

Neurologic Outcome After Prematurity: Perspectives of Parents and Clinicians

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abstract

BACKGROUND: Parents and clinicians caring for premature infants face high-stakes and time-sensitive decisions about care. We aimed to characterize how parents and clinicians discuss outcome in the context of decision-making for premature infants.

METHODS: In this qualitative descriptive study, we used a case-based, prospective design. Cases of extreme prematurity were targeted. Parents and clinicians completed semistructured interviews about care decisions longitudinally in the first year of life. Interview data were analyzed by using directed content analysis.

RESULTS: Sixteen parents and 53 clinicians of 10 infants completed 178 interviews ($n = 115$ parent; $n = 63$ clinician). Two primary themes emerged. First, parents and clinicians discussed prognostic information differently from each other. Parents focused on whether their infant would survive, whereas clinicians concentrated on neurologic outcome and the potential for life with disability. Parent discussion of the future was broad and rooted in hope and spirituality. Clinician prognostic language was narrowly focused and probabilistic. Second, we identified barriers and facilitators to a shared understanding of infant outcome. Clinicians perceived that parents were unaware of or unable to process important information about the big picture. Parents valued consistent therapeutic relationships; transitions of care and underused roles of the care team undermined this consistency. Clinical uncertainty forced parents and clinicians to “wait and see” about the future.

CONCLUSIONS: Parents and clinicians discuss and weigh information about the future differently from each other as they consider choices for extremely premature infants. Future work should characterize the impact of these differences on prognostic communication and decision-making.



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WHAT'S KNOWN ON THIS SUBJECT: Parents and clinicians of premature infants often face life-and-death decisions. Little is known about how parents and clinicians discuss, understand, and weigh prognostic information when making high-stakes and time-sensitive choices.

WHAT THIS STUDY ADDS: Parents and clinicians discuss and weigh prognostic information differently from each other as they consider choices for premature infants. Whereas parents focus on survival, hope, and spirituality, clinicians concentrate on future neurologic outcome and the potential for disability.

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Parents and clinicians caring for premature infants are often faced with high-stakes and time-sensitive decisions about care: whether to place a gastrostomy tube, when to consider withdrawal of life-sustaining treatment, or how to balance the possibility of death with the potential for life with disability. These decisions often hinge on parent and clinician understanding of infant outcome; however, little is known about how parents and clinicians discuss, understand, or weigh prognostic information as they make decisions.

Despite advances in neonatal care, many extremely premature infants die or experience neurodevelopmental impairment.¹⁻³ The range of neurodevelopmental impairment can vary dramatically, from children with isolated impairment in a single domain to children with profound intellectual disability and quadriplegic cerebral palsy. Despite a growing literature in prognostication for premature infants, it remains challenging to provide tailored prognostic estimates to families. It is also unclear if and how parents use information about the future to make decisions or what outcomes matter most as they do so.^{4,5}

Studies of decision-making in adult critical care suggest that surrogates and clinicians do not always have a shared understanding of a patient's prognosis.⁶⁻⁹ Although this discordance may sometimes be related to misunderstanding medical information,⁶ caregiver perception of a prognosis is influenced and guided by personal values, hopes, and spiritual beliefs.^{6,9,10} In the NICU setting, a study of family conferences about prognostication showed that prognostic disclosure was typically broad and optimistic and lacked detail regarding implications for future infant health or quality of life. At the end of these conferences, parents and clinicians shared

a concordant understanding of future infant outcome in only 2 of 19 cases.¹¹ Other qualitative studies report that mothers of infants in the NICU may underestimate the severity of their infant's illness compared with clinician estimates,^{12,13} and whereas clinicians may focus on the delivery of medical information, parental decision-making is guided by religion, spirituality, and hope.¹⁴ Parents and clinicians bring valuable, complementary perspectives to caring for premature infants; understanding how these perspectives differ is necessary to inform how to best align parent-clinician understanding of an infant's future.

Here, we aimed to characterize the ways parents and clinicians describe neurologic prognosis when discussing treatment decisions in the NICU and to identify factors that helped or hindered a shared understanding of infant outcome.

METHODS

We used a qualitative descriptive design to evaluate how parents and clinicians discussed prognostic information. Data for this analysis were taken from a prospective, case-based, longitudinal, qualitative study of the decision-making process of parents and clinicians caring for infants with chronic life-threatening conditions. To be considered a case for study inclusion, a minimum of 1 parent, the attending physician, and 2 additional clinicians had to agree to participate. Approval was obtained from the Duke University Institutional Review Board.

Setting and Participants

The larger study used a purposive sampling technique to select infants with 3 specific complex, life-threatening conditions, including extreme prematurity (<26 weeks' gestation), complex congenital heart disease, and genetic disorders. Patients were identified by daily

screening of NICU admission logs. Parents were approached for recruitment within 24 to 48 hours after birth or admission to the NICU. Inclusion criteria for parents included the ability to speak and understand English. When 2 parents were enrolled, data were collected separately from each parent. Across the study, a total of 35 infants, 60 parents, and 202 providers were enrolled with an average of 5 health care providers per case and a 92% rate of complete data collection across all time points. Two sets of parents who were approached declined participation; 3 additional sets of parents enrolled but withdrew before data collection. There were no cases in which parents consented and a clinician declined. Within each diagnostic category, sampling continued to include infants of varied race and socioeconomic status. A purposive sampling technique was used to provide an informationally representative sample. Data for this analysis included 9 cases of infants born prematurely.

Study Procedures

Semistructured interviews were conducted with parents at study enrollment, at least monthly until death, or 1 year after enrollment, as well as within 1 week after a life-threatening event. Clinicians caring for the infant, including bedside nurses, advanced practice practitioners, social workers, consultants, and neonatologists, were interviewed at study enrollment, within 1 week of a life-threatening event, and at infant death or 1 year after enrollment. After life-threatening events, data were collected from clinicians caring for the infant at the time of the event. All interviews were conducted in English. Questions targeted information about parent and clinician perceptions of previous or anticipated decisions. Prognostic content primarily emerged during discussions of decisions made and rationale for decisions, for

example, with the prompt, “What were you thinking about when you made that decision?” Interviews were audiotaped and transcribed. Process notes were made after each interview, including the context of the interview and any interruptions or important observations. Interviews were completed by 2 research nurses and 1 social worker; training included mock interview sessions supervised by 2 study team members (S.L.D. and D.B.), weekly joint review of transcripts, and regular debriefing.

Data Analysis

Descriptive statistics were used to summarize quantitative data. A directed content analysis was performed to identify prognostic language.¹⁵ A codebook was developed and refined iteratively, informed by existing frameworks for coding prognostic language.^{16,17} NVivo 11 was used to organize and index codes. All cases were double coded by 2 study team members, and discrepancies were resolved in consensus with the lead author. After coding and review, the analysis involved discussion of the key themes and subthemes characterizing the content, language, and context of prognostic discussion. These themes and subthemes were discussed until saturation was reached.

RESULTS

We studied 178 interviews ($n = 115$ parent interviews; $n = 63$ clinician interviews) from 9 cases (16 parents and 53 clinicians of 10 infants; 1 case included twins) with extreme prematurity. Infant, parent, and clinician characteristics can be found in Tables 1 and 2. Prognostic codes were more common in clinician interviews than parent interviews, with a median of 6 and 1 prognostic codes per interview, respectively. Here, we present 2 primary themes and relevant subthemes. Supportive quotations can be found in Tables 3 and 4.

TABLE 1 Infant and Maternal Characteristics

| Characteristics | <i>n</i> (%) or median (range) |
|---|--------------------------------|
| Infant ($N = 10^a$) | |
| Gestational age, wk, median (range) | 23 (23–26) |
| Sepsis, <i>n</i> (%) | 6 (60) |
| Intraventricular hemorrhage, <i>n</i> (%) | 4 (40) |
| Necrotizing enterocolitis, <i>n</i> (%) | 2 (20) |
| Death, <i>n</i> (%) | 3 (30) |
| Parent ($N = 16$) | |
| Mother, <i>n</i> (%) | 9 (56) |
| Father, <i>n</i> (%) | 7 (44) |
| Age, y, median (range) | 26 (19–35) |
| Race and/or ethnicity, <i>n</i> (%) | |
| White | 5 (31) |
| African American | 9 (56) |
| American Indian | 2 (13) |
| Level of education, <i>n</i> (%) | |
| High school or less | 12 (75) |
| Some postgraduate education | 4 (25) |
| Annual income, \$, <i>n</i> (%) | |
| <15 000 | 2 (12.5) |
| 15 000–25 000 | 6 (37.5) |
| 26 000–50 000 | 4 (25) |
| 51 000–75 000 | 4 (25) |

^a One case included a set of twins.

Theme 1: Parents and Clinicians Discuss and Value Neurologic Prognosis Differently From Each Other When Considering Care Decisions for Infants

Parent Discussion of the Future Focused on Survival, Whereas Clinician Discussion of the Future Focused on Neurologic Outcome and the Potential for Disability

Parent discussion of their infant’s future was represented by 3 primary topics: future development and survival, future therapy needs, and future equipment needs. Within prognostic discussion, a large majority of prognostic codes (327 of 369) were devoted to discussion of

future development and survival, with the remainder primarily being devoted to discussion of technology or equipment, including gastrostomy tubes, tracheostomies, and ventriculoperitoneal shunts. At some point during the study, parents from all cases discussed infant survival, including worries about potential infant death or discussion of their infant’s survival despite poor prognostic predictions by clinicians. Discussion of survival occurred not only at study entry and after life-threatening events; parents generally discussed survival throughout the hospital course and beyond. Those parents who did discuss information

TABLE 2 Clinician Characteristics

| Characteristics ($N = 53$) | <i>n</i> (%) |
|------------------------------|--------------|
| Attending physician | 16 (30) |
| Fellow | 5 (9) |
| Social worker | 10 (19) |
| Nurse practitioner | 7 (13) |
| Registered nurse | 15 (28) |
| Race and/or ethnicity | |
| White | 46 (87) |
| African American | 1 (2) |
| Hispanic | 6 (11) |
| Sex | |
| Male | 13 (25) |
| Female | 40 (75) |

about future outcome emphasized infant survival or quality of life: “We’re hoping that even with all of this, if she pulls through, that she will have a normal life,” (mother, case 1).

Although the overwhelming majority of parents discussed worries about infant survival, parents in only 2 cases discussed concerns about future neurologic development or made any comment about whether their child would walk or talk. Many parents described sentiments like, “We’ll love [him or her] no matter what happens.” Other families felt that outcome was out of their control and that “whatever is going to happen is going to happen.” The ways in which parents thought about prognostic information was often connected to their role as a parent. Some parents envisioned what life would be like after discharge: “I imagine dressing her and taking her to church, and that’s what keeps the hope alive,” (mother, case 1). Others had pragmatic considerations about how to navigate an uncertain prognosis: “It’s so foreboding, I got to thinking the other day...I haven’t even sent out birth announcements,” (mother, case 2).

Conversely, the majority of clinician prognostic discussion was explicitly related to infant development and concrete developmental milestones (for example, walking and talking). In all cases, clinicians discussed an individual infant’s prognosis within the context of their clinical experience and discussed similar cases or existing literature. Clinicians emphasized concerns about disability in most cases ($n = 7$). Many clinicians divided concerns for developmental problems into 2 categories: (1) expected neurodevelopmental risk associated with prematurity and (2) added neurodevelopmental risk in the setting of neurologic injury. Some clinicians described neurologic injury as “devastating” or “catastrophic.” For many clinicians, especially bedside nurses, concerns about a poor

neurologic prognosis were tied to concerns about infant suffering.

Parent Discussion of the Future Was Broad and Intertwined With Hope, Spirituality, and Exceptionalism; Clinician Discussion of the Future Was Probabilistic and Specific

Throughout all cases, parent prognostic discussion was broad, with nearly every parent using language like, “[She or he] will get through this,” or hoping their child would “make progress.” Developmental or clinical concerns were also described in broad terms like, “I know [she or he] will be behind” or worries that “things will go downhill.” Prognosis was rarely discussed in probabilistic terms. Whereas prognostic discussion was vague, discussion of daily medical care was not. Within each case, parents adopted medical jargon over time, especially as it related to bedside care.

Parents used exceptionalism in their discussion of individual infants; individual infants were called “fighters” by a parent in most cases ($n = 7$). Some parents described individual children as “miracles” or a “miracle baby.” In later interviews, some parents described their child’s unexpectedly reassuring development in ways such as, “You’d never know [he or she] was a ‘preemie.’” Many parents described that their child would or did “pull through” medical complications. Across cases, parent discussion of prognostic information almost always co-occurred with discussion of hope or spirituality.

Clinician discussion of outcome across cases targeted the individual infant and referenced specific outcomes. Clinicians often discussed population-based estimates and used statistics to provide context for individual infants. Although clinicians did reference hope in their interviews, references to hope were often followed by a caveat: “To me,

hope means...is different than prognosis. So, my hope might be a lot higher than my prognosis,” (nurse practitioner, case 7). Although less common, some clinicians also used exceptionalism (for example, “fighter” or “miracle”) to describe an infant’s course.

Theme 2: Barriers and Facilitators to a Shared Understanding of Infant Outcome

Clinicians Perceived Parents Did Not or Could Not Understand Information About Prognosis

Clinicians articulated concerns that parents were not able to internalize important information about their child’s status. These concerns were sometimes concrete; for 1 case, multiple clinicians were concerned that a language barrier prevented parents from receiving consistent and clear information. For 5 cases, concerns were raised that parents did not understand how sick their infant was or the potential for significant disability. This finding was best illustrated in 2 cases in which the infant had a grim neurologic prognosis. With both of those cases, nearly all clinicians voiced concern that parents were not able to process information about outcome; bedside nurses voiced significant moral distress. Concurrent interviews from parents revealed that, in fact, long-term outcome weighed heavily on their minds, as highlighted by one mother’s worry (case 7):

I wonder, will she be able to walk, or crawl, or what will we have to do for her? ... and all aspects of trying to get her to walk, or help her to walk ... or will we have to push her around in a wheelchair? ... I do think about how [the] overall outcome will be.

Parents Valued Consistent Therapeutic Relationships; Transitions of Care and Underused Roles of the Care Team Undermined This Consistency

Parents from all cases referenced gratitude toward clinicians, with several parents referencing a given provider’s compassion. Parents

described receiving much of their communication about their infant's course from the bedside nurses. Some parents and nurse clinicians referenced a desire for nurses to be involved in major discussions with the team. Despite the frequent discussion of spirituality by parents, discussion of chaplain involvement was rare, occurring with only 2 cases.

Parents expressed frustration when it appeared that members of the health care team were not on the same page. Parents described several ways in which they perceived a lack of consensus: disagreement between the primary and specialty teams, switched plans as a team member changed, and different approaches to bedside care among varied nurses or units. In nearly all cases ($n = 7$), clinicians referenced being unsure of who had previously discussed the neurologic prognosis with families and what had been said.

Parents appreciated when there was continuity of care, especially regarding those clinicians who had been with them throughout their infant's hospital course. For many cases, the patients received follow-up in a clinic staffed by the same providers who cared for their infant in the hospital; parents were proud to share with clinicians what their child had achieved since discharge. Several parents specifically commented on the value of the primary nursing model. One mother (case 4) articulated the following:

It's just a relief to know that there's someone there who knows what he does, how often he does it, what's considered normal, what's considered abnormal. I just feel that the primary care you receive from the primaries is just above and beyond. They're all good, but you can see a difference in the primary care.

Clinical Uncertainty Forced Parents and Clinicians To Wait and See About the Future

Throughout all cases, parents discussed the difficulties of the daily uncertainties that made up their NICU

experience. Many of them felt as though they had to wait and see or take things day by day. Some parents described the difficulty of waiting for information and feeling unsure of what to expect. Most parents expressed that the uncertainty was stressful. For many parents, concerns about uncertainty continued throughout the study, even once the child was doing well after discharge.

Prognostic uncertainty, and the difficulty with providing precise estimates, was also voiced by multiple providers. Across cases, multiple clinicians described the sentiment, "Kids can surprise you." Many clinicians (such as the social worker in case 9) discussed previous cases and experiences, often with an emphasis on an unexpected, positive outcome:

I've seen some amazing things over the years, amazing things...in babies that are truly just miracles. And so, I tell families, 'I'm never going to take away your hope. What I want to hopefully achieve through the medical team is that you have a realistic understanding of what's going on, that you know what the issues are and what we're doing for your child,' but that I'll always walk with them being very hopeful about what's going on.

DISCUSSION

Our results suggest that clinicians and parents think about future infant outcome differently from each other as they consider choices for critically ill infants. Whereas clinicians framed developmental outcome as central to decision-making, parents focused overwhelmingly on hope for survival and the reasons why their child might beat the odds. We identified factors that helped or hindered a joint understanding of the big picture. These findings can be leveraged to help clinicians align prognostic communication with those outcomes valued most by parents and families. Here, we suggest 4 ways in which these findings can be translated into intervention development.

First, parent discussion of prognosis nearly always intersected with discussion of hope. It is possible that clinicians may misperceive parent expression of hope as a lack of understanding, especially when the prognosis is poor. In parent interviews, it was clear that parents could concurrently understand medical reality and maintain hope. This finding supports existing data that parents do not view hope and realism as mutually exclusive, even when the prognosis is grim.^{18,19} Parent expressions of hope for a miracle may further represent a deeper grasp of reality than that perceived by clinicians; parents may have understood that a "good" outcome would be unlikely, on the order of a miracle.²⁰ To help align parent and clinician understandings of outcome, clinicians should recognize that hope is central to how parents understand prognostic information and their role as a caregiver,²¹ and provides an important means of coping with a poor or uncertain prognosis.²² When clinicians perceive that hope is a barrier to a shared understanding of infant outcome, it may be appropriate to reorient, rather than take away, hope.²³ Other strategies might include asking parents about their understanding of their child's prognosis and talking with families about "hoping for the best yet preparing for the worst."²¹

Second, parents and clinicians may value the importance of future outcome differently when they think about making decisions. Although these interviews aimed to target similar content between clinicians and parents, clinicians were 6 times more likely to discuss future outcome than parents were. Our data also suggest that whereas clinicians may focus on future infant disability, parents are primarily focused on infant survival. This finding supports existing literature that it is difficult for parents to think concretely about

TABLE 3 Theme 1: Parents and Clinicians Discuss and Value Prognostic Information Differently From Each Other When Considering Care Decisions for Infants

| | |
|---|--|
| Parent discussion of prognosis | |
| "That it is a hard road. It is a journey. And she could have a point where she just goes downhill, which, that's okay. She [the clinician] tells us the outcome, what to expect. From her, you know it's going to be a hard road, you know that this isn't going to be easy, and she believes that [the child]'s going to make it." (Mother, case 7) | |
| "I can't get cocky, and be like, 'This is going to be fine,' because whatever is going to happen is going to happen, no matter how I feel. I realize that. I don't have control over what's going to happen to her." (Mother, case 2) | |
| "I'm just going to keep the faith and keep praying that what's supposed to happen is going to happen. I know my little girl is going to be here. I'm just hoping my little girl continues her fight and she wins. Regardless of how everything looks to the naked eye, my baby girl is fighting. You hear me?" (Mother, case 3) | |
| "[I hope] that she can catch up with the babies her age. Some babies catch on; some babies take longer than others. And just, that's it. Basically, ain't nothing really." (Mother, case 6) | |
| "I know they're [the medical team] here to do what they can, but deep down, He's [God] the only one that can save her. I just left everything in His hands from here on out because whatever happens, happens. But I feel really good that she's going to come home in December. She's going to come home." (Mother, case 9) | |
| Clinician discussion of prognosis | |
| "She may not hear, she may not see, she would end up with cerebral palsy more than likely, or she would not be able to move at all. He [the neonatologist] gave them the worst possible scenario. He gave them percentages with the kind of brain damage that she had. ...I think he said somewhere in the 70%–80% would have severe neurologic deficits." (Nurse practitioner, case 7) | |
| "It's a combination of things, I guess. Twenty-two to 23 [weeks' gestational age] under the best of circumstances have a difficult time. The mortality is high, and the side effects are also high, a 22- to 23-weeker with a grade IV bleed, hypotension requiring dopamine, epinephrine, vasopressin, hydrocortisone... I think it puts that child at, the chance[s] of that child having a normal or near-normal neurologic outcome are dismally small...30% mortality rate in that group here." (Neonatologist, case 1) | |
| "When some of these babies have bilateral grade 4 bleeds, they have no hope of having any kind of real quality of life, and we know this, the literature supports this. One hundred percent of kids with bilateral grade 4 bleeds long-term don't do well." (Neonatologist, case 6) | |
| "I just hope that [the child] continues on as well as she has. I mean she's really almost...I hate to say, 'miracle baby,' but you know, really, I mean, from what the anticipated outcome was, she's really exceeded a lot of expectations." (Social worker, case 8) | |

outcome when faced with the possibility that their child could die.²⁴ For parents of critically ill infants, it will sometimes be necessary to discuss the possibility of infant death or survival with disability in the same conversation. When possible, however, discussion of decision-relevant information should occur outside of periods of infant and family crisis. Added family support, in the form of the palliative care service, pastoral care, and social work, may help families manage fear of infant death while processing information about what life might look like should their infant survive.

Third, parents valued longitudinal, consistent relationships with team members. These findings provide additional support to the primary nursing and team models, in which a single bedside nurse and/or clinician takes primary leadership of longitudinal patient care. This finding aligns with existing guidelines for patient-centered care in critical care settings that recommend consistent nursing and

physician assignment for all critically ill patients.²⁵ When continuity is not possible, teams can enlist the help of consulting services, including palliative care teams, for added consistency.²⁶ Despite frequent references to spirituality throughout parent interviews, use of the chaplain service was rare. Future work should focus on how to incorporate chaplaincy programs meaningfully into the care team. After discharge, families valued the care model in which early developmental follow-up was provided by clinicians who knew the infant and family in the NICU.

Finally, both parents and clinicians noted that prognostic uncertainty and the daily complexity of life in the NICU undermined their ability to see and discuss the big picture. Prognostic uncertainty can be a source of short- and long-term distress for families caring for critically ill infants.²⁴ Uncertainty is also difficult for clinicians. For health professionals caring for adults with advanced illness, uncertainty about

illness trajectory affects whether, when, and how clinicians discuss prognosis and end-of-life care.²⁷ Clear communication about prognostic uncertainty throughout the clinical course can help families strike a balance between hope for the future and the potential for poor outcomes.²⁸ Discussions about an uncertain prognosis can be framed around parents' wishes for the best but include acknowledgment of the worst possible situations, allowing parents to make informed decisions about care without having to accept a scenario as inevitable.²⁹ Interventions that enable families to prioritize and organize medical information, such as journals and question-prompt lists, may further help guide discussions about the big picture.³⁰

This study was performed at a tertiary medical center, and findings may not be generalizable to other health systems and hospital types. The use of audio recordings limits our ability to understand the nonverbal cues of participants.

TABLE 4 Theme 2: Barriers and Facilitators to a Shared Understanding of Infant Outcome

Clinicians perceived parents did not or could not understand prognostic information

"My impression of them was that they were in shock. It just seems like nothing was real to them. They seemed in shock. You would tell them something, and you could see that you were telling them something, but definitely the message wasn't always getting through." (Nurse, case 1)

"I think the staff, generally, here gets concerned if they feel that the plan of care, either that the parents aren't informed or that the parents don't understand, which is a different thing and that may not be true, the parents may understand and be choosing differently than we wish they would choose." (Social worker, case 3)

"Even if I tell parents it's going to take 4 or 5 months of them being in the hospital, it's very hard to conceive. [The mother is] focusing a lot on small things, and I was telling her today, the sodium being down, 'Well, the sodium is down today, it's up tomorrow, it's down the next day.' ...I think they're not concentrating on the big picture because they don't understand the degree of this, what's going on. And they're concentrating on the sodium." (Neonatologist, case 7)

Parents valued consistent therapeutic relationships

"I think, to her, the primaries [are] important 'cause they know [the child]; they've been working with her long enough, and they know what she needs and what makes her comfortable." (Father, case 7)

"For the most part, when you get the same nurses all the time that we're happy with, it's good. ...And they know her. They know she doesn't like to lay this way or that way...and all the little things about her." (Father, case 2)

"Now he's on the [other] team, and the advantage of that is that the attending will also be the one that does his follow-ups, so I think it's good that they get to know him now because that's who he'll be seeing with his follow-ups." (Mother, case 4)

Clinical uncertainty forced parents and clinicians to wait and see about the future

"We'll never feel secure until we're home with him...and probably then won't even feel secure until he's bigger. You know? It's just, it's very scary. He's doing well, he's stable, but to me, that doesn't mean anything. So, it's a scary place to be very uncertain. And [there is] nothing that I can do can change it." (Mother, case 4)

"They said it looks pretty good for her, that we have to take 1 day at a time. You never know what can happen. ...You get nervous walking back there to see what they're going to say today." (Mother, case 1)

"They just, you know, they said it's going to be a rocky road over the next bit of time. So, you know, it's hour by hour, day by day." (Father, case 2)

"It's very hard to predict the future. That's why I try to stay away [from] that. ...And I think the fellows, for instance, I was telling them that you cannot apply that. You cannot guess because...kids are miracles walking, grade 4 that you see in the follow-up clinic that are perfect, go to school and learn. So, you can never predict. There are some cases, though, that are devastating." (Neonatologist, case 1)

"There's always a little bit of uncertainty. You can't say 100%, 'I know he's not going to survive,' you have to say, 'I've never seen a baby in his condition survive. Even if he did survive, he would have to go through a huge amount, and is it worth putting him through that for, you know, a 1%, or 2%, or 10% chance of survival?' And that's hard." (Neonatologist, case 8)

Clinicians were primarily interviewed around the time of life-threatening events, whereas parents were interviewed both at the time of life-threatening events and times of relative clinical stability. Although interviews were performed in close proximity to events of interest, they remain subject to recall bias. Sample size limitations did not allow for the stratification of findings along demographic variables, including educational attainment, which varied among participants. This study sample included 9 cases; smaller

samples obtained by using purposive sampling techniques are used in qualitative studies and are oriented toward informational representation to allow for in-depth study of the phenomenon. The number of interviews and participants, as well as the breadth of participant roles, strengthens our findings.

CONCLUSIONS

This study highlights that parents and clinicians consider information about the future differently from each other

as they make choices for infants born extremely premature. Parents and clinicians must partner to make complex decisions about infant care; misunderstandings or differences in beliefs between parents and clinicians around the value of prognostic information threaten shared decision-making. Future work should characterize what type of prognostic information is most valuable to families, how prognostic information is best communicated, and the impact of neurologic prognosis on decision-making for infants.

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REFERENCES

- Rogers EE, Hintz SR. Early neurodevelopmental outcomes of extremely preterm infants. *Semin Perinatol.* 2016;40(8):497–509
- Stoll BJ, Hansen NI, Bell EF, et al; Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Trends in care practices, morbidity, and mortality of extremely preterm neonates, 1993–2012. *JAMA.* 2015;314(10):1039–1051
- Younge N, Goldstein RF, Bann CM, et al; Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Survival and neurodevelopmental outcomes among periviable infants. *N Engl J Med.* 2017; 376(7):617–628
- Janvier A, Lorenz JM, Lantos JD. Antenatal counselling for parents facing an extremely preterm birth: limitations of the medical evidence. *Acta Paediatr.* 2012;101(8):800–804
- Dupont-Thibodeau A, Barrington KJ, Farlow B, Janvier A. End-of-life decisions for extremely low-gestational-age infants: why simple rules for complicated decisions should be avoided. *Semin Perinatol.* 2014;38(1): 31–37
- White DB, Ernecoff N, Buddadhumaruk P, et al. Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. *JAMA.* 2016;315(19):2086–2094
- Cox CE, Martinu T, Sathy SJ, et al. Expectations and outcomes of prolonged mechanical ventilation. *Crit Care Med.* 2009;37(11):2888–2894; quiz 2904
- Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. *J Am Geriatr Soc.* 2000; 48(suppl 5):S70–S74
- Boyd EA, Lo B, Evans LR, et al. “It’s not just what the doctor tells me:” factors that influence surrogate decision-makers’ perceptions of prognosis. *Crit Care Med.* 2010;38(5):1270–1275
- Zier LS, Burack JH, Micco G, et al. Doubt and belief in physicians’ ability to prognosticate during critical illness: the perspective of surrogate decision makers. *Crit Care Med.* 2008;36(8): 2341–2347
- Boss RD, Lemmon ME, Arnold RM, Donohue PK. Communicating prognosis with parents of critically ill infants: direct observation of clinician behaviors. *J Perinatol.* 2017;37(11): 1224–1229
- de Wit S, Donohue PK, Shepard J, Boss RD. Mother-clinician discussions in the neonatal intensive care unit: agree to disagree? *J Perinatol.* 2013;33(4): 278–281
- Boss RD, Donohue PK, Arnold RM. Adolescent mothers in the NICU: how much do they understand? *J Perinatol.* 2010;30(4):286–290
- Lemmon ME, Donohue PK, Parkinson C, Northington FJ, Boss RD. Communication challenges in neonatal encephalopathy. *Pediatrics.* 2016;138(3): e20161234
- Miles MB, Huberman AM. *Qualitative Data Analysis: An Expanded Sourcebook.* 2nd ed. Thousand Oaks, CA: Sage Publications, Inc; 1994
- Gramling R, Norton SA, Ladwig S, et al. Direct observation of prognosis communication in palliative care: a descriptive study. *J Pain Symptom Manage.* 2013;45(2):202–212
- van Vliet LM, van der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *J Clin Oncol.* 2013;31(26):3242–3249
- Kamihara J, Nyborn JA, Olcese ME, Nickerson T, Mack JW. Parental hope for children with advanced cancer. *Pediatrics.* 2015;135(5):868–874
- Arnolds M, Xu L, Hughes P, McCoy J, Meadow W. Worth a try? Describing the experiences of families during the course of care in the neonatal intensive care unit when the prognosis is poor. *J Pediatr.* 2018;196:116–122.e3
- Superdock AK, Barfield RC, Brandon DH, Docherty SL. Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: a qualitative study. *BMC Palliat Care.* 2018;17(1):107
- Reder EA, Serwint JR. Until the last breath: exploring the concept of hope for parents and health care professionals during a child’s serious illness. *Arch Pediatr Adolesc Med.* 2009; 163(7):653–657
- Schenker Y, White DB, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM. “It hurts to know...and it helps”: exploring how surrogates in the ICU cope with prognostic information. *J Palliat Med.* 2013;16(3):243–249
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol.* 2007;25(35):5636–5642
- Lemmon ME, Donohue PK, Parkinson C, Northington FJ, Boss RD. Parent experience of neonatal encephalopathy. *J Child Neurol.* 2017;32(3):286–292
- Davidson JE, Powers K, Hedayat KM, et al; American College of Critical Care Medicine Task Force 2004-2005; Society of Critical Care Medicine. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med.* 2007;35(2):605–622
- Richards CA, Starks H, O’Connor MR, et al. When and why do neonatal and pediatric critical care physicians consult palliative care? *Am J Hosp Palliat Care.* 2018;35(6):840–846
- Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med.* 2007; 21(6):507–517
- Evans LR, Boyd EA, Malvar G, et al. Surrogate decision-makers’ perspectives on discussing prognosis in the face of uncertainty. *Am J Respir Crit Care Med.* 2009;179(1):48–53
- Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics.* 2014;133(suppl 1):S24–S30
- Lemmon ME, Donohue PK, Williams EP, Brandon D, Ubel PA, Boss RD. No question too small: development of a question prompt list for parents of critically ill infants. *J Perinatol.* 2018; 38(4):386–391

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