

# Communication Challenges in Neonatal Encephalopathy

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abstract

**BACKGROUND:** Families must process complex information related to neonatal encephalopathy and therapeutic hypothermia.

**METHODS:** In this mixed methods study, semi-structured interviews were performed with parents whose infants were enrolled in an existing longitudinal cohort study of therapeutic hypothermia between 2011 and 2014.

**RESULTS:** Thematic saturation was achieved after 20 interviews. Parental experience of communicating with clinicians was characterized by 3 principle themes. Theme 1 highlighted that a fragmented communication process mirrored the chaotic maternal and neonatal course. Parents often received key information about neonatal encephalopathy and therapeutic hypothermia from maternal clinicians. Infant medical information was often given to 1 family member (60%), who felt burdened by the responsibility to relay that information to others. Families universally valued the role of the bedside nurse, who was perceived as the primary source of communication for most (75%) families. Theme 2 encompassed the challenges of discussing the complex therapy of therapeutic hypothermia: families appreciated clinicians who used lay language and provided written material, and they often felt overwhelmed by technical information that made it hard to understand the “big picture” of their infant’s medical course. Theme 3 involved the uncertain prognosis after neonatal encephalopathy. Parents appreciated specific expectations about their infant’s long-term development, and experienced long-term distress about prognostic uncertainty.

**CONCLUSIONS:** Communicating complex and large volumes of information in the midst of perinatal crisis presents inherent challenges for both clinicians and families. We identified an actionable set of communication challenges that can be addressed with targeted interventions.



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**WHAT'S KNOWN ON THIS SUBJECT:** Neonatal encephalopathy is complex and associated with significant morbidity and mortality; parents' experience of communicating with clinicians in this condition has not been well described.

**WHAT THIS STUDY ADDS:** Parents of encephalopathic infants reported fragmented communication, difficulty organizing information, and long-term stress due to their infant's uncertain prognosis. Targeted communication interventions should help parents organize information, emphasize the big picture, and prepare families for ongoing prognostic uncertainty.

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*"It's so much more than just having a traumatic birth. It's the death of the dream of imagining yourself giving birth and holding your baby with your husband there. It's this magical moment that you think about forever. Whereas...it soon becomes a trauma situation."*

Therapeutic hypothermia (TH) is the only brain-specific treatment of neonatal encephalopathy. Despite the benefit of TH for many infants, nearly one-half of treated patients die or survive with significant disability.<sup>1-4</sup> The decision to initiate TH must be made within 6 hours of birth and often results in neonatal transfer to a referral center distant from the parents.

Initial conversations about neonatal encephalopathy and TH generally occur in the midst of a crisis. Parents are unprepared for a medical emergency or complex medical decision-making. Data suggest that parents can experience depression and anxiety in the face of their infant's critical illness<sup>5-7</sup>; as many as one-quarter of mothers of high-risk infants can go on to have posttraumatic stress symptoms.<sup>8</sup> Importantly, the way that clinicians interact and communicate with parents can mediate both short- and long-term emotional trauma.<sup>9,10</sup>

The goal of the present study was to characterize the parental experience of communicating with clinicians about TH and neonatal encephalopathy. We chose to explore this complex topic by using a qualitative methodology in which recruitment continues until no additional thematic content emerges.<sup>11,12</sup> Our goal was to identify communication patterns that helped or hindered parents' ability to hear important medical information and process the possibility that their infant could die or survive with serious disability. Isolating communication patterns can inform communication interventions for this population.

## METHODS

### Participants and Design

This mixed methods study was conducted at an urban referral Level IV NICU. Care for asphyxiated infants in our NICU includes a standardized 72-hour TH protocol involving frequent blood samples, continuous amplitude-integrated or video electroencephalographic monitoring, 2 head ultrasounds, and 1 MRI after TH. Infants with multiorgan dysfunction receive additional, individualized interventions.

From an existing longitudinal cohort, the study recruited English-speaking parents of infants who: (1) were treated with TH between 2011 and 2014; (2) survived to NICU discharge; and (3) were at least 6 months old at the time of study recruitment.

The institutional review board approved the study with the following recruitment strategy: eligible parents received an introductory letter and opt-out postcard. Parents who did not opt-out were contacted by telephone; those who agreed to participate provided written consent.

### Questionnaire and Data Collection

Participants completed an audio-recorded semi-structured interview. The interview instrument was adapted from our previous research,<sup>13</sup> a review of the literature, and discussion with experts in neonatology, palliative care, and pediatric neurology. Questions targeted parent recall of their communication with clinicians about the birth, TH and subsequent neonatal hospital course, and infant prognosis. One interviewer (M.E.L.) completed all interviews. Infant medical charts were reviewed for clinical information.

### Data Analyses

Transcript content was analyzed according to the qualitative technique of thematic saturation.<sup>11,12</sup> Three

investigators (R.D.B., P.K.D., and M.E.L.) independently coded each transcript, then met to compare codes and resolve differences through repeated discussion. Key themes were identified by the frequency with which they occurred in each interview. Recruitment was stopped when no additional thematic content emerged. Descriptive frequencies of quantitative data were produced by using SPSS version 22 (IBM SPSS Statistics, IBM Corporation, Armonk, NY).

## RESULTS

Fifty-one parents of infants treated with TH were eligible for study inclusion; 20 participated (Table 1). Children were between 7 and 38 months old at the time of the interview.

Parental experience of communicating with clinicians during the peripartum and neonatal periods was characterized by 3 principle themes: (1) a fragmented pattern of clinician-parent communication mirrored the chaotic maternal and neonatal course; (2) the challenges of discussing the complex therapy of TH; and (3) the uncertainty of prognosis after neonatal encephalopathy. Parents described what went well and what they wished could have gone differently. Age of child at the time of the interview did not affect the results. Illustrative quotations for each theme are presented in Tables 2, 3, and 4.

### Patterns of Clinician-Parent Communication

There were many commonalities in the maternal and neonatal clinical courses of participants: an unremarkable and desired pregnancy carried to term, an urgent and chaotic delivery, immediate separation of the neonate from the parents, 72 hours of neonatal TH followed by days to weeks of hospitalization, and long-term monitoring for

**TABLE 1** Infant and Maternal Characteristics

Characteristic	Median (Range) or N (%)
<b>Infant</b>	
Gestational age, wk	39 (35–41)
Birth weight, g	3190 (1990–4470)
Race (white)	14 (70)
Male	10 (50)
Inborn	3 (15)
Nonreassuring fetal heart tracing	14 (70)
Mode of delivery	
Vaginal	5 (25)
Assisted vaginal	2 (10)
Cesarean delivery	2 (10)
Emergency cesarean delivery	11 (55)
Apgar score	
5 min	3 (1–7)
10 min <sup>a</sup>	5 (2–8)
Base deficit <sup>b</sup>	19.4 (7.3–33.8)
Intubated	7 (35)
Given anticonvulsant agents	12 (60)
MRI performed	20 (100)
Time to full oral feeding, d <sup>c</sup>	8 (5–32)
NICU length of stay, d	12.5 (7–32)
<b>Maternal characteristics</b>	
Age at birth, y	32 (18–42)
Pregnancy planned	16 (80)
Primigravida	7 (35)
Father present at delivery	20 (100)
Knows other children with complex chronic conditions	12 (60)
Someone else knew what was happening with the infant before mother <sup>d</sup>	12 (60)

<sup>a</sup> n = 19.

<sup>b</sup> n = 17, information missing from referring hospital.

<sup>c</sup> n = 17, three remaining infants discharged with gastrostomy or nasogastric tube.

<sup>d</sup> Father of infant in all cases.

neurodevelopmental delays. These commonalities created predictable patterns of clinician–parent communication.

### Who

Although neonatal encephalopathy and TH are generally managed by neonatal specialists at referral centers, most parents first learned of these topics from clinicians with no special expertise. Because the pregnancies were generally low risk, the maternal-fetal crisis and subsequent cesarean delivery occurred at a community hospital for most parents (85%). After initial resuscitation, the neonatal team quickly left the operating room, with minimal time for communication. Many parents (60%) said that the obstetric and anesthesia teams provided the initial information about the infant. Limited or confusing details about the neonate from these nonpediatricians prompted concern and mistrust for some parents.

Maternal clinicians often continued to be primary sources of information about the infant. Six (30%) mothers remained at the community hospital for >24 hours after delivery, with

**TABLE 2** Illustrative Quotations From Theme 1: Fragmented Communication Process

Theme 1—Fragmented Communication Process	
Who	My doctor stitched me up and then she ran to the NICU to check on [my baby]. She was the one who actually came and told me. (10) I feel like [the birth hospital] was not entirely sure what to tell us. (4) My husband wasn't even telling me anything. Later on, he said "I thought you knew, I thought they told you what was going on." No, I had no idea. (13) I specifically asked for the nurse that was taking care of my daughter that day to come with me [to the family meeting], because he had been taking care of her throughout the time she was there. He came there to help me to understand what they were saying, if it got more into the doctor terms and I couldn't understand it. (8)
When	I didn't start to piece together a lot of information until after I was out of the hospital and really got a chance to speak to my husband and my family members and get an overall understanding of what was going on. (13) That [lack of information] went on, in my opinion, for too long with very little information...I had a lot of family pushing for information. So that was a really stressful part of everything. (9) When I woke up from surgery, I was asking; I knew his heart had stopped and I was asking, "Is he OK, is he OK?" and they [said] "we will talk about it later." I was very mad that they would not tell me anything right then. (2)
How	They were all pretty clear about what it is they were here to do, what their role was, and asking me if I had any questions about it. (19) I liked that the [NICU doctor] sat me down and said "I'm going to explain a lot of things and then when you have questions let me know." But I don't think we knew what to ask. (3) I wish I could have been able to ask them more about the information that I should keep and what I should not worry about retaining...It would have been helpful if somebody had said, "This might be a long road...get a notebook, write this stuff down, the date, the doctor, all this stuff will come back to haunt you later on...it'll be good to have this information" (8) I like that they went over everything verbally and then they also gave us this packet of information. It was nice for us to read the information again, because it is hard to digest when you hear it the first time. (4)

Numbers after quotes represent participant identifiers.

**TABLE 3** Illustrative Quotations From Theme 2: Communication Content: Complex therapies

Theme 2—Communication Content: Complex therapies	
The “big picture”	I still to this day don’t understand what happened. (7) It [a family meeting] would give us a time to sit down and really get an understanding of what was going on, like a comprehensive understanding, as opposed to bits and pieces here and there. To really understand what the plan was for her, because a lot of times the plan changed. I understand it’s dynamic, but it always seemed to be something we were chasing. We didn’t really know what was what was going on, or what we needed to really look for. (13) I was so overloaded from medical terminology that I didn’t understand what was happening. They were able to be like, “Here’s the medical term, but this is what it means.” (4)
Emotions and information	We were too much in our own grief, in our own kind of like emergency, like in shock. (18) [Speaking about the MRI] I wish they had been a little gentler with us, it was very clinical, very cold, very sterile...they put her in a capsule that looks like a spaceship and wheeled her into another room where we couldn’t watch and we couldn’t be with her... we had no idea what was going on. (5) I would have loved for a therapist or a counselor, somebody to help me process everything that had happened. (16)
Uncertainty about novel therapies	I understand the treatment is so young there’s not much on what to expect. (7) We didn’t know anyone who had anything like [the cooling protocol]. We felt very alone; no one that we could talk to and see their experiences...that was difficult. (2) I remember waking-up [from cesarean delivery] and my husband came in and said, “I’m going to have to go because [baby] is being transferred...she’s had some trauma to her brain because of lack of oxygen. This protocol has been recommended to us and I think we should do it. I signed the papers.” And then he was gone. (3)

Numbers after quotes represent participant identifiers.

**TABLE 4** Illustrative Quotations From Theme 3: Prognosis After Neonatal Encephalopathy

Theme 3—Prognosis after neonatal encephalopathy	
Did not or could not hear	Upon discharge they gave me information saying, talk to Infants and Toddlers [early intervention program], they need this, they need that, but I did not know why. I didn’t know what Infants and Toddlers was. (1) I remember them saying that he might not have normal social skills. At the time I didn’t understand what that meant. (16) We worried if she was going to be ok, if she was going to still keep living. And then after we got out of the woods with that and she was able to breathe, then it was time to think about you know, other things that could happen. Eventually, is she going to be able to do normal things that others can do? (18)
Wait and see	They couldn’t give us any indication on what may or may not be wrong. It was just day by day; we’re just going to have to see how she does for the next 6 months. And I don’t think you understand what that means to a parent. It can really mess up the mom when she doesn’t know how her kid’s going to be. (14) It [prognosis] could be anything from slower developmental functioning, to difficulty learning that seemed very mild, to an inability to see, to talk, physical disability. It just seemed like the range was massive. The full range of brain function was on the table. (19) I liked that she [neonatologist] was willing to talk to us and give us suggestions of actual real things we could do with her right then. (12)

Numbers after quotes represent participant identifiers.

little direct communication with their infant’s medical team. Even after NICU discharge, obstetricians filled important information gaps. One mother described that her obstetrician reviewed the neonatal MRI with her at a postpartum visit.

Many parents (75%) remembered that most of their communication about their infant happened with nurses. Nurses were particularly valued participants in important discussions, as parents believed the nurses could advocate for their infant and interpret what physicians said. Parents commonly were uncertain who their infant’s “primary” physician was; they felt the primary nursing model

promoted communication consistency. Parents appreciated when team member roles were clearly defined.

Few parents sought outside information about TH during the NICU hospitalization; those who did search the Internet found the content “shocking.” After the NICU stay, parents commonly researched neonatal encephalopathy and long-term outcomes. When asked whether it would have been helpful in the NICU to talk with another parent with TH experience, one-half (50%) readily agreed; some (20%) thought this option could have been overwhelming.

### *When*

The timing of clinician–parent communication was dictated by the urgent birth and largely uniform TH course. Many mothers (65%) underwent emergent cesarean deliveries with general anesthesia and resultant altered mentation. Parents complained of privacy policies that delayed disclosure of medical information to extended family, including information about whether the infant was alive.

Parents preferred to control the timing of important conversations regarding serious results or infant prognosis. They also wanted choice about who would be present for

those conversations. They felt overwhelmed when information about long-term neurodevelopmental risks was disclosed simultaneously with the possibility of neonatal death. Some were offended to hear their infant's brain injury and neurodevelopmental prognosis discussed during teaching rounds; others found rounds confusing because different opinions were presented, and the final plan was not clear.

Most parents felt the flow of information was too slow. Some recommended a designated staff member to communicate timely information. Nearly every parent described a process of piecing together information held by different family members, or via discharge documentation, after the NICU stay.

#### *How*

Information transfer worked best when >1 parent or family member received information simultaneously, even if via speakerphone.

Nearly every family had gaps in understanding because 1 person received medical information that he or she had to relay and interpret for the remaining family. This struggle to relay information was stressful. Mothers were at highest risk of misunderstandings because their postpartum recovery reduced the number of early and direct conversations with neonatal clinicians. Maternal understanding was improved when neonatal clinicians came to the mother's room for updates. One mother was pleased that a NICU nurse video-recorded updates, allowing her to feel more present.

Seven (35%) parents remembered having "family meetings," away from the bedside. Parents found that these meetings permitted them to ask "big picture" questions that they felt uncomfortable raising on rounds. They also permitted discussion of

potentially upsetting information to happen away from their infant's bedside. In general, parents received most of their information in their infant's room and from nurses. Several described how practical information from NICU front desk staff (eg, regarding visiting hours or parking) reduced anxiety.

Few parents felt they had been able to ask good questions in the NICU. Parents valued written information, which they used after NICU discharge to put together the fragmented information. Several reported that receiving written materials early on, particularly technical information about the NICU or TH, was overwhelming; this confusion was ameliorated when clinicians reviewed the materials with them, allowing time for questions. Parents described several methods that they used, or wish they had used, to manage the large quantity of information about the maternal and neonatal concerns, such as journals or notebooks. Parents would have liked clinicians to help them organize and prioritize information so it could be more useful after NICU discharge.

#### **Communication Content: Understanding Complex Therapies**

##### *The "Big Picture"*

Nearly all parents remember feeling bombarded with technical information that confused the "big picture" about why their infant was being cooled and what the cooling was expected to do. Parents felt that clinicians prioritized practical or technical details, with less discussion of their overall relevance.

Notably, although one-third of participants had some baseline medical knowledge, nearly all wanted clinicians to use simple, lay language, especially because few participants had any previous experience of the NICU or TH. Parents found simpler information was easier to understand and pass along, and was less frightening.

At the time of our interviews, many parents maintained incomplete and inaccurate information about TH and about why their infant had received TH. Some confused symptoms of neonatal encephalopathy with reactions to TH; others believed that sedatives used during TH caused some of the infant's problems. Only 5 parents recognized that the EEG and brain MRI were key prognostic tests. Several parents told us that they still wished someone could review what had happened and help them understand the overall situation. Some advocated for written discharge information that clarifies how "big picture" concerns are related to the need for specific longitudinal follow-up.

#### *Emotions and Information*

Overwhelming emotions coincided with their introduction to the technical information about TH. Parents needed help to manage emotions to really hear that information. They valued simple invitations from clinicians to share emotions, such as "How are you doing?" Parents got emotional support from the interdisciplinary team, including pastoral care. A few believed that the presence of a hospital chaplain made them worry that their infant was dying.

#### *Uncertainty About Novel Therapies*

Multiple parents were anxious that their infant was receiving what they perceived to be a novel treatment (ie, TH). Some understood initially that TH was a relatively new treatment with limited outcome data; others did not and were distressed to later learn this fact. Some believed that their infant received experimental treatment.

The sense that TH was an unproven treatment heightened parents' sense of responsibility for "making the decision to cool." Many felt that they had been asked to choose whether to cool their infant; this perception was

entangled with needing to consent for neonatal transfer. Parents were stressed by the perceived need to make such an important decision. This responsibility was particularly burdensome when the mother was under anesthesia; couples had rarely prepared for the father to make serious medical decisions for the infant if the mother was incapacitated.

### Prognosis After Neonatal Encephalopathy

#### *"I Did Not—or Could Not—Hear the Information"*

At the start of TH, most parents were preoccupied by the possibility of their infant's death; only after the infant began to stabilize could they process information about long-term outcomes. Some first understood at the NICU follow-up clinic that their infant was at risk for developmental vulnerabilities.

Some parents attributed their gaps in understanding to clinician jargon about neurodevelopmental concerns (eg "problems with social skills" or "need for developmental follow-up"). Many perceived the developmental prognosis as so vague and uncertain that they had no idea what to expect. At the time of the interview, 70% of parents reported that their children had developmental delays in  $\geq 1$  domain (motor, language, cognition, or feeding). Fifty-five percent reported language delay; about one-half (55%) of those parents recalled no NICU discussions of possible language delay. A similar number of parents (55%) reported motor delay; 45% of those parents recalled no NICU discussions of possible motor delay. One-quarter of parents reported that their child had behavioral problems; none recalled NICU discussions of these possibilities.

#### *"Wait and See"*

Most parents reported that clinicians told them that nothing

was certain about their infant's long-term prognosis; they would have to "wait and see." At the time of our interviews, most parents still felt burdened by this indefinite uncertainty, which continued to make them anxious and vigilant. Many worried about how to judge their child's behaviors, wondering whether difficulties with sleep or anger were "normal" versus "brain injury." Families described treating their infants as "vulnerable children," modifying their approach to parenting and discipline because of the child's traumatic experience. Parents wished clinicians could or would signify when their child was "out of the woods."

## DISCUSSION

Parents of encephalopathic infants treated with TH in this sample faced a consistent set of challenges. For most, an uncomplicated pregnancy ended in a crisis that prompted urgent medical interventions. Mothers spent hours to days incapacitated, often at a distant hospital. Fathers were unprepared for their role as primary communicators and medical decision-makers. The infants received a technical therapy and were at risk for dying and lifetime disability. Families struggled to process medical information and needed help managing their emotions so they could participate more effectively in their infant's care. Although some parents still lacked important medical details months to years later, more felt overwhelmed by technical details and lacked confidence in their understanding of the "big picture." All parents left the NICU with some degree of prognostic uncertainty, and they were unprepared for how stressful this situation could be for months to years afterward. Our findings build on previous descriptions of parental experience of hypothermia<sup>14</sup> and neonatal neurologic care.<sup>15</sup> We

defined patterns of communication challenges experienced by parents, and these patterns highlight opportunities to more fully prepare families for the short- and long-term. We identify 5 areas that could benefit from targeted communication interventions.

First, most infants were born at a community hospital and transferred urgently to a referral center. Previous parent descriptions suggest that infant transfer to<sup>16</sup> and from<sup>17</sup> the NICU can be particularly trying for families and warrants added parental support. Although birth location has not been found to affect infant outcomes with TH,<sup>18</sup> our data suggest that emergent neonatal transfer in TH contributes to family knowledge deficits. Early communication, often from nonpediatricians, was generally incomplete and set the stage for family understanding of TH and their infant's status. Understanding often improved once both parents arrived at the NICU. This finding suggests that effective communication strategies must incorporate the community providers, obstetricians, and other health care professionals who are the "first responders." Specific strategies could include written materials and community outreach to enhance knowledge about TH among maternal clinicians and pediatricians. Timely feedback to community clinicians about an infant's TH course could enhance professional education and promote accurate information transfer to the mother. Once the parents arrive at the referral center, neonatal clinicians should consistently review the peripartum and neonatal course to address knowledge gaps.

Mothers were often physically separated from their child and many were dealing with their own physical and emotional recovery, leaving them poorly informed about their infant's condition. Telephone calls from the infant's clinicians were less helpful than in-person conversations. Future

communication interventions could leverage technology to allow mothers still admitted at other hospitals to view NICU rounds, updates, and nursing care in real-time. Virtual visiting interventions have been trialed in the NICU with some success, and warrant further study.<sup>19,20</sup>

Parents had difficulty understanding the “big picture” about their infant’s condition and treatment. Information about TH is technical; most infants received additional interventions for multiorgan dysfunction. It is not surprising that parents struggled to navigate this large volume of information and synthesize which tests or treatments were key. Practical interventions to help families organize information, such as written materials and journals, could be adapted for this high-risk population.<sup>21–23</sup> Parents also found it challenging to articulate their questions for clinicians. Question prompt lists, which provide high-yield questions to guide clinical encounters, have been shown in other settings to decrease unmet information needs and patient anxiety and to improve patient satisfaction.<sup>24–27</sup> These lists could be adapted for this population.

Families universally valued the role of the nurse, not just for bedside infant care but as key advocates and interpreters in serious discussions. This finding supports the value of the primary nursing model on

infant and family outcomes.<sup>15,28,29</sup> Communication interventions should leverage these relationships. When possible, infants undergoing TH should have a primary nurse, as parents identify that this arrangement promotes better communication. The results of this study and others<sup>30</sup> suggest that nurses be active, valued participants in all major discussions with the family.

Finally, prognostic uncertainty characterizes acute care of encephalopathic infants and is stressful to families.<sup>14</sup> As prognostication for these infants improves,<sup>31,32</sup> we must concurrently prepare families for and provide sustained support around uncertainty. When possible, clinicians should eschew overly vague prognostications and, as many families suggested, provide a combination of best, worst, and most-likely outcomes. Clinicians providing follow-up care should revisit how a child’s prognosis changes over time. Many families worried that their child may develop major neurodevelopmental impairment years after discharge from the NICU, despite normal early development. Routinely assessing for this anxiety during follow-up visits may be helpful.

Our study has several limitations. A recruitment strategy that required families to “opt in” and provide both oral and written consent could have undermined participation by

families with limited resources. Non-English-speaking and bereaved parents were excluded from the study; defining communication challenges experienced by these populations is an important next step. This study was performed at a single US referral center; results may not be generalizable to other health care systems. Because our sample included several medically savvy parents, we may have underestimated parents’ typical information needs. Most participants were mothers; given the differences between maternal and paternal experiences around the time of birth, the paternal perspective deserves further study. Finally, interviewing families after discharge may result in recall bias, and information is likely informed by emotional adaptation.

## CONCLUSIONS

Novel therapies present novel opportunities for intervention. We found that common, actionable communication challenges can occur in neonatal encephalopathy. We hope these data provide a framework for designing future interventions to improve communication between families and clinicians.

## ABBREVIATION

TH: therapeutic hypothermia

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