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Parent Experience of Neonatal Encephalopathy: The need for family-centered outcomes

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Abstract

We aimed to characterize the parent experience of caring for an infant with neonatal encephalopathy. In this mixed methods study, we performed semistructured interviews with parents whose infants were enrolled in an existing longitudinal cohort study of therapeutic hypothermia between 2011–2014. Thematic saturation was achieved after 20 interviews. Parent experience of caring for a child with neonatal encephalopathy was characterized by 3 principle themes. Theme 1: Many families described cumulative loss and grief throughout the perinatal crisis, critical neonatal course, and subsequent missed developmental milestones. Theme 2: Families experienced entangled infant and broader family interests. Theme 3: Parents evolved into and found meaning in their role as an advocate. These data offer insight into the lived experience of parenting an infant with neonatal encephalopathy. Primary data from parents can serve as a useful framework to guide the development and interpretation of parent-centered outcomes.

Keywords

parent; neonatal encephalopathy; hypoxic ischemic encephalopathy; therapeutic Hypothermia

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Introduction

Infants with neonatal encephalopathy are at high risk of death and neurodevelopmental disability.^{1–3} Therapeutic hypothermia and emerging interventions offer promise in improving infant health; however, long-term optimal neurodevelopmental outcome relies on family resiliency and capacity to participate in early intervention, medical monitoring, and close follow-up. In order to optimize infant outcomes, we must concurrently work to understand and improve family outcomes. Characterizing the long-term parent experience of caring for an infant with neonatal encephalopathy is a necessary first step in defining family-centered outcomes for this population.

Existing data demonstrate that parenting influences the trajectory of development for infants born with serious conditions including prematurity,⁴ bronchopulmonary dysplasia,⁵ as well as hypoxic-ischemic encephalopathy.⁶ Postnatal post-traumatic stress disorder related to an emergent delivery and life-threatening neonatal condition affects nearly a quarter all neonatal intensive care unit mothers in the short term,^{7–9} and can adversely affect long-term infant cognitive outcome.¹⁰ Neonatal prognostic uncertainty is another source of long-term parental stress.¹¹ For those parents whose infants do go on to have chronic health care needs, families are at risk of emotional difficulties, social isolation, and family member divisions.¹² These negative family outcomes risk undermining parent capacity to care for a child with medical complexity.

Characterizing the lived experience of parents caring for an infant affected by neonatal encephalopathy can help clinicians identify and improve outcomes that matter to families. We have previously described common communication challenges faced by families whose infant undergoes therapeutic hypothermia in the neonatal intensive care unit.¹³ Here, we aimed to characterize the longitudinal parent experience of neonatal encephalopathy in an effort to identify ways to improve family outcomes in the short and long term.

Methods

Participants and Design

Data for this study were taken from an existing interview data set. This qualitative study was conducted at an urban referral center with a level 4 neonatal intensive care unit. At our center, typical care for encephalopathic infants includes a standardized 72-hour therapeutic hypothermia protocol, continuous amplitude-integrated or video electroencephalographic monitoring, two head ultrasounds, and one brain MRI following therapeutic hypothermia. Infants with multi-organ dysfunction receive additional interventions.

From an existing longitudinal cohort, we recruited English-speaking parents of infants who 1) were treated with therapeutic hypothermia between the years of 2011–2014, 2) survived the neonatal period and 3) were at least 6 months old at the time of study recruitment.

The Institutional Review Board approved the study. Eligible parents received an introductory letter describing the study and an opt-out postcard. Parents who did not opt-out were contacted by phone. Parents who agreed to participate completed written consent.

Questionnaire and Data Collection

Participants completed a semi-structured interview that was audio recorded. The interview instrument has been described previously. Questions targeted for this analysis focused on the parent's experience of the birth (e.g. *Tell me about your labor.*), neonatal intensive care unit course (e.g., *What sorts of problems did you worry your baby would have?*), and life after hospital discharge (e.g., *What challenges have you faced in caring for your child?*). One interviewer (ML) completed all interviews. Infant medical charts were reviewed for clinical information.

Data analyses

Interviews were transcribed and analyzed using the qualitative technique of thematic saturation in which recruitment stops when no additional thematic content emerges.^{14, 15} Each transcript was independently coded by three investigators (RB, PD, and ML) and differences were resolved through repeated discussion. Descriptive frequencies of quantitative data were produced using SPSS 22 (IBM SPSS, Chicago, IL). Prior work focused on parent communication with clinicians; here we target the parent experience of neonatal encephalopathy.

Results

Fifty-one parents of infants treated with therapeutic hypothermia were eligible for study inclusion and 20 participated (Table 1). At the time of the interview, children were between 7 and 38 months old.

Longitudinal parent experience of neonatal encephalopathy was characterized by 3 themes: 1) Longitudinal grief: The grief that accompanied the acute period often extended beyond the neonatal course, and was characterized by descriptions of episodic loss as children experienced delayed milestones or new diagnoses. 2) Entangled family and infant interests: Families struggled to balance infant needs with maternal health needs, needs of other children, and overall family needs. 3) Advocacy: Parents evolved into advocates for their children and desired to serve as resources to other families. Representative quotes for each theme can be found in tables 2, 3, and 4.

Theme 1: Repeated losses/longitudinal grief

The majority of families in our cohort (80%) had desired and healthy pregnancies. Given the common etiologies of perinatal asphyxia, many mothers experienced complications (uterine rupture, placental abruption) necessitating an emergent cesarean-section (55%). These mothers described the replacement of their expectations of a vaginal birth with descriptions of a sterile environment in which they were isolated from their family members. A subset of mothers had a complication in the setting of a vaginal birth after cesarean section. For these women, who made an active choice to avoid cesarean section, grief surrounding the birth process was amplified. Many mothers feared losing the ability to have future children. Overall, mothers grieved the loss of controlled birth experience, feeling as though they had been “robbed” of a “rite of passage.”

In neonatal life, many parents experienced disruption of the much awaited bonding with their infant. Early on, this was manifested in parent's inability to hold their infant during therapeutic hypothermia. Several families talked of how long it felt before the first day they were allowed to hold their infant. Many families grieved the absence of their "normal baby" and the presence of machines. For some mothers, the disrupted bonding experience included inability to breastfeed, either in the therapeutic hypothermia period, or later due to infant oromotor dysfunction.

Once the acute crisis was over and families returned home with a vulnerable infant, many families experienced a loss of their prior way of life. For some, this loss was concrete – for example, losing a job or lost time due to medical appointments. For others, this loss was abstract, and described as not knowing what could have been. More broadly, some parents felt as though the normal parenthood experience had been taken from them.

Theme 2: Entangled Infant and Family Interests

In the perinatal period, many families had guilt or regrets about the balance of maternal: infant priorities around the time of birth. Most felt that they had participated in choices-- vaginal birth after cesarean section, consent to external version or epidural-- which they perceived prioritized maternal health and might have adversely impacted their child's outcome. Most mothers and their neonates experienced a perinatal emergency; some women felt that their acute medical concerns were de-emphasized relative to their baby's. For parents who delivered away from the referral center, maternal care and discharge was often driven by how sick the baby was and by need for maternal presence for infant decision making. Many mothers were transferred for their ongoing postpartum care to the referral center where their infant was being cooled; some described difficulty transitioning away from their personal medical team to a team of clinicians they had never met, while other mothers described delay in maternal transfer as stressful.

As they kept vigil over their newborn in the neonatal intensive care unit for days to weeks, many parents had difficulty integrating their infant's immediate and predicted medical needs into the "big picture" of their family's life. Families often felt torn about the needs of their other children at home, yet they were also reluctant to leave hospital because they worried that something would happen to their baby in their absence. Some families struggled to find transportation or housing during the acute period and many were forced to take added leave from employment as a result of their infant's illness. Many families commented on the inability to do normal daily activities (sleep, eat, or shower) and appreciated services or individuals that allowed them respite.

After hospital discharge, many infants needed close medical follow-up and therapies and had complex daily care needs. Some parents struggled to balance financial and professional responsibilities with their infant's medical needs, resulting in lost work or the need for financial assistance. When both parents did continue to work, some mothers worried that their infant's medical or developmental progress was suffering because their parents were less present. Quality childcare was difficult for several families, and family life was further disrupted by the need for medical equipment and health care professionals in the home (e.g. home health nurses). Many families worried, not just that their child would have long-term

consequences of brain injury, but that the inability to overcome those could be due to their parenting shortcomings.

Theme 3: Advocacy

In the perinatal period, some mothers described evolving from a passive participant in her own medical care into an advocate for their baby. This feeling of advocacy was at times intensified by feelings of blame or guilt about the birth process. Many mothers grieved that they either could not or did not control what had happened at birth and that they “knew” or “should have known something was wrong.” Some families, now understanding the potential etiologies for neonatal asphyxia, regretted allowing certain interventions or blamed clinicians for what they perceived as delayed action. One parent described how letting go of this guilt allowed her to better parent her child, stating “if I blamed myself I could not take care of my daughter.”

As the infant’s hospital stay evolved, families learned to parent a sick infant and appreciated nurses and clinicians who involved them in daily care. Some parents became frustrated by their perception that daily medical routines could be undermining their infant’s progress; for instance the fact that occupational therapists were not available overnight when the infant was most ready to attempt oral feeding. A minority of families reported that they had “protected” their baby from unnecessary procedures. Several parents advocated for early discharge and felt as though their baby would do better at home than in the neonatal intensive care unit.

Once they returned home with their infant from the hospital, many parents reported doing “what they had to do.” Though the daily care burdens were often challenging, parents learned to cope. Parents described advocating for appropriate services, and some described current or desired roles as advocates for other families of infants in the neonatal intensive care unit (e.g. participation in hospital family advisory council). Some families reflected on early prognostic predictions through the lens of how their child had “proved them wrong.” When asked by the interviewer, several parents denied that their children had any delays, but in response to other questions disclosed needs for therapies, missed milestones, or relevant co-morbidities (e.g. autism, seizures). Many of the families that did describe delays in some form, continued to describe their children as “perfect” and “normal.” Those who described adapting to life as a parent of a child with, or at risk of, developmental delays, felt the need to be more vigilant and patient than other parents.

Discussion

While hypothermia and other neonatal interventions offer promise for infants with neonatal encephalopathy, family resiliency and engagement remain critical for long-term infant outcome. Early introduction of appropriate therapies and developmental follow-up are a cornerstone of the care of encephalopathy;¹⁶ these interventions can only be optimized if we build family capacity to meaningfully participate.¹⁷ For all neonatal intensive care unit graduates, sociodemographic variables, including family income, parent marital status, and maternal education status, inform medical and educational outcomes.^{18, 19} As we work to improve infant outcomes in neonatal encephalopathy, we must concurrently work to

understand and improve the lived experience of families caring for those infants. Parents in our cohort described complex ways in which their role as a parent evolved during their child's birth, hospital course, and early childhood. Each of these themes highlights an opportunity to better support families to maximize family and infant outcome.

First, our data suggest that families experience significant grief. In the neonatal intensive care unit, an additional layer of parent support in the form of a palliative care team, social work, and pastoral care should be considered for all families.²⁰ Automatic palliative care consults, or triggers, for all encephalopathic infants, or those with severe encephalopathy, could provide longitudinal support for families after discharge. While it is well known that families experience significant distress when caring for a critically ill infant,^{21–23} our data additionally suggest that for some families, feelings of loss and grief recur over time as children miss milestones or receive new diagnoses. Regularly assessing family well-being in clinic and outcome studies is an important next step in defining specific family needs. Clinicians should familiarize themselves with local and online resources for families. Providing ongoing family support of patients with neonatal encephalopathy beyond the hospital course may be an important way to foster parent resiliency and engagement.

For many families, a tension existed between parent and infant interests. In the acute period, this was most evident in the challenges that arose when balancing maternal health concerns or preferences with infant outcome. Many parents experienced guilt; these feelings should be acknowledged and discussed. Some families in our cohort could not be present in the hospital due to transportation, housing, or competing family obligations. Hospital resources that allow families to be more present in the neonatal intensive care unit should be prioritized. Many families are asked to make serious medical decisions in the acute period. Helping these families disentangle family and infant interests can facilitate informed and shared decision making. Real or perceived trade-offs between infant and family well-being were stressful for many families; previous data suggest that poor infant health informs family function and caregiver health.^{24, 25} Better defining and measuring the outcomes that families experience (e.g. financial strain, work lost) is necessary to ensure that families receive adequate supports. Further, better defining the range of outcomes that families experience is necessary to ensure families have the information they need to make informed decision for their infant.

Many parents in our cohort described their evolution into a role as advocate. For some, this involved health advocacy for their child, for others, this involved participating in formal advocacy roles (e.g. family advisory council). Those families who did describe advocacy roles generally felt these roles helped them cope with some of the challenges they faced in the neonatal period and after discharge. Parent-centered research efforts offer an additional way for families who have experienced neonatal encephalopathy to serve as key stakeholders in study design, data interpretation, and dissemination. Some parents described advocacy concurrently with blame or mistrust of clinicians. Due to the clinical circumstances that may be associated with neonatal encephalopathy, an infant's diagnosis, care, and outcome can have real or perceived medicolegal implications. Active strategies to build trust with the medical team might include the primary nursing model,²⁶ regular family meetings, and communication tools.²⁰

Our study is not without limitations. First, our recruitment strategy may have decreased participation with families with limited resources. Non-English speaking parents were excluded from the study; the experience of these families is not captured in these data. Paternal perspective was not fully captured in the data set and warrants dedicated study. Interviews may have resulted in recall bias. Understanding how baseline infant and family factors impact these themes, and how themes interact with each other, is an important area of future work. Finally, these data were collected at a US referral center and may not be generalizable to other health systems.

There is a growing interest in defining family-centered and parent-reported outcomes in fetal,²⁷ infant,²⁸ and childhood²⁹ conditions. The themes from this study suggest we should build on these efforts to define and measure family-centered outcomes in neonatal encephalopathy. Families experienced recurrent grief and feelings of loss; this suggests that negative family outcomes can be far-reaching and likely impact overall family well-being. Families had trouble disentangling infant and family outcomes; clarifying family outcomes can arm families to make informed decisions for their children in the neonatal intensive care unit and after discharge. Families value their role as an advocate for their child; as interest in patient-centered outcomes research grows, our data suggest that families would welcome opportunities to serve as stakeholders in these efforts.

Infant outcomes are tied to family outcomes. As we work towards family-centered outcomes in neonatal encephalopathy and other neonatal neurologic conditions, primary data from parents can help us begin the daunting task of defining, measuring, and improving outcomes that matter to families.

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Table 1

Maternal and infant characteristics

Maternal Characteristics	Median (range) or N (%)
Age (years)	32 (18–42)
Pregnancy planned	16 (80)
Primigravida	7 (35)
Knows other children with complex chronic conditions	12 (60)
Infant Characteristics	
Gestational age (weeks)	39 (35–41)
Birth weight (grams)	3190 (1990–4470)
Race (white)	14 (70)
Male	10 (50)
Inborn	3 (15)
Non-reassuring fetal heart tracing	14 (70)
Mode of delivery	
Vaginal	5 (25)
Assisted vaginal	2 (10)
Planned cesarean section	2 (10)
Emergency cesarean section	13 (55)
Apgar score	
5 minutes	3 (1–7)
10 minutes	5 (2–8)
Neonatal intensive care unit length of stay	12.5 (7–32) days
Developmental delay	
Motor	11 (55)
Cognitive	12 (65)
Language	11 (55)
Feeding difficulty	10 (50)
Current therapy needs	
Speech therapy	5 (25)
Occupational therapy	8 (40)
Physical therapy	13 (65)
Other *	5 (25)

* Other forms of therapy described included applied behavioral analysis therapy, equine therapy, and play therapy.

Table 2

Illustrative quotations from Theme 1: Repeated losses/longitudinal grief

Theme 1: Repeated losses/longitudinal grief	
<i>Birth</i>	<p>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. (16)</p> <p>You know, they wouldn't let me see him. They wouldn't even let me get close to him or see him at all. They wheeled him out of the room. They just let me see the top of his head, as they wheeled him out.(10)</p> <p>We had accounted for a lot of different scenarios, and challenges we might face. But never in our lives did it occur to us – let's plan for going to the hospital, having the baby, and then having him flown to another hospital.(20)</p>
<i>NICU*</i>	<p>I purposely didn't google stuff because I didn't want to feed into my already sickeningly scared thoughts.(14)</p> <p>The cooling process is three days of just laying there with nothing you can do. There are no signs of anything. She's just laying there, so it can kinda be a little crazy, just looking at your kid.(6)</p> <p>You have all these plans for bringing your baby home. As bad as it is, just enjoy your baby, even when they're in there, because it's so different and it's so hard and you can't touch them. And everything is beeping and you don't know if it's your baby's monitor or somebody else's baby's monitor that's beeping, and you don't know if it's beeping because something fell off, or it's beeping because something is really wrong. As stressful as it is, try and enjoy your baby as much as you can. Even if you're not doing this as planned.(20)</p>
<i>Home</i>	<p>We didn't know anyone who had anything like that [therapeutic hypothermia]. We felt very alone. No one that we could talk to and see their experiences, the whole thing. That was difficult.(2)</p> <p>[Baby's name] is going to special needs for the rest of her life. It may not be as dramatic as other children could be. But she is labeled as that. And because of that I have to take certain steps, meaning patience is much more advanced with her. Sometimes she'll cry for no reason. And it's not because she's colicky, it's not because she's teething. It's just because she's overly emotional and her brain is trying to process too many things. It doesn't have the networking that normal child's brain would have.(8)</p> <p>I never really thought about how the physician would probably be, sort of, "a check in", who is constantly saying, well here are the milestones, here's where we should be, we're concerned if we're not... So when you hit a milestones benchmark, that's the point at which you find out there's something that you should be looking at. Given the history, you really want to make sure there isn't anything you're missing.(19)</p>

* Neonatal intensive care unit

Table 3

Illustrative quotations from Theme 2: Entangled Infant and Family Interests

Theme 2: Entangled Infant and Family Interests	
<i>Birth</i>	<p>The OB, she was really the only person who was concerned about me. That felt really good because obviously when something like this happens, all of the focus goes onto the baby and being able to process and cope with what happened to me goes to the wayside. (16)</p> <p>I wasn't transferred with him... They said in order for my insurance to cover it there would need to be a medical reason... I ended up just staying at [birth hospital]... I didn't realize at the time....I knew it was bad, but I didn't realize how bad. We were lucky that it didn't go the other way, but when he [was transferred], I think it could have warranted me getting transferred.(10)</p> <p>I want people not to take any risks, like I took when my baby was breech... I took the risk of doing the [external] version and I regretted it for a while. Even now if I think about it, I feel I should not have done that. Maybe that is what caused it. (15)</p>
<i>NICU*</i>	<p>Should I really have fought for him to get out of the hospital? Maybe I made a mistake. You know, he probably needed to stay in there a little bit longer.(1)</p> <p>My boyfriend was very lost. He shut down completely and became a little unemotional because he didn't understand everything that was being thrown towards us. He couldn't process it. And it made our relationship a little more difficult, while we were in that time of need.(8)</p> <p>As a mother going through that major surgery, the difficulty in being there and hearing all of this [information] right after you have gone through major surgery; I felt like I didn't have enough time in those initial hours to process what was going on. I didn't get the full picture until the next day. It was a little scary.(9)</p> <p>It's impossible to sleep in the NICU unit, even though they are incredibly well appointed and inclusive. You're not going to be able to sleep with all the bells and whistles going off. And it was really helpful to go to the family room and sleep for a night.(19)</p>
<i>Home</i>	<p>I thought that if I was home with him and gave him attention and all the things that I thought that he...I thought that we could heal him (16)</p> <p>I have worked every day since I was 15. I no longer work, because of the seizures and his health concerns. I don't know anybody who is qualified to take care of him that is not a nurse. So my goal in working with him was to try to get him to be as normal as possible so that I can eventually put him in childcare, so I can go back to work, and we can get back to a normal home life. (1)</p> <p>He required so much, especially in the beginning. And our poor daughter, her whole summer was just...it really stank for a summer. Everything revolves around a new baby when they're born, but when your new baby basically almost died, it really revolves around the new baby. So, it was probably pretty rough for her. I feel bad that so much time was taken from her. (20)</p>

* Neonatal intensive care unit

Table 4

Illustrative quotations from Theme 3: Advocacy

Theme 3: Advocacy	
<i>Birth</i>	<p>They took the straps off my stomach, which I would never let someone do again.(14)</p> <p>I remember one nurse was trying to run down c-section risks as quick as possible, because I couldn't even sign anything. It had to be a verbal agreement at the time and I just remember yelling at her, "<i>I had a c-section already. I know what it is, just go.</i>"(8)</p> <p>I probably should have had a c-section way sooner than I did. But I also just, I wished for a natural birth as well, so I was kind of fighting myself on that one. (1)</p>
<i>NICU*</i>	<p>You're probably with your child a whole lot more than the attending or the resident for the baby. It does matter what you see, whether it's better or worse than what the doctors are telling you. You should be extremely vocal about what you are seeing, versus what they are seeing. You need to be the squeaky wheel.(12)</p> <p>They were thinking of putting a PICC line in. I advocated not for it, I didn't want it... They held off and in the end it worked out; they listened to me. Because I think if I didn't say nothing they would have put that PICC line in.(6)</p> <p>Make sure that you're your child's advocate. That's why [husband's name] and I almost never ever left the NICU, because I did feel like it's better to be present... Always make sure that you ask enough questions so that, as a parent, you know that everything being done is something that you understand and agree with.(3)</p>
<i>Home</i>	<p>He's a little one wordy. She [developmental pediatrician] implied that he might be developing some sort of autism spectrum something or other... I think he is developing at a fine rate and I'm worried for my own sake that continuing to see a pediatrician that focuses so much on development detracts from everything else... He's been—honest to goodness—other than the oxygen and the keppra—honest to goodness—I'm pretty sure he's been like any other child.(7)</p> <p>My husband and I are so eager to participate in any studies that will help other parents.(5)</p> <p>When I was pregnant I wanted a baby with curly hair, a girl baby with curly hair. She has that. Except for this issue about autism, my daughter is so beautiful and just perfect and just like I wanted.(15)</p> <p>She's made little, I mean to us, it's a lot of progress. To someone looking in, it probably doesn't look like anything at all. But every little thing counts to us.(18)</p>

* Neonatal intensive care unit