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Parent Perspectives on Readiness for Discharge Home after Neonatal Intensive Care Unit Admission

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Objective To explore the parent perspective on discharge home from the neonatal intensive care unit (NICU).

Study design We interviewed parents of NICU graduates with a range of demographic characteristics and medical complexities to explore parent perspectives on readiness for discharge. Interviews were transcribed and coded by a 6-member team. We performed content analysis to identify themes and develop a family-centered conceptual framework around readiness for NICU discharge.

Results We interviewed a total of 15 parents who experienced NICU stays with 18 infants. Parents who have experienced NICU discharge have a spectrum of needs that evolve from the time the child is in the NICU, at time of discharge, and at home afterward. These needs consistently centered around 5 themes—communication, parent role clarity, emotional support, knowledge sources, and financial resources.

Conclusions Parents described many ways the system could have better prepared them and connected them with essential resources. Summarizing the voices of the parents who participated in this study, we have compiled a series of practical recommendations for clinicians to use in daily practice to help parents feel prepared and confident for the transition home from the NICU. *(J Pediatr 2019;205:98-104).*

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Premature and full-term infants who are cared for in a neonatal intensive care unit (NICU) are at higher risk for chronic medical conditions, often requiring complex care after discharge.[1,2] Many infants with chronic medical conditions experience high rates of emergency department visits and readmissions after discharge from the hospital.[3] A key factor in the likelihood of these episodes may be a family's readiness for discharge.[4]

It is a stressful experience for parents when a newborn is sick enough to require a NICU admission.[5,6] Illness in a newborn has a significant effect on the well-being and function of the entire family unit. Stays in the NICU often involve parental separation from their critically ill infants, which can impede parent-child bonding and leave parents struggling to define their role in the care of their child.[7] Regardless of the physical layout of the NICU and ability of parents to room-in, many parents feel disempowered during their child's NICU stay.[8] At discharge, it becomes especially important to consider parental ability and confidence to take on the care of their child at home. A parent's NICU experience sets the tone for ongoing interactions with the health care system; therefore, optimizing the relationship at this juncture may have a lasting effect on those interactions.

Little is known about the parent perspective on the NICU discharge process. Incorporating parental perspective in the discharge process has the potential to improve satisfaction, prevent complications, and decrease the rates of emergency department visits and hospital readmissions. Improved parental empowerment and preparation for the transition home has potential for positive effects on parental physical and emotional health as well as the health of the child. We performed a qualitative study to analyze the parent perspective on readiness for discharge home from the NICU.

Methods

We used a medical ethnographic approach to understand the attitudes, beliefs, and behaviors about discharge readiness experienced by parents of infants who were discharged from the NICU. Ethnography is the study of culture or the "acquired knowledge people use to interpret their experience and generate social behavior."[9] Medical ethnography studies the language, beliefs, and values of a group of people

NICU	Neonatal intensive care unit

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to understand how they conceptualize their health conditions and process their experiences within a particular health care environment.[10,11] We chose this method to explore the parent perspective on discharge from the NICU to build a parent-centered conceptual framework that could inform interventions to optimize this experience and potentially improve the physical and emotional health of both parent and child.

The research team identified parents through parent and community connections and recruited volunteers willing to share their experiences and reflections on their NICU hospitalization, focusing specifically on discharge processes. Methods of recruitment included printed flyers in clinic settings at hospital and community centers, community announcements and brochures at professional educational events and family support groups, booths at NICU family reunions, posts in online communities such as hospital NICU Facebook groups, word of mouth, and personal referrals. Participation was voluntary. We purposely selected participants to include a range of education levels as well as families with public and private insurance. We also included parents of children with various degrees of medical complexity who had been hospitalized in a range of NICU settings, including community and tertiary NICUs. Finally, we included parents whose children had never been readmitted after discharge and parents who had experienced multiple readmissions. This purposeful sampling technique was used to ensure representation of parents with a range of characteristics anticipated to be potentially relevant to perceptions of discharge preparedness.[12]

Interviews were conducted over the phone by a member of the research team, with a second member of the research team transcribing the interviews verbatim. Standard prompts were used during the interviews, with the goal of using open-ended questions to encourage parents to elaborate on their experiences and insights.[13,14] We revised the interview guide over the course of the interview process. We continued interviews until saturation was reached, meaning the same themes were resurfacing consistently in each new interview.[15,16]

The interviews were structured around the following general questions: (1) Describe what was involved in getting your family ready for discharge from the hospital. List as many steps as you can. (2) How would you have prepared differently? (3) What worked well? What did not? What was the most helpful piece of advice/instruction you received? What was not helpful? (4) What are things you needed to know or do at discharge to go home and to be comfortable in your role as a parent managing the following aspects of your child's care at home?

Data Analyses

Data were analyzed using deductive and inductive content analysis to identify themes that describe the spectrum of needs for parents experiencing discharge home from NICU.[15,17,18] The 6-member multidisciplinary analysis team, which included clinicians (pediatric surgeons and a nurse), an expert in qualitative research, and a parent of a former NICU patient, reviewed and independently coded the first 3 interview transcripts. This group met after each interview until the group agreed on a coding structure organized into thematic domains. These domains were (1) knowledge, (2) emotional state, (3) emotional resources, (4) physical resources, (5) socioeconomics, (6) medical support, and (7) expectations/preparedness. The analysis team was divided into two 3-person coding teams, with each team reviewing one-half of the remaining transcripts. Each of the coding teams met regularly in coding sessions to reach consensus in assigning codes to the data. The entire team met to discuss and clarify discrepancies in the use of codes and to achieve consensus in the interpretation of the final thematic analysis. Atlas.ti software (Scientific Software Development, Berlin, Germany) was used to manage the data, enter group consensus codes, and conduct queries of coded data for the final analysis. The study protocol was reviewed by the Nemours Institutional Review Board and deemed exempt from formal review.

Results

We interviewed a total of 15 parents (14 mothers and 1 father) who experienced NICU stays with 18 infants (11 singletons, 2 sets of twins, and 1 set of triplets). The highest education level of parents ranged from high school to graduate school. All participants were married except one. Participants' children were discharged from a range of NICUs, including community hospitals and tertiary referral centers. Eleven of 18 infants were discharged home with a device such as feeding tube or tracheostomy. About one-half were readmitted within the year after NICU discharge (**Table I**).

Parents described a spectrum of needs during their NICU stay, at the time of discharge, and once they were home from NICU. These needs were classified into 5 broad categories: communication, parent role clarity, emotional support, knowledge and training, and financial resources. These 5 categories surfaced consistently throughout each parent's journey, and the specific needs evolved as parents progressed from one stage of the experience to the next (**Figure 1**; available at www.jpeds.com). Illustrative quotes for each of the themes described below are presented in **Table II** (available at www.jpeds.com).

Communication

During their stay in the NICU, parents needed clear, consistent, and ongoing communication with their team of health care providers, especially during and after provider-to-provider handoffs. When there are turnovers in the care team that result in changes to the plan of care, parents perceived a lack of continuity and communication. As one participant stated, "In our NICU, there was a new doc that came through almost daily, so I didn't feel I had anyone on the medical side that was giving me clear and consistent information. . .. I didn't feel there was a unified plan from the team."

Parents also needed their providers to set appropriate expectations about the inevitable setbacks in their child's clinical course. Parents struggled with feelings of failure throughout the general course of stay in the hospital and after discharge, but the effect was magnified when their providers set unrealistic expectations or were overly optimistic. As 1 parent

Table I. Participant characteristics

Relationships to child	Age (y)	Race or ethnicity (options: Caucasian, Hispanic, Asian, African American, other)	Marital status	Education	Child age (y, unless specified in months)	Sex of child	Devices at discharge	Primary insurance	Hospitalization after discharge? (Y/N)	How many?
Mom	38	Caucasian	Married	Postgraduate	5	M, M	N/A	Private	N	
Mom	35	Caucasian	Married	Postgraduate	2.5	M	NG tube	Private	Y	2
Mom	?	Asian (East Indian)	Married	College	18 mo	M, M	NG tube	Private		
Mom	29	African American	Single	Technical college	1	M	No	Medicaid	N	
Mom	38	Caucasian	Married	Postgraduate	5	M	N/A	Private	N	
Mom	22	Caucasian	Married	High school	18 mo	F	NG tube	Private	N	
Mom	24	Caucasian	Married	High school	18 mo	F	No	Private	N	
Mom	34	Caucasian (Orthodox Jew)	Married	Some college	11 mo	M	NG tube/ND, pulse ox	Medicaid	Y	8
Mom	43	Caucasian	Married	Postgraduate	8	M	O_2 monitor, GJ tube, feeding pump, suction device, oxygen	Private	Y	6
Mom	29	Caucasian	Married	College	1	M	NG tube, kangaroo joey, G tube, O_2, pulse ox, suction	Private	Y	8
Mom	40	Caucasian	Married	Some college	3	F	G tube, trach, vent, oxygen, nebulizer, etc	Private	Y	3
Mom	38	Caucasian	Married	Postgraduate	20 mo	M, F, M	NG tube, NG tube, 0	Private	N	
Mom and Dad	27	Caucasian	Married	College	14 mo	M	NG tube	Public (Canada)	Y	3
Mom	47	Caucasian	Married	Postgraduate	8	F	VP shunt, trach, sat monitor, NG tube and then G tube, oxygen	Private	Y	8

G, gastrostomy; *GJ*, gastrostomy-jejunostomy; *N/A*, not applicable; *ND*, nasoduodenal; *NG*, nasogastric; *VP*, ventriculoperitoneal.

expressed, "When you receive those overly optimistic messages from doctors, it made me feel like I must be doing something wrong as a care provider and parent. That was a big struggle and a big part of my mental anguish."

After discharge home, parents need ongoing communication with the numerous specialists involved in the care of their child. When they did not have someone to coordinate that communication, parents felt lost and confused regarding whom to trust, with advice coming from different directions. Others had high expectations regarding the ability of a primary care provider to coordinate a large care team, but the reality fell short of expectations. Parents needed pediatricians who were comfortable with the medical complexity of their child, but finding such providers was an unexpected challenge for many of them. One parent stated, "Our experience was that our. . . community pediatrician team was not competent working with us at all. Anytime we had a problem or challenge, they'd always just send us to the hospital. If your only choice is going to the [emergency department] no matter what kind of question you have. . . once we felt confident enough, we started making our own judgment calls on it."

Parent Role Clarity

Parents expressed a need for clarity regarding their roles and responsibilities while in the NICU. They wanted inclusion in conversations about their child's care and engagement in decision making, but often struggled to find a way to be involved. Several parents stated that they did not realize they had a voice and could affect the plan of care for their child and how it related to the timing of discharge. Parents expressed that they needed to be reminded that first and foremost they are parents, and they should trust those instincts even in the medical milieu of the NICU. One parent described her feelings: "One thing that happens in the NICU. . . your power gets taken away, your confidence is gone, you can't hold your children. Everyone telling you how to do everything is very disempowering."

Throughout the NICU stay, parents wanted to be confident in their instincts and judgment. However, they struggled because of learned dependence on monitors in the NICU that indicated the stability of their child. At discharge, they needed to trust their parental instincts and be confident in their ability to care for their child, but found the sudden removal of monitors to be an inadequate transition process. One parent suggested rebuilding a parent's caregiving confidence occurs in part by gaining experience in the parenting role:

> *Just keep building up the experience base and trusting that you are getting better at it in building experience and that you can do it. . . The more we lived with it and tried it and embraced it, then the more confident we felt, the more empowered we became, the more competent we became at working through things. Then after weeks and months, we began to make really good decisions, like we knew what to do. That definitely didn't feel that way the first couple of weeks.*

Once home, parents need to continue to feel empowered and confident in advocating and caring for their child, as reinforced and affirmed by their health care providers. As 1 parent explained: “Building up a parent’s confidence and trust in instinct is really important. My cardiologist told me two weeks ago, ‘Does anyone tell you at least once a week that you’re doing a fantastic job, you’re working so hard?’ and it meant so much. I mean you’re not really sure you really can do it or that you’re going to be fantastic, but if that’s the case, it’s really helpful so you don’t freak out as much and you trust yourself.”

Emotional Support

Parents identified the need for emotional support and self-care throughout their stay in the NICU, extending to their adjustment to life at home, because they experienced significant emotional stress during the entire process. Even when they were aware of resources available to them while in the NICU, parents needed to understand when and how to use them, and they needed encouragement to use them: “When I was in the NICU I was so stressed I secluded myself. I remember them having some people you could go talk to, and I eventually joined with Facebook, but it was like I couldn’t talk to nobody really. You could, but you couldn’t. All the things you wanted to say you couldn’t because you’re so worried about yourself, your baby, is he going to survive, are you going to come out of there?” Parents who were open to sharing their feelings were able to take advantage of available resources. Other parents were reluctant to seek out resources because they were overwhelmed and did not know how to reach out or did not understand how resources could help them.

Parents needed to feel prepared for the level of fatigue and feelings of disappointment that could surface after discharge. When they do not receive adequate preparation, they experienced a tremendous amount of guilt after the transition home. As 1 mom expressed, “If there was more of a prep that you have been through a traumatic process, you have looked into the abyss of whether your child will live—that is not something most parents go through. Be gentle with yourself.”

After discharge, parents must assume around-the-clock care coverage at home, which is a significant change from having NICU nurses feed and administer medications whenever the parents need a break. Parents identified a need to set up a system of care before their child is discharged from the NICU. After discharge, they described the intensity of care required at home as physically, mentally, and emotionally exhausting, causing fatigue and sleep deprivation that was incomparably greater than what they had experienced with prior healthy children. Once overwhelmed, they did not have the energy or the time to secure much-needed respite care for themselves or to free them up to tend to everyday responsibilities at home and at work.

Once home, parents described a need to balance the importance of self-care and the needs of their child. Some needed professional help to manage emotional stress and anxiety. Others needed to feel a part of a community of parents with similar experiences and helpful perspective. Parents often needed help connecting with this community. One parent revealed: “It is such an important part of transition to connect parents in the NICU to parents outside the NICU who have been through things. Apart from all the medical challenges I am facing, it is so hard to find that part of the community. Suddenly you are part of a niche community which you need to find and it’s very difficult.”

Knowledge and Training

To learn and retain knowledge on how to care safely for their child while in the NICU, parents needed access to reliable sources of information, available when they were ready. When parents lack the information they need, they turn to other sources, some of which are unreliable and provoke anxiety. When the information given did not match what they were able to understand and process, they felt overwhelmed and unable to participate.

In transitioning home from the NICU, parents needed to know how to prepare for the unexpected. Learning the basics of everyday care did not adequately prepare them for what to do or how to troubleshoot deviations from the predicted path. As one mother expressed,

> *It was a HUGE learning curve figuring out once, so okay now that you have identified that your baby’s sick, so then what does that mean? We know if she turns blue we need to call 911, but what about the fact that she’s spitting up all this stuff, all these intricate lines about when you need to get intervention. Those are really hard to figure out, so cloudy to know because it’s probably very different for each child. We began to get to know [our baby] so when* ***this*** *happens she’s actually OK, but when* ***that*** *happens it’s a signal that she’s going downhill, but it took quite a while to figure that out.*

Parents need adequate knowledge of potential equipment-related issues in the transition to home. Parents described home medical equipment that required professional electrical inspections and installations, differences in quality of the function between home equipment and hospital-grade equipment, and a need for multiple training sessions to be comfortable.

Parents of children with complex needs need to know how to screen for and manage the quality of home nursing services available to them. When they lack this knowledge, they are ill-prepared for gaps in reliable coverage, as described by this parent: “Once we got home with the nurses and began spending time with them, it became pretty clear pretty quickly which ones we work better with than others. . . the choice was to have someone we didn’t feel comfortable with or doing it ourselves. There were times we just stayed up all night with her or lay on a mat beside her bed with the pulse ox on and the alarm set every two hours to check.”

The need for reliable sources of information continued once parents took their child home from the NICU. As one mother stated, “Where do we reach out for resources? To have things that they worked so hard in the hospital for, it would be nice to have some of that carry through for the first year.” Parents filled in knowledge gaps by contacting other parents in the community or even their own relatives. One parent stated, “We didn’t get much advice for transitioning home. We had those videos but as far as advice on living at home, here’s your baby, good luck. Here you go. There wasn't a lot of advice. I got most of my advice from my mom and my siblings who all have kids."

Financial Resources

Finally, parents needed financial support for the strain caused by the NICU hospitalization. Parents indicated that supplemental financial resource identification before discharge simplifies their burden. Financial strain was particularly prominent after discharge home, because many parents did not face financial realities while in NICU. As 1 parent put it, they were "out of sight, out of mind." Coming home to medical bills added to the other stressors associated with the transition home.

Discussion

We have described a spectrum of needs of parents who have experienced discharge home from the NICU. We found that the nature of parental needs evolves from the time the child is in the NICU, at time of discharge, and at home. These needs consistently centered around 5 themes: communication, parent role clarity, emotional support, knowledge sources, and financial resources.

Our findings are consistent with several other studies evaluating the parent perspective on transitions home from the hospital. Aydon et al interviewed parents of premature infants during a NICU stay and after discharge home, and concluded that there needs to be improved transfer of information and promotion of parent contact with a multidisciplinary team. Information was the essential component of preparation for transition home.[19] Leyenaar et al and Solan et al interviewed parents and other caregivers of children of all ages.[20,21] Leyenaar et al described several themes that emerged around planning for hospital-to-home transitions for parents of children with medical complexity, including effective engagement with health care providers and respect for families' discharge readiness. Solan et al highlighted parental concerns about the lack of information and emphasized the point that parents questioned their readiness for discharge and often lacked confidence in postdischarge care.[21]

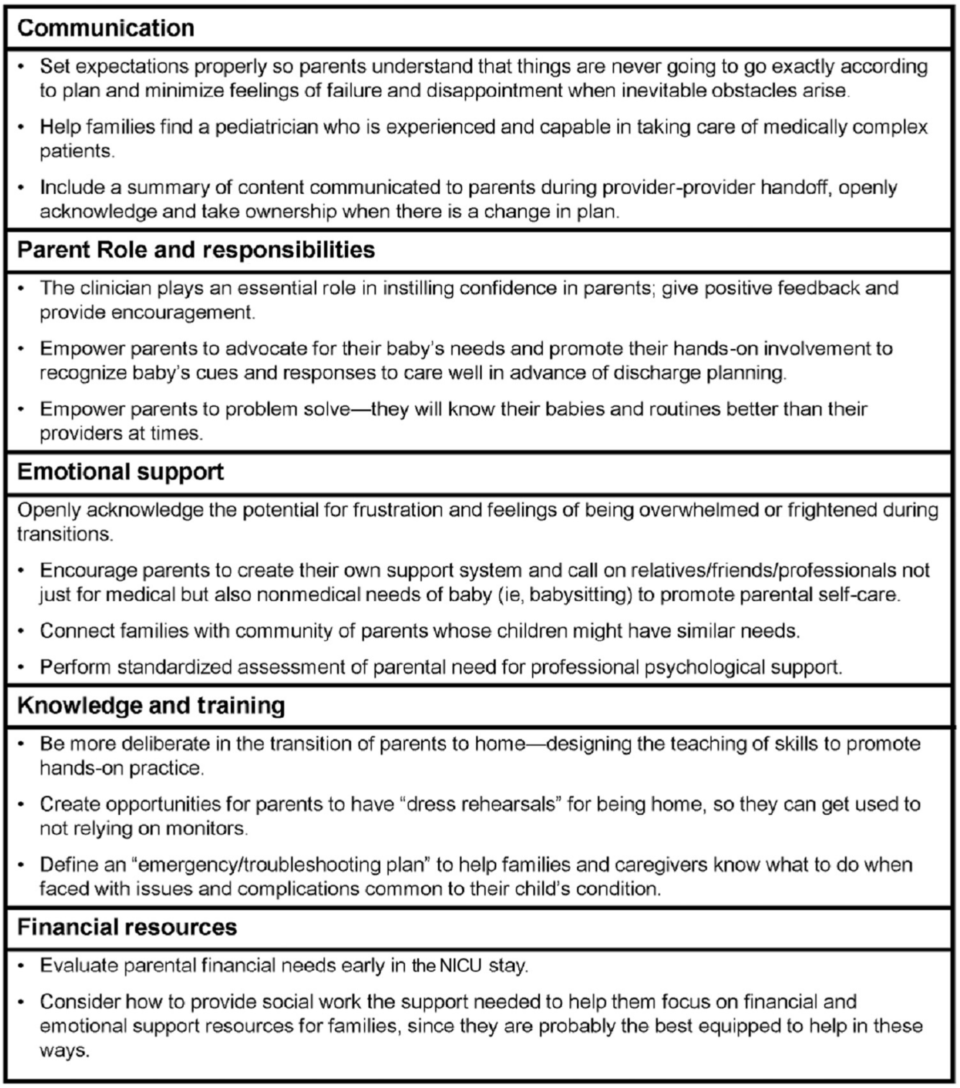
We found that parents consistently described communication challenges when they perceived that different providers gave them conflicting messages. This expands on previous observations related to poor communication and has important implications for health care providers regarding handoffs in patient care. Provider-to-provider handoff should consistently include a summary of what has been communicated to families, so providers can acknowledge and take ownership when plans inevitably change. Families need to understand whether the change is prompted by a change in the patient's condition or a new opinion from a new team. The theme of challenges in information processing is a consistent finding in other studies.[19,21] Our study identifies practical opportunities to optimize readiness for discharge by ensuring home equipment is functional, practicing administration of medication and feedings, and preparing parents for potential complications.

Parents reported that they struggled to claim their role as part of the decision-making team while their infants were in the NICU. Umberger et al surveyed the parents of infants with necrotizing enterocolitis and found that 22% of parents did not feel like decision makers in their baby's care.[8] Our participants taught us that gaining experience caring for their sick child and being encouraged by their health care providers helped to instill confidence and empowered parents to care safely for their child and advocate for their child's health. Although some participants expressed concerns about not feeling ready at time of discharge, several raised the counter perspective of being able to be discharged earlier if empowered to do so. As 1 parent said, "No one ever said, 'how are you feeling?' Nobody said: 'Here's another option, would you be comfortable taking this and getting out of here and going home?' We could have gone home sooner, had I known. . .." This is an important finding, because it suggests that effective parental empowerment might help to shorten NICU length of stay.

The emotional stress created when one's child is in the NICU is well-documented,[6,22,23] and the participants in our study framed this challenge by emphasizing the importance of self-care. Parents described many ways in which the system could have better prepared them and connected them with essential resources. Summarizing the voices of the parents who participated in this study, we have compiled a series of practical recommendations for clinicians to use in daily practice to help parents feel prepared and confident for the transition home from NICU (**Figure 2**).

Our study has several limitations. Although we attempted to interview a diverse group of parents, our sample was predominantly Caucasian and married, and therefore may not be generalizable. This study, similar to any qualitative study, represents the perspective of a small number of parents, and findings should be validated using quantitative methods in a larger and more representative population. The conduct of interviews until saturation, sampling parents from multiple NICUs, and the fact that our study revealed themes similar to previously published studies on this topic support the trustworthiness of our findings.

Early anticipation of discharge and the recognition of parental needs surrounding educational empowerment are keys to improving parental confidence, decreasing stress and anxiety, and having a measurable effect on outcomes such as length of stay and postdischarge health care use. The use of a standardized, reproducible educational-behavioral intervention program for parents in the NICU resulted in decreased parental stress while in NICU and decreased anxiety and depression after discharge home[24] and was associated with decreased length of stay and improved developmental outcomes.[25] An educational intervention for parents of preterm infants showed that parents expressed improved understanding and confidence in caring for their infants and were less likely to go to the emergency department after discharge compared with those who did not have the intervention.[26,27] A systematic review of family-centered hospital-to-home transition processes showed that a family-tailored discharge education and transition needs assessment was associated with improved patient outcomes and decreases in health care use.[28]



Communication

- Set expectations properly so parents understand that things are never going to go exactly according to plan and minimize feelings of failure and disappointment when inevitable obstacles arise.
- Help families find a pediatrician who is experienced and capable in taking care of medically complex patients.
- Include a summary of content communicated to parents during provider-provider handoff, openly acknowledge and take ownership when there is a change in plan.

Parent Role and responsibilities

- The clinician plays an essential role in instilling confidence in parents; give positive feedback and provide encouragement.
- Empower parents to advocate for their baby's needs and promote their hands-on involvement to recognize baby's cues and responses to care well in advance of discharge planning.
- Empower parents to problem solve—they will know their babies and routines better than their providers at times.

Emotional support

Openly acknowledge the potential for frustration and feelings of being overwhelmed or frightened during transitions.

- Encourage parents to create their own support system and call on relatives/friends/professionals not just for medical but also nonmedical needs of baby (ie, babysitting) to promote parental self-care.
- Connect families with community of parents whose children might have similar needs.
- Perform standardized assessment of parental need for professional psychological support.

Knowledge and training

- Be more deliberate in the transition of parents to home—designing the teaching of skills to promote hands-on practice.
- Create opportunities for parents to have "dress rehearsals" for being home, so they can get used to not relying on monitors.
- Define an "emergency/troubleshooting plan" to help families and caregivers know what to do when faced with issues and complications common to their child's condition.

Financial resources

- Evaluate parental financial needs early in the NICU stay.
- Consider how to provide social work the support needed to help them focus on financial and emotional support resources for families, since they are probably the best equipped to help in these ways.

Figure 2. Practical steps for clinicians to support parents in the NICU.

In conclusion, our study further refines the definition of the family-centered transition process by representing the parent perspective on transitions home from the NICU and demonstrates how parental needs evolve from the time the baby is in the NICU to the point of discharge and at home. This finding has important implications regarding educational interventions for parents that are intended to improve discharge readiness. We hope to validate this framework further in future studies and to develop interventions that will empower parents to feel confident and prepared to care safely for their children at home after discharge from the NICU. ■

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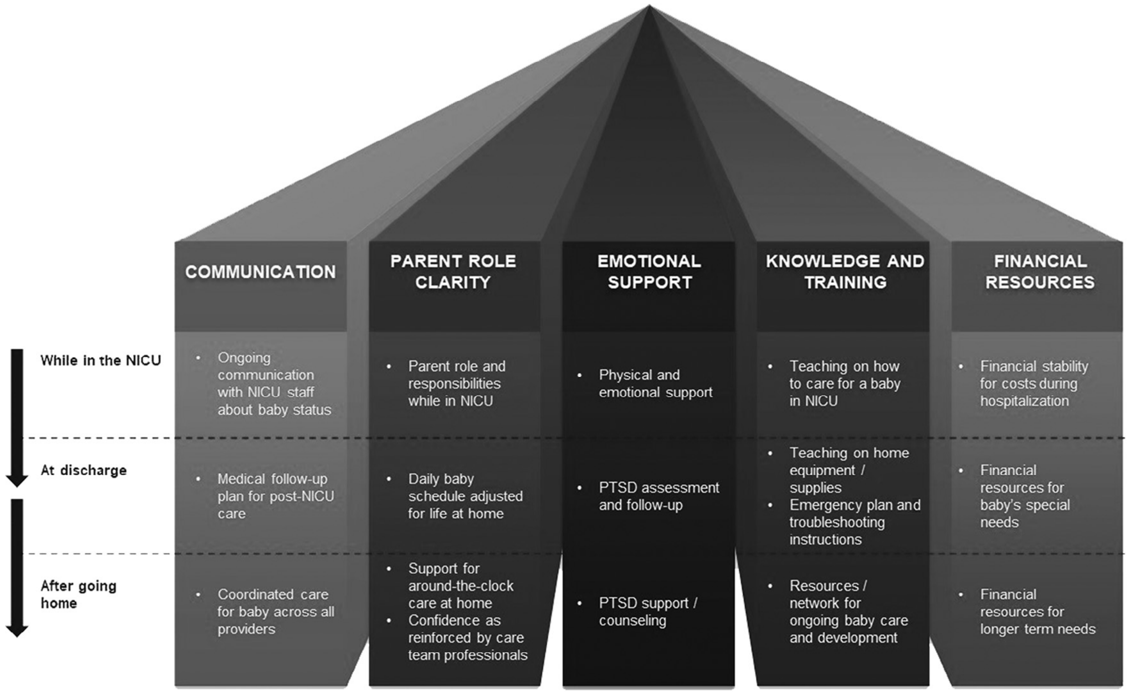

	COMMUNICATION	PARENT ROLE CLARITY	EMOTIONAL SUPPORT	KNOWLEDGE AND TRAINING	FINANCIAL RESOURCES
While in the NICU	Ongoing communication with NICU staff about baby status	Parent role and responsibilities while in NICU	Physical and emotional support	Teaching on how to care for a baby in NICU	Financial stability for costs during hospitalization
At discharge	Medical follow-up plan for post-NICU care	Daily baby schedule adjusted for life at home	PTSD assessment and follow-up	Teaching on home equipment / supplies Emergency plan and troubleshooting instructions	Financial resources for baby's special needs
After going home	Coordinated care for baby across all providers	Support for around-the-clock care at home Confidence as reinforced by care team professionals	PTSD support / counseling	Resources / network for ongoing baby care and development	Financial resources for longer term needs

Figure 1. NICU family needs for safe transition. *PTSD*, Post-traumatic stress disorder.

Table II. Illustrative quotes

While in the NICU	At discharge	After going home
Communication		
I asked a lot of questions and I felt I got really different answers from different people.. . .I needed to know your baby is going to grow, or do one fortified feed a day, or try breastfeeding first. I didn't feel there was a unified plan from the team, and reassurance that your boys are big enough and healthy enough and transitioning to breastfeeding was good enough. In our NICU there was a new doc that came through almost daily, so I didn't feel I had anyone on the medical side that was giving me clear and consistent information. -Interview #1	We had a doctor who did not agree with us getting discharged, so it was me and the nurses on staff fighting to go home because we felt ready to go. The MD prior was okay with us learning how to do the feeding tube NG tube and learning how to place it so we could go home, but the doctor on call that day was not, so we had to fight for it. -Interview #6	Always more people telling you what to do and it's challenging to filter that and know what's happening with your baby and know what's best. With pediatrician, then with OT, then GI doctor. Everyone had different opinions. Coming from all angles. We were managing about 9 different specialists so we were getting info from all different people, and not all of it jives with what you're seeing with your baby. We felt so lost, and who's in charge, and where do we go from there? -Interview #2
The inconsistencies were challenging our marriage and challenging our family. Some of those meetings might have made it so we could have felt a little more in control of an out-of-control situation. -Interview #14		The difference in my expectation of what my pediatrician was going to do for me versus what I actually ended up getting was significant. . . .. I was expecting them to serve as my son's medical home, coordinating care. Because in the NICU, everything was under one roof: if I asked a nurse, she directed me to the right person or answered for me. Once you are out of the NICU. . .. The parents, you are the medical home of your child -Interview #3
	Parent role clarity	
I'm a mother, yes, but I still need some type of say so. I'm all for being told this is what's best, but if you know for sure this ain't going to hurt. . .it doesn't hurt to [let them] try. When you in the NICU you can't do nothing but participate in changing the diaper. If I say I'm going to be here every 3 hours, don't change my baby's diaper! I want to be involved. It helps with you psychologically. You already messed up, you already hurting because you don't know what's happening, you blaming yourself, so you want to make up for that! -Interview #4	Our biggest fear was the breathing. I was surprised that the anxiety level at home was different than in the hospital. All the monitors and everything going on and her heart rate and breathing and coming home I was afraid we wouldn't have the monitors. But it was helpful not to have it. They told us about parents getting addicted and they did a pretty good job of really preparing us to look at our daughter and skin color and how she's breathing and letting us wean from the monitors, covering them up, about blocking everything and shifting our focus to her and not the monitors. -Interview #7	Sleep deprivation really messed with my mental health. It's something I cerebrally knew and something I experienced with [baby with heart and feeding problems]. The sleep deprivation I experienced with 2 preemie twins was beyond anything I experienced with [my prior child]. -Interview #1
Had we started to look at that idea of going home 4 weeks before that, we could have gone home sooner, had I known it was supposed to be my focus, I could have said, “Let's go home and work with the team here to get more bottle fed at home instead of pushing so hard to get fully eating orally, and we could just get home." . . . No one ever said, “How are you feeling?” [They were only focused on] “Keep them fed, keep them fed.” Nobody said: “Here's another option, would you be comfortable taking this and getting out of here and going home?” -Interview #14	We were not as prepared as we thought we were. We were not prepared for the feedings every 3 hours and the NG tube. The nurses. . .didn't require us to wake up for every feeding that they were required to do. It was a learning experience coming home and realizing how much it entailed. For the most part, they tried to prepare us for that but we didn't realize everything the nurses did while we were down there. -Interview #6	I don't think we knew how much it would be and got enough help. Even now we probably don't have enough help. We had a nurse come, she offered to come, and she sat with me and asked questions, but I don't need another person to sit with me. I need someone to come take care of him for a few hours. -Interview #8
	Maybe you telling [parents], hey, this is what your nurses are doing, and you're going to have to be the one to do it. Maybe you could realize it ahead of time. I wasn't thinking that way. It was completely different. Breastfeeding, it was so easy, just unpin my shirt. To come home with meds and NG tube stuff and equipment. . . Nobody there said to me, not that I can remember, I don't think maybe the social worker came and asked if you had support, la la la, but no one said “have someone at home. It will help you immensely.” -Interview #11	I would probably have more help around me. At the time, it sounded appealing to be at home and be alone with our little family after so much craziness in the hospital. We needed to set up a really good support system. It's a big adjustment to go from so much help with the nurses (they're amazing and do so much) and to go from around the clock help and constantly answering questions to just us, it's not a good idea. -Interview #2

(*continued*)

Table II. Continued

While in the NICUs	At discharge	After going home
Emotional support		
When I was in it, I knew I need help. Couldn't get myself out of it easily. I didn't have ready-made family to help. It wasn't as easy as calling my mom. -Interview #1	Yeah! I think just having a little bit more, like the things I was not prepared for was the emotional aspect of it. There's such a stigma over postpartum depression and anxiety and depression over bringing home a baby for the first time, and the. . .constant crying. There are videos and there's no talking about it or going over it or resources or just having a good discussion on it to get comfortable. -Interview #6	I feel like when you're in the hospital, all you can think about is getting home, and when you get there, you're disillusioned about what it means to take care of someone with that level of medical needs without medical support immediately by you. That was very hard for me. That first week was extremely hard. From this emotional side, how are they preparing you for the feelings? I think nobody did mention that, and I do think that might have been helpful. I felt bad, like my daughter is finally home, and I was feeling guilty for the feelings I had about it. It was really hard, I felt very depressed, and I think it was the weight of the responsibility without the support we had had the entire time. -Interview #13
The social service worker was great, I was very honest with her initially, I had a lot of support for the psychological support, I was very open with her: "here are my challenges, and here's how we're going to come through this freakout process." She was good about checking in with me a lot and asking leading questions. -Interview #14	I think that our craniofacial team was trying to help prepare us for, all these like sort of learning pieces, educational pieces just caring for her. Also I remember several times them just saying you will know how to take care of her and you will know how to love her. Just trust that you will and that you have the support and you can call us at any time, and feel empowered and confident about that bc we've seen you guys doing a great job, and you do know how to do this. -Interview #16	What I would share with another parent who is going through something like this, that you. . .have to be kind to yourself and take care of yourself because if you can't take care yourself, you're not going to be able to take care of your baby. So even though it's a completely overwhelming situation you have to find the space to cope and stay centered and take care of yourself somehow. -Interview #16
		We went to counseling. Yeah, we did couples counseling, and I also continued private counseling after that point, just for some of the ongoing anxiety and stress associated with his care. . .I wish we had done it sooner. -Interview #15
	Knowledge and training	
You don't want too much info right away, after a couple of months went by, you get rid of the first couple of issues and move on to the next step and deal with those, or even some pamphlets about it, or here's what's coming down the road, or here's what's going to happen. After 2 months, a little more info would be nice and we had no idea. I was staying off Google and I didn't want to know anything. -Interview #7	Nothing can prepare you for going home, for the fact that you can't just call a nurse or MD, you are it, you're the first line of defense, I didn't know that apparently the air in the hospital is much less dry than it is. So my daughter had a plug the second day at home, and satting at 50%, and it was really scary. I learned after that we needed to do nebulizer treatment so she could get adjusted to different air. We just didn't know and it would have been helpful. -Interview #13	If you are facing challenges and this doesn't turn out to be a quick fix and he doesn't mature into a quick feeder, here are some resources to help, here's where you call, here's where you come back to check into. -Interview #1

(*continued*)

Table II. Continued

While in the NICUs	At discharge	After going home
A nurse told me: Don't use the Internet. And it's true! The worse things you read, you dig more and more. As much as you want to educate yourself, that was a wonderful piece of advice. Talk to your doctor, but stay off the Internet. -Interview #3	Within a few days, he was vomiting up the NG tube out of his stomach and choking on it a minimum of 8 times a day, and we had to replace it over and over every day. I didn't find out for at least a couple months or maybe more that this isn't normal, and that other families only replace the tube once a month. I was doing it sometimes like 12 times a day! I had no idea what was normal. We didn't know who to talk to, my husband was traveling. I was alone for a lot of the time dealing with it. I didn't know what to do. I had no idea what to expect and was totally unprepared, and I thought I was doing something wrong. -Interview #2 I did not feel prepared for dealing with the feeding pump equipment. The training we got for the pump was 45 minutes by the home health care rep, and that was just not sufficient in my opinion. If there had been more of a handover to using that particular pump in the hospital instead of the nurse using their pump . . ., not that we're walking out the door with something new, hooking him up to our pump basically an hour before we leave. -Interview #9	Even providing parents with info on how to be their own advocate, on phone numbers or resources that are available, I think that would make a huge difference. From our health region, I have not met another family. Through a personal acquaintance, we know of a family in Alberta with a child who has feeding issues as well. I've definitely reached out to her as well with a few areas of specific concern to see how their health system has addressed issues and what other strategies we could try. -Interview #15
	Financial resources	
Now, my grandma she live down the street from me, so she was the one that was supporting me and my oldest son. So my grandma, she helped me a lot with my son, and came back and forth and brought me back and forth. It was getting really expensive, spending money I didn't have. When I was working. . .I was on month-to-month checks and I was able to manage the rest. So when I wasn't working, I didn't have no money to be spending on that cafeteria. -Interview #4	It was our 30th day inpatient, this shy looking guy in loafers appears. It turns out he's from accounting and billing, because we were inpatient for 30 days, WA state has insurance program that would pick up whatever our primary insurance didn't cover. The fact that we didn't have to worry about the financial aspects of his care was amazing. When he was on a feeding tube, he was on elemental formula that cost $80 per can, plus pump cost, we were looking at $1500 per month out of pocket just to feed him. Thankfully, I don't remember what happened, we ended up going on Consolidated Omnibus Budget Reconciliation Act, but I cannot imagine having financial stress on top of everything else. -Interview #9	Once we came home it was an insurance mess. That was the worst part, coming home to thousands of dollars of medical bills. In the NICU it was out of sight out of mind, and you didn't think, but coming home it's this whole other mess you have to deal with and navigate. That's what we had to deal with just coming home was the insurance piece. -Interview #7

GI, Gastrointestinal; *NG*, nasogastric; *OT*, occupational therapy.