Parents' Perceptions Regarding Readiness for Their Infant's Discharge from the NICU

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Abstract

Purpose: To identify what parents need to feel ready for the discharge of their infant from the neonatal intensive care unit (NICU).
Design: Qualitative.
Sample: 20 parents of infants admitted to a Canadian Level III NICU were interviewed (2011–2012) and asked to identify what they require to feel ready for discharge. Interview transcripts underwent qualitative content analysis to produce a descriptive summary of parents' perceptions of their needs.
Results: Parents indicated a need for information and hands-on experience to enhance their readiness for discharge. Observations of their infant and of the NICU environment impacted parents' perceptions of their infant's readiness for discharge, which influenced perceptions of their own readiness for discharge. Finally, parents require tailoring of information and experiences to meet the unique needs of their family.

Keywords: discharge; infant; intensive care; parent; preterm; qualitative research

Preterm birth (an infant born earlier than 37 weeks gestation) is currently one of the most significant, worldwide perinatal health challenges.[1] Despite prevention efforts, rates remain elevated in the United States[2] and are continuing to rise in Canada.[3] Consequently, more infants are being admitted to neonatal intensive care units (NICU). Preterm and full-term neonates are admitted to the NICU for additional medical assistance to help them adjust to extrauterine life or to sustain normal bodily functions and may be hospitalized for several months.[4] Many infants will be discharged directly from the NICU, where care of the infant is mainly provided by health care professionals (HCP), to home, where parents are expected to assume full caregiving responsibility. The NICU is an environment of advanced medical technology that limits parents' interactions with their newborns, often preventing them from providing basic care to their infants.[4] It is not surprising that discharge from the NICU has been shown to be an anxiety-provoking experience for parents.[5–7] Mothers of infants in the NICU have been found to experience a "renewed crisis" upon discharge,[8] and several studies have shown that parents do not feel prepared to take on their infant's care at this time.[7–9]

Readiness for Discharge

Ensuring that parents feel adequately prepared to take their infant home from the NICU may be important for achieving positive health outcomes for infants and their parents. In studies of other patient populations, comprehensive discharge preparation has resulted in fewer hospital readmissions after discharge, fewer total days rehospitalized, and lower health care costs postdischarge.[10,11] Readiness for discharge, a judgment or perception regarding the patient's immediate state and their perceived ability to

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manage their care needs at home,[12] is an important predictor of how well individuals cope postdischarge.[13] Greater readiness for discharge has been found to be predictive of fewer hospital readmissions in a population of adult medical-surgical patients.[13] When the hospitalized person is a child, the parents' readiness for their child's discharge will be an important factor in both the child and the parent's postdischarge experience and outcomes. For example, mothers of term infants who do not feel ready at the time of discharge have more difficulty coping postdischarge.[12] The American Academy of Pediatrics has recognized this and recommends that physicians base their discharge decisions for hospitalized high-risk infants on the readiness of the infant, the family, and the community health care services.[14] Qualitative studies have identified parents' readiness for their child's discharge as a crucial dimension of a parent's experience of moving from hospital to home.[15,16] In studies of postpartum women, low readiness for discharge has been associated with greater physical and psychosocial problems, inadequate infant care behaviors, and greater use of health care services.[17–19]

Little is known about readiness for discharge among parents of infants requiring NICU hospitalization and what might enhance their readiness for discharge. Sneath performed an integrative review of the literature on a related topic of parents' perceptions of their preparedness for their infant's discharge home from the NICU, and 13 articles were found.[20] Data from parents' perspective are lacking, and the few studies that have explored parents' perspectives have shown that parents do not feel ready to take on their infant's care at discharge.[7–9,20] A disconnect between what parents feel they require to facilitate discharge from the NICU and what HCPs believe parents need has also been identified, further highlighting the importance of eliciting parents' perceptions of their needs.[21–23] Moreover, there is a need for studies exploring parents' perceptions of what they require to feel ready for discharge to be carried out in different center, with participants of different cultures, ethnicities, and socioeconomic status.[20]

Previous studies investigating parents' experiences of discharge have provided some data on parents' informational needs related to preparing for their infant's discharge from the NICU. Parents require information about feeding, weight gain, and recognizing signs of illness such as irregular breathing patterns, temperature control/monitoring, and infant development—specifically the varied physical and behavioral characteristics of preterm infants.[15,23–29] Although these data are important, many of these studies are dated, and the nature and complexity of the infant's care has changed with advances in medical procedures and technology. In addition, infants are being discharged at an earlier gestational age than before, potentially altering parents' perceived needs.[30]

There is a need for the development of an intervention program to enhance parents' readiness for discharge from the NICU and subsequent testing of the effects on the immediate and long-term health outcomes for infants and their families. One crucial step in developing such a program involves acquiring knowledge of what the targeted population (i.e., parents) would consider to be an effective, feasible, and acceptable intervention.[31] To date, no studies have explored parents' perceptions of what the essential ingredients might be of a feasible, acceptable NICU readiness-for-discharge program.

In summary, discharge from the NICU is an anxiety-provoking experience for parents. Adequate discharge preparation may facilitate this challenging transition and enhance parents' readiness for their infant's discharge. The overall aim of this study was to identify what parents need to feel ready for discharge of their infant from the NICU. Specifically, (a) What do they require? (b) When do they want it? (c) In what format do they want it provided? and (d) Who do they want to provide it?

METHODS

A qualitative descriptive method was used to gain an in-depth understanding of parents' perceptions regarding what they need to feel ready for their infant's discharge from the NICU. Qualitative descriptive studies seek to provide a comprehensive overview of an event and to describe the event in "everyday terms."[32]

Twenty parents of infants admitted to the NICU for a minimum stay of five days were recruited between June 2011 and April 2012 from an open-space design, Level III NICU in a large university teaching hospital in Quebec. Maximum variation sampling, with variation on the target phenomenon—in this case the discharge process—was used. To maximize variation with respect to perspectives of the discharge process, parents were sampled at two different time points, ten parents predischarge and ten postdischarge.

To participate, parents had to be 18 years of age or older and speak English or French. Infants had to be stable as determined by a clinician and in the parents' care after discharge. Infants who were (a) diagnosed with grade IV intraventricular hemorrhage, (b) diagnosed with trisomy 21 malformation, (c) being transferred to the children's hospital, (d) palliative, and (e) born to mothers suffering from addiction were excluded from the study because these infants have more extensive and specific care needs.

After receiving approval from the Research Ethics Board of the university and of the participating hospital, eligible participants were approached during their infant's hospitalization by the Clinical Nurse Specialist (CNS) to briefly explain the study and obtain permission for the first author to contact them. Participants were contacted either in person or by telephone to further explain the study and answer any questions before obtaining informed and written consent. Mothers and fathers were approached; if both parents of an infant chose to participate, they were interviewed separately, each counting as a participant.

Once informed and written consent was obtained, a demographic questionnaire was completed to provide a description

of the study participants. Data were collected using face-to-face, semistructured interviews conducted by the first author, lasting approximately 60 minutes. Interviews took place at the hospital in a private room or at the family's home. Participants in the predischarge group were interviewed before going home with their infant, whereas participants in the postdischarge group were interviewed three to eight weeks after leaving the NICU to allow parents time to transition to life at home. Information was also collected from the infant's medical chart about the infant's medical condition.

Interviews were audio recorded and transcribed verbatim. Interview transcripts were read through multiple times to get familiar with the data and to "get a sense of the whole."[33,34] Data underwent qualitative content analysis, starting with the process of open coding; transcripts were read through line by line, and categories were freely generated with the assistance of NVivo software. The list of categories was discussed and examined with the study investigators as the interviews were completed, and categories were compared and collapsed into broader subheadings.[35] This edited list of categories and subheadings was continually revised as new data were collected. After the final interview, the list of categories and subheadings was organized into higher-order themes. Transcripts were read through once more by the research team to ensure these themes accurately captured the breadth of the data.

Credibilty, dependability, confirmability, and transferability were addressed to ensure the trustworthiness of the study. Credibility was achieved by ensuring methodological coherence between the study question and methods.[36] Peer debriefing was also used to ensure credibility.[37] The study investigators met regularly to discuss data-collection issues, such as adjustments to the interview guide, and data analysis, such as revising the coding scheme and presentation of results. Data were simultaneously collected and analyzed to allow for adjustments in interviews to be made as new information was acquired. An audit trail (i.e., reflective notes and coding decisions) was maintained to ensure dependability.[36,38] Field notes consisting of new ideas and insights were kept by the first author during the interviews to ensure confirmability.[38] A clear description of the study participants, data-collection process, and subsequent analysis in this report enhances transferability.[38]

RESULTS

The characteristics of the participants and their infants are outlined in Tables 1 and 2. Sixteen (80 percent) mothers and four (20 percent) fathers participated; ten (50 percent) parents were interviewed predischarge (eight mothers, two fathers), and ten (50 percent) parents were interviewed postdischarge (eight mothers, two fathers). Parents were on average 35.9 years of age (*SD* = 5.7). Nineteen (95 percent) participants were either married or living with their partner, and 11 (55 percent) were first-time parents. Four (20 percent) of the parents had twins. The infants' mean gestational age at birth was 31.1 weeks (*SD* = 3.1), and the mean birth weight was 1436.9 g (*SD* = 488.1). At the time of the interview, the infants were on average 56.8 days old (*SD* = 42.5).

TABLE 1 ■ Parent Demographic Characteristics (*N* = 20)

Characteristic	*N* (%)
Education	
Junior college or less	5 (25)
Trade/technical program certificate	1 (5)
University	14 (70)
Currently employed	
Yes	16 (80)
No	4 (20)
Maternity/paternity leave	
Yes	16 (80)
No	4 (20)
Country of birth	
Canada	12 (60)
Other	8 (40)
Primary language spoken at home	
English	8 (40)
French	4 (20)
Other	8 (40)

Four main themes were identified regarding parents' perceptions of what they require to feel ready for discharge (see Figure 1). Parents indicated a need for information, including information about routine infant care and preparing for unexpected events. Parents also required hands-on experience caring for their infant to enhance their readiness

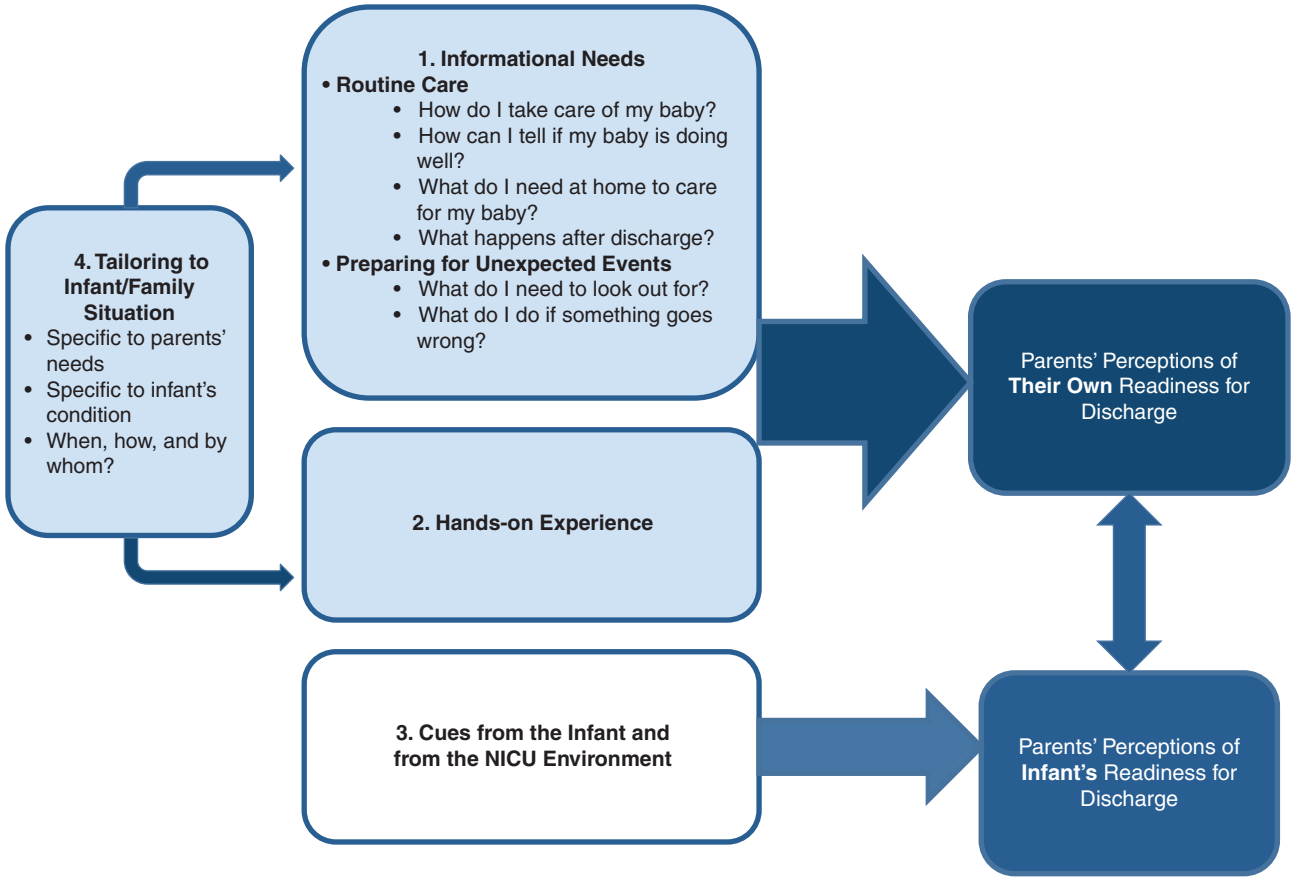
TABLE 2 ■ Infant Characteristics (*N* = 24)

Characteristics	*n* (%)
Mode of birth	
Spontaneous vaginal delivery	8 (33.3)
Cesarean section	16 (66.7)
Reason for admission	
Prematurity	24 (100)
Respiratory distress syndrome	9 (37.5)
Intrauterine growth restriction	5 (20.8)
Grade I intraventricular hemorrhage	1 (4.2)
Bronchopulmonary dysplasia	1 (4.2)
Medical treatments	
Mechanical ventilation	8 (33.3)
CPAP/HFNC	15 (62.5)
Intravenous or central line	22 (91.7)
Isolation	2 (8.3)
Chest tube	1 (6.3)
Gavage/TPN	21 (87.5)

Abbreviations: CPAP = continuous positive airway pressure; HFNC = high-flow nasal cannula; TPN = total parenteral nutrition.

Note: All values presented as *n* (%) except where otherwise indicated.

FIGURE 1 ■ Themes and categories.



for discharge. Cues from the infant as well as from the NICU environment impacted parents' perceptions of their infant's readiness for discharge, subsequently affecting parents' perceptions of their own readiness to bring their infant home. Finally, parents highlighted the importance of tailoring information and experiences to meet their specific needs. Each of these major themes will be discussed in turn.

INFORMATIONAL NEEDS

Routine Care

Parents' informational needs related to the four following questions: how to care for the infant on a daily basis, how to recognize if the infant is doing well, what supplies are needed to care for a preterm infant at home, and what are the post-discharge follow-up procedures.

How Do I Take Care of My Baby? Learning to care for their infant was identified by parents as important in preparing for their infant's discharge. Infant feeding in particular was a topic parents wanted information about during the hospitalization as well as at home. The infant's sleeping arrangements was also a topic that raised many questions. Table 3 outlines the specific infant care topics parents considered to be important.

How Can I Tell If My Baby Is Doing Well? Parents wanted to know what physiological markers could be observed at home to ensure their infant was healthy. Many parents were anxious about leaving the well-regulated environment of the NICU where their infant was weighed before and after feeds and vital signs were continuously monitored. Parents questioned if they should purchase equipment such as scales and respiratory monitors to continue monitoring their infant at home.

Several parents did not know how they would be able to ensure that their infants were meeting their daily caloric needs and maintaining their weight at home. This concern was especially prevalent for breastfed infants. One mother stated, "It's so regimented here and monitored that you just don't have those tools at home, so how was I going to recognize that she was full or that she was getting adequate nutrition?" Although most parents were able to identify signs that the infant was ingesting a sufficient amount of breast milk or formula (e.g., number of wet/soiled diapers; infant is finishing the bottle), reassurance that the infant was maintaining or gaining weight only came from appointments with a community nurse or pediatrician when their infant was weighed.

Preterm infants' breathing patterns were a concern for several parents, particularly for those whose infant had

TABLE 3 ■ Informational Needs

Infant feeding
General
How to recognize when a baby is hungry
How to stimulate a baby to keep eating if he/she is falling asleep
What is a nipple shield and how to use one
How to store/prepare frozen breast milk
How to position a baby and bottle to prevent choking
When to burp a baby
What if a baby spits up after feeding, does he/she need more
How to transition between bottle feeding and breastfeeding
Specific to transition home
How to schedule feedings at home
How to coordinate twins on the same feeding schedule at home
How to switch to on-demand feeding
Is it normal for a baby to eat more at home?
How to know when the volume of feedings should be increased
Changes to expect in a baby's breastfeeding behavior as he/she develops
Diaper changing
What is the proper technique (wipe front to back)?
What size of diapers to buy
Bathing
How to reduce heat loss during a bath
Administering vitamins/iron/medication
Proper technique to avoid choking
Holding infant skin to skin
How to do this
Temperature
Which route should be used and what are the acceptable ranges?
How often should a baby's temperature be taken at home?
What type of thermometer to buy
How warm should a baby's room be?
How should a baby be dressed?
Sleeping
Where should a baby sleep?
Should a baby be positioned on a 30°–45° angle while sleeping?
How many blankets should be used?
How to swaddle a baby
What to do if a baby will not sleep

respiratory complications. Many parents reported vigilantly monitoring their infant at home to make sure they were breathing: "It's that fear of I don't have the monitor now for my babies, so I will be the monitor." One mother found it reassuring when a nurse reviewed what she should look for to ensure her infant was adequately oxygenated, "Color, you know whether she's limp . . . they explained the signs to me . . . So I'm confident with that." Once home, several parents reported being surprised to hear the sounds their infant made while sleeping that had been masked by the noise level in the NICU. Parents wanted to be informed that these sounds were normal before discharge.

What Do I Need at Home to Care for My Baby? Although most parents had begun preparing the home during the mother's pregnancy or during the infant's hospitalization, questions remained about whether any specialized supplies or equipment were needed for a preterm infant. Questions included the following: what size diapers and bottle nipples to purchase, what type of thermometer to use, and whether adaptations to the car seat are required to accommodate a preterm infant. One parent suggested that "a checklist of what you definitely should have at home for a premature [baby]" would be useful. Several parents thought that providing this information early on in the infant's hospitalization would be helpful, allowing time to locate and purchase the items that were not necessarily readily available.

What Happens After Discharge? Information about postdischarge follow-up was important to help parents feel ready for discharge. Parents whose infant met the age and weight criteria to be followed by the in-hospital follow-up clinic wanted to know how to make an appointment, how many visits there would be, and the duration of follow-up. Immunizations, including information about the vaccine as well as scheduling, was a topic parents wanted more information about before discharge in order to make the appointments. Many parents already had a pediatrician for their infant before giving birth, but, for those who did not, they appreciated being given a list of pediatricians to contact while their infant was still hospitalized.

Preparing for Unexpected Events

Preparing for unexpected events was a key topic parents required information about to enhance their readiness for discharge. Parents wanted to know what they should look out for regarding potential sequelae infants could face as a result of being born preterm, as well as how to recognize and manage signs and symptoms of illness. Parents wanted to know what to do, who to call, and where to go if their infant's health status was compromised, including what to do in an emergency.

What Do I Need to Look Out For? Because all of the infants in this study were born preterm, concerns about potential risks the infant could face in the future were common. Some parents had difficulty articulating concerns because they did not have enough information, "I don't know really right now if . . . everything [is] fine, if there's perhaps some risks coming up because he's two months early, should we be aware of . . . any changes?" Many parents read books and searched online to obtain information regarding concerns such as signs of cerebral palsy and sudden infant death syndrome.

Growth and development of the preterm infant were areas of interest. Parents wanted to know what they could expect after leaving the NICU and if their infant would be delayed in reaching developmental milestones. "I know she's a preemie . . . she's going to be like a little late. Like when do I expect her to sit down, to see, to move, smile?" In addition, parents felt, that prior to discharge, NICU staff should warn them that their infant could behave differently at home, especially in terms of feeding and sleeping habits, and to be prepared for a change in the infant's routine.

Worries about the infant's immunity were prevalent during the transition home, particularly for parents with other children who attend daycare or school. Several postdischarge parents were not aware that they should limit the amount of visitors in their home or that their infant should not be taken out in public right away and would have liked to have this information before discharge. Recognizing signs of illness was also identified by parents as important to prepare for discharge: "How to recognize when they're sick . . . when they're dehydrated . . . all that information is very useful." One mother wanted more information about how to recognize her infant's different cries to determine if there was something wrong.

In addition to risks to look out for regarding their infant, parents also reported a need to be reminded of the ever-present risk of postpartum depression (PPD) for parents. Some parents received pamphlets at the time of the infant's birth outlining the risks of PPD as well as signs to be aware of, but these had been long since forgotten by the time the infant was discharged.

What Do I Do If Something Goes Wrong? Parents wanted information about what to do if their infant's health status was compromised at home. Specific concerns ranged from emergency situations (e.g., infant stops breathing) to less urgent problems (e.g., infant has a cold, is constipated, or has diarrhea). Several parents wanted to know how to calculate the dose of an antipyretic if their infant developed a fever. Parents wanted a list outlining steps to take, who to call, and where to go under different circumstances. Some parents were unsure which hospital to take their infant to in case of emergency.

Parents found the government-published handbook *From Tiny Tot to Toddler*[39] to be a helpful resource that addresses many of these health concerns and actions to take; however, many parents agreed that content specific to preterm infants is lacking. Some parents felt strongly that an infant cardiopulmonary resuscitation course should be part of discharge preparation to be better equipped to handle an emergency situation.

Contact with the NICU postdischarge was helpful during the transition home. One mother explained that, if she had questions or concerns, "it would be useful to speak to somebody who actually took care of [my baby]." One father was reassured after receiving a phone call from the CNS one week postdischarge however, he would have preferred to have it sooner (within 24 hours of discharge). Some parents were told by NICU staff that they could call and speak with a nurse if they had questions. A parent who was unaware of this option thought the NICU should have a telephone hotline available during designated hours for parents to call. Furthermore, parents felt more secure when HCPs they came into contact with postdischarge (e.g., pediatrician, community nurse) had a complete health history of their infant.

HANDS-ON EXPERIENCE

The second major theme identified was the need for hands-on experience for parents to feel ready for discharge. Parents recounted how experiences such as taking on their infant's care in the safe environment of the NICU were paramount in increasing their readiness for discharge. Some parents described initially feeling nervous handling their infant: "You're always scared you're going to drop them because they're so tiny." Hands-on experience was identified as an important means to help parents gain confidence in their caregiving abilities and overcome doubts about whether they could manage caring for their infant. Positive feedback from the NICU staff also enhanced parental readiness for discharge. Parents appreciated when staff encouraged and facilitated their involvement in their infant's care. One father stated, "I think the entire four weeks we were [in the NICU], they were kind of gradually helping us be more autonomous, getting ready for home."

Much of the day-to-day care (e.g., bathing) was learned through observation of and demonstration by the nurses. "You see different people, you see different ways . . . I learn from seeing different things, and I choose my own after." When performing a skill for the first time, parents preferred to have the nurse demonstrate before trying themselves under the nurse's supervision. One first-time father stated he felt like "a pro" after being coached by nurses on how to feed his infant. Even for parents with other children, having an infant in the NICU was a novel experience, and they appreciated having the chance to relearn these skills in the security of the NICU.

Parents identified several specific experiences that enhanced their readiness for discharge and eased the transition home. Staying overnight in the parent room and taking on full caregiving responsibility of their infant helped parents get a sense of what life might look like at home. Parents who did not have this opportunity were surprised to discover at home that their infant was not sleeping through the night. Encountering unanticipated situations while in the NICU was also seen as helpful. For example, one mother described how experiencing a choking episode with her infant while in the NICU gave her confidence that, if a similar event occurred at home, she would know how to handle it.

CUES FROM THE INFANT AND THE NICU ENVIRONMENT

Parents' perceptions of their infant's readiness for discharge influenced perceptions of their own feelings of readiness regarding bringing their infant home. Parents described how observations and cues from their infant affected their perceptions of their infant's readiness for discharge. Spending as much time as possible in the NICU gave parents time to "get to know" their infant, helping them recognize these cues. Cues from the NICU environment such as their infant's bed location in the unit and how staff spoke about their infant also affected parents' perceptions of their infant's readiness for discharge.

Cues From the Infant

Perceiving their infant as ready for discharge was found to be a key factor in whether or not parents saw themselves as ready for discharge. Parents looked for cues from their infant to determine whether or not they thought their infant was ready to be cared for at home. Indicators that enhanced parents' perceptions of their infant's readiness for discharge included the following: infant off of monitors ("She's ready to go home. She's better because there are not a lot of monitors"), infant approaching the prescribed weight and age criteria for discharge, a lack of or reduction in apneic and bradycardic episodes, and infant feeding exclusively from a bottle or breast. In addition, being informed about the routine test results (e.g., hearing test) prior to discharge reassured parents that their infant was healthy and ready to go home. Spending time in the NICU also allowed parents to witness their infant's progression throughout the hospitalization. One mother explained, "Because if I wasn't [in the NICU] every day, I would be wondering, 'What am I taking home, am I taking home a baby that's still sick?' But to see everything that he'd been through until the end, yeah, it reassured me that he was good enough to come home."

Cues From the NICU Environment

The NICU where this study took place is an open unit that is divided into two sections: an acute area for sicker infants and a step-down unit for stable infants who require less monitoring. The sections are not separated by any barriers, and "borders" are redefined according to bed occupancy. Many parents independently interpreted their infant's bed position in the NICU as a gauge of the infant's readiness for discharge: "You kind of equate where you [*sic*] baby is to how healthy he is." As their infant moved away from the acute area of the unit, "on the baby-go-home track," parents were able to start shifting their focus to preparing for discharge. Many parents viewed the step-down unit as the final step before going home. Several parents identified this period of hospitalization as the ideal time for discharge preparation to start. Feelings of shock and surprise upon hearing their infant was ready for home were common, especially for parents whose infant was never moved to the step-down unit, "[Discharge] was like a surprise thing, you know, because I wasn't expecting it; I thought I had to go [to the step-down unit]." Hearing NICU staff say that their infant was doing well also increased parents' perceptions of their infant's readiness for discharge: "Hearing people say that he goes home, that helps already."

Parents appreciated when efforts were made to simulate the home environment in the NICU. One mother described it as a "small, small test run of what [home] is going to be like." Interventions that provide parents with a better sense of what life at home might look like, such as taking the infant off of all monitors and switching the infant to on-demand feeding were seen as helpful steps in the transition from NICU to home.

Parents identified environmental indicators that decreased their perception of their infant's readiness for discharge. The infant being treated as a patient (i.e., continuously monitored) until the day of discharge led many parents to infer that their infant was "not normal," impacting their transition home. This led some parents to replicate the structure of the NICU environment at home: keeping the infant "in isolation," "charting" (e.g., number of soiled diapers), taking the infant's temperature regularly, pumping breast milk into a bottle to monitor how much the infant is consuming, and rigidly adhering to the feeding schedule implemented in the NICU.

TAILORING TO INFANT AND FAMILY SITUATION

Parents emphasized the importance of tailoring information and experiences to the individual needs of their family. The specific nature of the infant's condition played a role in shaping parents' needs for discharge. Furthermore, a variety of preferences regarding when, how, and by whom information designed to enhance parents' readiness for discharge should be provided were identified.

Specific to Parents' Needs

Several parents thought that discharge preparation should be "based individually on the parent's situation." Parents recognized the impact that their unique circumstance had on their needs for discharge and wanted information and experiences to be tailored accordingly. Parents for whom this was not their first child appreciated when nurses acknowledged their previous experience and identified information and experiences that might be particularly useful for enhancing levels of readiness of first-time parents.

Specific to Infant's Condition

Parents wanted information specific to their infant's health condition and preferred speaking directly with HCPs. The more parents understood about their infant's medical issues, including diagnoses, treatments, and tests, the more prepared they felt. One parent wanted a meeting with the doctor and nurse, "so you can address all these questions and fears and hopes that you have for them . . . individualized

for this little boy." Another mother felt that HCPs should provide anticipatory guidance regarding problems that could arise at home based on the specific challenges their infant faced while in the NICU.

When, How, and by Whom?

Further highlighting the need to individualize interventions aimed at enhancing parents' readiness for discharge, opinions varied about when such interventions should start: "It's a case-by-case issue when you're going to . . . start talking to parents about going home." Some parents felt that preparation should begin on admission; others felt that a few days to one week before discharge would be adequate and providing it earlier would be useless because "that information is going to get lost anyway." Parents emphasized the delicate balance of giving enough warning without offering false hope. Most parents agreed that waiting until the day of discharge was too late. For many parents, receiving information once was sufficient; however, having the opportunity to follow up and ask questions was essential.

Parents had their preferred method of receiving information designed to enhance their readiness for discharge, influenced by their learning style, (e.g., "I don't like reading to get info"), and chosen means of gathering information. Face-to-face conversation was a favored method of receiving information because it allowed parents to ask questions and clarify elements they did not understand. Informal conversations with nurses at the infant's bedside were also valuable means of receiving information. Written material was suggested by some parents but only to supplement information already discussed in person. Parents suggested that books about premature infants should be stored in the NICU to facilitate access to information while visiting their infant.

The CNS-led group support and information sessions for parents offered at the NICU were another preferred means of acquiring information. As one father stated, "It's one thing when you have experts telling you, but it's another thing when parents are giving practical experience." Not only did parents find it helpful to hear other parents' questions and advice, for many it also served as a support group. Online resources (e.g., website, NICU parent network) were also suggested methods of providing information.

Nurses were seen as the ideal HCPs to help parents prepare for discharge, since they "are the ones who take care of the baby, they know better than everyone else." Some parents spoke to the difficulty of maintaining a sense of continuity because of nurses' shift work. A nurse removed from the infant's daily care but who parents are familiar with, such as a CNS, was suggested as someone well suited to preparing parents for discharge because she/he is able to follow the family's evolution throughout the hospitalization and be more attuned to the family's needs. Parents wanted more information from the physicians about their infant's health status. A multidisciplinary approach to preparing for discharge was suggested by most parents to provide all of the information they needed.

DISCUSSION

The study findings provide a deeper understanding of what parents' perceptions are regarding what they need to feel ready for discharge of their infant from the NICU. A summary of implications for practice is outlined in Table 4. Parents identified a wide range of informational needs to be met for them to feel ready. In particular, parents wanted information about how to care for their infant, signs that their infant is thriving, equipment needs, postdischarge follow-up, and preparing for unexpected events, including risks to watch out for, growth and development of the premature infant, recognizing signs and symptoms of illness, and what to do in an emergency. These findings are congruent with previous studies that have looked at parents' informational needs concerning discharge.[15,23–29] Moreover, parents in this study expressed a desire for information specific to their infant, echoing findings from parents in Snowdon & Kane's study.[40]

Infant feeding was an important information topic for parents, most likely because all of the infants were born

TABLE 4 ■ Implications for Practice

Provide anticipatory guidance regarding changes to expect in the infant's behavior, particularly feeding and sleeping, during the first 2–3 weeks postdischarge and warn parents that the infant may not behave the same way as he/she has been in the NICU.
Encourage and facilitate parents' participation in caring for their infant while in the NICU to help parents get a sense of what life at home might look like.
Help parents assess their infant's status by identifying and recognizing physiological signs by looking at their infant, as opposed to relying on the monitors.
Be mindful that seemingly routine activities may be misinterpreted by parents; provide explicit explanations whenever possible in a language parents will understand.
Ask parents what their needs are. Provide information specific to their infant wherever possible and tailor information and experiences to each individual parent, being sensitive to the parents' readiness.
Provide anticipatory guidance by helping parents identify potential situations that may arise at home and help them problem-solve (i.e., What would you do if your infant started to choke?). Organizing issues as plans or patterns of action may hold more meaning for parents, thus helping them retain information.[49]
Links should be strengthened between hospital and community follow-up to maintain continuity of care postdischarge.

preterm, making weight gain a primary focus during hospitalization. Preterm infants are also more prone to issues affecting feeding such as reflux and poor suck, swallowing, and breathing coordination,[41] perhaps contributing to an increased need for information. Feeding as a primary concern for parents of preterm infants has been reported in other studies, not only during hospitalization but also well beyond discharge.[6,24,26,27]

Equally as important as information, parents attributed their feelings of readiness for discharge to acquiring hands-on experience. Parents described how taking on their infant's care in the safe environment of the NICU was crucial for building confidence in their caregiving abilities and enhancing their readiness for discharge. These findings support previous studies that have reported that parents expressed a desire for more hands-on practice while in the NICU.[9,22,24,29] Furthermore, rooming-in with their infant prior to discharge, such as the care-by-parent program, has been shown to help parents feel prepared for discharge.[42,43] Not having confidence in their ability to handle their infant was a common reason that mothers did not feel ready to take their infant home in McHaffie's study of mothers of very-low-birth-weight infants.[44]

The results of this study bring to light the impact that parents' observations and interpretations of cues from their infant and from the NICU environment can have on their readiness for discharge. These findings are of particular interest because this phenomenon has not to our knowledge been described in previous studies. It is important for HCPs to be aware that, despite what parents are told about their infant's readiness for discharge, parents' interpretations of various indicators may lead them to perceive their infant as not ready and could have a negative impact on the transition home. In Murdoch and Franck's study of mothers of NICU infants, mothers had difficulty perceiving their infant as medically stable at home.[45] This created feelings of apprehension and fear that their infant would deteriorate without the support of the NICU.[45] In addition, findings from this study as well as McHaffie's research show that events considered "routine" by NICU staff, such as moving the infant's bed to another location in the unit, can be of great significance for parents and should be adequately explained.[46]

In this study, when parents perceived that their infant was ready for discharge, they then perceived themselves as ready to care for their infant at home. Parents looked for signs from their infant as well as signs from the NICU environment that indicated to them that their infant was ready to leave the security of the NICU. The interdependence of perceptions of infant and parent readiness for discharge has been previously described by Costello and Chapman.[43] In Smith, Young, Pursley, McCormick, and Zupancic's[47] study, the infant's health and physiological maturity was one of three predicting factors of whether or not parents felt prepared for discharge. Several parents in this study described how the experience of seeing their infant off the monitors while still in the NICU reassured them that their infant was ready to go home. Ensuring that parents have time to adjust to caring for their infant without any monitors or regular vital sign checks would appear to be a key factor in enhancing parents' readiness for discharge.

Results from this study suggest that parents want information and experiences to be tailored to their family's situation. Taking the time to understand what parents' perceptions of their needs for discharge are would appear to be an important first step in enhancing parents' readiness for discharge. This individualized approach to care is also supported by mothers in McKim's[27,28] and Jones'[48] studies, who expressed a need for information to be individualized to meet their unique needs.

Limitations

This study was conducted in one Canadian urban setting, and it is not known to what extent these findings are generalizable to other settings. The open-space design of the unit where the study took place could also have had an effect on parents' perceived needs. The use of a convenience sample may have biased the sample to include parents who visit the NICU extensively, since the parents who were approached to participate were accessible in the unit. In addition, although fathers were invited to participate in this study, many of them were working during the day when recruitment took place. Parents who are less present in the NICU may not feel as ready for discharge and might have different needs. Most parents interviewed in this study were older, well-educated, and living with their partners, potentially impacting their needs for discharge and feelings of readiness. Finally, all of the infants in this study were relatively stable at the time of the interview and had either already gone home or were approaching discharge. It is not known whether parents of sicker infants would have similar needs.

CONCLUSION AND FUTURE DIRECTIONS

Findings from this study fill a gap in the literature by providing further insight into what parents of NICU infants require to feel ready for their infant's discharge. Parents identified a range of informational needs and experiences that need to be tailored to each infant and family situation. Understanding the importance that parents' interpretations of cues from their infant and from the NICU environment can have on the transition home is an important finding that to our knowledge has not been previously described in the literature. Future studies should be conducted at different centers and include parents of varying backgrounds, levels of education, and socioeconomic status in order to gain a broader understanding of parents' needs in relation to enhancing their readiness for discharge. Studies should be done to determine whether parents' perceptions of their readiness for discharge impact their postdischarge adjustment. Aspects of the infant's hospitalization, such as severity of illness and length of stay, should also be examined to

understand how these factors are associated with parents' readiness for discharge.

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