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Original Article

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## ABSTRACT

**BACKGROUND:** Neonatal seizures and antiseizure medications both have potentially serious consequences on the developing brain. As such, optimal treatment of neonatal seizures remains unclear. Moreover, little is known about parental experiences, concerns, or unanswered questions. We conducted an online survey to assess parental perspectives regarding neonatal seizures and their management, along with their suggestions for specific high priority research topics. **METHODS:** Parents whose children had neonatal seizures were recruited through social media support groups to complete an online survey. Respondents progressed through a tiered series of questions about their experiences with neonatal seizures and antiseizure medications. **RESULTS:** There were 126 eligible respondents. On a Likert scale, parents reported that neonatal seizures had a major effect on their families (median 10 of 10; interquartile range 3; n = 85). They also reported that antiseizure medications had a significant impact on their families (median 7 of 10; interquartile range 5.5; n = 75). The emotional impact of the uncertainty regarding seizures and medications was highlighted. Effects on neurodevelopment, continued seizures, and adverse effects of medications were some of the most commonly reported parental concerns and their highest priority research topics. **CONCLUSIONS:** Both neonatal seizures and the medications used to treat them contribute to parental worries and have major impact on families. Patient-centered outcomes research should focus on the risk–benefit ratio of neonatal seizures and antiseizure medication. The emotional impact on parents related to the uncertainty regarding both immediate and long-term neonatal seizure management is important to address in the clinical setting.

**Keywords:** neonatal seizures, survey, phenobarbital, levetiracetam, patient-centered outcomes, parent, epilepsy, antiseizure medication

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## Introduction

Neonatal seizures occur in one to four of every 1000 live births and have serious implications for long-term risk of

epilepsy and neurodevelopmental disabilities.<sup>1,2</sup> Despite their prevalence and consequences, controversy exists regarding how best to manage neonatal seizures and improve outcomes. Surveys of physicians suggest that there is a considerable variation in practice.<sup>3–7</sup> Such variation may be related to a lack of evidence to support medication selection or to guide the optimal duration of therapy.<sup>3,8</sup>

Importantly, studies of patient or parental opinions of seizure management for older children and adults demonstrate that their goals and priorities do not always match established medical definitions of success.<sup>9</sup> An extensive

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literature search revealed no published data regarding parental perspectives on neonatal seizures and antiseizure medication.

Given the need for further research to determine appropriate antiseizure medication use and duration of treatment for neonatal seizures, it is important to understand families' perspectives to ensure that research objectives align with patient and family values and that studies are designed to include patient-centered outcomes. Our goal was to begin to fill this knowledge gap by conducting an online survey to assess parental perspectives regarding neonatal seizures and antiseizure medication and to solicit their suggestions for specific high priority research topics.

## Methods

The institutional review board at the University of Michigan reviewed this project and determined it was exempt from a formal evaluation. An online survey designed to assess parental perceptions of neonatal seizures and antiseizure medication was conducted in September 2015. The survey was developed and pilot tested in partnership with a parent advisory group. An online survey tool was used to conduct the survey (<https://umichumhs.qualtrics.com>; survey questions are listed in Figure). Respondents progressed through a tiered series of questions that directed them to appropriate follow-up questions based on responses to initial stem questions (Figure). Respondents who indicated that their child did not have seizures were not asked to answer any follow-up questions. Similarly, those who indicated that no medication was administered to treat seizures were not asked questions about antiseizure medications. When respondents indicated that their child both had seizures and received antiseizure medication, they were directed to answer questions about the effect that the seizures and medications had on their infants and their families. The questions were paired such that questions about seizures always preceded questions about antiseizure medications.

Respondents were made up of a convenience sample obtained through social media outlets. On three consecutive days, postings were made on three distinct social media pages hosted by a partner organization ([HandtoHold.org](http://HandtoHold.org)). The three pages provide access to separate peer support groups for families of newborns who spent time in the neonatal intensive care unit, were born prematurely, have special needs, or died. The post included a brief statement inviting parents of children who had experienced neonatal seizures to fill out a short survey about their experiences and included a link to the online survey tool. The survey remained active for 11 days (to capture two weekends).

Responses to questions that had forced choice answers were tallied. Open-ended questions were examined using thematic content analysis.<sup>10</sup> The units of analysis were the message characteristics of parents' comments. Open coding was first used without regard for relative importance to appreciate the breadth of conceptual possibilities across the data. Conceptual categories were created that were salient across participants within each question topic and the categories were summarized into overarching themes. The frequency of responses within the themes and categories were then tallied. Respondents often commented on multiple categories and themes and these were all counted.

## Results

During the 11-day study period, 159 surveys were opened and 156 were started. IP addresses were able to identify the approximate location of 120 respondents. This demonstrated that surveys were submitted from all regions of the United States (Northeast,  $n = 10$ ; Midwest,  $n = 27$ ; South,  $n = 50$ ; West,  $n = 19$ ) based on regional divisions used by the United States Census Bureau. Fourteen respondents submitted surveys from other countries including Canada ( $n = 4$ ), Australia

( $n = 4$ ), England ( $n = 3$ ), New Zealand ( $n = 2$ ), and Brunei ( $n = 1$ ). One hundred twenty-six parent (or primary caregiver) respondents (81%) identified that their child experienced neonatal seizures and were therefore eligible to complete additional questions in the survey. Of these, 120 (93%) stated that their newborn received medication for the seizures and these respondents were eligible to complete questions related to antiseizure medications. Five respondents indicated that their newborn did not receive medications for the seizures and therefore were only eligible to complete questions related to the seizures themselves. One respondent did not answer the question regarding whether their child took medications. Among 81 parents who provided information about their infants' antiseizure medications, 72 parents (87%) indicated that their newborn received phenobarbital. Levetiracetam was the second most commonly named medication ( $n = 25$ ; 31%).

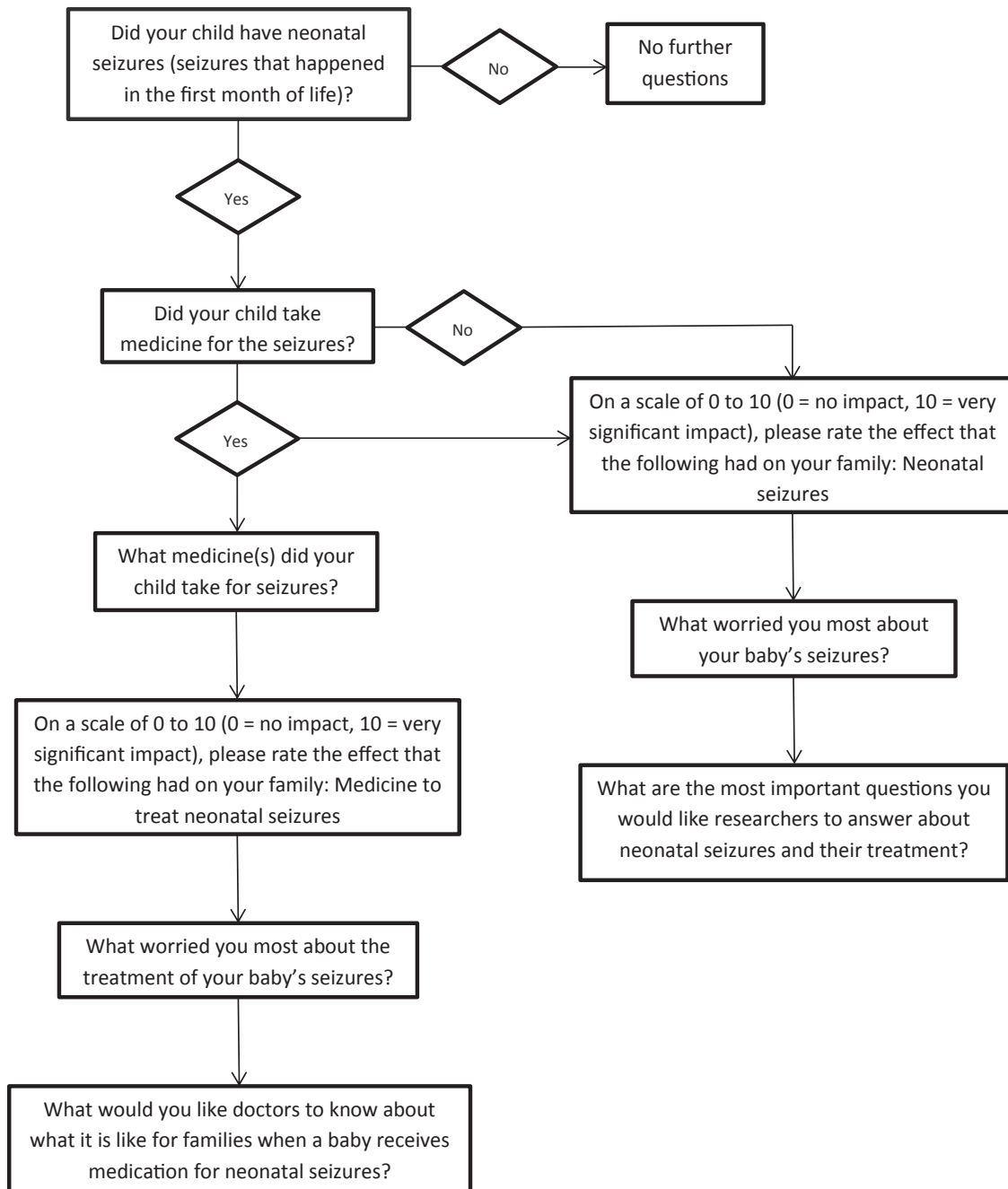
On a scale of 0 to 10 (0 = no impact, 10 = very significant impact), parents responded that neonatal seizures had a major effect on their families (median 10; interquartile range 3;  $n = 85$ ). They also reported that medications used to treat neonatal seizures had a significant impact (median 7; interquartile range 5.5;  $n = 75$ ).

Eighty-four respondents answered the open-ended question, "What worried you most about your baby's seizures?" The main themes were brain damage or impact on development ( $n = 44$ , 52%), continued seizures ( $n = 22$ , 26%), cardiorespiratory implications ( $n = 6$ , 7%), the cause of the seizures ( $n = 6$ , 7%), uncertainty about what was happening to their child ( $n = 4$ , 5%), death ( $n = 4$ , 5%), nonspecific implications for the future ( $n = 11$ , 13%), and other concerns ( $n = 9$ , 11%). Other concerns included issues such as pain, not understanding seizures, and having seizures occur when asleep.

Eighty-one respondents answered the question, "What worried you most about the treatment of your baby's seizures?" The main themes included short term adverse effects ( $n = 27$ , 33%), long-term adverse effects ( $n = 24$ , 30%), unspecified adverse effects ( $n = 22$ , 27%), therapeutic failure ( $n = 10$ , 12%), uncertainty about the medications ( $n = 3$ , 4%), nature of the medication itself ( $n = 6$ , 7%), nothing ( $n = 2$ , 2%), and other concerns ( $n = 6$ , 7%). Other concerns included time to wean off medications, process of medication administration, and poor communication about medications.

Seventy-seven respondents answered the open-ended question, "What would you like doctors to know about what it is like for families when a baby receives medication for neonatal seizures?" The main themes were the emotional impact ( $n = 42$ , 56%), concerns about adverse effects ( $n = 25$ , 32%), importance of more information and training ( $n = 20$ , 26%), importance of good communication ( $n = 11$ , 14%), and other concerns ( $n = 10$ , 13%). Examples of other concerns included considering alternative treatments, personal ethics, and questions about the baby's future. Some representative responses to this question are listed in Table 1.

Seventy-two respondents answered the question, "What are the most important questions you would like researchers to answer about neonatal seizures and their treatment?" Many of the responses were related to prognosis, including the long-term impact of the medication ( $n = 13$ , 18%), the long-term impact of the seizures ( $n = 8$ , 11%), and unspecified long-term impacts ( $n = 22$ , 31%).



**FIGURE.**  
Online survey flow for parents of newborns with seizures.

Twenty-five respondents (35%) wanted more research on medication effectiveness and choices, five of whom specifically mentioned alternative treatments. Other responses suggested research into appropriate timing of medication discontinuation ( $n = 3$ , 4%), prevention or cause of neonatal seizures ( $n = 8$ , 11%), risk of future seizures ( $n = 9$ , 13%), and other suggestions ( $n = 6$ , 8%). Other suggestions included research into what happens during a seizure, what types of seizures warrant treatment, and signs that a seizure may occur. Four respondents did not have specific suggestions for research (6%). Some representative responses to this question are listed in [Table 2](#).

## Discussion

We report the results of a survey designed to assess parents' concerns about neonatal seizures and antiseizure medications, as well as their priorities for future research. When rated on a Likert scale, parents of newborns with seizures who responded to this online survey indicated that both seizures and antiseizure medications had important impacts on their families. Concerns about long-term developmental outcomes were noted most frequently when parents were asked about their worries in regard to the seizures; they also worried about how antiseizure

**TABLE 1.**

Representative Responses to the Question, What Would You Like Doctors to Know About What it is Like for Families When a Baby Receives Medication for Neonatal Seizures?

Themes	Representative Responses
Emotional impact	“The medication is a reminder that things aren’t ‘normal’ when you so desperately want them to be.” “Seizure meds are just as scary for parents as is an actual seizure. We don’t know which is the lesser of two evils.”
Concerns about adverse effects	“It’s very scary for your new baby to be experiencing seizures let alone medicines that could possibly effect how they function.”
Importance of more information and training	“We aren’t doctors. These med names are new to us. We don’t understand why they need multiple types of meds. It would have also been good to know that the seizures could stop and to be given hope.”
Importance of good communication	“We want to be part of the process, why a medication is chosen and what thoughts go into the decision, goal setting with parents is important.”

medications were affecting their children. These concerns were noted more frequently than all others, including treatment failure, the cause of the seizures, and even death. This theme was also reflected in the open-ended questions, in which many respondents posed questions about whether the seizures or the medications are more consequential for the child.

Concerns about the potentially detrimental effects that medications may have on neurodevelopment have persisted in the neonatal neurology community and are echoed by parent respondents to our survey.<sup>8,11,12</sup> Therefore, although it is important to ensure adequate treatment of neonatal seizures to improve long-term developmental outcomes, future research should also focus on the risk–benefit ratio of neonatal seizures and their treatments as parents indicated this is an important research priority. Research focusing on this risk–benefit ratio was followed closely by suggestions to find more effective medications, although it is unclear what respondents define as effective because previous research has shown that definitions of effectiveness often differ between families and the medical community.<sup>9</sup> Further research is needed to explore the meaning of effective treatment for parents of children with neonatal seizures.

In addition to the direct effect of medication on the infant, the emotional impact of administering neonatal seizure medications was also of significant concern to parents, with more than half of respondents identifying this as something they wanted doctors to know about. Stronger evidence to support the selection of antiseizure medication and guide the duration of therapy could help clinicians to

better support parents through an emotionally trying experience. Concerns about the child’s health seem to be enmeshed with the process of giving a medication, given that respondents noted that medication administration was a reminder that their infants were not normal and that giving a medicine was more complicated than it appears at face value. Moreover, respondents indicated that their child’s seizures and treatment strongly impacted their entire family, but they did not describe the nature of the impact. Further research should explore the multiple dimensions of family impact of neonatal seizures and anti-seizure medications. In the meantime, clinicians should have heightened awareness of the possible impact on parents’ psychosocial health and compliance with treatment. Assessment and other supportive measures should be implemented.

This study has limitations. Data were derived from a convenience sample and there were no measures in place to prevent people who did not have experiences with neonatal seizures from completing the survey. However, the tiered presentation of questions was designed to prevent respondents without experience from being directed onward, and the quality and specific nature of the responses we received suggested that the survey was appropriate for most, if not all, respondents. This also suggests that, although this was not a previously validated survey, the results are valuable. It is possible that the order in which questions were posed could have influenced parents’ responses. Respondents were asked early in the survey if their child took antiseizure medications, which could have biased their responses to focus on antiseizure medications.

**TABLE 2.**

Representative Responses to the Question, What are the Most Important Questions You Would Like Researchers to Answer About Neonatal Seizures and Their Treatment?

Themes	Representative Responses
Long-term impact of the medications	“How do you know the medication is less detrimental than the seizure?”
Long-term impact of the seizures	“How do seizures affect development?”
Unspecified long-term impacts	“Long-term consequences and predictability”
Medication effectiveness	“Why do some medicines work for a while, then not work anymore?”
Appropriate timing of medication discontinuation	“When a seizure is caused by a traumatic event, does the child need to continue on meds and for how long?”
Prevention or cause of neonatal seizures	“Why do they have them? Is there prenatal care to prevent it?”
Risk of future seizures	“I just wonder...are we over medicating these babies to prevent something that might never even happen.”

However, questions about seizure impact preceded queries about medication impact; reversal of this order might have resulted in even stronger emphasis on concerns regarding seizure treatments.

The respondents were likely strongly motivated, because they completed an online survey with little prompting, which may have led to overemphasis of some response themes. It is possible that parents polled in different settings (e.g., intensive care unit, clinic, or electroencephalography laboratory) might raise a different set of questions or concerns. In addition, we did not collect demographic data on respondents beyond location noted by IP address, so it is difficult to determine how reflective our sampling was of all parents with children who had neonatal seizures. Despite these limitations, this study can help guide clinical practice and prioritization of patient-centered research topics.

### Conclusions

This study provides essential new data about parents' perspectives on neonatal seizures and antiseizure medications. Parents are concerned that both neonatal seizures and the medications used to treat them may be detrimental to their children and this contributes to parental worries. In addition, the emotional impact on families of the current uncertainty regarding optimal treatment strategies is an important consideration in medical decision making. Parents indicated that neonatal seizure research should be designed to help elucidate the risk–benefit ratio of seizures and antiseizure medications. Further work should be designed to define parental definitions of success and to explore the emotional impact of seizures and antiseizure medications on families. The present results provide an important starting point to support development of research objectives that align with patient and family preferences are designed to include patient-centered outcomes.

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