

# Barriers and facilitators to preparing families with premature infants for discharge home from the neonatal unit. Perceptions of health care providers

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## Barriers and facilitators to preparing families with premature infants for discharge home from the neonatal unit. Perceptions of health care providers

**Objective.** To explore Colombian health care provider perceptions of barriers and facilitators to preparing families with premature infants for discharge home from the neonatal intensive care unit (NICU).

**Methodology.** Using a qualitative descriptive design, in-depth semi-structured interviews were conducted with fifteen neonatal health care providers (HCPs) in Colombia. Data were analyzed using qualitative content analysis. **Results.** Participant responses centered on three main themes: 1) establishment of the parent-infant bond, 2) acquisition of parenting skills, and 3) getting ready for the transition from hospital to home. Barriers to preparing parents for NICU discharge included obstacles to parental visiting in the NICU, communication barriers, difficulties related to the establishment of successful breastfeeding, insufficient human resources and poor links between hospital and community-based resources. Facilitators included the availability of social aids for vulnerable families, 24-hour telephone access to the neonatal units, tailored educational materials and group sessions, continuing education for staff and the community-based Kangaroo Program available to parents post-discharge. Adolescent mothers, indigenous parent and working fathers were identified as particularly challenging to reach and engage in discharge preparation. **Conclusion.** Neonatal HCPs identified numerous challenges as well as helpful strategies for preparing families for hospital discharge. Additional studies are needed on the experience of neonatal discharge from the perspective of parents of premature infants in Colombia, to help inform optimal interventions for supporting families during the transition from hospital to home.

**Key words:** neonatal nursing; intensive care, neonatal; patient discharge; patient-centered care; Colombia.

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### **Barreras y facilitadores para las familias con bebés prematuros que se preparan para el alta de la unidad neonatal. Percepciones del personal de salud**

**Objetivo.** Explorar las percepciones del personal de salud neonatal sobre las barreras y facilitadores para las familias con bebés prematuros que se preparan para el alta de la Unidad de Cuidado Intensivo Neonatal – UCIN-. **Metodología.** Utilizando un diseño cualitativo descriptivo, se realizaron entrevistas semi-estructuradas a profundidad a 15 profesionales de la salud neonatal en Colombia. Los datos fueron analizados mediante el análisis de contenido. **Resultados.** Las respuestas de los participantes se centraron en tres temas principales: 1) el establecimiento del vínculo entre padres y el niño, 2) la adquisición de habilidades parentales, y 3) preparación para la transición del hospital al hogar. Las barreras para la preparación de los padres para el egreso del niño, incluyen desde los obstáculos a los padres para la visita en la UCIN, las barreras de comunicación, las dificultades relacionadas con el establecimiento de la lactancia materna exitosa, los recursos insuficientes de personal de salud y escasos vínculos entre el hospital y la comunidad. Los facilitadores fueron la disponibilidad de ayudas sociales para las familias vulnerables, el acceso telefónico de 24 horas a las unidades neonatales, los materiales educativos adaptados, la educación continua para el personal de salud, y la disponibilidad para los padres del Programa Canguro de base comunitaria después del alta. Las madres adolescentes, los padres que trabajan y la familia indígena fueron grupos identificados como particularmente difíciles para que participaran en la preparación del alta. **Conclusión.** El personal de salud identificó numerosos desafíos, así como estrategias útiles para la preparación de las familias para el alta hospitalaria del prematuro. Se necesitan estudios adicionales en la experiencia del alta neonatal desde la perspectiva de los padres de bebés prematuros en Colombia, para ayudar a documentar las intervenciones óptimas para apoyar a las familias durante la transición del hospital al hogar.

**Palabras clave:** enfermería neonatal; cuidado intensivo neonatal; alta del paciente; atención dirigida al paciente; Colombia.

### **Barreiras e facilitadores para as famílias com bebês prematuros que se preparam para a alta da unidade neonatal. Percepções do pessoal de saúde**

**Objetivo.** Explorar as percepções do pessoal de saúde neonatal sobre as barreiras e facilitadores para as famílias com bebês prematuros que se preparam para a alta da Unidade de Cuidado Intensivo Neonatal – UCIN-. **Metodologia.** Utilizando um desenho qualitativo descritivo, realizaram-se entrevistas semiestruturadas a profundidade a 15 profissionais da saúde neonatal na Colômbia. Os dados foram analisados mediante a análise de conteúdo. **Resultados.** As respostas dos participantes se centraram em três temas principais: 1) o estabelecimento do vínculo entre pais e o menino, 2) a aquisição de habilidades parentais, e 3) preparação para a transição do hospital ao lar. As barreiras para a preparação dos pais para a saída da criança, incluem desde os obstáculos aos pais para a visita na UCIN, as barreiras de comunicação, as dificuldades relacionadas com o estabelecimento da lactância materna exitosa, os recursos insuficientes de pessoal de saúde e escassos vínculos entre o hospital e a comunidade. Os facilitadores foram a disponibilidade de ajudas sociais para as famílias vulneráveis, o acesso telefônico de 24 horas às unidades neonatais, os materiais educativos adaptados, a educação contínua para o pessoal de saúde, e a disponibilidade para os pais do Programa Canguru de base comunitária depois da alta. As mães adolescentes, os pais que trabalham e a família indígena foram grupos identificados como particularmente difíceis para que participassem na preparação da alta. **Conclusão.** O pessoal de saúde identificou numerosos desafios, bem como estratégias úteis para a preparação das famílias para a alta hospitalar do prematuro. Precisam-se estudos adicionais na experiência da alta neonatal desde a perspectiva dos pais de bebês prematuros na Colômbia, para ajudar a documentar as intervenções ótimas para apoiar às famílias durante a transição do hospital ao lar.

**Palavras chave:** enfermagem neonatal; terapia intensiva neonatal; alta do paciente; assistência centrada no paciente; Colombia.

## Introduction

Premature birth (i.e., birth at gestational age of less than 37 completed weeks) is the second largest cause of mortality in children younger than five years, and accounts for approximately 11% of all live births worldwide.<sup>1</sup> Colombia has a high burden of caring for premature births with a national premature birth rate of 18.3%, a significant proportion of whom are born to adolescent mothers.<sup>2</sup> Technological advances have contributed to the survival of increasingly premature infants, who often face lengthy hospitalizations in the neonatal intensive care unit (NICU) and may be discharged home with continued health care needs. Preterm birth and hospitalization of a premature infant in the NICU has been identified as a crisis event for families in Colombia<sup>3</sup> and elsewhere.<sup>4</sup> It is critical to ensure that families are well supported in the NICU to assume their parenting role in preparation for their infant's transition from hospital to home. Lack of parental readiness for NICU discharge has been associated with higher rates of hospital readmissions, poorer utilization of follow up primary care services, infant feeding and health problems, higher stress and poor self-care management abilities at home.<sup>5</sup>

To date, there is no literature specifically addressing the neonatal discharge process in Colombia. However, there are a number of studies on parental experiences of the neonatal discharge process from other countries. Studies from both Latin America<sup>6</sup> and North America<sup>7</sup> have found that parents experience fear and apprehension at the time of NICU discharge, when they make the transition from being supported by neonatal staff to going home and providing full infant care on their own.<sup>6,7</sup> Concerns about infant feeding have been identified as a particularly important source of parental anxiety during the transition from neonatal care to home.<sup>8,9</sup> However little is known about how health care providers identify and address parental concerns related to neonatal discharge in different cultural contexts. A few studies have found that health care professionals

and parents have differing views about the degree of parental readiness for discharge from the NICU,<sup>5,10</sup> pointing to the need for clearer understanding of how health care professionals view their role in helping prepare families for neonatal discharge.

There is an emerging body of literature regarding effective strategies for improving the NICU discharge process, although the extent to which these practices are implemented in Colombia is not known. Teaching parents basic infant care skills and how to assess and meet their infant's needs prior to going home is critical to help parents develop a sense of competency and autonomy.<sup>11</sup> Family-centered care models that promote the involvement of parents in infant care and decision making encourage parent-infant bonding and help parents feel better prepared to assume their parenting role following discharge from the NICU.<sup>12,13</sup> Finally, ensuring continuity of care for families following NICU discharge has also been identified as crucial for helping parents feel more prepared for the transition to home and to support the future health and development of their baby.<sup>14,15</sup>

Despite recognition of the importance of adequately preparing families for NICU discharge, there is scant literature on barriers and facilitators related to the NICU discharge process. A recent Brazilian review of the nursing role in the NICU discharge process identified numerous barriers that nurses face when preparing families for hospital discharge, including difficulty establishing a trusting relationship with parents who fear their infant is receiving inadequate healthcare, poor collaboration amongst staff, and difficulty in providing information on the day of discharge due to parental anxiety and stress.<sup>16</sup> A Canadian study describing the NICU working environment found that discharge planning, parental support and teaching were the neonatal nursing activities that were most frequently rationed when resources were limited in the work environment.<sup>17</sup> These

findings may be particularly relevant to Colombia, where nurses often face high stress working conditions, long shifts and workforce shortages.<sup>18</sup> Given the above-mentioned gaps in the literature and the high rate of preterm birth in Colombia, the main purpose of this study was to explore Colombian health care provider (HCP) perceptions of barriers and facilitators to preparing families with premature infants for discharge home from the NICU.

## Methodology

**Setting and participants.** This study used a descriptive qualitative design to explore HCP perceptions of the neonatal discharge process. The study setting was a large, university-affiliated NICU referral center in a northwest region of Colombia. The NICU had 14 intensive care, 20 intermediate care and 6 basic care beds. There were 12 additional basic care beds in a separate step-down neonatal unit in the adjacent children's hospital. As the hospitalized infants' condition improved, they were transferred from intensive to intermediate and finally to basic care (either in the NICU or adjacent step-down unit) prior to hospital discharge. For the purpose of this study, the term 'neonatal unit' was used to describe both the NICU and step-down unit. The neonatal team was multidisciplinary and included physicians from several specialties (e.g., neonatology, pediatric surgery, psychiatry), nurses, auxiliary nurses, speech therapists, physical therapists, social workers and nutritionists. Both nurses and auxiliary nurses were responsible for providing patient education related to neonatal discharge.

**Recruitment and data collection.** All HCPs in the neonatal units were eligible to participate in the study if they had at least one-year experience in neonatal care, and were willing to be audio recorded. A combination of convenience and purposive sampling was used to recruit the HCPs, to obtain a variety of perspectives on the neonatal discharge experience. HCPs from the NICU and step-down unit were informed of

the study via information flyers as well as short verbal presentations during change-of-shift given by the first and third authors, who provided their contact information. Interested participants contacted the authors directly to learn more about the study and to schedule an interview. Data collection took place between October and December 2013. Data collection and analysis were conducted simultaneously; saturation of information was reached after 15 interviews, at which point recruitment was stopped. The first author conducted one individual semi-structured interview with each participant. Prior to beginning the interviews, participants provided written informed consent and completed a short socio-demographic questionnaire. The interview questions explored HCP views of 1) parents' needs and concerns related to discharge of their premature infant from the neonatal unit; 2) their role in helping parents prepare for hospital discharge; 3) barriers or challenges to preparing parents for hospital discharge, 4) facilitators or supports for helping parents prepare for the transition from hospital to home, and 5) recommendations for improving the neonatal discharge process. All interviews were conducted in Spanish by the first author (who is fluent in Spanish), in a private room, and were audio-recorded. Interviews lasted from 30 to 60 minutes.

**Analysis.** Audiotapes were transcribed verbatim and analyzed in Spanish; findings were then translated into English for publication purposes. The transcribed data were coded and analyzed using qualitative content analysis.<sup>19</sup> In the first coding cycle, open coding was used to generate initial codes that captured the transcripts' primary content and essence. Similar codes were collapsed into broader sub-categories and categories, generating a coding framework. To enhance credibility, all co-authors independently coded the first six transcripts and agreed on a coding framework. A deductive and inductive process followed for the coding of the remaining interviews, using the established codes and adding new codes and categories that emerged from the transcripts to the coding framework.

A number of strategies were followed to enhance the trustworthiness and rigor of the data analysis.<sup>20</sup> Credibility was enhanced by collecting data from multiple perspectives (e.g., nurses, physicians, auxiliary nurses) and holding regular peer-debriefing meetings with all co-authors throughout the analysis process. Only one of the co-authors (SO) was an expert in NICU care and was familiar with the study setting. Although she used her experiences to provide insights into the interview data, all co-authors participated in coding the emergent themes and categories. Study dependability, confirmability, and transferability were strengthened by keeping an audit trail consisting of detailed documentation of the study context, participant characteristics, study procedures, and data analysis process. Ethics

approval for the study was obtained from the McGill University Faculty of Medicine Institutional Review Board, as well as the research ethics committees of the Antioquia University Faculty of Nursing and the participating hospital.

## Results

### Participant characteristics

A total of 15 health care professionals were interviewed. Twelve participants were recruited from the NICU and three from the step-down unit. Characteristics of the participants are presented in Table 1.

**Table 1.** Participant characteristics (*n*=15)

Characteristics	n	%
Gender		
Male	2	13.3
Female	13	86.6
Age (years)		
25-30	7	46.6
31-40	3	20
> 40	4	26.6
(no answer)	1	6.6
Experience in neonatal care (years)		
1-2	2	13.3
3-5	6	40
6-10	2	13.3
More than 10	5	33.3
Health care profession		
Nurse	6	40
Auxiliary nurse	5	33.3
Physician	3	20
Speech therapist	1	6.6

### Barriers and facilitators to preparing families for discharge

Several participants noted that their unit's philosophy of care was that discharge preparation

begins as soon as the infant is admitted to neonatal care. During the interviews, participants spoke about the challenges of becoming a parent with an infant in the neonatal unit, as well as barriers and facilitators to helping parents prepare for the

transition from hospital to home. As presented in Table 2, participant perceptions of barriers and facilitators related to preparing parents for discharge over the trajectory of their infant's

hospitalization centered on three main themes: 1) establishment of the parent-infant bond, 2) acquisition of parenting skills and confidence, and 3) discharge day and follow-up care.

**Table 2.** Barriers and facilitators to preparing families for neonatal discharge

Main parental challenges	Barriers	Facilitators
Establishment of the parent-infant bond	<ul style="list-style-type: none"> <li>• Socioeconomic and cultural barriers</li> <li>• Short maternity leave</li> <li>• Far distances between hospital and home</li> <li>• Costs and inconveniences of transportation/temporary housing</li> <li>• Competing demands (other children, work, school)</li> <li>• Restrictive hospital visiting hours</li> <li>• Medicalized neonatal unit environment</li> </ul>	<ul style="list-style-type: none"> <li>• Social aids (e.g., shelters, bus passes &amp; food assistance)</li> <li>• 24-hour telephone access to the neonatal units</li> </ul>
Acquisition of parenting skills	<ul style="list-style-type: none"> <li>• Communication barriers (e.g., language, education level)</li> <li>• Lack of parental engagement</li> <li>• Difficulties establishing lactation and breastfeeding</li> <li>• Insufficient of human resources</li> </ul>	<ul style="list-style-type: none"> <li>• Educational materials &amp; groups</li> <li>• One-to-one bedside teaching</li> <li>• Continuing staff education</li> <li>• Consistent information given to parents by the neonatal team</li> <li>• Standardized discharge teaching tool (in process)</li> </ul>
Discharge day and follow up	<ul style="list-style-type: none"> <li>• Health insurance barriers</li> <li>• Administrative procedures for transferring care to the community</li> <li>• Lack of access to specialized/emergency care in rural areas outside of the city</li> <li>• No follow-up system for families post-discharge</li> </ul>	<ul style="list-style-type: none"> <li>• Kangaroo Program</li> <li>• Office in hospital to help administrative procedures for follow care in the community</li> </ul>

### **Establishment of the parent-infant bond.**

Participants identified numerous factors that contributed to parent-infant separation and impeded parent-infant bonding in the neonatal unit. Several participants noted that having an infant in the neonatal unit was very inconvenient for families and a central concern of parents was “how much longer will the infant stay in the hospital.” Given Colombia’s short maternity leave (i.e., 3 months), employed mothers were anxious for their infants to be discharged home so that they could spend as much time with their babies as possible before returning to work. Transportation costs and long distances between hospital and home were identified as significant barriers to parental visiting, particularly for low-income families. Parents who lived far from the city faced additional financial and practical challenges related to living in temporary housing during the hospitalization of their infant: *They are provided with housing, but the barrier is that over there they are piled up, they sleep five to six in one room...the mothers cry...the food is very bad* (P7). Many parents had work obligations and/or other young children to care for at home, limiting their visits to the neonatal unit. Restrictive hospital visiting hours (8am-6pm) further contributed to parent-infant separation. Participants also pointed out that even when parents were present, the highly medicalized neonatal unit environment acted to separate parents from their infants: *Their [parents’] first experience is fear: fear of putting their hand in the incubator... for example they say: ‘can I touch him?’ or ‘can I hold him?’* (P1).

Participants identified adolescents, working fathers and indigenous parents as having particular challenges related to parent-infant bonding. For example, adolescent mothers often faced competing demands with school and wanted to return home as fast as possible to continue their education. Fathers were viewed as less involved with infant care in the neonatal unit due to social and cultural norms related to the traditional role of fathers as family providers: *Almost always it is the father who is the financial provider...the father needs to work to provide for his family* (P4). Infant care teaching in the

neonatal unit was therefore typically directed at mothers as the assumed infant’s primary caregiver, impeding the development of the paternal role. Indigenous parents (or other rural families living in poverty) faced additional challenges to parent-infant bonding related to their cultural and social realities. For example, participants reported that for indigenous or poor families, bringing a sick infant home from the hospital could be a significant burden to both the family and their community. It was not uncommon for indigenous or poor parents to gradually detach themselves from their infant, coming less often to the neonatal unit and sometimes even abandoning their newborn. As one physician described: *When they [mothers] see that their newborn will not survive the conditions of the community, and not serve the community’s needs, they start to detach themselves* (P15). Participants acknowledged that these cultural beliefs and values clashed with the medical team’s focus on treatments and saving lives: *It’s not that they are careless, but that it’s their philosophy of life...this is a cultural barrier; where neonatology tries to save lives of infants of very low gestational ages but the people from far municipalities and rural areas do not see this to be very useful, especially the indigenous people* (P7).

Participant identified a few facilitators that were in place in their hospital to help promote parent-infant contact. Social aids such as food and accommodation assistance were available for some parents who lived far away and required support in order to visit their newborn in the hospital. Indigenous mothers had access to special shelters through an indigenous health organization that also provided them with daily meals. Participants also mentioned that parents were able to telephone the neonatal staff at any time to ask questions or inquire about their infant when they were unable to visit to the unit: *I often tell the mother if she is sick or if she all of a sudden does not have any bus passes left, to call us by phone...* (P12). However this was not a formal service, and several participants noted that to increase parental presence in the neonatal unit, the visiting hours policy should also be expanded to allow around-the-clock parental visiting. This

would help accommodate parents who could only visit their infant in the late evening or night due to their work or family obligations.

**Acquisition of parenting skills.** Although the neonatal units did not have a formal discharge protocol, participants described a variety of competencies that parents were expected to have prior to their discharge home. These included having adequate knowledge, skills and confidence to perform basic infant care (e.g., infant diapering, bathing and cord care; infant feeding; skin-to skin care; recognition of newborn cries) as well as specialized care for infants with specific medical needs (e.g., medication administration, oxygen therapy, gastrostomy/colostomy care). Standard discharge teaching for all parents also included alarm signs and symptoms requiring medical attention, as well as information on post-discharge follow-up. Criteria used to determine infant readiness for discharge from the neonatal unit included physiological stability, sufficient weight gain, and establishment of a stable infant feeding method. Although most participants perceived their unit's discharge teaching to be comprehensive, a few noted that parents did not receive cardio-pulmonary resuscitation training, which they thought could be beneficial especially for parents that needed to travel far distances to access health care services.

Participants identified four main barriers to helping families acquire the knowledge and skills needed to assume infant care following hospital discharge: 1) communication barriers, 2) lack of parental engagement, 3) breastfeeding challenges and 4) insufficient human resources. Participants described a number of communication barriers related to language, cultural beliefs, educational level, illiteracy, parental cognitive capacity and maternal age. Language and cultural barriers were particularly salient for indigenous mothers who spoke native dialects and understood little or no Spanish, requiring creative means of communication. For example, one participant described using graphics to explain the concept of time in relation to the position of the sun and moon in the sky, in order to teach an indigenous

mother how to administer medications to her newborn: *When the sun rises you give one, when the moon comes out you take another... we rely on a portfolio with images to teach them [indigenous mothers]* (P1). Teaching parenting skills and transmission of medical information was also noted to be more difficult among parents who were young, poorly educated, or had low intellectual capacities, requiring other support persons such as the infant's grandparents to be present for discharge teaching and preparation: *Due to many sociocultural factors, as much as you explain to them, some people never understand what is being told to them and do not leave [the hospital] adequately prepared. Many times we require extra help from grandparents for adolescents and people with intellectual or cognitive impairments* (P8).

Participants described two distinct types of parents in the neonatal unit: those who were very committed and actively participated in their infant's care and progress, versus parents who appeared disinterested and/or passive and were more difficult to engage in infant care. Adolescent mothers in particular were described as being more passive and disengaged from their infants, and more reliant on the neonatal unit staff or their family members to take care of their infants for them: *They are very quiet, they are always waiting for what you are going to say, they practically do not ask questions* (P9). However participants acknowledged that many other parents also expected the neonatal unit staff to perform all the care during their infant's hospitalization and did not seem motivated to learn basic infant care skills in preparation for discharge: *They believe that it's the nurse's role to do all the basic care for their newborn and that they will start taking care of their infant once they are at home* (P15).

Although the neonatal unit strongly promoted breastfeeding and was in a hospital that had official certification as a "breastfeeding-friendly" center, participants noted that mothers of preterm infants experienced a variety of challenges to the establishment of successful breastfeeding prior to hospital discharge. Barriers to the initiation and



maintenance of milk production included mother-infant separation and hospital policies that did not allow infants in the neonatal unit to be fed mother's milk that was expressed outside of the hospital, to ensure the safety of the milk. Participants also expressed concern that some mothers did not have safe and/or sufficient storage space at home to freeze their milk for future use when the infant returned home: *Sometimes we don't know what resources they have at home...some do not have a refrigerator, or the electricity cuts out...so this mom cannot store her breastmilk* (P15).

The transition from gavage, cup or parenteral feeding of the infant to direct breastfeeding was also identified as difficult for mothers. Participants reported that mothers often feared their infant would have apneic episodes at the breast or would not latch on properly, or that they would not have enough milk to satisfy their newborn's needs: *Their [mothers] greatest fear is that the baby will not latch on, so we start reassuring them that the baby doesn't know how to yet, the baby still needs to learn how...*(P14). Adolescent mothers in particular lacked confidence in their ability to breastfeed: *It's difficult for them because they still do not think that they have breasts that are capable of producing good breast milk* (P9). Although there was a lactation room with certified lactation educators to promote and educate mothers about breastfeeding, it was located in another building and mothers preferred to stay with their infant: *The lactation room isn't in the unit, it's in the children's hospital...they (the mothers) say: 'I come here to see my baby, why would I leave from here and go over there for 2 hours?'* (P1).

Finally, several participants identified insufficient human resources as a key barrier to helping parents prepare for hospital discharge. For example, nurses on the unit had many administrative tasks and heavy patient loads, limiting their availability to provide parents with discharge teaching: *The workload is heavy, we have many procedures to do, we have a lot of assistance and administrative work to do, we don't have that much time* (P1). Limited resources and conflicting schedules also

made it difficult for physicians to meet with parents to discuss important medical issues: *Sometimes the physician is busy and the parents are there, or the opposite the physician has time but the parents do not come, this is a barrier* (P7).

Participants described a variety of strategies, tools and programs developed by their units to help overcome obstacles to parental education and facilitate acquisition of parenting skills and confidence. Given the variations in parental learning styles and expectations, many participants acknowledged the importance of tailoring their discharge teaching to each parent's individual needs: *We have all types [of parents] here, the needs vary for each [parent]* (P1). Several educational handouts and materials (e.g., props, posters, pictures) had been created to address parents' educational needs, as well as educational groups led by interdisciplinary teams on topics such as rehabilitation exercises, breastfeeding, basic infant care and special care for babies with specific pathologies.

One-to-one bedside teaching was also identified as an important strategy for verifying whether parents were ready for hospital discharge: *A facilitator is that we have the opportunity to assess if the mothers and fathers are ready for discharge or not at the bedside, we do everything in person* (P9). Whereas registered nurses had advanced training in neonatal care, continuing education opportunities for the auxiliary nurses on topics such as infant safety, infant care, breastfeeding and common pathologies of premature babies was also mentioned as a facilitator for adequately preparing families for discharge: *We have many educational materials, we receive continuing education, we have protocols, we have many tools* (P6). An additional key facilitator was that the health care team had a unified approach for preparing families for discharge and provided parents with consistent information and teaching: *Something that is very important, because parents may get confused if some of us were to say one thing and then others something different; in this unit we all speak the same language* (P3). Participants noted that parent

discharge teaching would be further enhanced once they initiated their new discharge teaching documentation tool that would be used to track the progress parents made towards achieving the parenting competencies required for discharge. This discharge teaching documentation tool was currently in the process of being approved by their institution to be included as a permanent part of the infant's medical record.

**Discharge day and follow-up care.** The participants interviewed had conflicting perceptions of whether families were adequately prepared to go home on the day of discharge. Whereas some participants were confident that most parents were ready for hospital discharge, others felt that there was too much information given on the day of discharge and that it was anxiety provoking to send infants home not knowing if their parents were truly prepared. Participants reported that many parents were worried about their newborn's long-term health outcomes and were concerned about their newborn's follow-up care. Arranging for post-discharge follow up care required many administrative tasks that were reported to be laborious, confusing and a challenge for families: *The administrative point of view of things worry them [parents] a lot because they are given so many papers and tasks to complete, so knowing about this beforehand would reduce the stress they feel in the moment of receiving all of these papers. Sadly, sometimes they return [home] without having completed important administrative tasks* (P13).

Participants noted that most families were lost to follow up after neonatal unit discharge because their health insurance would not allow them to be followed by a pediatrician in their hospital. Follow up was a particular concern for families that lived far away from the city and did not have access to tertiary or quaternary care services in their home town in case of emergencies. Follow up care for infants discharged from the neonatal unit with oxygen or other medical devices (e.g., colostomy, medication) was also stressful for parents who weren't sure how to acquire the necessary materials and complete all the paper

work for the health insurance to cover costs. Participants acknowledged that many parents were also in need of increased social support after returning home with a premature infant. This was considered especially important for adolescent mothers who were not seen as being fit to take full responsibility for their newborn and needed more family support to take care of their newborn at home: *We look for another caregiver, someone the adolescent mother can go to after her baby is discharged from the unit* (P4).

Participants mentioned a few facilitators and recommendations for helping families manage the transition from hospital to home. One participant recommended having a more standardized means for assessing parents' readiness at the time of hospital discharge: *A way for us [HCPs] to verify that they [parents] are ready for discharge and then they feel secure if they see that we evaluated them, and if they perform well it's because they are ready to bring their baby home* (P13). Participants also referred to an office in their hospital that helped families with some of the paperwork involved for insurance authorizations or referrals to providers for follow up care in the community upon returning home. Another key facilitator mentioned by the participants was the local community-based Kangaroo Program, which consisted of an interdisciplinary team of physicians, nurses and a nutritionist that follows the infant's development and progress post discharge until he/she reaches a certain weight. Participants reported that mothers who were referred to the Kangaroo Program felt relief and more secure about the discharge and transition back home: *When they are informed about the Kangaroo Program, they leave feeling more secure* (P8). However, many mothers did not have access to the Kangaroo Program because they lived outside of the city or their health insurance did not cover it. A few participants suggested the implementation of a formalized telephone service where nurses and physicians would follow up on parents after discharge, answer any questions they had, and assess how they were managing the care of their infant at home.

## Discussion

This study explored HCP perspectives on the process of preparing families for discharge from the neonatal unit in a Colombian context. Barriers and facilitators related to preparing parents for NICU discharge centered on three main themes: 1) establishment of the infant-parent bond, 2) acquisition of parenting skills and confidence, and 3) discharge day and follow up care. These themes are consistent with previous work that indicates that parents with infants in the neonatal unit progress through stages of increasing engagement with their infants over time. For example, Heermann *et al.*<sup>21</sup> conceptualized developmental stages that mothers with infants in the NICU go through, starting by being passive bystanders or “outsiders” to becoming engaged mothers or “partners” with HCPs in their newborn’s care. Applying principles of family-centered care in the neonatal unit such as encouraging parents to participate in their infant’s care, promoting skin-skin parent-infant contact, and therapeutic communication between the nurse and parents can facilitate parent-infant bonding and increase parental readiness for their infant’s discharge.<sup>12,22</sup> These studies highlight the importance of a relational approach to care that focuses on establishing a trusting relationship and open communication with parents, to help them bond with their infant and assume their parenting role in the neonatal unit.

Our findings revealed sub-groups of parents who may be more challenging to engage in preparation for neonatal discharge, including working fathers, adolescent mothers, indigenous families and those living in poverty. Other studies have noted that fathers are typically absent from the NICU due to their traditional breadwinner roles.<sup>4,23</sup> This is an important issue as fathers’ presence and their relationship with their infants have a positive influence on maternal and infant attachment behaviors.<sup>22</sup> Strategies such as receiving consistent information from HCPs, receiving short written educational materials, engaging fathers in infant care at every visit and being able to talk to a male HCP have been shown to help fathers regain a

sense of control and fulfill their roles as protectors, fathers, partners and breadwinners.<sup>23</sup> Further study is needed to identify the most effective strategies and benefits related to involving fathers in infant care in the Colombian context.

The challenge of preparing adolescent parents for hospital discharge is of particular concern in contexts such as Colombia where there is a high rate of preterm births among adolescent mothers.<sup>2</sup> (2). Walsh and Goser<sup>24</sup> also found that adolescent mothers with infants in the NICU had difficulty visiting their child throughout the hospitalization, a desire to continue their education, a lack of parental confidence and engagement at the bedside, and a need for outside family and social support. Closer examination of the experiences of adolescent mothers during and post-NICU discharge is needed in Colombia, to help inform optimal strategies for helping prepare adolescent parents for the transition of their premature infants from hospital to home.

In our study, indigenous families and those living in poverty were identified as having significant barriers to visiting their infants in the NICU, particularly as many of them had their infants transferred to the referral NICU from distant rural communities. Previous studies have also shown that low-income parents of premature infants have difficulty visiting the hospital related to competing demands such as work or other children to care for at home, as well as transportation costs and far distances to travel.<sup>25</sup> We identified additional challenges to caring for indigenous families related to language and cultural differences. For example, participants referred to cases of infant abandonment among indigenous and poor rural mothers who believed caring for a premature or sick infant would be a burden to their community. This is a unique finding that merits further exploration, to better understand the particular needs and concerns of vulnerable families with premature or ill infants. More study is needed of sociocultural influences on parenting behaviors in

the NICU, and how these may influence parental readiness to be discharged home with premature infants who may have continued health care needs.

Participants identified the establishment of successful breastfeeding as a common concern for parents as they prepared for their infant's discharge home. Mother-infant separation and lack of resources for milk expression and storage at home have been previously reported as important barriers to the initiation and maintenance lactation as mothers wait for their premature infants to be mature enough to feed directly on the breast.<sup>8</sup> Our findings indicate that the transition from gavage/cup feeding to direct breastfeeding is another challenging step that requires HCP support, particularly among mothers with limited access to their hospitalized infant. Congruent with previous studies, participants mentioned continuing education for staff as a facilitator to ensure that HCPs are providing consistent information and promoting evidence-based breastfeeding practices to mothers.<sup>26</sup> The particular neonatal unit examined in this study had many educational resources and strategies in place to support breastfeeding (e.g., promoting skin-skin contact, educational groups and materials, access to lactation room and electric pumps in the unit, continuing education for staff) that were in line with current guidelines.<sup>26</sup> However one effective intervention for enhancing breastfeeding support not mentioned by the study participants that may be particularly beneficial to low-resource settings in Colombia is the use of breastfeeding peer support in hospital and at home for mothers of premature infants.<sup>26</sup>

Our findings also highlighted the challenge of evaluating parental readiness for neonatal discharge, particularly on the actual day of discharge. Participants pointed to the need for standardized discharge planning tools and evaluation methods to help ensure parental readiness for discharge. These recommendations are consistent with published guidelines for NICU discharge of premature infants.<sup>5,15</sup> Our participants identified individualized, one-to-one

teaching at the bedside as an important strategy for preparing families for NICU discharge. One-on-one bedside teaching allows more opportunity for HCPs to provide tailored information on the many topics required by parents before discharge.<sup>27</sup> Participants also identified the need for more systematic and formal links between the neonatal units and community-based services. The current transfer of care from hospital to the community was viewed as fragmented, involving many administrative tasks that were confusing for parents, and lacking mechanisms for tracking families post discharge to ensure they were able to follow up with ongoing medical issues and access available community health services. Similar challenges to the coordination and transfer of care have been identified in previous studies of the NICU discharge process.<sup>5,15</sup> Participants in this study recommended implementing a formalized telephone follow-up service as one strategy for maintaining continuity with families post-discharge. Improving communication between the neonatal team, primary care providers, medical specialists and community health agencies about ongoing medical issues is a key strategy for ensuring a smooth transfer of care of premature infants between hospital and home.<sup>5</sup> However, more comprehensive discharge planning requires sufficient human resources. Staff shortages and administrative tasks have been previously reported as barriers to preparing families for discharge in the NICU.<sup>13,17</sup>

**Conclusion.** This is the first study we are aware of to examine the process of preparing families of premature infants for neonatal discharge in Colombia, and contributes to the scant literature on the transition of infants from neonatal units to home. Our findings highlight the importance of enhancing parent-infant contact in neonatal settings, to increase parental engagement in infant care and facilitate the acquisition of parenting confidence and skills prior to hospital discharge. HCPs in this Colombian setting described specific challenges to discharge preparation related to vulnerable patient populations (e.g., adolescent mothers, indigenous families, uneducated parents or those living in poverty), limited health care

resources and a fragmented health care system. The HCPs also identified the importance of a unified team approach to discharge preparation; individualized teaching tailored to parents' specific educational needs; the use of systematic tools to guide and evaluate parental preparation of hospital discharge; and improved links between hospital and community-based services for families with premature infants.

A limitation of this study is that the findings were specific to one hospital in Colombia and may not be generalizable to other neonatal units. Another limitation is that we did not interview HCPs from disciplines such as nutrition and social work, which may have additional information to offer on NICU discharge preparation. In addition, the parental concerns, barriers and facilitators related to the NICU discharge process identified in this study were from the perspectives of HCPs and may not be congruent with the viewpoints of the parents themselves. Additional studies are warranted to better understand the experience of Colombian parents with premature infants and their perceptions of how HCPs can best help them prepare for the transition of their infants from hospital to home.

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