

# Parent-Physician Partnership at the Edge of Viability

Eric Ruthford, MS,<sup>a</sup> Miri Ruthford, BS,<sup>b</sup> Mark L. Hudak, MD<sup>c</sup>

In this article, a father and mother thoughtfully reflect on their experiences surrounding the imminent birth of their son Gabriel at the edge of viability. They suggest that physicians should try to understand the values and motivations that will influence parental decisions before reviewing with them the probability of survival and the most likely range of functional outcomes. A neonatologist not clinically involved in Gabriel's care recounts new lessons learned and previous lessons validated during this collaboration that can help neonatologists establish stronger partnerships with families.

## PARENTS' NARRATIVE

When my wife, Miri, developed preterm labor at 21 weeks and 4 days of gestation, we were suddenly thrust into a very unfamiliar world. My wife's physicians offered us the unthinkable choice of an elective abortion, advising that it was likely that our son would be born before he had a chance to survive or that he would be extremely disabled if he did survive.

While in the antepartum unit, every day was a crisis. The doctors did not try to understand the values and motivations underlying our wish to give Gabriel a chance for life. Although we heard statistics that augured a poor chance for a good outcome for Gabriel, we had a difficult time connecting those numbers to our infant. We believe that truly informed consent is only possible if parents can make that connection.

When birth became imminent at 22 weeks and 6 days, 2 neonatologists counseled us that standard practice was to not resuscitate infants born before 23 weeks and 0 days and that many neonatologists in our region believed that resuscitation was unethical in the 22nd week.

The neonatologist who arrived 30 minutes after Miri's water broke said, "At this stage, I don't recommend that babies should be intubated because the results are so poor. If you give birth after midnight—that's just the line for when we'll intervene—I'll be the one who comes and resuscitates the baby, but my heart won't fully be in it."

Hearing the doctor's recommendation, and understanding that he was ambivalent about resuscitating our son, increased both our stress and our frustration. We were Gabriel's parents—how could the doctor deny him care? We felt that the physician was not respecting our autonomy.

We turned for advice to a family in our church. Their daughter had been born prematurely and had suffered a neonatal stroke as a complication of hypoplastic left-heart syndrome. Her first doctors had offered palliative care, but the parents opted for treatment at a specialized facility. At 15 years of age, she was cheerful, walked independently, and communicated like a 6- to 7-year-old child. Her family did not regret the special care they needed to give her and had planned to transition care to her siblings as the parents aged.

But nonetheless, I did waver for a moment after hearing the negative assessment. I asked my wife, "Is there

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<sup>a</sup>Father of Gabriel Ruthford; <sup>b</sup>Mother of Gabriel Ruthford; and <sup>c</sup>Department of Pediatrics, University of Florida College of Medicine—Jacksonville, Jacksonville, Florida

Mr Ruthford, father of Gabriel, conceptualized the manuscript, drafted the initial parents' narrative, critically reviewed subsequent versions of the manuscript, contributed to the Introduction and Joint Conclusion sections, and approved the final manuscript as submitted; Ms Ruthford, mother of Gabriel, assisted with drafting the initial manuscript, reviewed subsequent versions of the manuscript, and approved the final manuscript as submitted; Dr Hudak critically reviewed and revised the initial manuscript, drafted the Neonatologist Commentary section, contributed to the Introduction and Joint Summary sections, and approved the final manuscript as submitted; and all authors approved the final manuscript as submitted.

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Address correspondence to Mark L. Hudak, MD, Department of Pediatrics, University of Florida College of Medicine—Jacksonville, LRC 3rd floor, 653-1 W 8th St, Jacksonville, FL 32209. E-mail: mark.hudak@jax.ufl.edu

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a point when you're trying too hard? What if he can never swallow?" My wife, however, was resolute. I called my priest, and he counseled me to listen to my wife.

We wondered why this doctor had made his recommendation. He was older, in his late 50s or early 60s. Perhaps for most of his career most infants born this early had died. Or he might have been thinking of other infants for whom prolonged treatment had ultimately failed and he wanted to spare Gabriel and us that longer suffering.

Or maybe he wished to spare us the burden of Gabriel being the rare survivor and likely to have severe disabilities.<sup>1</sup> Two-thirds of women in the United States choose to have an abortion if their fetus is found to have Down syndrome.<sup>2</sup> Perhaps he assumed that we might have a similar perspective.

We would have seriously considered palliative care if our physicians had depicted a poor quality of life for Gabriel, which to us meant excessive pain and suffering that would be life-long. But we would never have chosen comfort care if the worst possibility for Gabriel was some degree of neurodevelopmental ability. In our minds, he could have a disability yet be happy—why deny him that chance?

In the end, Gabriel was born before midnight, at 11:20 PM. The neonatologist arrived and expertly resuscitated Gabriel, who began an eventful 5-month NICU stay.

After Gabriel came home, I read extensively and learned that the doctors' recommendation not to resuscitate in the 22nd week was consistent with accepted medical practice at the time as summarized in the 2010 guidelines.<sup>3</sup> We were happy later to read the revised 2015 guidelines<sup>4</sup> that set the lower limit at 22 weeks and to discover

that the hospital had abandoned using 23 weeks and 0 days as a "line in the sand" in favor of a more individualized approach.

After much reflection, we offer some thoughts on how to improve antenatal counseling.

- Physicians should seek to understand the values and motivations that underlie the wishes that parents express. If parents ask the physician to not resuscitate their infant, the physician can probe this by saying, "What, in your mind, are some reasons for this decision?" Although some may think this is insensitive, an honest response will help illuminate underlying parental concerns and allow the physician to speak directly to them.

Our motivations were driven both by our religious value that all life, no matter how brief, glorifies God and by our belief in Gabriel's autonomy—if he could survive, we owed him that chance.

- When an infant is going to be born in to the "gray zone" in which resuscitation is a parental choice, the physician can say, "Your child will be welcome in our nursery." Such an approach would have greatly diminished our stress without introducing bias either way and would have affirmed Gabriel as a person. Miri remembers being especially frustrated during the antenatal counseling that the doctors talked about him as a medical condition, not as Gabriel—we had picked his name at that point—or even as, "your baby." Miri viewed 22 weeks and 6 days as a description of her condition, not as a way of describing Gabriel, and she regarded the statistics relating gestational age to outcomes as being similarly impersonal.
- The physician can talk about the differences between a child

who lives an hour in the delivery room versus one who lives for a few days or weeks in the NICU. Some parents might believe that a short goodbye would be easier. Other parents might feel worse if they did not give their child a chance to survive. We were in the latter camp, and were sobered but not dissuaded when the doctor who recommended against resuscitation told us that setbacks and failures in an infant's treatment become harder to take later on. In our 5-month NICU stay, Gabriel did have setbacks that frightened us and we often feared that he might not survive: but we never had second thoughts about our decision to offer him a chance for life.

- For some parents, statistics about functional outcomes will influence decisions. Optimally, outcomes should be more robustly descriptive. "Profound to severe disability" and "severe to moderate disability" sounded to us like "life without parole." It would be helpful to hear directly from the parents of a premature infant about their perception of their child's happiness—and their own. For parents concerned about their child's future abilities, a visit from a pediatric neurologist or developmental specialist who can provide first-hand knowledge about the daily lives of former premature infants could be similarly instructive. For parents concerned about the expense of care and about their inability to leave money in their wills to a potentially disabled adult, a visit from a financial case worker could help. Alternatively, an online system or binder with printed materials might convey information in all 3 areas.

Gabriel is now a happy, active preschooler who plays and runs

with other children his age, but he has a few limitations. A gastrostomy was necessary so he could leave the NICU, and he still uses it to receive fluids. He is able to eat all his food by mouth, but it must be pureed, and he receives weekly feeding therapy. When Gabriel taught himself the alphabet with the aid of a Fisher Price talking toy he received for his third birthday, we fleetingly thought he was unimpaired, until I looked up what “moderate impairment” meant: scoring below 70 on the Bayley Scales of Infant Development II Mental Developmental Index. Gabriel had tested at that level several times. We accept that Gabriel has moderate impairment, which right now means that Gabriel might enter kindergarten a year late. To us, presenting this outcome to parents as a possible reason to withhold care is a clear physician bias.

### NEONATOLOGIST COMMENTARY

Even in situations where time permits the physician to have the quality dialogue advocated by the Ruthfords, both the parents who anticipate the birth of their child at the edge of viability and their obstetric and neonatal physicians confront uncertainty and experience strong emotions including anxiety, sadness, and pain. Parents want to know if their child will survive, whether embarking on the struggle to achieve survival in the end will outweigh whatever pain and suffering the infant may experience, and what capacity the child will have for a “reasonably” normal life. Unfortunately, we physicians are not oracles who can answer these questions; we cannot say, for instance, that an infant will live or will die if parents ask us to intervene. We can only speak qualitatively or quantitatively about likelihoods; but how do parents

process what a 15% survival means for their infant?<sup>5</sup> Different sets of parents who confront similar circumstances in this gray zone can rationally embrace different but equally loving decisions. Given that we physicians have our own experiences, beliefs, and yes, biases, nuances of parental decision-making can sometimes unsettle us, especially if their wishes are at odds with how we might think we ourselves would respond.

The Ruthfords speak eloquently about how difficult it was for their physicians to try to understand their motivations. They also describe how perplexed they were about the hospital’s line in the sand that created a profound dichotomy on the basis of an unwavering gestational age threshold. Although the professional community is now moving toward supporting an informed parental decision to attempt resuscitation in certain infants born at 22 weeks’ gestation, at some point does not a physician have the right and responsibility to not resuscitate a neonate on the basis of professional judgment? Would anyone in 2017 countenance aggressive resuscitation of an infant born at 21 weeks because parents wanted to do everything possible? The hope is that both parents and physicians can reach decisions that are “reasonable” given good information that speaks to current survival and outcomes. Although we should respect parental autonomy, even this ethical principle has limits within our society, especially if it is widely agreed not to be in the best interests of the child.

In Gabriel’s case, his parents wanted his physicians at least to offer him a chance for life, even knowing that their physicians believed that the likelihood of survival was slim. No one told them that it was certain that he would experience chronic pain or unhappiness should he survive; if someone had, that may have

changed their decision. They decided to love a child with developmental challenges—although perhaps without understanding completely what that might mean. They suggest that parents have an opportunity to talk with other parents of premature infants who survived with disability. Perhaps neonatologists should have the same opportunity to challenge their biases. An increasing literature attests to the fact that many disabled survivors of prematurity self-report an acceptable quality of life and do not regret their survival.<sup>6,7</sup> And should not that be a key consideration for all of us?

### JOINT CONCLUSION

Imminent birth of an infant at the edge of viability presents multiple challenges to parents and physicians who must decide on a course of treatment that reflects both the informed consent of the parents and the best interests of the child. The suddenness of the birth, the uncertainty of survival, parental worry about the infant’s pain and suffering in the NICU, and the ambiguity of longer-term functional outcomes elicit emotions that make these discussions difficult. Exploring the fundamental motivations behind parental desires can guide information sharing to be more illuminating than a recitation of survival statistics or graded descriptions of long-term neurodevelopment that do not meaningfully convey a child’s potential abilities. Under similar circumstances, 2 sets of parents may reach different but nonetheless supportable informed decisions. A physician often has these discussions thinking what he or she would decide in a similar circumstance. Yet in the gray zone, the physician is obliged to put aside personal bias to forge a partnership with the parents and to support their most informed decision on behalf of themselves and their child.

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