



Experiences of Mothers of Extremely Preterm Infants after Hospital Discharge[☆]



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ABSTRACT

Purpose: The purpose of this study was to describe and understand the experiences of mothers of extremely preterm infants during the first twelve months at home following discharge from a neonatal intensive care unit.

Design and methods: A qualitative, interpretative approach using Gadamer's philosophical hermeneutics was carried out. One focus group and fifteen in-depth, semi-structured interviews were conducted twelve months after hospital discharge. Responses were recorded, transcribed and analyzed using computer-assisted qualitative data analysis.

Results: The study's participants were twenty women. The following themes emerged from the data analysis: 1) 'The journey home: the discharge process', which included the sub-themes 'escaping the hospital environment: between desire and fear' and 'preparing parents for hospital discharge: practice and formal support'; and 2) 'The difficulty of living with an extremely preterm infant', including the sub-themes 'the challenge of an unexpected form of childcare', 'overprotection of and bond with a child with special needs' and 'disturbance in the social/familiar setting: when a mother becomes a nurse'.

Conclusions: The process of hospital discharge and the first months at home are difficult. The birth and care of an extremely preterm infant affect the mothers' quality of life as well as their family and social life. Practice and early discharge programmes can make the discharge process easier.

Practice implications: The knowledge and understanding of the experience of mothers of extremely preterm infants in the first months at home after hospital discharge could help healthcare professionals to develop educational strategies and counselling interventions in accordance with the mothers' needs.

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Introduction

The leading cause of neonatal mortality in developed countries is preterm labor (Von Linsingen, Bicalho, & de Carvalho, 2017). Approximately 11.1% of newborns around the world are born premature, before reaching 37 weeks of gestation (WG) (Blencowe et al., 2013). Extremely preterm infants (<28 WG), due to their physical prematurity and low birth weight, are much more likely to experience developmental delays

and face behavioral challenges (Jarjour, 2015). Caring for an extremely preterm infant starts in the delivery room and continues into the neonatal intensive care unit (NICU) (Anderson & Cacola, 2017). Here, infants are frequently tube-fed, their weight is closely monitored and they may receive oxygen therapy (Aagaard, Uhrenfeldt, Spliid, & Fegran, 2015; Dellenmark-Blom & Wigert, 2014). These processes interrupt the preparation and expectations of the mother (Aydon, Hauck, Murdoch, Siu, & Sharp, 2017; Twohig et al., 2016) as well as the mother-infant bond and relationship (Sisson, Jones, Williams, & Lachanudis, 2015; Tooten et al., 2014). Although the presence of parents in the NICU has increased (Al Maqhaireh, Abdullah, Chan, Piaw, & Al Kawafha, 2016), the environment, work routines and the complex needs of these infants become obstacles that stand in the way of a mother's role (Raines & Brustad, 2012; Sisson et al., 2015). The fragility of an extremely preterm infant can reduce the participation of parents in their care (Aydon et al., 2017; Kerr et al., 2017), and the parents'

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separation from the child creates stress, anxiety and a weaker bond (Kerr et al., 2017; Neri et al., 2017; Segre, McCabe, Chuffo-Siewert, & O'Hara, 2014; Spinelli et al., 2016).

Neonatal nurses facilitate the interaction between parents and newborns in the NICU (Aydon et al., 2017; Fernández Medina et al., 2017). Involving parents in kangaroo care (skin-to-skin contact) (Moore, Bergman, Anderson, & Medley, 2016), feeding and medicine administration (Busse, Stromgren, Thorngate, & Thomas, 2013; Ikonen, Paavilainen, & Kaunonen, 2015) increases their confidence and competence as the primary caregivers, preparing them for discharge (Purdy, Craig, & Zeanah, 2015). Neonatal nurses teach parents in feeding, promoting wellbeing, detecting signs of illness (Aagaard et al., 2015) or preventing of sudden infant death syndrome (Aydon et al., 2017).

Discharging infants from hospital is a complex process and a real challenge for healthcare professionals (Quinn, Sparks, & Guephart, 2017). Discharge training takes place during the stay in the NICU and includes: an analysis of the family's needs, educating parents about the care of the infant and ensuring an outreach of social support for the parents (Purdy et al., 2015). Nurses reinforce and evaluate this knowledge upon discharge, providing parents with the necessary materials and setting up follow-up appointments (Patel et al., 2017). Around 20% of extremely preterm infants require follow-up and specialized care at home (Boykova, 2016). After discharge, parents take on the responsibility of infant medical care such as oxygen therapy or nasogastric feeding at home (American Academy of Pediatrics Committee on Fetus and Newborn, 2008; Bowles, Jnah, Newberry, Hubbard, & Roberston, 2016), which are complicated procedures that require appropriate training and monitoring (Lopez, Anderson, & Feutchinger, 2012). Despite receiving training by neonatal nurses, mothers of extremely preterm infants encounter difficulties at home (Raines & Brustad, 2012), hospital readmission rates increase (Boykova, 2016) and family life is disrupted (Bowles et al., 2016).

Hospital discharge is much anticipated by the parents (Garfield, Lee, & Kim, 2014). However, the transition from the NICU to home can be a precarious experience (Purdy et al., 2015). Parents must assume the sole responsibility of caring for their child (Lopez et al., 2012), causing confusion (Aagaard et al., 2015), stress (Bowles et al., 2016) or anxiety (Boykova, 2016). Several studies have explored the experiences of parents of premature infants after discharge (Bakewell-Sachs & Gennaro, 2004; Murdoch & Franck, 2012; Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013). However, few of them have focused on extremely preterm infants. The purpose of this research was to describe and understand the experiences of mothers of extremely preterm infants during the first twelve months at home following discharge from a neonatal intensive care unit.

Design and methods

The study followed an interpretive qualitative research methodology based on Gadamer's philosophical hermeneutics. Hermeneutic phenomenology allows us to reflect on and give meaning to our experiences. The hermeneutic circle establishes a dialogue where the interpreter and the text question each other. Understanding a phenomenon involves merging horizons, a process that requires acknowledging the researchers' pre-understanding of the topic (Gadamer, 2005).

Participants

Mothers of extremely preterm infants admitted to the NICU were selected using a purposive sampling technique. The NICU had 15 units, 12 for neonatal care and 3 individual units for children up to 14 years of age. It is a traditional open-bay NICU (Level III) model, open to parents 24 h a day, where maternal participation is limited to breastfeeding and skin-to-skin contact. Inclusion criteria were: to be over 18 years old and to be the mother of an extremely preterm infant (<28 WG and <1000 g) who had been discharged from a NICU to home at least twelve

months prior to participating in the study. The exclusion criteria were: to refuse to participate in the study and/or to be the mother of an infant diagnosed with a chromosomal anomaly, congenital disease or neural tube condition.

Data collection

Data collection took place between June and September 2016 among mothers of extremely preterm infants who were admitted to the NICU of a hospital in the southeast of Spain. A total of 22 women agreed to participate, although two mothers were withdrawn from the study; one due to maternal physical problems and the other due to her later desire not to participate. A focus group (FG) and in-depth interviews (DIs) were conducted. The FG, with a duration of 90 min, was carried out on the premises of the local university and started with the question, "What is your experience related to the first twelve months at home following discharge from the NICU?" The DIs, with an average duration of 40 min, were conducted at the interviewee's home. Data collection stopped after data saturation was reached and participants' sociodemographic data were collected. Firstly, the FG was conducted, and from this, any questions that still remained unclear were addressed in the DIs. The information was recorded and transcribed, creating a hermeneutic unit analyzed with Atlas-ti 7.0.

Data analysis

The analyses of the FG and DIs was performed according to a modified form of Fleming's steps (Fleming, Gaidys, & Robb, 2003), which is consistent with a Gadamerian-based hermeneutic research method. The first step was to decide if the methodological assumptions were related to the research question; this was deemed to be true. In the second stage, the researchers reflected upon the discharge process to identify their pre-understanding on the subject. The third step was to achieve understanding via dialogue between the researchers and the participants. New questions arose during this stage, such as, "What needs arise for new mothers of extremely preterm infants during the first twelve months at home?" The fourth step aimed to comprehend the phenomenon through a dialogue with the text. The participants' experiences were re-examined after reading the transcriptions and new questions emerged: "How did the care of the extremely preterm infant influence family life?" The researchers identified units of meaning, sub-themes and themes by examining each sentence. The fifth step established the trustworthiness and validated the credibility of the results in the context of the study. After the FG and DIs, each participant was given a copy of the transcripts to be reviewed and verified. With regards to transferability, a clear description of the study context, the data collection and analysis processes was given to all the participants. The transcripts provided a detailed description of the experiences of mothers of extremely preterm infants after hospital discharge that may allow for transferring the results to similar contexts. To ensure confirmability, each transcript was reviewed by the participants, who identified the content and verified the results. The data were analyzed separately by three researchers and their differences were discussed until an agreement was reached. Throughout the study, as a measure of reflection and interpretation of the hermeneutic method, a reflection diary was completed. Researchers also authenticated the findings by establishing an audit log to ensure dependability.

Ethical considerations

This study was approved by the Ethics and Research Committee of the Department of Nursing, Physiotherapy and Medicine of the University of Almería. All participants were informed about the study's aim, participated voluntarily and signed an informed consent form.

Results

A total of 20 women participated in the study. Five women took part in a FG and 15 participated in DI (Table 1). The age of the mothers was between 27 and 41 (median 33). The gestational age of the infants was between 24 + 5 weeks and 27 + 2 weeks (median 26 + 0), the birth weight was between 520 and 970 g (median 805). The time since discharge was between 13 months and 19 months (median 15). Ten infants in this study were discharged with oxygen therapy and an apnea monitor, four were discharged with an apnea monitor, two went home on tube feeds and the rest of the infants were discharged without special care needs. Eight of the infants had older siblings at home. Results revealed themes that emerged in relation to existential lifeworlds (concept introduced by Edmund Husserl meaning “a state of affairs in which the world is experienced”) and were organized into units of meaning, five sub-themes and two main themes (Table 2). Together, they contribute to understanding the experiences of mothers of extremely preterm infants after hospital discharge.

The journey home: the discharge process

This category shows the participants' experiences upon leaving the hospital after their hospitalization period in the NICU. Experiences about the transition between hospital and the family home were identified. These experiences were marked by a great need for adaptation and development of maternal capabilities.

Escaping from the hospital environment: between desire and fear

Being released from hospital is one of the most highly anticipated moments for parents of extremely preterm infants. The emotional rollercoaster of premature labor, accompanied by a long hospital stay, drives mothers to think only about one thing: “escaping from the hospital environment.” The majority of participants revealed that the preparation for hospital discharge was marked by emotional ambiguity. Feelings of happiness and joy are mixed with those of fear, anxiety, and uncertainty towards the new situation and the great responsibility that comes with an extremely preterm infant. Leaving the security of the hospital and going home was described by the mothers as a mix of nerves, emotions and unpredictability.

Table 2
Themes, sub-themes and units of meaning.

Category	Subcategory	Units of meaning
1. The journey home: the discharge process.	1.1 Escaping the hospital environment: between desire and fear.	Happiness. Fear. Complications. Lack of preparation. Mother and child face-to-face interaction.
	1.2. Preparing parents for hospital discharge: practice and formal support.	Family hospital rooms. Early discharge home care programs. Lack of resources after discharge. Lack of coordination of health teams. Lack of specialized personnel. Help for parents.
2. The difficulty of living with an extremely preterm infant.	2.1. The challenge of an unexpected form of childcare.	Stress and isolation. Residual guilt. Obsession with child's development. Adaptation to the family environment. Controlling mothers. The loss of “the ideal child”.
	2.2 Overprotection of and bond with a child with special needs.	Loss of bond. Distorted interaction. Overprotection. Intrusive mothers.
	2.3. Disturbance in the social/familial setting: when a mother becomes a nurse.	Loss of social relationships. Effect on relationship with partner. Setbacks in professional development. Social support and associations.

“I felt immense joy and happiness but at the same time a lot of fear because you're going home with a child that has problems”. (DIW3).

According to the study's participants, the amount of stress and anxiety upon hospital discharge depends on the degree of prematurity, the length of the hospital stay, and the need for constant care of the child. Mothers are aware of the medical complications, the risk for readmission and the slow development of the extremely preterm infant.

Table 1
Socio-demographic data of the participants (N = 20).

Participant	Age	Marital status	Level of education	Gestational weeks	Multiple birth	Birth weight	Days NICU	Dependance technology	Months at home after discharge	First child
FGW1	35	Married	Advanced degree	25	No	800	62	Oxygen + apnea monitor.	13	Yes
FGW2	37	Married	Advanced degree	26	No	800	58	Apnea monitor.	14	Yes
FGW3	38	Married	Advanced degree	27	No	840	65	Tube feeds	17	No
FGW4	36	Married	Advanced degree	27	Yes	940	54	Apnea monitor.	13	Yes
FGW5	27	Cohabiting	College degree	26	No	970	50	Tube feeds	15	Yes
DIW1	35	Married	College degree	27 + 2	No	970	37	None.	15	No
DIW2	28	Married	Some college or technical training	27	No	875	33	None.	18	No
DIW3	31	Married	Advanced degree	26 + 4	No	950	35	Tube feeds	14	Yes
DIW4	30	Married	Advanced degree	25	Yes	575	66	Oxygen + apnea monitor.	15	Yes
DIW5	32	Cohabiting	College degree	24 + 5	Yes	520	63			
DIW6	36	Married	Advanced degree	26	Yes	560	52	Oxygen + apnea monitor.	13	No
DIW7	32	Cohabiting	College degree	25 + 3	No	525	55			
DIW8	33	Married	Advanced degree	26	Yes	940	52	Apnea monitor.	15	Yes
DIW9	36	Married	Advanced degree	26	Yes	820	60			
DIW10	34	Cohabiting	College degree	27 + 1	No	840	63	Oxygen + apnea monitor.	14	Yes
DIW11	45	Married	Advanced degree	25	No	607	58	Oxygen + apnea monitor.	16	No
DIW12	41	Cohabiting	Advanced degree	26	No	740	34	Oxygen + apnea monitor.	19	Yes
DIW13	34	Cohabiting	College degree	27 + 1	No	900	38	None.	14	Yes
DIW14	45	Married	Advanced degree	26	No	810	62	Oxygen + apnea monitor.	16	No
DIW15	32	Married	College degree	25 + 2	No	597	59	Oxygen + apnea monitor.	13	No
DIW16	36	Cohabiting	Some college or technical training	27	No	800	48	None.	18	Yes
DIW17	28	Married	College degree	26 + 2	No	795	50	Apnea monitor.	15	Yes
DIW18	30	Married	College degree	25 + 1	No	740	52	Oxygen + apnea monitor.	13	No

Sensory, respiratory, or feeding issues, as well as emotional and cognitive difficulties, are common. The fear of not being able to deal with unforeseen problems or deadly complications, as well as the thought of their babies becoming ill and having to go back to hospital, haunts mothers. Although the mothers stated that these thoughts are often overcome by the sheer excitement of bringing a child into the family, the participants do not feel prepared to go home with such a small infant without the proximity of the nurses. This viewpoint was shared not only by mothers who already had children but also by first-time mothers.

“When you’re in the hospital, you want to leave but later you panic thinking about taking a baby that weighs 2 kg (4lb) home with you. If you have any questions, you can call a nurse...but at home, you’re alone”. (FG).

Preparing parents for discharge: practice and formal support

Upon discharge, the participants experience the transition into full motherhood. This comes with all its typical responsibilities in conjunction with a child that demands a special type of care. In line with the statements of the study’s participants, the information, guidance, and involvement in the care of an extremely preterm infant in the NICU allows the mothers to develop confidence in their skills and prepare themselves to take their baby home. Yet, many still request to stay in an individual room with their baby the last few days leading up to discharge in order to confirm their abilities in caring for the child with supervision from the neonatal nurses. This arrangement allows the participants to clarify any concerns or questions they may have, practise what they have learned, and develop a sense of autonomy and independence.

“You take home a child that you barely know, a stranger...with special needs. It’s important to be able to at least spend one night with your child before you go home.” (DIW1).

The women who participated in the study recognize the importance of programs in which a neonatal nurse monitors home care after hospital discharge. As part of the process of adaptation to the family home, participating in these programs helps the participants to feel more confident and supported in their competence as a mother.

“If you are in a home care program you feel more confident, it’s a huge support, because if you have any questions you can call a nurse. But if you are discharged normally...you face anything that could happen alone”. (FG).

Communication with nurses and pre-discharge training is fundamental for participants to be able to effectively manage the healthcare equipment they take home. This equipment allows them to monitor their child’s wellbeing and recognize physiological signs of concern that require a visit to the hospital. Some of the participants of the study showed dependence to this healthcare equipment.

“I was constantly worried about observing my child, whether he was breathing or not. When you take the equipment (pulse oximeter) home, you become addicted to it even though you don’t want to look at it. I recorded the heart rate daily on my phone to later analyse it and check if it was normal”. (DIW2).

Mothers of the study point out a lack of specific health, social, and educational resources available when the infant is discharged from hospital, especially in extremely preterm infants with serious physical problems or disabilities. Our participants request better coordination among primary care teams and specialist care teams. The community nurse, responsible for the care plan and the allocation of assistance and public health resources, can play an integral role in attending to the problems of an extremely preterm infant after discharge. Nevertheless,

mothers consider that the competence of community healthcare personnel is insufficient, demanding specialized staff who are familiar with dealing with extremely preterm infants and their families.

“Hospital discharge should involve psychological and physical assistance for the babies...but also for the parents, by specialized personnel” (DIW8).

The difficulty of living with an extremely preterm infant

This category reflects participants’ experiences of living with and raising an extremely preterm infant. This reveals the relationship that the mother establishes with her child and the influence of the demanding nature of constant caretaking in a social and family context.

The challenge of an unexpected form of childcare

The first months at home prove challenging for mothers of extremely preterm infants. The mothers stated that hospital discharge is accompanied by frequent medical check-ups, which require returning to hospital. This situation generates a feeling of uncertainty, stress and anxiety because of the amount of information that mothers receive, which prevents them from getting over the anxiety of the infant’s hospital stay. The participants note that the joy associated with bringing an infant home from hospital is suppressed as they never really completely disconnect from the hospital environment. Although they recognize the importance of periodic check-ups, they feel that going back stands in the way of the development of their relationship with their child.

“The worst part is that it’s not even over when you leave the hospital, it just keeps going, and that’s the most complicated part...”. (FG).

After hospital discharge, the participants experienced that the demanding level of monitoring and care necessary for an extremely preterm infant with technology dependence affects the mothers’ quality of life and daily routine. Some participants continue to suffer from the emotional burden of the hospitalization in the NICU, feeling despair upon realizing that they are unable to raise their infant as they had hoped, which makes even breastfeeding more difficult. Many extremely preterm infants suffer from bronchopulmonary dysplasia, and they need oxygen therapy and constant monitoring of vital signs at home. The study’s participants, aware of the special needs and demands of their extremely preterm infant, cannot treat their child as they would treat a full-term newborn. As one participant states, while they adapt to the role of being a mother they also feel isolation, stress and guilt related to premature labor.

“I feel guilty because I was really stressed and now I feel like I’ve missed out on nearly the first year of my child’s life and that makes me sad”. (DIW14).

The fragility of an extremely preterm infant is always weighing on a mother’s mind, and they get used to being a constantly-worried and overprotective mother. Any factor associated with the growth and development of their child generates anxiety. The mothers cannot help but compare their children to other full-term children. Each step in the progress of their child is a milestone, and if they do not reach it, it leads to frustration, feelings of disappointment and hiding this information out of the fear of stigma.

“That sense of fragility, of not wanting to show it, of not feeling proud of your son... you don’t want people to feel sorry for him, although you think he’s the most beautiful and the bravest...” (FG).

The obsession with the growth and development of the child leads participants to look for information, ask for help, and seek immediate medical attention upon noticing any unusual signs or change in behavior. The participants revealed their obsession with adapting the child’s

belongings in their home in order to favor the stimulation and optimal neurodevelopment of their child.

"I need to know that everything is okay, all the toys in my house have been bought strategically to stimulate them" (DIW5).

Overprotection and bond with a child with special needs

Participants describe a very peculiar bond with their extremely preterm infant; different from the one they have with their other full-term children, as they considered them "a special child". The emotional relationship between the participants and their children is distorted by feelings of guilt, which are associated with the loss of "the ideal child." In the family home, this interaction is affected by potential complications, long-term developmental delay, and care needs; as one participant states, it even affects the way she disciplines and educates her son.

"I let him do almost anything because I think he is weaker and he has physical problems. I can't say no to anything, because when I do, I start getting images in my head of what a hard time he had". (DIW11).

The relationship between mother and child is thus marked by overprotection and intrusion; our participants define themselves as obsessive and controlling mothers.

"The overprotection is related to the fear I felt when he was hospitalized, because he was there...but you never knew what could happen the next day". (DIW4).

Disturbance in the social/familiar setting: when a mother becomes a nurse

Our participants told us that the demanding nature of caring for an extremely preterm infant, coupled with the perception of the child as a "sick child", generates strict guidelines that affect all aspects of family life. In an attempt to protect the child, the participants impose strict hygiene measures such as constant hand-washing and sterilization of objects used when feeding the extremely preterm infant. These standards are carried over into their social lives, putting restrictions on visits from family and friends with the excuse of maintaining a sleep schedule or preventing possible infection of the child. According to the participants, the situation leads to a loss of social relationships, accentuating the feelings of isolation that mothers already experience.

"Many of us who go through the birth of an extremely preterm infant lose the connection we have with friends. They don't understand that they can't come over because your child can easily get sick". (FG).

Other mothers explained how some therapies for the infant, such as oxygen therapy, can also affect their quality of life.

"I couldn't leave the house because I had to take the oxygen with me... and on top of that, I couldn't sleep with the machine (apnea monitor) on, I was exhausted...". (DIW9).

According to the participants, the prematurity of a child also affects the relationship between parents. Although women say they have the support of their partner, they often feel misunderstood. The excessive monitoring and demanding nature of the care provided to their child prevents them from having any time left for their partner. The participants stated that family life is reorganized when the frequency of medical check-ups, amount of medical equipment at home, and the risk of complications all decrease. This change usually comes about after approximately one year.

"You can't find and time for intimacy with your partner, at the beginning you are so focused on the baby that it is hard to adjust". (DIW6).

The relationship between the mother and other children in the family can also undergo a big change because of the exclusive dedication of

the mother to the extremely preterm infant. However, according to the participants, having other children does contribute to a more accelerated reintegration into normal family life after hospital discharge. In addition, the mothers stated that premature labor usually hampers a woman's professional career. Our participants stop working in an attempt to reduce their guilt, make up for the separation during hospitalization and to cope with the needs of the child more effectively.

"I spent a year and a half not working because I wanted to be with him, I had missed so much during his hospitalization...I wanted to make up for lost time". (DIW15).

After the hospital discharge, the support of other mothers is considered a very valuable resource. The majority of the participants stayed in contact with other women that they met in the NICU. They also mentioned using social networks to get in contact with other mothers that have gone through similar circumstances and as a resource when they have questions about caring for their child. In this way, associations for mothers of preterm infants are also a fundamental form of support.

"I am still in contact with many mothers from the hospital and their experience has encouraged me and guided me in how I have to treat my son". (FG).

Discussion

The objective of this study was to describe and understand the experiences of mothers of extremely preterm infants during the first twelve months at home following discharge from a neonatal intensive care unit. Usually, the hospital discharge is a joyful event for mothers, but it also brings about fear, uncertainty and anxiety (Raines, 2013). The separation of a mother and her child, the physical health aspect, and the inability to supervise the child's care in the NICU all compromise the bond (Fernández Medina et al., 2017; Hall, Kronborg, Aagaard, & Brinchmann, 2013) and closeness (Aagaard et al., 2015; Al Maqhaireh et al., 2016) that a mother feels with her infant. As Smith, Hwang, Dukhovny, Young, and Pursley (2013) and Sneath (2009) stated, mothers do not feel prepared to take on the full care of their child at home (Aydon et al., 2017). As in other studies (Smith et al., 2013), our results point to the need to train mothers in the NICU (Larsson, Wågström, Normann, & Thernström, 2017a, 2017b), the importance of staying in hospital together as a family (Patel et al., 2017) and the participation in early discharge programs at home (Toral-López et al., 2016). These initiatives, developed during the stay in the NICU, allow for learning and practising one's role as a mother (Aagaard et al., 2015). The hospital discharge involves facing any problems that the extremely preterm infant has without the direct support of a professional (Bowles et al., 2016), which is especially difficult in cases of technology dependence. Consistent with our results, being responsible for the operation of oxygen therapy devices, mechanical ventilators or infusion pumps can cause stress and anxiety in mothers (Toral-López et al., 2016). The decrease in quality of life is associated with the degree of prematurity of the infant, which in conjunction with intrinsic characteristics of each mother, may set back the preparation for discharge carried out by nurses (Raines, 2013). It is not easy to live with an extremely preterm infant at home. Mothers' concerns may include the feeling of fragility (Aydon et al., 2017), feelings of maternal incompetence (Raines, 2013), developmental deficits (Aagaard et al., 2015) and the risk of hospital readmission (Ingram et al., 2017). Parents of extremely preterm infants are attuned to even small changes in their child. These changes are often perceived with uncertainty and they turn to health services when the child suffers even a very minor illness (Garfield et al., 2014). The fragility of a premature baby (Garfield et al., 2014), the parents' caregiving difficulties and the lack of consistency in the primary healthcare system (Bowles et al., 2016), complicate care at home after hospital discharge. Consistent with our findings, the loss of "the ideal child" can aggravate

the residual guilt that mothers feel (Boykova, 2016), generating attitudes of overprotection or obsessive monitoring of the child's psychomotor development (González-Serrano et al., 2012). A parent-oriented discharge plan for preterm infants in neonatal care reduces the risk of readmission (Ingram et al., 2016), and early discharge home care programs (home supervision by a neonatal nurse) reduce anxiety and stress levels, increasing confidence and reassurance in one's abilities as a mother (Toral-López et al., 2016). While these measures are considered positive, they are not sufficient (Dellenmark-Blom & Wigert, 2014), and thus, mothers demand more social support and specialized healthcare professionals (Franck, McNulty, & Alderdice, 2017).

Hospitalization in the NICU reduces the interaction between a mother and her child and it affects their bond after discharge (Fleury, Parpinelli, & Makuch, 2014). According to Lakshmanan et al. (2017), extremely preterm infants' families constantly deal with chronic diseases and daily medical procedures, which have a negative impact on their quality of life. True to our findings, taking care of a preterm baby together with other children can create relationship issues (Aagaard et al., 2015), causing a mother to withdraw from her professional career and cause social isolation (Lakshmanan et al., 2017; Murdoch & Franck, 2012). Families need time to adapt to their new responsibilities and daily routines, requesting support to do so (Bowles et al., 2016). The lack of an integrated social support system leads mothers to seek guidance from other mothers of extremely preterm infants (Franck et al., 2017), helping to develop coping and self-care strategies that improve the well-being of the whole family (Bowles et al., 2016). Additionally, involving the whole family in decision-making and childcare prior to discharge (Aydon et al., 2017; Purdy et al., 2015) can increase a mother's confidence in her ability to care for an extremely preterm infant at home.

Limitations

This study is not without limitations. Our results help to understand the experiences of mothers of extremely preterm infants about the first twelve months at home after hospitalization. In the NICU where the study was performed, extremely preterm infants, preterm infants, newborn full-term infants and children up to 14 years old share the same physical space and may have influenced the experience of the participants.

Conclusions

This study underlines the difficult experience of the discharge of an extremely preterm infant and the first months at home. The experience is defined by feelings of uncertainty, stress, anxiety and the lack of maternal competence. Information, practice and discharge programs help mothers to feel better prepared to look after their child at home. The bond between mother and child is negatively affected after discharge because the mothers develop obsessive and intrusive tendencies. The intensity of caring for an extremely preterm infant affects the quality of the mothers' family, social and work life. The contact with other mothers of preterm infants is a fundamental resource in managing care needs at home.

Practical implications

Understanding the experiences of mothers of extremely preterm infants who have been discharged from hospital gives us an insight into their needs and hardships. This allows for the improvement of nursing care during and after hospital discharge. Neonatal nurses provide the necessary information about home care of extremely preterm infants. However, the development of strategies and family-centred interventions is necessary. For example, the family's care provision to extremely preterm infants could be facilitated through the provision of private rooms during hospitalization in the NICU, which would foster positive

interaction among all family members. Special emphasis should be placed on maternal health given that the physical and mental health of the mother could influence the wellbeing of the child and the rest of the family. There is also a requirement to provide a home healthcare support program tailored to the needs of each family as well as a phone service to respond to any queries following hospital discharge.

Additional evidence is needed on the mothers' needs and the obstacles that they face at home. The family dynamic should also be studied from the point of view of fathers. The experience of neonatal nurses should also be explored in order to determine the factors that can influence the discharge process of extremely preterm infants and the obstacles that are found at home. Lastly, an observational study would allow us to determine more precisely the relevance of the problem and the variables involved among those affected.

Conflict of interest

No conflict of interest has been declared by the authors.

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