

Borderline Viability

Controversies in Caring for the Extremely Premature Infant



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KEYWORDS

• Extreme prematurity • Perivable • Viability • Ethics • Decision-making

KEY POINTS

- There is general consensus regarding threshold levels that describe the gray zone on the limits of viability, and gestational age alone should not be used solely in making a decision.
- There is no evidence to support a mandate on a trial of assessment and treatment in the gray zone, although it is permissible to take this approach with family agreement.
- Supporting parental decision-making in the gray zone before delivery and afterward in the NICU is ethically permissible and is the ideal.

INTRODUCTION

Controversy surrounding the decision to resuscitate at the limits or borderline of viability has been at the center of neonatal ethical debate for decades. This debate has led to numerous reports, from individual institutions, councils, and advisory committees, that all have remarkable consistency in the development of gestational age-based guidelines.^{1–18} The consensus based on outcome data has led to recommendations and common practice of two threshold levels of care: a lower threshold of no resuscitation (<22 weeks), and an upper threshold of obligatory resuscitation (25 weeks). The 22- to 24-week range then becomes the gray zone. Although there are differing caveats among the guidelines regarding physician assessments or strength of recommendations from the ethical perspective, the gray zone has become the gestational age spectrum in which resuscitation is based on parental choice. The outer thresholds represent limits on parental authority to make a decision. The underlying goal in any of these guidelines is to limit overtreat and undertreat of the neonate, to support parents, yet rely on a best interest standard for the neonate. Decisions are centered on the dilemma that withholding resuscitation leads to certain death, yet resuscitation leads to an uncertain future with the possibilities ranging from death to

No conflicts of interest to disclose.

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Clin Perinatol 41 (2014) 799–814
<http://dx.doi.org/10.1016/j.clp.2014.08.005>

perinatology.theclinics.com

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considerable medical, emotional, societal, and financial risk to normal life. After decades of debate and reasonably consistent consensus statements regarding resuscitation, what if any are the remaining controversies?

Some might see controversy at the larger social or policy level, such as concerns of legal or regulatory conflicts with the guidelines, or suggestions that the guidelines as a whole are discriminatory. For most, however, controversy arises at an individual case-by-case perspective with disagreement on what is actually best for a particular neonate. This is often portrayed as a conflict between parental autonomy and the child's best interest.

This article reviews legal or regulatory concerns that may contradict ethical discussion and guidelines, discriminatory and scientific basis concerns with consensus guidelines, and personal controversy about how to determine best interest, and suggests that guidelines are a reasonable place to start in helping determine parental authority and autonomy. It also addresses controversies raised in counseling and costs.

LEGAL CONFLICT WITH GUIDELINES?

It is rare that when physicians and family agree on a plan there are any legal ramifications. Although it is beyond the scope of this article to review in detail the pertinent legal cases that might have an impact on this issue, there are at least four cases that deserve mention. One case is that of a father who withdrew support on his 26-week gestation infant after he was resuscitated against parental wishes. The father was acquitted of wrong-doing.¹⁹ A second case involved a physician who started resuscitation per parental wishes, but stopped when the infant was not responding. The physician was accused of failure to provide full resuscitation and violating informed consent. He was acquitted.²⁰ Then there were two cases in which physicians unilaterally resuscitated the baby, one against parental wishes because of institutional pressure, and the other with later claims of violating informed consent.^{21,22} In both cases parties were acquitted. The pattern in each of these cases is that of unilateral decision-making. Yet despite contradictory outcomes (two survived with some neurodevelopment impairment (NDI), and two died), all defendants were acquitted. Perhaps the message is the courts do not want to lay blame in these difficult situations, at least after they occur.

Despite the results of these individual legal cases, there is potential danger in the stacking of some federal regulations, namely the Born-Alive law, Emergency Medical Treatment & Labor Act (EMTALA), and CAPTA (Child Abuse Prevention and Treatment Act), that could lead to mandated emergency medical treatment.²³ The law has supported the idea that the periviable birth is an emergency.^{21,22,24} The labor and delivery unit could be held to the same EMTALA requirements as an emergency room.²⁴ EMTALA makes no claim that resuscitation is necessary, only that there should be a screening examination. It does not define what that assessment entails, nor does it argue for mandated treatment.²⁴ A Texas case raised the question of whether a periviable birth should be considered an emergency exception to informed consent.²¹ Some authors and even some of the guidelines seem to agree with this line of reasoning by leaving open the possibility of changing perinatal decisions after birth.^{2,3,9,25} The stacking of some case law and federal regulations can lead to the claim that all infants should be given a trial of assessment and treatment.^{23,25}

ARGUMENT 1 AGAINST GUIDELINES: A TRIAL OF ASSESSMENT AND TREATMENT FOR ALL

The emergency claim that would require a trial of assessment and treatment of all periviable newborns is based on four premises²⁵: (1) assessment of gestational age after

birth is more accurate; (2) assessment of vigorousness adds prognostic information; (3) testing treatment responses in first hours to days provides more facts or certainty to help determine long-term prognosis and therefore decreases speculation; and (4) treatment withdrawal is ethically equivalent to withholding, from the parents' perspective. Are these four premises all true for all cases at the limits of viability? If not, a mandate is not justified.

RESPONSE TO MANDATORY TRIAL OF ASSESSMENT AND TREATMENT

Premise 1: Assessment of Gestational Age After Birth Is Most Accurate

The argument for mandating a neonatal assessment of gestational age at delivery is essentially based on a belief in the uncertainty of gestational age measurements. Proponents argue that, although there can be some discussion and advanced care planning with prospective parents on their wishes, decisions should be contingent on the neonatologist's assessment at birth in the delivery room.^{2-4,9} The argument is that estimates of gestational age can vary, sometimes up to 1 to 2 weeks gestation, which leads to uncertainty, and therefore may not be reliable for prognostication. This has important implications, especially if the range of accuracy can place a newborn at either end of the guideline thresholds.

There are, however, more and less accurate assessment tools (Fig. 1). There is evidence supporting that obstetric modalities of dating are superior to a well-trained neonatal clinician's assessment of gestational age by examination.²⁶⁻³⁰ In fact, research on accuracy of the Ballard examination revealed that clinicians overestimated gestational age by 2 weeks, with a range of ± 4 weeks.²⁹ This is evidence

Certainty of Gestational Age Measures

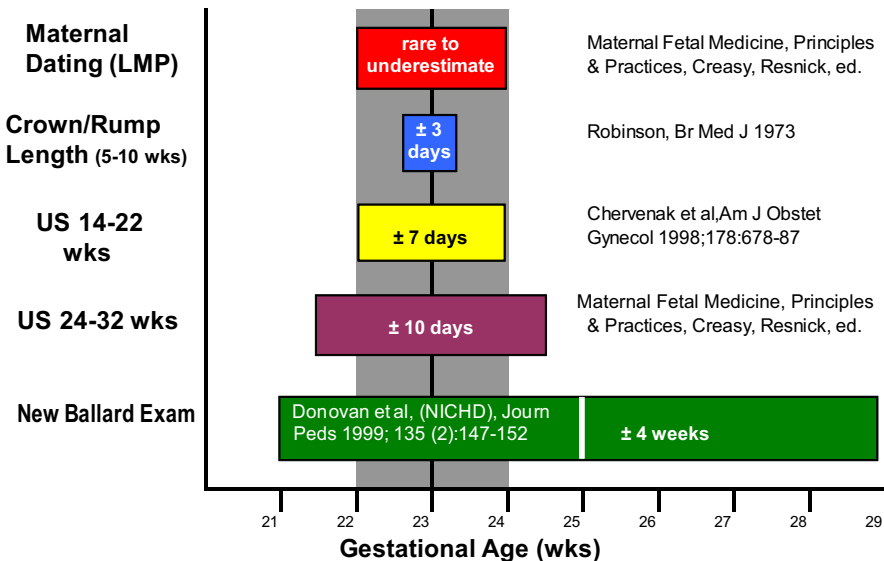


Fig. 1. Accuracy of gestational age assessment tools. Accuracy measurements of different gestational age assessment tools within the gray zone of borderline viability, assuming 23 weeks gestational age, graph demonstrates potential range of error in measurements. US, ultrasound; LMP, last menstrual period.

that the neonatal examination is the least accurate assessment, and should never override obstetric dating. Also, although obstetric dating has its level of uncertainty, it must be acknowledged that the epidemiologic outcome data used in developing existing consensus guidelines are based on similar uncertainties, and thus they remain applicable.¹⁸ Finally, the most recent guidelines now acknowledge one should not look at gestational age alone, but take into account other factors that help predict outcome (weight, gender, singleton, steroids).³¹ The fact remains that gestational age, albeit not solely, is still a factor in outcome predictions, and the most accurate measurement available should be used in discussions and decision-making. The only time this should be the neonatal examination is when there is no prenatal information available, thus making it a real emergency.

Premise 2: Assessment of Vigorousness Adds Prognostic Information and Therefore Decreases Uncertainty

Although it seems natural to assume that the more vigorous-looking preterm may be more mature acting and therefore do better, the data again do not support this premise. Using Apgar scores as a marker of vigorousness, neither the 1- nor 5-minute Apgar score can help predict survival or survival with or without morbidities.^{32–34}

Premise 3: Testing Treatment Responses in First Hours to Days Provides More Facts or Certainty to Help Determine Long-Term Prognosis and Therefore Decreases Speculation

What responses in this time frame provide factual versus speculative predictions? Although there are some infants who are too immature to even survive this short period of time, the ability to support and keep alive babies for longer and longer time has certainly improved to the point that the average time to death has increased from 4 days to now weeks.^{31,35–37} Certainly a grade 3 to 4 intraventricular hemorrhage increases risk, but the significance and certainty of any neurologic prediction remain speculative. At the same time one-third of infants with a normal head ultrasound at 1 week develop significant neurologic handicaps.³⁸ Physiologic response in these first days provides no prediction of other illnesses, such as necrotizing enterocolitis, bronchopulmonary dysplasia, patent ductus arteriosus, iatrogenic infection, and retinopathy of prematurity, which are also associated with significant NDI, and late death. Physiologic stability based on serial assessments for an individual infant are imperfect to begin with and grow less accurate each day.³⁹ Incorporating intuitions of “die before neonatal intensive care unit (NICU) discharge” and head ultrasound does improve prognostication. A child who has even a single day of corroborated prediction of “die before NICU discharge” and any degree of head ultrasound abnormality (grade 2 or worse) has only a 4% of being alive without NDI at 2 years.⁴⁰ This would require NICU teams to begin the practice of predicting death before discharge more routinely in their rounds. Although some facts may emerge, uncertainty remains, and so prognosis remains speculative.

Premise 4: Treatment Withdrawal Is Ethically Equivalent to Withholding (From the Parents’ Perspective)

The equivalence of withdrawing and withholding life-sustaining medical treatment is well supported in ethics and the law.^{41–47} To provide a trial of therapy with the option of withdrawal should the prognostication become worse is a reasonable and permissible process to undertake. Despite the ethical and legal support, however, data suggest that even physicians find it more difficult to withdraw than to withhold.^{48,49} This should be reason enough to accept that at least some parents may psychologically

feel different about choosing to withhold versus withdraw. Whether this feeling is based on a sense of moral responsibility about a more deliberate act (killing vs letting die), remaining uncertainty or disbelief in prognostication, or the commitment of time and effort they have already been through with the baby is not clear. What is clear is that all parents who can come to the decision to withdraw find it extremely difficult, and that not all parents may be able to come to this decision.

PRETERM BIRTH CAN BE BUT IS MOST OFTEN NOT AN EMERGENCY SITUATION

The science and ethics support that there are factual problems with each premise of emergency trial of assessment and treatment mandate. What is distinctively different in the perinatal care environment is that in most cases there are reasonable and accurate data on the fetus (gestational age, sex, weight, maternal steroids) that can help with prognosis, and time to counsel families about these issues before initiation. Perinatal data from surveys that include births at the margin of viability suggest that up to two-thirds of such pregnancies have complications that would bring the mother to the attention of the obstetrician days or weeks before delivery.⁵⁰ Only a small minority of births at the margins of viability occur so precipitously that there are insufficient data or time. Prenatal prognostication and decision-making, although not perfect, are not based on ignorance. Because there have been no legal cases against physicians and parents who collaborate in these decisions, the legal concerns should be minimal.

The consensus guidelines suggest that if the situation is emergent because facts are not known or there is no time to talk, one should resuscitate first, evaluate, and talk later. The medical team needs to start treatment if they are ever going to be able to have the conversation about family values and wishes. Finally, even though there is no medical evidence to support a mandate on a trial of assessment and treatment in the gray area, it does not mean a family cannot be supported in this decision (discussed later).

ARGUMENT 2 AGAINST GUIDELINES: THEY ARE DISCRIMINATORY AND LACK ETHICAL AND SCIENTIFIC BASIS

Several authors have challenged the ethical and scientific basis for setting up these thresholds, claiming they set up too simple of rules for a complicated ethical decision.^{51–55} They argue that preterm infants seem to have a different moral status than everyone else. There are few to no other policy statements in the literature regarding resuscitation from an age perspective for any other life-threatening situation (eg, head trauma, near-drowning, meningitis, stroke, or burns).⁵² Survey literature has shown that despite similar outcome data, preterm infants are less likely to be resuscitated than older children and adults, and the authors argue that the best-interest standard is not applied to these infants.⁵⁶ This raises concern of discrimination or gestational ageism.¹⁸

Ageism Within and at the Border of the Gray Zone

Meadow suggests that there is some level of ageism even within the gray zone. There are four possible outcomes for the borderline viable preterm infant: (1) palliative comfort care leading to death; (2) resuscitation and NICU intervention, but the infant dies anyway; (3) resuscitation and NICU intervention with survival but significant NDI; and (4) resuscitation and NICU intervention with eventual discharge and no significant NDI.^{57,58}

Most clinicians would like to avoid numbers 2 and 3. For some parents, however, having an infant in group 2 is not necessarily the worst thing. For these parents, “giving

your baby a chance,” even if he or she dies, is sad but may not be worse than the alternative of not trying at all. For these parents, the worst outcome is group 3. He rightly states that for this scenario, there is a different calculation that should come into play during antenatal counseling: the proportion of NICU survivors (not all births) who survive without NDI. Although the traditional outcomes of survival and intact survival combined are steeply dependent on gestational age, the percentage of NICU survivors who are free of NDI is flat over the 22- to 25-week gestational range at approximately 50%.^{57,58} If this is true, then why do some neonatologists and guidelines declare treatment as obligatory at 25 weeks, yet permissible or not at 23 weeks? Why should the parent of a 23-week gestation infant have the choice of resuscitation or not, yet the parent of the 25-week infant may not? There seems to be discrimination against the 23-week infant.

Response to Ageism

Responses to ageism could go in one of two directions. First, assume all these 23- to 25-week infants should be treated equally and with consistency. This would require changes in current medical practice. There are two ways there could be more consistency. Either there should be a mandated trial of assessment and treatment for all preterm infants in the gray zone, or parents should have a choice on whether they want a trial of assessment and treatment or palliative care. If there is a mandate, this essentially eliminates any upper threshold of any consensus guideline. If one allows a trial based on parental choice, the upper threshold might have to be raised for consistency.⁵

When comparing the neonate with the older patient, it is argued one is undervaluing the preterm infant. However, one could turn it around and suggest that parental permissibility is the correct ethical way, and perhaps could be a model for the older population. The second direction to take is to explore whether there are differences between the preterm infant within the gray zone and with older patients that justify a different approach.

Wilkinson¹⁸ suggests there are three potential reasons for a justified difference. First, there is the possibility of greater harm or burden of treatment. In the short term, these infants require 3 to 4 months in the hospital, with many requiring 10 to 16 painful or stressful procedures a day.⁵⁹ He makes an argument that for a newborn a “keep alive” mistake is potentially worse than a “let die” mistake.⁶⁰ His claim is that death for a newborn is not as bad a death as for an older child because they have not established relationships, nor developed preferences, plans, or hopes. It deprives them of their future life, but they will not be aware to regret it. What is bad is the absence of experience rather than the experience of a negative. A “keep alive” mistake is potentially worse because if it is a life not worth living it is a net burden and caused greater harm.⁶⁰

A second difference is that typically there is time and opportunity for counseling and discussions in advance that may not be there for the comparative scenarios of the older patient suggested in the literature.⁵² Perhaps the neonatal community is ahead of its time, and other groups could consider whether they would want to create consensus guidelines, but again most of these might be on withdrawal based on prognosis, unless nonemergent situations.

Third, perhaps there is a difference in how one makes a best interest judgment for the preterm versus the older patient. Although for some parents the calculus and value of outcome that Meadow presents might be true, there are others who might believe that NICU care and death is a bad outcome they would like to prevent their child from experiencing. Wilkinson⁶⁰ claims parents have a weightier role based on their own interests.

ARGUMENT 3: DOCTOR KNOWS BEST

Often the real moral controversies come up on a case-by-case basis at the borderline viable newborn. Batton⁵¹ acknowledged the difficulty for the American Academy of Pediatrics (AAP) Committee on Fetus and Newborn in formulating guidelines because of individual personal convictions. The goal in this article cannot be to change anyone's mind. However, thinking about constructs of pediatric surrogate decision-making, and recognition of conflicting interests and uncertainties, might help physicians become more comfortable in being tolerant and flexible within the guidelines.

BEST INTEREST

All consensus statements, and all those who have concerns about those consensus statements, would likely agree that the goal of neonatal medicine is to minimize undertreatment and overtreatment of the extremely premature infant. All advocate that the decision-making process ought to be based on the concept of the infant's best interest. The best interest standard, theoretically a beneficence-based decision for the patient whose wishes are unknowable, is the core ethical principle in neonatal surrogate decision-making. Because the newborn is immature and vulnerable, an adult is to make decisions on behalf of it. It is considered the right and responsibility of the parents to be the ones to make these best interest decisions.^{46,61} However, there are limitations placed on parental authority based on the idea that children need to be protected from unwise parental decisions, such as in cases of abuse or neglect. Controversy arises when parents and health care staff might view a child's best interests differently, often based on their own model or interpretation of what is best.⁶² The argument often becomes circular. Although the concept of parental autonomy and parental permission suggests the parents, based on their values, are the ones to weigh the benefits and burdens of medical therapy for their child in determining what is best, there are times parental autonomy can be overridden.

Although best interest is central to the ethical language in neonatology, there are those who argue it is incoherent, unrealistic, unknowable, or overly individualistic.^{63,64} On the one hand the principle is meant to be objective. One is to ignore or negate all other interests except that of the infant's self-regarding interest. In doing this, however, one has a tendency to pit the parental and family interests against the infant's interest as if they are not interrelated. If, on the other hand, one is to allow parental and family interests and values to define best interest, then it seems subjective. Finally, there are provider interests that must be acknowledged in neonatal care, such as personal ego, program development, or financial payment.

Others argue best interest is a pragmatic standard of reasonableness.⁶⁵ If one thinks of best interest as a simple narrow concept on how to make decisions for any incompetent patient it becomes too restrictive. Instead, if one understands best interest as a construct of action-guiding principles, it can be helpful. What the words or construct of best interest should do is make medical professionals think.⁶⁶ Medical experts have the expertise on disease processes and data. They need to acknowledge that parental values provide the meaning to that prognosis.⁶² "The best interest principle is to serve as a regulative ideal, not as a strict and literal requirement, because parents' obligations toward their other children as well as their own legitimate self-interests can conflict with doing what maximizes the child's well-being, and sometimes takes precedence over it."⁶⁷

CONSTRAINED PARENTAL AUTONOMY

Another construct for pediatric decision-making is that of constrained parental autonomy.⁶⁴ In this construct, the infant's interests are not taken in isolation, but within the framework of an intimate family. If the self-regarding interests of a child conflict with the family goals or interests, the parents may compromise the interests of the child, as long as it is not sacrificing the child's basic needs. The constraining of parental autonomy is based on respect for persons. Respect is (1) owed to all individuals based on the individual's personhood; (2) is owed proportionate to actualized capacities and potential; and (3) varies depending on the relationship. This construct permits wide parental autonomy and respects the freedom of parents to balance competing claims of family members, provided that each has basic needs met. This rings true in everyday parenting as limits are set, and sacrifices are asked, of children and parents every day.

UNCERTAINTY AND HARM

When making a decision for an extremely preterm infant there are actually many levels of uncertainty.⁶⁰ On one level there is medical prognostic uncertainty. What complicates predictions includes variations in an individual's genetic or physical susceptibilities, their psychological ability to cope with the physical, neuroplasticity, and the environment. These help determine experiential uncertainty; how happy or unhappy will the survivor be, how difficult will they find their outcome, how much pain will they experience? This is why for some significant NDI is tolerable and for others mild cerebral palsy or attention-deficit issues may seem insurmountable.⁵² Finally, there is moral uncertainty; what ought we to do, what ethical framework or rules should we apply, or how do we weigh values to consider what is right or wrong to do, and what risks do we take?

One of the problems with any advancing technology is that the vector of technical success may not necessarily be in sync with the vector of outcomes valued. Except for the rare, true biologic vitalist, most would agree with the premise that death can be preferable to a life with severe, intolerable deficits.⁶⁸ In other words, there is a life not worth living because the current and future burdens for the individual outweigh the future benefits.⁶⁹ As neonatal care pushes the limits of viability, infants who would have died now survive, many with significant NDI, and those that would have survived with significant NDI are now surviving with moderate to little NDI. Yet the value ordering is that in some cases death may be preferable. The uncertainties in this model include (1) what is the definition of intolerable deficits (experiential uncertainty), (2) at the time of intervention it is not known whether the baby has been benefited or harmed (prognostic uncertainty), and (3) it is not clear how to judge what ratio between the best and worst outcome (9:1 vs 2:8) is acceptable. In the end, who decides what risk to take for an individual infant (moral uncertainty)?^{60,68}

If one accepts that the preterm infant's interests are intertwined with the potentially competing family interests, there are added uncertainties. Although there are stories of how the surviving infant has enriched the family experience, there are costs to families of a surviving infant with significant NDI. For prospective parents these might include a higher divorce rate; higher rates of psychological or physical health issues; and increasing care needs leading to parents being unable to work or work fewer hours, which leads to lower income. At the same time, the costs of an impaired newborn are estimated at more than three times that of a nonimpaired child.^{60,70} Siblings' lives can be enriched by greater psychological maturation, empathy, and appreciation, or they can develop depression, loneliness, anxiety, and have lower self-esteem and social functioning.⁶⁰

Thinking more about the models of surrogate decision-making and the different levels and forms of uncertainty can help the individual physician in dealing with their opinions and concerns about these vulnerable infants and families. When facing uncertainty in clinical situations, the clinician must form a partnership with their patient and the parent; explore values to negotiate the meaning of a prognosis, incorporating the objective and subjective components of best interest; and weigh competing interests.^{62,64,69} Sometimes a truly best or right decision might be unknowable. Instead, when dealing with hard choices the notion of “satisficing,” that is to satisfy to some extent and suffice, given the constraints on the decision-making process might be the best that can be done ethically.⁷¹ By adopting an approach that accepts the finite limits of what can be known at any given moment, uncertainty is less formidable.

DEBATE ABOUT COUNSELING

NICUs have moved toward the concept of family-centered care. Much of this was in response to parent advocates voicing concerns about families being at the mercy of accelerated technology. Although it is easy at some level to think about family-centered care as supporting parental involvement through education and understanding of their infant and child, its basis was about being involved in decision-making.^{72,73} It seems the acceptance of the concept of family-centered care, combined with the acceptance that clinicians should counsel about outcomes in these scenarios, is secondary to the underlying assumption that parents actually do need to participate in decision-making, which means parents should have a choice. Again, where is the controversy?

I defer to the article on informing and educating parents about the risks and outcomes of prematurity elsewhere in this issue by Kim and Basir. It is worth mentioning, however, that there is some discussion, if not debate, about what counseling should entail. The AAP provides guidance in suggesting the prospective parents receive detailed information on range of survival rates and of the types and rates of short- and long-term disabilities that can be expected, and the treatments necessary to achieve this.¹⁰ There are those who are concerned about the AAP’s recommended approach. They argue that people do not understand statistics and percentages or groups, there is a well-known “framing effect,” that informed consent discussions in stressful situations are not well remembered, and that emotions play a significant role in decision-making.^{74,75}

Decision analysis shows that two things are required to make decisions about patient care: probability (P) and utility (value).⁷⁶ Properly defined values help dictate the necessary accuracy of probability estimates needed for making diagnoses, prognoses, and treatment decisions. (How certain does our diagnosis have to be before we decide to act?) The decision to resuscitate is said to be sensitive to the probability of handicap, so the use of accurate probability estimates is imperative. Assigning different values to the same set of outcome probabilities can result in different decisions. The decision to resuscitate is sensitive to the values-assigned outcomes. Evidence-based medicine experts point out that values are important because individuals present with subjective outcome descriptions (or their own set of values) to outcomes. Helping parents explore and in some way assign values is essential to practicing evidence-based medicine. This is consistent with the negotiated model of best interest.⁶²

There is evidence about what parental values versus physician or health care team values might be. There are detailed and rigorous assessments of health status, health utilities, and health-related quality of life for premature infants.^{77–80} These studies

reveal that many parents adapt and judge their child's quality of life to be good. At the same time, however, there are concerns raised regarding quality of life studies in general.^{60,81} These might include a reporting bias, where only the healthier patients who can report actually do, whereas the more ill survivors either have died or are so low in functioning they cannot participate. Parents may rate the child's quality of life more positively as a defense mechanism to avoid cognitive dissonance.⁸²

Knowing many of those involved in the debate, it is not clear to me that there is much controversy. Most, if not all, agree and recommend framing the data in the positive and negative way. Most, if not all, acknowledge that comprehension of some short- and long-term outcomes is only part of the story. Most, if not all, acknowledge that an important part of counseling is not only giving the data as best can be done, but also includes listening to hopes and goals the parents have for their child, exploring values to add meaning to a probability outcome. This means more than accepting the simple goal of "doing everything," hoping their child can survive without suffering and get through it all without deficits. It is also the beginning of an exploration of possible thresholds of what a parent might consider success, or a life worth living. For many, the 50% chance at survival and then a 50% chance of being "OK" is worth a trial of therapy, but counseling must move beyond this. There is a need to develop a trusting relationship of mutual respect, one where clinicians can openly hear from parents their values, their hopes, and their thresholds. Only then can clinicians also respectfully help guide them in decision-making for resuscitation, but also on level of care once in the NICU, including the possibility of withdrawal of support.

DEBATE ABOUT COST

The issue of cost often arises during discussions regarding the resuscitation of the borderline viable infant. Writings on the ethics of extreme prematurity frame this as a complex issue of balancing interests of infants, parents, professionals, and society. The United Kingdom's Nuffield Council on Bioethics states "There is now much broader public awareness of the need for difficult choices to be made by the providers of national healthcare... Contentiously, this has caused questioning of whether funds spent on resuscitating or prolonging the life of babies where the prognosis is very poor are spent appropriately."⁶

What are some facts about NICU cost? Direct costs of NICUs are in the billions of dollars range. In 2004 it was estimated at \$21 billion.²⁰ NICUs are often profit centers for hospitals and departments of pediatrics in academic centers.²⁰ This has led to the high number of neonatologists per live birth in the United States compared with other countries.²⁰ Within the NICU costs increase with decreasing gestational age and birth-weight, with approximately 7% of cases accounting for 90% of the total costs.⁸³

Despite these costs, there are arguments that a policy to limit neonatal care to this population saves little costs, whereas lives will be lost.⁸⁴ When compared with medical ICUs, neonatal treatment and care is more cost-effective because those who die do so early, therefore 90% of the costs are spent on survivors.⁸⁵ Thus, why pick on the premie? Rationing should be done elsewhere.

In response to this, others share some concerns. First, as medical treatments are getting better, and some of the dying infants are living longer, efficiency may be getting less.⁸⁶ Second, Medicaid and other community resources are almost never limited to what is spent in the NICU.^{6,86,87} Economic studies of this population have difficulty in measuring post-NICU costs, for example, of day-care services, respite care, schools, voluntary organizations, and families as a result of modifications of their everyday activities.⁶ An EPICure study that looked at spending in hospital inpatient, outpatient,

community health, drugs, education, additional family expenses, and indirect costs over 12 months at age 6, reported a range of two to six times the cost for extremely low-birth-weight children compared with a control group of term infants.⁸⁸

Finally, the claim that rationing certain levels of care in the NICU would save fewer dollars than rationing in other areas of medicine is not a reason to spend resources disproportionately in the NICU. Camosy⁸⁶ argues that a person's dignity is not violated by refusing him or her a disproportionately large share of community resources, but giving someone just such a share does violate the right to equal treatment of those left with a disproportionately small share. Perhaps just as in the development of guidelines, the NICU can be a leader, encouraging a more just medical service.

SUMMARY

Although there continues to be ethical discussion about extremely premature infants, it is not clear there are many hotly debated controversies. There is a broad consensus on guidelines that are available as just that, guidelines. There are excellent conversations in the literature about counseling and how it can be improved, in how to provide data, and how to assess values. The real controversies regarding the borderline viable neonate are when an individual physician may disagree with the consensus or the parent. However, understanding the concepts of a negotiated model of best interest or constrained parental autonomy, along with an acceptance of the medical, experiential, and moral uncertainties on a case-by-case basis perhaps can help each participant be more comfortable.

Guidelines can be helpful as a framework and a starting place, but also have their limitations.⁸⁹ "It is tough to have a single guiding principle when (i) you are not sure what is actually in the patient's best interest and (ii) any decision you make has negative consequences for somebody else's interests. The hard cases are those where ethical principles come into conflict – when 'best interests' bangs up against 'do no harm'; when 'respect for autonomy' is challenged by 'medical professionalism'. Then, concern for the 'best interests of the child' may need to be tempered by other legitimate ethical claims. The child's interests come first, but when it is unclear what is in the child's interest, then we must consider the interests of parents, siblings, doctors, nurses and even of society."⁹⁰

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