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Parent preferences for neurodevelopmental screening in the neonatal intensive care unit

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Abstract

AIM—To determine whether, and how, neonatal intensive care unit (NICU) parents want to receive information on disability risk in their children from early neurodevelopmental screening.

METHOD—This was a qualitative interview study. Parents of hospitalized infants born preterm completed semi-structured interviews. Data were analysed using a directed content analysis approach.

RESULTS—Thematic saturation was achieved after 19 interviews. Four themes characterized parent perceptions of early neurodevelopmental screening: (1) acceptability: most parents were in favour of neurodevelopmental screening if parents could refuse; (2) disclosure of results: parents want emotional preparation for results, especially false positives; (3) emotional burden of uncertainty: parents of children in the NICU balance taking their infant's illness 'day by day' and preparing for an uncertain future. Parents expressed distress with screening that increased uncertainty about the future; and (4) disability: prior experience with disability informs parent concerns.

INTERPRETATION—Parents interpret the risks and benefits of NICU developmental screening through the lens of prior experiences with disability. Most expressed interest in screening and emphasized a desire for autonomy, pretest counselling, and emotional preparation.

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Identifying infants at highest risk for neurodevelopmental impairment is a priority for clinicians and researchers, as morbidity surpasses mortality for even the most extreme preterm groups.[1] Clinicians are increasingly able to predict future neurological impairment in acute settings using novel tools to stratify risk for neurological morbidity. The implementation of early neurodevelopmental screening raises questions about when and how to deliver information about neurodevelopmental risk to families.

Cerebral palsy (CP) is one neurodevelopmental impairment for which early screening is increasingly possible. Recent evidence suggests that a diagnosis can be accurately made before 6 months corrected postnatal age, using a combination of a functional motor assessment, history, brain imaging, and standardized examinations, including the General Movements Assessment (GMA) and the Hammersmith Infant Neurological Examination.[2] Early diagnosis can facilitate earlier intervention, which may maximize neuroplasticity and mitigate comorbidities in both motor and cognitive domains.[3–5] Yet, providers may be hesitant to adopt CP screening programmes in the neonatal intensive care unit (NICU) owing to concerns that it will overidentify infants who ultimately do not develop CP. There is also the potential that positive screening for neurodevelopmental risk could affect parenting and bonding for families of these infants.

Screening tests for later neurodevelopmental risk require unique considerations as compared to other tests routinely performed in the NICU. Routine tests such as head ultrasounds, X-rays, and other standard-of-care medical examinations are often done without parental consent, given that they have limited short-term risks, are in the medical interest of the child, and can affect the infant's treatment in real time. In contrast, tests such as the GMA, and even some radiology studies such as magnetic resonance imaging obtained for prognostication, often do not acutely affect care but rather provide risk stratification for later disability diagnoses months or years later. Parental views on tests in these preference-sensitive settings are particularly important as we consider how to incorporate parent preferences into clinical decision-making.

To date, no prospective studies have explored parent preferences and concerns regarding screening tests for neurodevelopmental risk. Retrospective parent data suggest that parents of children later diagnosed with a disability, such as CP, would have preferred earlier diagnosis to initiate neurodevelopmental treatments.[6–9] However, parents in the midst of stressful NICU hospitalizations may have different perspectives. Our prior work with NICU parents suggests that not all families welcome information about long-term outcomes during acute hospitalizations.[10] Their infants may still be critically ill with uncertain survival to discharge, or parents themselves may have acute stress disorders that could affect understanding of complex information.[11] Here, we aimed to identify whether, and how, parents of children in NICUs want to receive information on disability risk from early neurodevelopmental screening.

METHOD

Study design

This qualitative study was approved by the Johns Hopkins Hospital Institutional Review Board and conducted at an urban level IV NICU and associated level III NICU. We recruited English-speaking parents of infants born preterm who, at the time of the interview: (1) were between 28 and 34 weeks' corrected age; and (2) had not yet been screened with GMA examinations. This gestational age range was selected to identify parents who were not experiencing the first few weeks after extreme preterm birth at the time of the interview. When a child reached 28 weeks' corrected age, study personnel approached the parents at the bedside, explained the study, and obtained written consent. Arrangements were made for an interview to occur at the time of enrolment or at a later date, per parent preference. If both parents of a two-parent family wished to participate they were interviewed separately. Data collection was conducted from 26th March 2018 to 4th June 2018.

Parents completed semi-structured audio-recorded interviews. All questions were open-ended and all questions were asked to all participants (see Appendix S1, online supporting information, for a full list of interview questions). To explore NICU parent preferences regarding early screening for neurodevelopmental impairment, we used a theoretical example of a 'non-painful, non-invasive test' as a proxy for tests like the GMA. Questions targeted parent reactions to the hypothetical screening test and also explored parents' prior exposure to disability, understanding of their infant's disability risk, and hopes and fears. One author (RAD) conducted all interviews. Infant chart reviews were conducted to assess the severity of infant medical comorbidities.

Analysis

All interviews were transcribed; transcripts were analysed using a directed content analysis approach[12,13] by three study team members (RAD, RDB, MEL). This approach was chosen owing to the presence of existing, but incomplete, research related to the topic of interest. Dedoose qualitative software, version 8.0.35 (SocioCultural Research Consultants, Manhattan Beach, CA, USA) was used for indexing and organizing codes and to monitor the audit trail. The three study team members (RAD, RDB, MEL) each created codes independently after review of each transcript; codes were later collated and collapsed into categories and themes within this subgroup of study team members. All discrepancies were resolved by consensus within a broader multidisciplinary study team specifically chosen to balance assumptions, consisting of neurology, neonatology, and neurodevelopmental disabilities specialists. Key themes were identified by the frequency with which they occurred throughout interviews; data collection continued until thematic saturation was reached after 19 interviews.[14] Illustrative deidentified quotes are included in the text and in Tables 1 and 2. Descriptive statistics were used to analyse quantitative data.

RESULTS

Nineteen parents, 15 mothers and four fathers, of 15 infants were interviewed. The median interview length was 25 minutes (interquartile range [IQR] 18–34min), with a maximum interview time of 68 minutes. Median infant gestational age at birth was 29.6 weeks (IQR 25.7–31.2wks), with a median corrected gestational age at the time of interview of 32.2 weeks (IQR 30.8–34.2wks). The parents of one infant were interviewed before 28 weeks owing to parental request. Infant and parent characteristics are given in Table S1 (online supporting information) (online supporting information).

Four themes characterized parent perceptions of early neurodevelopmental screening: (1) acceptability (parent perspective on theoretical NICU screening); (2) disclosure of results; (3) emotional burden of uncertainty; and (4) parent prior experience with disability and perception of their infant's disability risk.

Theme 1: acceptability (parent perspective on theoretical NICU screening)

Perceived benefits of early neurodevelopmental screening—Parents described multiple ways that screening for neurodevelopmental disabilities like CP in the NICU could help them (Table 1). Many ascribed value to having 'more information'; some suggested that knowing everything about their infant is a characteristic of a 'good parent'. Parents felt that early awareness of their infant's risk for neurodevelopmental disability would permit multiple types of planning: (1) emotional adjustment to a potential diagnosis; (2) timely engagement of early interventions and therapies with the help of NICU staff; and (3) preparing the whole family to adapt to the child's needs. Parents believed these efforts would offer their child the best outcome possible. A minority of parents supported testing because a negative result would reassure them that their child was 'normal'.

Perceived negatives of early neurodevelopmental screening—Parents acknowledged that screening might cause anxiety, further compounded by the baseline level of stress in the NICU. One parent noted that a test focused on screening for disability was a focus on the negative aspects of the child. Parents further detailed the potential negatives associated with a false-positive result in particular (see Theme 2).

Parent autonomy versus the child's interests—Sixteen parents were in support of the neurodevelopmental screening test for their infants, and three parents reported that they would refuse screening. None of the three parents who refused screening was a member of a parental dyad. Many parents were conflicted or ambivalent about whether other parents should be able to refuse this test, but, ultimately, most (n=14/16) of the parents who wanted screening themselves supported the right of refusal of other parents. Parents ultimately respected the right of parents to choose the information they wanted to know about their child, especially as most felt that neurodevelopmental disabilities like CP cannot be prevented. While most parents supported parent autonomy to refuse screening, many wondered why parents would do so, and articulated the necessary balance between appropriate parent autonomy and the potential benefit of intervention for the child. A few parents (n=2) felt that screening refusal would be unethical as, in their view, children deserve every potential benefit of earlier diagnosis.

Theme 2: disclosure of results

Approach to testing and disclosing results—The majority (*n*=16/19) of parents wanted the hypothetical ‘non-painful, non-invasive screening test’ for neurodevelopmental disability for their child (Table 2). However, parents wanted to understand, before screening was undertaken, any potential harm to their child. They wanted to be meaningfully informed about test accuracy. Two parents named a particular threshold of accuracy before they would consider the test (one desired 80% accuracy, another >30%). Parents wanted help emotionally preparing for the results, as most imagined that hearing the results would be stressful. Some conflated screening results with a confirmed diagnosis. Overwhelmingly, parents wanted to hear test results from experts who could answer questions. Parents felt it would be important to know the likely severity of disability to help them imagine the future and plan for needed resources. Many wanted to receive the results in the NICU, where supports like social workers were available.

Impact of false-positive results—The emotional burden of a false-positive test was particularly distressing, although most parents understood this potential result of a screening test. Some noted that knowing the false-positive rate would be helpful. Most anticipated a stressful waiting period between a positive screening result and a definitive diagnosis, but still felt that this stress was outweighed by the potential benefit of early intervention, especially if the test was non-painful and non-invasive. Some worried that they would become overprotective of their child after a positive screen. Others worried that a positive screening would cause clinicians to overreact to ‘minor’ neurodevelopmental concerns. Still others worried that a false-positive result might affect their parenting of and bonding with their child. Despite these worries, only one parent said she would refuse the test owing to the possibility of a false-positive result. Those parents who advocated for learning as much information as possible prenatally were more accepting of a test that might have a false-positive result postnatally.

Theme 3: emotional burden of uncertainty

Take things ‘day by day’—Parents placed the uncertainties associated with neurodevelopmental screening in the context of daily NICU uncertainties. Parents described how their infant’s NICU hospitalization included multiple tests and interventions with uncertain outcomes. For many, taking things ‘day by day’ helped them cope with recurrent uncertainties and reduce worry.

> ‘I’ve definitely been taking it day by day. I’m choosing not to stress myself out about something that I know nothing about, which is tomorrow; I have no idea what it’ll hold’.
>
> (P2)

Many described themselves as planners who wanted to know about future risks to prepare. Even those parents who were planners still felt that focusing on each day was necessary in the face of overwhelming potential concerns. This ‘day by day’ focus was reflected in parents’ characterizations of their infant’s health problems; most limited their descriptions to concrete respiratory or feeding concerns, as opposed to concerns about their infant's future development.

Looking for information—Some parents felt unsure of their infant's neurodevelopmental prognosis and indicated that they had not heard much about their infant's future or were looking for information. Others had heard a little, but described how the wide range of potential outcomes made it difficult to have concrete expectations. Parents expressed a tension between information overload and wanting to know more. One parent believed physicians were withholding information, and another reported having to 'pry' information about development from physicians. Those parents who did not receive information from physicians sought it elsewhere, including from bedside nurses (*n*=4), physical therapists (*n*=2), friends (*n*=2), or Facebook (*n*=1).

Theme 4: disability – parent experience and expectations for their infant's future

Prior experience—All but one parent detailed previous personal or professional exposures to disability. Some had a family member with a disability, including spina bifida, visual impairment, intellectual disability, and Down syndrome. Others described exposure to people with disabilities at work in their specific areas of expertise, including physical therapy, speech therapy, nursing, psychology, and education. Some shared their own diagnosis of a disability. Nearly half of parents reported some experience with people with CP, via summer camp, a respite house, patients, and friends. Those with prior experience with CP described the range of deficit involvement. Those parents without prior experiences with CP had misconceptions and confusion about the diagnosis.

Value placed on outcome—Parents were asked to consider which neurodevelopmental outcomes they felt were most important to their child's future. Many articulated that neurodevelopmental outcome was not important, with sentiments like 'what will be will be', or that survival was the only important outcome.

> 'Ma'am, to tell you the truth, I don't have no worry my baby going to talk or walk, whatever. As long as she's in my presence and care and she's still breathing and alive, I don't care'.
>
> (P14)

Others discussed that, regardless of infant outcome, they would adapt their parenting approach to make sure their child was set up to succeed. Most accepted the possibility of disability, and many described that their hopes and dreams for their child would not change if their child had a disability. One parent described concerns that the diagnosis of a disability would 'label' their child in a way that would limit their potential.

Some parents worried about specific kinds of disability. In descending order, parents prioritized cognitive skills (*n*=6), future independence (*n*=6), blindness (*n*=4), and 'quality of life' as reported by parents (*n*=3). A minority (*n*=2) worried most about motor skills or CP. Parents noted that prior experience with disability helped them see the range of possible outcomes, armed them with relevant skills, and contextualized what disability might mean for their family. For some parents, their prior experience with disability drove which outcomes they worried about most.

Lastly, we had too few fathers (n=4/19) to make definite assumptions about differences in paternal and maternal opinions on developmental screening. A brief analysis shows that the four parental dyads, when interviewed separately, did not differ on desire for screening tests, but within-pair differences were observed within the value placed on different potential outcomes.

DISCUSSION

Optimizing neurodevelopmental outcome after neonatal illness is a priority for parents, clinicians, and researchers. Early identification of infants at highest risk for disability is increasingly feasible and could catalyse interventions both in the NICU and after discharge to improve long-term outcomes.[15,16] In light of the increased use of early screening, we sought to identify parent perspectives on neurodevelopmental testing.

Parents either were in favour of neonatal screening in order to seek information to plan for the future or declined information on the basis of ‘what will be will be’. For a few families, disinterest in screening tests hinged on the idea that a positive result would not change infant management. This suggests that providers should ask parents to describe their prior experiences with screening tests, in pregnancy or with other children, to help the medical team explain neurodevelopmental screening in light of these previous experiences, and can highlight when early screening might change management. For example, in children at high risk for CP, environmental interventions focused on early motor learning can improve outcomes over standard care.[3,5,17]

Parents offered concrete suggestions about how to disclose and explain screening test results. Almost all wanted pretest counselling for emotional preparation. They felt results should be shared immediately, even in the stressful NICU environment, to give them time to process the new concerns, engage with early interventions, and begin family adaptations while surrounded by multidisciplinary supports. Even in the setting of a high-sensitivity and high-specificity screen, the chance for false-positive and false-negative results remained an important issue for parents.

Parental autonomy was important to parents. Despite the fact that only a few parents indicated that they would refuse the screening test, the vast majority thought that other parents should be able to refuse. Some parents were conflicted about why parents would refuse the test and debated if the child’s best interests should trump parental consent. These findings raise important questions about if and how to best inform parents about routine testing in the NICU. For example, in many NICUs screening tests, like the GMA examination, are performed without consent as part of routine physical therapy or neurodevelopmental examination. The debate of whether consent is needed for screening procedures, especially when early intervention could be effective, is echoed in other aspects of paediatric testing. The American Society of Human Genetics, for example, supports the current practice of newborn screening without consent but advocates for enhanced education so that parents are more aware of screening and their prerogative to opt out.[18,19] Our results suggest that, even in the setting of non-invasive and non-painful assessments, parents value the opportunity to be informed about, and potentially refuse, screening.

While many families had personal or professional experiences with disability, some parents knew very little about individual conditions or had broad misconceptions about the nature of individual disabilities. Previous experience with disability drove parent understanding of infant risk. These findings highlight the importance of assessing parents' baseline knowledge of disability, and providing additional education before discussing testing or disclosing results. Parent education materials and communication tools, like question prompt lists, may help clinicians assess parent information need and tailor counselling.[20]

Finally, parents had varied thoughts about which outcomes mattered most to them, with many prioritizing cognitive outcomes and future independence. Physicians and researchers have primarily chosen outcomes in neonatal research; parents may weigh the value of certain outcomes differently from clinicians. For example, while the majority of studies of neurological prognosis emphasize motor outcome, a minority of parents in this study cited motor outcome as a key concern. Moving forward, efforts to engage parents in the selection and development of outcomes should be encouraged.

This study is not without limitations. Our recruitment strategy may have decreased participation by families with limited resources. Parents were only approached if they were at the bedside and available for an interview; parents who were at work or performing other childcare duties were not as likely to be available. Our parents were highly educated, which may have affected their worries about disability and preferences for testing. The perspectives of non-English-speaking parents were not captured and warrant dedicated study. The infants in this study happened to be relatively low risk from a neurological standpoint, with only one infant with a grade 3 intraventricular haemorrhage. It is our routine practice to inform parents of the potential relationships of all grades of bleeding (from 1–4) with later developmental disability. It is possible that a cohort with higher average grades of intraventricular haemorrhage might have had different concerns regarding disability after receiving such counselling. Attitudes about testing may differ by ethnicity, previous pregnancy experience, and the presence of other children; our sample size did not allow for comparisons between these groups. Lastly, the interviews were performed and analysed by physicians; it is possible that additional responses or interpretations might have been garnered by social workers, counsellors, or other staff members.

Parents interpret the risks and benefits of developmental screening in the NICU through the lens of prior experiences with disability and choices about prenatal screening. Most expressed interest in screening for developmental disability but emphasized the importance of parent autonomy, pretest counselling, and emotional preparation for results disclosure.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS

GMA	General Movements Assessment
NICU	Neonatal intensive care unit

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What this paper adds:

- Most parents with infants in the neonatal intensive care unit expressed interest in early screening for developmental disability.
- Prior experience with disability informed concerns about specific deficits.
- Parents emphasized a desire for autonomy, pretest counselling, and emotional preparation.

Table 1:

Representative quotes – early screening for neurodevelopmental risk: parent perspective on theoretical neonatal intensive care unit screening

Perceived benefits of early developmental screening
‘At least in my mind I would know we’re being proactive and really trying to do something about it whether or not she may have it’ (P13). ‘I just can’t see how that would be negative. As long as the intervention is not invasive or painful, to me, it’s not a bad thing. If it was something that would have some kind of side effect to the child, then that wouldn’t be OK’ (P15). ‘It’s like speech therapy. It couldn’t hurt him to do speech therapy if he had a lisp or no. I would feel more confident, even if he doesn’t have it, to know that he’s already getting whatever it is, then to always be in the back of my head, “I wonder if he’d got it”‘ (P8).
Perceived negatives of early developmental screening
‘I think that you’re just going to cause yourself much more anxiety than you need to…there’s already so many things going on in this NICU world…I’m not one to put more trouble on us, or her, or the family’ (P16). ‘That’s a big focus on something that is negative…a lot of things could happen’ (P17).
Parent autonomy vs child’s interests
‘I don’t think that they should [refuse] because ultimately, it’s the right of the baby to be able to have that information when available’ (P1). ‘I’m thinking back again to some of those informed consents that I did for him. I had the right to refuse donor milk. I had the right to refuse the PICC line, even though it seemed to me that was obvious. Everybody gets a PICC line. I guess that we should have a right to refuse the test. That doesn’t make it morally right for a person or a parent to decide to do that. They have to understand going through the same paperwork like I did with those other things’ (P4). ‘We really try to make our decisions based on what’s best for him. If it gives us stress that doesn’t matter as long as he can get some benefit’ (P9). ‘I guess everyone deserves to have their own opinion on it, but if it’s going to help children I feel like everyone should just do it. But I feel like every parent has the right to decide what they know about their children’ (P7).

Parent study number is in parentheses. PICC, peripherally inserted central catheter.

Table 2:

Representative quotes – disclosure of results: parental approach to test results and their impact

Approach to testing and disclosing results
‘It’s important to me to be informed of what’s going on. I think it’s standard procedure to get a head scan and someone mentioned, “Oh, he has a haemorrhage in his brain”. And I was like, wait, wait, wait. How do you know? And they were like, “Oh, from the scan…it’s procedure”. Well, nobody told me about it. They eventually did another one a week later and it was fine, but I wish I would have been told so I could ask about it’ (P17). ‘I would want to get the results while he was here or as soon as possible, as soon as they’re available’ (P11). ‘It doesn’t matter to me [who tells us results] as long as the person is skilled and well-versed in what they’re talking about, and they’re basing it on research and facts. The person who can answer the most questions. If it’s an advanced practice person, if it’s a specialist, even if it’s a team of those folks. I would want the people who can answer the questions the best’ (P9). ‘I feel like if they could give the results while he’s still in the NICU, we have, as parents, more access to doctors to be able to ask follow-up questions as we think on them versus if we are already home, then the questions might not come until a couple of days later’ (P11).
Impact of false-positive results
‘I don’t know if there’s enough studies to know what the percentage of that go wrong, but I would want to know that when I got the results of the test. We think this is possible, but 70% of the time this is right, 30% it’s wrong. That’s up to then us, as parents, to decide what to do with that information’ (P8). ‘I think then more testing should be done before it’s actually done on baby subjects where there’s also a probability to affect their lives. Continue animals and other research testing before it’s run on us’ (P10). ‘Oftentimes things get tested, and you start projecting that. Nothing has actually proven to you yet that that exists, it’s just the test said there’s a probability…you start projecting certain behaviours on a child’ (P2). ‘It is a very emotional rollercoaster to go through…you too as a parent would be put through the therapies that are being used and learning this whole lifestyle that you may not actually need to be conditioned for’ (P16).

Parent study number is in parentheses. NICU, neonatal intensive care unit.