

# Life after neonatal seizures: Characterizing the longitudinal parent experience

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## Objective

To describe the experience of parents caring for children impacted by neonatal seizures and characterize this experience across several time points in childhood.

## Methods

### Study design and participants

- Prospective, observational, multicenter study
- Parents of neonates with acute provoked seizures were enrolled between 2016 and 2018

### Inclusion criteria

- Seizure onset at < 44 weeks corrected gestational age
- Seizures due to an acute provoked cause

### Data collection

- Parents completed surveys at NICU discharge, 12-, 18-, 24-months, and 3-, 4-, 5-, 7-, and 8-years of age
- Surveys included demographic information and open-ended questions targeting parent experience

### Qualitative analysis

- Responses were coded and analyzed using a conventional content analysis approach

## Results: Participant characteristics

### Caregiver characteristics (n = 320)

Parent role	
Mother	257 (80.3)
Father	58 (18.1)
Legal guardian	5 (1.6)

Age at birth (years)	
Mother	32 (15-48)
Father	34 (20-54)

### Infant characteristics (n = 287)\*

Seizure etiology	
Hypoxic-ischemic encephalopathy	123 (47.1)
Ischemic stroke	76 (26.0)
Intracranial hemorrhage	51 (16.3)
Other	37 (10.6)

\*for 33 children, 2 caregivers completed at least 1 survey

## Results: Longitudinal parent experience

### We identified three primary themes in parent responses:

#### Theme 1: Personal Burden of Care

Parents experienced emotional distress, financial strain, physical demands, and fears associated with their child's future development and potential for seizures

Table 1: Illustrative Quotations from Theme 1

Emotional burden	"She is sick often and it still triggers flashbacks to when she was a newborn."
Physical demands	"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."
Financial strain	"Not being there for him due to the need of money. I am mostly working to provide for them."
Fear of future seizures and the unknown	"She hasn't had any seizures since she was 6 months old but I live in fear of them returning"

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

Parents described difficulties navigating their parenting role, including managing their child's challenging behaviors and understanding their child's needs amidst neurodevelopmental impairment

Table 2: Illustrative Quotations from Theme 2

Balancing my many roles	"The amount of care my child needs prevents me from living my own life."
Learning to understand my child's needs	"He doesn't know how to tell me when he is feeling bad."
Managing my child's challenging behavior	"The most difficult part 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: Joys of Being a Parent

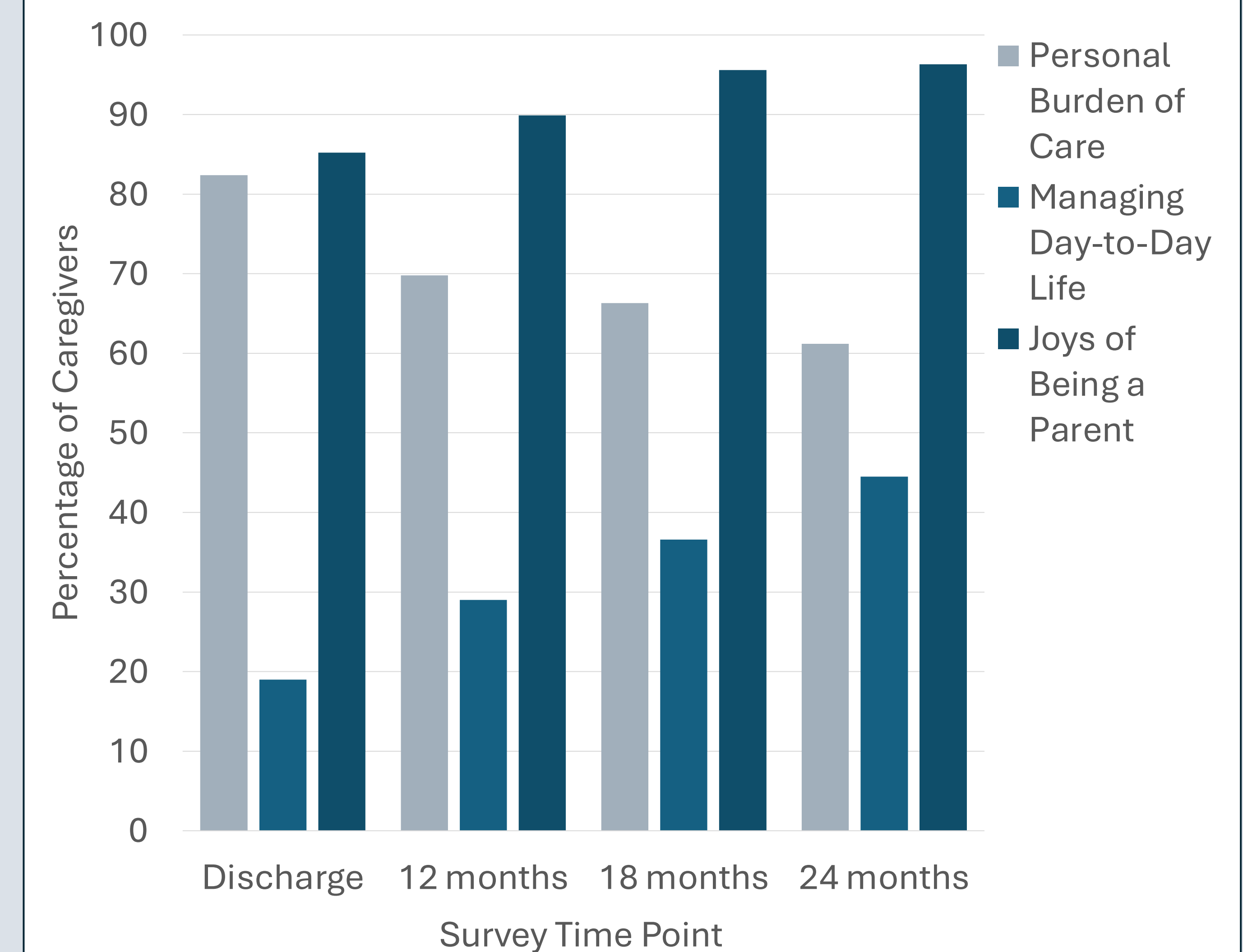
Parents valued bonding with their child, being a caregiver, and watching their child's personality grow

Table 3: Illustrative Quotations from Theme 3

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."
The bond between my child and family	"She loves me so much. I'm her world and she is mine"
Holding space for hope	"...I have learned to never give up hope. He fights and so will we right along side him."
Being able to care for my child	"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."
Getting to know my child's personality	"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."

## Results: Thematic frequency

Figure 1. Thematic code frequency per survey time point



## Conclusions

- Caregivers experienced **persistent challenges** across different developmental stages
- For nearly all parents, **challenges existed alongside the joys of being a parent**
- Future interventions should 1) acknowledge and promote parent resiliency, 2) address caregivers' psychosocial needs longitudinally, and 3) provide enhanced support for parents navigating the care of children with medical complexity

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