Enhancing NICU Care and Communication: Perspectives of Moderately Preterm Infant Parents

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abstract

BACKGROUND: Moderately preterm infants (MPTI) comprise a large proportion of NICU admissions and are an understudied population. The unique experience of families with MPTIs has yet to be examined in the literature. Describing MPTI parent needs and preferences may inform interventions to improve care and outcomes for this population.

METHODS: Semistructured qualitative interviews were performed with English-speaking birth parents of infants born between 32 and 34 weeks gestation to describe their NICU experience and identify areas for improvement specifically surrounding care team inclusion, education, discharge, and communication. Interviews were recorded, transcribed, and analyzed using directed content analysis. Enrollment ceased when the data reached thematic saturation.

RESULTS: Sixteen birth parents participated. Four themes emerged around parent-medical team connectedness, parental confusion, discharge readiness, and the desire for a use of a mix of in-person and electronic communication methods (e-mail, texting, apps, etc) for communication. MPTI parents valued a strong connection with the medical team; however, they described a lack of knowledge regarding the reasons for admission and ongoing management. Near discharge, parents desired more information regarding feeding, reflux, and breathing patterns. Parents preferred in-person discussions but described a role for electronic methods to improve their understanding of their infant and discharge readiness.

CONCLUSIONS: From the MPTI parent perspective, clinicians can focus improvement efforts on communication, specifically around reasons for admission, discharge planning, and anticipatory guidance. These results may serve as a foundation for initiatives to improve the MPTI parent experience and potentially parent and MPTI outcomes.

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DOI: https://doi.org/10.1542/peds.2023-064419

Accepted for publication Mar 5, 2024

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

WHAT'S KNOWN ON THIS SUBJECT: The NICU admission is stressful for many parents and some are unprepared for discharge. Parental stress level does not correlate with infant illness severity. Previous research has largely focused on parents of extremely and very preterm infants.

WHAT THIS STUDY ADDS: To our knowledge, no researchers have examined the moderately preterm infant parent NICU experience despite this population's prevalence. Our study describes knowledge gaps, discharge preparedness, and communication preferences of moderately preterm infant parents.

To cite: Osborne AD, Worsley D, Cullen C, et al. Enhancing NICU Care and Communication: Perspectives of Moderately Preterm Infant Parents. *Pediatrics*. 2024;153(6):e2023064419

Most families do not expect to have a preterm infant that needs admission to the NICU. Understandably, parents have described feeling disempowered, stressed, and anxious during their infant's NICU admission.[1,2] Additionally, many parents feel unprepared for discharge and to care for their preterm child at home.[3] An important role of NICU staff is supporting and adequately preparing families for discharge to enable the infant and family to thrive at home.[2,3]

The majority of premature infants are born moderately to late preterm (32–36 weeks), compared with very or extremely preterm (<32 weeks).[4] In 2021, 10.5% of live births in the United States were premature, of which 85% were moderately to late preterm.[4] Despite moderately preterm infants (MPTI) being a large population of NICU admissions, these infants and their families are rarely the focus of research. Standards of MPTI medical care have been extrapolated from the care of extremely preterm and full-term babies,[5] of which they are neither. The NICU experience of MPTI parents may differ from parents of infants born at younger gestational ages, as MPTIs are often the most stable NICU patients and may have less frequent or briefer interactions with providers. However, MPTIs remain at risk for many adverse outcomes of prematurity.[5–7] Their admissions are often weeks in length because of feeding immaturity, apnea of prematurity, and immature thermoregulation. Long term, MPTIs are at risk for respiratory problems, rehospitalizations, and neurodevelopmental disability,[7,8] and it is imperative NICUs adequately support MPTIs and their families.

Active parental engagement and support during admission is an important initial step to prepare families for success at home. The greatest source of parental stress during NICU admission is the alteration of the parental role. The level of this stress cannot be predicted based on the child's gestational age or severity of illness.[9] Parents of a MPTI with an uncomplicated NICU stay may still experience a great deal of stress. Maternal emotional well-being, infant readmissions, and healthcare cost may be improved with family-centered care (FCC) interventions and adequate parental discharge readiness.[3,10] FCC is a healthcare delivery philosophy that recognizes and respects the family as an integral part of the healthcare team and has become a strategy to promote parental empowerment and improve outcomes.[10] Little is known about the MPTI birth parent NICU experience. Learning more about the MPTI parent experience may inform targeted interventions to improve care and outcomes for this relatively large population. Therefore, in this study we aimed to identify opportunities for improvement by describing the experience of MPTI parents in our NICU.

METHODS

We conducted a qualitative study using semistructured interviews among parents of preterm infants born between 32 weeks + 0 days and 34 weeks + 6 days gestation to describe the experience, knowledge gaps, and communication preferences of MPTI parents. The study team consisted of 2 experienced qualitative researchers and 3 physicians with qualitative research experience. Parents with infants born ≥35 weeks were excluded as these infants were not routinely admitted to the study NICU. Data were collected between November 2021 and February 2022. The study met criteria for IRB review exemption. Parents were excluded if English was not their preferred language or if their child was deceased. Eligible participants were invited to participate sequentially near their infant's discharge date by an investigator either in-person or over the phone. Eligible parents were provided a study information sheet. If an eligible parent was interested in participating, an investigator called or emailed according to the parent's preference 1 to 2 weeks after the infant's discharge to schedule the interview. All parents who chose to participate provided verbal consent. One author (A.O.) intermittently provided care to some of the participants' infants; in these cases, the interview was performed by another investigator.

The interview guide was developed by reviewing existing literature and using FCC as a shaping concept with the intention of understanding perspectives about parent knowledge of their infant's condition, discharge preparedness, and communication preferences (Supplement). The guide was developed iteratively by all authors as interviews progressed to encompass the most salient topics to participants. After the first 4 interviews, 2 trained qualitative researchers (A.O. and D.W.) refined the questions and broadened the scope to allow the guide to be more open-ended and elicit more in-depth responses about participants' experiences. Thematic saturation was reached after interviewing 15 birth parents, and 1 additional interview was completed as previously scheduled. Parent and infant demographic data were obtained via self-reported questionnaire. Each participant received a $15 gift card for their time.

This study took place at a 38-bed urban Level III NICU within a birthing hospital staffed with pediatric trainees, fellows, and advanced practice providers in addition to nurses, social workers, lactation consultants, and attending neonatologists. Upon admission, a standardized NICU orientation is provided by nursing. This may occur all at once or be introduced over time depending on the family's needs. The NICU is an open pod design with limited availability of overnight rooms and no time visitation restrictions for parents. Daily rounds occur at the patient's bedside to include parents if present. If no parents are present for rounds, they are updated daily by phone. For extremely preterm infant families, meetings with the medical team are scheduled at 1 week, 1 month, and at 34 weeks postmenstrual age; the unit does not have formal meeting recommendations for MPTI families.

Interviews were audio recorded and transcribed verbatim with identifying information removed from the transcripts. Transcription was completed by a third-party transcription company. NVivo 12 software[11] was used for facilitating coding and data organization. Interviews were conducted over the phone at a mean of 32 days post infant discharge. Interviews lasted between 25 and 45 minutes. Data were analyzed using directed content analysis.[12] Responses to open-ended questions were analyzed using standard methods of inductive theory-building and the constant comparative method to develop a modified grounded theory about aspects of MPTI parents' receipt of FCC, including knowledge sharing, communication, and discharge preparedness.[13] Transcripts were reviewed by 2 researchers (A.O. and D.W.) and independently coded. The coding team met frequently to discuss discrepancies. The first phase of open coding generated a codebook with salient themes. In the second phase of axial coding, code definitions and the codebook were further refined to determine detailed concepts suggested by the data. Themes were developed across all codes through team discussion and consensus. Member checking was performed during data collection and postanalysis to affirm validity of results.

RESULTS

Thirty-nine birth parents were approached for study recruitment, with 16 parents (41%) completing the interview. One parent declined participation, 4 parents did not respond to initial outreach, and 18 parents who were interested in participating were unable to be reached by investigators despite multiple attempts. All participants identified as female. Fourteen singleton and 2 twin parents were interviewed. One-fourth of participants had prior experience with preterm infants, and the median birth gestational age was 34 weeks with a median length of stay of 21 days. Fifty-six percent self-identified as Black and approximately half of the participants had a household income of under $50k and were enrolled in federal benefit programs (Table 1); this is reflective of the patient population of the study site. Four themes emerged from the interviews (Table 2).

Theme 1: Medical Care Team Inclusion and Connection

Overall, most parents felt they were well-supported by NICU staff during their child's admission, particularly by nurses. Several parents reported feeling "part of the team." It was helpful for parents to be present on rounds and be included in care discussions. They acknowledged they did not always understand the medical complexities, but appreciated being present and found that writing down questions to ask later was helpful. Parents turned to the nurses for clarification and felt the nurses "did an excellent job educating." They appreciated how each nurse had a different way of explaining information, which helped parents better understand their infant. Parents described NICU staff as "very welcoming" and appreciated staff that made frequent calls to them when they were not physically present.

Parents formed their strongest connection with the nurses and described them as "phenomenal." Nurses were families' main contact and staff source of prematurity education. Nurses were viewed as empathetic, patient, and understanding. Parents' trust in NICU staff was developed through their relationships with nurses. Some parents noted that they sympathized with the difficulties of being a NICU nurse and

TABLE 1 Participant Characteristics

Birth Parent and Infant Characteristics (parent *n* = 16, infant *n* = 18)	
Gestational age, median (IQR)	34 w 0 d (32 w 5 d, 34 w 4 d)
Length of admission, median days (IQR)	21 (12–30)
Infant age at interview, median days (IQR)	51 (37–63)
Birth parent age, mean years ± SD (range)	31 ± 7 (18–42)
Female, %	100
Race, %	
White	44
Black	56
Spanish, Hispanic or Latinx origin, %	0
College degree, %	44
Married or live-in partner, %	75
Other children, %	38
Prior experience with preterm infants, %	25
Receiving WIC or SNAP, %	50
Household income < $50K per year, %	54 (*n* = 13)
Personal cell phone with internet access, %	100

IQR, interquartile range; SNAP, supplemental nutritional assistance program, WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

TABLE 2 Major Themes and Quotes from Participants

Theme	Supporting Quotes
Medical team inclusion and connection: Parents overall felt well-supported in the NICU, mainly attributable to the nurses' support, but reported mixed feelings about the connectedness and inclusion with their care teams.	"I just think being parents of any NICU child is really scary. So, if the doctors could take more time and just sit down with you. I understand that they have 50 other babies that they have to attend to and families and that kind of stuff, but I would just feel – if they could just sit down for a little, really explain to you what is going on" (ID 5). "I was always included in everything that went on with my son, any decisions that they made, they always talked to me about everything before anything" (ID 44). "It was a really traumatic experience in many ways, but your staff made everything so much better … Some of the nurses there, I just, I think that they are just the kindest, smartest, most wonderful people" (ID 14). "I talked to them, I done cried in front of them, I was able to always express myself without judgment around them" (ID 36).
Confusion regarding NICU care: Parents felt confusion around the reason for NICU admission and the ongoing NICU care.	"I wish I received more support when it came down to the medical aspects of it. For someone who never had a premature baby, I didn't understand anything that was going on. Just literally all of the medical terminology that came with her being so early, I wish I kinda had it dumbed down for me" (ID 20). "Honestly, to this day, I still don't really know why he was admitted" (ID 5). "Communication needs to be super, super clear, they [NICU staff] all need to be on the same page" (ID 25).
Discharge readiness: Parents felt prepared for discharge; however, they reported wanting more lead time about the anticipated discharge date.	"They did rounds on Monday and was like oh she's going home tomorrow, so there was literally no time for me to prepare mentally, physically, or anything like that" (ID 36). "The only thing that I would have liked, although I understand why this did not happen, is a better sense of the timeline sooner … I would ask every day, and everyone would be like well, we can't really say, and then it was just 1 day, they were like oh, she's going home tomorrow, and it was wow, it was sort of a huge shock" (ID 4). "My husband and I teased that we don't know how our friends who didn't have NICU experiences take their kids home. We felt so much more educated and prepared to take our son home to know how to feed, know how to burp, how to dress and diaper, so I think that we felt really well prepared from a perspective of feeding, changing, diapering, et cetera" (ID 31). "I was not that comfortable. I was overwhelmed again, and I was scared" (ID 23). "It was just a lot all at once, so I didn't expect that, I was just coming up there to see her, so I literally came up there and then not only that, I was by myself. My husband was at work, my mom was at work, so I was by myself, and I had to, I came in there probably for about 5 minutes and I had to leave right back out to go back to get her car seat and stuff like that. I was prepared, but I wasn't prepared and then not only that, I was still scared and worried and I know that I'm a good mom, we have that in us, but it's just I've never experienced this before with having a baby that early." (ID 19)
Methods of communication: Parents currently use and desire a mix of in-person and electronic methods (e-mail, texting, apps, etc) for routine information and communication.	"[To learn about prematurity,] I did some Googling, read up online about issues with prematurity and specifically, her gestational age and prematurity, what is likely from that point, but it was mostly probably talking to the NICU staff and then her doctors" (ID 11). [In response to how they learned about their preterm infant: "I mean social media for sure, internet for sure. That's probably the main basis that we got our information" (ID 14). "I wish they gave us some information to take home versus just going over it." (ID 9) "Honestly, it all depends on the situation. I can, I always like to talk over the phone. Email is always good and face to face is always better" (ID 3). "I'm sure websites or handouts would be helpful, just something you can go back and reference, or texting for something like that" (ID 23).

appreciated how their work may affect their communication with parents.

There were some parents who did not feel comfortable speaking with the care team. These parents cited lack of privacy in the unit and difficulty forming a relationship with the team. Additionally, some parents were unsure how to contact their infant's physician, but they knew they could reach a nurse at any time.

Theme 2: Confusion Regarding NICU Care

Although parents overall felt supported by clinicians during their child's admission, they experienced confusion over their child's care plan. Suboptimal communication with medical providers contributed to their confusion. Mothers often remembered meeting a neonatology provider before delivery but reported they were unable to internalize information about the NICU and prematurity at that time. Parents voiced that they did not understand the reasons for NICU admission, their infant's daily plan, or the equipment and technology being used. Specifically, the alarms of monitors was very distressing to parents. They wished for more education regarding monitors and vital signs from staff rather than needing to educate themselves. Additionally, parents described wishing for use of less medical terminology as this contributed to their anxiety and made it difficult for them to participate in shared decision making. They received frequent medical updates from physicians and staff, but reported wanting to often know more details than what was provided.

Parents reported care plans and event interpretations differed between physicians, front line clinicians, and nurses, which added to their confusion. Parents perceived not all members of the medical team were aware of updates and suggested team communication could be improved with high-quality handoffs at shift change.

Theme 3: Discharge Readiness

When asked about discharge readiness, most parents felt prepared to take care of their preterm infant at home. In fact, several parents felt they may be more prepared to care for their infant than a first-time parent who did not have an infant hospitalized in the NICU because of the education and support they received. Parents appreciated both the prematurity-specific anticipatory guidance and routine infant care education (ie, preparing formula, bathing, setting up the car seat). Nevertheless, they commonly described being "scared" and "anxious" around the time of discharge because of feeling "on my own" after discharge. First-time parents were more apprehensive to bring their preterm infant home than parents who had other children.

Although overall prepared, parents wished they had more notice of the planned discharge date and described the process as "rushed." Many parents reported asking daily about discharge and were still surprised on the ultimate discharge date.

After discharge, parents described continuing to have unanswered questions. They worried about apnea of prematurity and had concerns about not being able to recognize abnormal respirations. Additionally, they wanted more information about reflux and skin disorders. Mothers were fearful of reflux and vomiting and how that may influence their infant's breathing. One mother called 911 shortly after discharge during a reflux event. Parents wished there were resources offered for reference once home. Parents were frustrated when some questions near discharge were labeled as best suited for their pediatrician because they often didn't see their pediatrician for days after discharge.

Theme 4: Methods of Communication

Birth parents had varying types of preferred communication with the care team, which was dependent on several factors including proximity of their home to the hospital, length of stay, and their ability to visit in-person. Overall, in-person conversation was the preferred method of communication if parents were easily able to get to the hospital. If the topic of conversation was "serious," parents indicated they strongly desired this to be done in-person than any other form of communication. For general updates, parents felt electronic methods would suffice. Parents reported never having a problem reaching staff and were able to talk with someone at any hour.

Texting was viewed favorably, but parents preferred a phone call to discuss complex issues and questions. Texting is rarely used for communication at the study NICU. Parents had several "yes or no" questions and felt having the option to text staff for quick questions that did not warrant a phone call would be helpful. These parents felt they would be doing nurses a favor by not bothering them with a nonurgent call and interrupting their workflow. Texting was viewed as beneficial even by parents who were in-person often, as texting would be able to provide quick updates during times they were absent, which they desired.

E-mail was also mentioned as a preferred communication method for nonacute issues and as a potentially helpful future reference. Some parents received informational paper pamphlets when they would have preferred an e-mail as they were concerned about losing the physical pamphlet. Parents also commented that educational "quick response" or "QR" barcodes throughout the unit were helpful.

Parents described many ways they learned about their child's medical conditions. Parents most commonly used basic internet searching to learn about the implications of prematurity, followed by discussions with the medical team. A mother specifically recalled searching "how are premature babies different from full term babies." Parents particularly praised the NICU nurses and appreciated their bedside education. Social media (individual accounts and peer Facebook groups) and YouTube were also used to gain information.

DISCUSSION

In summary, 4 themes emerged from this study of MPTI birth parents: (1) feelings of care team connectedness and inclusion, (2) confusion surrounding NICU care, (3) discharge readiness, and (4) the value of both in-person and electronic communication methods. This study complements existing literature and adds novel insight about how staff can better support MPTI birth parents. Our research importantly describes the positive and negative aspects of their NICU experience. Table 3 summarizes recommendations to improve the communication and support provided to MPTI parents.

FCC in NICUs is inconsistently practiced despite being recommended by the American Academy of Pediatrics[14] and demonstrating benefits compared with standard care in relation to parental mental health, parental confidence, bonding, and length of stay.[15–18] FCC is guided by the core principles of: dignity and respect, organizational flexibility, effective information sharing, formal and informal support, collaboration, and family empowerment.[14] A previous qualitative study of parents of very low birth weight infants ($<$1500 g), with the majority of the infants born before 29 weeks, identified lapses in the receipt of FCC.[19] Similarly, the current study of MPTI birth parents also demonstrates that FCC is not experienced universally as evidenced by parent-reported gaps in communication and knowledge relating to their infant's condition and healthcare. Specifically, MPTI parents desire clearer communication around the reason for admission, daily NICU care, and discharge planning. Several families recalled receiving information about MPTIs during an antenatal consult, but based on our findings, the care team should review this information with parents after birth and consider creating a durable resource for parents to reference.

TABLE 3 Change Ideas to Address Areas for Improvement as Described by Moderately Preterm Infant Parents	
Theme	**Recommendations**
Medical team inclusion and connection	NICU units should encourage all staff to learn about and promote family-centered care. Leadership should recognize the positive impact nurses can have on the NICU experience and ensure nursing is adequately equipped and supported. Through family feedback, units can identify areas for improvement in their own units to address.
Confusion regarding NICU care	Staff should clearly communicate with parents the reason(s) for admission and ongoing care in the NICU. Units should create a resource for parents to reference with this information. Parents should be oriented to their infant's environment including medical technology during admission. Staff should ensure high-quality handoffs of all clinical team members.
Discharge readiness	Clinicians should give parents as much advance notice of discharge as possible. Begin discharge planning as soon as able to help parents prepare their homes and themselves emotionally. Units could consider reaching out to families shortly after discharge to check-in and offer support or referrals if needed.
Methods of communication	Staff could consider tailoring their method of communication based on parent preference, as it may vary. Staff should become familiar with and assist families with identifying reliable electronic resources. Development of comprehensive electronic educational resources for moderately preterm infant parents should be considered at a national, local and community level.

In addition to needing improved communication during admission, parents described having unanswered questions after discharge and the desire for increased support to facilitate a seamless transition home. Previous studies have shown many parents feel unprepared to take care of their infant at the time of NICU discharge.[2,3] In the current study, most parents stated they felt prepared for discharge; however, as the interviews continued, they described needs for improvement around discharge preparedness. Peri-discharge parents wanted more information regarding reflux, breathing patterns, and routine infant care.

Parents indicated that informational resources available for reference would be beneficial. Electronic resources were viewed favorably, as well as electronic methods of communication (ie, texting, e-mail). Online and technology-based support has previously been recognized as a mechanism to deliver FCC.[20] A systematic review of NICU electronic health interventions found that in all studies examining electronic health interventions, parents were accepting of electronic interventions in the NICU.[21] Most NICU mothers feel electronic messaging would improve communication; however it should not replace verbal communication.[22] Our results further strengthen that parents prefer in-person updates but acknowledge a role for electronic communication and resources in the NICU.

Both NICU parents and nurses recognize the crucial role neonatal nurses have in preparing parents to be confident primary caregivers for their infant through encouragement, education, and modeling.[19,23,24] In our study, MPTI parents reported working "with" the nurses and almost all of their stories describing FCC involved nurses. Nurses and healthcare leaders should recognize this critical role of nursing and devise strategies or programs to educate and empower NICU parents.[23]

To our knowledge, there have not been any recent studies on the NICU and discharge experience of MPTI parents despite their prevalence. Our study adds novel insight into how NICUs can improve the support provided to this unique and large population of NICU families. Additionally, we describe what parents wish they had more information about and how they would like to receive this information.

We acknowledge limitations to our research. Because of funding constraints, our study excluded parents who prefer languages other than English. Consequently, our results may not reflect challenges related to language barriers or reflect these parents' experience with receipt of FCC. Additionally, recall bias is possible as interviews occurred weeks after discharge. Our study was limited to birth parents that exclusively identified as female at a single NICU, and thus, our findings may not be generalizable to all MPTI caregivers. Future work involving partners and other caregivers would be useful as their perspectives and needs may differ from the birthing parent.

CONCLUSIONS

Birth parents of MPTIs describe valuing medical team connectedness, gaps in knowledge surrounding NICU care, desiring more advanced notice of discharge, and the potential benefit of electronic resources. NICU staff can focus improvement efforts on communication, specifically around reasons for admission, discharge planning, and anticipatory guidance. These results may serve as a foundation for future projects to improve parental understanding of prematurity, discharge processes, and communication with MPTI parents.

ABBREVIATIONS

FCC: family-centered care
MPTI: moderately preterm infant

FUNDING: This study was supported by an internal grant from the Division of Neonatology at The Children's Hospital of Philadelphia.

CONFLICT OF INTEREST DISCLOSURES: The authors have no conflicts of interest relevant to this article to disclose.

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