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Isolated and On Guard: Preparing Neonatal Intensive Care Unit Families for Life with Hydrocephalus

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Abstract

Objective—This study was aimed to characterize the parent experience of caring for a child with posthemorrhagic hydrocephalus and to describe parent preferences for counseling in the neonatal period and beyond.

Study Design—This was a qualitative interview study. Parents of infants born preterm with posthemorrhagic hydrocephalus completed semistructured interviews. Data were analyzed using a content analysis approach.

Results—Thematic saturation was reached on parent communication preferences after 10 interviews. Parent experiences of infant hydrocephalus broadly fell into two time periods, the neonatal intensive care unit (NICU) and after NICU discharge. The themes of uncertainty, isolation, hypervigilance, and the need for advocacy were common to each phase.

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Conflict of Interest
None declared.

Conclusion—Parents expressed interest in the development of tiered NICU counseling tools that would provide evidence-based and family-centric information to (1) initiate connections with community and peer resources and (2) combat the isolation and hypervigilance that characterized their family experience of living with hydrocephalus.

Keywords

neonatal intensive care unit; hydrocephalus; parents; qualitative research

Infant posthemorrhagic hydrocephalus requiring neurosurgical intervention predominantly affects the smallest and most of the preterm infants. Infants with hydrocephalus are at increased risk among preterm comparisons for adverse neurodevelopmental outcomes[1–3] persisting to school age.[4] Children requiring shunt placement are at the highest risk of neurodevelopmental impairment[4] and associated medical complexity. Abnormal motor outcomes include a spectrum from cerebral palsy to fine motor coordination problems. Other areas of neurodevelopment impacted by hydrocephalus include cognitive delay (intellectual, memory, and executive deficits), psychological challenges (chronic pain, depression, anxiety, and attention deficit/hyperactivity disorder), and sensory impairment such as cortical visual impairment.[5–9] Children with hydrocephalus also frequently have comorbid conditions like dysphagia and chronic lung disease and neurological complications like epilepsy that additionally increase neurodevelopmental risk.

The burden of hydrocephalus, associated disabilities, and chronic illness is not isolated to the child but impacts parents, family members, and health and education systems. While infants and children with hydrocephalus spend just short periods with clinicians, parents are continuously responsible for care coordination and optimizing their child’s developmental trajectory. Time in the neonatal intensive care unit (NICU) is an opportunity to help families prepare for a lifetime of caring for a child with hydrocephalus, yet literature to support the best practices for this counseling is sparse. Data from other neonatal populations suggest that neurologic counseling often emphasizes uncertainty about developmental outcomes, leading to acute and chronic distress for parents.[10] Other data report that clinician prognostication in NICU family conferences is typically nonspecific, with more emphasis on hoping for positive outcomes than on preparing for challenges that lie ahead.[11]

To optimize child development and parent wellbeing after a diagnosis of infant hydrocephalus, we must first understand the types of counseling that best prepare families. In this study, we aimed to (1) characterize the parent experience of caring for a child with hydrocephalus in our geographic area of the East Coast of the United States and (2) describe parent preferences for counseling in the neonatal period and beyond based on recollections of counseling received.

Materials and Methods

Study Design

The Johns Hopkins Hospital Institutional Review Board (IRB00218377) approved this qualitative study. Study design, including recruitment and data collection procedures, was developed in partnership with The Hydrocephalus Association. Participants were selected via a convenience sample; English-speaking parents of children who had been diagnosed with neonatal posthemorrhagic hydrocephalus were recruited at the 2019 Hydrocephalus Association “WALKS to End Hydrocephalus” in Baltimore, MD, and Washington, DC. We also recruited parents who had participated in previous studies with our group and had expressed interest in being contacted for future studies.

Parents completed audio-recorded telephone interviews between November and December 2019. One author (R.A.D.) conducted all interviews. Interview questions were open-ended and targeted parents’ experience with NICU counseling and communication about hydrocephalus, parents’ roles in decision-making around procedures in the NICU, and family preparedness for the lived experience of hydrocephalus both in the NICU and after discharge.

Analysis

Three study team members (R.A.D., R.D.B., and M.E.L.) analyzed interview transcripts using a conventional content analysis approach.[12] We chose this inductive approach due to the incomplete nature of existing research related to this topic. Data collection continued until thematic saturation was reached on parent communication preferences. All themes were derived from the data. Descriptive statistics were used to analyze quantitative data.

Results

A total of 10 parents of 10 different infants were interviewed. Most were mothers (8/10), Caucasian (6/10), and had more than a high school education (8/10). At the time of the interview, the median age of children with hydrocephalus was 3 years (interquartile range [IQR]: 3–7.5 years). Nine of 10 infants received their first shunts before NICU discharge; their average NICU stay was 108 days. The one infant who did not receive a shunt in the NICU received it 3 months after discharge at 6 months chronologic age. The median number of shunt malfunctions in the children was 6.5 (IQR: 5–10.25; Table 1).

Parent experiences of infant hydrocephalus broadly fell into two time periods: in the NICU (Table 2) and after NICU discharge (Table 3). Each time period brought unique challenges to families; however, the themes of uncertainty, isolation, hypervigilance, and the need for advocacy were common to each phase. Parents provided concrete suggestions (Table 4) to improve early and ongoing counseling about hydrocephalus.

In the Neonatal Intensive Care Unit

Diagnosis of Hydrocephalus

The initial diagnosis of hydrocephalus was described by participants as traumatic, confusing, and isolating (Table 2). Parents were often caught off-guard by the first conversation with clinicians, as the diagnosis was completely unfamiliar and parents were left wanting more information than received. Many turned to other information sources, like the internet, to fill these voids. Early conversations were dominated by a diagnostic uncertainty that was difficult for parents. Many were confused about how hydrocephalus would affect their child's development and potential for independence. The new diagnosis often magnified existing feelings of isolation in the NICU; hydrocephalus was yet another diagnosis that was difficult to understand, hard to describe to family members, and brought few peers who could share the experience. No participant remembered being referred to a support group or to other parents of children with hydrocephalus while in the NICU; one participant reached out to the Hydrocephalus Association after finding information herself online.

Facing the First Shunt

Variable time had passed for participants between their child's initial intracranial shunt and the study interview; 8 of 10 initial shunts were placed within the last decade (>2009). For the two participants with older children, there may not have been treatment options beyond ventriculoperitoneal shunt; neither remembered the shunt as a meaningful "decision," but simply what their child needed. The eight families whose children received shunts in the later epoch described variable experiences. Some remember that the decision was emergent due to symptomatic hydrocephalus; these families recall minimal participation other than "giving consent." Among infants not needing emergent intervention, few participants remember discussing treatment options. A few remember conflicting opinions between clinicians about treatment options which was distressing.

Many families described a prolonged and anxious waiting period between the hydrocephalus diagnosis and initial shunt placement. A few parents did not understand the reasons for delaying intervention; these parents often turned to the bedside nurse for advice and advocacy.

Some families learned about additional neurosurgical procedures, such as third ventriculostomy, after their initial shunt was placed, often on the internet. Some had residual regret and guilt that they may have missed an opportunity to advocate for an alternative.

After Neonatal Intensive Care Unit Discharge

Waiting for a Shunt Malfunction

Many parents expressed that the counseling received around the time of the first shunt did not adequately prepare them for life with a shunt (Table 3). Parents did not remember learning about the timing, frequency, or setbacks associated with shunt malfunctions. They felt unprepared for the over-whelming emotional burden of life centered around waiting and preparing for shunt malfunctions. They learned to dread the next shunt malfunction and felt constantly "on guard" about their child's behavior and health.

This responsibility for being the first to recognize a shunt malfunction triggered parent anxiety and fear. Participants reported that their child had not "read the textbook" about shunt malfunction, and rarely presented with the symptom repertoire they were expecting after NICU counseling. Parents reported being confused if their child's symptoms signified shunt malfunction; many turned to other parents for medical advice, if they were fortunate enough to have such contacts.

Impact on Family Life

Participants described multiple delays and disabilities affecting their child with hydrocephalus, including epilepsy and cerebral palsy. Most had recurrent hospitalizations and shunt failures that left children afraid of medical settings, sometimes consistent with a posttraumatic stress response. Parents of older children detailed learning difficulties, including problems with executive function and behavior that presented challenges in school and the workforce. Older children sometimes grappled with feeling "broken" or different than peers. Parents described having to educate peers about hydrocephalus. Parents of older children were relieved that their child could monitor their own symptoms.

Participants described how their parenting approach was often defined by hydrocephalus. For some, hydrocephalus created a sense of fragility about the child so much, so that parents never allowed the child to be away from them. Sometimes hydrocephalus impacted parenting of siblings who received less individual parent time and were isolated from typical experiences of childhood. Siblings sometimes became experts in hydrocephalus and shunts, with anxiety about symptoms in the affected child.

Parents also reported that hydrocephalus had a profoundly isolating effects on their personal relationships. Parents felt they could not rely on other family or daycare providers to care for the child, due to unfamiliarity with hydrocephalus and possible shunt malfunction. Family travel was limited due to worries about the potential need for urgent treatment for a shunt malfunction and access to a children's hospital. Some described challenges to their marriages; for others, the experience brought them closer as a family.

Discussion

The numbers of former premature infants with posthemorrhagic hydrocephalus surviving to childhood and beyond are growing. Advancements in neonatology and neurosurgical technique have reduced mortality and increased chronic morbidities associated with hydrocephalus.[13] Parents of children with medical complexity are frequently called upon to fill gaps in a "fragmented and uncoordinated health care system, functioning as case managers, medical record keepers, and patient advocates."[14] As a result of these demands, these families have increased rates of financial strain and caregiver physical and mental illness.[15–17]

Families of children with posthemorrhagic hydrocephalus requiring shunt placement are vulnerable to the unpredictable and life-threatening nature of shunt malfunction and the substantial challenges of managing home health care coordination.[18] Yet the specific needs of these caregivers are under-studied. Our findings, taken together with complementary data from the United Kingdom[15] and Israel,[17] highlight the need to better prepare families via (1) robust neonatal counseling and (2) longitudinal family supports to promote parent resilience in the face of the isolation related to an uncommon disease.

This sample of parents struggled to remember communication, preparing them for vulnerable time points in their family's hydrocephalus journey, including diagnosis, prior to neurosurgical intervention, and at discharge. New NICU counseling tools, as parents recommend, could provide information in a tiered fashion to be comprehensive but not overwhelming. A variety of tools already developed by families of children with medical complexity, including binders and organizers, could be adapted for hydrocephalus-specific needs.[16] Existing data suggest that parents of critically ill infants may be unsure of what questions to ask; a question prompt list intervention is one strategy to increase parent engagement.[19] For example, many parents in our study described guilt over not advocating for alternatives to shunt placement, including third ventriculostomy, despite data-supporting shunt placement as standard of care in this population.[20] A question prompt list could facilitate conversations with clinicians about this and mitigate parental guilt for not asking the "right" questions.

Tools for this population should also target balanced information about the range of outcomes with hydrocephalus; existing data support the idea that parents can process complex information about prognosis, while concurrently holding space for hope.[21] Our previous work with NICU parents suggests that most parents are prepared to receive information about potential disabilities, as it helps them identify resources and advocate for their child.[22] Informational videos or booklets with national and local resources should be easily available, along with testimonies of parents describing their family's journey. Creation of these tools calls for collaboration between parents, advocacy organizations, neurosurgeons, neurologists, neonatologists, and others with expertise.

A pervasive theme for families in our study was that family life was always under the shadow of potential complications from hydrocephalus, and that clinicians had not prepared them for this reality. Parents' hypervigilance often began in the NICU during the "wait-and-see" period prior to the first shunt when parents dreaded each ultrasound and apneic event and continued after discharge with the weighty responsibility of being the primary person to trigger evaluation for malfunction. This responsibility was particularly stressful because the symptoms of shunt malfunction were often outside of what was remembered from NICU counseling. Future work should explore whether these perceptions result from lack of counseling and/or the inability to process information amidst crisis. Since symptoms of shunt malfunction are known to change over time, especially as a child's fontanelle closes, interventions to support parents should be longitudinal and include neurosurgeons with expertise in the identification, management, and follow-up of hydrocephalus. Data suggest that educational tools can successfully prepare parents of older children to identify symptoms of shunt malfunction,[23] but little work has targeted parents of infants with hydrocephalus. Further exploration of this is important for families and clinicians alike.

Loneliness and isolation related to the diagnosis of hydrocephalus occurred for all families in this cohort as recurrent hospitalizations and comorbidities separated them from a typical family life of daycare, playdates, and travel. This finding concurs with multiple studies of parents of children with medical complexity who report social isolation due the demands of caring for a sick child.[24,25] Parents of infants with hydrocephalus appear to be specifically vulnerable due to a lack of diagnosis-specific community awareness and support. Parents wished for more connections with other parents of children with hydrocephalus, as these relationships became essential antidotes for family isolation and sources of emotional support and medical knowledge. A long NICU hospitalization is an opportunity for clinicians to actively connect parents with peer-led parenting programs, shown to be effective in other groups of chronic critical illness.[26] Parents in the NICU may be at varying stages of information processing, however, and may not realize the significant need for support until later, emphasizing the need for presentation of resources across the course of the hospitalization. Additionally, nurses were often cited by parents as sources of support; this emphasizes the ongoing need to ensure these clinicians at the bedside are involved and armed with the most accurate information about hydrocephalus care.

Strengths and Limitations

There are several potential limitations to this study. Our recruitment strategy targeted participants in Hydrocephalus Association Walks and previous research studies; both populations may underrepresent families with an uncomplicated hydrocephalus courses (rates of shunt malfunction were higher in this cohort than in the general hydrocephalus population), those without access to peer-support programs, and parents who are less engaged with their child's health care. Additionally, our participants were predominantly Caucasian, most had at least a bachelor's degree, and all resided on the East Coast of the United States. As such, the demographics of the participants in this study likely do not represent that of the entire posthemorrhagic hydrocephalus shunt population at our institution or other children's hospitals across the country. Further research is needed to capture the experiences of a larger sample of parents of children with posthemorrhagic hydrocephalus who are more representative of the racial, educational, and geographic diversity across the United States. In addition, our data are limited to parent report of clinician counseling; recording of parent counseling in real-time is an important next step. Despite these limitations, the experiences of this small high-risk cohort can be used to identify opportunities for improved communication.

Conclusion

Parents of children with posthemorrhagic hydrocephalus can experience feelings of isolation and hypervigilance while bearing the numerous emotional and practical burdens of caring for a child with hydrocephalus. These experiences begin in the NICU but may endure for years. Future interventions should target the development of tiered, step-wise NICU counseling tools that provide evidence-based and family-centric information and that initiate connections with community and peer resources.

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Key Points

- Infants with posthemorrhagic hydrocephalus are at risk for adverse neurodevelopmental outcomes.
- The parent experience of caring for a child with posthemorrhagic hydrocephalus is not well-described. In this interview study, parents described uncertainty, isolation, and hypervigilance.
- These findings call for structured NICU counseling and longitudinal family supports after discharge.

Table 1

Parent and child characteristics

Parent characteristics (*n* = 10)	***n* (%) or median (interquartile range)**
Age (y)	42 (37.25–46.75)
Gender	
Female	8 (80)
Male	2 (20)
Race	
Caucasian	6 (60)
African	1 (10)
African American	1 (10)
Hispanic	1 (10)
Middle Eastern	1 (10)
Level of education	
Master’s degree	6 (60)
Bachelor’s degree	2 (20)
High school	2 (20)
Employment	
Employed	7 (70)
Not employed	3 (30)
Child characteristics (*n* = 10)	
Age at time of interview (y)	3 (3–7.5)
Number of siblings	1 (1–1.75)
Number of shunt malfunctions	6.5 (5–10.25)
Length of NICU stay[a] (d)	108 (96–113)
Presence of shunt in NICU	
Yes	9 (90)
No	1 (10)
Hospital transfer	
Yes	6 (60)
No	4 (40)

Abbreviation: NICU, neonatal intensive care unit.

[a] Only reported for 9 of 10 children.

Table 2

Representative quotes: NICU experience: diagnosis and facing the first shunt

Diagnosis: the first conversation
It was puzzling because I'd never heard of it before. That was the first time ever hearing about hydrocephalus, the first time hearing about the shunt being put in his head, all of that. It was foreign talk. (P5)
You know how people explain they're going to pass out and they get that blackness peripherally that kind of starts moving to the center until they pass out? It felt like cognitively that happened to me…, it was very hard for me to hear past the first part: "This is what it is. There's no cure. The only treatment is brain surgery." I just remember feeling pretty overwhelmed, but again at the same time dead and lost…. I remember thinking, was she ever going to be able to live independently, go to school, play sports, go to college, get married? (P8)
I think (the neonatologist) felt like he was being totally transparent, but it just came out in a way that was really negative, and obviously super scary. He shared so many things about just really dire outcomes, both physically and cognitively…, very much information overload. How can a parent process that when they just found out the kid just had a brain bleed? I would say compared with the day he was born so early, I would say that actually was probably the worst day of the whole time. It feels very isolating. (P9)
We were very lucky, because the way that the information was presented was very gentle, very caring but also empowering. They were like "you have some control over her development…, there are things you can do." It was that hope and potential that still remained that really has still stuck with me. (P6)
I'm not saying cancer isn't scary, but with cancer, everybody knows where to go, what to do. It's much more out there. With hydrocephalus, nobody even knows what it is, let alone where to go to get a support group. (P1)
Facing the first shunt
They would do the ultrasounds every Wednesday… You just dread it…. The wait and see was brutal. (P9)
We would watch our baby have a really hard time coming back from all these bradycardia events. We would use the nurses as advocates…it was harder sometimes to convince neurosurgery that something was wrong. You just have to wait for that moment where it's very clear what's going wrong. We were not understanding why we were waiting. (P6)
I believe the neurosurgeons are the ones who came up with the plan as far as the shunt to treat. Obviously, we gave consent to do the procedure. (P2)
Why programmable or not programmable? Didn't even know there was such a thing. Why wasn't ETV being considered? We didn't even know what it was. I feel like there were conversations that we didn't know to be a part of. Then finding out, only through self-education and getting involved, that there were a ton of decisions and conversations, why weren't we there for real? (P7)

Abbreviations: ETV, endoscopic third ventriculostomy; NICU, neonatal intensive care unit.

Note: Parent study number is in parentheses.

Table 3

Representative quotes: life after NICU discharge: waiting for a shunt malfunction and impact on family life

Waiting for a shunt malfunction
How do I live a normal life without thinking that there's shunt failure? How do I recognize the symptoms that it's a shunt failure versus a cold, or he's just cranky, or he's gassy, or he's teething? That's probably been the most difficult part- when you have a relatively healthy child, when things come up you deal with them. Here, you're almost like anticipating it. (P1) She never showed any warning signs of your shunt not working. (Child) does not follow any textbook whatsoever for any of her diagnoses. I also have another mom that I met in the NICU…. If something is going weird with him, she'll message me. He's not on a textbook either. We bounce things off each other first before we're like, "OK, we're going to ER," just for comparison, because you don't really know. (P3) I always feel that I'm (child)'s voice. I'm the only one who knows when she's not acting right or something's going on. (P2)
Impact on family life
Child development He's had to go through so many surgeries and just the physical pain, and it stays. That's given him his own little version of anxiety. When he sees any type of bedding that resembles a medical setting, he just loses it, even if it's just going to be not invasive at all, even if it's just the pediatrician (P9). She is alone more than she's with people. She isolates herself. She has very low self-confidence…, feeling like she's different…, she feels like she's broken. Like she doesn't work right. She was never invited to birthday parties, so your heart is crushed. It's really hard for me to watch her not have friends. She can't be alone all that time. (P8)
Parenting
You become really cautious. Maybe you treat your child like more fragile than they really are. You're always on guard…. You'll always have the fact that your child could go into surgery the next day, literally, in the back of your brain. That's not normal. That's not normal parenting. You're highly vigilant…. It's exhausting. (P10) Perpetual guilt for her twin brother who's not experiencing things that I know that he could. I took him hiking for the first time a couple of weeks ago and he told me it was the best day of his life. Why haven't we taken him hiking before? Because we can't take her hiking. (P7)
Personal relationships
I'm asked sometimes, what's the worst part about hydrocephalus? I always say, it is the loneliest condition. Hydrocephalus, there's no commonality in how you get it, whether it's genetics, IVH (intraventricular hemorrhage), or a tumor. There's no commonality on how many revisions you'll need. There's no commonality if you have a shunt or not. There's no commonality on whether you're going to get a PhD or have an ID (intellectual disability). It's just lonely. (P7) I don't like to spend time away from her. My husband and I have, I think, only been away from our kids one night. It's hard to leave her alone with other people because I'm always afraid something's going to happen, like a malfunction. (P6)

Abbreviations: ER, emergency room; NICU, neonatal intensive care unit.

Note: Parent study number is in parentheses.

Table 4

Representative quotes: parent suggestions regarding information and support needs

Information needs: diagnosis, first shunt, and NICU discharge
What I definitely don't remember…, (being) reiterated how many kids go through this and still are amazing, happy. (P9) I wish I would have known that having these many surgeries was something that could be a big possibility. I thought shunt and done. That obviously isn't the case. (P2)
I don't know if there's a way to gauge or interview parents when they received the diagnosis. Maybe they have a sit down and are told about some of the materials that are available for them. "Are they interested in them now?" I think it's a very personal experience…. I think it's more a matter of knowing that that stuff is available to them and then they can gauge what they want and when they want it. (P6)
I think it needs to be tiered, almost like "This is what you need to know when you get your diagnosis. This is what you need to know after the surgery is done." I don't think it should be all at once. (P7)
Someone to talk to that had a child, or experienced the things that we were experiencing, that would've been helpful. It would be nice if they were able to hook people up with other parents that are willing to share experiences. (P2)
Even with the symptoms of when he was in shunt failure, I felt like that wasn't even described to us properly. It was just like, "Oh, is he vomiting? Does he seem like he's sick? Does he have a fever?" It's so much more than that. I think it's helpful for parents to know what to look for and how the condition is going to shape their life and the child in a more meaningful way. (P10)
We had to take a CPR class. What if there was a short video…, just explaining like the parts of a shunt and how they work and maybe your signs to look for. Not everybody can learn with someone just telling you. (P3)
Support needs: anticipating uncertainty, reducing isolation, and facilitating advocacy
I think the services that would be helpful…, is somebody that you can reach out to with a hotline, for example, talking to someone who is very knowledgeable about hydrocephalus and all of the things that come with it that can talk to you when you have questions. Should I take him to the ER? Should I not? How many times do families run to the ER when their child has the flu because they think they're in shunt failure? There needs to be a more sophisticated way of managing that. (P10)
One may need one revision their entire life, where another might need dozens. I think it's really important to sit down with parents and say, "This condition is all over the map. It's going to look different for your kid than it might for another kid. Here are all the things that you should be keeping an eye on." (P10)
Hydrocephalus was his first big diagnosis, but the reality was it was very likely that he was going to have CP. He was going to have epilepsy and some of the learning things. That reality, maybe there's opportunity to share more openly about some of those realities, to make it less isolating and less negative. Now that I've met so many people, they all have sort of similar stories, they all have CP, epilepsy, hydrocephalus. It makes you realize that you're not alone. There's a lot of kids like (child) even if we don't see them every day. (P9)
There's a whole community of people here who are ready to be with you when you need them. I always say that I understand you might not want that right now, but just know that we're here for you. (P8)
Hundred percent trust your instincts…. I think that parents know their child better than anybody else…. I think you just have to know that you have a lot of information that can be valuable to doctors. Maybe that textbook answer or diagnosis doesn't apply to your child, it's "OK" to push back if you think differently. (P10)

Abbreviations: CP, cerebral palsy; CPR, cardiopulmonary resuscitation; ER, emergency room; NICU, neonatal intensive care unit.

Note: Parent study number is in parentheses.