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Prognostic Discussion for Infants with Neurologic Conditions: Qualitative Analysis of Family Conferences

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Abstract

Objective: We characterize the content and role of prognostic discussion for infants with neurologic conditions.

Methods: In this descriptive qualitative study, we prospectively enrolled infants (age < 1 year) in the intensive care unit with a neurologic condition anticipated to have ≥ 1 family conference about prognosis or goals of care. We audio-recorded family conferences as they occurred. We used a rapid-cycle qualitative approach to identify and refine themes.

Results: Forty infants and 61 parents were enrolled; 68 family conferences occurred for 24 infants. The majority of infant cases (n=23/24, 96%) and conferences (n=64/68, 94%) included discussion of neurologic prognosis. Common infant diagnoses included prematurity (n=12, 52%), genetic conditions (n=9, 35%), and brain malformations (n=7, 30%). We identified two themes relating to the characterization of the infant's prognosis: 1) *Predictions of impairment* and 2) *Rationale for prognostic predictions*. We identified three themes characterizing the role of prognostic discussion: 1) *Aligning parent and clinician understanding of infant outcome*, 2)

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Author Contributions

MEL, HCG, DB, and PAU contributed to the conception and design of the study; MEL, MCB, SB, JKD, MGJ, ECK, and PAU contributed to the acquisition and/or analysis of data;MEL and MCB drafted a significant portion of the manuscript or figures.

Potential Conflicts of Interest

Nothing to report.

Influencing decision making, and 3) *Preparing for life at home*. We identified two themes characterizing discussion of prognostic uncertainty: 1) *Multi-layered types of uncertainty* and 2) *Holding space for hope alongside uncertainty*.

Interpretation: In this cohort of infants with neurologic conditions and their parents, we identified salient themes characterizing the content and role of discussion about neurologic outcome. Our findings highlight that prognostic discussion focuses on anticipated impairments, informs decision making, and helps families prepare for home life. Future work should characterize whether these findings align with parent preferences for prognostic disclosure.

INTRODUCTION:

Up to one-quarter of all infants admitted to the neonatal intensive care unit (NICU) have a neurologic diagnosis.[1] Nearly all infants in the NICU are at risk of neurodevelopmental impairment. Providing information about infant prognosis is a necessary element of shared decision making and can help families prepare for the future.[2–4] One critical job of clinicians caring for critically ill infants is to help parents understand their child's developmental potential.

Conversations about developmental outcomes are often high-stakes. Many parents of infants with neurologic conditions face difficult choices about the provision, withdrawal, or withholding of life-sustaining treatment. In common neonatal neurologic conditions – neonatal seizures and neonatal encephalopathy – the majority of deaths occur in the context of decisions about life-sustaining treatment.[5,6] These decisions are likely informed not only by medical facts, but also by the ways in which neurologic prognoses are communicated.

Studies in adult critical and neurocritical care suggest that prognostic discussion is highly variable and vary by specialty.[7] Surrogate decision makers often leave discussions with misperceptions about their loved one's prognosis[8–10] due to misunderstanding, personal beliefs, and avoidance of frank prognostic disclosure.[11,12] Adult surrogate decision makers highly value information about death and neurologic outcome, even in the face of uncertainty.[13] Data from the adult neurocritical care setting suggests that prognostic discordance between physicians and surrogates is common in the context of differences in understanding and optimistic beliefs.[14] Existing data in the adult traumatic brain injury setting further suggest that adult surrogates and clinicians have different prognostic communication preferences from each other. While adult surrogates value the provision of numeric prognostic estimates and the reduction of prognostic uncertainty, clinicians often prefer to omit numeric estimates in the context of perceptions of surrogate numeracy and insufficient data to support prognostication.[15,16]

Prognostic discussion for infants with neurologic illness differs from adult settings in important ways. Parents of infants have not experienced life at home with their child and lack information about their child's prior preferences and values. Unlike many adult settings, most parents expect to leave the hospital with an infant who is entirely dependent on their care; conversations about prognosis in this setting often involve helping parents conceptualize extending that dependence. Existing data suggest that clinicians and parents caring for pre-term infants may value and reflect on prognostic information differently from

one another.[17] While parents may prioritize discussing the likelihood of survival, clinicians may prioritize sharing information about the risk for neurologic impairment.[17] Improving prognostic communication for neonates with neurologic illness has the potential to mitigate parent distress, improve decision making quality, and align parent-clinician expectations about infant outcome. Understanding how neurologic prognosis is communicated in current clinical practice is a necessary first step towards the design of interventions to support prognostic communication.

Despite the high stakes underlying conversations about outcome, few studies have characterized how they occur. Here, we aimed to characterize 1) the content of prognostic discussion, 2) the roles of prognostic discussion, and 3) discussion of prognostic uncertainty in parent-clinician conferences for infants with neurologic conditions.

METHODS:

Participants:

In this descriptive qualitative study, we prospectively enrolled critically ill infants with a neurologic condition, their parents, and members of their medical team between the years of 2018 and 2020.[18] Infant inclusion criteria were: 1) Presence of a neurologic condition, defined as any condition requiring a pediatric neurocritical care consult, 2) Age < 1 year at the time of enrollment, 3) Admission to an intensive care unit (neonatal, pediatric, or pediatric cardiac intensive care unit), and 4) Anticipated conversation about prognosis or goals of care, as determined by the health care team. Participants were enrolled at a single tertiary referral center in the Southeastern United States. Parents provided written informed consent, while clinicians provided assent to conversation recording. The Duke University Health System Institutional Review Board approved this study.

We used a purposive sampling strategy to inform study duration, in which the study continued until infants were enrolled in pre-specified categories, stratified by variables of 1) time of neurologic diagnosis (prenatal vs postnatal), 2) race (Black, White, other), and 3) infant outcome (survival vs. death). This strategy was used to enhance informational representation.[19] Family conferences were audio-recorded as they occurred. The timing, participation, and content of family conferences was dictated by the clinical care team. All cases with at least one audio-recorded family conference were included for analysis. This analysis occurred in the context of a larger study in which parents completed longitudinal surveys and semi-structured interviews; the present analysis targets recorded family conference data.[18,20,21]

Qualitative Analysis:

Analytic approach—Audio recordings were transcribed and de-identified. We used a rapid-cycle qualitative approach to identify and refine themes within and between cases.[22–24] While a variety of rapid assessment strategies have been presented,[25–28] our analysis was guided by the analytic approach described by Hamilton,[29] in which domains are drawn from the data or data collection guide, transcripts are summarized, and a matrix is

used to identify key findings. Rapid-cycle qualitative approaches have been demonstrated to yield comparable findings to in depth qualitative analysis.[22,23]

A structured summary was compiled for each case by two analysts working independently (MEL, MCB, SB, MGJ). Structured summaries targeted information related to the *a priori* defined domains of 1) discussion content, 2) role of neurologic prognosis in discussion, and 3) prognostic uncertainty. The research team met weekly to review and refine structured summaries in consensus (MEL, MCB, SB, JKD, MGJ, PAU). Themes and subthemes were identified and refined inductively through a standard process of iterative discussion, serial memo writing, and iterative review of structured summaries.[22–24] NVIVO qualitative software was used to index and organize data. The Standards for Reporting Qualitative Research were used to guide results reporting.[30]

Team composition and training—Our team includes individuals with expertise in qualitative study design (DB), decision making (PAU), neonatology (SB), neonatal neurology (MEL, HCG), and qualitative analysis (MCB, JKD, DB, MEL). Members of our team include physicians (MEL, SB, HCG, PAU), nurse scientists (DB), and clinical research staff (MCB, JKD, MJ). To facilitate iterative training and enhance consistency, two senior team members (MEL and PAU) were present for consensus discussions.

RESULTS:

Forty infants and 61 parents were enrolled; 68 family conferences occurred for 24 infants (*n*=24/40, 60%). For 16 infants, no family conference was recorded due to lack of occurrence during the study period (*n*=13) or lack of study team availability for recording (*n*=3). No clinicians declined recording (Figure 1). All but four family conferences (*n*=64/68, 94%) included some discussion of neurologic prognosis; these 64 conferences included 23 infants and 36 parents with a median of 3 family conferences (range: 1–8) per case. Common infant diagnoses included prematurity (*n*=12, 52%), genetic conditions (*n*=9, 35%), and brain malformations (*n*=7, 30%). The average length of stay was 123 days (range: 23–243). Two children died prior to discharge from the hospital (Table 1).

Conferences had a median duration of 43 minutes (range: 8–85 minutes). Discussion of prognosis was led by either attending neurologists (*n*=27, 42%) or neonatologists (*n*=33, 52%) in the majority of conferences. Palliative care clinicians were present in the majority of conferences (*n*=38, 59%). The infant's bedside nurse was present in a minority of the conferences (*n*=16/64, 25%). Other topics discussed included medical status updates, decisions about whether to withhold or withdraw life-sustaining treatment, and preparation for discharge. Most conferences included clinicians from more than one discipline, with a median of five participants (range: 1–10) per meeting (Table 2).

We identified two themes related to the characterization of the infant's prognosis: 1) *Predictions of impairment* and 2) *Rationale for prognostic predictions*. Within the domain of prognostic discussion roles, we identified three themes: 1) *Aligning parent and team understanding of outcome*, 2) *Influencing decision making*, and 3) *Preparing for life at*

home. Within the domain of prognostic uncertainty, we identified two themes: 1) *Multi-layered types of uncertainty* and 2) *Holding space for hope alongside uncertainty*.

Characterization of Prognosis:

Predictions of impairment.—Most discussion of neurologic prognosis focused on the likelihood that a child would experience functional impairments. These impairments were explored in three levels, ranging from general to specific.

First and most commonly, discussion of prognosis remained general and lacked reference to discrete milestones or functions. For example, a neurologist caring for an infant with a mitochondrial disease shared: *"I am afraid that we're not going to have totally typical development." (Case 11, Neurologist).* Discussion often used nonspecific phrases sharing concern for future "developmental delays" or "concerns about [name's] development."

Second, clinicians framed prognosis as a range of potential impairments one might expect from a given condition, which could range broadly from mild disability to life threatening. As a neurologist explained to the family of an infant with myotonic dystrophy:

> "Often times whenever people have muscle differences it can be big where the person has more problems. And it can be mild where you can walk, you can breathe, you can talk, you do everything, but tight grips, things like that, can be hard. It could be a huge range." (Case 26, Neurologist)

Third, some clinicians and parents explicitly discussed discrete milestones, for example, walking or talking: *"His disabilities will be very significant and that may mean things like not walking, may mean things like not talking as you and I are talking right now, having significant trouble in school." (Case 03, Neurology fellow).*

The above examples all illustrate ways that clinicians and families discussed potential functional impairments. However, in a minority of conferences, clinicians balanced discussion of potential impairments with a positive discussion of expected abilities. For example, one neurologist shared:

> "One thing I want to make sure you hear, as we spend a lot of time talking about what kids can't do… I also wanted to say, kids with this condition know who their parents are. They smile. They laugh. They communicate in some way… We are here to help you absolutely maximize all of those things and to walk with you to make sure that we're celebrating all those joys too." (Case 20, Neurologist)

Rationale for prognostic predictions.—Clinicians used varied sources of information to justify a given prognostic prediction. First, and most commonly, clinicians used patient-specific information, for example, results of recent neuroimaging or the infant's neurologic exam: *"Based on what I'm seeing on exam, looking at the imaging, looking at how he's doing, I'm very concerned that he's going to have difficulty moving forward, just in general." (Case 05, Neurology Fellow)* Some clinicians used language suggesting that the infant's clinical course was the primary driver of infant outcome:

> "[Baby] is our bus driver and we are riding a bus with [baby]. I like to think that we're on a journey with [baby]. I don't know where [baby] is going. I don't know what paths and turns and detours we're gonna take with [baby]." (Case 11, Neonatologist)

Second, some clinicians used population-based information to describe outcome, most often to describe how critical illness can modify outcome. Clinicians referenced relevant literature in a minority of conferences. When literature was referenced, it was typically used to bolster neurologic predictions. In a few conferences, clinicians discussed limitations in existing data, including the absence of data relevant to the infant, the poor quality of existing literature, and/or the lack of specificity in existing data. For example, after a father of an infant with intraventricular hemorrhage asked for clarification around the definition of "moderate" impairment, the neurologist shared:

> "Moderate's hard because if I were to say to you, your child might have great communication and intelligence, but a really bad hemiparesis, they're gonna be in the moderate category and that's gonna be different than a kid who might have mobility but very significant cognitive impairment, right? But they're both gonna categorize as moderate in the studies. And so, it can look really wide." (Case 07, Neurologist)

Third, clinicians justified prognostication based on their own experience or the experience of a trusted colleague. In several conferences, parents and family members initiated this discussion by asking clinicians for their clinical experience caring for patients similar to their child, using questions like, "*Had you all ever had a baby in there with this situation?*" In a few conferences, specialists cited experts at other institutions who they had contacted for advice or shared relying on a "gut feeling" based on their previous clinical expertise.

While prognostic discussion was often initiated and led by clinicians, parents often supplemented this discussion by offering their own perspective of what would drive their child's outcome. Some referenced their child's current presentation, for example, emphasizing their child's current movements. Others discussed how the child's intrinsic characteristics left room for optimism, for example: *"My view of the whole thing is that he's strong. I feel like he'll overcome." (Case 05, Father)*

Roles of prognostic discussion:

Aligning parent and team understanding of outcome.—Prognostic discussion often served as a way to help align parent and clinician understanding of infant outcome. Some clinicians began by exploring baseline parent perceptions and beliefs about prognosis, for example: *"So far what have you heard and what's your understanding of baby [name]'s imaging and what's going on in his brain?" (Case 34, Neurology Fellow)* In several conferences in which the team perceived neurologic prognosis to be grim, parents articulated the potential for a positive outcome. Clinicians then proceeded to discuss prognosis in additional detail, in an effort to align the parent's understanding of outcome with that of the team. For example, a mother of an infant with holoprosencephaly shared her belief that her daughter will not have trouble with motor skills: *"I don't think she'll have problems with*

that just cause how she moves her legs." Shortly thereafter, the neurologist explained the developmental challenges experienced by most children with her daughter's condition:

> "When we think about motor skills and semilobar holoprosencephaly, almost all children have motor differences and motor challenges... Most children with this condition need the help of something else to help them walk." (Case 21, Neurologist)

In another case, the father of an infant with Trisomy 18 shared that, despite his child's condition, he *"sees her doing quite well in the future….so regardless to knowing whatever this, if she has any disabilities, whatever, we want to go through the therapy with her and move on with it."* Shortly thereafter, the geneticist explained:

> "So, I just want to make sure you do understand that, even though there are reports of patients that have, you know, lived into the teens, you know, it's not what we might consider for of the normal childhood and normal life, okay? So, once again, that is the rare exception. It's well over ninety percent that don't make it past one year for the reasons that we just talked about… So, I just want to make sure that we're being realistic and that you folks, you understand, you know, what we're talking about here." (Case 15, Geneticist)

Influencing decision making.—Approximately half of conferences discussed decision making about the provision, withdrawal, or withholding of life-sustaining treatment. Clinicians in these discussions linked neurologic prognosis to the decision in two primary ways. First, clinicians used discussion of neurologic prognosis to explain why life-sustaining therapies were necessary for survival. Clinicians counseling parents about tracheostomy placement, for example, cited concerns about respiratory drive and secretion management as central to why the procedure was necessary. Discussion of gastrostomy tube placement typically included concurrent discussion of concern for long-term oral feeding potential.

> "Because of where that the damage occurred in her brain, that does make me a little bit concerned about the coordination of the movements that are needed for swallowing…And so, it's too early for me to tell and we're really bad at predicting that….And so, time will only tell me, you know, how, what her potential is for getting better and improving that, but how much time that will take, I don't know." (Case 28, Speech therapist)

Second, clinicians described neurologic prognosis alongside decisions to limit life-sustaining treatment, for example, during conversations to place a "do not resuscitate" order. In these discussions, clinicians and parents related neurologic prognosis to concerns for future infant quality of life. At times, parents and clinicians discussed the relationship between neurologic prognosis and quality of life differently from each other. One father of an infant with intraventricular hemorrhage shared:

> "The perception I have is all the doctors here say, well she's doing really well and wouldn't consider any type of comfort care options because well, she should have a good quality of life. And that's such a subjective term…(Case 07, Father)

Some clinicians discussed prognosis in an effort to introduce palliative care services and/or to reframe goals towards care focused on comfort. In one of these conversations, a neurologist discussed the trade-off between remaining in the hospital to receive intensive medical treatment and going home for an infant with semilobar holoprosencephaly:

> "If I kept her in one room in a bubble and she still ended up passing away at some point during childhood or adolescence, or I don't know, versus if I had her explore her whole world you know, with us all the time and got the same, how would I feel? And that's something only you can answer." (Case 21, Neurologist)

Preparing for life at home.—Neurologists and neonatologists led discussions about how to screen for early delays and what to expect in terms of early developmental skills. First and most often, this involved discussion of early intervention services and developmental follow-up. For an infant born extremely premature, the neonatologist shared:

> "Our physical therapist will show you how to help his motor development to help him really reach his potential. You'll get physical therapy at home too, through our [early intervention] program. So, we'll make a referral to them so you'll be getting ongoing therapy to help him really reach those milestones." (Case 29, Neonatologist)

Second, clinicians discussed how to recognize signs of concern, such as seizures or symptoms of increased intracranial pressure. For a child with hydrocephalus, a neurologist counseled about the potential appearance of seizures in the infant period:

> "Seizures in young children can look really different than adults just like you said. So, babies don't shake, or rarely shake like adults do. They might stiffen or just one arm might shake or one leg. Sometimes children have eye movements where their eyes get stuck in one direction and they don't move. " (Case 20, Neurologist)

Third, clinicians in several conferences discussed how many parents adjust their expectations for their child over time and learn to celebrate even minor improvements in function. For example, one neurologist shared the challenge associated with learning to adjust to life with disability, while simultaneously mourning the loss of a typically developing child:

> "You can love exactly who he is and totally mourn the life that he didn't get to have, that you didn't get to have with him. And sometimes you need the cheerleader rally for the future; we'll do it, and sometimes you need the hugs." (Case 33, Neurologist)

Prognostic uncertainty

Multi-layered types of uncertainty.: Statements of prognostic uncertainty typically accompanied present alongside discussions of prognosis. Uncertainty discussion often focused on whether or not an outcome would occur (e.g. being unsure whether a patient would survive or experience neurodevelopmental impairment). Some conversations included multiple, layered types of uncertainty, such as first discussing uncertainty about whether a child might have neurodevelopmental impairment, followed by uncertainty about how

severe that impairment might manifest. Many clinicians explicitly referred to "grey" areas in prognostication:

> "So somebody else might say that they can tell you exactly what's gonna happen. If someone tells me how she'll look in a month or in two months or three months, they're making it up. There is grey." (Case 26, Neurologist)

The stakes of this uncertainty could be high, as underscored by one mother who shared why she was considering removing the ventilator in her child with brain injury: *"Because there's a chance she's gonna have a life that we don't necessarily think is a good life for her to have." (Case 7, mother)* In conversations about death, clinicians shared uncertainty about when, where, or how a patient might die. For one child with a mitochondrial disorder, the neonatologist shared: *"We know his outcome is gonna be short because of his disease process. We don't know how long that will be but we know that he's gonna have a shorter lifespan." (Case 11, Neonatologist)*

Some conversations about prognostic uncertainty also included statements of uncertainty around the cause of the infant's neurologic condition. During these discussions of etiologic uncertainty, some parents named the challenges associated with not knowing how their child's condition occurred or if they could have done something to prevent it.

Holding space for hope alongside uncertainty.: Clinicians shared a number of reasons that the outcome remained uncertain: challenges with the data, the plasticity of the newborn brain, and the role of early intervention services. Both parents and clinicians linked statements of uncertainty to hope for a better outcome than expected.

In several conversations, clinicians or parents shared how the intrinsic qualities of the patient or family left room to hope for a given outcome. Parents and clinicians routinely referred to infants as "fighters," which parents sometimes used to underscore why their child would defy clinician predictions. In several conferences, clinicians emphasized the critical role parents play in optimizing outcome. For example, a palliative care clinician shared with the parents of twins:

> "The girls have the best thing they can have, which is a family that is gonna be there for them, doing all the things that they need… It's not the size of the grade four. It is where you go to live and how much time they're gonna spend with you playing and you…doing all the exercises that PT and occupational therapy says… The girls got the best." (Case 07, Quality of life attending)

Sometimes, parents or clinicians discussed uncertainty alongside hope for a miracle amidst grim news. In one conference for an infant with a genetic condition, a PICU fellow discussed joint hope for a miracle following a direct conversation about expected infant death:

> "We never want to take away; we're never trying to take away anyone's hope. And we always join you in hoping for a miracle. And we're happy to be wrong. We love being wrong." (Case 06, Pediatric intensive care unit fellow)

DISCUSSION:

In this cohort of infants with neurologic conditions and their parents, clinicians communicated complex and high-stakes information about the future to families. The clinical contexts of prognostic communication were diverse. Some parents were given information about prognosis in the context of a life-limiting genetic diagnosis, while others received information about the impact of an acute brain injury that followed an otherwise uncomplicated pregnancy. Despite this heterogeneity, we identified salient themes that can inform interventions to improve prognostic communication for infants across a wide range of neurologic conditions.

Prognostic discussion was typically framed in the context of expected inabilities or impairment and less often framed in the context of expected abilities or functional skills. Existing data from parents suggests that parents value balanced, concrete information about both their child's expected function and their expected impairments.[17,31,32] Similarly, the Americans with Disabilities Act National Network highlights the importance of emphasizing abilities over limitations.[33] Taken together, existing data and recommendations suggest that clinicians should frame prognostic information in terms of the range of anticipated abilities, inclusive of both impairments and areas of relative strength.

Prognostic discussion served many roles in family conferences. In some conferences, clinicians used prognosis to attempt aligning parent-clinician understanding of infant outcome. In others, it was explicitly linked to a decision at hand, either as relevant background information or as a way for parents to understand more about their child's expected quality of life. Data from other pediatric settings suggest that clinicians and parents incorporate information about neurologic prognosis into decisions about life-sustaining treatment differently from each other.[17,34] These differences can be a source of moral distress and parent-team conflict.[35] A shared decision making approach is the preferred framework to support decision making in the neonatal intensive care unit and other critical care settings.[4,36] Shared decision making is a process by which clinicians partner with parents to share available medical information, elicit and clarify values, and help parents integrate values and medical facts into a health care decision.[4,37] A key element of shared decision making is eliciting and clarifying parent values, which may include discussion of future quality of life. As seen in this cohort and others, parents and clinicians may hold different values around how neurologic prognosis relates to quality of life.[17] For parents of children with serious neurologic impairment, neurologic prognosis can be a central, valued aspect of their family's identity.[38–40] One strategy that clinicians can use in this context is to begin with exploring what quality of life means to an individual parent and tailor discussion of prognosis accordingly.[41–44]

Some parents heard new information about potentially significant developmental impairments alongside new information about life-and-death decisions. Presenting emotionally charged, high stakes information together in this way may undermine a parent's ability to make an informed decision. Existing data suggest that cognitive and emotional overload leads decision-makers to rely on heuristics and biases, or even to avoid decisions entirely.[45,46] Adult surrogate decision makers appreciate receiving information

about prognosis longitudinally over time, with information introduced early in the intensive care unit course.[47] Future work should characterize whether longitudinal pacing of prognostic information and/or uncoupling the delivery of prognostic information from complex decision making is valued by caregivers of critically ill infants.[48]

Prognostic uncertainty is a reality of intensive care and is amplified in the infant period due to neuroplasticity and limitations in available biomarkers. In this cohort, prognostic uncertainties could be stacked on top of one another, such that parents were asked to process accumulated uncertainties about why their child had a neurologic condition, whether their child would survive, and the degree of neurologic impairment to expect. Existing data suggest that prognostic uncertainty can result in both short and long-term distress.[31,32] Despite this, most parents and surrogates appreciate honest information about prognosis, including associated uncertainty.[13] The best case, worst case, most likely framework has been used to help place boundaries on prognostic communication amidst uncertainty in other disciplines.[49–51] Future work should characterize whether this framework is an effective strategy for neurologic prognostic counseling.

Our study has several limitations. Conversations were recorded within a single tertiary institution, which limits transferability to other contexts and settings. The act of recording conversations may have altered clinician and/or parent behavior and communication. Important conversations about prognosis occur in multiple formats; this analysis does not capture information shared on routine rounds or other communication venues. Our analysis excludes conferences for which a translator was required. While our design allowed for the identification of broad themes of prognostic disclosure, it did not allow for detailed analysis of language itself; for example, quantifying the use of probabilistic and non-probabilistic language. We lack detailed information about clinician characteristics. Understanding how parent-clinician racial or ethnic concordance influences communication and prognostic concordance is an important area of future study. Our analysis only captures information stated explicitly in the conference. As a result, our ability to interpret clinician knowledge, the potential impact of biases and heuristics on prognostication, and parent communication preferences is limited. The strategies presented here require validation in future work that gathers data directly from parents about their preferences for prognostic disclosure.

Prognostic conversations are high-stakes interactions that help families understand their child’s medical condition, make decisions about life-sustaining treatment, and prepare for life at home. Our findings highlight potential opportunities to improve how clinicians introduce and revisit conversations about outcome for critically ill infants. Future studies should evaluate the impact of prognostic disclosure strategies on parent medical knowledge, unmet communication needs, and well-being.

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SUMMARY FOR SOCIAL MEDIA IF PUBLISHED

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What is our current knowledge on the topic?

Discussing neurologic prognosis helps parents make decisions for their child and prepare for life at home.

What question did this study address?

In this descriptive qualitative study, authors characterized how clinicians and parents discussed prognosis for critically ill infants with neurologic conditions.

What does this study add to our knowledge?

In this study of real-time communication between clinicians and parents, prognostic discussion for infants focused on the potential for neurologic impairment and served to align parent and clinician understanding of outcome, inform decision making, and help parents prepare for life at home. Prognostic discussion included varied, multi-layered types of prognostic uncertainty that allowed parents to hold space for hope alongside the potential for an uncertain outcome.

How might this potentially impact the practice of neurology?

These findings highlight potential opportunities to study and improve prognostic communication. Future work should characterize parent preferences for prognostic disclosure and assess the impact of prognostic disclosure strategies on the quality of communication and shared decision making.

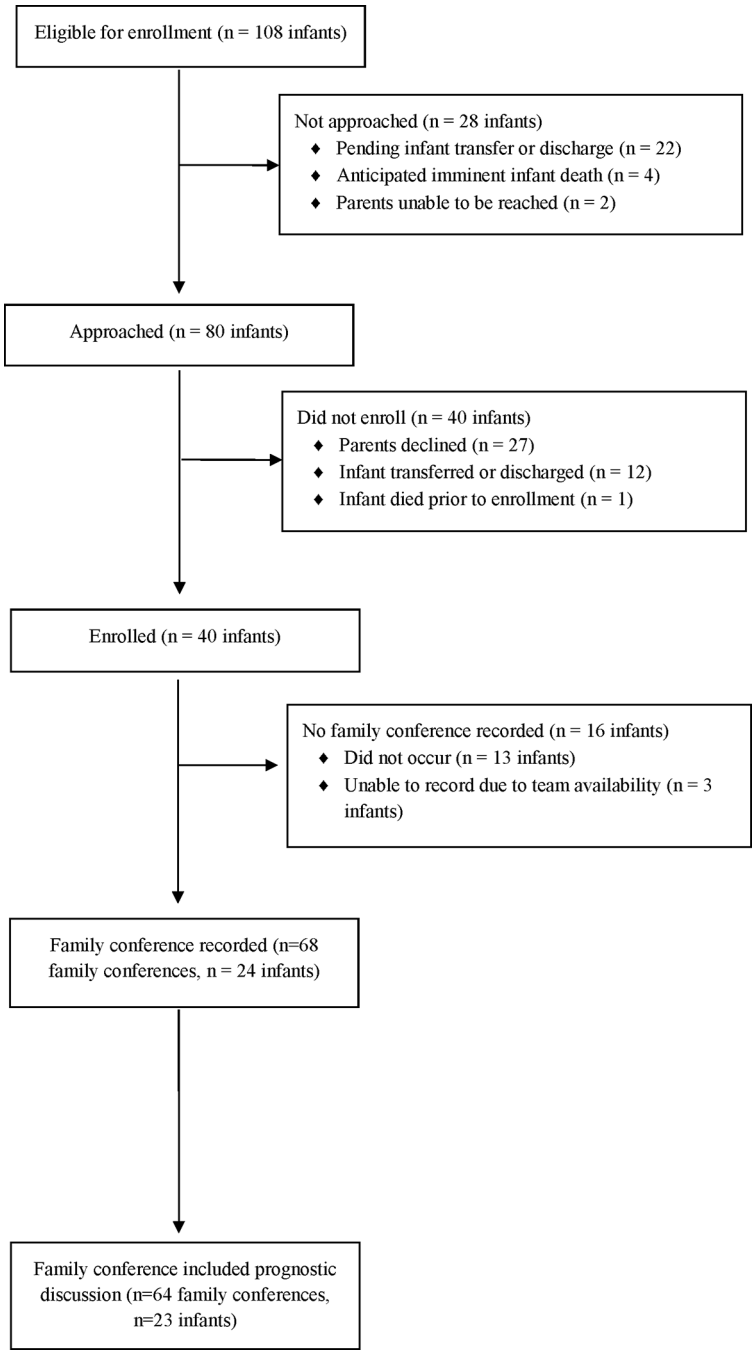

Figure 1.
Enrollment and Data Collection Diagram

Table 1:

Infant and Parent Characteristics

Characteristic	Median (Range) or *n* (%)
Infant Characteristics (*n*=23)	
Gestational age at birth, wk	34 (23–40)
Sex, female	12 (52)
Medical conditions	
Prematurity	12 (52)
Genetic disorders	9 (35)
Seizures	10 (43)
Hypoxic ischemic encephalopathy (HIE)	5 (22)
Intraventricular hemorrhage	8 (35)
Brain malformation	7 (30)
Interventions	
Tracheostomy	6 (26)
Gastrostomy tube	16 (70)
CSF diversion	5 (22)
Mechanical ventilation	21 (91)
Code/chest compressions	8 (35)
Parent Characteristics (*n*=36)	
Age, y	31 (19–43)
Gender	
Female	22 (58)
Male	11 (38)
Other/not reported	2 (4)
Race and ethnicity	
White	12 (33)
Black	21 (58)
Asian	2 (6)
More than one race	1 (3)
Hispanic/Latinx	3 (8)
Level of education	
Less than high school	3 (8)
High school/GED	11 (31)
Some college	8 (22)
Associate’s or trade degree	1 (3)
Bachelor’s degree	4 (11)
Graduate or professional degree	3 (8)
Annual household income	
Less than $25,000	12 (33)

Characteristic	Median (Range) or *n* (%)
$25,000–$34,999	8 (22)
$35,000–$49,999	4 (11)
$50,000–$74,999	2 (6)
$75,000–$149,999	4 (11)
$150,000 or more	5 (14)
Other/not reported	1 (3)
Previous involvement in family member's ICU care	11 (31)

Table 2:

Meeting characteristics

Characteristic	Median (Range) Or *n* (%)
Meeting Characteristics (*n*=64)	
Number of meetings per case	3 (1–7)
Meeting length, minutes	44 (8–85)
Family members	
Mother present	64 (100)
Father present	40 (63)
Extended family members present	18 (28)
Total family members present	2 (1–7)
Team members	
Clinician type present[a]	
Neonatology	54 (84)
Neurology	36 (56)
Palliative Care	38 (59)
Other specialists[b]	20 (31)
Medical/NP student	9 (14)
Unit staff present	
Bedside Nurse	16 (25)
Social Work	50 (78)
Physical, Occupational, and/or Speech Therapy	5 (8)
Total team members present	5 (1–10)

[a]Clinician type includes attending physicians, trainees, and APPs.

[b]Other specialists include cardiology, endocrinology, genetics, neurosurgery, pulmonology, otorhinolaryngology, hepatology, pediatrics, and pediatric intensive care.