



Research Letter

A Novel Question Prompt List for Parents of Neonates With Seizures

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Introduction

Parents of neonates with seizures experience challenges with both immediate and long-term uncertainties regarding their child's care.¹ Furthermore, it can be difficult for parents of critically ill infants to know what to ask their care team while navigating the hospital course.² One evidenced-based strategy to enhance communication and facilitate question asking is through a question

prompt list (QPL).³⁻⁵ A QPL is a structured set of questions that parents can use to prepare for an upcoming conversation with the care team. We aimed to develop a QPL for parents of neonates with seizures.

Methods

In this prospective, observational, multicenter study, parents of neonates with acute provoked seizures were enrolled at Neonatal Seizure Registry (NSR) sites between July 2016 and March 2018. Parents completed surveys at discharge; 12, 18, and 24 months; and 3, 4, 5, 7, and 8 years. Three sources were used to develop QPL content: (1) open-ended survey questions asking parents to identify questions they had about their child's condition at discharge, questions parents wished they would have asked at discharge when reflecting back, or advice parents would give another parent in a similar situation; (2) an existing QPL created for neonatal intensive care unit parents⁶; and (3) feedback from the NSR Parent Advisory Panel. The Parent Advisory

Institutional review board statement: This study was approved by the local Institutional Review Board (IRB) at each individual study site within the *Neonatal Seizure Registry* (e.g., HUM00114541 at the University of Michigan; August 7, 2016).

Informed consent statement: Written informed consent was provided from a caregiver of each enrolled neonate.

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TABLE.
Sample Characteristics (n = 104)

Variable	n (%) or Median (Range)
Parent characteristics	
Caregiver completing surveys	
Mother	86 (82.7)
Father	18 (17.3)
Age at birth, y	
Mother	32 (24-48)
Father	34 (22-52)
Infant characteristics	
Sex	
Female	42 (40.4)
Male	62 (59.6)
Race	
White	75 (72.1)
Black/African American	8 (7.7)
Asian	4 (3.8)
Other	12 (11.5)
Unknown	1 (1.0)
More than one race	4 (3.8)
Ethnicity	
Hispanic or Latino	14 (13.5)
Not Hispanic or Latino	86 (82.7)
Primary diagnosis	
Hypoxic-ischemic encephalopathy	49 (47.1)
Ischemic stroke	27 (26.0)
Intracranial hemorrhage	17 (16.3)
Other acute etiology	11 (10.6)
Age at hospital discharge, d	13 (4-210)
Medical comorbidities	
Congenital heart disease	6 (5.8)
Extracorporeal Membrane Oxygenation (ECMO)	4 (3.8)
Congenital diaphragmatic hernia	0 (0)
Dialysis	0 (0)

Panel contributed to question generation and QPL organization and synthesis. The Parent Advisory Panel is composed of key community organization and parent members who provide critical input on all NSR studies. Collated questions were synthesized and edited for clarity.

Results

A total of 336 caregivers of 303 infants were enrolled. Of these, 104 caregivers generated at least one question (Table). Mothers (n = 86, 82.7%) and fathers (n = 18, 17.3%) had median age 32 and 34 years, respectively. Primary seizure etiologies included hypoxic-ischemic encephalopathy (n = 49, 47%), ischemic stroke (n = 27, 26%), and intracranial hemorrhage (n = 17, 16%).

Thirty-four questions were extracted from open-ended survey responses. Initial Parent Advisory Panel feedback included recommendations to streamline questions to limit information overload. Through iterative discussion with the study team, questions that were more relevant to the postneonatal period were not included. The Parent Advisory Panel aided in condensing the QPL to 21 questions (Figure). The neonatal intensive care unit QPL did not contribute any additional content. Questions were categorized into five primary topics: (1) understanding my baby's seizure diagnosis, (2) my baby's antiseizure medications, (3) what to expect for my baby's future, (4) what to do in case of seizures after my baby goes home, and (5) finding

information and support. Additional space for parent-generated questions was added to the tool based on parent and study team member feedback.

Discussion

Here, we present a novel, parent-informed communication tool to facilitate meaningful dialogue about neonatal seizures. Prior work has demonstrated that QPLs have the potential to enhance parent participation, reduce parent anxiety, and help address unmet informational needs.³⁻⁵ This QPL may help parents prompt conversations about seizure diagnoses, medications, and outcomes. The QPL can also be used by clinicians to prepare for and provide anticipatory guidance regarding common questions of importance to parents. Furthermore, these questions could guide development of priority educational materials and resources for families.

Notably, not all parent-generated questions were included in the finalized QPL. QPL content was condensed to focus on commonly asked questions relevant to the neonatal period. Given that parent informational needs evolve over time, a complementary QPL for parents of older children with seizures could be a valuable next step.

This study has limitations. Despite a geographically diverse sample and longitudinal study design, only approximately one third of caregivers submitted questions, the majority of whom were mothers. Open-ended survey questions fell at the end of a longer survey, and some parents may have opted not to share questions due to survey fatigue, lack of questions to offer, or prioritizing other open-ended questions. Question generalizability may be limited by homogeneity within our sample. Furthermore, as noted by the Parent Advisory Panel, QPLs may be overwhelming to some parents and may contribute toward feelings of information overload. Although we tried to proactively address this potential risk, the impact of this QPL on parent well-being and information overload warrants dedicated study. Additionally, existing data demonstrate that within pediatric specialty clinic appointments, QPLs may be less effective at promoting question asking for parents from traditionally underserved groups.⁵ Further research is needed to test the feasibility, acceptability, and effectiveness of the QPL across populations.

We have developed a QPL from the perspectives of parents of neonates with seizures to enhance parent-provider communication and prompt parents to ask questions about their child's care. Further research should evaluate the effectiveness of the QPL on parent quality-of-care outcomes such as question asking, knowledge, understanding of information, and well-being.

CRedit authorship contribution statement

Natalie K. Field: Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Hannah C. Glass:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Linda S. Franck:** Writing – review & editing, Methodology, Conceptualization. **Renée A. Shellhaas:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Justin Means:** Writing – review & editing. **Monica E. Lemmon:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Question Prompt List for Parents of Neonates with Seizures

Instructions: Check the box next to questions you would like answered by your baby’s health care team. On the right hand side, make note of any additional questions that you may have.

Understanding my baby’s seizure diagnosis

What are seizures? _____

What caused my baby’s seizures? _____

Can seizures hurt my baby or cause pain? _____

How do seizures affect my baby’s brain? _____

My baby’s antiseizure medications

What antiseizure medication(s) is/are my baby taking? _____

What are the side effects of my baby’s antiseizure medications? _____

Why does my baby need antiseizure medications? _____

What should I do if my baby misses a medication dose? _____

How long will my baby need to be on antiseizure medications? _____

What to expect for my baby’s future

What should I expect for my baby’s future development? _____

How can I help support my baby’s development? _____

Will my baby need developmental therapies? _____

What types of doctors will my baby have? _____

Could my baby have more seizures in the future? _____

What to do in case of seizures after my baby goes home

How will I know if my baby is having a seizure? _____

What should I do if I think my baby is having a seizure? _____

In what situations should I call 911? _____

Finding information and support

Where can I find more information about my baby’s condition? _____

Are there any support groups that I can join? _____

What mental health resources are available for parents? _____

Who can I call if I have questions or concerns? _____




FIGURE. A question prompt list designed to guide discussion between parents of neonates with seizures and their child’s care team. The color version of this figure is available in the online edition.

Declaration of Competing Interest

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