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Author manuscript

*Arch Dis Child Fetal Neonatal Ed.* Author manuscript; available in PMC 2020 November 01.

Published in final edited form as:

*Arch Dis Child Fetal Neonatal Ed.* 2020 November ; 105(6): 634–639. doi:10.1136/archdischild-2019-318612.

## Parent experience of caring for neonates with seizures

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**Contributors** ML contributed to study design and conception, supervised data collection and analysis and drafted the initial manuscript. HG and RAS conceptualised and designed the study, supervised data collection and participated in data analysis and interpretation. MCB and BB participated in data analysis and interpretation. Parent partners KG, LG and KP contributed to study design and conception, data analysis and data interpretation. CJW, TC, JS, CJC, CT, SLM, NSA and EER supervised data collection and contributed to data interpretation. LSF conceptualised and designed the study, supervised data analysis and interpretation and drafted the initial manuscript. All authors reviewed and critically revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The institutional review board for every site approved the study.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request. De-identified data will be made available on publication to researchers who provide a methodologically sound proposal for use in achieving the goals of the approved proposal. Proposals should be submitted to shellhaa@med.umich.edu and hannah.glass@ucsf.edu. De-identified data will be made publicly available in compliance with PCORI Policy for Data Management and Data Sharing on final completion of the Neonatal Seizure Registry study.

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## Abstract

**Objective**—Neonates with seizures have a high risk of mortality and neurological morbidity. We aimed to describe the experience of parents caring for neonates with seizures.

**Design**—This prospective, observational and multicentre (*Neonatal Seizure Registry*) study enrolled parents of neonates with acute symptomatic seizures. At the time of hospital discharge, parents answered six open-ended response questions that targeted their experience. Responses were analysed using a conventional content analysis approach.

**Results**—144 parents completed the open-ended questions (732 total comments). Four themes were identified. *Sources of strength*: families valued medical team consensus, opportunities to contribute to their child's care and bonding with their infant. *Uncertainty*: parents reported three primary types of uncertainty, all of which caused distress: (1) the daily uncertainty of the intensive care experience; (2) concerns about their child's uncertain future and (3) lack of consensus between members of the medical team. *Adapting family life*: parents described the many ways in which they anticipated their infant's condition would lead to adaptations in their family life, including adjusting their family's lifestyle, parenting approach and routine. Many parents described financial and work challenges due to caring for a child with medical needs. *Emotional and physical toll*: parents reported experiencing anxiety, fear, stress, helplessness and loss of sleep.

**Conclusions**—Parents of neonates with seizures face challenges as they adapt to and find meaning in their role as a parent of a child with medical needs. Future interventions should target facilitating parent involvement in clinical and developmental care, improving team consensus and reducing the burden associated with prognostic uncertainty.

## INTRODUCTION

This experience is a journey that causes depression, even with a lot of support and knowledge. It affects every aspect of our lives and changes our quality of life in ways we are not even aware of yet.

—Mother of infant with neonatal seizures due to ischaemic stroke.

Neonatal seizures have a major impact on the lives of children and their families. The mortality rate in neonatal seizures is as high as 25%, and many survivors experience

neurological morbidity, including developmental delay, cerebral palsy, intellectual disability and postneonatal epilepsy.<sup>12</sup> Parents of neonates with seizures experience challenges of their own: they must adapt to a new reality of caring for a child with medical needs and an uncertain future outcome.

It is well-established that parents of infants in the neonatal intensive care unit (NICU) experience high rates of anxiety, depression and symptoms of post-traumatic stress.<sup>3-9</sup> Parenting an infant in the NICU can change beliefs about parental roles, expectations about development and how parents interact with their child.<sup>10,11</sup> Similarly, parents of older children with epilepsy have high rates of depression and anxiety; up to one-third experience post-traumatic stress disorder.<sup>12-22</sup> Parents of children with medical complexity or chronic illness are similarly at high risk of psychosocial challenges. Compared with parents of healthy children, families caring for children with medical complexity are at increased risk of physical illness, mental illness, divorce, job loss and financial hardship.<sup>23</sup> Parents caring for children with chronic illness may experience burnout as a result of providing for unremitting care needs and uncertain outcomes. Others may feel underprepared or lacking in resources to care for their child.<sup>24</sup> Parents of children with medical complexity may face additional out-of-pocket, often unreimbursed costs for resources adapted to their child's medical needs.<sup>25</sup> Given that many parents caring for neonates with seizures will later care for children with epilepsy, chronic illness and/or medical complexity, the neonatal period represents an opportunity to identify families in need of short-term and long-term support.

Understanding the parent experience of caring for infants with neonatal seizures is critical to optimise both parent and infant outcome.<sup>26,27</sup> In this study, we aimed to describe the parent experience of caring for infants with seizures at discharge from the NICU in hopes of identifying targets for intervention.

## PATIENTS AND METHODS

### Setting and participants

We conducted a prospective, observational cohort study of neonates with acute symptomatic seizures and their parents treated at the nine sites of the US-based *Neonatal Seizure Registry* (NSR) between July 2016 and March 2018.<sup>228-31</sup> The NSR includes a Parent Advisory Panel, with one parent partner per site. Infant inclusion criteria were: (1) neonates <44 weeks postmenstrual age at seizure onset and (2) seizures due to an acute symptomatic aetiology. One parent was enrolled per infant. When two parents were available to participate, parent preference dictated which parent was enrolled. Participating parents provided written informed consent.

### Study procedures

Parents enrolled in the study completed an electronic surveys at hospital discharge, including demographic information and six open-ended questions. The questions were developed in partnership with the Parent Advisory Panel and asked participants to comment on a range of potential impacts of neonatal seizures and seizure treatments on parent and family well-being (box 1).

## Data analysis

Thematic inductive analysis was used to examine the data and report themes and subthemes emerging from the data set.<sup>32</sup> Open-ended responses were analysed using a conventional content analysis approach, in which codes and categories were developed from the data.<sup>33</sup> The codebook was developed and refined iteratively with input from parent stakeholders. NVivo V.12 software was used to organise and index codes. All responses were coded by two study team members (MCB, BB); 20% of responses were double-coded, with a Cohen's kappa >0.7 for all themes. After coding and review, the study team discussed key themes and subthemes characterising the content, language and context of parent experience and reached consensus on the themes and subthemes. Study team members included clinicians, non-clinician academics and parents. Parent Advisory Panel members participated in codebook development, data analysis and interpretation.

## RESULTS

Of 150 parents enrolled, 144 completed the discharge survey. Most participants (n=111, 77%) were mothers; 32 (22%) participants were fathers and 1 parent did not specify role. These parents provided 732 total comments (table 1). The most common infant seizure aetiologies included hypoxic-ischaemic encephalopathy (n=55, 38%), ischaemic stroke (n=41, 29%) and intracranial haemorrhage (n=31, 22%). Four primary themes were identified: sources of strength, uncertainty, adapting family life and emotional and physical toll. Representative quotations from each theme can be found in box 2.

### Theme 1: sources of strength

His medical team was always in agreement about his care. It felt good knowing they were all on the same page and not questioning other doctors. It helped me feel confident in their decisions.

—Mother of infant with seizures due to hypoxic-ischaemic encephalopathy

Parents described sources of strength that helped them navigate the NICU experience, including team and family consensus, the ability to contribute to their child's daily and ongoing care and the joy of developing a bond with their infant. This theme was endorsed by the majority (n=131/144, 91%) of respondents, and described by most mothers (n=101/111, 91%) and fathers (n=29/32, 91%).

**Consensus**—Most parents (n=86/144, 60%) reported high levels of consensus among their child's clinical team and family members when making decisions about their child's medical treatment. They outlined how three types of consensus—consensus among medical team members, consensus among family members and consensus between the family and the medical team—helped them feel confident their child was receiving the necessary care.

**Contributing to care**—Parents valued opportunities to contribute directly to their child's treatment and progress. Much of the NICU experience was marked by feelings of uncertainty and helplessness. In contrast, parents appreciated opportunities to participate in

any aspect of their child's care. Parents were grateful for activities that allowed them to parent their child in the NICU, including the opportunity to hold their child, perform routine care and participate in therapies. Parents looked forward to being the primary caregiver after discharge.

**Bonding with the infant and watching the child's progress**—Parents expressed hope and joy from the bond they developed with their child and from watching their child's medical progress. Despite the constraints of the NICU setting, parent participants found pleasure in everyday parent-infant interactions and activities, such as holding their child, changing their child's diapers and watching their child's personality develop.

## Theme 2: uncertainty

We are not privy to the discussion about treatment duration. This made us uncomfortable and unhappy with the doctors. It makes it harder to plan for the future.

—Mother of infant with seizures due to ischaemic stroke

Parents described the challenges associated with immediate and long-term uncertainty, including the daily uncertainties of the hospital course, long-term prognostic uncertainty and lack of certainty and consensus among the medical team. The majority of parents (n=103/144, 72%) endorsed this theme, including most (n=77/111, 69%) mothers and (n=26/32, 81%) fathers.

**NICU medical uncertainty**—Parents described challenges associated with immediate uncertainties—unknown duration of treatment with antiseizure medication, uncertainty about aetiology and lack of clarity about discharge timing. Parents experienced anxiety while waiting for medical test results such as neuroimaging. Others worried that the clinical team may not discover the cause of their infant's seizures and described the difficulty of 'wanting and waiting for answers'.

**Prognostic uncertainty**—Many parents (n=93/144, 65%) expressed concern about their child's uncertain future, especially as it pertained to the child's medical progress and developmental potential. This concern was reported by a higher proportion of fathers (n=26/32, 81%) than mothers (n=67/111, 60%). Parents were worried about the possibility of their child experiencing future seizures and the potential of the long-term side effects from antiseizure medication. Parents specifically described how uncertainty about their child's future cognitive, visual and motor abilities contributed to stress and anxiety.

**Lack of communication and consensus**—While many parents reported consensus as a source of strength, some (n=17/144, 12%) expressed uncertainty due to the lack of communication and consensus between medical team members and family members. Parents described concerns when members of the medical team disagreed with each other or when parents themselves were not in consensus with the medical team. Miscommunication and lack of communication with families regarding their child's medical care contributed to parents' fear of the unknown.

### Theme 3: adapting family life

We are usually hands-off, laid back parenting style folks, but because we don't know how her condition will play out during development we are likely to be more worried, aware, and concerned that she hits her milestones on time.

—Mother of infant with seizures due to ischaemic stroke

Parents anticipated the many ways in which they may need to adapt, rethink and reorganise their family life, including their daily responsibilities as a caregiver, approach to parenting, family lifestyle and work and financial plans. Over two-thirds of parents (n=97/144, 67%) endorsed this theme, including most mothers (n=75/111, 68%) and fathers (n=22/32, 69%).

**Adapting to caregiving for a child with medical needs**—Parents commented on the many ways in which they would need to participate in and facilitate their child's essential medical treatment: traveling to appointments, administering medicine, managing medical equipment and finding appropriate childcare. Parents emphasised the importance of staying informed of their child's illness and receiving necessary training to handle complex medical challenges.

**Adapting parenting approach**—Parents described how their child's illness could cause them to modify the way in which they parent. Parents discussed devoting more attention and time to their child's physical and developmental needs by becoming actively involved in daily caregiving and therapies, especially through the facilitation of oral feeding skills. They reported a heightened sense of vigilance, such as monitoring their child for future seizures and developmental delay. Some parents described feeling uncertain how to determine the difference between typical child behaviour and behaviours related to their medical condition.

**Adapting family lifestyle**—Parents discussed the ways in which their child's condition may necessitate adjustments to their family lifestyle. Parents emphasised extra planning and caution when engaging in recreational activities, participating in social events and being in public places. Parents voiced concern that their child's condition could result in their family being more isolated due to the inability to visit family or to travel.

**Work and finances**—Nearly one-quarter (n=35/144, 24%) of parents expressed worries that their child's medical and developmental needs could impact employment and finances related to the need for extended parental leave and absenteeism due to multiple appointments. Parents also worried about having the ability to pay for their child's extended medical care.

### Theme 4: emotional and physical toll

Having to stand back and watch doctors take care of her and help her while I couldn't even hold her was the most difficult part.

—Mother of infant with seizures due to hypoxic-ischaemic encephalopathy

Parents described how their child's seizures, hospital course and associated uncertainties impacted their well-being; parents described feelings of helplessness, anxiety, fear and

physical symptoms. Nearly half of parents (n=66/144, 46%) endorsed this theme, including 53 mothers (48%) and 13 (41%) fathers.

**Helplessness**—Some parents felt helpless stemming from their inability to alleviate their child's pain or to physically touch their child due to the interference of medical equipment. Parents expressed feeling 'out of control' in the hospital setting while bedside nurses and other clinicians assumed the parental role as caregiver.

**Anxiety, stress and fear**—Some parents described general feelings of anxiety and worry, while many attached these feelings to specific concerns about future seizures and seizure treatment. Parents described the impact of stress, anxiety and worry on other aspects of their life, including their marriages and daily routines. One parent described stress associated with reliving the 'trauma' of their child's birth.

**Physical toll**—Some parents also voiced concerns about how they would cope with the current and future physical challenges involved in caring for a child with seizures. Several parents observed that they already suffered from loss of sleep or that caregiving required a lot of extra physical energy. One parent described ongoing pain as she recovered from a difficult childbirth.

## DISCUSSION

Data from our contemporary, multicentre sample of parents whose newborns had acute symptomatic seizures demonstrate potentially modifiable challenges and sources of strength. Parents described the difficulties associated with short-term and long-term uncertainty and anticipated the ways in which they may need to adapt their family life and expectations to care for a child with medical needs. The emotional toll of the hospital experience, hallmarked by feelings of hopelessness, anxiety, and fear, was mitigated by sources of strength that helped parents cope with acute challenges.

Our findings are consistent with previous studies of the early parenting experiences in other medical conditions, including neonatal encephalopathy.<sup>2734</sup> Our findings complement existing literature describing experiences of fear and anxiety around the time of discharge among parents of preterm infants as they transition to caring for their infant at home.<sup>3</sup> Like parents in our cohort, parents in previous reports described the difficulties associated with the delayed ability to serve in a parental role, and the resultant joy as the infant-parent bond develops.<sup>33536</sup> The major themes were expressed at similar rates between mothers and fathers. A higher proportion of fathers identified uncertainty, particularly prognostic uncertainty, as a concern. Differences in the experiences and perceptions of mothers and fathers of NICU infants have been reported, but remain understudied.<sup>37</sup>

Clinicians and researchers can use these findings to develop interventions tailored to the needs of parents with newborn seizures and other neurological conditions. First, parents appreciated opportunities to bond with and contribute to their child's care, which tempered feelings of helplessness. Many of the interventions to promote parent integration into NICU care for preterm infants, such as parent skin-to-skin holding of the infant, providing infant



comfort during painful procedures or teaching parents to provide developmentally supportive care, may be effective interventions to promote parent-infant attachment and parenting self-efficacy for parents of newborns with seizures.<sup>38</sup>

Second, parents valued medical team consensus. While lack of consensus was reported in a minority of responses, parents were distressed when they disagreed with the medical team, or when members of the medical team disagreed with each other. These findings suggest that teams should work to build consensus with each other and with parents. Emphasising team consensus, when present, may reduce the anxiety associated with medical uncertainty. Interventions that improve the consistency of care team communication with parents may improve consensus and help parents develop trust in the medical team.<sup>1139–41</sup>

Third, many parents anticipated adaptations to their family life beyond those associated with seizures and seizure treatment. Parents anticipated needing to modify their approach to parenting and expressed concerns about changing their family's lifestyle to accommodate a child with medical needs. Other parents had concrete concerns about work and finances. These findings are consistent with existing literature surrounding the financial and emotional distress that can accompany parenting a child with medical complexity.<sup>25</sup> Interventions to improve parent well-being must look beyond newborn medical management and recognise the broad impact of newborn illness on diverse aspects of parent and family life.<sup>42</sup>

These findings should be considered in the context of this study's strengths and limitations. Although the sample was large, the participants were predominantly mothers and further characterisation of fathers' perspectives is needed. Programmes to support families may have varied by site, or over course of the study period. This study focused on the parent experience at hospital discharge, and future work should explore how these perspectives evolve over time.

Similar to parents in our study, parents of older children with epilepsy describe the challenges associated with uncertainty and the impact of epilepsy on everyday activities and social relationships.<sup>43,44</sup> Our findings suggest that, for parents impacted by seizures in the neonatal period, these challenges begin immediately. Interventions to support parents of children with neurodevelopmental risk should begin in the neonatal period and target 1) involving parents in clinical and developmental care 2) promoting team consensus, 3) facilitating consistent communication and 4) addressing parent psychosocial needs, including emotional and financial distress. Offering support services for parents early in the child's course offers an opportunity to promote parent resilience and improve parent outcomes in the short-term and long-term.

## CONCLUSION

The results of this contemporary, multicentre study identified specific opportunities for interventions to address the needs of parents caring for newborns with acute asymptomatic seizures. Future research should characterise how early interventions for parents might alter the ongoing impact of these challenges and sources of strength on infant development, parent mental health, quality of life and resilience.



## Acknowledgements

The authors would like to thank the Neonatal Seizure Registry parent partners, including Dana Annis, Tristan Barako, Marty Barnes, Claire Brown, Karla Contreras, Jennifer Guerriero, Libby Hill, Terri Long and Gwen Ma.

**Funding** Funded by PCORI grant number CER-1507-31187. MEL is supported by the National Institute of Neurological Disorders and Stroke of the National Institutes of Health under award number K12NS098482 and the Derfner Foundation. CJC is supported by NIH K23 NS092923. CJW is supported by K02NS102598.

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**What is already known on this topic?**

Neonates with seizures have a high risk of mortality and neurological morbidity.

Little is known about the parent experience of caring for neonates with seizures at discharge from the hospital.

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**What this study adds?**

Parents of neonates with seizures identified challenges and sources of strength that future interventions may leverage to promote parent resilience, support infant development and address the needs of families impacted by neonatal seizures.

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**Box 1****Discharge survey open-ended questions**

1. What level of agreement or doubt was there among the medical care team about the duration of antiseizure medication treatment? How did that make you feel? How did it impact your family?
2. Will your child's treatment affect your usual family routines? If so, how?
3. In what other ways might your child's treatment impact you and your family?
4. The most positive part of caring for my child is:
5. The most difficult part of caring for my child is:
6. Do you have any worries/concerns/fears about your child's seizure condition or treatment? Please describe.

**Box 2****Representative quotes****Sources of strength**

“His medical team was always in agreement about his care. It felt good knowing they were all on the same page and not questioning other doctors. It helped me feel confident in their decisions.”

—Mother of infant with seizures due to hypoxic-ischaemic encephalopathy

“We feel in control, feel that we are doing something that can directly help him.”

—Father of infant with seizures due to hypoxic-ischaemic encephalopathy

“We didn’t get much bonding time right after birth so we learnt to love any time we get with him and any moment that we get to see his little personality.”

—Mother of infant with seizures due to perinatal arterial ischaemic stroke

**Uncertainty**

“I had a lot of anxiety because I didn’t know if he was being treated as thoroughly as he should be and because I was scared. I wanted to make sure nothing was done too quickly.”

—Mother of infant with seizures due to cerebral parenchymal haemorrhage

“The unknown. Not knowing when or if he will have more seizures. Not knowing if he will have delays.”

—Mother of infant with seizures due to ischaemic stroke

“We are not privy to the discussion about treatment duration. This made us uncomfortable and unhappy with the doctors. It makes it harder to plan for the future.”

—Mother of infant with seizures due to ischaemic stroke

**Adapting family life**

“We will need to plan life around his meds dosing, weaning, and observing for seizures.”

—Father of infant with seizures due to hypoxic-ischaemic encephalopathy



“We are usually hands-off, laid back parenting style folks, but because we don’t know how her condition will play out during development we are likely to be more worried, aware, and concerned that she hits her milestones on time.”

—Mother of infant with seizures due to ischaemic stroke

“We are an athletic family. Not sure if our baby will grow up to do the activities we love.”

—Mother of infant with seizures due to subarachnoid haemorrhage

“I am a single career mom. [My son’s] intensive therapy schedule will take a toll on all my routines, career potential and \$ vs a normal baby, not to mention emotional state.”

—Mother of preterm infant with seizures due to hypoxic-ischaemic encephalopathy

### **Emotional and physical toll**

“Having to stand back and watch doctors take care of her and help her while I couldn’t even hold her was the most difficult part.”

—Mother of infant with seizures due to hypoxic-ischaemic encephalopathy

“It’s just very scary.”

—Mother of preterm infant with seizures due to cerebral parenchymal haemorrhage

“The other difficult parts are common to all new parents (sleep, new routine, c-section scar, recovery time, etc) and not unique to her condition of stroke and seizures.”

—Mother of infant with seizures due to ischaemic stroke

**Table 1**

## Infant and parent characteristics

	n (%) or mean (SD)
<b>Infant characteristics (n=144)</b>	
Sex, female	59 (41)
Term ( $\geq$ 37 weeks)	119 (83)
Length of stay, days	26 (27)
Primary diagnosis	
Hypoxic-ischaemic encephalopathy	55 (38)
Ischaemic stroke	41 (29)
Intracranial haemorrhage	31 (22)
CNS infection	8 (6)
Other	9 (6)
Medical comorbidities	
Congenital heart disease	16 (11)
ECMO	7 (5)
Discharged home with gastrostomy tube	15 (10)
<b>Parent characteristics (n=144)</b>	
Gender, female *	111 (77)
Race	
White	85 (59)
Black/African-American	13 (9)
Asian	11 (8)
American Indian/Alaskan Native	2 (1)
Native Hawaiian/other Pacific Islander	2 (1)
Mixed race	5 (4)
Other	19 (13)
Unknown/Not reported/Declined to answer	7 (5)
Ethnicity	
Hispanic or Latino	27 (19)
Not Hispanic or Latino	112 (78)
Unknown/Not reported/Declined to answer	5 (3)

\* One parent did not report the gender.

CNS, central nervous system; ECMO, extracorporeal membrane oxygenation.