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The Perinatal-Neonatal Care Journey for Parents of Preterm Infants

What Is Working and What Can Be Improved

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ABSTRACT

Preterm birth is traumatic for parents, but there are few reports of parents' views on how the healthcare journey can be improved. This secondary thematic analysis used focus group data from parent consultation on proposed neonatal services standards for Northern Ireland to discover parents' experiences and recommendations for the perinatal, neonatal, and home care phases. Parents of preterm infants ($n = 40$) described their healthcare journey as positive overall and were grateful for the caring and competent care providers they encountered. However, parents described experiences that varied in quality and family centeredness across the care journey from perinatal to home care. They noted inconsistencies in healthcare team communication and provider practices and reported receiving limited emotional and practical support at all phases. In the perinatal phase, parents described difficult situations of discovering medical problems leading to preterm birth. In the neonatal intensive care unit phase, they also experienced unmet needs for involvement in decision making, financial strain, and difficulty coping with transfers and discharge. Parents experienced emotional challenges and lack of support in the home care phase. Parents identified actions that health systems can take to improve the consistency of care and communication across all phases and settings to encourage better collaboration and transitions in care.

Key Words: childbirth experience, family-centered care, neonatal intensive care, nurse-patient relationship, parents, perinatal care, preterm

There are many sources of stress for new parents of preterm infants at each phase of healthcare journey. However, most of the research to date has focused on a single phase of the journey or is based on health system service lines, and does not consider the totality of the parent experience from the discovery of medical problems that might lead to preterm birth through to being at home with their baby after discharge from the neonatal intensive care unit (NICU). Although the qualitative literature describing parents' perceptions of their experiences is relatively sparse, and primarily from mothers, several themes have emerged. Preterm birth is often unexpected and life-threatening for the baby and/or the mother. Parents describe the experience as one of shock and disbelief and being scared and excited.[1–3] Once the baby is transferred to an NICU, parents describe feeling overwhelmed, powerless, and fearful,[2,4] but as time stretches on with their baby's extended NICU stay, parents describe chronic stress related to the prolonged uncertainty and inability to develop their parental role.[5] They also describe feeling self-doubt, dependence on or conflict with the healthcare team, as they seek to establish their parental role in a setting where they feel they lack knowledge and skill.[6,7] Once parents go home with their baby, these feeling of stress and self-doubt often persist, as

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parents must navigate a new set of healthcare services for their babies without the constant vigilance of the NICU team.[8,9] Black et al[8] and Watson[4] both used the concept of liminality to describe parents' feelings of "in-between-ness" and being in a prolonged intermediate or transitional state during the perinatal-neonatal care journey. These themes appear consistent across NICUs in high-income countries.

Parents have rarely been directly asked their views on how the perinatal-neonatal healthcare journey can be improved. If knowledge about the stresses and challenges faced by parents of preterm infants is to be effectively translated to practice, parents need to be engaged differently, not just as informants about the problem of support for parents, but as codevelopers of solutions. In doing so, the whole of the parents' perinatal-neonatal journey must be examined in context. Therefore, to guide quality improvement efforts in supporting parents or preterm infants, we sought to discover parents' views, experiences, concerns, and recommendations about the care provided to them and their babies throughout the perinatal and neonatal healthcare journey in a UK context.

METHODS

This secondary analysis is based on data gathered as part of the Neonatal Care Pathway Parent Consultation,[10] an initiative to obtain parent feedback on the Neonatal Network of Northern Ireland proposed Neonatal Services Vision and Standards.[11] Each year there are approximately 25 000 infants born alive in Northern Ireland, with 1 in 20 requiring intensive care and/or high-dependency care in an NICU. There are 7 NICUs in Northern Ireland and babies may be transferred between units according to clinical need. The purpose of the consultation was to learn more about parents' experiences, concerns, and recommendations regarding the healthcare provision over the course of the perinatal-neonatal care journey from the onset of labor until after the infants were discharged home. Focus group methodology was chosen to bring parents together in a way that encouraged them to share their experiences and identify issues of individual and common concerns as well as possible solutions.[12] The primary data for this secondary analysis were the session notes from the focus groups conducted as part of a stakeholder engagement exercise, and as such research ethics approval was not required as the data were anonymous and collected for the purpose of service evaluation.

Participants

Parents of babies who received care in 1 of the 7 NICUs in Northern Ireland within the past 3 years were invited to participate via a notice about the project posted on the TinyLife Facebook page. Parents provided an e-mail address or phone number if they were interested to learn more and then were contacted by Family Support staff from the TinlyLife Charity, who explained the purpose of the consultation and invited them to attend the focus group sessions. Focus groups were held in local settings. Parents were informed that no identifying information would be used in any presentations or publications.

Procedures

Focus groups were led by skilled facilitators from the TinyLife Charity. A facilitator question guide (Supplemental Table 1, available at: http://links.lww.com/JPNN/A8) and focus group protocol were used to ensure a uniform approach across groups. Each group spent approximately 10 minutes discussing each phase of the healthcare journey, from antenatal (prenatal) to home. Facilitators asked additional questions to clarify a point or understand the importance to parents of a particular situation. The discussions were recorded on flipcharts for parents to view and verify.

Analysis

The session notes were transcribed and merged into 1 document representing responses from all 5 groups. Thematic content analysis was then used to identify themes within parents' experiences and recommendations.[13–15] The units of analysis were the message characteristics of parents' recorded comments. Open coding was first used without regard for relative importance to appreciate the breadth of conceptual possibilities across the data. Conceptual categories that were salient across participants within each phase of the perinatal-neonatal healthcare journey (perinatal, NICU, and care at home) were discussed and agreed upon by 2 members of the research team (LF and FA). Consensus was reached among all authors on the final themes and illustrative comments.

RESULTS

Five focus groups were conducted over a 2-week period, with a total of 40 parent participants. Ten parents who agreed to participate were then unable to attend the sessions. Participants were mainly mothers ($n = 33$) and the 7 fathers all participated along with their female partner. The 33 families had a total of 51 preterm infants among them (see Table 1 for sample characteristics). Some of the main themes that emerged from the focus group discussions were specific to the phase of the perinatal-neonatal care journey. Parents discussed how they discovered during the perinatal period there was a problem and the difficulties of the

Table 1. **Sample characteristics**

Characteristic	*n* (%)
Gender	
Female	33 (83)
Male	7 (17)
Age group, y:	
≤18	0
18-25	3 (8)
26-35	18 (45)
>35	19 (47)
Marital status	
Single	4 (10)
Married	34 (85)
Separated/divorced	0 (0)
Other	2 (5)
Employed	36 (90)
Has disability	2 (5)
Belonging to ethnic/minority group	1 (3)
Living in a rural community	16 (40)
Number of children younger than 3 y	56
Number of children born preterm	51
NICU length of stay, wk	
1-2	16 (31)
3-4	12 (24)
5-8	15 (29)
≥9	8 (16)
Number of infants who stayed in more than 1 NICU	18 (35)

Abbreviation: NICU, neonatal intensive care unit.

immediate postpartum period. Themes specific to the NICU phase included involvement in decision making, financial strain, and challenges with transfer and discharge. Two themes unique to the home care phase were the emotional challenges for parents and limited other sources of community support for parents. Common themes across all phases were inconsistencies in communication and provider practices and insufficient information and support for parents. Each of these is described next with illustrative quotations. Recommendations from parents about how perinatal services could be improved are summarized.

Perceptions of perinatal care

Discovering there was a problem

Many parents stated that the possibility of having a premature or ill baby was not raised at antenatal appointments, even for high-risk pregnancies with multiples. Most parents learned that their baby would be delivered prematurely just before delivery, often within hours or a day or 2 before at most. Some parents reported that they experienced disbelief and this made it difficult for them to fully comprehend that they were having the baby quite soon. Many parents did not want to think that it would really happen.

The experiences of discovering they were in preterm labor varied widely among participants. Some women noticed changes in their pregnancy, which in turn led to premature labor. However, they felt they were not always listened to by healthcare providers. Only one parent who had a previous preterm birth commented about being aware of the signs of labor. One mother said: "No one believed I was in labor until they checked and I was 5 cm dilated." However, some mothers spoke about their water breaking and not realizing what was happening. Mothers who came to hospital because of a concern were either sent home or admitted and only told the staff would "keep an eye on it, see how it goes." One mother thought she was dying before discovering she was 8 cm dilated at 24 weeks. One mother was transported to London within hours of being told she could lose her babies at 24 weeks 2 days. She remained hospitalized in London and her twins were born at 28 weeks. Another mother refused a cesarean section and continued the pregnancy for 5 days.

Difficulties of the immediate postpartum period for preterm parents

Mothers for the most part did not wish to be in a postnatal ward with other mothers who had full-term healthy babies. They described how being put on the postnatal ward with mothers who had full term healthy babies was distressing, and that they did not want to see the other babies.

Mothers also found it extremely difficult emotionally if they were discharged but their baby was not also discharged, or if one baby was discharged and the twin was not. They felt that staffs need to be very sensitive to how difficult it is to leave when your baby is not discharged with you, especially when seeing other mothers leave with their babies. Some mothers discharged themselves, so they could go to the hospital where their baby was transferred, and these mothers did not receive the standard postpartum discharge examination or have arrangements made for their own follow-up care.

Fathers also found the delivery period difficult and felt excluded. Some commented that they were left not knowing what was happening for a long period, which increased their stress levels. When the baby was born, they did not know where they should go—to their wife or with their baby. This was even more difficult if the mother was very ill and/or the baby was taken to a different hospital.

Perceptions of NICU care

Parents gave high praise when staff demonstrated respect and thoughtfulness, such as when staff called babies by their names, gave parents up-to-date information about how the baby was during the parents' absence, greeted parents by name, and asked how they were feeling. Some parents commented that individual staff went out of their way all of the time, were always so positive, and fussed over them and their baby at discharge. When parents felt they and their babies were known as individuals, they felt listened to and more a part of the baby's care team. Differences in the perceptions of NICU care on the basis of length of stay or other infant or parent characteristics did not emerge from the focus group discussions.

Inclusion in decisions about the infant's care

The majority of parents felt they were included in decision making. However, others commented that staff could not remember their baby's name, did not discuss treatments or treated babies without parents being informed or included. Parents whose babies were transferred between NICUs had many contrasting examples of being included and then excluded (or vice versa) in decision making between one unit and the other. Parents whose babies stayed in a single unit also commented sometime were not kept informed about provider concerns about the baby's conditions or involved in decision making, including decisions about discharge.

When parents felt that they were "in the way," excluded from decision making, excluded from their baby's care, or lacked access to information, they reported becoming depressed and seemed to have difficulties in bonding with and caring for their baby. If the parents were excluded or witnessed staff not responding to a baby quickly enough, it instilled a lack of confidence and mistrust in the staff.

Financial strain

The financial cost of travelling to an NICU every day, particularly if they had to travel long distances, put a financial strain on parents and added to the level of stress that they were under. Some parents who lived long distances from the hospital could not visit as often as they would have liked to. They expressed feelings of guilt at not being able to be with and bond with their baby, and the distance also negatively affected the mothers' ability to breastfeed. Parents talked about spending more on petrol to visit their baby in the NICU than the maternity pay they received each week, and they felt embarrassed to ask for food vouchers. Staff did not always remember to give the vouchers to them, despite their clear need.

Challenges when infants are transferred between NICU

Eighteen parents reported that their infants had been cared for in more than one NICU. Some babies were transferred early after birth to the regional unit. In these cases, the mother did not get to go with the baby and fathers were torn between going to look after the baby and staying to support the mother. Most often, they followed the baby. Transfers were also frequent from the regional center to a local unit, sometimes in response to a parent request to have the baby moved closer to home. When the new unit was perceived to be better than what they had come from, parents settled quickly, but if not, parents often wanted to return to the original unit and staff.

Often the transfer happened quite quickly and there was not enough time for parents to be properly informed and have all their questions answered. The earlier and the more often that transfers were discussed, the less distressing it was when it happened. Even when the mother was in labor, having had thoroughly discussed the transfer reduced the anxiety and stress.

The suddenness of discharge from the NICU was another challenge for parents. Most parents said they were talked to informally about the possibility of discharge over a few days. Some parents said that the word "home" was rarely used and then "all of a sudden it [discharge] was happening." They observed that staff often did not want parents "to get their hopes up." However, often there were arrangements and practicalities that needed sorting out, such as getting time off work, arranging for equipment, and finding childcare for other children. Parents wanted to have notice to prepare themselves, even if things changed. Discharge preparation was felt to be a "tick-box exercise" and very rushed, as time for discharge approached. Parents commented that it felt that staffs were going quickly through the treatments and aftercare without parents having an opportunity to ask questions or gain fuller understanding. Parents also recognized that they can become used to the NICU environment and dependent on the healthcare team, leading to a fear of going home or caring for their baby at home. In a few cases, the babies were discharged from the NICU to the maternity ward and then the mother and baby were discharged together.

Perceptions of caring for preterm babies at home

Emotional challenges for parents at home

Caring for babies at home was the topic that generated the most discussion by parents. They talked about how difficult it was going home and about how they adjusted. Parents experienced a range of emotional reactions from "The best feeling/great" to "Wanted to go back/phoned to go back/nervous" to feeling "Exhausted" or "It was an anticlimax" or "I felt depression as it was not how I imagined it would be."

Many parents commented that the reality of having a premature baby and what they had gone through often did not hit them until months later. Some parents talked about feeling isolated and becoming depressed when the full emotional weight of what they had experienced with the birth of a premature baby and the how their parenting experience would not be as they imagined "hit home." Some parents commented that this might happen after the baby had been home for quite a while, when the postdischarge support services provided to all UK parents, such as postpartum midwifery visits and health visitor home visits had been withdrawn.

Limited sources of other support for parents at home

Some parents received visits from a TinyLife family support officer or volunteer. Some also attended TinyLife's baby massage classes, sensory room, or parent support groups. Parents commented that these were often the only opportunities they had to talk to someone, share their story, and hear other parents' experiences. They found it useful to "deal with the emotional upheaval" they continued to experience. Often the TinyLife volunteer visitor offered help with the baby's care, with other children and with housework, and this was felt to be invaluable. Other sources of group peer support that were identified were HomeStart, Sure Start, or breastfeeding support groups.

Inconsistent communication and care practices

A universal theme across all phases of the healthcare journey was inconsistency in communication and care. Table 2 shows examples by journey phase. In the perinatal phase, parents were informed about the preterm labor by different providers: a consultant physician (attending physician) or junior physician, or midwife. How healthcare providers informed parents about imminent preterm birth was felt to be very important but sometimes not done especially well, particularly if it was an urgent situation. For example, according to one parent, the consultant "held back [information] so that [her] blood pressure would not increase." Another parent recalled, "Everything was very vague and the information confusing." Parents commented about the lack of consistency in healthcare providers once in hospital, never seeing the same person twice. Handover from provider to provider was a particular problem because there was incomplete transfer of information about their baby's condition and treatment, and this increased the risk of something important being missed that could adversely affect their baby's health.

By the time of the baby's transfer to the NICU, most parents understood the reasons for admission. A few parents commented that they were not told about their baby's admission to the NICU for quite some time: "It was 5 days before I spoke to the doctor—I had to ask." One mother was told her baby was taken to the NICU well before she could get there, which she felt gave her time to adjust after giving birth before going to the unit. Some parents were told to prepare for the worst-case scenario with regard to their baby's outcome and expected it, but it ultimately did not happen.

Most parents had nothing but praise for the healthcare providers across perinatal-neonatal settings and felt that nursing staffs were caring toward babies and were supportive of parents. However, some parents reported that there were not enough staff and mothers were left unattended on labor wards. They also saw babies in the NICU left to cry and nappies not changed for long periods. These experiences made them feel that they needed to stay in the unit and that they could not leave their babies for fear they would not be well looked after.

Consultants were described as establishing a good, straightforward relationship with parents. Consultants "told it as it was," and when asked questions, they explained things in a manner that parents could understand. However, some reported that consultants did not have great people skills. Nurses were felt to be the best at communication and were very approachable. Parents commented that they could ask anything and that "no question was a stupid question." Some parents talked about staff going the extra mile to ensure that parents were included in care discussions.

When parents had experiences in one unit that were not carried out in another, this was distressing. It led parents to ask questions about why there were differences and sometimes caused them to become angry. Parents voiced similar concerns about inconsistencies in care practices among providers and in the training and support parents received for providing kangaroo care, feeding, and bathing their baby. Many expressed the view that this was important for fathers as well as mothers. The inconsistencies in bathing practices were particularly notable. There was a wide variation in bathing frequency and procedures used and taught by different care providers. Moreover, parents were often told that contradictory practices were being done for the purpose of "infection control." Examples of the positive and negative experiences parents had with kangaroo care, feeding, bathing, and nappy changing are shown in Table 3.

Once babies were discharged from the NICU, parents felt they were discouraged from contacting the NICU with concerns about the baby and were told to

Table 2. **Common experiences for parents across the perinatal-neonatal healthcare journey**

Theme	Examples
Inconsistency in communication	Perinatal phase • Some mothers were told directly about impending preterm delivery; others overheard providers discussing their baby's transfer; other were told but given insufficient details • Parents were given conflicting advice on managing preterm labor • Healthcare providers changed frequently and did not seem to communicate with each other and failed to pass on important information, such as breech position of baby or need for antenatal corticosteroid injection
	NICU phase • Sometimes parents were excluded from the unit during medical rounds, were not provided opportunities to meet with consultants and ask questions, and were unable to see their baby's notes • Fathers felt left out; one father noted that no one spoke to him at all, only to his wife • Healthcare providers did not seem to communicate with each other and failed to pass on important information such as when another nurse had already given a drug to their baby, possibly averting a medication error • Parent observations of their baby's condition were not passed on to other staff members and sometimes led to delayed detection of a critical change in a baby's condition • Communication about transfers was variable and there was variation between units regarding how parents received information or were included in the care of their babies. Parents described being informed about the reason for transfer by a consultant or nurse. Some parents were offered information or the opportunity to go see the other unit, but most parents did not feel the need to visit the other unit beforehand
	Home care phase • Almost all parents were given information about follow-up appointments, but they were not always told when and there were difficulties with follow-up communications and logistics, especially with appointments at different hospitals • They were given conflicting information about child development with no consideration for the babies' adjusted age and often they had to "fight"
Inconsistent and insufficient information and support	Perinatal phase • Some parents found stories about other premature babies from Web sites of local or national charities • Some parents were given leaflets or recommended books or DVDs from the NHS or local or national charities • Some parents felt that the information they received made them feel paranoid • Other parents felt they did not get enough information (eg, about preeclampsia or twin pregnancies)
	NICU phase • Parents were often confused about NICU terminology. For example, parents were confused about use of the word "beds" and what this meant in terms of where and when the baby would be born. They thought staffs were referring to a hospital bed, not an incubator or cot (bassinet) in a specialized NICU. They did not understand that when they were told there were "no beds" at a referral NICU, it meant that the NICU was full or that it lacked the nurses to staff the "beds." This added to their confusion and concern about why their babies were transferred into different hospitals much farther away • Some mothers commented that the midwife could have been more sensitive when calling the home and did not seem to know that their baby was not at home. One mother commented that the midwife talked about babies dying and the mother was very distressed by the visit
	Home care phase • Health visitors had not read the baby's file and gave conflicting information and instructions about feeding or bathing. For example, some health visitors were encouraging the baby to be bathed every day, yet the hospital had discouraged this, telling parents once a week unless it was necessary enough

Abbreviations: NICU, neonatal intensive care unit; NHS, National Health Service.

Table 3. **Parents' experiences of infant caregiving in the NICU**

Neonatal care activity	Positive parent experiences	Negative parent experiences
Holding and kangaroo care	• Most but not all parents had experienced kangaroo care	• Some parents felt that they would have liked to have done more kangaroo care • Some parents felt they had to ask permission to hold baby, were not allowed until the baby was quite a bit older, received little help and support, with some staff actively discouraging them
Feeding	• When mothers received a lot of support and encouragement, they developed the confidence to continue • Breastfeeding coordinators and a number of other staff were highly praised • NICU staffs were felt to have provided the best support rather than maternity staff • Many parents had received a breast pump and support from TinyLife, which they felt was very helpful	• Some parents felt that staff would prefer to bottle feed, often not getting the breast milk out of the fridge to use. They reported staff made comments such as "I don't think you should breastfeed your premature baby. You will just become depressed," "Breastfeeding will only delay your baby leaving the unit by another two weeks, so I would bottle feed if I was you," and "Since it takes you so long to express would you rather not be with your baby?". • Not having somewhere private to breastfeed was an important concern for many mothers • Some parents had to ask for breast pump and then that a breast pump being rolled up to the bed and left with no instruction or support
Bathing	• Most parents were able to bathe their baby even if it was just before going home	• Some parents were told about bathing or only talked through the process rather than actually getting to bathe the babies
Nappy changing	• Parents in most units shown how to change their baby's nappies	• A few parents felt that they were actively discouraged from changing nappies and caring for their baby

Abbreviation: NICU, neonatal intensive care unit.

contact their general practitioner. Parents described complicated and inconsistent appointment and follow-up schedules. Appointments took place at intervals from weekly to monthly for a year or more. Some parents described having to fight for their baby to be seen for follow-up care. One parent commented that they had not seen the same consultant since their baby was discharged and this meant having to tell their story over again every visit. Most follow-up appointments took place in the hospital the baby was discharged from, but some were at other hospitals because of different conditions and treatments needed.

Some parents commented on the great support and encouragement they received from health visitors (ie, public health nurses). However, some reported that the health visitor only came once and many others had a difficult time with their health visitor. They described feeling under pressure from the health visitor when their baby's weight and growth were compared with a full-term baby despite the parents' observations that their baby was now doing quite well for having been born so early. Parents felt that often health visitors had a lack of understanding about the needs and development of a premature baby. Parents also felt that health visitors often lacked confidence, seemed afraid if the parents asked questions, and almost could not wait to get out of the house. Many parents felt that health visitors and community midwifes required additional training or that there should be specialist health visitors for babies discharged from NICUs.

Inconsistent and insufficient information and support

Most parents did not receive any formal education or written information about preterm birth during pregnancy, even when they were labeled as having a high-risk pregnancy. Parents felt there should be high-quality free information available electronically as well as in written form and that they should not be required to purchase essential information.

In contrast to wanting more information about pregnancy and birth, getting leaflets about the NICU before delivery was not a high priority for parents. Many parents got such leaflets but did not read them. Verbal communication, especially talking to someone, was more important for parents, especially when it was uncertain to which NICU a baby might be transferred. All parents mentioned that they were shown hand-washing techniques and received information on infection control.

Parents faced many emotional challenges having a baby in the NICU and felt they needed more information and support. It was particularly difficult to not feel that the baby was theirs and that they felt they had to get permission to touch or do anything with their baby. Many mothers commented that they missed their community midwife home visits because they were often in the NICU and not at home. The mothers felt they missed helpful information and support about their own postpartum care because of these missed visits.

Very few parents reported a positive experience in terms of the aftercare support they received except for the follow-up appointments. All parents talked about needing support or someone to talk to when they "hit the brick wall" and the magnitude of what they had been through was realized. This could happen months, or even a year, later when very few support services are available to assist parents. Parents who had a particularly negative experience felt that an opportunity to debrief and make sense of what had happened to them during their perinatal-neonatal journey. Parents would have been useful.

Parent recommendations

Parents made a number of recommendations that they felt would improve care and support across all phases of their perinatal-neonatal healthcare journey, and including some recommendations for antenatal care, as shown in Table 4. Several overarching themes in the recommendations related to information and family-centered care and peer support.

Although written information was not a high priority for most parents and many did not read the leaflets and books they were given, they felt it should still be provided and that it be easy to understand. Some parents felt that there was not enough appropriately written information, especially about potential conditions or treatments that the mother might encounter and how they may affect the baby. Leaflets need to be short and simple. Parents also suggested that more information be included in the pregnancy book, on video/DVD, or in a mobile application. Parents did not mention receiving links to or using hospital or National Health Service Web sites.

It was also very important to many of the parents that all expectant mothers get basic information about preeclampsia so that if symptoms begin they know what to do. They felt that pregnant women should be given information on particular conditions that cause preterm birth and advice on the signs to watch for. One parent stated: "If you or your baby has a particular condition then learn what to expect, what to watch for and what to do."

Parents felt that a family-centered approach was important at all phases of their healthcare journey and it was particularly crucial when their babies were in the NICU. Most parents felt that they should be actively included in decision making and the care of their babies from an early stage. They also felt care should be individualized and focused on the needs of the family rather than the health system.

Although some parents said that nothing would have made their perinatal/neonatal journey any easier, many valued support from nonmedical sources other than the clinical team or hospital staff. One parent commented that "hope came from seeing and hearing other parents' experiences." Parents valued being able to speak to someone who had been through a similar situation, and many parents commented on the importance of peer support for pregnant women at risk for having a premature baby. They mentioned how their partner was a great help. Many mothers said that being in the same hospital as their baby helped them cope. They also commented that fathers need peer support during and after delivery and they need clear information about what is happening to their partner and baby, as well as about what they specifically can do to help. Parents felt that they should be offered a volunteer visitor and/or the opportunity to attend local parent support groups. They valued the personal contact from the TinyLife charity over receiving leaflets with information about support services. Having a system of peer support in place available from the baby's first admittance through to when they were home for up to a year was voiced by many parents as something that would have helped with many practical and emotional aspects of the care pathway. They felt that peer support persons did not need to be medically trained but could be another parent or volunteer.

Table 4. **Recommendations from parents on how healthcare providers can support a better patient and family experience**

Stage of the parent journey	Parent recommendations
Perinatal	• Doctors/midwives need to listen if a parent suspects that there are problems • Link to one person through the process—antenatal through to discharge from the NICU • Give dip sticks out to parents to do every day and teach them to check own blood pressure • Provide more free information about twins/multiples • Provide more information to prepare practically • Remember parents in denial—many parents cannot believe that the baby(ies) are actually going to be delivered • Some parents felt being given full information is best, but others felt that “ignorance was bliss” • Need for consistency, regardless whether you are a private patient or not • Families should be given information about preterm birth and preterm babies, even if everything goes well. They can choose to look at it or not • Start talking about the possibility of a premature baby, as soon as it is a possibility • Staffs need to be more gentle when communicating about imminent preterm birth to parents • Mothers delivering very preterm babies should have a separate room—but not be forgotten either • Provide a skilled professional or peer counselor to talk with parents about their feelings after preterm birth • Provide mothers help with breastfeeding • Provide additional support for parents when discharged without baby
Neonatal unit	• Tell parents as soon as it is a possibility that their baby will be transferred and why. Go back to parents with frequent updates and help them sort out practical arrangements • Explain reasons for transfer and what it means to “find a neonatal bed” at another hospital • Provide opportunities for parents to visit the NICU beforehand • Make the NICU more family focused • Provide information on different conditions that might affect a premature baby and what to expect • Arrange for someone for parents to talk to, especially peer support • Provide support and empathy for parents • If mistakes are made, recognize them, apologize, and learn lessons • When things do not go as planned, debrief with parents • Provide transportation and food vouchers
Care at home	• Provide parents with access to a community midwife/health visitor to call as soon as possible when they get home • Have the same person consistently following up with home visits • The community midwife who visits a mum after discharge should be the same one who comes back when the baby released • Health visitor and midwives should receive special training for care of premature babies (not going on checks for full-term babies) or there should be specialist health visitors or midwives to give support for families with premature babies • Offer volunteer support to help at home with feeding or other care • Have a helpline to phone for information and support specific to premature babies

Abbreviation: NICU, neonatal intensive care unit.

DISCUSSION

This analysis provides new insights into the experiences of parents with preterm infants from the first knowledge that they were going to give birth to a preterm baby through to caring for their babies at home. Parents were overall very grateful for the care and support that they and their babies received from the healthcare team throughout the whole of the healthcare journey from antenatal care to follow-up at home. They had few comments about the antenatal phase of their journey and focused primarily on the perinatal, NICU, and home care phases. Their perceptions of the perinatal-neonatal journey were characterized by common themes of inconsistent communication, inconsistent care practices, and limited information and support. Parents had vivid recollection of their perceptions of the helpful and not so helpful interactions with healthcare providers. Many opportunities for improvement of the perinatal-neonatal care pathway were raised in the focus group discussions.

Previous qualitative research from across the world has focused primarily on parents' internal psychological state at different stages of the perinatal-neonatal care journey.[1–3,5] Although the emotional impact of a preterm birth is clearly evident in the experiences of parents in this analysis, the many challenges presented by interactions with the healthcare team, the variability of care processes and mysteries of the healthcare system dominated the discourse at all stages of the perinatal-neonatal care pathway. Consistent with previous international research,[8,9] this analysis highlights that transitions in care from perinatal to NICU settings and from NICU to home care were particularly difficult for parents.

Fathers felt that the healthcare providers often excluded them from their baby's caregiving and decision making. These findings are consistent with the limited studies of the experiences of fathers of preterm babies.[16,17] Fathers often experienced the double burden of concern for the well-being of the baby and of the baby's mother. Because of this, and the overall lack of health professional and social support for fathers of preterm infants, new strategies are urgently needed to improve the access to quality support for fathers of preterm infants.[18,19]

Hospital-based interventions to reduce stress and support for parents of preterm infants during the neonatal period can improve postdischarge outcomes for parents and infants.[20–24] Contextual factors are also important to consider, including the amount and quality of family or healthcare provider support.[25] However, little research has been done on interventions to mitigate stress during the perinatal and post-discharge phases of the preterm birth experience. A recent review of research on transitions from hospital to home in parents of preterm infants found that parents face many challenges, similar to the findings of the present analysis, and that it is an individualized process for which there are no existing instruments for measuring parental adjustment.[26] Moreover, the findings from the present analysis suggest that there is little translation of research evidence to practice. Parents continue to want more information and support, and desire for greater involvement in care and decision making during the NICU stay and after discharge.[9,27] Parents in this analysis provided specific recommendations for healthcare providers to improve care delivery and in particular the quality of information, family-centeredness, and peer support across all phases of the perinatal-neonatal care journey. The recommendations made by parents in this study are also likely to be relevant across healthcare settings internationally because, as noted earlier, many of the difficulties encountered by parents in this study are similar to those identified in studies from different countries and health systems. Further research is needed to better understand the specific information needs, and the ideal forms for communication of essential information, for parents at all stages of the healthcare journey, from antenatal care through to care of the preterm infant at home over the first year. Further research is also needed on new methods to efficiently and effectively educate healthcare providers who interact with parents to improve their parent education, communication, and support skills.

The findings of this analysis should be considered in light of several limitations. First, this is a secondary analysis, which limits the depth of information for some topics. Prospective studies are needed to further explore parents' experiences and recommendations and determine saturation of identified themes. Second, several sampling issues should be considered. The findings are limited to a single geographical area and the data from the 5 sites were pooled. Thus, there may have been nuances in the specific experiences and recommendations relative to site that were not revealed in the findings. However, the findings are consistent with previous surveys and reviews of parent experience of NICU care.[5,27–29]

CONCLUSIONS

In summary, the healthcare experiences of parents of preterm infants vary in quality at all stages of the healthcare journey from perinatal to home care. Parents readily identified actions that health systems can take to improve the consistency of care and communication that they felt would have a positive effect on the experience and outcomes for their families. These findings are being used to inform quality improvement initiatives in the local context to increase patient and family engagement at all stages of the perinatal-neonatal care journey. It is also clear that these themes resonate with existing literature, which predominantly looks at distinct time points in the postnatal journey, and offer valuable reflections for international practice and policy. The focus group methodology described is a useful approach to initiating greater engagement and could be used in an ongoing manner to provide feedback on the effectiveness of strategies implemented to address the parent needs and concerns. Strategies to increase communication between healthcare providers across the maternity, neonatal, and community care settings as well as between parents and healthcare providers are needed to encourage better collaboration and transitions in care. Future research should evaluate the effectiveness of interventions to better address the unmet support needs of parents, and especially of fathers, and to improve the perinatal-neonatal family-centered care experience and outcomes.

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