moral judgments.²¹⁷ In some cases, doctors may

204. *E.g.*, *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984); *In re C.A.*, 603 N.E.2d 1171, 1180 (Ill. App. Ct. 1992), *cert. denied*, 610 N.E. 3d 1264 (Ill. 1993). *See supra* notes 196-198 (discussing cases in which courts have implicitly recognized the advisability of parental decision-making in upholding parental decisions to withhold or withdraw treatment).

205. *E.g.*, Newman, *supra* note 63, at 51.

206. *Developments*, *supra* note 44, at 1608.

207. *Id.*

208. Shapiro & Barthel, *supra* note 196, at 835.

209. Newman, *supra* note 63, at 51 (quoting PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 218 (1983)).

210. *See, e.g.*, Task Force on Ethics of the Society of Critical Care Medicine, *supra* note 134, at 1438 ("Parents . . . must demonstrate the ability to understand the facts of their child's condition and prognosis and be able to put the child's best interest above other considerations.").

211. *E.g.*, FROHOCK, *supra* note 13, at 48-49.

212. *See id.* (relating one doctor's description of omissions in treatment to hasten death in cases with a poor prognosis).

213. *E.g.*, FROHOCK, *supra* note 13, at 56.

214. *Id.*

215. Newman, *supra* note 63, at 51.

216. *Id.* *See also* Bedrick, *supra* note 32, at 282 ("We read articles in which intensive care nurseries proclaim with pride the weight and gestational age of the smallest baby they have had survive in their units.")

217. Newman, *supra* note 63, at 51.

cross the fine line between conventional and experimental treatments.²¹⁸ Whether a doctor provides less aggressive or more aggressive treatment, problems can arise in communication with parents.²¹⁹ The physician usually has an authoritative position vis-a-vis the parents in discussions of treatment options and may present options with a slanted view.²²⁰ Communication also may be less effective if doctors are uncertain about the medical situation or if they do not provide parents with enough information because of delicacy, time constraints, or a lack of appreciation of the wide gap between the parents' understanding and their own.²²¹ In such cases, parental consent may not be truly informed.²²² One physician illustrates these problems in describing an experience that occurred with a premature infant with whom he had tried experimental procedures:

The baby was presented at grand rounds as a triumph of mechanism-guided treatment, and I was made to feel like a hero. My rescue fantasy was fulfilled.

I was very disappointed that the parents did not share these joyous feelings of high adventure. . . . They were completely overwhelmed by what I was doing to prolong the life of this . . . baby. I tried to focus their attention on the miraculous present, and I was annoyed that their thoughts were fixed on an uncertain future. They kept asking about long-term outlook. I was forced to admit I had no idea about prognosis because few, if any, infants of this size ever survived. . . .

218. See *id.*, at 33-37 (explaining the difficulty of distinguishing between experimental treatment and conventional treatment). Newman states:

When medical hypotheses are rigorously tested, presented in the professional literature and subject to widespread scrutiny and criticism, truly worthy techniques pass from the domain of research to the domain of accepted conventional therapy. The precise moment of passage is impossible to ascertain. Indeed, there is no exact moment, but a transition time in which a therapeutic idea is more or less accepted, more or less regarded as useful in certain generally defined situations.

Id. at 34.

219. *E.g.*, FROHOCK, *supra* note 13, at 160-61.

220. *Id.* As Frohock explains:

Nowhere is the inequality between parents and doctors more clearly expressed than in the transmission of information. Most of the time physicians will fairly and lucidly lay out various options so that parents can make a choice. But when they want parents to select a particular option, they will present the facts of the case and the proposed therapy in terms designed to sway the parents. For example, by labeling a therapy as "experimental" or "untested" or "new and radical," a doctor can be reasonably sure of a negative response. If the negative choice is still not forthcoming, the doctor can say that the therapy is "unknown" or "of marginal benefit" of [sic] has "unpredictable side effects." On the other hand, if a doctor describes a therapy as "promising" or "improved" or "hopeful" or "quite possibly effective," the parents are more likely to select that treatment.

Id.

221. GUSTAFS & YOUNG, *supra* note 3, at 159.

222. *Id.*

As I take a long look back at this experience, I see that the moral judgment of these parents was much more highly developed than mine.²²³

C. HOSPITAL ETHICS COMMITTEES

Many hospitals, particularly tertiary care centers, have developed internal ethics committees to provide guidance and/or review for difficult treatment decisions.²²⁴ An ethics committee may be made up of physicians, nurses, attorneys, clergy members, medical ethicists, hospital administrators, and community members.²²⁵ While few courts have critiqued the role of ethics committees in treatment decisions for incompetent patients,²²⁶ commentators have noted benefits, as well as problems, with committee involvement.²²⁷

On the one hand, ethics committees may provide expedited, flexible, and objective review in a nonadversarial setting.²²⁸ They may promote consistency in the decision-making process.²²⁹ They also may ensure that community values are incorporated into the process.²³⁰ Committees can provide additional expertise from doctors and nurses not directly involved with the patient and a forum for full, interdisciplinary discussion of treatment options.²³¹ This may help to counter any individual physician biases.²³² Committee involvement may facilitate communication between the parents and the attending physician,²³³ which may lessen the intimidation that parents may feel in dealing with a physician.²³⁴ The committee can ensure that parents are fully informed about the medical facts²³⁵ and that they are making a rational decision rather than an emotional

223. William A. Silverman, *Overtreatment of Neonates? A Personal Retrospective*, 90 PEDIATRICS 971, 971-72 (1992).

224. E.g., Rebecca A. Havlisch, *Treatment Decision-Making in the Neonatal Intensive Care Unit—Governmental Regulation Compromises Parental Autonomy*, 13 WM. MITCHELL L. REV. 951, 981-82 (1987).

225. E.g., *Developments*, *supra* note 44, at 1612. See also 45 C.F.R. §§ 84.55(a) & (f) (providing guidelines for a model Infant Care Review Committee developed by the Department of Health and Human Services).

226. *But see In re Quinlan*, 355 A.2d 647, 668-69 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (suggesting involvement of an ethics committee in treatment decisions primarily to diffuse responsibility).

227. E.g., Shapiro & Barthel, *supra* note 196, at 849-50.

228. Rhoden, *supra* note 82, at 1343.

229. *Id.*

230. *Developments*, *supra* note 44, at 1612.

231. Newman, *supra* note 63, at 55.

232. Shapiro & Barthel, *supra* note 196, at 848.

233. Newman, *supra* note 63, at 55.

234. GUSTAITIS & YOUNG, *supra* note 3, at 160-61.

235. *Id.*; Shapiro & Barthel, *supra* note 196, at 848.

one.²³⁶ Finally, review and guidance from an ethics committee may prevent judicial involvement.²³⁷

However, commentators also have noted disadvantages and dangers of ethics committee involvement in treatment decision-making.²³⁸ A committee may make unsatisfactory compromises to achieve consensus, and it may inappropriately diffuse decision-making responsibility.²³⁹ Physicians on the committee may only serve to reinforce biases of the treating physician,²⁴⁰ and members may be motivated by institutional biases.²⁴¹ If a committee with nonphysician members has a great deal of influence over treatment decisions, it may venture into the unlicensed practice of medicine.²⁴² In addition, privacy and confidentiality for patients and families may be jeopardized if nonmedical and even noninstitutional committee members learn the details of each case.²⁴³

Some of these potential dangers may be avoided by making committee review optional and subject to parental consent.²⁴⁴ Legal limitations on committee authority and a guarantee of parental access to committee records may be advisable.²⁴⁵ Commentators also have argued that ethics committees should "work from clearly articulated principles and guidelines."²⁴⁶ In addition, committees may benefit from the membership of parents of handicapped children who can provide a perspective on the results of treatment decisions.²⁴⁷

D. JUDICIAL INVOLVEMENT

Commentators have noted that routine judicial involvement may be ill-suited to treatment decisions for premature infants for several reasons.²⁴⁸ First, the courts are not able to respond quickly enough or knowledgeably enough to these unique, complex, and rapidly-changing medical situations.²⁴⁹ Furthermore, litigation may involve additional

236. Newman, *supra* note 63, at 55.

237. Shapiro & Barthel, *supra* note 196, at 849. For a discussion of the merits of judicial involvement, see *infra* part IV.D.

238. *E.g.*, Newman, *supra* note 63, at 55-56.

239. *Id.*

240. *Id.*

241. See *Developments, supra* note 44, at 1612 (explaining that members may fear institutional liability or costs).

242. Newman, *supra* note 63, at 56; Shapiro & Barthel, *supra* note 196, at 850.

243. Shapiro & Barthel, *supra* note 196, at 850.

244. *Id.*; Robert M. Kliegman et al., *In Our Best Interests: Experience and Workings of an Ethics Review Committee*, 108 J. PEDIATRICS 178, 182-183 (1986).

245. *Developments, supra* note 44, at 1612-13.

246. Rhoden, *supra* note 82, at 1343. See also Kliegman et al., *supra* note 244, at 179-82 (describing operative principles of a working ethics committee).

247. Kliegman et al., *supra* note 244, at 186.

248. *E.g.*, Newman, *supra* note 63, at 57.

249. *Id.* See also FRODOCK, *supra* note 13, at 124 ("[T]he logic of law . . . [involves] disinterestedness, adversarial proceedings, conclusive decisions, objective interests, and even rights. It is not easy to see how a legal hearing can remain consistent with the special commitments,

stress for parents and physicians alike and may sacrifice family privacy.²⁵⁰ The cost of counsel often will be prohibitive for parents who already face huge medical bills.²⁵¹ Finally, one commentator has argued that requiring judicial approval only for nontreatment decisions sends parents the message that consenting to aggressive treatment is the path of least resistance.²⁵²

Several courts have agreed that routine judicial oversight of decisions to withhold or withdraw treatment from incompetent persons would be inappropriate.²⁵³ However, these decisions indicated that courts remained open to hear such cases if needed.²⁵⁴ Other courts have agreed that judicial involvement is not necessary in all cases but have carefully limited that policy.²⁵⁵ Finally, some courts have expressed a judicial preference for court approval in all cases of withdrawal of treatment from incompetent persons.²⁵⁶

consultative and cooperative actions, serial and tentative decisions, and particularized interests of neonatology.”).

250. Newman, *supra* note 63, at 57.

251. Shapiro & Barthel, *supra* note 196, at 849.

252. Newman, *supra* note 63, at 58-59.

253. *In re Quinlan*, 355 A.2d 647, 669 (N.J.), *cert. denied*, 429 U.S. 922 (1976); *In re Rosebush*, 491 N.W.2d 633, 637 (Mich. Ct. App. 1992); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983).

254. *Quinlan*, 355 A.2d at 669; *Rosebush*, 491 N.W.2d at 637; *Barber*, 195 Cal. Rptr. at 493.

255. See *In re L.H.R.*, 321 S.E.2d 723, 723 (Ga. 1984) (confining a decision that judicial oversight was unnecessary to cases involving withdrawal of “death-prolonging” treatment and specifically leaving open the question of whether judicial approval was required for withdrawal of “life-prolonging” treatment); *In re Guardianship of Hamlin*, 689 P.2d 1372, 1378-79 (Wash. 1984) (limiting this policy to cases in which the patient was in a persistent vegetative state and being maintained by life support machines and specifying that any party involved could obtain judicial intervention); *In re Guardianship of Barry*, 445 So. 2d 365, 372 (Fla. Dist. Ct. App. 1984) (stating that courts must be available to hear such cases “whe[n] doubt exists, or there is a lack of concurrence among the family, physicians, and the hospital, or if an affected party simply desires a judicial order”).

256. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1976). The *Saikewicz* court reasoned that “such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created” and stated that “[w]e take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts . . . to any committee, panel or group” *Id.* at 434-35. This view was more recently expressed by three judges on the Minnesota Supreme Court who concurred in a decision to remove life-support systems from an incompetent adult but specifically disagreed with the majority opinion that judicial review was not required in such cases. *In re Conservatorship of Torres*, 357 N.W.2d 332, 341 (Minn. 1984) (Kelley, J., Yetka, J., and Peterson, J., concurring specially).

The majority stated in a footnote: At oral argument it was disclosed that on an average about 10 life support systems are disconnected weekly in Minnesota. This follows consultation between the attending doctor and the family with the approval of the hospital ethics committee. It is not intended by this opinion that a court order is required in such situations.

Id. at n.4. Nevertheless, the concurring justices rejected this statement, and Justice Kelley stated, “I am of the view that in all cases when the decision of continued life or likely death is involved there should be a court procedure similar to the procedure followed in this case.” *Id.* at 341.

E. GOVERNMENTAL INVOLVEMENT

Federal involvement in medical decision-making for infants has been criticized for practical reasons.²⁵⁷ Congress and federal agencies are prone to compromise and to pressure from special interests.²⁵⁸ Also, Congress and federal agencies are ill-equipped to mandate narrow policies in such a complex and uncertain area of medicine.²⁵⁹ Federal policies may threaten state constitutional protections as well.²⁶⁰

State governmental involvement may be criticized for some of the same reasons, but some commentators have suggested that state statutes which specifically address withholding or withdrawal of medical treatment from minors and infants would be helpful.²⁶¹ The child abuse and neglect statutes of most states may be inapplicable to such situations or may not deal with them adequately.²⁶² On the other hand, statutes which deal with withdrawal of care from adults may not take into account the roles of the child and its parents.²⁶³ Courts in recent years have requested state legislatures to take action in this area.²⁶⁴

V. CONCLUSION

Should the infant in our hypothetical case receive surgery? Should his ventilator treatment be continued, and if so, for how long? In making these decisions, all parties involved should focus upon the best interests of the infant. The best interests standard is more useful than a nondiscrimination approach, which would fail to recognize that this infant's disabilities are inseparable from his life-threatening medical problems.²⁶⁵ The best interests standard is also more useful than a substituted judgment approach, which is not logically applicable to any patient who has never been competent.²⁶⁶ To ascertain the infant's best interests, the benefits of treatment should be weighed against the probable burdens.²⁶⁷ This balancing test necessarily involves quality of life considerations because ben-

257. *E.g.*, Havlisch, *supra* note 224, at 978.

258. *Id.*

259. *Id.*

260. Newman, *supra* note 63, at 15-24.

261. *E.g.*, *Developments*, *supra* note 44, at 1609-11.

262. *See* Newman, *supra* note 63, at 13-15 (explaining that a parental decision to withdraw care based upon the child's best interests cannot be characterized as neglect).

263. Lisa Hawkins, *Living-Will Statutes: A Minor Oversight*, 78 VA. L. REV. 1581, 1584-85 (1992).

264. *See, e.g.*, *In re Conroy*, 486 A.2d 1209, 1220 (N.J. 1985) (explaining that "[a]s an elected body, the Legislature is better able than any other single institution to reflect the social values at stake" and that "[i]n addition, it has the resources and ability to synthesize vast quantities of data and opinions from a variety of fields and to formulate general guidelines").

265. *Supra* note 59 and part III.A.

266. *Supra* part III.C.

267. *Supra* part III.D.

efits and burdens are defined qualitatively from the infant's perspective.²⁶⁸

In our hypothetical case, the infant's mother wants surgery withheld and ventilator treatment withdrawn. As a parent presumed to act in her child's best interests, she should have a primary role in making such decisions.²⁶⁹ However, the mother's discretion should not be unchecked. Doctors should ensure that she is making informed and rational decisions based upon the child's best interests in light of the medical prognosis, and not based upon fear or bewilderment.²⁷⁰ On the other hand, the doctors' discretion should also be checked.²⁷¹ A hospital ethics committee should ensure that the doctors, too, are motivated by the child's best interests. If the doctors agree with the mother that treatment should be withdrawn or withheld, the ethics committee should perform this checking function merely by reviewing the medical facts and determining whether the decision to withhold or withdraw treatment is reasonable in light of those facts. If doctors disagree with the mother or among themselves, the ethics committee should play the role of a mediator, taking a more active role to facilitate communication between the parties and to ensure that all parties are using appropriate decision-making standards.²⁷² If this process works, judicial intervention should not be necessary.²⁷³ If the court must get involved, then it, like the ethics committee, should first act as a mediator. If the court must decide whether treatment should be withdrawn or withheld, then it, too, should employ the best interests standard and weigh the benefits of treatment against the burdens.

Following these guidelines will not produce an ideal result for this infant or for his mother. The most that can be hoped for is that the mother and the doctors will make informed treatment decisions in light of the infant's best interests. This standard may at least prevent withdrawal of treatment too hastily. It may also prevent continuation of treatment for too long.

Jennifer Stokley

268. *Supra* part III.D.1.

269. *Supra* part IV.A.

270. *Id.*

271. *Supra* part IV.B.

272. *Supra* part IV.C.

273. *Supra* part IV.D.

