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Neurodevelopmental Risk: A Tool to Enhance Conversations With Families of Infants

Monica E. Lemmon, MD[1,2,3], **Hanna E. Huffstetler, BA**[3], **Pamela Donohue, MS**[4,5], **Madelaine Katz, BA**[3], **Mary C. Barks, BA**[3], **Emma Schindler, BA**[3], **Debra Brandon, PhD, RN, CCNS, FAAN**[1,6], **Renee D. Boss, MD**[4,7], **Peter A. Ubel, MD**[8]

[1]Department of Pediatrics, Duke University Medical Center, Durham, NC, USA

[2]Department of Neurology, Johns Hopkins Hospital, Baltimore, MD, USA

[3]Margolis Center for Health Policy, Duke University, Durham, DC, USA

[4]Division of Neonatology, Department of Pediatrics, Johns Hopkins Hospital, Baltimore, MD, USA

[5]Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, USA

[6]School of Nursing, Duke University, Durham, NC, USA

[7]Johns Hopkins Berman Institute of Bioethics, Baltimore, MD, USA

[8]Fuqua School of Business, Sanford School of Public Policy, School of Medicine, Duke University, Durham, NC, USA

Abstract

Parents of infants at risk of neurodevelopmental impairment require clear and individualized information about what to expect for their child, yet data suggest they have difficulty knowing how to ask for this information. Here, we pilot a Question Prompt List (QPL) with parents of infants at risk of neurodevelopmental impairment. To assess real-time use of the QPL, we recorded family meetings and collected data from parents and clinicians about the QPL experience. Qualitative data were analyzed using directed content analysis. Ten parents were enrolled. In family meetings, clinicians universally acknowledged the QPL and most used the QPL to guide meeting content.

Corresponding Author: Monica E. Lemmon, MD, Department of Pediatrics, Duke University Medical Center, Durham, NC 27710, USA. monica.lemmon@duke.edu.

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ML conceived of the study, led the analysis and interpretation of data, and drafted the manuscript. HH aided in data analysis, interpretation, and drafted the manuscript. PD aided in study conception, study design, and data interpretation. MK aided in data acquisition, data analysis, and interpretation. MCB aided in the data analysis and interpretation. ES aided in data analysis and interpretation. DB aided in study conception, data analysis, and data interpretation. RB aided in study conception, study design, and data interpretation. PU aided in study conception, study design, and data interpretation. All authors critically reviewed the manuscript and gave final approval.

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Madelaine Katz is now affiliated with Gillings School of Global Public Health, University of North Carolina.

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Approval was obtained from the Duke University Institutional Review Board (Pro00077143); all participants provided written consent.

All parents who used the QPL found it useful and would recommend the tool to others. In interviews, parents described that the QPL offered novel questions and facilitated more prepared answers from the team. Future studies should test the impact of this QPL on parent understanding and communication quality.

Keywords

question prompt list; communication; neonate; neurology

Effective communication between doctors and patients is the foundation of high-quality health care, especially in the context of serious illness.[1] For hospitalized infants at risk of neurologic impairment, their course can be a frightening, overwhelming, and stressful experience for families.[2–4] Data from parents show that good communication with clinicians improves their experience in the neonatal intensive care unit[5,6] and frames how they make important care decisions for their child.[7,8] Yet the urgency and complexity of neonatal intensive care can undermine this communication, which can impede family understanding of infant condition and may leave parents unsure of what questions to ask.[7]

Existing data demonstrate that patients and families ask few questions of clinicians, even in high-stakes clinical encounters.[9] Yet it is clear that families participate more meaningfully in decision making when clinicians invite them to discuss their specific questions or concerns.[9] Question prompt lists (QPLs) are one promising communication tool for improving these interactions. QPLs provide families with a condition-specific list of suggested questions that they can ask clinicians, and appear to increase question-asking in the context of doctor-patient consultations.[8,10,11] Two QPLs have previously been designed for the pediatric setting. One targets parents of children recently diagnosed with attention-deficit hyperactivity disorder (ADHD); parents and clinicians universally found the tool to be useful and to facilitate question-asking.[10,12] Another targets adolescent asthma; most users had very positive feedback about the QPL[13] and found that it facilitated youth question-asking.[11]

In previous work, our team developed a QPL for parents of infants with neurologic conditions in the neonatal intensive care unit. The QPL content was universally endorsed by parents and clinicians; content domains include communicating with the medical team, the big picture, making decisions with the medical team, infant development, and preparing for life at home. Condition-specific domains include seizures, therapeutic hypothermia, gastrostomy tube placement, and ventriculoperitoneal shunt placement.[14] This tool is novel compared to existing QPLs in that it provides both a workbook of suggested questions for parents and a worksheet where parents can indicate high priority questions to share with clinicians before a family meeting. Here, we pilot this QPL in the neonatal intensive care unit, examining real-time use in recorded family meetings. Our objectives were to (1) determine the feasibility of QPL use in a family meeting, (2) examine QPL acceptability to parents and clinicians, and (3) characterize QPL use in family-clinician meetings.

Methods

Subjects and Recruitment

This was a prospective, pilot study of neonatal intensive care unit infants, their families, and their clinicians. Parents were eligible if they had a scheduled family meeting and if their infant was at risk of neurodevelopmental impairment. Parents were excluded if (1) infant death was anticipated within 72 hours of study enrollment, (2) the expected neonatal intensive care unit stay was less than 72 hours, or (3) they did not speak English. The clinician who led the family meeting was also enrolled and all participants in family meetings provided written consent for audio-recording.

Study Design

Upon enrollment, study team members introduced the QPL workbook to parents using a standardized verbal script, which included an introduction to the tool and discussed that not all QPL content would apply to them or their child. Parents then completed a baseline survey that assessed demographic information and initial satisfaction with the tool.[15,16] Once they reviewed the QPL workbook, parents completed the worksheet in which they identified up to 3 high-priority questions; the worksheet was shared with the health care team prior to the audio-recorded family meeting. Shortly after the family meeting, clinicians and parents were surveyed about their satisfaction with the QPL.[15,16] Within the following week, parents also completed an audio-recorded, semistructured interview about their experience using the QPL. Recordings from the family meetings and parent interviews were transcribed and deidentified.

Data Analysis

Descriptive statistics were used to summarize survey data. Family meetings and parent interviews were analyzed using a directed content analysis approach.[17] Directed content analysis is a method of qualitative data analysis that uses existing theory-relevant research to guide the synthesis of data and generation of themes.[18] For family meetings, a coding manual was developed to ensure relevant data from the family meetings were captured. Parent/caregiver statements seeking a response from the health care team during the family meetings were coded as questions. To characterize QPL use, 4 study team members reviewed meeting transcripts and came to consensus on if and how the QPL was used in each meeting. For parent interviews, content targeted for analysis included parent experience, satisfaction, and concerns with the QPL, as well as suggestions for improvement.

Results

Participant and Meeting Characteristics

Ten parents of 11 infants enrolled in the pilot study; 1 parent was the mother of twins. One parent declined to use the QPL. Although all parents were invited to enroll in the study, only 1 parent per infant enrolled, and parents identified themselves as the infant's mother in all cases. Infant and maternal characteristics are shown in Table 1. The majority of infants were premature; some had neonatal seizures, hypoxic ischemic encephalopathy, and brain malformations. All infants were mechanically ventilated, and nearly two-thirds required gastrostomy tube placement. Three infants died, 2 died before discharge. All but 2 parents (78%) had no prior experience with a family member in an intensive care unit. Overall, parents were highly educated; most (89%) had education after high school.

For each case enrolled, one family meeting was recorded. Meeting characteristics are shown in Table 2. Nearly all meetings included an attending neonatologist, who led the meeting in all but one case. Most meetings additionally included a social worker and at least 1 consultant physician, most often a neurologist. In one meeting where an attending neonatologist was not present, the parents co-led the discussion and used the questions listed in their QPL worksheet as a guide to do so. Meetings uniformly included discussion of the infant’s status. Most meetings also included discussion of vision or neurologic development and the need for or results of neurologic testing, including MRI, electroencephalography, or electromyography.

QPL Acceptability

Survey data on parent and clinician satisfaction with the QPL is found in Table 3. Parents uniformly agreed that the questions in the QPL workbook were useful. Nearly all parents (n = 9, 100%) and clinicians (n = 9, 90%) would recommend the tool to other neonatal intensive care unit parents. The majority of parents (n = 6, 67%) and clinicians (n = 7, 70%) agreed that the QPL helped them prepare for the family meeting; many parents agreed that it made it easier for them to ask questions and put their thoughts into words (n = 7, 78%). No parents found the QPL to be overwhelming. All parents who used the QPL (n = 9) completed a semistructured interview. The interviews highlighted a unanimously positive view of the QPL, and all participants felt the tool was useful. Many (n ¼ 5) felt that the QPL would be useful to them in the future; those who did not gave suggestions for how to improve the value of the tool, including providing it earlier in the hospital stay and farther in advance of their meeting (n = 5). One parent noted that some of the questions made her anxious; subsequent interviews indicated that questions about infant death were particularly difficult to read. Most parents, however, acknowledged that they were necessary to include.

In interviews, parents provided insight into how both the QPL workbook and worksheet benefited the communication with their health care team and could be optimized in future work. Representative quotes can be found in Table 4. Participants expressed that the QPL workbook and worksheet improved their communication with their health care team in 2 major ways. First, the QPL workbook presented novel content that the families had not previously thought to ask (n = 5). Most families expressed that while they had already generated questions about their baby’s care on their own, the QPL workbook brought up topics and items that they did not know to ask, were unsure how to ask, or did not know if it was appropriate to ask in family meetings (n = 7). Parents described that the QPL helped them realize that certain types of questions were “on the table,” or that it gave them “permission” to ask about a given topic. Second, parents appreciated the opportunity to share their questions with their child’s health care team in advance of the meeting via the QPL worksheet. Families specifically valued that their health care team was already aware of their high-priority questions before going into the meeting, and described clearer communication and better-prepared answers from the team:

> I think in this [family meeting], since the providers had a chance to see some of my questions, they were a little bit more prepared. I think they were more able to anticipate my reaction or my emotions in it. (case 6)

Suggestions for Improving QPL

Participants offered suggestions for how the QPL process could be improved. First, parents wanted to receive the QPL workbook earlier in their neonatal intensive care unit stay or earlier in advance of the family meeting (n = 5). As described in Table 1, the infants in this study were in the neonatal intensive care unit for a median of 7 weeks before the families received the QPL. Parents described the first few weeks in the neonatal intensive care unit as overwhelming and hectic, and felt the tool would have helped during that critical time. As said by one mother:

> I joked at the very beginning that I had a crash course in medical school. It was like those first 3 weeks were just overloaded with information and that would’ve been incredibly helpful to have at that point in time. That’s [the QPL] like the perfect thing to hand to a new mom. (case 1)

Second, while all parents appreciated a paper QPL format, a couple of parents would have additionally appreciated an online version that they could share with other family members who were not at the hospital (n = 2).

Impact of QPL on Family Meetings

The QPL was referenced by clinicians in all recorded meetings; we observed clinicians using the QPL in 3 ways. First, clinicians would explicitly address each of the parents’ questions listed on the QPLworksheet one-by-one and/or “circle back” to the questions at meeting end. In one meeting where no attending physician was present to lead the discussion, the QPL was used as a template for the content and order of the entire conversation. Second, clinicians interspersed QPL worksheet questions into their regular meeting flow. In these cases, clinicians would reference the list, then proceed with the meeting by reviewing infant status by system or issue, addressing parents’ listed questions along the way. Third, the QPL worksheet was acknowledged at the beginning of the meeting; however, clinicians proceeded to discuss alternate information chiefly unrelated to the questions listed in the worksheet. This happened in one family meeting; even in this meeting, mom later reflected that the QPL facilitated more prepared discussion from the team.

In cases where 2 parents were present, both were involved in formulating or asking questions from the QPL. Parents asked a median of 20 questions in family meetings; however, in 2 family meetings, parents asked more than 40 questions each. Parents listed an average of 8 questions on their QPL worksheet (range: 2–14). No questions from the QPL sections on gastrostomy tubes, seizures, ventriculoperitoneal shunts, or therapeutic hypothermia were listed by parents on the QPLworksheet. When reviewing all questions asked by parents in family meetings, 23 of the 162 questions (14%) asked during the family meeting coincided with questions from the QPL. The majority of these (52%) were taken from the QPL sections about the "Big Picture (Supplemental Data)." Even questions that were not from the "Big Picture" sections of the QPL still concerned big picture topics such as communication between clinicians and families in the neonatal intensive care unit and long-term outcome. All other question types were listed infrequently on the QPL worksheets, and were only discussed in 1 or 2 family meetings.

Some questions in the QPL were difficult to answer for individual children (for example, "Can you tell me what caused my baby's problems?"). When these questions arose in family meetings, clinicians did not always know the answer, but still addressed parents' concerns in useful ways. For example, clinicians acknowledged the importance of the question and forecasted when this information would become available. Many clinicians engaged other team members—social workers, specialists, bedside nurses—to help answer questions that were outside of their personal scope (for example, "How do other families cope with uncertainty?").

Discussion

Clinicians caring for infants with serious illness are tasked with communicating complex information about neurodevelopmental risk and infant outcome, often amidst significant clinical uncertainty. This is the first study to characterize the use of a communication tool in this context, and the first study of a QPL in a multidisciplinary meeting. Most parents and clinicians found the QPL workbook and worksheet to be useful, reporting that the tool helped them prepare for the family meeting, would be helpful in the future, and they would recommend the QPL to other families. These findings support previous data suggesting that QPLs are powerful communication tools in both adult and pediatric care.[19–23] Our prior work suggests that parents of critically ill children may find it hard to (1) know what questions to ask of the medical team, (2) see the big picture of their infant's condition, and (3) feel empowered to ask questions in a family meeting setting; this pilot study suggests that the QPL can address all of these challenges.[24]

The QPL was meaningfully used in nearly all recorded meetings and was used to guide the meeting the majority of the time. All meetings included at least an acknowledgment of parents' listed questions at meeting start. Although this study's design limits our ability to compare QPL–driven meetings to standard care, meeting content and clinician feedback suggest that the presence of the QPL workbook and worksheet changed the way in which meetings were run and ensured parent-prioritized content was addressed.

Although the QPL workbook contained 10 categories, the overwhelming majority of parent-selected content came from the "Big Picture" section. Even questions that parents came up with on their own targeted big picture information. Taken together, this finding suggests that when parents are prompted to think beyond the daily details of intensive care, they want to know more about their infant's future and what life might look like at home. Further, QPL questions represented a minority of total question content; parents were only prompted to identify up to 3 high-priority questions. We propose that the value of this intervention is not in the sheer number of questions asked, but instead in its ability to ensure parent-important content is addressed. Parent-generated questions not currently included in the QPL will be used for further refinement of the intervention.

In our initial development of this tool, 2 main concerns were voiced by parents and clinicians.[25] First, both groups raised concern that questions about death would be alarming to families. Although a minority of parents did endorse that these questions made them anxious, all parents in the current study noted them to be important and necessary to include. Second, clinicians voiced concern that many of the questions may be too difficult to answer for an individual family. Here, we showed the ways in which clinicians navigated their own uncertainty and made a plan with families to provide additional information as it was available.

Parents offered important suggestions on how to improve the QPL. Our results suggest that future QPLs for this population should (1) focus on big picture content, (2) be provided to families early in the hospital course, and (3) be adapted for digital use. The QPL includes content that could be relevant at different times in the hospital course; for example, parents may need additional information about communicating with their team early in the hospitalization, while information about preparing for life at home is most appropriate at discharge. Additional areas of study should include longitudinal QPL use, incorporation of QPLs into the outpatient setting, and adaptation of this QPL to other neurology patient populations. Neurologists are often involved in high-stakes conversations with patients and families about outcome; our results suggest that QPLs may be particularly useful in this setting.

This study had several limitations. This pilot study targeted acceptability; important next steps include determining the impact of QPL use on communication quality as compared to standard care. We did not characterize physician or parent meeting goals; future work should explore whether a QPL can help align parent and physician agendas. Many families articulated planning to continue to use the QPL after study end; longitudinal QPL use warrants additional study. We chose to audio-record meetings to minimize intrusion, though videotaping meetings may have yielded additional information on nonverbal cues. This study occurred at a single tertiary care center with a highly educated parent sample, and results may not be generalizable to other health care settings. One family declined to use the QPL, suggesting that this tool may not be valued equally by all parents. Finally, our parent sample was exclusively mothers; the perspectives of other family members warrants additional study.

Parents and clinicians valued the use of a QPL in high-stakes family meetings for infants at neurodevelopmental risk. Future research should examine the impact of a QPL on parent engagement and decision making in the intensive care unit. Communication and decision support tools represent promising strategies to improve care for pediatric neurology patients and the families who care for them.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Infant and Maternal Characteristics.

Characteristic	Median (range) or n (%)
Infant characteristics (n = 11) Gestational age at birth, wk	35 (23–40)
Age at enrollment, wk	7 (1–29)
Medical conditions	
Prematurity	7 (64)
Brain malformation	3 (27)
Congenital heart disease	3 (27)
Seizures	3 (27)
Hypoxic ischemic encephalopathy (HIE)	2 (18)
Intraventricular hemorrhage	1 (9)
Medical complexity	
Mechanical ventilation	11 (100)
Gastrostomy tube	7 (64)
Tracheostomy	2 (18)
Days on the ventilator	31 (4–190)
Care coordination	
Palliative care	7 (64)
Pastoral care	7 (64)
Number of family meetings	2 (1–6)
Maternal characteristics (n = 10) Age, y	
Age, y	28 (22–36)
Previous involvement as family member of patient in ICU*	2 (22)
Race and ethnicity	
White	7 (70)
African American	3 (30)
Hispanic	1 (10)
Native American	1 (10)
Level of education	
High school or some college	3 (30)
Associates or technical degree	2 (20)
Bachelor’s degree	3 (30)
Graduate degree	2 (20)
Annual income*	
<$10 000	1 (11)
$20 000-$30 000	1 (11)
$60 000-$70 000	1 (11)
>$100 000	2 (22)
Not reported	4 (44)

Table 2.

Meeting Characteristics.

Meeting characteristics (n = 9)	**n (%)**
Family members	
Mother	9 (100)
Father	5 (56)
Grandmother	1 (11)
Grandfather	1 (11)
Other	1 (11)
Health care team members	
Neonatology attending physician	8 (89)
Social worker	7 (78)
Consultant physician[a]	6 (67)
Nurse practitioner	6 (67)
Bedside nurse	4 (44)
Palliative care	3 (33)
Other[b]	8 (89)
Content addressed	
Infant status update	9 (100)
Discharge preparation	8 (89)
Medical equipment	8 (89)
Infant development and outcome	7 (78)
Neurologic testing	7 (78)

[a] Consultant physicians included representatives from neurology, neurosurgery, cardiology, endocrinology, and ophthalmology.

[b] Other participants included fellows, residents, medical students, and speech therapists.

Table 3.

QPL Acceptability: Parent and Clinician Survey.

	Parents (n = 9)[a]	Clinicians (n = 10)
QPL would help me prepare for the family meeting	4 (3–5)	4 (1–5)
Questions easy to understand	5 (4–5)	4 (1–5)
QPL would make it easier for me to ask questions	5 (3–5)	–
Questions were useful to me	5 (4–5)	–
Helped me think of questions I had not thought of before	4 (1–5)	4 (1–5)
Helped me put some of my questions into words	4 (2–5)	–
Some questions make me anxious	2 (1–4)	–
It was overwhelming to read	1 (1–2)	–
QPL will be useful in the future	4 (3–5)	4 (1–5)
Would recommend QPL to other parents	4 (4–5)	4.5 (1–5)

Abbreviation: QPL, Question Prompt List.

[a] The parent that did not utilize the QPL also did not complete the acceptability survey. Survey responses were obtained using a 5-point Likert scale, strongly disagree (1) to strongly agree (5). Responses are reported as median (range).

Table 4.

QPL Acceptability: Representative Quotes From Parent Interviews.

QPL content
It helped me to open my brain up to other questions that I could be asking. (case 9).
It helped me think of questions that I wanted to ask and it asked questions that I wanted to ask that I hadn't quite, that I hadn't thought of myself. (case 3).
The questions that deal with loss were very hard....It made me process things and think about things that I hadn't previously considered before, which is fine. It's important. It absolutely should be in there. It just, it makes you sad. (case 1).
Like this, to have some of those general questions that I probably wouldn't have thought of or maybe would have tried to ask a different way but it wouldn't be as specific. (case 10).
QPL optimization
If there was some kind of online…my husband wasn't able to come every day and we really weren't able to put our heads together and talk about things that we wanted to add. (case 3).
Somebody sitting down and explaining what the book is, the questions, "here are questions you can ask your team at rounds or at a family meeting" … if that was given in the beginning and someone said "oh, I know this seems overwhelming because it's a lot of questions, but these are questions that you might have that they can answer if you ask them." You just don't know to ask. (case 7).
It would have been useful to have it a little bit earlier just to have more time to go through it, but that might just have a lot to do with my situation. We've had another baby…so we just didn't have a whole lot of time to get it done but we did get it done, I mean it was enough time, I just, it would have been nice to have a little bit more. (case 5).
Impact on communication
We liked especially some of the questions in there about finances and how much it was going to cost, because those are questions we had but we weren't sure if those were questions that were appropriate during the family meeting…so it was nice to see those listed in the QPL, just knowing that those could be options to discuss. (case 4)
And even just having that [QPL worksheet] for a family meeting. They just become overwhelming…going into a family meeting is very intimidating especially when there's lots of people involved. We've had upwards of 15 to 20 people plus people on the phone and it's hard to remember what you want to say and it gets emotional. I think it's really helpful in those situations, especially when it's something that's sensitive or emotional or hard to talk about. (case 7).
[The QPL helped me get the information I needed by] making the doctors accountable and answer the questions that haven't been answered, and making them look at my face and hear my questions, and see my concern. That I'm not trying to be difficult, but I'm a parent. (case 5)

Abbreviation: QPL, Question Prompt List.