Barriers to Transition to Home From the Neonatal Intensive Care Unit

A Qualitative Perspectives of Parents and Healthcare Providers

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ABSTRACT

The objective of this study was to explore the challenges faced by parents of former neonatal intensive care unit (NICU) patients in transitioning home from parents' and healthcare providers' perspective. We conducted semistructured individual and group interviews with parents of former NICU patients and healthcare providers. Themes from the individual interviews framed the group interviews' contents. The group interviews were recorded and transcribed, and thematic analysis was performed to identify themes. We conducted individual and group interviews with 16 parents and 33 inpatient and outpatient providers from November 2017 to June 2018. Individual interview participants identified several barriers experienced by parents when transitioning their infant home from the NICU including parental involvement and engagement during NICU stay and during the discharge process. Further exploration within group interviews revealed opportunities to improve discharge communication and processes, standardization of parental education that was lacking due to NICU resource constraints, support for parents' emotional state, and use of technology for infant care in the home. Parents of NICU patients face serious emotional, logistical, and knowledge challenges when transitioning their infant home from the NICU. Understanding and mitigating the challenges of transitioning infants from NICU to home require multistakeholder input from both parents and providers.

Key Words: barriers, neonatal intensive care unit, NICU/neonates, qualitative research, transition to home

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Parents experience distress following their newborn infant's hospitalization in the neonatal intensive care unit (NICU).[1] This stress may be amplified by multiple factors such as infants' appearance, complex medical conditions, NICU setting, medical jargon, and physiological risk of their infant undergoing numerous medical procedures.[1] A systematic review of qualitative studies demonstrated common themes of increased stress and decreased mental health in NICU parents,[2] and this parental stress and anxiety continue to last for up to 6 months and up to 18 months post-NICU discharge.[3]

Transitioning of care of the critically ill infants from the NICU to home is challenging for parents and caregivers.[4] Parents experience unmet emotional needs

and lack of support at home following discharge from the NICU.[5] Thus, it is vital to prepare and support parents beyond the NICU for a smooth transition to home. Previous studies conducted in Canada and the United States have found that healthcare providers and parents differ in their views regarding hands-on experience in the NICU, parents' readiness for discharge from the NICU, and infant care and management at home.[6,7] These studies highlight the need for a clear understanding of roles and responsibilities of parents and providers in the discharge process. While additional global studies have focused on parents' experiences of having their infant in the NICU,[8] parental involvement in caring for their infant in the NICU,[9] and discharge preparation and readiness of parents for discharge to home,[6] little is known about the challenges faced by parents/caregivers of infants after discharge from the NICU in the United States. Given this gap in knowledge, we aimed to identify the challenges faced by NICU parents when transitioning from the NICU to home from the perspectives of both parents and healthcare providers.

METHODS

We followed the Standards for Reporting Qualitative Research (SRQR) reporting guidelines when writing our manuscript to ensure transparent and rigorous reporting of our findings.[10]

Sampling and recruitment

This study used a descriptive qualitative design, using both individual and group interviews, to obtain a wide range of possible responses. A purposeful sampling strategy was used to recruit the participants. During outpatient clinic visits, parents of former NICU patients with complex medical conditions were informed about the study and the purpose of semistructured individual interviews. At our institution to enhance family-centered care in the NICU, an advisory council of parents of former NICU parents has been established. For group interviews, parents of former NICU patients having complex medical conditions participating in the NICU advisory council were informed of the study and were recruited by phone or e-mail by an NICU nurse who was part of our research team. These NICU advisory council members were appropriate for the group interviews, given that they had a delivered a premature infant with multiple comorbidities who was admitted to the NICU and had an extended NICU stay. Outpatient and NICU healthcare providers were recruited by e-mails and face-to-face discussions and through recommendations

from other potential participants. We sought to have participants with varied healthcare roles (physicians, registered nurses, discharge coordinators, respiratory therapists, physical therapists, case managers, and social workers) and experience to understand their perspective of the barriers to a successful transition to home from the NICU. This study was approved by The University of Texas Health Science Center at Houston institutional review board (HSC-MS-18-0391).

Data collection

Individual interviews

We conducted semistructured individual face-to-face interviews with parents of former NICU patients and outpatient and NICU healthcare providers between November 2017 and February 2018. Parents who participated in these individual interviews were recruited from the outpatient clinics and were not a member of the NICU advisory council. Parents and outpatient providers were interviewed in a private room in the outpatient clinic, and the NICU providers were interviewed in a private room in the hospital. Prior to the individual interviews, a verbal consent was obtained from the participants. To maintain consistency in data collection, the same author conducted interviews with each participant. An interview guide was used for all participants to introduce the purpose of the interview with a consistent manner. Throughout the interviews, standard prompts were used along with open-ended questions to encourage participants to elaborate their experience starting with general challenges of having an infant in the NICU and their NICU experiences and then navigating them toward specific challenges based on the emerging findings. The interviews explored the participants' views with specific objectives regarding (1) day-to-day challenges of NICU and outpatient clinic patient care, (2) barriers to a successful transition to home from the NICU, (3) parents' concerns and needs related to discharge process, and (4) challenges of caring for infants at home. These individual interviews were not recorded, but the key points and the field notes were documented during the interviews, which were elaborated immediately after termination of the interviews. These interviews were terminated once we reached saturation.

Group interviews

Semistructured individual interviews formed the basis of the group interviews' content. We conducted a 2-hour focus group interview session with parents of former NICU patients on November 29, 2017. We

also held two 2-hour focus group interview sessions with healthcare providers on June 17 and 18, 2018. Before the beginning of the group interviews, all participants signed written informed consent. An experienced qualitative researcher facilitated the group interview sessions, which were audio-recorded and transcribed. Field notes were recorded by the research team members to describe the context of responses, emotional cues, and interaction of the participants.

Data analysis

Individual interviews

Following each semistructured individual interview, data analysis was completed by reviewing the key points, interview content, and the field notes, which were categorized into different categories by the research team consisting of a pediatric surgeon, neonatologists, a pediatric surgery resident, an NICU nurse, a research nurse, and a research associate. We used the "Ishikawa diagram," also known as the "fishbone diagram," to plot themes. In a fishbone diagram, the focused problem or the outcome to be improved is the fish's head, and the backbone of the fish consist of a long spine with the arrow pointing toward the direction of the arrow implies the items intersecting the spine may be a causative factor of the main problem. The large bones attached to the spine are the areas that are contributing to the problem, and the smaller bones are related to the major causes. For example, inadequate preparation of parents in the hospital regarding the durable medical equipment for home use (cause) can be attributed to an unsuccessful transition to home (effect/problem). Following each interview, the fishbone diagram was modified using the iterative process based on the data collected from the participants until we reached saturation. On a fishbone diagram, the main causes of the problem that is being studied is generally grouped into different categories, namely, 5 Ps (patients, providers, policies, processes, and procedures), 6 Ms (machine [equipment], methods, materials, measurement, manpower, and mother nature), and 4 Ss (surrounding, supplier, systems, and skills)[11] but can be customized depending upon the problem that is being studied. For our study, we categorized the main causes into policies and processes, equipment, information/materials, parents/family, healthcare providers, and hospital environment/electronic health record.

Group interviews

Audiotapes of the group interview sessions were transcribed, and a thematic analysis was conducted to analyze the data. We coded a segment of data that was relevant to or captured any interesting point about the research question instead of line-by-line coding. In the first coding cycle, core research team members consisting of an NICU nurse, a research nurse, and a research associate were designated as coders, who familiarized themselves with the transcript and came up with the free codes after discussion to capture the transcripts' essence and primary content. Similar codes were collapsed into broader categories that were compiled to generate a coding framework. To increase the calibration, the aforementioned 3 coders independently coded the first 10 pages of the transcript and met for consensus to finalize the coding framework, which included categories with definition. Following consensus, the remaining transcript was coded, and Atlas.ti (version 8.2.4; build 559; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) software was used to conceptualize the broader categories to generate themes across participants.

FINDINGS

For our study, we developed themes for the individual and group interviews instead of having overarching themes.

Individual interviews

We interviewed a total of 23 participants, including 8 parents, 3 pediatricians, 1 pediatric pulmonologist, 7 nurses, 2 respiratory therapists, and 2 discharge coordinators. The median duration of the interview was 45 minutes (range, 30-60 minutes). The characteristics of the participants are shown in Table 1. Both parents and healthcare providers identified multiple barriers to a successful transition to home during these interviews, displayed in Figures 1 and 2, respectively.

Parental involvement during their infant's NICU stay

Parental and family involvement in the NICU was adversely affected by numerous conflicting demands such as household work, employment due to completion of maternity leaves, and other children to take care of at home. Parents' time with their infant in the NICU was limited because of their personal and professional obligations. Participants identified additional barriers to a successful transition to home related to financial needs, transportation issues, and language, social, and cultural differences.

Parental engagement and NICU discharge process

Parental level of engagement during the NICU course also affected parental education and comprehension

Table 1. Participants' characteristics

	Individual interviews (*N* = 23)		Group interviews (*N* = 26)	
	Parents, *n* (%)	Healthcare providers, *n* (%)	Parents, *n* (%)	Healthcare providers, *n* (%)
Gender				
Male	0 (0)	2 (13.3)	1 (12.5)	2 (11.1)
Female	8 (100)	13 (86.7)	7 (87.5)	16 (88.9)
Providers' role				
Pediatrician	...	3 (20)	...	2 (11.1)
Pediatric pulmonologist	...	1 (6.7)	...	0 (0)
Neonatologist	...	0 (0)	...	2 (11.1)
Nurse	...	7 (46.7)	...	5 (27.7)
Respiratory therapist	...	2 (13.3)	...	2 (11.1)
NICU discharge coordinator		2 (13.3)		1 (5.6)
Physical therapist		0 (0)		1 (5.6)
Outpatient clinic coordinator	...	0 (0)	...	1 (5.6)
Case manager	...	0 (0)	...	2 (11.1)
Social worker	...	0 (0)	...	2 (11.1)
Number of years of experience				
<2	...	1 (6.7)	...	1 (5.6)
2-5	...	2 (13.3)	...	1 (5.6)
6-10	...	4 (26.7)	...	4 (22.2)
11-15	...	2 (13.3)	...	4 (22.2)
>15	...	6 (40)	...	8 (44.4)

Abbreviation: NICU, neonatal intensive care unit.
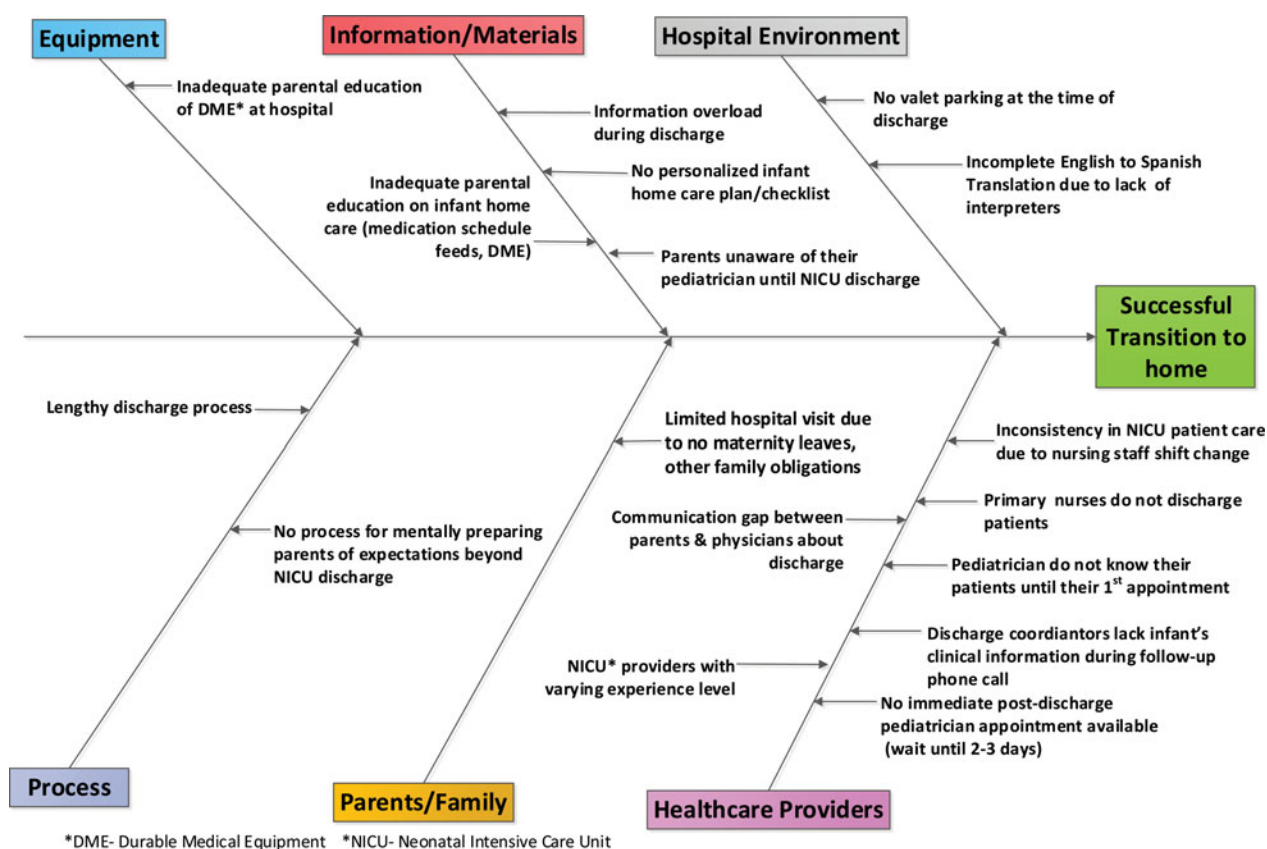
Figure 1. Fishbone diagram of barriers identified by parents. This figure is available in color online (www.jpnnjournal.com).
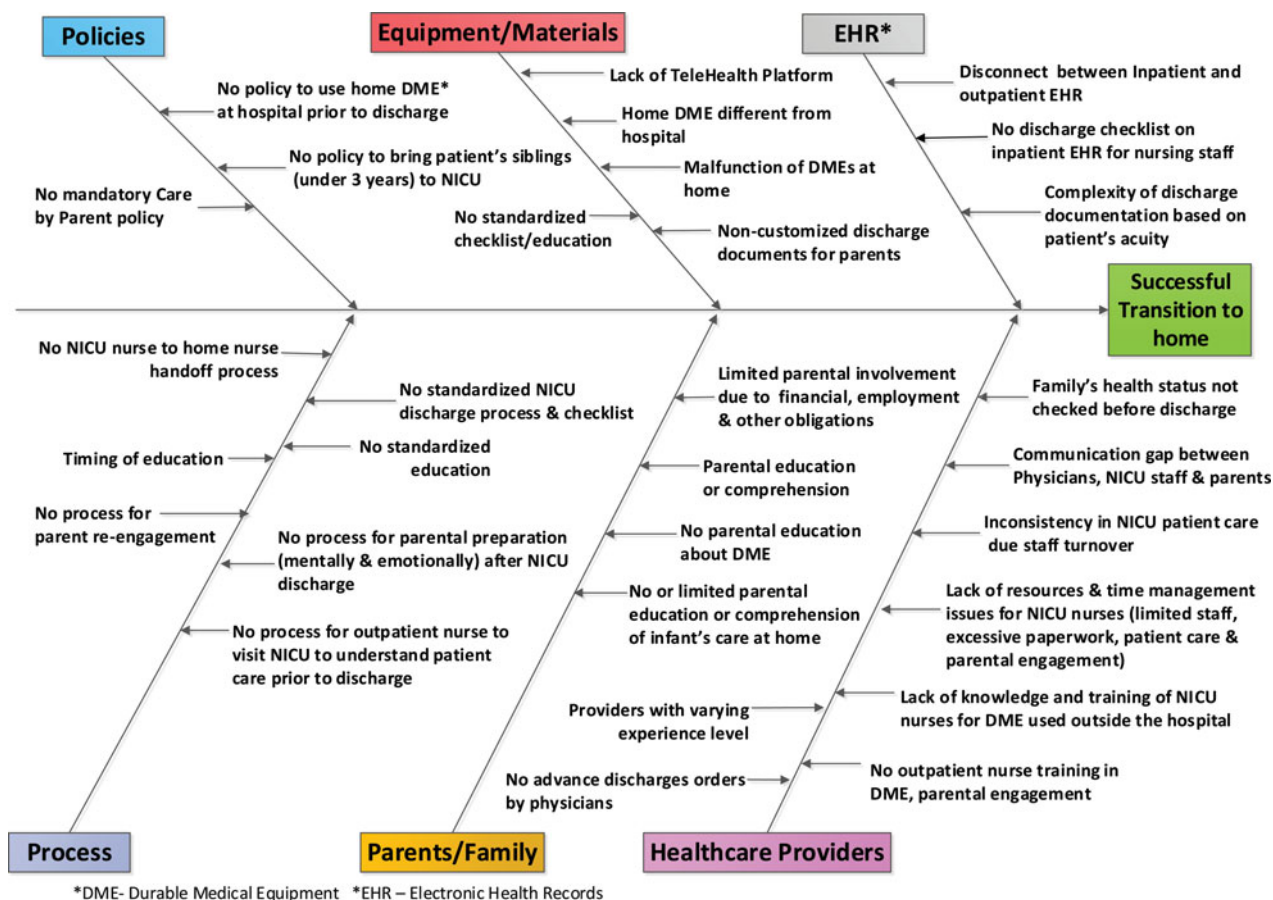
Figure 2. Fishbone diagram of barriers identified by healthcare providers. This figure is available in color online (www.jpnnjournal.com).

at the bedside before discharge. On the day of NICU discharge, parents felt overwhelmed because of the timing and content related to infant's health status, feeds, and medications as discharge education. Healthcare providers felt that there were discrepancies in the NICU discharge process due to lack of standardized discharge process and checklists, and it was mostly dependent upon nurses' experience. Furthermore, nurses developed their own discharge-related checklist to help them with the discharge process, given the complexity of the discharge-related paperwork. However, these checklists were not disseminated to the entire team, adding to inconsistencies in the discharge process. All providers felt that staffing issues in the NICU adversely affected their clinical care duties, thereby affecting parental education and engagement. Healthcare providers attributed to lack of mandatory implementation of "care by parent" hospital policy before NICU discharge also contributed to some degree of parental inexperience in managing their infant at home, which affected the successful transition of home.

Transition of infants' care after NICU discharge

A systematic regimen and a checklist for the infant's hospital feeding schedule and medications that are followed in the NICU were not always shared with the parents at the time of discharge. There were no standardized parental education materials or checklists for bedside nurses and respiratory therapists to follow while educating parents in the NICU to prepare them for discharge and at home. These identified factors influenced parental readiness for transition to home, and parents felt it ultimately affected their infant's care at home. In addition, there were no standardized handoff processes between inpatient providers to community pediatrician offices and home health professionals, which adversely affected a successful transition to home.

Group interviews

Eight parents and 18 healthcare providers participated in the group interviews, and their characteristics are

shown in Table 1. The group interviews generated more than 100 pages and 45 000 words of parental and healthcare providers' experiences, reflections, descriptions, and opinions. Forty different codes were identified that were collapsed into 5 major themes: (1) communication, (2) hospital discharge, (3) emotional state of parents, (4) parent as an expert, and (5) technology, as shown in Table 2.

Communication

Communication between healthcare providers and parents was identified as a challenge while in the NICU. Parents expressed concerns about communication regarding their infant's treatment plan and discharge information. Specifically, they felt there were inconsistencies in communication with and between NICU providers. Healthcare providers also identified communication as a barrier and attributed discrepancies in communication to varying experience, expertise, and clinical staff's shift changes within the NICU. In addition, because of NICU human resource constraints, limited availability of time of clinical staff, and nonstandardized parental education, there were inconsistencies between parents and providers. Parents who knew both Spanish and English perceived that non–English-speaking parents did not receive complete information from providers who spoke only English. Thus, the language was perceived as one of the significant barriers in communication between parents and healthcare providers.

Hospital discharge process

The hospital discharge process was associated with anxiety for most parents due to a lack of prediction and adequate notification regarding their child's discharge timing. Parents' expectations were often in conflict with the reality of the discharge process, due to communication gaps between parents and providers in addition to a lack of preparedness of parents to go home. Parents who were either highly or sporadically engaged were comfortable taking care of their infant in the NICU but felt stressed at the time of discharge. Several providers also noted that there was no standardized discharge process, parental education process, and a standardized checklist for preparing an infant's discharge. Given this communication gap among providers and lack of standardized discharge process also affected the timing of discharge that was not planned ahead of time.

Emotional state of parents

Postdischarge from the NICU, parents felt a range of emotions from stress and anxiety to confidence and feeling empowered. Parents often felt isolated at home, as they did not have the support system of NICU nurses to care for their infant at home and felt frustrated, as they did not have any help at home. Parents reported being fearful of having guests over to their homes due to the risk of an infant falling ill and felt the need to monitor their surroundings constantly. Parents who received assistance from home health professionals perceived these professionals to be inconsistent, negligent, unprofessional, and incompetent, which left them furious and anxious. Finally, according to providers, there were no NICU processes to prepare and support parents emotionally while in the NICU and after transitioning to home.

Parent as an expert

Parents took control of their situation at home eventually and prepared their own schedule for feeds and medications for caring for their infant at home. Parents also created a visual tool on a whiteboard of all the daily care and management needed for their infant, which helped parents define their role and gave them the confidence to take care of their infant at home. Thus, parents took ownership of their infant's care and demonstrated their expertise by teaching their other family members how to care for their infant at home.

Technology

Parents often turned to technology (iPhone or smartphone) and used social media platforms to guide their infant's management as well as for emotional support after discharge from the NICU. Parents added their infant's daily schedules, tasks, and doctor appointments on their phones to keep track of the infant's care. They also set up alarms and reminders to remind them of the upcoming tasks such as medication, feeds, and periodically checking temperatures. Parents who opted to have a home health nurse for their medically complex infant made sure that the home health nurse also records this information on his or her iPhone or smartphone, which helped in information sharing. Some parents even joined social media platforms to interact, share their stories with other NICU parents, and provide social and emotional support to each other. However, joining social media ensued stress and anxiety, especially when other members of the social media platform shared their stories that left the parents apprehensive about their infant's health.

Common barriers from individual and group interviews

Our study participants from the individual and group interviews identified multifactorial barriers to a successful transition to home. They identified inconsistencies in communication between parents and providers, which

Table 2. Emergent themes and illustrative quotations from the group interviews

Theme 1: Communication
Subtheme: Inconsistency
"I think the switching of the doctors makes it kind of hard because some of the doctors don't know your child and some do. Like, we had, you know, two main doctors that we saw a lot and then we'd have one or two that came in, you know, randomly, every now and then, and they'd want to do something ridiculous and then it would throw her back to steps, you know, and—and, you know, it was the same with, uh, one of our nurse practitioners not." (P)
"And I hear Nurse A teach something way different than Nurse B and C." (HP)
Subtheme: Information sharing
"Or just those parents that, um, with the language. I mean, my thing with the Spanish was like—I'm very outspoken about that because I could hear other parents trying to like speak Spanish or speak English and they would translate and I knew the translation was horrible and I knew that they weren't telling them all the little details that they needed to know."
"Here, they have, uh, always have a cell phone on them for emergency line, 24 hours. Because they—I called at like 2:00 in the morning and they were like send me a picture of what you're talking about." (P)
"But for a parent who's taken their kid the first-time home after three months of in the NICU, it's a big thing. So that's when the video, or just a phone call even to a provider who knows—at least has access to the chart can see, Okay, does this baby need to be seen tomorrow, even constipation, simple as that." (HP)

Theme 2: Hospital discharge
Subtheme: Discharge process
"Like three days before they would try to like wean down the oxygen, you know, sort of thing and she wasn't doing it. And so we thought, they're going to give it another week. And then it seemed like the next day or the day after that a new doctor came in, had no—he was youngish, a youngish guy and he was just like you're going—you're going home today." (P)
"Standardizing care by parent, anything, and everything, all the discharge teachings." (HP)
"And it is nurse driven to prepare a child for discharge, and if you have not ever worked in level 2, and you are a critical, critical nurse, then, preparing for discharge is not something that you always real, real comfortable with." (HP)
Subtheme: Expectations
"It was like, do you walk us to the front doors? Like, do you make sure she's in a car seat? Um, and they were like, nope, because she was on oxygen." (P)

Theme 3: Emotional state
Subtheme: Frustration
"And nobody understands what—when I think my baby DSATed and I can't tell and you know." (P)
"I mean, it, it's crazy to us how sometimes, we see them two to three days after discharge. You know, mom who comes in, and it's just like, we know they've done care-by-parent. We know they've been there for three months, at least minimum, for our kids. And it's just like, they, they look just deer in a headlight. They don't know what's going on. They, they're so overwhelmed." (HP)
Subtheme: Scared/fear
"And you don't want to have people over to the house because, you know, it—you're afraid that they're going to get your child sick and she's on oxygen and—and we did, you know, spend—we had RSV in the fall and yeah." (P)
"And, I think that for a lot of families, there's also maybe even a mistrust with doctors or being in a hospital, medical environment. They're afraid to ask questions, and they know that they don't understand what they're being said, but they're not going to tell you that they don't understand." (HP)
Subtheme: Ability to cope
"I mean, you figure it out quickly. It's like you' being thrown into a fire and you just got to do it." (P)
Subtheme: Home health professionals
"I found and we had actually one—our son almost died because we had a nurse, complete negligence. They—she had never—they sent her to us and did not—she wasn't familiar with a trach—vent—trach and vent. So his alarm—he was disconnected and his alarm kept going off and I woke up in the middle of the night and she was standing over it just hitting silence on the alarm, silence on the alarm and he was blue." (P)
"Well, we have home providers. They're not NICU home providers. We have home nurses, but all of them—every home nurse is not the same." (HP)

Theme 4: Parent as an expert
Subtheme: Confidence
"My husband's like, you're not an RN, you know that, right? I was like, yes, I am. I felt like—you know you feel empowered because it's like—yeah. You become one. It's a blessing and a curse being in the NICU because, you know, you don't want to be there. It's the darkest days of your lives, but like it's a blessing because you have these great nurses who like teach you, empower you." (P)

(continues)

Table 2. Emergent themes and illustrative quotations from the group interviews (*Continued*)

Subtheme: Ownership

"And so I used that as a tool to train other people to assist myself and my spouse. And they were able to follow that schedule that I had made for them so that that kind of gave myself a break. I wouldn't necessarily leave them alone with my son, but I could—I felt comfortable knowing that I've already showed them how to do something. I can step away and they've got this schedule to follow." (P)

Theme 5: Technology
Subtheme: Smartphone app/social media platform

"So I just basically took the—his daily schedule, the 24-hour schedule that—of everything that went on—especially, uh, meds and feeds and everything. But I—I did this. I went into my reminders and I just—starting at—first thing, 8:00 in the morning, his first med that's given, 8:00. He's got his medication and then his breathing treatment and at 9:00 is feed and then 10:00 these meds. So—and I have it set to go off at that time. And then I have all of our nurses at home put the reminders on her phone." (P)

"I belong to a group on Facebook, several groups on Facebook. One of them is called Mothers of Trach Babies. And it's all trach—only trach parents, no—uh, advertising or anything. But it's—and their diagnoses range—there's probably 300, 400 different diagnoses for reasons why these kids have trachs. But it's been the best for me, the best platform to go to for us to say, okay, this is what my son's doing. Has anybody ever seen this before? What did you do? And it gives you an idea of what to expect when you go home and how it looks." (P)

Abbreviations: HP, healthcare provider; P, parent of a former NICU patient.

was attributed to providers' varying experience levels and discrepancies in discharge planning, which ultimately affected parental education in the NICU. Because of a lack of standardized discharge-related process and checklist, nurses managed to prepare their own checklist to manage the discharge-related paperwork and process, which was not shared across the NICU. Inconsistency in parental education while in the NICU and at the time of discharge left most parents anxious and confused. Both parents and providers noted gaps in information sharing, which affected infants' care and discharge timing while in the NICU and largely impacted the transition to home and caring of infants at home.

DISCUSSION

This study explored parents' and healthcare providers' perspectives regarding challenges in transitioning from the NICU to home. Our findings are consistent with the barriers noted in the United States and across the globe as stated in the literature. Leyenaar et al[12] after interviewing family caregivers and providers concluded that effective engagement with healthcare providers, respect for families' discharge readiness, care coordination, and timely and efficient discharge process were priorities among other hospital-to-home transition domains. Similar findings were noted in studies conducted by Burnham et al[13] and Berman et al[14] regarding parental discharge readiness from the NICU. These studies concluded that parents need personalized information regarding infant care and hands-on experience in the NICU in addition to clear communication with NICU providers, clarity on parental roles, emotional support with information on reliable sources of knowledge, and financial resources.[13,14]

Parents and healthcare providers perceived inconsistency in communication in the NICU. Parents also perceived that they were receiving conflicting information from different providers regarding their infant's health status. Several studies focusing on patient-provider communication have highlighted that patients and providers have different information needs.[15–17] Gallagher et al[18] conducted 19 interviews with 14 families and demonstrated parental desire of consistent, accurate, and honest information for engaging in their infant's treatment. Other studies have also shown that parents feel stressed, isolated, and excluded from the parental role in caring for their child in the NICU when they receive inconsistent information because of poor communication with the NICU staff.[15,19]

Discharge planning begins at NICU admission and is coordinated by multidisciplinary teams. Often, NICU staff assesses the infant's discharge readiness but does not assess the parents' readiness.[13] Our participants perceived that they had conflicting information regarding the timing of discharge. Having a predicted discharge date helps prepare both parents and healthcare providers.[20] The providers in our study perceived that there was no standardized discharge process and a discharge-related checklist for them to use. Without a standardized process and a checklist, discharging patients is mainly dependent on clinical experiences of nurses. Studies have shown that having a family-centered discharge process with the use of checklists improves communications among the multidisciplinary teams and also reduces stress for patients, physicians, and nursing staff.[20,21]

Preparing parents for discharge is a complex process and includes bedside teaching and information needs—routine care, preparing for unexpected events, hands-on

experience and skill demonstration, and use of durable medical equipment. Parents and healthcare providers perceived that there were no standardized parental education and personalized infant care checklists. After admission to the NICU, parents were redirected to a Web site containing the educational materials to orient themselves with the NICU environment. Although this Web site included basic information about the NICU, it was not personalized for parents or families. A personalized checklist for parents, when introduced in the hospital, serves as a dual purpose of a gradual introduction of all the essential contents necessary for learning their child's needs and a tool for tracking their progress.[22,23] The use of checklists also helps parents to locate and purchase essential items that are needed for their infant's care at home.[13] The introduction of a personalized infant care checklist while in the NICU and its continuous use can instill confidence in parents toward a smooth discharge and transition to home.

This study's strengths include the study site, a busy level VI NICU, and the diversity of participants (parents of NICU graduates, pediatricians, nurses, social workers, case managers, respiratory therapists, physical therapists, NICU discharge coordinators, and an outpatient clinic coordinator). This is the first study that uses a combination of qualitative data analysis and a fishbone diagram to plot barriers and analyze the association causes impeding the successful transition to home of NICU patients using semistructured individual and group interviews. Using such methodologies, we can highlight the main causes visually and can guide future interventions to address the identified barriers.

Study weaknesses include that it was conducted at a single center and so the results may reflect the patient care and culture of the institution. Thus, these results may not be generalizable to other NICUs. Although we attempted to include both fathers and mothers in our interviews to understand their perspective, our sample was predominately mothers and therefore their views may not be generalizable to fathers. To mitigate the issues of generalizability, we included both parents and healthcare providers in our study, which adds credibility to our findings. In addition, the parental perspective of the barriers was congruent with those identified by the providers, which adds validity to our findings. There was a selection bias, as parents in the group interviews were primarily recruited from the Memorial Hermann NICU Parental Advisory Committee. There is a possibility of recall bias as we interviewed parents of former NICU patients. Before enrolling the parents, we did not measure their baseline NICU experience and understanding, time since discharge from the NICU, and a lack of objective third party assessor might be another limitation. Finally, we could not recruit home health nurses who may have additional information to offer. Further studies are warranted to understand the needs of both parents and healthcare providers to build a cohesive team that can address the barriers and gaps we have identified in this study.

CONCLUSION

This is the first known study that conducted individual and group interviews with parents of former NICU patients and healthcare providers that have utilized both qualitative data analysis and a fishbone diagram to identify and plot the barriers for the transition to home. Multifactorial challenges such as communication gaps, hospital discharge processes, and the emotional state of parents were identified by both parents and providers as barriers when transitioning their infant's home from the NICU. Understanding and mitigating these challenges in an NICU requires multistakeholder input from both parents and providers. We are currently developing interventions based on feedback from the NICU to mitigate the identified barriers and help facilitate the transition to home from the NICU. Specifically, we are developing a comprehensive transition to home program, a smartphone-based technology app, which is yet to be implemented to help reduce parental stress, streamline parent-provider communication, and standardize the discharge and parental education process. Our study findings and the comprehensive transition to home program we are developing can provide a platform for both parents and providers in other NICU settings to engage families in successful transition to home.

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