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THE PROBLEM OF NON-IDENTITY IN VALUING NEWBORN HUMAN LIFE

Sadath A. Sayeed*

“[I]t is impossible for the courts to calculate the relative benefits of an impaired life versus no life at all.”¹

“[T]here is a presumption that continued life is in the best interests of a patient.”²

INTRODUCTION

There is no quick and easy fix that resolves the tension between a moral intuition that we ought to do as much as we can to safeguard and preserve newly born human life and an intuition that some babies facing daunting odds to survive long or survive well, even with medical intervention, ought to be allowed to die. In challenging clinical cases, where conscientious people might disagree about how to proceed, prioritizing one set of values almost always necessitates the sacrificing of other important values. American legal opinion in statutory, regulatory, or common law form directly on point is limited.³ Much of what is available only seems to aggravate existing ethical strain.⁴

Despite vociferous published criticism of the federal Baby Doe regulations,⁵ and the more recent Texas and Wisconsin state court

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1. *Miller v. HCA, Inc.*, 118 S.W.3d 758, 768 (Tex. 2003).

2. *Montalvo v. Borkovec*, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002).

3. *See, e.g., Burks v. St. Joseph’s Hosp.*, 588 N.W.2d 927 (Wis. Ct. App. 1998).

4. *See generally* Sadath A. Sayeed, *The Marginally Viable Newborn: Legal Challenges, Conceptual Inadequacies, and Reasonableness*, 34 J.L. MED. & ETHICS, 600, 600–10 (2006).

5. 45 C.F.R. § 1340.15 (2008).

opinions quoted at the outset, it is a mistake to simply dismiss the arguments contained within such legal pronouncements.⁶ The logic within this line of controversial opinion extends back to the work of legal scholar John Robertson, who in 1974, argued: “One who has never known the pleasure of mental operation, ambulation, and social interaction surely does not suffer from their loss as much as one who has. . . . Life and life alone, whatever its limitations, might be of sufficient worth.”⁷ A skeptical and conservative tradition of questioning the permissibility of allowing quality-of-life judgments to enter into a surrogate’s decision-making calculus challenges a parallel normative impulse within clinical neonatal practice to recommend against offering medical therapy when it is believed to offer minimal or limited benefits and risks serious burdens to the newly born.⁸

In this paper, I take a closer look at the analysis of neonatal treatment dilemmas offered by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which was first published in 1983.⁹ I employ its framework for ethical decision-making to defend the following conclusion: exceedingly few newborns who stand a chance at extended life should be denied a trial of medical treatment. My interpretation is meant to be provocative. In order to show this, I extend the analysis to a case in which a newborn’s viability is highly doubtful. I argue that whether one speaks in terms of benefits or

6. See generally Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS, 187 (2007); John J. Paris et al., *The “Emergent Circumstances” Exception to the Need for Consent: The Texas Supreme Court Ruling in Miller v. HCA*, 24 J. PERINATOLOGY 337 (2004).

7. John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 254 (1975). I note only in passing here that there may be a problem with assigning an ability to judge life’s worth to one who has “never known the pleasure of mental operation.” *Id.*

8. See generally Laurence B. McCullough, *Neonatal Ethics at the Limits of Viability*, 116 PEDIATRICS 1019 (2005); Sadath A. Sayeed, *Baby Doe Redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A Cautionary Note on Normative Neonatal Practice*, 116 PEDIATRICS e576 (2005).

9. See generally PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS* (1983) [hereinafter *Commission*].

interests, a plausible case can be made for initiating potentially life-saving therapy in such cases. This claim challenges a widely accepted professional norm of either not offering or strongly recommending against resuscitative therapy in cases of doubtful viability. I then conclude with a decidedly less analytical reflection on neonatal treatment dilemmas. I suggest that it is a mistake to insist that we must always prioritize a newborn's survival interests and, further, that it is implausible to think that, as a rule, the interests of others cannot or should not influence clinical decisions to treat or not treat individual patients. However, I do not attempt to philosophically reconcile the conflict between consequentialist and deontological positions on this issue. Instead, I argue more empirical work needs to be carried out to help clarify why our intuitions might be mixed about the moral value of newborn life.

I. A FRAMEWORK FOR ETHICAL DECISION-MAKING

In 1983, the President's Commission published a comprehensive analysis to inform ethical decision-making involving "seriously ill newborns."¹⁰ The framework that was developed followed careful study and deliberation by authorities in the fields of medicine, law, philosophy, theology, and other relevant disciplines. By virtue of its diverse authorship and political sponsorship, the analysis arguably represented a compromised opinion with the goal of generating consensus policy. The Commission's articulation of the Best Interests Standard and its framework for decision-making as it applies to newborns is not amenable to mathematical proof; it is only one possible understanding.¹¹

10. *Id.*

11. See discussion *infra* Part III. For the purposes of this argument, I make important initial assumptions both about the conceptual plausibility of the Commission's analysis and its normative influence in subsequent discourse about clinical decision-making. The philosopher Loretta Kopelman has recently championed an understanding of the Best Interests Standard that seems notably different than the one offered by the President's Commission. Among other things, she claims that "[t]he meaning of the Best Interests Standard in making practical decisions . . . does not require ignoring all other duties, allocation plans for scarce resources, or others' interests in deciding what ought to be done for someone." Kopelman, *supra* note 6, at 188. The Commission, on the other hand, argues that "[t]he

To begin with, the Commission noted newborns' "subjective wishes, real or hypothetical, are impossible to discern with any certainty" and so it borrowed from legal tradition an alternative decision-making mechanism: an objective measurement of interests.¹² Because never-competent persons' preferences cannot be known, protecting welfare rather than honoring subjective desire becomes the core moral consideration for surrogates. With that aim, a series of semi-factual determinations, such as degree of pain and suffering, quantity of life, and opportunity for future self-determination, merit close attention by anyone performing the interests assessment. The Commission did not define all of the potentially relevant factors that could enter into a specific evaluation or how much weight particular factors should receive, but a proportional balancing of perceived benefits and burdens accruing to the incompetent constitutes the essential analysis.

The Commission insisted that the standard be "very restrictive," requiring disabling conditions to be so severe that "continued existence would not be a net benefit to the infant."¹³ Given the decisive agency of the surrogate decision maker in this assessment, the Commission cautioned that proxies are "obligated to try and evaluate benefits and burdens from the infant's own perspective."¹⁴ Of course, newborns have no *informed* perspective to speak of, but discrete experiences of pain, comfort, satiety, warmth and the like are processed in the early developing human brain. These immediate

standard] excludes consideration of . . . effects of an impaired child's life on other persons, including parents, siblings, and society." *Commission, supra* note 9, at 219. Kopelman seeks a standard that offers pragmatic utility; she argues against an interpretation that is "self-defeating, unrealistic, or narrowly focused on the needs of a single individual." Kopelman, *supra* note 6, at 194. The President's Commission, on the other hand, seemed unapologetic in accepting the challenge of a strictly individualistic construction of the standard: "although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants." *Commission, supra* note 9, at 219. The Commission's work predates Kopelman's recent discussion by more than two decades, and this temporal fact calls into question her assertion that recent confusion about the standard's meaning stems from inattention to why it was developed. Kopelman, *supra* note 6, at 188. Her claim that the standard's "meaning is clear from its usage" also seems strangely ignorant of a legal interpretation such as that contained in the *Montalvo* opinion. Kopelman, *supra* note 6, at 194.

12. *Commission, supra* note 9, at 134.

13. *Commission, supra* note 9, at 218.

14. *Commission, supra* note 9, at 219.

factors might initially seem most relevant to the benefit-burden analysis.¹⁵ The Commission, however, further conditioned what it meant by adopting the infant's own perspective:

For many adults, life with severe physical or mental handicap would seem so burdensome as to offer no benefits. However, this assessment arises largely from the adults' existing hopes and aspirations that would be forever unfulfilled. From the perspective of an infant who can be helped to develop realistic goals and satisfactions, such frustrations need not occur.¹⁶

With this understanding, surrogates are put on guard against the influence of their own psychological predispositions and socio-cultural attachments in making benefit-burden assessments for their young, unencumbered offspring—strictly speaking, it is not their life experience that matters.

Put more forcefully, a *normal* view of the meaning and value of certain life experiences is not relevant to a *newborn's* best interest analysis because she has no appreciable sense of normalcy. One striking conclusion that can be drawn from this decision-making constraint seems to be as follows: while a parent might readily refuse life-saving medical treatment for himself because he prefers not to be left mentally and physically worse off, he may not choose the same for his newborn child based on highly personalized concerns about an untoward outcome. “[T]he concept of ‘benefit’ excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment.”¹⁷

Having sketched the contours of what the Best Interests Standard means for newborns, the Commission next attempts to guide actual bedside decision-making about whether to proceed with medical

15. See discussion *infra* Part II.B.4.

16. *Commission, supra* note 9, at 219 n.79 (citing Karen M. Metzler, *Human and Handicapped*, in *MORAL PROBLEMS IN MEDICINE* 358 (Samuel Gorovitz ed., 1976)).

17. *Commission, supra* note 9, at 218. The Commission does not further define what counts as idiosyncratic.

therapy for those who are seriously ill by dividing potential treatments into three possible categories: 1) clearly beneficial, 2) ambiguous or uncertain, or 3) futile.¹⁸ Initial treatment classification is privileged to the attending physician, but the Commission acknowledged that this assessment may be problematic and provided that there may be occasions to allow for intra-institutional or external court re-assessment.¹⁹

The Commission first offers a paradigmatic example of a case in which available treatment should be regarded as clearly beneficial: “[t]he handicaps of Down Syndrome . . . do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.”²⁰ This conclusion would thus appear to foreclose the ethical acceptability of any alternate benefit-burden evaluation by surrogates. According to the Commission, it is in the best interests of newborns with Down Syndrome to receive life-saving treatment regardless of what parents or physicians might think.²¹

Regarding futile therapies, the Commission again offers two specific clinical examples: “anencephaly or certain severe cardiac deformities.”²² Futility is not formally defined, but the Commission

18. *Id.*

19. *Id.*

20. *Id.* at 219.

21. The Commission concludes so despite acknowledging a background prevalence of contrary professional attitude:

Surveys of physicians show that most would follow parental wishes to stop treatment for at least some abnormal infants. When California pediatricians were polled in 1975 about how they would treat a Down Syndrome baby with a life-threatening intestinal obstruction (assuming parental agreement and immunity from existing laws), 17% said they would do “everything humanly possible” to save the baby’s life, while 61% would give ordinary medical care but “nothing heroic” (meaning the baby would die without the operation to remove the obstruction). In a national study in 1977, pediatricians and pediatric surgeons were asked whether they would acquiesce in a parental decision not to treat a Down Syndrome infant having congenital heart disease. Even though immunity from the law was not mentioned, 85% of the pediatric surgeons responding and 65% of the pediatricians said they would follow the parents’ wishes. A third study found that 51% of the pediatricians surveyed in Massachusetts would not recommend surgery for a Down Syndrome infant with intestinal blockage.

Commission, supra note 9, at 208.

22. *Commission, supra* note 9, at 219.

states that potential treatments “do not help the child, are sometimes painful for the infant . . . , and offer no reasonable probability for saving life for a substantial period.”²³ In terms of connecting futility to duration of survival, the Commission specifically states that “[t]he moment of death for these infants might be delayed for a short time” with on-going therapy and limits this classification to those babies who will die within “hours or days, not years.”²⁴ It acknowledges that disagreement may exist between physicians and parents about when a set of medical facts might be sufficient to constitute futility. Significantly, it concludes that therapy deemed futile by physicians should still be given in cases where parents request it as long as “substantial suffering for the child” can be avoided.²⁵ In such cases, the Commission also makes room for conscientious provider objection and grants the opportunity for such individuals to withdraw from clinical care.

The Commission finally details what it considers to be the most problematic category: so-called “ambiguous” cases, where opinions might acceptably diverge on how to weigh severity of burden or amount of benefit and handle uncertainty. The Commission perceives that the majority of clinical cases involving seriously ill newborns should result in a classification that treatment is either beneficial or futile; few cases will truly be ambiguous. It then provides two specific case examples of ambiguity: “a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator dependent premature infant whose long-term prognosis becomes bleaker with each passing day.”²⁶ These examples are notably constrained in terms of predicted outcomes and both describe patients whose current conditions and future prognoses seem well forecasted. The first case emphasizes pain and limited life span; the second case, dependence on medical technology and a rapidly

23. *Id.*

24. *Id.* at 219. There is an apparent inconsistency here, in that anencephalic babies who are mechanically ventilated can conceivably live for years.

25. *Commission, supra* note 9, at 220.

26. *Id.*

deteriorating condition. Though not explicitly stated, these examples could be understood to mean that ambiguity about treatment should only attach after some concrete, patient-specific facts are available for evaluation.

Consistent with this interpretation, the Commission rejected adoption of pre-determined categorical thresholds that might govern treatment choices prior to birth:

[Objective] criteria would be justified if there were evidence that their adoption would lead to decisions more often being made correctly

. . . .

. . . [B]irth weight limits or checklists for severity of spina bifida have not been shown to improve the quality of decisionmaking in ambiguous and complex cases. Instead, their use seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers.²⁷

Here is a potentially very important practical constraint on providers and parents. The Commission argues that, prior to birth, in cases where available treatment is *not obviously futile*, fetuses with a chance for survival as newborns ought not automatically be lumped into a “no treatment” box just because treatment is also not obviously beneficial. Such pre-categorization might serve a goal of expediency, and in many cases, ease adult anxieties, but to the Commission, this seems to come at too high a price.

Taken in totality, it is plausible to read the President’s Commission as articulating a very narrowly focused decision-making standard that demands surrogates focus their exclusive attention on the possible well-being of an individual newborn patient. Consistent with this interpretation, the Commission insists that decision makers “must have reason to believe that the patient will be maximally benefited”

27. *Commission*, *supra* note 9, at 221, 223.

by their choice regarding treatment.²⁸ Certain considerations such as “the value that others find in the continuation of the patient’s life, perhaps in terms of their estimates of the patient’s actual or potential productivity or social contribution,” have no place in the interests assessment.²⁹ Other surrogate claims, such as an assertion that an incompetent would elevate the emotional or financial toll on her family over her own survival interests, require “especially stringent standards of evidence.”³⁰ Because newborns are by definition never competent, the Commission prohibits imputation of such altruism.

II. EXTENSION OF THE FRAMEWORK TO CASES OF DOUBTFUL VIABILITY

I now extend the President’s Commission’s analysis to the case of a neonate born extremely prematurely whose long-term survival is doubtful. I choose this clinical case because, historically, obstetric and neonatal providers have approached the decision to resuscitate such babies with trepidation. Professional hesitation stems largely from a conscientious concern that, even with the best available medical care, such newborns face depressingly low chances of long-term survival and high chances of significant functional morbidity with survival. More controversially, it is possible to contend that providing treatment in cases of doubtful viability would be futile or not in the best interests of these newborns. With the President’s Commission’s framework for decision-making in mind, I hope to cast suspicion on such a characterization.

A. Professional Approach

In the United States, no uniform policy has governed the approach providers or parents actually take in deciding about treatment in cases of doubtful viability at the time of birth. There is a specter of federal

28. *Commission, supra* note 9, at 135 n.42.

29. *Id.*

30. *Commission, supra* note 9, at 136.

regulatory policy that lurks in the shadows of normative clinical practice, but it remains unclear what practical effect it may exert on actual decision-making.³¹ No standardized template exists to communicate information about likely outcomes in such cases to expectant parents. Individual providers are largely left to their own conscience in deciding how to approach antenatal counseling and delivery room management.³² Predictably, some variability across physicians and institutions exists.³³

Attitudinal surveys suggest that most providers in the United States are reluctant to initiate potentially life-sustaining medical care for neonates born below twenty-three weeks.³⁴ The authors of a recent, large national survey published in 2007 noted the following:

[The] lower edge of viability, as determined functionally by the self-reported behavior of neonatologists in the delivery room, is 500 g/23 weeks and has remained there for at least the past several years. The large majority of neonatologists in 1996 and in 2003 would not resuscitate infants below that BW/GA limit, regardless of the expressed wishes of the parents.³⁵

In that study, for neonates born below twenty-three weeks or 500 grams, only 36% of respondents would honor parents' expressed wishes to initiate treatment, 57% would provide "comfort care" alone, and 4% would provide "full resuscitation."³⁶ Respondents were also asked to rank the relative importance of six possible

31. Sayeed, *supra* note 8, at e576–e585.

32. See generally Russell W. Chesney, *Children As Clinical Research Subjects*, 147 J. PEDIATRICS 579 (2005); Joseph W. Kaempf et al., *Medical Staff Guidelines for Periviability Pregnancy Counseling and Medical Treatment of Extremely Premature Infants*, 117 PEDIATRICS 22 (2006).

33. Maureen Hack & Avroy A. Fanaroff, *Outcomes of Children of Extremely Low Birth Weight and Gestational Age in the 1990s*, 53 EARLY HUMAN DEV. 193, 194 (1999).

34. Justin P. Lavin, *Attitudes of Obstetric and Pediatric Health Care Providers Toward Resuscitation of Infants Who Are Born at the Margins of Viability*, 118 PEDIATRICS S169 (2006); Jehanna M. Peerzada et al., *Delivery Room Decision-Making at the Threshold of Viability*, 145 J. PEDIATRICS 492 (2004); Jaideep Singh et al., *Resuscitation in the "Gray Zone" of Viability: Determining Physician Preferences and Predicting Infant Outcomes*, 120 PEDIATRICS 519 (2007).

35. Singh et al., *supra* note 34, at 523.

36. *Id.* at 521. The authors do not further define what is meant by "full resuscitation."

concerns—viability, futility, quality of life, resources, litigation, religion—in informing their initial treatment decisions. The study authors expressed reassurance about their findings; informants were “well-motivated” insofar as “patient-oriented outcome variables” (futility, viability, quality of life) were emphasized over “societal or personal concerns” as reasons for their choices regarding the appropriateness of treatment.³⁷

One other assessment of provider attitudes toward treatment decisions in cases of doubtful viability bears brief mention because it broaches the question with the President’s Commission’s framework squarely in mind.³⁸ Investigators in this regional six-state study asked respondents to choose whether available treatment should be regarded as clearly beneficial, futile, or of uncertain benefit for neonates born at several early gestational ages. Below twenty-three weeks, 93% of physicians regarded treatment as futile and only 33% were willing to provide such treatment upon parental request.³⁹ The investigators also queried about motivating factors in cases of uncertain benefit and found that the medical condition of the neonate at the time of delivery and the likelihood of death were most important to respondents in deciding whether to initiate or withhold treatment; long-term suffering of the infant was ranked next, followed by likelihood of mental retardation and likelihood of cerebral palsy.⁴⁰

The professional attitudes predominant in both of these surveys largely mirror the opinion of the Neonatal Resuscitation Program Steering Committee which, in conjunction with the American Heart Association (NRP/AHA), includes in its formal guideline that a gestational age less than twenty-three weeks or birth weight less than 400 grams might constitute sufficient grounds for providers to unilaterally refuse to offer resuscitation.⁴¹ What influence, if any, the

37. *Id.* at 523.

38. Peerzada, *supra* note 34, at 492–93.

39. *Id.* at 494.

40. *Id.* at 496.

41. *See Part 13: Neonatal Resuscitation Guidelines*, 112 CIRCULATION IV-188, IV-193 (2005).

opinion of the NRP/AHA exerts on the opinions of actual providers of neonatal care is difficult to ascertain. It may also be possible that NRP/AHA policy is rather more reflective of the apparent consensus findings in these observational studies. Regardless, this collective body of empirical evidence suggests a broad inclination on the part of neonatal providers in the United States to *unilaterally* demarcate situations within clinical practice where they may justifiably decide against initiating potentially life-saving medical treatment for extremely premature newborns regardless of the opinion of others who may also have a stake in the outcome.⁴²

B. Analysis of the Professional Approach

The NRP/AHA chose to offer examples of objective criteria (birth weight and gestational age) that might systematically exclude some live born neonates from receiving resuscitative therapy without individual evaluation after birth. The President's Commission, on the other hand, advised against the use of such across-the-board thresholds unless it could be adequately demonstrated that "correct" decisions were reliably obtained.⁴³ If such cases can non-controversially be regarded as instances of futility, then no problem should exist. And indeed, a superficial analysis might conclude that because consensus opinion among providers appears to be that treatment below twenty-three weeks is futile, a policy that reflects such opinion is acceptable.

But is it the case that initiating resuscitative treatment to a neonate born below twenty-three weeks is futile?⁴⁴ In order to answer this

42. Istvan Seri & Jaquelyn Evans, *Limits of Viability: Definition of the Grey Zone*, 28 J. PERINATOLOGY S4, S7 (2008).

43. See discussion *supra* Part I.

44. This is not meant to be just a rhetorical or academic question. In February 2007, the national media covered the hospital discharge of a "miracle" baby previously born just under *twenty-two weeks* from a Florida hospital. This newsworthy case represented the earliest reported survival of an American neonate because conception was achieved by *in vitro* fertilization with precise dating. At the time of discharge, the almost five-month-old had suffered a mild brain hemorrhage and needed oxygen for chronic lung disease, but her discharging doctors believed that her "health concerns [would] not have major long-term effects." A neonatologist involved in the infant's care remarked that there may be a "need to reconsider our standard for viability in light of [this] case. Over the years, the technology that

question, a transparent definition of futility is first needed. That clinicians have at times been inclined to take advantage of futility's notorious imprecision and multiplicity of intended meanings has been criticized by close observers of medical practice.⁴⁵ Perhaps the least problematic definition of futility is physiological, which roughly means that, even with all available treatment, death can only be postponed for a short period of time. The President's Commission's discussion of futile treatment in the context of seriously ill newborns most closely corresponds with such a tight conceptualization.⁴⁶

1. *Survival Data*

Given a pervasive professional attitude with respect to viability under twenty-three weeks, actual survival data for neonates born below this threshold are quite limited.⁴⁷ Because almost no neonates are resuscitated below this gestational age "cutoff," there are plausible grounds to worry about the perpetuation of a self-fulfilling prophecy. Indeed, in the absence of ubiquitous provider commitment to attempt resuscitation when newborn viability is unlikely, one recent commentator suggested that published "survival rates may underestimate maximum survival possible."⁴⁸ What survival data are available must be interpreted cautiously because just as individual physiological fitness affects outcome, so do the background conditions which describe where, when, and how a neonate below twenty-three weeks is born.⁴⁹

we have available to save these premature babies has improved dramatically." Tom Strode, *Premature Baby Who Had Record Survival May Change View of Unborn, Specialists Say*, BAPTIST PRESS, Feb. 26, 2007, <http://www.bpnews.net/bpnews.asp?ID=25045>; see also *21-Week-Old Miracle Baby Survives at Baptist Hospital*, Feb. 19, 2007, <http://www.nbc6.net/health/11056409/detail.html>.

45. See Paul R. Helft et al., *The Rise and Fall of the Futility Movement*, 343 NEW ENG. J. MED. 293, 295 (2000).

46. See discussion *supra* Part I.

47. See Hack & Fanaroff, *supra* note 33, at 195.

48. John M. Lorenz, *Management Decisions in Extremely Premature Infants*, 8 SEMINARS IN NEONATOLOGY 475, 477 (2003).

49. There is no question that to optimize whatever innate chances exist for survival, an extremely premature newborn would do well not only to be born to parents who are committed to maximizing that chance, but also at an institution capable of providing the highest quality intensive care right after birth,

Large epidemiological studies from the United Kingdom and United States verify this last observation.⁵⁰ Investigators in the United Kingdom undertook to prospectively collect outcomes data for neonates born between twenty and twenty-six weeks' gestation during a ten-month period in all of the 276 maternity units operating in the United Kingdom and Ireland in 1995. As an observational study, there was no attempt to control for the quality of available medical services or the attitude of providers at neonatal point of entry:

In a study such as this, with data from a large number of centers of various sizes and staffing structures and inevitable differences of approach to the birth of an extremely preterm infant, we could neither standardize nor validate definitions of resuscitation attempts; thus, the delivery-room treatment of those reported to show signs of life but not admitted to the neonatal intensive care unit was not recorded. It is a matter of conjecture whether a more aggressive universal policy of resuscitation would have altered these outcomes.⁵¹

There were 4,004 early births during the ten-month time study period that met criteria for evaluation. 1,185 extremely premature newborns were reported to have shown signs of life. 843 of these babies were admitted to a neonatal intensive care unit and the remainder died in the delivery room. 314 infants survived to be discharged home, representing an approximately 39% rate of survival for all admitted newborns and a 7.8% rate for all recorded births. More detailed analysis revealed that between twenty-two and twenty-three weeks

and at a time when the available providers are also prepared and willing to use all of the possible therapeutic tools at their disposal.

50. See, e.g., James A. Lemons et al., *Very Low Birth Weight Outcomes of the National Institute of Child Health and Human Development Neonatal Research Network, January 1995 Through December 1996*, 107 PEDIATRICS 1 (2001); Neil Marlow et al., *Neurologic and Developmental Disability at Six Years of Age After Birth*, 352 NEW ENG. J. MED. 9 (2005); Jon E. Tyson et al., *Intensive Care for Extreme Prematurity—Moving Beyond Gestational Age*, 358 NEW ENG. J. MED. 1672, 1679 (2008).

51. Nicholas S. Wood, *Neurologic and Developmental Disability After Extremely Preterm Birth*, 343 NEW ENG. J. MED. 378, 383 (2000).

completed gestation, 16% of newborns were admitted to a NICU, and 1% survived to discharge; between twenty-three and twenty-four weeks, 54% were admitted, and 11% survived to discharge.⁵²

By way of comparison, in the United States, a collaborative group of academic intensive care nurseries known as the Neonatal Research Network of the National Institute of Child Health and Human Development reported survival outcomes from its centers between January 1995 and December 1996.⁵³ In this publication, 21% of neonates (twelve of fifty-six total infants) born between twenty-two and twenty-three completed gestational weeks by best obstetrical estimate survived to discharge, whereas between twenty-three and twenty-four weeks roughly 30% survived.⁵⁴ In 2008, the same group published a much more sophisticated survival analysis of neonates born between twenty-two and twenty-five weeks for the subsequent years 1998 through 2003.⁵⁵ In this latter study, nearly 4,500 neonates were prospectively followed after birth, and 83% of these babies received intensive care in the form of (at least) mechanical ventilation. However, only 23% of neonates born below twenty-three weeks received intensive care as compared to 99% of those born above twenty-five weeks.⁵⁶

Detailed statistical analysis of this large U.S. cohort allowed the investigators to conclude that a single-factor model (such as gestational age or birth weight) was poorly predictive of outcome as compared to a model that included five clinical factors.⁵⁷ A more robust estimation of clinical outcomes for both mortality and degree of morbidity can be generated by inputting gestational age, weight, sex, exposure to antenatal steroids, and singleton versus multiple birth into the calculation. The authors conclude: “Our findings

52. See Marlow et al., *supra* note 50, at 16.

53. See Lemons et al., *supra* note 50, at 1.

54. *Id.* at 4. The difference in survival on the two sides of the Atlantic at least in part likely reflects point of entry into neonatal care. All of the NICHD centers are capable of providing advanced intensive care. The same cannot be said of all of the 276 British maternity units.

55. See Tyson et al., *supra* note 50, at 1672.

56. *Id.* at 1677.

57. *Id.* at 1679.

challenge the widespread use of gestational-age thresholds alone in deciding whether to administer intensive care to extremely premature infants.”⁵⁸ In the spirit of improving actual clinical practice, these investigators also produced an “estimator” based on aggregate outcomes for the study cohort, which is freely accessible on the internet.⁵⁹ This calculator produces interesting results. For example, with the following inputs: twenty-two weeks, 450 grams, female gender, exposure to antenatal steroids, and singleton birth, a 21% chance of survival is generated for a mechanically ventilated neonate. If the gestational age is increased to twenty-three weeks, but *gender* is changed to male while holding the remaining variables constant, the chance of survival only marginally increases to 23%.

2. Analysis of Initial Claim of Futility

The U.S. Network’s latest study is provocative for at least two reasons: first, it calls into question a traditional normative clinical practice of basing treatment decisions exclusively on one factor such as estimated gestational age or birth weight; second, it slams the door on blanket claims that treatment below twenty-three weeks ought conclusively to be regarded as physiologically futile.⁶⁰ No neonatal

58. *Id.*

59. NICHD Neonatal Research Network (NRN): *Extremely Preterm Birth Outcome Data*, http://www.nichd.nih.gov/about/org/cdbpm/pp/prog_epbo/epbo_case.cfm.

60. In 2007, perhaps with forehand knowledge, the Committee on Fetus and Newborn, a leadership group within the American Academy of Pediatrics (AAP), specifically considered and rejected a treatment classification scheme based on gestational age or birth weight. It offered several reasons for its decision:

[We] decided against this categorical approach for several reasons. First, the prognosis for extremely premature infants is influenced by other factors besides gestational age, such as fetal gender and corticosteroid exposure. Second, . . . we felt that these demarcation lines are not fixed but have moved over time and may continue to do so. Third, the concept of standard gestational-age cutoffs for active intervention is problematic because there is considerable center-to-center variability in outcome below 25 weeks’ gestation, both in mortality and morbidity; . . . much of the variability in outcome among centers results from differences in the attitudes and beliefs of medical staff regarding the potential for intact survival at very early gestation.

Edward F. Bell et al., *Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns: In Reply*, 119 PEDIATRICS 1267, 1268 (2007). In its policy statement, the Committee on Fetus and Newborn

provider concerned with issues of justice could plausibly maintain that a statistical difference in survival of 2% between a twenty-two-week female and a twenty-three-week male is sufficient to decisively change a judgment about the appropriateness of initiating intensive care.

There is the further arithmetical puzzle of trying to equate a one in five chance of long-term survival with a claim of physiological futility. Even if the most accurate portrayal of survival probabilities would describe a range of possibility (say zero to 20%), a plausible basis for such a claim is lacking; a robust conception of futility does not so easily accommodate a wide statistical spectrum of survival outcome. Though not perfectly analogous, a physician could not tell a competent adult patient who faced a one in five (or even one in ten) chance of survival with treatment that such care was not indicated because it stood *no* reasonable chance of working.⁶¹ A neonatal patient obviously cannot protest as an adult patient, but incompetency does not magically evaporate the underlying objection.

This is not to deny that providers might have other reasons to try and justify a unilateral decision not to offer treatment, but any claim sounding in futility must be considered question-begging. Perhaps cognizant of that rejoinder, the 2005 NRP/AHA guideline does offer a broader argument in its published opinion: “unacceptably high

offered a strategy for care that follows from the anticipated prognosis: 1) no treatment when “early death is highly likely and survival would be accompanied by high risk of unacceptably severe morbidity,” 2) treatment when “survival is likely and risk of unacceptably severe morbidity is low,” and 3) treatment according to parental desires when the “prognosis is uncertain but likely to be very poor and survival may be associated with a diminished quality of life for the child.” Committee on Fetus and Newborn, *Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns*, 119 PEDIATRICS 401, 402 (2007). This decision-making approach bears close resemblance to the tripartite treatment classification scheme of the 1983 President’s Commission. Key qualifiers such as “highly likely,” “high risk,” and “unacceptably severe” are left undefined; as such, the Committee leaves some space for clinicians and parents to fill in the inescapable value judgments. This opinion does not specifically supplant the NRP/AHA policy guideline.

61. See Helft, *supra* note 45, at 293 (“Several authors sought consensus by attempting to determine empirically the threshold for a physician’s judgment that further treatment would be futile. In various studies, the threshold, expressed in terms of the physician’s prediction of the chance of survival, ranged from zero to sixty percent, although responses tended to cluster around five percent. Critics argued that the great variability in responses would make consensus on a specific threshold for decisions about futility unlikely.”).

morbidity is likely among the rare survivors.”⁶² With this clarification, it becomes transparent that much professional clinical perspective is animated not only by a concern about chance of survival but also by the quality of that survival.

3. *Data on Long-Term Outcomes*

Professional concern about unacceptably high morbidity is informed by follow-up data collected during two decades documenting permanent diminishment in extremely premature survivors’ cognitive and developmental capabilities as older children.⁶³ The 1995 U.K. study described earlier prospectively collected outcomes data on all survivors of extremely premature birth who reached six years of age.⁶⁴ The surviving batch of children underwent standardized cognitive and neurological assessments at early school-age and was matched against a control group of children born at full-term in the same study year. Between twenty-two and twenty-three weeks, a total of 138 neonates were reportedly live born, of which twenty-two were initially sent for further intensive care. Two of the twenty-two neonates who received some form of sustained medical intervention survived to discharge and were followed up at the six-year assessment.⁶⁵ One child was found to be mildly disabled and the other severely disabled.⁶⁶ The U.S. NICHD (National Institute of Child Health and Human Development)

62. See Part 13: *Neonatal Resuscitation Guidelines*, *supra* note 41, at IV-193.

63. See Hack & Fanaroff, *supra* note 33, at 194.

64. See Marlow et al., *supra* note 50, at 9.

65. No information is provided regarding the reasons treatment was stopped for the other twenty newborns who initially received intensive care. Presumably, some died despite all efforts, and others had treatment withheld out of concern for severity of injury or predicted poor outcome. See discussion *supra* Part II.B.1; Marlow *supra* note 50, at 16.

66. See Marlow, *supra* note 50, at 16. Investigators defined disability as severe if it was considered likely to make the child highly dependent on caregivers and included nonambulant cerebral palsy, an IQ score more than three standard deviations below the mean, profound sensorineural hearing loss, or blindness; “moderate” if it was considered likely that reasonable independence could be reached, and if it included ambulant cerebral palsy, an IQ score two to three standard deviations below the mean, sensorineural hearing loss that was corrected with a hearing aid, or impaired vision without blindness; “mild” if the child was found to have neurologic signs with minimal functional consequences or other impairments such as squints or refractive errors. *Id.*

Network also evaluated eighteen to twenty-two month developmental outcomes for survivors of the study cohort followed from 1998 to 2003.⁶⁷ Investigators extended their statistical analysis and projected that had intensive care been universally initiated for all neonates born between twenty-two and twenty-three weeks in their study cohort, among the small number of survivors (zero to 9% of all treated), between zero and slightly over 50% would have survived without profound impairment and between zero and approximately 33% would have survived without impairment.⁶⁸

4. Analysis of a Broadened Claim Regarding Unacceptably High Morbidity

Based on this kind of data, all of us might reasonably agree that there is good basis to worry about significant, life-long developmental burdens that are likely to manifest in survivors of extremely premature birth. And, no doubt, some conscientious neonatal providers feel obligated to avoid introducing into the population children with grave permanent handicaps. The authors of the 2008 NICHD study rather strikingly contend “a strength” of their work includes the “assessment of profound impairment, an outcome that some persons consider to be worse than death.”⁶⁹ This assertion brings to the foreground the fundamental dilemma facing all stakeholders in cases of improbable newborn survival: we must make a judgment about the value of another human being’s life, before that individual is really capable of appreciably experiencing it. Is a unilateral professional medical value judgment that treatment is not indicated when there is only a 15% chance of survival with an 80%

67. See Tyson et al., *supra* note 50, at 1673.

68. See Tyson et al., *supra* note 50, at 1678–79. Degree of impairment was defined by reference to the measured results of standardized, age-appropriate developmental testing. Survivors were classified as impaired if they performed poorly on one of two developmental tests, or they had moderate or severe cerebral palsy, or bilateral blindness, or bilateral hearing loss requiring amplification. Impairment was profound if mental development could not be tested, or if the child always needed adult assistance to move.

69. *Id.* at 1679.

chance of severe disability acceptable? What if a parent disagrees?⁷⁰ Providers of neonatal care are entitled to interpret statistically predicted long-term outcomes for neonates born extremely prematurely, but it is one value judgment among many. Physicians do not, by virtue of their technical expertise, possess any special insight into this enduring *moral* problem.⁷¹ Parents, child advocates representing the state, and judges might also all have thoughtful, informed, and relevant opinions.

On the interpretation of the President's Commission's framework for decision-making offered here, it is plausible to conclude that initial treatment would confer a greater potential benefit to a neonate precariously positioned at birth between twenty-two and twenty-three weeks than "comfort care" alone.⁷² Perhaps needless to say, from the perspective of one who desires to remain alive, the provision of life-sustaining treatment is an all-or-nothing proposition. When maximizing the chance of survival is the primary interest of such a person, the fact that the statistical probability of success is 99% or 1% should not matter—what matters is that we prioritize whatever chance exists over all other concerns.

The President's Commission insists that a surrogate's treatment decision must be thought to maximally benefit the newborn since we cannot discern his or her subjective wishes. In the hierarchy of possible benefits for a newborn, survival (I contend) is necessarily a default priority. It is a precondition to measuring all other potential benefits and burdens. This does not mean that the benefit of survival cannot be trumped; rather, it means that in the absence of strong evidence to the contrary, we ought to assume that a newborn would

70. Again, these are not rhetorical questions. Decisions about whether to treat doubtfully viable newborns are made nearly every day in the United States and elsewhere and will continue to need to be made for the foreseeable future.

71. See Robert M. Veatch, *Why Physicians Cannot Determine if Care Is Futile*, 42 J. AM. GERIATRIC SOC'Y 871 (1994).

72. At a minimum, because the claim for physiological futility has hopefully been dispelled, a case for ambiguity exists—which would argue for at least respecting initial parent requests for treatment below twenty-three weeks. I do think there is room to push for the more provocative claim that it is a net benefit from the infant's perspective to provide initial treatment below twenty-five weeks regardless of what any other stakeholder thinks.

want to maximize his or her chance of survival. This is precisely the position of the court in *Montalvo*.⁷³

This is also, in fact, how many physicians instinctively rank the interests of premature neonates born beyond twenty-five weeks gestation who possess much better up-front odds of survival without serious morbidity.⁷⁴ In one of the attitudinal provider surveys previously cited, 91% of respondents were prepared to provide treatment in such cases regardless of parental wishes to the contrary.⁷⁵ The fact that physicians are prepared to override a natural surrogate's informed decision about the disutility of medical care suggests that we accept the general proposition that newborns possess independent interests that can be considered separate and distinct from parents. Moreover, it suggests that survival is most often the paramount interest we ought to be concerned about.

Regarding quality-of-projected-life, the President's Commission insists that surrogates take seriously the notion that it is the perspective of the infant that matters most. This qualifier, I argue, makes it exceptionally difficult to turn a *risk* of unacceptable outcome (even if great) into a presumption about what should follow. Why shouldn't we expect the perspective of a neonate born at twenty-two weeks to be as follows: *if treatment is the only chance I have at a small, but real opportunity for a not unbearable human life, I'd be inclined to risk the high chance of death and high chance of permanent disability for that small chance of survival, of creating my own autobiography. If I die despite being treated, I am almost certainly no worse off than had treatment not been started. If I survive, and things go terribly bad for me, others can make a more informed choice to end my life once it is clearer that the life that I actually experience is "worse than death."*

73. *Montalvo v. Borkovek*, 647 N.W.2d 413 (Wis. Ct. App. 2002).

74. See Peerzada et al., *supra* note 33, at 495; Singh, *supra* note 34, at 519; Seri, *supra* note 41, at S6.

75. See Peerzada et al., *supra* note 33, at 493.

Some may recognize in this narrative a bow to the philosopher Derek Parfit's non-identity problem.⁷⁶ For a specific person standing in an *ex ante* position who has yet to experience a life full of avoidable burdens, that encumbered life will still, almost always, seem more valuable than no life at all. It is death's ineffability coupled with genuine uncertainty about how one might eventually adapt or cope to an objectively compromised human existence that appropriately pulls us toward a life-extending moral sensibility. This narrative also reinforces an intuition that individual human beings can be regarded as distinct and separable from one another even when cognitively naïve.⁷⁷

In order to make this argument, there is no need to deny that all rational persons ought to prefer a life without significant burdens. Instead, it means that we should not casually annihilate an impersonal (but subjectively-derived), foundational interest in survival for the sake of an impersonal (but objectively-derived) interest in avoiding an unburdened future life.⁷⁸ The problem of risk assessment is inescapable in these clinical situations. My modest claim is that it is, often times, nothing more than an assertion to insist that the probabilities of an acceptable outcome for the newborn are too poor to justify an attempt at rescue. Someone is passing judgment on the available statistics and that judgment is filled with values that deserve unbundling.

76. See generally DEREK PARFIT, REASONS AND PERSONS (1984).

77. The law certainly assumes that persons are distinct from one another, and regardless of the fit, it seems obligated to formally do so at the moment a baby is separated from a pregnant woman. See *Roe v. Wade*, 410 U.S. 113, 133 (1973).

78. The President's Commission's analysis suggests another argument for this claim about the primacy of newborn survival interests. It concluded neonatal intensive care treatment in cases of Down Syndrome was paradigmatically beneficial. Commission, *supra* note 9, at 6. Yet, we know that a non-trivial percentage of these newborns will end up most severely retarded, with untestable cognitive capabilities using standardized tests; we know that a non-trivial percentage of these newborns will end up entirely dependent on adult care in the home or a nursing facility because of their profound disability. Despite the statistical certainty of these devastating outcomes in some fraction of these children, the Commission did not regard treatment to the class of such newborns as ambiguous. If the concern in cases of doubtful viability is not so much about survival, but instead quality-of-survival, it is difficult to reconcile this worry with the position of the President's Commission in cases of Down Syndrome. If consistency across newborns matters (an issue of justice), we should be prepared to treat like cases similarly.

A small set of experiential data lends indirect empirical credibility to the logic of the *ex ante* argument. In 2007, U.S. investigators published an analysis of results from a series of self-assessments made by former very low birth weight and premature infants who had survived into their twenties.⁷⁹ The authors concluded that these persons “may have adapted to their functional limitations by [twenty] years of age” and could find “no influence on young adult satisfaction with health, subjective well-being, or health perceptions, despite the persistence of neurosensory impairments and their associated long-term medical, surgical, and psychosocial problems.”⁸⁰ Similar findings are documented in a series of studies tracking long-term outcomes for a cohort of 150 very low birth weight survivors for over twenty years in Canada.⁸¹ No significant differences in self-reported quality of life between normal controls and these survivors were found, despite the latter group reporting “more functional limitations in cognition, sensation, mobility, and self-care.”⁸² In discussing their findings, the Canadian investigators critically commented:

[Children] born with impairments . . . have never known life to be any different. They have adapted to their disabilities while growing up and perhaps made the necessary adjustments with less conscious effort. When we reported [that these] adolescents . . . viewed their lives fairly positively[,] . . . the findings were received with some skepticism and disbelief. . . . [Some] pointed to some element of denial and self-deception as mechanisms for coping. This is one interpretation. However, the consistency with which our cohort . . . described themselves as having good

79. Maureen Hack et al., *Self-Perceived Health, Functioning and Well-Being of Very-Low-Birth-Weight Infants at Age 20 Years*, 151 J. PEDIATRICS 635, 635 (2007).

80. Hack et al., *supra* note 79, at 639.

81. Saroj Saigal et al., *Self-Perceived Health-Related Quality of Life of Former Extremely Low Birth Weight Infants at Young Adulthood*, 118 PEDIATRICS 1140, 1140 (2006).

82. *Id.*

quality of life, taken together with the improvements in their life trajectories to adulthood, support the concept that this is real.⁸³

Such real world observations must be regarded cautiously. It would be a mistake to presume their general applicability or transferability to all survivors of extreme prematurity, particularly since the marker of very low birth weight does not always correspond with extreme physiologic immaturity.⁸⁴ Borderline viable babies that survived twenty years ago may be quite different than the ones we must deal with today. On the other hand, the recent U.K. and U.S. outcome studies that document significant handicaps in more recent survivors from the late 1990s also require substantial qualification. Though categorization of disability is objectively based, such a medicalized documentation of impairments offers only one particular view of “outcome.” Such point-in-time depictions in toddlers and pre-schoolers cannot be sufficient in and of themselves to make sweeping judgments about *these children as developing moral beings*. The findings do not automatically confirm an “unacceptably high” morbidity without someone else’s accompanying value judgment; they do not make an open-and-shut case about an outcome’s being “worse than death.”⁸⁵ We must remind ourselves here: worse than death to whom?⁸⁶

83. *Id.* at 1145–46.

84. The studies also do not capture any self-perceptions about quality of life in the most cognitively compromised survivors. Saigal analyzed the caregivers’ assessment in such cases. *See Saigal, supra* note 81.

85. *See Tyson et al., supra* note 50, at 1679.

86. *See Montalvo v. Borkovek*, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002) (“This determination could vary greatly based on the parents’ beliefs. One set of parents may view a particular disability as ‘worse than death,’ while another set of parents would not. Such a process, not unreasonably, has kaleidoscopic, unending implications.”). The substantive concern about whose perspective matters is also well supported by the empirical studies of Peter Ubel and colleagues:

To date, there are no perfect measures to determine just how happy people are. And there is no gold standard to estimate people’s subjective quality of life. Nevertheless, whatever makes up happiness or quality of life, it appears that many illnesses have far less impact on subjective quality of life than many of us would predict. This is good news. As much as we strive to reduce the burdens of illness, it is comforting to remember the strength of the human spirit. At the same time, it is worth remembering how this strength of spirit complicates quality of life measurement.

5. Analysis of a Composite Claim Regarding the Burden of Treatment

Skeptics of my preceding analysis could still argue that should an extremely premature newborn follow the statistical trend and die, the initiation of treatment will only have amounted to a net avoidable burden on the infant. Moreover, the probabilities suggest that intervention in the majority of cases will amount to nothing more than our multiplying greatly the number of instances where unnecessary pain and suffering is forced on otherwise doomed newborns. In short, the immediate burdens of treatment to many outweigh the marginal benefit to a few.

Whatever the strengths of this mixed utilitarian calculus across individuals, at least part of this retort problematically relies on a retrospective rather than prospective framing of the problem.⁸⁷ It is easy to regard failed interventions as avoidable, but my question remains: should they be examined from the perspective of the about-to-be born or just-born human being? If that is the view that ought to matter most, the need to accurately gauge the burdens of treatment, in particular immediate pain and suffering, becomes paramount. It is reasonable to argue that one need not endure torture to affect a fleeting chance of survival. The standard components of neonatal resuscitative and intensive care include mechanical ventilation, needle sticks, medications, and uncomfortable handling by providers from time to time. Are these interventions burdensome enough to discount a presumed interest in survival?

This is a dubious claim for at least two reasons. First, many premature neonates who are more mature, with better probabilities of survival, receive exactly the same interventions immediately after birth and for days and weeks thereafter, and few stakeholders object

Peter A. Ubel et al., *Whose Quality of Life? A Commentary Exploring Discrepancies Between Health State Evaluations of Patients and the General Public*, 12 *QUALITY OF LIFE RES.* 599, 605 (2003); see also Heather P. Lacey et al., *It Must Be Awful for Them: Perspective and Task Context Affects Ratings for Health Conditions*, 1 *JUDGMENT & DECISION MAKING* 146, 146 (2006).

87. See discussion *infra* Part III.

to the burdens of such interventions in those cases.⁸⁸ Second, we have the ability to mitigate pain associated with these interventions with analgesia. We may not be very good about doing so in practice, but such a professional failing cannot justify classifying the interventions as overwhelmingly burdensome. Again, adopting the perspective of the naïve newborn, why shouldn't she have a greater interest in taking the small chance of long-term subjectively acceptable survival if her doctors promise to at least attempt to relieve pain adequately during their rescue efforts?⁸⁹

Treatment that is too painful or causes too much suffering can be discontinued once enough evidence exists to suggest that a particular infant's life has become overwhelmed by such burdens.⁹⁰ The worst-off survivors of extreme prematurity are typically hospital-bound for several months, and opportunities to stop care present themselves in less dramatic ways than removal of an endotracheal tube.⁹¹ Nevertheless, it is important to acknowledge that, as time passes for such patients, it typically becomes more difficult *not* to extend life because demonstrable, intractable pain is much less frequent. And we

88. Can such interventions amount to torture in one instance and standard of care in another simply by virtue of their chance of working? I think so, but it is not obvious to me that a 0–20% chance of survival—even with high risk of lifelong disability—is so awful that we ought to consider them too burdensome. This again requires a value judgment. Thus, I leave it as an open question; nevertheless, if I adopt the perspective of the newborn most interested in maximizing her chance of survival, I might be skeptical that the statistical case is easily made.

89. If we choose to emphasize the high probability of death and the immediate burdens of treatment, it is easy to forget that only with initial intervention can individualized diagnostic and prognostic information be collected. In cases of ambiguity, the Commission suggests that specific information-gathering is essential to guide ethical decision-making: “[t]he longer some of these babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals can be on whether further treatment is warranted or futile.” *Commission, supra* note 9, at 221.

90. Emotionally, it often feels harder to stop once a human life has started receiving support, but this should not be an insurmountable obstacle when there is little disagreement about overwhelming burden. *See, e.g.*, Timothy E. Quill et al., *Palliative Options of Last Resort*, 278 J. AM. MED. ASS'N 2099, 2100 (a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia).

91. Pragmatically, it is sometimes harder to find something to stop once a human life moves beyond the need for intensive care, but again, this need not be an insurmountable obstacle when there is no disagreement about overwhelming burden. A few commentators assert that withdrawal of nutrition and hydration is morally different in the case of infants and children, but the plausibility of this position is doubtful. *See generally* Thomas A. Shannon & James J. Walter, *Artificial Nutrition, Hydration: Assessing Papal Statement*. NAT'L CATHOLIC REP., Apr. 16, 2004, at 9.

have yet to develop an adequate tool to reliably measure infant suffering.⁹² Indeed, it seems no small irony that, months after birth, uncertainty about long-term quality of life for severely injured survivors of extreme prematurity more often leads to provision of more life-sustaining care (for example, shunting hydrocephalus and placing gastrostomy tubes), while, at the time of birth or just before it, a worry about the risk of these exact same outcomes seems to provide a rationale to reject initial life-extending interventions.⁹³

III. A FINAL, PERSONAL REFLECTION ON THE MORAL IMPORTANCE OF NEWBORN SURVIVAL

I have argued that if we take seriously the claim that it is the perspective of the newborn that matters most, it should always be controversial to presume a quick death is better than taking a chance at life extension in the absence of hard evidence that overwhelming short or long-term pain and suffering must accompany treatment. Put in preferred language often found in pediatric clinical ethics, if primary attention to the newborn's best interests is demanded, exceedingly few newborns ought to be denied initial possibly life-saving medical treatment. I have attempted to locate a plausible basis for this claim within the framework for decision-making provided in 1983 by the President's Commission. The argument is, however, available independent of the work of the Commission, and remains, in my opinion, the most important and enduring normative legacy of the federal Baby Doe regulations.⁹⁴

92. See Alexander A. Kon, *Neonatal Euthanasia Is Unsupportable: The Groningen Protocol Should Be Abandoned*, in 28 THEORETICAL MEDICINE AND BIOETHICS 453, 453 (2007) ("Without the testament of the patient herself as to the nature and magnitude of her suffering, physicians can never accurately weigh the benefits and burdens of a child's life, and therefore any such system [of euthanasia] would condemn to death some children whose suffering is not unbearable.").

93. This may simply verify the intuition that providers and parents find it much easier to accept and cope with an early human death because personal attachments and bonds of affection are less cemented. The moral importance of this intuition needs further elucidation. See discussion *infra* Part III.

94. Despite the continued presence of the Baby Doe regulations, law on this issue in the United States remains largely passive: it reacts to, rather than compels, action. Judges only face neonatal treatment dilemmas involving real children with developing biographies after a value conflict has arisen. In such cases, the non-identity puzzle no longer exists as philosophical exercise. When a stakeholder

As long as it is plausible to claim that an individualistic, exclusively patient-centered interpretation of best interests is correct, an advocate for a newborn can turn a modicum of uncertainty about outcomes or ambiguity about the correct balancing of benefits and burdens into a defensible rationale to prevent life-ending clinical decisions.⁹⁵ It is surprising that despite the complete logic of this position, few involved in actually providing neonatal intensive care or who have expertly commented on life-ending decisions for neonates eschew allegiance to the Best Interests Standard.⁹⁶

As mentioned in the introduction to this essay, interpretations of the Best Interests Standard are not amenable to conclusive proof. It may be that many participants in and close observers of neonatal intensive care are comfortable with a working ethical paradigm that on-the-ground admits of several possible meanings.⁹⁷ It may be that parents and providers are comfortable knowing that on any given day in any given two hospitals, the best interests of extremely premature newborns facing basically exactly the same odds of survival and risk of morbidity will be evaluated oppositely under the standard. Nevertheless, from the perspective of declarative law with one eye toward prospective consistent treatment across individuals, we should appreciate the problem created.

Today, actual clinical decisions to end newborn human life that take place behind closed doors in hospitals are rarely externally scrutinized. Legally restrictive interpretations of the Best Interests

comes before the bench articulating a reasonable basis for believing that it would be better to proceed with treatment, judges are almost always inclined to lend a sympathetic ear. Legal judgments, just like medical judgments, are naturally predisposed to encourage life-preserving behaviors. This might help explain, in part, why physicians in places like Texas have strongly supported legislation that offers judicial bypasses in cases where providers believe further treatment to be futile. *See, e.g.*, Robert L. Fine et al., *Medical Futility in the Neonatal Intensive Care Unit: Hope for a Resolution*, 116 PEDIATRICS 1219, 1222 (2005); Robert D. Truog, *Tackling Medical Futility in Texas (author's reply)*, 357 NEW ENG. J. MED. 1558, 1559 (2007).

95. *See* McCullough, *supra* note 8, at 1021.

96. *See, e.g.*, Nuffield Council on Bioethics, *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*, Nov. 2006, at xvii, available at http://www.nuffieldbioethics.org/go/ourwork/neonatal/publication_406.html; *see also* Committee on Fetus and Newborn, *Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns*, 119 PEDIATRICS 401, 403 (2007).

97. *See, e.g.*, D. Micah Hester, *Interests and Neonates: There Is More to the Story Than We Explicitly Acknowledge*, 28 THEORETICAL MEDICINE AND BIOETHICS 357, 358–59 (2007).

Standard in the context of such non-treatment decisions are rare enough that they have failed to substantially change normative professional practice. No neonatal physician can deny that we occasionally make specific individual life-ending decisions without all of the facts necessary to firmly predict whether a patient's future life will be full of overwhelming pain and suffering. In particular, early decisions to stop intensive care for extremely premature infants who have suffered large intracranial hemorrhages or for newborns who have suffered from some other form of serious brain injury (asphyxia or congenital) are typically not based on concerns about protracted pain and suffering as much as concern about a child's predicted minimal future cognitive capacities.⁹⁸ Yet, even these reasonable predictions about poor neurological outcome are no substitute for their actual manifestation.

We can be and are very occasionally surprised when a child survivor whose neurological prognosis was initially quite grim appears to be adapting well to his or her permanent handicaps. We do not have and may never have a reliable and comprehensive set of forecasting tools, because static radiological imagery and lab markers are incapable of telling us how a child may or may not adapt to her future socially-constructed environment. At the beginning of life, it is difficult to account for the potential plasticity of any given neuronal circuitry, and even harder to account for the responses of any given social community. So, if we are being brutally honest, we need to admit that in some clinical cases when we retreat from newborn life extension, it is too early to declare that life will not be "worth it" to the child should she survive for decades with loving attention from family and others. To admit this is not to say that our worry is inauthentic at the moment of debating the value of providing life-sustaining care.

Perhaps there really is no need to perturb the current pragmatic equilibrium. Nevertheless, in these concluding remarks, I also offer

98. Stephen N. Wall & John Colin Partridge, *Death in the Intensive Care Nursery: Physician Practice of Withdrawing and Withholding Life Support*, 99 PEDIATRICS 64, 66 (1997).

that it is both naïve and unrealistic to believe that important external considerations do not influence providers and parents in making treatment decisions for gravely ill newborns. Though robust empirical evidence is lacking, I suspect many neonatologists consider both the immediate and long-term negative impact a severely disabled child might have on a family, and (less frequently) the impact on society when recommending against the initiation or for the discontinuation of treatment.⁹⁹ I also suspect many parents instinctively worry about the immediate and long-term negative impact a severely disabled child might have on their own relationship and other siblings when they choose to avoid potentially life-saving treatment, regardless of how physicians counsel them.¹⁰⁰ Some qualitative data supports what is anecdotally a familiar observation in neonatal and pediatric intensive care: some families are irreparably traumatized with the introduction of a gravely disabled infant into their lives.¹⁰¹

It remains vexing to know whether and how to factor this real psycho-social risk into our treatment decision-making calculus. On the provocative interpretation of the President's Commission's analysis offered in this essay, external costs (emotional, social, financial) such as those that accrue to the family or society, are deemed irrelevant because they do not specifically attend to the core interests of the child. Some recent commentators also continue to tow the professional party line charitably describing neonatal health care providers as being "well-motivated" when their treatment decisions are informed by "patient-oriented outcome variables" (futility, viability, quality of life) rather than "societal or personal concerns."¹⁰² I question the sensibility of perpetuating such simplistic

99. Here, I speak as a practicing neonatologist who has had occasional conversations with colleagues about such matters.

100. Here again, I speak as a practicing neonatologist who has had occasional conversations with parents about such matters.

101. Dennis Drotar et al., *The Impact of Extremely Low Birth Weight on the Families of School-Aged Children*, 117 PEDIATRICS 2006, 2010-11 (2006); Saroj Saigal et al., *Impact of Extreme Prematurity on Families of Adolescent Children*, 137 J. PED. 701, 705 (2000).

102. See Singh et al., *supra* note 34.

dichotomies in defining when treatment decisions are ethical and when they are not. First, as I hope this essay has demonstrated, I doubt whether many in clinical medicine possess analytically sound definitions of futility and viability. These terms are not only liable to abuse, but they always entail value judgments. Second, I very much worry about a dominant vantage of normalcy that creeps into judgments about what constitutes an unacceptable quality of life for a child. A life where one is only capable of enjoying the simplest of primitive pleasures may still be of some value to the one in possession of that life.

Finally, I am also increasingly persuaded that we need more transparent discourse regarding when and why emotional, psychosocial, and financial costs and burdens to persons other than newborns can and *ought* to ethically matter in neonatal treatment dilemmas. I do not believe that decisions to end life-support for newborns can only be justified when we exclusively attend to so-called patient-oriented outcome variables. Few of us, physicians and patients included, are obstinate deontologists. That is, few of us are really prepared to claim that no matter the cost to others, it is *never* acceptable to sacrifice the possible benefit to one individual for the sake of larger benefits.¹⁰³ We have a psychological tendency in

103. For example, imagine that we did institute a comprehensive policy of initiating and continuing life-saving treatment for all newborns, infants, and children who had statistically small chances of survival, and if successful, who might reasonably enjoy some aspects of extended life. Imagine that, over time, this policy depleted the pool of financial and human health care resources because of the intensity of services provided to this small group of patients. Imagine as a result of the shift in resource allocation, routine coverage of many other highly valued health care services became unavailable for a much larger segment of the pediatric population. Now, many more children suffer preventable health-related harms that, while not lethal, are disabling (more than toothaches, less than appendicitis). Is it obviously wrong in such a world to stop prioritizing the interests of this minority of life-threatened children over the aggregate health interests of the others? The 2008 NICHD study estimated an extra 1,749 hospital days per zero to nine survivors per newborn treated between twenty-two and twenty-three weeks. The cost for each hospital day was estimated at \$3,400. The study concluded "that extending intensive care to all of the most immature infants would entail considerable suffering, resource use, and cost in order to benefit only a small proportion of infants." See generally Tyson et al., *supra* note 50, at 1678, 1680. Here, I only dispute the authors' claim regarding considerable suffering and I applaud the admission of benefit to some survivors. It is not a given that any child survivor would have a life "worse than death." Nevertheless, such a policy would extract a heavy toll in terms of resources and expenses, and it is those costs that are capable of doing moral work.

clinical medicine to frame ethical questions as either-or propositions. However, there ought to be room for more nuanced analysis.

We might start with acknowledgement that when important values are in genuine competition with each other, the prioritization of one set necessarily entails the *sacrifice* of others. Strong intuitions are relentlessly reinforced in the practice of clinical medicine and push us to frame value trade-offs in ways that minimize our concern about violating any individual patient's intrinsic moral worth. We feel obligated as doctors to emphasize some significant cost or burden imposed on our identified patients before we feel comfortable also including more traditional utilitarian reasoning. At the clinical bedside, the idea that we *ought* to trade away the life of a patient for the sake of the overall material and social well-being of others must be psychologically resisted.

Preposterous hypotheticals are not needed to make the case about a place in clinical ethics for interpersonal consequentialist reasoning. In a 2009 observational study of a high-quality academic intensive care unit in India that faces severe constraints, hard decisions about which neonates to invest scarce resources into are routinely made.¹⁰⁴ Perhaps not surprisingly, in a country where there exists essentially no health insurance, patients pay for almost all care out-of-pocket, and there exists no community safety net for families that are left to care for seriously and permanently handicapped children, physicians admitted that they heavily factored both familial and social variables into specific treatment decisions.¹⁰⁵

104. Ingrid Miljeteig, Sadath A. Sayeed, Amar Jesani, Kjell A. Johansson, & Ole F. Norheim, *Impact of Ethics and Economics on End-of-Life Decisions in an Indian Neonatal Unit*, 124 PEDIATRICS e322–28.

105. *Id.* at e324–25. (“Providers understood ‘intact survival’ to be absence of neurologic disability and absence of a need for costly treatment in the future. They noted a duty to avoid pushing treatment on a family when a neonate was likely to end up ‘a compromised child.’ Informants offered as partial justification for their practice the reality that India possesses an inadequate system of supporting children with disabilities, particularly with respect to rehabilitation, long-term treatment, and appropriate educational services, and the reality that many families are poorly prepared to take on such burdens: ‘As there is no social security system for these premature and the commitment from the family is not there in our society, we try to limit ourselves to the babies where it is likely to get better.’”).

I do not conclude that the providers in India got the value trade-off “right”; rather, I conclude that, under conditions of stress, there might be a plurality of positions that can be rationally defended. We can and should lament the lack of resources available in such places, and advocate for more support from all possible corners, but there still remains a problem of how to counsel the stakeholders on the ground facing real clinical cases while they wait for the background conditions to improve. It is not obvious to me that these Indian physicians must demand parents bankrupt themselves and their existing families in order to take home a seriously disabled child who will likely be neglected and receive minimal support in an impoverished community. It is not obvious to me that Indian physicians facing these systemic constraints ought to assume custodial care for these newborns if and when parents abandon them in the hospital. For me, these are complex questions that do not lend themselves to simple “yes” or “no” ethical answers. At a minimum, they call attention to what remain poorly analyzed and understood issues involving the *social* determinants of neonatal death and survival and its social meaning.

To its credit, the President’s Commission seemed keenly aware of the broader implications of a normative policy that most often encourages life extension for newborns at high risk of serious disability:

Adoption and foster care should be available for parents unable to raise their seriously handicapped child. To aid parents, support that is responsive to the emotional and financial demands of handicapped persons and their families should be available. . . . Public support for effective voluntary organizations and governmental programs is the inescapable extension of society’s deep interest in sustaining life in neonatal intensive care units.¹⁰⁶

106. *Commission, supra* note 9, at 228.

After more than thirty years of providing neonatal intensive care, it remains unclear that even in the United States we have met our obligation to support either handicapped survivors or their families.¹⁰⁷ Though the state has thankfully progressed beyond providing “storage space and ‘hay, oats, and water’” for the worst-off survivors of neonatal intensive care, it is also a stretch to claim that we have done all that we should to make life manageable for families who must endure after our initial medical success.¹⁰⁸ Rather strikingly, the Commission also stated:

[T]o the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised.¹⁰⁹

We need more open public reflection on what ought to follow from such a compromise. Interestingly, health care economists have mathematically modeled something like early newborn and infant interests in the form of “acquired life potential.”¹¹⁰ Implemented into a cost-effectiveness analysis, it is an “age weight” that allows for the systematic discounting of treatment interventions the earlier one stands in the stream of temporal life. The notion of acquired life potential follows from two controversial assumptions: 1) life acquires value only as it acquires self-awareness, and 2) life acquires

107. The social availability of adoption and foster care cannot be denied in the United States. But there can also be no denying a very peculiar sociological dynamic that seems called for if we suddenly began to push strongly for this “option” on biological parents. Neonatal providers would be relieved of taking into consideration the wishes of parents initially and instead would relay the facts regarding predicted morbidity outcomes for at-risk newborns. Physicians would next introduce the idea that if biological parents are not willing to play along with a treatment trial, they could opt out of the presumptive decision maker role. Physicians would then need to assist parents in coming to terms with formally transferring custody of their newborns to the state, at least temporarily. Even placing issues of coercion and the promotion of a sense of parental abandonment aside, I cannot imagine such a professional practice ever becoming routine.

108. *Commission, supra* note 9, at 228.

109. *Commission, supra* note 9, at 229.

110. Dean T. Jamison et al., *Incorporating Deaths Near the Time of Birth into Estimates of the Global Burden of Disease*, in *GLOBAL BURDEN OF DISEASE AND RISK FACTORS* 427, 438 (Alan D. Lopez et al. ed., 2006).

additional value as it develops bonds with others. The intuition behind these assumptions is arguably not so radical: many accept the claim that the death of a newborn is not as great a loss either to the newborn or to the rest of us as is the death of an older child, teenager or adult.¹¹¹

If this intuition reflects something deeper than superficial sentiment, it calls for a fuller accounting not only by philosophers and economists, but also by those who claim to have a stake in medical treatment decisions for seriously sick newborns. As dangerous as it may be, I believe this kind of intuition partly explains why conscientious doctors in India behave the way they do under what must be disheartening conditions. The notion that newborns are not full moral beings as compared to more developed persons might be understood as a way to preserve our deontological leanings. It shies away from regarding cognitively naïve human beings in purely instrumental terms. To borrow from philosophical tradition, we are no longer comparing apples to apples but acorns to trees, and it thus becomes easier to justify according them different amounts of respect. In the end, it may also help explain why, in places like the United States, we seem sociologically capable of allowing two clinical norms to co-exist in tension: we stand ready on a moment's notice to invest hundreds of thousands of dollars to save the life of one critically ill newborn (an acorn is still worth something), while simultaneously, we stand ready to avoid such investment even when there are not unreasonable grounds to believe that a newborn could go on to value her own life just as much as the rest of us are capable of doing (but an acorn is not worth everything).

111. The natural intuition plays out further—death at an elderly age does not seem so great a loss as deaths at younger ages. An extended discussion of this intuition, its relation to the abortion question, and the problem of neonatal interests and defining moral personhood is beyond the scope of this paper and its author. See generally John Harris, *The Concept of the Person and the Value of Life*, KENNEDY INST. OF ETHICS J. 293, 293–94 (1999); see also generally JEFF MCMAHAN, *THE ETHICS OF KILLING: PROBLEMS AT THE MARGINS OF LIFE* (Oxford Univ. Press 2002).

