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Family-Centered Care for Children and Families Impacted by Neonatal Seizures: Advice From Parents

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ABSTRACT

Background: Parents of neonates with seizures are at risk of mental health symptoms due to the impact of illness on family life, prognostic uncertainty, and the emotional toll of hospitalization. A family-centered approach is the preferred model to mitigate these challenges. We aimed to identify strategies to promote family-centered care through an analysis of parent-offered advice to clinicians caring for neonates with seizures.

Methods: This prospective, observational, and multicenter (Neonatal Seizure Registry) study enrolled parents of neonates with acute symptomatic seizures. Parents completed surveys about family well-being at 12, 18, and 24 months corrected gestational age. Parents were asked open-ended questions eliciting their advice to clinicians caring for neonates with seizures. Responses were analyzed using a conventional content analysis approach.

Results: Among the 310 parents who completed surveys, 118 (38%) shared advice for clinicians. These parents were predominantly mothers (n = 103, 87%). Three overarching themes were identified. (1) *Communicate information effectively:* parents appreciate when clinicians offer transparent and balanced

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information in an accessible way. (2) *Understand and validate parent experience*: parents value clinicians who display empathy, compassion, and a commitment to parent-partnered clinical care. (3) *Provide support and resources*: parents benefit from emotional support, education, connection with peers, and help navigating the health care system.

Conclusions: Parents caring for neonates with seizures appreciate a family-centered approach in health care encounters, including skilled communication, understanding and validation of the parent experience, and provision of support and resources. Future interventions should focus on building structures to reinforce these priorities.

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Introduction

Although the conditions that cause neonatal seizures are heterogeneous, data suggest that parents caring for infants with seizures experience similar challenges: navigating uncertainty, adapting family life, and processing the emotional and physical toll of a neonatal intensive care unit (NICU) hospitalization.¹ At hospital discharge, over half of these parents may experience symptoms of anxiety or depression.² Nearly all parents have ongoing contact with the health care system and must navigate their child's care in specialty clinics and early intervention programs.

Existing evidence and practice guidelines recommend a patient- and family-centered care approach to improve quality of health care for children and should include attention to family support, high-quality communication, and family involvement in caregiving.^{3–5} Family-centered care is an approach to care centered on partnership between the family and the health care team. Core principles include information sharing, respecting and honoring differences, partnership and collaboration, negotiation, and providing care in the context of the family and community.^{6,7} Interventions to enhance family-centered care have been shown to promote parent-infant bonding, foster parent-provider trust and shared decision-making, build peer support, and improve parent mental health and child developmental outcomes.^{5,8–14}

Understanding how to support and communicate with families impacted by neonatal seizures is critical to optimize both parent and child outcomes.^{11,12,15} The aim of this study was to characterize parent-offered advice to health care teams caring for children and families impacted by neonatal seizures.

Materials and Methods

Setting and participants

We conducted a prospective, observational cohort study of children who experienced acute symptomatic seizures as neonates, along with their parents, treated at the nine sites of the US-based Neonatal Seizure Registry between July 2016 and March 2018.^{16–20} Neonates were considered for inclusion if their seizures were due to an acute symptomatic cause (i.e., hypoxic-ischemic encephalopathy, ischemic stroke, intracranial hemorrhage, or other acute brain injury). We analyzed all parent responses, including those offered by the parent of one infant who was ultimately diagnosed with a genetic condition in addition to neonatal seizures and ischemic stroke. The Neonatal Seizure Registry includes a Parent Advisory Panel, with one parent partner per site. Inclusion criteria were caring for a child with acute symptomatic seizure onset before 44 weeks postmenstrual age. The local institutional review board for every site approved the study, and parents provided written informed consent.

Study procedures

One parent or other legal guardian per family completed surveys near the time of discharge from the NICU and when their child reached 12, 18, and 24 months corrected age. Parents completed the surveys online or by telephone interview with a trained research assistant. Parents could complete surveys in English or Spanish. These surveys included six optional open-ended questions at each time point. 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 well-being over time. Each survey contained one to two questions requesting advice for the health care team. At 12 months corrected gestational age, participants were asked two questions: “*Looking back at the time of discharge from the NICU, what advice do you have for the clinical staff?*” and “*Looking back over the past year of caring for your baby, what advice do you have for the clinical staff?*” At 18 and 24 months corrected gestational age, participants were asked one question: “*Looking back, what advice do you have for the clinical staff?*” Parent responses to any of these questions about advice for clinicians were included in this analysis.

Data analysis

Free-text responses were analyzed using a conventional content analysis approach.²¹ A team of multidisciplinary researchers reviewed literature relevant to communication in neonatal intensive care settings. Given the lack of an established framework for this setting, the team developed a novel codebook to identify the content and nature of parental recommendations to the clinical team. Two qualitative research analysts independently pilot tested the codebook across a randomly selected subset of responses until consensus was reached. The research team met regularly to achieve consensus, iteratively refining the codebook to improve dependability and confirmability of applied codes. The codebook was developed and refined in partnership with the Parent Advisory Panel. NVIVO V.12 software was used to organize and index codes. All responses were coded by two study team members (M.C.B., S.B.), and discrepancies were resolved through team consensus. After coding and review, the study team discussed key themes and subthemes characterizing the content, language, and context of parent responses. Themes and subthemes were discussed with the study team until consensus was reached.

Results

A total of 310 parents of 305 infants enrolled. Of the 310 parents who completed surveys at any of the three time points, 118 parents (38%) of 115 neonates provided advice for the health care team at one or more time points. For three neonates, two parents participated. Most participants who responded were mothers (n = 103, 87%) (Table 1).

The most common seizure etiologies included hypoxic-ischemic encephalopathy (n = 53, 46%), ischemic stroke (n = 27, 24%), and intracranial hemorrhage (n = 18, 16%). As no major differences were noted in the types of responses at the three time points, thematic analysis was conducted on the total sample of responses. Three main themes were identified: (1) communicate information effectively, (2) understand and validate our experience, and (3) provide support and resources (Table 2).

Theme 1: communicate information effectively

Parents suggested behaviors that clinicians could adopt to improve communication with parents. The majority of parents (n = 69, 58%) shared advice related to this theme, including most (n = 59, 57%) mothers and (n = 10, 67%) fathers.

Tell us everything

“Be truthful to the parents and provide a wide variety of potential outcomes.”

Parents advised clinicians to disclose all information related to their infant's condition, including diagnosis, treatments, and prognosis. Some parents urged clinicians to avoid giving false hope and holding back information, and others cautioned against “sugar-coating” information.

TABLE 1.
Infant and Parent Characteristics

Characteristic	n (%) or Mean (S.D.)
Infant characteristics (n = 115)	
Sex, female	53 (44)
Term (≥38 weeks' gestation)	89 (77)
Length of stay, days	24.3 (25)
Primary diagnosis	
Hypoxic-ischemic encephalopathy	53 (46)
Ischemic stroke	27 (24)
Intracranial hemorrhage	18 (16)
CNS infection	7 (6)
Other	10 (9)
Medical comorbidities	
Congenital heart disease	11 (10)
Congenital diaphragmatic hernia	0 (0)
ECMO	5 (4)
Dialysis	0 (0)
Race	
White	85 (74)
Black/African American	10 (9)
Asian	6 (5)
American Indian/Alaskan Native	1 (1)
Native Hawaiian/other Pacific Islander	0
Mixed race	1 (1)
Other	4 (3)
Unknown/not reported	5 (4)
Declined to answer	4 (3)
Ethnicity	
Hispanic or Latino	13 (11)
Not Hispanic or Latino	101 (88)
Unknown/not reported/declined to answer	1 (1)
Discharged home with gastrostomy tube	8 (7)
Parent characteristics (n = 118)*	
Gender, female†	103 (87)

Abbreviations:
 CNS = Central nervous system
 ECMO = Extracorporeal membrane oxygenation
 * For three infants, two caregivers completed at least one survey.
 † One parent did not report their gender.

Choose words carefully

“I think a big thing clinical staff should know is that we literally remember everything they say and are filing it away to help us understand the situation. They have a ton of power to shape our state of mind.”

Parents described the importance of word choice and emphasized that each conversation is likely to be remembered by parents long after the health care encounter. Parents specifically highlighted that words like “seizure” and “brain damage” were frightening, and these terms required additional explanation and emotional support. One parent shared how her relationship with the team suffered because the team referred to her child as “baby boy,” instead of his given name.

Communicate as a team

“PLEASE make sure you are all on the same page.”

Some parents asked the health care team to address the communication issues between team members and families. Parents reminded clinicians of the frustrations associated with the lack of communication and consensus among members of their child's health care team. Parents also described how infrequent updates and conflicting information from the team members contributed to confusion about their child's care.

Repeat information as many times as we need it

“The only thing I would say to the staff is please have patience. I know they are busy, but sometimes I needed more explanations or asked the same question over and over. Those children are our world and it's hard to understand what is going on with them.”

When communicating medical knowledge, parents advised members of their child's clinical team to be patient with their ability to understand and process medical information. Some responses in this subtheme expressed how important it was to parents when health care team members repeated information about the child's condition multiple times. Parents described how the emotional toll of caring for an infant with seizures hindered their ability to process and accept medical knowledge.

Give us balanced information

“It's important to have some positive things in the mix for parents to look to and feel hope for.”

Parents emphasized the importance of providing balanced information when discussing the impact of seizures on their child's future. Parents suggested that clinicians give the full range of possible outcomes, as opposed to focusing on worst-case scenarios. Some parents requested that information about their child's future be presented in terms of their capabilities: “Doctors should take the time to talk about the things that most children with your child's condition CAN do.”

It's okay to say “I don't know”

“Don't traumatize parents with uncertainties before having a better idea of what's going on.”

TABLE 2.
Frequency of Codes at 12, 18, and 24-Month Survey Timepoints

Participant Responses n (%)	Overall, n = 118	12 Month, n = 50	18 Months, n = 58	24 Months, n = 77
Communicate information effectively	69 (58)	25 (50)	30 (52)	34 (44)
Tell us everything	38 (32)	13 (26)	15 (26)	15 (19)
Choose words carefully	18 (15)	6 (12)	7 (12)	10 (13)
Communicate as a team	15 (13)	8 (16)	3 (5)	5 (6)
Repeat information as many times as we need it	14 (12)	3 (6)	8 (14)	4 (5)
Give us balanced information	11 (9)	4 (8)	4 (7)	4 (5)
It's okay to say "I don't know"	6 (5)	2 (4)	2 (3)	3 (4)
Understand and validate our experience	65 (55)	27 (54)	21 (36)	41 (53)
Be compassionate	31 (26)	11 (22)	10 (17)	18 (23)
Meet us where we are	25 (21)	9 (18)	11 (19)	12 (16)
Take our concerns seriously	20 (17)	10 (20)	3 (5)	9 (12)
Empower us to participate in our child's care	15 (13)	5 (10)	5 (9)	6 (8)
Provide support and resources	37 (31)	16 (32)	14 (24)	14 (18)
We need care too	15 (13)	5 (10)	5 (9)	8 (10)
Educate us	13 (11)	5 (10)	3 (5)	5 (6)
Connect us with peers	10 (8)	5 (10)	2 (3)	3 (4)
Help us navigate care	10 (8)	6 (12)	4 (7)	1 (1)

A few parents advised health care team members to reveal the level of uncertainty associated with predictions of their child's future especially as it pertained to the child's medical progress and developmental potential. Parents described the added stress and fear associated with clinicians discussing poor outcomes without also disclosing the uncertainty of such predictions. One parent mentioned how admissions of uncertainty provided "a source of hope for a positive outcome in years to come."

Theme 2: understand and validate our experience

Parents advised that the health care team understand and validate their role as a parent. Comments related to this theme were shared by over half (n = 65, 55%) of respondents and described by most mothers (n = 57, 55%) and fathers (n = 8, 53%).

Be compassionate

"Compassion is king."

Many parents referenced the need for clinicians to be compassionate. These comments were often quite simple: "Be compassionate." Others connected compassion to empathy and asked clinicians to show kindness regardless of parent behavior. "Treat families with compassion, even if they aren't the most polite at the time."

Meet us where we are

"Treat the patients and families like you were the one in that situation."

Nearly a quarter of parents asked health care team members to imagine themselves in the parental role of caring for children with neonatal seizures. Parents requested empathy from their child's health care team: to treat parents in a manner consistent with understanding and sharing their perspective. Parent asked clinicians to keep in mind how challenging and traumatic it is for parents to navigate the critical care setting. Some respondents described empathy as showing authentic emotions and reserving judgment.

Take our concerns seriously

"Listen to the parents, they have intuition and understandings about their babies."

Parents urged the health care team to hear their concerns and answer their questions. Some parents stressed the importance of setting aside time to answer their questions, "even if they ask the same thing over and over" or consider their questions trivial. Other parents reminded clinicians of their significant role as their child's caregiver and advocate, advising the members of the health care team to address their concerns in a serious and respectful manner.

Empower us to participate in our child's care

"Know that as a parent in that situation, I didn't really start to feel like a parent because so many other people are taking care of your baby. All the things the staff does to involve you in the care really helps."

Parents desired opportunities to contribute directly to their child's treatment and progress. Respondents asked clinicians to provide opportunities to participate in all aspects of their child's clinical care. Several parents specifically expressed the importance of parent-infant bonding during the initial hospitalization for neonatal seizures through being able to hold their child. Parents appreciated when the health care team facilitated parent-infant bonding.

Theme 3: provide support and resources

Parents described numerous ways the health care team could provide support and resources to families caring for children with neonatal seizures. Approximately one-third of parents (n = 37, 31%) shared comments related to this theme, including mothers (n = 34, 33%) and fathers (n = 3, 20%).

We need care too

"Don't forget that the parents need care too, the baby is obviously the first priority, but even a small gesture for the parents goes a long way."

Some parents emphasized the need for emotional support from members of their child's health care team. Some parents offered concrete suggestions of how team members could provide such support, including promoting parent self-care. For example, one parent shared *“Encourage them to take care of themselves because you are taking care of their little one.”*

Educate us

“Remember that you are constantly educating while doing your job. That must be very difficult but try to keep it in mind so you can build up these parents caring for babies with unique needs.”

Parents described the need for education and advice to prepare for their role as caregiver. Parents requested instruction on ways to support their child's developmental progress through therapy and exercises. Instructions on administering medications, monitoring for future seizures, and determining the difference between typical child behavior and behaviors related to their medical condition were important to parents. Other parents urged the health care team to provide sufficient time for comprehensive teaching around the time of hospital discharge.

Connect families with peer support

“I would love to see a program where parents of older children connect with parents of infants to share experiences.”

Parents described the importance of connecting with other parents and families who had been through a similar experience. Some parents shared how peer support could help them process emotions, understand medical information, and prepare for the future.

Help families navigate care

“It would have been nice to have the social worker be involved a little more-coordinate the teams of doctors, make sure everyone was on the same page, facilitate those conversations.”

Some parents highlighted the importance of team members who could help them navigate care for their child. Several parents specifically mentioned the importance of social workers. Other parents described a desire for team members to actively connect them with resources, for example, information about where family members could stay overnight. A few parents described the need for help transitioning to home, coordinating follow-up appointments, and managing medical equipment.

Conclusions

Data from this multicenter sample of parents provide actionable advice to health care teams caring for children and families impacted by neonatal seizures. Parents offered advice in three key themes: (1) communicating effectively, (2) understanding and validating parents' experiences, and (3) providing support and resources (Fig). Domains of advice persisted over time, suggesting that these concepts remain salient to parents long after the initial hospitalization. Clinicians, educators, and researchers can leverage these insights to inform interventions.²²

The majority of parents identified ways in which the health care team could more effectively communicate amid crises. Many of

these suggestions are consistent with existing literature; parents value when communication is transparent, accessible, and coordinated.^{11,15,23} When predicting the potential for future impairment, parents appreciated when clinicians provided balanced information that included a clear spectrum of neurodevelopmental outcomes. Parent emphasis on providing balanced information, including positive information, may seem at odds with concurrent requests for transparency. While this incongruence could result from sample heterogeneity, it is also consistent with existing data from parents of premature infants suggesting that parents are able to process grim prognostic information concurrently with maintaining hope for an alternative outcome.²⁴ Taken together, these findings suggest that clinicians should not avoid disclosure of negative prognostic information due to concerns about removing hope. When appropriate, clinicians should disclose not only information about expected impairments but also information about expected function. Framing the discussion as the best, worst, and most likely outcomes is one evidence-based strategy to discuss a range of potential outcomes.^{15,25} Prognostic uncertainty is a common feature of care for children with neurological conditions, and clinician approaches are variable; parents appreciated when clinicians were honest about this uncertainty.^{25,26} Interventions to improve communication skills have been effective in many disciplines and should be adapted to this context.²⁷⁻³³

Most parents emphasized the need for clinicians to understand and validate their experiences. Their recommendation was clear—parents appreciated when clinicians showed compassion, empathy, and patience. Clinicians aspire to treat patients and families with empathy and compassion; however, clinician fatigue,

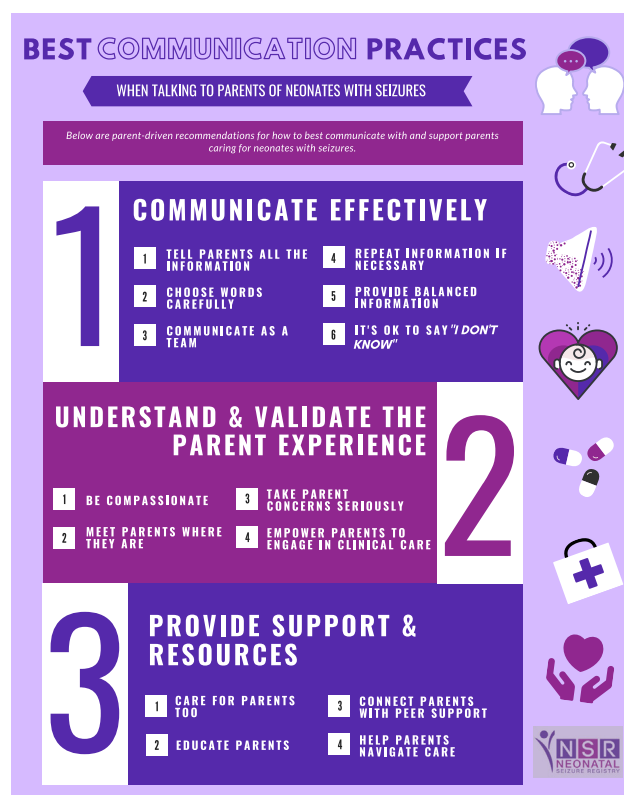


FIGURE. Best communication practices. This infographic includes parent-offered advice for clinicians communicating with families. The color version of this figure is available in the online edition.

moral distress, and burnout may undermine a clinician's ability to sustain these ideals.^{34,35} Interventions to enhance parent support must also address provider well-being.³⁶ Parent responses expand on the existing literature and comments shared by this cohort at discharge, which emphasize the importance of parent involvement in clinical care.^{12,13,37} Our findings underscore the value of supporting and encouraging parents to safely hold their child despite critical illness at every opportunity, including during therapeutic hypothermia.³⁸

Finally, parents highlighted the need for increased support and access to resources. Data from this cohort and others highlight an urgent need to screen for and address parent mental health symptoms.² Parents also desired access to training and resources that extended beyond education associated with seizures and seizure treatment, including helping families navigate the health care system and connect with peer support. Parents in this study described the potential benefits of having access to sleeping options, financial resources, and psychological counseling. These findings highlight that interventions to improve parent well-being should incorporate a broad range of psychosocial needs outside of typical medical management.^{3,12}

These findings should be considered in the context of this study's strengths and limitations. Although the sample was large and geographically diverse, only approximately one-third of parents completed the optional open-ended response questions to offer advice to the health care team. Because the etiologies of neonatal seizures are heterogeneous, parent responses are likely informed by their infant's underlying diagnosis, not the presence of neonatal seizures alone. The phrasing of the survey itself may have decreased responsiveness from parents who had a positive experience with the health care team. Questions were presented in a single order and may have resulted in priming or order bias. Surveys were available exclusively in English and Spanish and cannot be generalized beyond these populations. Our study design aimed for a single parent or caregiver to be enrolled per family; this strategy may have decreased participation by fathers. The paternal perspective is an important focus of future work. Parent demographic data were limited, and we were unable to assess the relationship between themes and parent sociodemographic factors.

The results of this contemporary and multicenter study identified modifiable behaviors and family-centered care strategies for clinicians to address the needs of parents caring for children impacted by neonatal seizures. Future work should focus on building structures to reinforce these priorities into health care delivery to better support parent well-being.

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