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## FROM NICU TO HOME: MATERNAL EXPERIENCES IN THE PRETERM BABY'S PRE-DISCHARGE<sup>1</sup>

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**ABSTRACT.** Preparing for the premature baby's discharge, which was hospitalized in a Neonatal Intensive Care Unit (NICU) after birth, is a complex process, permeated by several maternal feelings and expectations. The objective of this study was to investigate maternal feelings and expectations in a moment near to their premature babies' hospital discharge. The participants were 42 mothers who answered a structured interview when the baby was about to be discharged. Qualitative analysis showed a greater maternal involvement in care for the baby when compared to previous moments of hospitalization, being that a moment of more closeness and proximity in the dyad. The role of hospital staff encouraging this involvement was highlighted, which was an important part of the transition to maternal care. This moment was also marked by various feelings and the maternal expectation of counting on the help from other relatives at home. It is important that baby's discharge is planned since the beginning of hospitalization, considering the emotional specificities of each mother.

**Keywords:** Premature birth; premature baby's discharge; motherhood.

## DA UTI NEO PARA CASA: VIVÊNCIAS MATERNAS NA PRÉ-ALTA DO BEBÊ PREMATURO

**RESUMO.** A preparação para a alta do bebê prematuro, que precisou ficar internado em uma Unidade de Terapia Intensiva Neonatal (UTI Neo) após o nascimento, é um processo complexo, permeado por diversos sentimentos e expectativas das mães. O objetivo do presente estudo foi investigar os sentimentos e as expectativas maternos no momento próximo à alta hospitalar de seus bebês nascidos prematuros. Participaram 42 mães, que responderam a uma entrevista estruturada quando o bebê estava a poucos dias de receber alta. Uma análise qualitativa revelou maior envolvimento das mães nos cuidados com o bebê em relação aos momentos anteriores da internação, sendo um período marcado por mais contato e proximidade entre a díade. Destaca-se a relevância do papel da equipe, incentivando esse envolvimento e sendo parte importante da transição para o cuidado materno. Esse momento também foi marcado por sentimentos diversos e contraditórios e pela expectativa materna de poder contar com a ajuda de outras pessoas da família nos cuidados em casa. Evidencia-se a importância de que a alta do bebê seja planejada desde o início da internação, considerando-se as especificidades emocionais de cada mãe.

**Palavras-chave:** Nascimento prematuro; alta do paciente; maternidade.

## DE LA UCI NEONATAL A LA CASA: VIVENCIAS MATERNALES ANTES DEL ALTA HOSPITALARIA DEL BEBÉ PREMATURO

**RESUMEN.** La preparación para la descarga del bebé, que ha sido internado en la Unidad de Cuidados Intensivos Neonatales (UCI Neo) después del nacimiento, es un proceso complejo, permeado por diferentes sentimientos y expectativas de las madres. El objetivo de este estudio fue investigar los sentimientos y expectativas maternas en

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el momento cerca de la descarga de sus bebés prematuros. Participaron 42 madres, que respondieron a una entrevista estructurada cuando el bebé estaba a unos pocos días de la descarga. Un análisis cualitativo reveló una mayor participación de las madres en el cuidado del bebé en relación con los períodos anteriores de hospitalización y un período marcado por un mayor contacto y acercamiento entre la díada. Se destaca la importancia del papel del equipo en el fomento de esta participación y una parte importante de la transición al cuidado de la madre. Este momento también estuvo marcado por sentimientos maternos diversos y contradictorios y la expectativa materna de contar con la ayuda de otras personas de la familia en el cuidado en domicilio. Evidenciase la importancia de que la descarga del bebé estea planeada desde el comienzo de la hospitalización, teniendo en cuenta las características emocionales de cada madre.

**Palabras-clave:** Nacimiento prematuro; alta del paciente; maternidad.

## Introduction

The birth of a premature baby is considered an experience that has consequences in the development of the child and in the family (Als, 2010; Boykova & Kenner, 2012). This fragile, physiologically immature baby will need to be cared for in a Neonatal Intensive Care Unit (NICU), a space with little privacy where staff, parents and babies coexist together, which especially influences the relationships established there (Fegran & Helseth, 2009).

It may be thought that the unexpected separation between mother and baby caused by premature birth could have a significant impact on the development of the mother-baby relationship that has been built so. For Winnicott (1966/2006), the integration is facilitated when both mother and baby are ready to carry on with their partnership after birth. In the context of prematurity, this facilitating aspect would not be present, since in addition to the physiological immaturity of the baby, mother and baby would not yet be ready for a partnership. There would thus be an interruption in the process of primary maternal preoccupation (Winnicott, 1956/1982) and an impossibility of the experience of mutuality to occur (Winnicott, 1963/1983). The primary maternal preoccupation, a state of maternal identification with the baby, allows for the baby's constitution and developmental tendencies to unfold. The mother's ego would be a facilitator in the organization of the baby's ego, since one does not exist without the other in this initial moment of life in which mother and baby are in a state of mutual dependence. Therefore, at this moment, we should think of mother and baby not even as a dyad but as a two-in-one, and that maternal experiences can influence the development of the baby, which occurs in the context of the mother-baby relationship.

In addition, Winnicott (1968/2006) deals with the silent communications that occur between mother and baby, emphasizing, besides corporeality, the affectivity that is implicit in these exchanges (Winnicott, 1963/1983). This communication would occur through the movement of the mother's breath and her smell, the beating of her heart, the use that the baby makes of its mother's face, as the reflection of itself. The baby feels all this when it is wrapped in its mother's lap, who adapts her movements to those of the baby and ensures mutuality (Winnicott, 1968/2006). All of this can be interfered with when the baby is born prematurely.

The care for the premature baby is initially provided by the NICU staff, who is also responsible for very invasive procedures, which makes it difficult and often restricts parental care. According to literature, parental involvement in baby care usually happens near the hospital discharge time. For parents participation in baby care would bring them closer to the child, strengthening their self-esteem and parental role, and reinforcing the motivation to go to the hospital (Baylis et al., 2014; Heinemann, Hellstrom-Westas, & Nyqvist, 2013). Some studies (Heinemann et al., 2013; Hutchinson, Spillett, & Cronin, 2012) point out that, after a time that varied between parents, they gained more confidence and energy regarding baby's recovery. There would be a reversal of the sadness felt at the outset by a greater focus and investment on baby care and on tasks aimed at it. At the same time, parents would still be concerned about possible emergency situations and the baby's clinical condition (Heinemann et al., 2013). A study of maternal feelings regarding the baby's hospital discharge showed that, at the time of discharge, 90% of the mothers felt ready to take care of the baby. These mothers demonstrated high levels of satisfaction and involvement with the process of discharge from the NICU (Meck, Fowler,

Claflin, & Rasmussen, 1995), which provides important data to reflect on the relevance of involving them in baby care throughout hospitalization.

Some studies recommend that planning for baby's discharge should begin as soon as it is admitted to the NICU (Damato, 1991; Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014; Rabelo, Chaves, Cardoso, & Sherlock, 2007). The idea is that the family is always involved in this planning, counting on a referral nurse who promotes communication and understanding about the development and behavior of the baby, as well as support for possible parental feelings of anxiety and stress (Damato, 1991). It is important to point out that planning for discharge, from the beginning, can be highly complex, since the clinical status of the baby is often critical and there is a risk of death. However, it is important for the family to establish a bond with the staff as early as possible so that they can feel confident about the care that their baby is receiving in the hospital and with the guidelines that they receive for home care, which can be done during discharge planning (Damato, 1991). In addition, making plans for baby's discharge can help parents to invest in their bond with it, which may be weakened due to the fear of losing it. In order for this process to be more appropriate, the staff should consider the moment (periods of high or low stress) and the format (verbally, printed, audiovisual, etc.) in which the information regarding discharge is presented to the family. It is important to consider that, in the context of prematurity, marked by continuous stress, the information can be gradually given to parents (Meck et al., 1995) in a clear, objective and non-technical way, so that what needs to be done and how to take care of the baby at home become accessible (Rabelo et al., 2007). In addition, it is recommended that a multidisciplinary staff should be involved in discharge (Als, 2010; Meck et al., 1995) and that the specific demands of each family should be identified and welcomed by the staff, who can guide them in the most appropriate way (Meck et al., 1995).

Besides the criteria for determining whether the baby will be ready for discharge, such as regulating its own body temperature, and being able to breastfeed associated with weight gain (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014; Smith, Hwang, Dukhovny, Young, & Pursley, 2013), accompanying the parents is an essential part of the discharge. It is expected that they feel, to some extent, emotionally prepared to take the baby home (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014). It is important to remember that the family is not prepared for the anticipated arrival of the baby, which makes the preparation during hospitalization fundamental (Smith et al., 2013).

Some studies suggest that experiences of preparing the family for the baby's hospital discharge are unique for each individual and that each mother, thus, experiences different (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014; Souza et al., 2010; Whittingham, Boyd, Sanders, & Colditz, 2014), and often contradictory (Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013) feelings in that period. Parents feel relieved and happy about the discharge, but they also feel anxiety and fear of taking full responsibility for the baby (Miles & Holditch-Davis, 1997), because tasks such as touching, holding, and breastfeeding can be seen as much more complex and the staff will not be near the mother to help her (Rabelo et al., 2007).

The study of Phillips-Pula et al. (2013), for instance, which retrospectively investigated experiences of mothers before baby's discharge from the NICU, found that they feared unknown situations, and that they mentioned not knowing what to expect or not knowing how to handle any situation with the baby. This fear had been present from the time the babies were born until they went home. Some mothers doubted that their babies were ready for discharge due to the baby's fragility or maternal insecurity. These findings were corroborated by Souza et al. (2010). Other studies mentioned the need for mothers to receive more information and guidance for home care (Meck et al., 1995; Whittingham et al., 2014).

Considering the complexity of the preparation for hospital discharge of a prematurely born baby, with all the impact on the baby and the family, this study aimed to investigate the feelings and expectations of mothers at the time of the premature babies' hospital discharges.

## Method

### Participants

Forty-two mothers whose babies were born prematurely and were hospitalized in public hospitals in Porto Alegre took part in the study. The babies were hospitalized in public hospitals in Porto Alegre and expected hospital discharge from the NICU staff. Mothers' age ranged from 19 to 43 years ( $M = 27.9$  years,  $SD = 6.23$ ). As for the marital status, 80.9% (34) of the mothers were married or were in stable relationship with a partner, 16.6% (7) were single and 2.4% (1) were separated. Of the total number of mothers, 52.4% (22) were primiparous, 28.5% (12) had two children and 19% (8) had three or more children. The babies' gestational age at birth ranged from 25 to 35 weeks ( $M = 30.5$ ,  $SD = 2.79$ ), with 45.2% (19) being moderately preterm, 33.3% (14) very preterm and 21, 4% (9) extremely preterm. The birth weight ranged from 615 to 2280 grams ( $M = 1222.5g$ ,  $SD = 369.4g$ ), with 57.1% (24) being of very low birthweight, 23.8% (10) low birthweight and 19% (8) extremely low birthweight<sup>3</sup>.

All the participants were part of the project PREPAR – Prematurity and Parenthood: from birth to the 36 months of the child (Lopes et al., 2012), which has been following 68 families of babies born prematurely in the first three years of life of the babies. The objective of the project is to investigate the experience of parenthood and the development of the baby in the context of prematurity. The project has six phases of data collection, from birth to 36 months of the baby's life, and in each of them, interviews were conducted with the baby's mother and father. Evaluations of its development were also performed. The research was carried out in three public hospitals in Porto Alegre, Brazil. The project was approved by the Ethics and Research Committee of the Federal University of Rio Grande do Sul (Process No. 22009015) and by the ethics committees of the hospitals participating in the study.

### Procedures, instruments and design

Mothers were contacted for the first time around the 15th day after delivery, in the NICUs where their babies were hospitalized, and invited to participate in the study. Those who accepted signed the Informed Consent and answered several instruments planned for this phase of data collection, including an Interview on Family Demographic Data (NUDIF/GIDEP, 2009a). Then, shortly before the baby was discharged, the participants were contacted again and answered the Preterm Infant and Mother Clinical Data Form/Pre-discharge (NUDIF/GIDEP, 2009b), which addressed general aspects of the mother and baby's health at the time before discharge, and the Interview on Motherhood in the Context of Prematurity/Pre-discharge (NUDIF/GIDEP, 2009c), a semi-structured interview performed in a semi-directed manner that encompassed several aspects of the experience of motherhood of a premature baby in the context of pre-discharge from the hospital. This interview included questions about the discharge of the baby from the hospital, the experience with the Kangaroo Neonatal Intermediate Care Unit (UCINCa)<sup>4</sup> (if the mother was there with the baby), how the mother was perceiving the development of the baby, among others. The interviews were conducted individually with each mother in the hospital ward, and respecting their privacy. This is a qualitative cross-sectional case study.

### Data Analysis

Data from the interviews were analyzed by the first two authors through inductive thematic analysis (Braun & Clarke, 2006). The thematic axes used were: 1) Maternal involvement with baby care in pre-

<sup>3</sup> The classification of gestational age at birth, following the guidelines of the World Health Organization (March of Dimes et al., 2012) is: extremely preterm babies, born with less than 28 gestational weeks; very preterm, born between 28 and 32 gestational weeks; and moderately preterm, born between 32 and less than 37 gestational weeks. As for birth weight, the classification is: born with less than 2500 grams are with low birthweight; born with less than 1500 grams are with very low birthweight; and born under 1000 grams are with extremely low birthweight (Institute of Medicine [US], 2007).

<sup>4</sup> Although this is the official term used by the Ministry of Health (Brasil, 2015), in the present study the term "kangaroo unit" will be used.

discharge; 2) Expectations regarding the discharge from the NICU; and 3) Expectations regarding home care.

## Results

Each result will be presented with a percentage between brackets. This quantification refers to the number of participants who presented verbalization referring to the theme in question, in relation to the total of participants in the study. In addition, vignettes were used to illustrate the findings.

### Maternal involvement with baby care in pre-discharge

Regarding the types of care identified, there was a variation among the mothers, mainly in relation to care activities, as well as the space in which the baby was hospitalized at that time. Three possibilities of space of care were observed within the NICU: incubator (23.8%), kangaroo unit (19%) and nursery (50%); not mentioned (7.1%). Routine tasks (such as feeding, changing diapers, among others) were identified and most mothers (73.8%) also reported care involving affective and proximity contact between mother and baby such as cuddling, holding, eye contact, kissing. For mothers whose babies were in the incubator and were transferred to the nursery, as well as those who were transferred with their babies to the kangaroo unit, care gradually became their responsibility: *"Now it's me who takes care of him, from the moment when I arrive up to when I leave". "[The nurse] only gives the medication. Before, I did almost nothing, but now, I can do everything. I can take care of him on my own"* (M30, nursery). Finally, in a few cases (12%), there were reports of extreme vigilance on the baby, mainly regarding its state of health: *"I am afraid that something might happen to him while he is asleep. Especially the issue of oxygen is what I have to be careful about, if the baby can breathe on his own"* (M39, kangaroo). It is important to note that all the mothers who mentioned extreme vigilance were in the kangaroo unit.

Regarding the feelings about involvement in care, several mothers (45.2%) reported a growing autonomy in caring for the baby in comparison to the moment after delivery, mainly after encouragement or authorization of the NICU staff: *"It is better because before I was not even able to hold her. Now I pick her up in my arms at whatever time I wish, I am the one who bathes my baby, I change diapers, I do everything there, I am the one who feeds her"* (M18).

On the other hand, four mothers reported that they had not yet performed any tasks of caring for the baby: in one case the baby was still in the incubator and the mother appeared only a few hours a day; for another mother the baby was still very fragile, which made it impossible for her to take care of her baby; in another case the mother did not get involved in the care due to communication issues between her and the staff; and in the fourth case the mother could not assume the tasks because she became ill and would spend only an hour a day in the hospital because she returned to work.

Another feeling reported by mothers (45.2%) was fear. 21.4% of the mothers (nine mothers) reported having fear, they said they lost it after a while due to the practice in the NICU. On the other hand, 23.8% of the mothers (10 mothers) were still afraid of caring for the baby. Among these 10 mothers, four reported that they stopped doing some care tasks for fear, three of them involving bathing and one diaper change.

The tiredness of routine (42.8% of mothers) was related to an increased involvement in care, which often included a long commute to a metropolis from other cities<sup>5</sup>: *"The bad thing is that you have to come every day to the hospital and you are usually tired. I even dreamed that I had to get a medical certificate, but I was not even at work. I am very tired"* (M29). For instance, a mother reported difficulty sleeping at night, thinking about the baby and being worried, which could aggravate the feeling of tiredness during the day: *"You go home and you don't know how the baby will be tomorrow. You do not even sleep well; every day that passes, you remain in expectation. I spend all day here, every day. You cannot stay home with your baby here"* (M32).

<sup>5</sup> The hospitals participating in the study were considered as references for treatment of prematurity and many families had to travel to the metropolis to visit the baby.

Many mothers (33.3%) reported having learned over time to care for the baby, comparing their current experience with the experience shortly after delivery. For them, learning would be related to the feeling of knowing the baby better, which would also bring a sense of competence in care: *"It is very good because I am learning; I am achieving my expectations as a mother. Until then, I had only given birth to her, now comes the learning phase"* (M28). Another feeling (33.3%) was feeling as a mother because of the possibility of taking care of the baby alone, with less interference from the NICU staff: *"I would feel like a mother when I started caring. Now I feel like a mother and I know he feels me like his mother, because his mother up there was everyone"* (M6). Being able to breastfeed the baby, for some mothers (14.3%), was related to the feeling of being a mother as discussed before.

A feeling of greater closeness and stronger bond to the baby was also noted, related to greater involvement in its care, especially those involving more physical contact, such as breastfeeding and holding the baby: *"Now it seems that I have become more attached to her as I am dealing with her, changing her diapers and being able to breastfeed her, bathing her"* (M36). Many mothers (31%) also reported feeling more difficulty going home and leaving the baby: *"It is getting more difficult when I leave the hospital because before I could not touch her, and I was not so attached to her, but now I got used to her and I spent the whole day with her"* (M17).

Four mothers hospitalized in the kangaroo unit with their babies reported the feeling of being isolated and trapped: *"I feel nervous to be confined in here. Before I would go there, visit her, stay for two to three hours, then I would go home and at night I would come back again, and now I cannot leave"* (M33). It is important to remember that in the kangaroo unit, the mother is the main responsible for the care and the staff is more distant, monitoring some clinical signs of the baby and intervening only if necessary.

Finally, the factors that promoted and limited the involvement of mothers in care are highlighted. The majority (62%) stated that the staff's encouragement (the invitation for mothers to engage in care or to teach mothers) acted as a positive factor for the involvement with the baby: *"The nurse said 'No, you have [to feed the baby] because at home you will not have us to do so', then I gave, it was ok, and he sucked quietly"* (M1). On the other hand, for one case this encouragement sounded as overcharging: *"Now it is being tougher, he left the NICU and I have to stay closer. The nurses ask us to stay closer. I already spend the whole day there, how can I come more often? I will have to spend the night here too"* (M34). With the baby's clinical improvement, some mothers (23.8%) reported feeling more encouraged to go to the NICU, since the care gradually became their responsibility: *"After she came here [to the nursery] I started coming here every day. This is because I am able to stay with her, it is me who takes care of her, not the nurses"* (M18).

Some mothers mentioned that seeing the baby without the NICU devices would help the involvement (21.4%): *"At first I could not remain two, three hours here. Now I can because I can hold her on my arms, I can touch her, before she was in that incubator with tubes and many things, and I could barely touch her"* (M8). Another aspect perceived as an encouragement for mother's involvement was the structure of the accommodation where the baby was hospitalized (14.3%): *"Here I can have a locker. Comfort, bed. I arrive tired. Here I can rest; I can stay with him without stressing myself"* (M38).

### **Expectations regarding the discharge from the NICU**

For most mothers (61.9%) the baby was ready to go home at the time of the interview, which had an emotional impact on them: *"As days go by we see the importance of each little wire, every little thing that is attached to her, and the emotional side becomes more affected when they take everything away and we see that she is already ready to go into the world, ready to leave"* (M14). However, for four other mothers their babies would still be immature to be discharged from the hospital: *"He is not ready yet, we have to wait. Because he does not feed when it is time for him to feed. I am afraid that he will lose a lot of weight. Then I want him to leave only when he is ready"* (M32).

Among the majority of the mothers (59%), ambivalence regarding discharge was noticed in their speeches: *"I am happy, sad and scared. Happy because he is leaving, sad because I am leaving my friends here, and scared because I am going to be with my three [children] and the baby will require much care"* (M19). The anxiety mentioned by more than half of the mothers (54.8%), was often related

to the weight gain as a crucial factor for the baby's discharge: *"It is mainly the anxiety about taking her away. It seems like it takes a long time, it never happens. But now she only needs one hundred and thirty grams more"* (M27).

Happiness towards baby's discharge appeared in the report of half of the mothers (50%); in some of them, it involved the fact that the family would finally be reunited: *"Oh, I am very happy, because then everyone will be reunited, with my daughters and her. We are separated, I am here and they are there"* (M14). Another feeling was fear (38%), and often involving the perception that the baby was vulnerable and might have to return to the hospital. On the other hand, many mothers (35.7%) reported feeling more relaxed at this time of transition home, especially due to the baby's clinical improvement. Three mothers mentioned that they did not raise expectations about their baby's discharge, in order to avoid disappointment.

Some mothers (26.2%) said that the baby itself would be struggling and also willing to leave the NICU: *"I think he is anxious to go home. We look at him, and he seems to be saying, 'I want to get out of here too' "*(M26). Another finding was the feeling of gratitude for the help that mother and family received during the baby's hospitalization (14.3% of the mothers): *"We will go to his aunt's house, who helped us a lot during the time that I was hospitalized, so we have to thank her. We will also have to say goodbye to the people at the milk bank, in the NICU, because I cannot leave here without thanking for all that they have done for us"* (M6). Three mothers reported the time of hospital discharge as a feeling of returning to the postpartum period, affirming that leaving the hospital could mean a new birth: *"I am going back to that moment when she was born; I am going to hold her and take her away with me"* (M25).

Finally, many mothers (35.7%) reported about their dependence on the NICU environment and the recommendations of the staff for the baby's discharge : *"He likes that incubator so much, I even joked with the nurses, I said I would take the incubator away with me, because when he gets home he will not want to stay in a bed, he will want to stay inside that warmth over here"* (M29).

### Expectations regarding home care

The last theme deals with maternal expectations regarding home care, and the possible inclusion of other people in the baby care routine . Regarding to these people, it was observed that most mothers (66.6%) expected to have the help of family members, such as the baby's maternal grandmother, aunts and even siblings: *"My mother is going to my house, and my husband's mother and my sister are going too. I think they already have more practice, I think they will know how to take good care of him , to bathe him"* (M15). Other mothers (14.3%) did not want help and understood that the moment at home would be exclusive for the mother with the baby and/or with the other children. Only four mothers said they would take care of the babies with the baby's father only.

Many mothers (43%) expected to be closer and more intimate with the baby: *"I want to pamper him a lot. Twenty-four hours on my lap, he kissing me, hugging me"* (M37). Many mothers (40.5%) considered the baby as fragile and demanding special care, besides having the expectation of keeping it away from the contact with other people from outside the home environment: *"I will take care of him as if I were a nurse for my little baby"* (M4). On the other hand, many mothers (31%) understood that since the baby had recovered from the NICU, he would be cared for just as any other baby and included in the family routine. Two mothers were more concerned about the commitment to the care for their other children after the baby's arrival at home: *"I am afraid of this, to leave the other [daughter] unassisted, of having to divide myself into many at the same time"* (M14)

Most mothers (52.4%) made comparisons between caring for the baby at the NICU and their expectations for home care: *"It is not like in the hospital 'No, it has to be at three o'clock, breastfeeding is at three o'clock ', so it is not like in the hospital. It is according to my own schedule."* (M29). On the other hand, few mothers (14.3%) reported the expectation that the care would be the same regardless of the environment.

Half of the mothers reported having no doubts about home care and that if they had, they would have the resources to deal with them. One mother reported that she would contact the NICU staff who cared for the baby : *"Now I think I do not have [doubts], I think that with the routine they were gradually*

*eliminated, maybe now I can show him that it is his mother who has experience. But if I have any problem, I will call the girls in the hospital"* (M3). However, some mothers reported doubts (30.95%) and many (47.6%) mentioned concerns about home care. Regarding to the concerns, mothers' reports referred to baby's health at home: *"My fears are the visits, the cold. I have this fear of her being at home and that something might happen to her, and I have fear of not having initiative, of not being able to take care of her."* (M25). Regarding the doubts, some reported difficulty of knowing how to act in emergency cases with the baby: *"I have a lot of doubts, if he vomits, or if he happens to stop breathing. These things that happened to him more frequently here."* (M37).

Finally, five mothers (12%) reported expectations about other people's reactions during the period of home isolation shortly after the baby's discharge, often recommended by the staff: *"I am afraid that people will not accept it well; I am afraid people may think that maybe I am being fussy, that I do not want to have any contact"* (M14).

## Discussion

The results showed that several feelings stood out in the experience of the mothers regarding the involvement in the care for the baby in the NICU at the time near hospital discharge; among them autonomy was the most mentioned. Literature indicates that some characteristics of this moment, such as the improvement in the clinical status of the baby and the attenuation of the situation of imminent risk of death, as well as the encouragement from the staff so that the mother becomes involved in the care, are the main factors that allow the mother to feel autonomy (Heinemann et al., 2013; Pal, Alpay, Steenbrugge & Detmar, 2013; Whittingham et al., 2014). In addition, it is important to consider that most of the babies were already outside the incubator, which also made a difference in mothers' involvement in the care. It should be pointed out that one participant from the present study perceived staff encouragement as demanding, which may end up becoming a source of stress in the NICU environment. Although several factors may influence the perception of this mother, it is essential that the NICU staff has a sensitive approach to the uniqueness of each case and can identify the most appropriate moment to ask the mother to care for her baby.

Another feeling that stood out was the fear regarding baby care, associated mainly with the possibility of hurting it. This could hinder maternal involvement in baby care in the NICU, since mothers could avoid doing some tasks with the baby. In addition, the fear of caring for the baby in the NICU could be prolonged, influencing the care after discharge. In the present study, seven of the 10 mothers who felt fear of caring for the baby in the NICU were also fearful of hospital discharge, which could be indicative of the influence of the fear of caring in later moments.

Tiredness was reported by the mothers mainly concerning the routine and stressful environment of the NICU. Whittingham et al. (2014) stress that during baby hospitalization, parents are faced with stressful situations, such as combining their activities from before the baby's birth with the new routine of visits to the hospital, the physical separation from the baby in the first moments of hospitalization and the feeling of lack of control over its clinical condition. At the time before discharge, mothers have usually been experiencing such situations for a long time, which can cause fatigue and exhaustion.

The mothers also reported having learned over time how to deal with their babies, which involved performing care tasks as well as discovering aspects of baby's temperament and preferences. Studies that investigated mother-infant interaction and bond in the NICU have stressed that the process of getting to know the baby and responding to its needs, which is essential for the development and consolidation of the mother-baby bond, is affected by the emergency situation of premature birth and by the baby's hospitalization, which may hinder or delay this learning (Brum & Schermann, 2004; Scortegagna et al., 2005). It can be thought that at the time of pre-discharge mothers were experiencing the transition from the exclusive care by the NICU staff to maternal care, being able to have more emotional willingness for the process of learning to deal with their babies.

One of the most known ways to promote contact between mother and baby in the NICU is the Kangaroo Mother Care, recognized for its benefits for the development of the low-birth-weight newborn and for the consolidation of the mother-baby bond in the context of hospitalization (Brasil, 2015). This



method advocates the mother staying with the baby in the hospital for as long as possible; however, an important finding of the present study was the feeling of isolation expressed by some mothers who experienced hospitalization with the baby in a kangaroo unit, poorly commented in the literature. In addition, in the present study, only mothers who were hospitalized with their babies reported extreme surveillance in relation to them, which may be related to the fact that one of the criteria for admission of the mother to the kangaroo unit with her baby is the ability to identify risk signs in it, such as shortness of breath (Brasil, 2015). Some authors have related surveillance to the concept of Primary Medical Preoccupation, which refers to a state in which the mother deals more with medical care than maternal care (Esteves, Anton, & Piccinini, 2011; Morsch & Braga, 2007). It is possible to think that this surveillance would also be linked to the trauma of the possibility of losing the baby, which usually goes around the entire hospitalization. These findings indicate that the hospitalization with the baby can overload the mothers, and it is important to highlight the need to follow up and develop studies that investigate the specificity of maternal experiences in this space.

Regarding the discharge from NICU, it should be pointed out that, although for most mothers the baby would be ready to be discharged, few considered that their babies could remain for some time in the hospital, since they would not be ready to leave the NICU environment, although the hospital staff was already planning the discharge. This may reflect the feelings of mothers themselves of not being prepared to take care of their babies alone, without the staff's support and apparatus of the NICU, which was observed in a certain portion of the participants as a feeling of dependence on the staff. The discharge process is gradual and permeated by ambivalence: it removes the mother from an environment that suggests safety, but at the same time imposes an emotional overload (Fegran & Helseth, 2009). It is important to discuss to what extent the mothers end up not considering their own experiences with the baby because they are more focused on the orientations given by the staff. This situation points to the importance of planning the discharge on a case-by-case basis, taking into account maternal perceptions about the readiness to take responsibility for the baby (Damato, 1991; Meck et al., 1995). In addition, it is important to reflect on the impact of the instructions of the staff for the first moments at home on the family routine after the discharge, and about how is it for the staff to provide guidance in a sensible and appropriate way for each case.

The ambivalence, commonly expected for this time of discharge (Fegran & Helseth, 2009), was very present in the reports of mothers. Although the discharge of the premature baby is usually a time of relief and happiness for mothers, they may also feel a lack of preparation to take care of the baby and have doubts about their ability to do so, which can lead to feelings of fear and anxiety (Miles & Holditch-Davis, 1997; Raines, 2013). This reinforces the need for these mothers to be accompanied by professionals during the baby's hospitalization, who can provide space to talk about their fears, fantasies and doubts.

Some mothers projected on their babies feelings about discharge and reported the expectation of having a new birth when the baby was discharged. It may be thought that both expressions reflect aspects of the maternal emotional world as a possibility of recovery from the traumatic context of prematurity - by "allowing" the baby to be reborn before going home - and including the baby as an important part of these experiences.

Facing the proximity of the moment when they will have to take care of the babies by themselves, mothers may feel anxious and unprepared (Griffin & Pickler, 2011; Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014). An important way to find support for this moment was the expectation of including other people in the care of the baby after discharge, which may reflect the importance of a support network that provides a holding for the mother-baby dyad at that time.

As discussed, the consolidation of the mother-infant bond in the NICU environment may be limited (Als, 2010; Fegran & Helseth, 2009). Most of the participants in this study made comparisons between this environment and home, emphasizing the expectations of greater autonomy and more intimacy with the baby, perceiving that after the discharge they could have more contact with it without the interference of the staff and of the NICU environment. This could indicate an expectation of reconnecting with the baby without the limitations imposed by the environment and the NICU staff.

## Final considerations

In conclusion, the present study focused on the experiences of mothers in the face of the hospital discharge of their premature baby, showing that it is a complex process, marked by ambivalent feelings and a greater involvement in baby care. It is necessary to point out some limitations of this study. It is worth noting the difficulty of dividing a complex process such as preterm baby's hospital discharge into themes. Although this study had the advantage of being able to explore the subjectivity of a certain group of mothers in this situation, it is important to carry out further studies about this very delicate moment of transition from NICU to home, exploring aspects that could not be contemplated in this study. For instance, by analyzing possible differences between groups of mothers according to baby's gestational age, length of hospital stay, place in the NICU where the baby stayed during hospitalization, among other factors. It is important to highlight that, when reporting mothers' feelings, their frequency was linked to the words used by the mother herself, which provides an important bias to be analyzed. It is possible that other feelings were present in this context if the analysis had happened differently, considering not only what was said literally.

Considering these findings, it was possible to notice potential effects of the traumatic experiences of the onset of hospitalization, for instance, the fear of caring for the baby. In view of these findings, it is important to emphasize that the discharge process should begin as soon as the baby is admitted to the NICU (Jefferies & Canadian Paediatric Society, Fetus and Newborn Committee, 2014; Meck et al., 1995; Rabelo et al., 2007), involving parents early in the care and routine of the baby. The staff involved in the care of these babies must be attentive to detect in parents any difficulties in this involvement, supporting them and making the necessary referrals. The importance of the staff in such moment was clear when, by inviting the mothers to be with the baby, made them feel encouraged and motivated to visit the NICU.

Just as the baby's recovery is a process, so is the process of becoming a mother for that baby, building a bond with it and returning to the first identifications, which were interrupted with the premature birth. It becomes evident that there is need of involving the mother in the care of her baby already in the NICU, with the assistance of a qualified staff and according to the specificities of each case. That makes it possible that the preparation for hospital discharge promotes a continuity between hospital and home care, which can have reverberations in baby care after discharge.

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