



## Research Paper

## Life After Neonatal Seizures: Characterizing the Longitudinal Parent Experience



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## ABSTRACT

**Background:** Parents of neonates with seizures report persistent symptoms of depression, anxiety, and posttraumatic stress. We aimed to characterize the parent experience of caring for children impacted by neonatal seizures, including longitudinal assessment across childhood.

**Methods:** This prospective, observational, multicenter study was conducted at Neonatal Seizure Registry (NSR) sites in partnership with the NSR Parent Advisory Panel. Parents completed surveys at discharge; 12, 18, and 24 months; and 3, 4, 5, 7, and 8 years. Surveys included demographic information and open-ended questions targeting parent experience. A conventional content analysis approach was used.

**Results:** A total of 320 caregivers completed at least one open-ended question, with the majority of respondents at discharge ( $n = 142$ ), 12 months ( $n = 169$ ), 18 months ( $n = 208$ ), and 24 months ( $n = 245$ ). We identified the following three primary themes. (1) Personal Burden of Care: Parents experienced emotional distress, financial strain, physical demands, and fears for their child's unknown outcome; (2) Managing Day-to-Day Life: Parents described difficulties navigating their parenting role, including

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managing their child's challenging behaviors and understanding their child's needs amid neurodevelopmental impairment; (3) My Joys as a Parent: Parents valued bonding with their child, being a caregiver, and watching their child's personality grow.

**Conclusions:** Parents of children impacted by neonatal seizures face persistent challenges, which are interwoven with the joys of being a parent. Our findings suggest that future interventions should promote resiliency, address caregivers' psychosocial needs longitudinally, and provide enhanced support for parents caring for children with medical complexity.

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## Introduction

"It can be isolating because no one understands what we're going through."

— Mother of 24-month-old child with history of neonatal seizures after ischemic stroke

Seizures occur more commonly within the neonatal period than any other time in a person's lifespan.<sup>1,2</sup> Neonatal seizures are a common manifestation of acute, underlying neurological injury, including hypoxic-ischemic encephalopathy (HIE), intracranial hemorrhage, and ischemic stroke.<sup>3,4</sup> In this vulnerable period, seizures are associated with an increased risk of mortality and adverse neurodevelopmental outcomes including cerebral palsy, epilepsy, and developmental delay; however, many children also experience seizure freedom and typical neurodevelopment.<sup>5–7</sup> Given heterogeneity in seizure etiology and other clinical variables among studies of children with neonatal seizures, anywhere from approximately 10% to 70% may experience typical neurodevelopmental outcomes.<sup>5</sup> Factors associated with low risk of adverse outcomes include term birth, absence of status epilepticus, and immediate response to antiseizure medications.<sup>5</sup>

The Neonatal Seizure Registry (NSR) demonstrated that during the neonatal period, parents of infants with neonatal seizures struggle to navigate the uncertainty of their child's future and face difficulties adapting family life to their child's complex medical condition.<sup>8</sup> In a subsequent NSR study, parents were shown to face persistent mental health challenges over time, with over one third reporting symptoms of anxiety and nearly one quarter reporting symptoms of posttraumatic stress when their child reached age two years.<sup>9</sup> Additionally, in older children with epilepsy and other chronic complex medical conditions, parents may experience increased parenting stress, anxiety, depressive symptoms, and impaired family functioning compared with families of healthy children.<sup>10–13</sup>

After their child's hospitalization in the intensive care unit, parents of critically ill children often experience symptoms of posttraumatic stress, regardless of their child's illness severity.<sup>14,15</sup> Furthermore, survivors of neonatal seizures may continue to face complex medical conditions throughout their life, which can have adverse impacts on parental mental health and family well-being.<sup>9–13</sup> However, little is known about how these challenges manifest longitudinally in other domains, such as the long-term impact physically, financially, psychosocially, and on day-to-day care. Understanding how the parent's lived experience evolves over time, particularly as children grow and develop, may allow health care providers to better empathize with parents and their children, promote adaptation and resilience, and identify areas for improved emotional, psychosocial, economic, and parenting support, thus improving family health outcomes.<sup>16–18</sup> The goal of the present study is to (1) describe the experience of parents caring for

children impacted by neonatal seizures and (2) characterize this experience longitudinally across early childhood.

## Methods

### Study design and participants

This prospective, observational, multicenter study enrolled parents of neonates with acute provoked seizures between July 2016 and March 2018. Participants were enrolled in two cohorts. Nearly half of the participants (150 of 303) were enrolled before discharge from the neonatal intensive care unit (NICU), whereas the rest of the participants were recruited before age 24 months from outpatient clinics at participating centers. Inclusion criteria were (1) seizures secondary to an acute provoked cause and (2) seizure onset occurred before 44 weeks postmenstrual age. Eligible participants were identified and screened by a study investigator or clinical research coordinator. The study investigator or clinical research coordinator described the anticipated risks and benefits of study participation. Parents' reasons for study decline included time commitment, not wanting to participate in research, and that they had already been through so much and did not want to remember past experiences.<sup>19</sup> This methodology has been well described in prior NSR studies.<sup>7–9,19–25</sup> The institutional review board approved the study at each participating NSR site. Parents provided written informed consent before enrollment.

A critical component of the NSR is the Parent Advisory Panel, composed of parent and advocacy group members. The Parent Advisory Panel is a key partner in the research life cycle for all studies within the NSR portfolio. Individual parents also join analytic teams and partner in manuscript writing and other dissemination efforts.

### Study procedures

Surveys were conducted electronically or by telephone interview in parents' preferred language of English or Spanish. Parents or legal guardians completed surveys at the time of their child's discharge from the NICU; when their child reached 12, 18, 24 months corrected age; and at ages 3, 4, 5, 7, and 8 years. Surveys included demographic information and several open-ended questions targeting parent experience. Open-ended questions analyzed are described in Table 1. The NSR Parent Advisory Panel aided in the development of these survey questions.

### Analyses

The study team included neonatal neurologists, epileptologists, neonatologists, nurse-scientists, parents of children with neonatal seizures, and health professions trainees. The current analyses include parent experience and demographic data from NICU discharge to when children reached age eight years. Our group

(NSR) has previously described the experiences of parents at the time of NICU discharge.<sup>8</sup> We include a portion of those data here to describe and contextualize the experience of parents longitudinally. Code frequencies are presented using descriptive statistics. Parent responses were coded and analyzed using a conventional content analysis approach.<sup>26</sup> A novel codebook was developed to organize responses into themes and subthemes within the parent experience. Two study team members independently coded all responses with discrepancies discussed and adjudicated in consensus with a senior team member. NVivo V.12 qualitative analytic software was used to index and organize data. Codes and patterns were collapsed into themes through iterative analysis and discussion. The study team met frequently to review the content and frequency of response data, discuss discrepancies in code application, and refine key themes and subthemes. The Parent Advisory Panel provided regular feedback and insights on the development of the codebook and interpretation of results. All results are reported in accordance with the Standards for Reporting Qualitative Research.<sup>27</sup>

### Results

We enrolled 336 caregivers of 303 children who were impacted by neonatal seizures. Of these, 320 caregivers ( $n = 257$  mothers;  $n = 58$  fathers;  $n = 5$  legal guardians) answered at least one open-ended survey question regarding their experience of caring for their child. For 33 children, two caregivers completed at least one survey across time points. The most common etiology of neonatal seizures was HIE ( $n = 123$ , 43%), followed by ischemic stroke ( $n = 76$ , 27%) and intracranial hemorrhage ( $n = 52$ , 18%). The majority of respondents identified as mothers, with a median age of 32 (range: 15 to 48 years) (Table 2).

Participant responses were characterized into three themes: (1) Personal Burden of Care, (2) Managing Day-to-Day Life, and (3) My Joys as a Parent. The themes were consistent across ages, but the specific ways in which they manifested were contextualized within the physical and developmental stages of childhood. Thematic code frequency analyzed from the overall sample and response data collected between discharge and the 24-month time points are found in Table 3. Representative quotations from each theme are presented in Tables 4–6. A minority of parents submitted responses between the three- and eight-year time points; these responses are presented separately (Supplemental Table 1).

#### Theme 1: Personal Burden of Care

“She hasn’t had any seizures since she was 6 months old but I live in fear of them returning.”

— Mother of 24-month-old child with history of neonatal seizures after HIE

Many caregivers described persistent challenges in caring for their child, including the emotional, physical, and financial burdens involved in fulfilling the caregiving role. Soon after hospital discharge, many caregivers emphasized the emotional impacts, often describing feelings of sorrow and helplessness for their child’s condition and fears for potential future seizures. From 12 to 24 months and beyond, some caregivers emphasized persistent fears for seizure recurrence, concern amid their child’s current developmental limitations, and worries related to their child’s future development and independence.

**TABLE 1.**  
Questions Analyzed Targeting the Longitudinal Parent Experience

Time Point	Question
Discharge-24 months	“The most positive part in caring for my child is:” “The most difficult part in caring for my child is:” “Do you have any worries/concerns/fears about your child’s seizure condition or treatment? Please describe.”
3 years-8 years	“The most positive part in caring for my child is:” “The most difficult part in caring for my child is:” “Do you have any worries/concerns/fears about your child’s seizure condition or treatment, or risk for seizures?” “Please tell us about your child and what about them makes you proud as a parent.”

#### Emotional burden

In more than half of the cases ( $n = 158$ , 55.1%), caregivers expressed negative emotional impacts, including struggling with feelings of inadequacy as a parent, experiences of helplessness and

**TABLE 2.**  
Sample Characteristics

Variable	n (%) or Median (Range)
Child characteristics ( $n = 287$ )	
Male sex	163 (56.8)
Race	
White	187 (65.2)
Black/African American	30 (10.5)
Asian	19 (6.6)
American Indian/Alaska Native	2 (0.7)
Native Hawaiian/other Pacific Islander	2 (0.7)
Other	21 (7.3)
More than one race	10 (3.5)
Unknown/not reported	13 (4.5)
Declined to answer	3 (1.0)
Ethnicity	
Hispanic or Latino	44 (15.3)
Not Hispanic or Latino	233 (81.2)
Unknown/not reported	9 (3.1)
Declined to answer	1 (0.3)
Seizure etiology	
HIE	123 (42.9)
Ischemic stroke	76 (26.5)
Intracranial hemorrhage	51 (17.8)
Other	37 (12.9)
Neonatal medical comorbidities	
Congenital heart disease	27 (9.4)
Congenital diaphragmatic hernia	1 (0.3)
ECMO	12 (4.2)
Dialysis	0 (0)
Hospital length of stay, neonatal (days)	15 (4-210)
Therapy needs at 24 months	
Early intervention	114 (39.7)
Occupational therapy	88 (30.7)
Physical therapy	87 (30.3)
Speech therapy	89 (31.0)
Vision therapy	25 (8.7)
Feeding therapy	28 (9.8)
Other	30 (10.5)
None	100 (34.8)
Parent characteristics ( $n = 320$ )*	
Age at birth (years)	
Mother	32 (15-48)
Father	34 (20-54)
Parent role	
Mother	257 (80.3)
Father	58 (18.1)
Legal guardian	5 (1.6)

Abbreviations: ECMO = Extracorporeal membrane oxygenation; HIE = Hypoxic-ischemic encephalopathy

\* For 33 children, two caregivers completed at least one survey.

**TABLE 3.**  
Code Frequency at Hospital Discharge and 12-, 18-, and 24-Month Survey Time Points

Theme	Cases per Time Point n (%)*				
	Overall, n = 287	Discharge, n = 142	12 Months, n = 169	18 Months, n = 208	24 Months, n = 245
Personal burden of care	262 (91.3)	117 (82.4)	118 (69.8)	138 (66.3)	150 (61.2)
Emotional burden	158 (55.1)	48 (33.8)	40 (23.7)	66 (31.7)	58 (23.7)
Fear of the unknown	213 (74.2)	99 (69.7)	78 (46.2)	94 (45.2)	99 (40.4)
Financial strain	17 (5.9)	5 (3.5)	6 (3.6)	4 (1.9)	4 (1.6)
Physical demands	55 (19.2)	3 (2.1)	24 (14.2)	27 (13.0)	26 (10.6)
Managing day-to-day life	184 (64.1)	27 (19.0)	49 (29.0)	76 (36.6)	109 (44.5)
Balancing my many roles	98 (34.1)	9 (6.3)	27 (16.0)	41 (19.7)	50 (20.4)
Learning to understand my child's needs	69 (24.0)	19 (13.4)	12 (7.1)	20 (9.6)	24 (9.8)
Managing my child's challenging behavior	75 (26.1)	0 (0.0)	11 (6.5)	25 (12.0)	43 (17.6)
My joys as a parent	283 (98.6)	121 (85.2)	152 (89.9)	199 (95.6)	236 (96.3)
Celebrating my child's growth	221 (77.0)	37 (26.1)	96 (56.8)	119 (57.2)	137 (55.9)
The bond between my child and family	216 (75.3)	64 (45.1)	79 (46.7)	104 (50.0)	117 (47.8)
Getting to know my child's personality	85 (29.6)	3 (2.1)	20 (11.8)	17 (8.2)	31 (12.7)
Being able to care for my child	112 (39.0)	38 (26.7)	24 (14.2)	36 (17.3)	35 (14.3)
Holding space for hope	23 (8.0)	8 (5.6)	6 (3.6)	3 (1.4)	5 (2.0)

\* A case represents an individual family unit. Code frequencies are reported at the case level, such that only one response per family unit was included at each timepoint.

isolation, and mental health challenges. Parents expressed feelings of sorrow from witnessing their child's illness and hospitalization—and continued trauma from their child's hospitalization years later—as one mother shared, “she is sick often and it still triggers flashbacks to when she was a newborn.” Some parents described challenges with stigma, including “dealing with staring and questions from strangers” and concerns about family members “passing judgement.” Some parents additionally emphasized challenges associated with the responsibility of supporting their child's neurodevelopment, as one parent described, “feeling like I never do enough to stimulate his brain and do the therapies to help him develop as far as he can.”

**Physical demands**

Some caregivers shared challenges with the physical demands of caring for their child. Although descriptions of physical demands were uncommon at the discharge time point (n = 3, 2.1%), some parents here and at 12 months emphasized physical exhaustion due to lack of energy and sleep, leading to difficulty caring for their child and balancing their own well-being. As children aged, some caregivers additionally cited the physical toll of caring for a heavier, stronger, and less physically mobile child as they grew and the associated uncertainty about how they would care for their child into the future.

**Fear of future seizures and the unknown**

In over two thirds of cases at discharge (n = 99, 69.7%), caregivers highlighted worries for their child's potential for future seizures, long-term neurodevelopmental impacts, and “wondering if [their child] will have a normal life.” Although the majority of parents shared concerns about fear of the unknown and worries for seizure recurrence at discharge, less than half reported these fears after 12 months. From 12 months to 24 months, and through later years, some parents highlighted persistent worries for future seizures and potential life impacts (e.g, developmental delays, bullying in school, self-sufficiency). Additionally, although some parents across time points shared they did not have concerns for seizure recurrence due to their child's current stability, several parents highlighted continued fears for future seizures despite their child's years of seizure freedom. For some, these worries were compounded by uncertainty in what to do in the event of a seizure, as one parent shared, “I'm always worried his seizures will return and I won't know what to do.” Furthermore, some parents of typically developing children described that their worries made it difficult to

enjoy some of the joyful moments in life, as shared by one mom, “... right now he seems like any normal child - I worry about enjoying that too much and realizing someday something is wrong.”

**Financial strain**

Caregivers also shared the financial toll of caring for their child, including challenges with affording medical bills, medications, transportation to appointments, and childcare. Some parents further expressed difficulties with balancing the time spent caring for their child with the time needed at their occupation to afford these many expenses, including one father who shared worries about “not being there for him due to the need of money.”

**Theme 2: Managing Day-to-Day Life**

“The amount of care my child needs prevents me from living my own life.”

— Father of 18-month-old child with history of neonatal seizures after HIE

Parents in the majority of cases (n = 184, 64.1%) encountered difficulties with adjusting daily life and navigating their parenting role in caring for their child. Those parents who shared responses related to this theme at discharge described difficulty navigating how to care for their child's complex medical needs and balancing the time commitment in caring for their child with other responsibilities. Parents at later time points, including age 12 and 24 months, additionally highlighted difficulties with learning how to communicate with their child and manage their child's challenging behaviors.

**Balancing my many roles**

In over one third of cases (n = 98, 34.1%), caregivers addressed challenges related to balancing various life roles while caring for their child. Responses related to this theme were more common at later time points (12 and 24 months) than at discharge (n = 9, 6.3%). Parents shared how caring for their child had caused difficulties fulfilling responsibilities with work, caring for other children, and spending time with their partner. Some parents expressed this was particularly challenging while balancing the care of their child's complex medical needs, including providing “24/7 care for [my child] at a time where she would be more independent at this age were she not injured,” “the constant appointments,” and “fitting in all of [my

**TABLE 4.**  
Illustrative Quotations for Theme 1: Personal Burden of Care

Subtheme	Illustrative Quotations
Emotional burden	<p>“Sadness for her disabilities”</p> <p>“[The most difficult part of caring for my child is:] Trying to explain medical concerns to family members and friends without them passing judgement to me or my child, sometimes I feel like I hold back information because I don’t want to hear your child is ‘fine’. You child is ‘just like the other kids’- because this is not a true statement. People think it is comforting but it is not. I feel as though they are undermining my child’s condition and what my child and my family has been through.”</p> <p>“The mom guilt immediately following when I lose my temper by shouting when I grow impatient. The guilt of feeling like he deserves a better mother than me (which is mostly motivating to become better), as well as the guilt of being depressed and detached due to postpartum depression following his birth.”</p>
Physical demands	<p>“How physically demanding it is. She’s on the go constantly and it’s exhausting.”</p> <p>“His lack of mobility is making it harder to care for him because he is getting bigger and heavier. His size will become an issue if he cannot start to get mobile on his own.”</p> <p>“I don’t have enough energy to keep up.”</p>
Financial strain	<p>“Monetary issues. I will need to spend more money on gas or transportation to appointments which I don’t have.”</p> <p>“...I’m scared about making everything work financially, and in a way that is best for him.”</p>
Fear of future seizures and the unknown	<p>“Worries that he will have seizures again in the future. Worries over things that could possibly trigger them, despite not having them for 3 years”</p> <p>“He hasn’t had seizure since he was discharged from the hospital the first time. I was told by the Neurologist that he might never have seizures or it might be years and years before he does. I fear that I wouldn’t know what to do for him if/when he has seizures, regardless of what stage in his life it happens.”</p> <p>“The fear of what he may and may not do. The fear he is going to be severely learning disabled. I always compare him to others when he isn’t doing something that other children his age are doing. I wonder if it is due to his history or just who he is.”</p>

child’s] therapies and exercises daily.” Additionally, some parents emphasized having little time for self-care and noticed a toll on their own health and well-being, including one parent who noticed it was particularly difficult “caring for myself while feeling like I am giving her enough attention.”

*Learning to understand my child’s needs*

Some caregivers additionally expressed challenges with understanding their child’s needs. At discharge, this typically manifested as challenges with managing their child’s unfamiliar medical condition and learning how to provide care after their child returned home from the NICU. At 12 through 24 months, caregivers shared challenges both with “not having the knowledge to properly care for my child” and “not knowing what [my child] wants due to the lack of communication.” For the limited parents who responded at time points three to eight years, the majority expressed experiencing difficulty understanding when and how to care for their child due to challenges with communication.

*Managing my child’s challenging behavior*

Some parents also shared difficulties with addressing their child’s challenging behaviors, including tantrums, self-harm behaviors, and emotional outbursts. Although no caregivers shared responses related to this subtheme at discharge, this idea was emphasized by nearly one fifth of parents at 24 months ( $n = 43, 17.6\%$ ); this includes one mother who shared, “the most difficult part

**TABLE 5.**  
Illustrative Quotations From Theme 2: Managing Day-to-Day Life

Subtheme	Illustrative Quotations
Balancing my many roles	<p>“I think finding the time to be a parent, caring for my child, but also meeting other responsibilities is a challenge.”</p> <p>“I have another child and I have guilt for not being able to spend enough time with both my children. Especially when my older son complains that I spend more time with his brother.”</p> <p>“I fail to take care of myself like I used to.”</p>
Learning to understand my child’s needs	<p>“Seeing him hurt (cry)/frustrated and not knowing exactly what he wants due to the lack of verbal communication.”</p> <p>“Not having the knowledge to properly care for my child.”</p> <p>“Having patience with him because he has many therapies, and we have to follow all instructions which is hard.”</p>
Managing my child’s challenging behavior	<p>“She has some strange habits like yelling constantly and she hits herself”</p> <p>“That he’s hitting independence milestones now, and sometimes it’s hard to get him to listen to peaceful coaching. Such as learning not to hit.”</p> <p>“His behavior now. He’s definitely a difficult child. Bangs head, bites hand, thrashes body when upset.”</p>

of caring for my child is his extreme and frequent temper tantrums and wondering if it is somehow related to his brain injury.”

*Theme 3: My Joys as a Parent*

“My son has changed my life completely. I am 2.5 years sober today because of him. He made me want to be the best mother I can be so he can live up to his highest potential and have as great of chance as any to be wonderful. My son lights up my entire life with how much love and happiness he radiates.”

— Mother of 24-month-old child with history of neonatal seizures after intracranial hemorrhage

Participants in nearly all cases ( $n = 283, 98.6\%$ ) highlighted the great joys of being a parent. Many caregivers soon after discharge expressed this joy manifested as feelings of love and admiration for their child and a sense of purpose in being a caregiver. At later time points, including 12 to 24 months, parents not only continued to share the joy they felt in bonding with their child but also expressed a growing delight in their child’s independence, accomplishments, and personality development.

*Celebrating my child’s growth*

In the majority of cases ( $n = 221, 77.0\%$ ) caregivers expressed a sense of pride in their child’s progress. Soon after discharge, over one quarter of caregivers ( $n = 37, 26.1\%$ ) shared responses related to



this subtheme, emphasizing the joy in seeing their child's medical improvement after hospitalization. From 12 to 24 months, the majority of respondents shared responses within this subtheme. At these time points and in later years, this included celebrating in their child's developmental milestones and overall growth. Additionally, some caregivers highlighted a distinct joy in observing their child's ability to overcome obstacles and surpass the expectations of others, particularly those on the medical team.

*Holding space for hope*

Despite an uncertain future, a minority of parents (n = 23, 8.0%) expressed feelings of optimism and hope when discussing their child's potential outcomes. Some parents described having hope for positive outcomes through trusting in faith and prayer. Other parents highlighted feeling hopeful for the future given their child's own persistence and determination, including one mother who shared, "I have learned to never give up hope. He fights and so will we—right along side him."

*The bond between my child and family*

Caregivers in the majority of cases (n = 216, 75.3%) discussed a deep bond shared between their child and their family. This deep bond remained a prominent subtheme over time, with many caregivers soon after discharge sharing experiences of returning home together after their child's hospitalization and the quality time spent together thereafter. This includes one mother who found joy in "everything from crying to changing diapers. We didn't get much bonding time right after birth so we learned to love anytime we get with him." At later time points, including 12 to 24 months, many parents shared joyful experiences of playing together, watching their child smile, and showing and receiving love from their child.

*Being able to care for my child*

Some parents additionally expressed joy in being a caregiver to their child. Soon after discharge, parents expressed gratitude for their child's survival and appreciated being able to care for their child after fears that their child would not survive. From 12 months and beyond, this theme often manifested as parents' appreciation for their role and accomplishments as a caregiver, including one

mother who valued "knowing her [child] well and therefore being able to meet her needs."

*Getting to know my child's personality*

Parents valued watching their child's unique personality grow, emphasizing their pride and excitement in watching their child engage in independent passions and interests and develop their own unique character traits. Of the limited parents who provided data between time points five and eight years, all provided responses related to this subtheme. When discussing the most positive part in caring for her child, one mother shared, "How rewarding it is, knowing that my child is the most amazing creature I've ever known, and I'm lucky enough to be his parent. He's a warrior, he's stubborn, he has a huge personality and I feel grateful that we have this much of him to know, and guilty that I doubted for so long how we would manage with a child with special needs."

**Discussion**

This study contributes to understanding the lived experiences of parents caring for children impacted by acute provoked neonatal seizures across childhood, as children grow and develop in the years after discharge from the NICU. Parents soon after discharge emphasized fears for their child's potential medical and developmental outcomes, sadness for their child's hospitalization, and uncertainty with managing their child's complex needs. From 12 months and beyond, parents described persistent worries regarding their child's future and additional challenges learning to communicate with their child and manage their child's challenging behaviors. Unsurprisingly, for nearly all caregivers, these challenges existed alongside the joys of being a parent. For parents soon after discharge, this was often described as bonding with their child, celebrating in their child's medical improvements, and gratitude in being a caregiver. During toddlerhood and later years, parents also emphasized the joy found through getting to know their child's unique personality and celebrating their child's achievements. These data highlight opportunities for intervention to support parents of children impacted by neonatal seizures longitudinally.

Although some caregivers shared that fears for their child's seizure recurrence improved with time, many parents described

**TABLE 6.**  
Illustrative Quotations From Theme 3: My Joys as a Parent

Subtheme	Illustrative Quotations
Celebrating my child's growth	"Seeing her learn new things and overcome the challenges of her stroke. We celebrate the smallest milestones because we know how much work has gone into it." "I celebrate her extraordinary recovery every time she stands up, every time she crawls. And every time she eats. They almost gave her an ng tube, and told us based on the MRI she may never bear her own weight. But God heals where man cannot, and she has slowly done everything they said she wouldn't be able to." "Being able to embrace and appreciate every milestone, no matter how small it may seem..."
The bond between my child and family	"She loves me so much. I'm her world and she is mine" "I love watching him light up and cheer up when he sees me when I pick him up from daycare after work. I love his cheerfulness especially when we play together. Knowing that I make a huge difference in his life and that I make a big impression on him is very rewarding."
Holding space for hope	"Having hope of him getting better. Right now, things are always changing, and we don't know when we will be able to take him home." "Just hoping it is a one time thing that happened during our stay and that they don't continue. Praying he will be okay."
Being able to care for my child	"That I could care for him at all. We almost lost him. Every day is a blessing, and he is a delight. Very silly boy." "Caring for my child in general is the most positive part. Knowing I'm caring for and helping my child is the best feeling in the world." "That I have the opportunity to care for him. There was a time when he was sick that I didn't think I would get that chance."
Getting to know my child's personality	"I love learning what he enjoys and is excited about, he's very into music and singing right now and it just delights me beyond measure." "He is a bright, happy child. He loves learning, loves music, loves animals, people, he loves to play and he can brighten anyone's day." "My child is super funny, smart, and fierce. I'm amazed that she can understand sophisticated ideas and ask all sorts of questions. She's caring and also a bit of a bruiser. All around tough little girl."

that these fears persisted, even in cases in which a child had experienced seizure freedom since NICU discharge. These fears were further amplified for some by not knowing what to do in the event of a seizure. Active strategies are needed to reassure caregivers about the risk of seizures and education with seizure first aid should seizures return. These strategies may include equipping families with a written seizure action plan,<sup>28</sup> connecting parents with support groups,<sup>29</sup> and providing seizure anticipatory guidance including verbal counseling on seizure safety and when to call emergency services.<sup>30</sup> An area for further research is the development of a communication tool, such as a question prompt list, for parents of older children with seizures to support parent informational needs as children develop and grow.

Parents additionally expressed emotional distress and burden, including immediate challenges associated with the hospitalization and later challenges associated with the fear of uncertainty. Some parents shared feelings of guilt, recurrent flashbacks, and/or experiences with stigma. These sentiments may provide further context for patterns of persistent mental health symptoms that emerged in this cohort previously.<sup>9</sup> Although this study is not designed to understand the relationship between child development and well-being, it is important to highlight that themes of parent distress and fear of the unknown were described alongside references to typical neurodevelopment. These data underscore the importance of uniformly supporting parent well-being over time, including routine, longitudinal screening for parental mental health and psychosocial needs.<sup>31–33</sup>

Importantly, the majority of parents in our sample emphasized difficulties with managing day-to-day life, with some caregivers sharing particular challenges caring for a child with complex needs. Although challenges associated with navigating day-to-day life may be universal to parents of most children, parents in this cohort shared unique challenges associated with learning how to understand and care for their child's needs amid neurodevelopmental impairment, managing challenging behaviors, and balancing their child's many medical appointments and therapy needs with work, social life, and family obligations. These shared experiences are consistent with literature of parents of children with developmental disabilities and special educational needs showing that behavioral challenges, low confidence in how to care for their child, and lack of professional support are risk factors for parent stress.<sup>34</sup> Existing data emphasize that parents of children with medical complexity may require evolving support.<sup>35</sup> Active strategies to support parents across the care trajectory may include complex care team involvement early in the child's care, and for parents managing complex and challenging behaviors, the utilization of evidenced-based therapy for behavioral management to further address parenting support needs as children age. By teaching parents behavioral techniques, interventions such as parent-child interaction therapy assist caregivers with behavior management skills, which may help to support the parent-child relationship and reduce parenting stress.<sup>36–39</sup> Family caregivers are vital members of the health care team, and although interventions at an individual level are important, these must occur alongside policies that support family caregivers. Potential policy priorities might include expanded access to behavioral therapy, respite for parents, telehealth services, high-quality nursing support, funded mental health services, and financial support for families.<sup>40–42</sup>

Despite a persistent burden of care, nearly all caregivers in this cohort emphasized the joy of being a parent. Parents valued their role as a caregiver, celebrated their child's accomplishments, and enjoyed watching their child's unique personality develop. Existing data of parents following their child's stay within the intensive care unit have shown that parental psychological factors including positive reappraisal and positive emotions experienced during

admission are associated with posttraumatic growth or positive psychological change after a traumatic event.<sup>43</sup> These findings highlight the role for interventions aimed at facilitating parental resiliency and positive parent-child relationships. Beginning in the NICU, clinicians can encourage caregivers in their role as a parent, highlighting their accomplishments as a caregiver and emphasizing the many important ways in which they are caring for their child.<sup>44,45</sup> As children age, health care providers may consider integrating strength-based communication strategies while talking with parents about their child, a strategy that reframes conversations toward children's abilities, growth, and accomplishments, reminding parents of triumphs and opportunities to celebrate and find joy.<sup>46,47</sup> Strength-based communication has been shown to enhance parental feelings of self-efficacy and promote positive emotional experiences when parents are thinking about their child.<sup>48</sup>

The strengths of this study should be considered alongside its limitations. There was limited response data from caregivers of children aged between three and eight years. Although these data were included for completeness, any quantitative results from these time periods should be interpreted with caution. We do not have demographic information about parents who were screened for enrollment but declined study participation. As a result, it is difficult to know whether parents who declined participation differed from the enrolled population in systematic ways. Furthermore, although a wide range of medical and demographic data for children within our sample were measured, we have limited data on caregiver sociodemographic information, which may impact their experiences. This analysis includes information about the experience of parents at NICU discharge, which our group has described previously.<sup>7</sup> Although including these data was necessary to contextualize the experience over time, we acknowledge that doing so may have resulted in some redundancy. Finally, our analyses did not capture how parent experiences vary by a child's degree of neurodevelopmental impairment, primary seizure etiology, epilepsy diagnosis, medical comorbidities, or care needs.

## Conclusions

In summary, these data offer insights into the lived experiences of parents caring for children impacted by acute provoked seizures over time. Parents experienced a burden of care that began in the neonatal period and persisted across multiple domains. The challenges of care were mitigated by joy and fulfillment in their role as a caregiver and witness to their child's progress. Our findings underscore the need for future interventions that (1) identify and address caregivers' psychosocial needs longitudinally, (2) foster parental resilience and posttraumatic growth, and (3) provide enhanced support for parents caring for children with complex medical and behavioral needs.

## CRedit authorship contribution statement

**Natalie K. Field:** Writing – review & editing, Writing – original draft, Formal analysis. **Linda S. Franck:** Writing – review & editing, Methodology, Conceptualization. **Renée A. Shellhaas:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Hannah C. Glass:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Kathleen A. Young:** Writing – review & editing, Formal analysis. **Saisha Dhar:** Writing – review & editing, Formal analysis. **Ashley Hamlett:** Writing – review & editing. **Betsy Pilon:** Writing – review & editing. **Katie Means:** Writing – review & editing. **Janet S. Soul:** Writing – review & editing. **Shavonne L. Massey:** Writing – review & editing. **Courtney J. Wusthoff:** Writing – review & editing. **Catherine J.**

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### Supplementary Material

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.pediatrneurol.2024.08.007>.

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