

Experience of mothers of premature babies from birth to discharge: notes of field journals

Vivência de mães de bebês prematuros do nascimento a alta: notas de diários de campo
Experiencia de madres de bebés prematuros del nacimiento al alta: notas de diarios de campo



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ABSTRACT

Objective: To describe the maternal care process mediated by nurses during the period of hospitalisation and discharge of premature babies.

Method: This is a descriptive, exploratory, and qualitative study, using the methodological framework of convergent care research, with seven mothers of premature babies admitted to a hospital in southern Brazil, from October to December 2011. Data from the mother's daily journals were submitted to content analysis.

Results: Analysis resulted in three categories portraying the path and the adaptation process of the mothers to the care of their premature babies, from preparation for discharge to overcoming her fears and insecurities concerning home care.

Conclusion: It is important for mothers in this initial and critical stage of hospitalisation of preterm infants to receive assistance, especially in terms of receptiveness and ongoing care, as a strategy to promote maternal autonomy and home adaptation.

Keywords: Mother-child relations. Infant, premature. Neonatal nursing. Intensive care units.

RESUMO

Objetivo: Descrever o processo de construção do cuidar materno mediado pelo enfermeiro durante o período de internação e alta de bebês prematuros.

Método: Estudo descritivo, exploratório e qualitativo utilizando o referencial metodológico da pesquisa convergente assistencial, envolvendo sete mães de prematuros internados em um hospital do Sul do Brasil, no período de outubro a dezembro de 2011. Os dados oriundos dos registros maternos em diários foram submetidos à análise de conteúdo.

Resultados: Da análise emergiram três categorias que retratam a trajetória e o processo de adaptação da mãe aos cuidados de seu bebê prematuro, desde a preparação para a alta, até a superação de seus medos e insegurança para o cuidar no domicílio.

Conclusão: Conclui-se pela importância de assistir adequadamente à mãe nesta fase inicial e crítica do bebê hospitalizado, enfatizando o acolhimento e a orientação permanente para o cuidado como estratégias promotoras da autonomia materna e da adaptação domiciliar.

Palavras-chave: Relações mãe-filho. Prematuro. Enfermagem neonatal. Unidades de terapia intensiva.

RESUMEN

Objetivo: Describir el proceso de construcción del cuidado materno mediado por el enfermero, durante la hospitalización y la alta de bebés prematuros.

Método: Estudio descriptivo, exploratorio y cualitativo, utilizando el marco metodológico de la investigación convergente asistencial, con siete madres de prematuros hospitalizados en un hospital en el sur de Brasil, entre octubre y diciembre 2011. Los datos originarios de los registros maternos en diarios fueron sometidos al análisis de contenido.

Resultados: El análisis originó tres categorías que retratan la trayectoria y el proceso de adaptación de la madre al cuidado de su bebé prematuro, desde la preparación para el alta hasta la superación de sus miedos e inseguridad para el cuidado domiciliario.

Conclusión: se concluye que es importante atender adecuadamente a la madre en esta fase temprana y crítica del bebé hospitalizado, subrayando la acogida y la orientación permanente para el cuidado, como estrategias promotoras de autonomía materna y adaptación domiciliar.

Palabras clave: Relaciones madre-hijo. Prematuro. Enfermería neonatal. Unidades de cuidados intensivos.

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INTRODUCTION

The premature birth and subsequent hospitalisation of infants in the Neonatal Intensive Care Unit (NICU) are highly traumatic and distressing events for parents⁽¹⁾, leading to a breakdown of the family unit due to the impediments, constraints, and situations undermining the family routine⁽²⁾.

The hospitalisation of a child in the NICU is a difficult and challenging experience for mothers and their families, since the highly modern and technological environment of the NICU separates the babies physically, psychologically, and emotionally from their parents⁽²⁻³⁾. Moreover, the families must face several problems during the period of hospitalisation, namely the experience of separation, fear of disease and the unknown, the hospital environment, and uncertainty about the present and the future of the family, that is, the clinical evolution of the baby and its survival⁽⁴⁻⁵⁾.

With regard to the mothers, hospitalisation in intensive care generates an overlapping of losses, namely the loss of the idealised child and the impossibility of being with the child at home. Being the mere bystander of the baby's care makes mothers feel deprived of their maternal function, unable to recognise themselves as mothers, and often unable to accept and acknowledge their child since a team has appropriated that care that a priori she should be providing. At present, it is not uncommon for mothers to harbour feelings of worthlessness, failure, and inferiority^(2,4,6).

In view of this delicate stage faced by mothers and families, any possibility of bonding with the baby can be compromised, causing disorder in the mother-child relationship. Thus, facilitating the approximation of parents with their child supports the establishment of emotional ties and, consequently, capacitates mothers to care for their child⁽⁶⁻⁸⁾.

It is known that a good relationship between parents and the nursing staff is essential to encourage bonding and the permanence of the parents in the ICU during the period of hospitalisation of preterm infants^(6,8).

Based on this premise, a growing number of studies have used qualitative methods to explore what the health team can do to help parents during the stay of babies in the neonatal unit, and to highlight areas of particular importance for their care^(1-2,9). Therefore, understanding the feelings and experiences of mothers during the permanence of their babies in intensive care can help the NICU team plan actions and better confront the situation with esteem and safety for the hospitalised infant⁽⁴⁾.

Consequently, the guiding question of this research was to understand how mothers experience the hospi-

talisation and discharge of premature babies. The aim of this paper was to describe the process of nursing care for mothers during the hospitalisation and discharge of premature babies.

METHODOLOGY

This is a descriptive, exploratory, and qualitative study based on the methodological framework of convergent-care research⁽¹⁰⁾. This study is part of a larger research dissertation⁽¹¹⁾ on the proposition of a discharge protocol for premature newborns.

The inclusion criteria were mothers of infants with a gestational age (GA) of less than 37 weeks, birth weight less than 1500 g, hospitalisation time greater than or equal to 72 hours, and residents of the municipality of Maringá or in the 15th health region.

The mothers were invited to participate and enrolled in the order of admission of their infants, from October to December 2011. During the hospital stay, the mothers were submitted to a preparation process for the discharge of their premature infants by the researcher. According to the premises of convergent-care research (CCR), during the period of stay in the maternal neonatal units, the researcher provided the mothers with guidelines, such as a demonstration of baby care and breastfeeding, clarified doubts, and encouraged participation of the family in caring for the baby. The training script implemented by the researcher, who was also a member of the nursing staff of the service in question, was based on the preparation models used in other institutions and on the needs mentioned by the mothers during this period. These interaction interfaces strengthen the mother-child bond and prepare mothers for baby care after discharge, with the permanent supervision of the nurse-researcher, and enable subsequent follow-up home care.

Once the mothers were included in the study, they were offered a kit (notebook, pen, pencil, and eraser) to record their experiences freely, without prior scripts. The mothers were asked to write in their journals whenever they felt the need to record something related to hospitalisation, interactions with the team, or when coping with or overcoming mother-child experiences. The records of the mothers were used to extract the body of this study, in an attempt to synthesize the maternal impressions resulting from this investigative and care-based intervention.

The methodological framework selected to analyse the data was content analysis, thematic mode⁽¹²⁾. The records of the mothers in the journals were transcribed, and the texts were read several times, from skim reading

of the general content to the exhaustive and systematic reading of the body of text. Since these records were free productions, the textual elements were filtered to those that were pertinent to the central theme, namely, the elements that addressed the mothers' experiences toward autonomy of care, under the supervision of the nurse-researcher. In this stage, segments of the text were underlined to identify the parts that corresponded to the study object and group similar records for coding and categorisation.

To preserve the identity of mothers participating in the study, they were identified with the "M" for mother followed by an Arabic number according to the order in which they were included in the research (M1, M2 ... M7).

This study was reviewed and approved by the standing committee of ethics in human research of the Universidade Estadual de Maringá under opinion #296/2011. This research observed all the ethical precepts regulated by Resolution #196/96 of the National Health Council⁽¹³⁾, replaced by Resolution #466/2012-CNS⁽¹⁴⁾, by means of instruction and signing of the informed consent statement. This study only included the participants who, after being notified of their rights and the form and objective of research, signed the informed consent statement.

■ RESULTS AND DISCUSSION

Seven mothers between the ages of 16 and 31 participated in the research. The minimum schooling level was incomplete secondary school, and only one of the mothers was single. One of the mothers (M4) had a history of prior abortion, at five months of pregnancy, and preterm labour followed by death of the neonate at the same hospital; the others had no previous experience with the hospitalisation of infants at birth. It is worth mentioning that all mothers who met the inclusion criteria and were invited to participate in the research agreed to participate.

With regard to the babies, four were boys and three were girls, with a gestational age of 31 to 36 weeks and a birth weight of 1560g to 2460g. The hospital stay period of the newborns ranged from 10 to 49 days. There was a case of congenital malformation (gastroschisis), resulting in a longer stay.

With regard to the approach of the central theme of the study, the use of journals by the mothers during the research proved to be a valuable instrument of data collection. The mothers used the journals as a sort of confidant and ally in times of distress, coping, resilience, and achievements of this period they experienced. Moreover, as the journals were freely filled, the participants were able to

express their particularities without jeopardizing achievement of the research objective. In general, the mothers displayed their journals with pride, and mentioned some of the experiences they recorded during informal meetings, thus revisiting these moments with the researcher. Once the data were transcribed and organised by filtering the elements related to the study theme, it was possible to outline three thematic categories: Experiencing the arrival of a premature baby; Participating in prematurity: the insertion of mother and baby in care; and Discharge of the baby: family expectations.

Experiencing the arrival of the premature baby

Motherhood is a special and unique moment expected by most women, and the process of pregnancy and childbirth significantly restructure the social role of women⁽⁷⁾. However, the possibility of a premature delivery and above all, seeing the infant in an NICU, forces mothers to face the prospect of having or not having their babies. The potential threat to the health of their infants can trigger feelings of impotence, emotional instability, and anxiety in mothers^(5,15).

[...] I was admitted to control the pressure, without knowing what was going to happen; very scared I was crying all the time, afraid that my baby was born before his time (Journal – M4).

I went to the hospital for an ultrasound, but deep down, I knew that the 'baby' was going to be born. I just didn't expect it to be on the same day or that he would go to the NICU. I was desperate, I was afraid of everything (Journal – M2).

When birth is premature, the mothers are shocked by the unexpected birth and fragility of the baby. The hospitalisation of the baby in the NICU disrupts the family and submerges the members into a period of crisis⁽⁴⁾.

The news of the hospitalisation of the newborn interrupts the dreams and expectations nurtured during pregnancy. The mothers feel frustrated, sometimes unhappy, or even guilty, and search for answers to justify that situation.

When I woke up and saw my baby in NICU I couldn't stop crying, for me it was the end of the world, it feels really bad and you can't think of good things (Journal – M2).

Coping with this situation is more difficult when hospitalisation is required immediately after birth⁽¹⁶⁾ because all

the desired plans have to be undone. The mothers are confronted with a situation they never imagined, and motherhood in this scenario generates feelings of fear, insecurity, and uncertainty in relation to the survival of the infants.

When he was born, he went straight to the neonatal unit. Then came the feelings of insecurity, fear (Journal – M7).

A study conducted with 18 mothers of premature infants at an NICU in the municipality of Montes Claros, Minas Gerais, showed that anxiety, sadness, grief, and suffering were the most prevalent feelings of the mothers in relation to the preterm birth and early interruption of pregnancy⁽⁵⁾.

The sense of loss of the child is another highly present element in the first days of stay in the NICU. Initially, it is a sense of loss of the dream of motherhood and the idealised child. This feeling also refers to the impossibility of fulfilling the maternal role of providing care and warmth to the child due to the physical and emotional distancing imposed by hospitalisation⁽¹⁵⁾.

This initial loss, represented by the immediate separation from the preterm baby, causes several emotional problems that must be overcome with the positive attitudes of the multidisciplinary team, by encouraging and boosting the self-esteem of parents, and enabling approximation and participation in the care of the newborn. These are ways of consolidating the emotional ties needed to overcome obstacles of the child-family dyad in the context of neonatal hospitalisation. Receptiveness toward the family is extremely important for their effective approach and participation in care, and should be valued in the first encounters with the admitted infant.

The arrival of mothers to the NICU is considered, by the nurses, an extremely delicate moment that requires careful intervention to diminish any fears and doubts, mitigate the shock of hospitalisation, and make it as minimally traumatic as possible⁽⁷⁾.

The fact that most newborns are very small is one of the visual impressions that causes most impact on the family in the initial contact with this foreign universe of the NICU. Another consideration when approaching the families, especially the mothers, as they enter this environment is the large amount of equipment and devices that, although necessary to support the life of newborns, generates concerns about the real chances of survival of the baby⁽⁷⁾.

[...] When I went to see him, he was in an incubator, with a device in the nose, CPAP, I was so scared, I didn't know what was happening (Journal – M6).

[...] He was breathing with a machine, the nurses there told me that it's just to help him, that I'm not supposed to be scared (Journal – M1).

Not understanding what is happening with the infant and the feeling of helplessness can cause the family to distance itself⁽⁷⁾. Consequently, the caregivers must interact and communicate with the family, and help the members understand the situation of the infant, its needs and possibility, the standards and routine of the unit, and, above all, how their presence and participation can help in the recovery of the infant^(2,7).

Information on any changes in the clinical status of the child can cause intense apprehension and anxiety, as well as a profound sense of helplessness and uncertainty about the future. Therefore, it is critical to strengthen the bond of trust between the team and the family with effective and constant communication.

Giving bad news to the family of a child in a grave condition is never easy, and depending on how this news is notified, the family can lose hope regarding the recovery of the newborn⁽¹⁷⁾.

During these moments, the professional must be highly sensitive and skilled in the use and choice of words to preserve any positive expectations in relation to the evolution of the sick child. The aim must be to help the family get through this time of crisis consciously and safely.

[...] I went to see my baby, I was all happy, hoping to see him better. But when I lifted the cloth that covered the incubator, I swear: the shock was huge, looking at my little baby and seeing him with all those devices, all those tubes [...] I left the NICU, aimless and unable to believe what was happening. A nurse came to me, and explained [...] (Journal – M6).

As the days pass, the mothers gradually change their attitude. They tend to get closer to their child as they gain more strength and overcome their fears. Once this step is completed, the mothers seek some identification with their child and start to observe the infant more closely.

[...] on this day he grabbed my finger, hard! That's where he gave me strength and I started to talk to him, his hair was still covered in blood, I noticed it immediately and decided to look closer, he remained the same, with all those machines [...] (Journal – M6).

This experience of knowing the child, of self-awareness of the maternal role, is an extremely important link in

the mother-child bond. The mother simultaneously identifies with the environment, learns about the dynamics of the NICU, and becomes familiar with the routines of the health workers and the people who work in the unit. As a result, she can form opinions and give ideas on everything that happens, and create positive links with the child and the team that are so important for the mother and her family.

Tuesday [...] he was quiet, peaceful, the nurses were trying to find a vein in him for tests [...] from that moment on, I started observing everything around me, I saw how well he was being treated by the entire team [...] I was more confident knowing he was in good hands (Journal – M6).

Research conducted with parents of newborns showed that after knowing and perceiving that the infant is being well cared for, the mothers felt better about entrusting the care of their child to the health team⁽¹⁶⁾. The feeling of safety associated with the appropriate receptiveness strengthens the team-child-family bond, and increases the time the family member remains in the unit to monitor the newborn with the team.

Participating in prematurity: the insertion of mother and baby in care

This category refers to the first care the mother provides to the newborn in the hospital. The participation of the parents effectively strengthens the bond with the infant^(6, 8), and after discharge, this practice acquired in the hospital is fundamental for the care provided at home⁽¹⁸⁾. For M3, the moment she was allowed to hold her daughter was essential to seal the bond between her and her child.

[...] Today I got to hold my baby for the first time after her surgery. I am very happy about that [...] warm her with the warmth of my body (Journal – M3).

This statement reveals the importance of the first contact between mother and child in the construction of ties that mitigate the fears experienced until that moment. Moreover, the gradual process of approximation makes the mothers feel secure and capable of performing maternal care. The statements show the importance the mothers give to small gestures of closeness, and the extent to which simple activities, such as changing nappies, become important milestones in the path toward appropriating the maternal role.

[...] they are teaching me how to change her nappy. It was a great experience because I had never learned anything before. But I think I did it right (Journal – M3).

It is the responsibility of the nursing professional, however, to monitor carefully each step in the construction of maternal autonomy given the implications that common procedures may have on the general status of newborns. In this regard, providing details of each orientation and accompanying each procedure can help mothers develop skills and the right techniques for safe care, thus eliminating the negative impression that this form of care is difficult.

The first bath is generally a moment of high expectations and makes mothers feel apprehensive and insecure due to the movements and reactions of the baby during the procedure. The umbilical stump and the apparent fragility of the premature also contribute to this uncertainty. Guidelines of the care delegated to the mothers must be repeated several times to ensure assimilation and practice until the mothers feel confident enough to perform the tasks. Health workers must monitor the evolution of this maternal autonomy by initially demonstrating and guiding the mothers, helping them with the care, and, finally, by overseeing completion of the procedure, while remaining available and receptive.

[...] I gave her first bath with the help of the “nurse”, I was a little afraid of holding her, when it was time to turn her around to wash her back, her bottom, because she moves a lot, I was afraid to drop her. But it all worked out (Journal – M4).

She, “the nurse”, taught me every detail, how to hold the baby in the bathtub firmly, answered my questions, and gave us lots of tips. Today was the first bath I could give him, let’s say, alone. But as I was afraid, the “nurse” was there giving me lots of support (Journal – M6).

Successive practicing and the gradual insertion of mothers in care make the procedures easier to perform and, consequently, more pleasurable. The resulting confidence makes the mothers feel more competent to take care of their own children.

[...] I checked in at 7:30, gave her second bath. I felt more confident, it was lovely (Journal – M4).

These observations reinforce the importance of involving the mother in the teaching-learning process not merely as a passive receiver of information, but above

all, as the subject of the educational process. It is worth noting that guidelines cannot be simply communicated to the parents; they must be understood and incorporated for them to effectively care for the newborn at home after discharge⁽¹⁹⁾.

Taking care of the premature infant requires knowledge and needs-driven assistance. Therefore, acknowledging the infant as at-risk with specific and individual care ensures a better professional interaction with the mother and family and facilitates competence and autonomy⁽¹⁸⁾.

By taking care of her infant, the mother feels useful and confident about newborn care. These moments of interaction make the mother feel rewarded, despite the turbulent situation she is experiencing, as shown in the following statement:

I learned to change him, and I also learned to the milk through the probe, I was feeling more useful, and also closer to my son. It was wonderful to hold him and be able to feed him, but my little one had no strength to suck correctly, he's still learning. But seeing him try to breastfeed, that was inexplicable! (Journal – M6).

The daily experience with the preterm baby is critical for the mothers' self-confidence and restructuring of the maternal role. These activities, implemented in the neonatal unit, prepare the mothers for the challenges of home care and give the professionals the opportunity to assess whether the care and educational assistance they provide is effective.

Discharge of the baby: family expectations

When is the baby going to be discharged? This is one of the most frequently asked questions of the family members to the workers at the neonatal units, regardless of the length of stay or the medical condition of the child. Even when the visits to the infant are eagerly awaited by the mothers, they suffer when they are forced to leave the child after each visit and anxiously yearn for the day of discharge, thus ending the separation that causes so much anguish in the family.

The anguish is represented by a state of constant anxiety while waiting for news of the clinical evolution of the baby and the proximity of this long-awaited moment. The search for more precise information points to the need of the family to renew hopes in relation to the recovery and the future of the infant. The possibility of breastfeeding the hospitalised child, in this case, can be a sign of improvement that signals the proximity of a hospital discharge.

Oh my god! I can't wait for my little angel to come home, I'd love it if the nurses gave me an estimate of when he's going to get out of there, or at least when he will start to breastfeed. I have so much milk (Journal – M1).

Another highly valued aspect in this context is the weight gain of the newborn. During the hospital stay, premature infants can suffer a range of complications that interfere with their weight gain and delay hospital discharge.

Today he was weighed again and he's 1,820. Wow! He's getting plumper by the day and soon I'll be home with my son, God willing (Journal – M2).

The anxiety expressed by the mothers in relation to the child may be influenced by social circumstances. Concerns about their other children at home, with the household chores and even with the marriage cause conflicts, suffering, and often keeps the mothers away from the infant at the hospital, or may even force discharge⁽²⁰⁾.

Every day I have more hope that he'll leave soon. His little sister is at home, she's anxious to meet the brother who was born, but has still not come home (Journal – M5).

The extended hospital stay usually exacerbates feelings of impatience, anxiety, and stress. The mothers usually compare the hospital environment to a kind of prison, in which they are subjected to a series of routines and external orders, and where they feel trapped and unable to express themselves.

I can tell you one thing: when we don't have an estimated discharge date, our nerves are on edge. I prefer them to say that I'm staying another 30 days than wait a long time without knowing. It looks like a box of prisoners with mothers, and I'm one of them. I imagined what it was like, but you only know when you are in my place, then you know how much we suffer (Journal – M3).

Discharge from the ICU to the medical nursing wards significantly increases the positive expectations of the mothers in relation to the discharge of newborns. However, this process of transferring the newborn from one sector to another requires mothers to adapt to the new environment, different hospital staff, and the new routine for the newborn, who must now receive the exclusive care of the mothers, now considered companions.

Today I was happier when I arrived, because I knew he was going to his room and was closer to leaving. But I didn't

like the service here (paediatrics nursing ward). The nurses act as if they were forced to do the work, not out of love (Journal – M5).

Although this step is intermediary between discharge and home care, the sudden transition causes the stress of adaptation, and is considered a moment of “un-care” by the mothers. This stage, which consolidates the education initiated in the NICU and UCI, requires a protocol that places the need for continued care in the forefront, regardless of the organizational service limits.

■ FINAL CONSIDERATIONS

The results show that the period of preterm birth causes anxiety, fragility, insecurity, fear, and challenges for the mothers. In these cases, nurses play a crucial role in building the bond between mothers and infants and the autonomy of mothers in relation to care. Within this process, appropriate communication between the health team and the family can renew hopes of recovery of the newborn, minimise maternal anguish, and encourage the family.

This study shed valuable light on the importance of providing guidance and continued supervision of the mothers during neonatal hospital stays, from admission and preparation for care and discharge, to post-discharge follow-up. The convergent-care research method used in this study allowed us to reveal the important role of nurses as mediators of the construction of the mothers’ autonomy for care.

This process includes receptive assistance as a premise for humanised care and the participation of the entire multidisciplinary team to ensure the permanence and participation of family/mother in care. In spite of the insecurities of the mothers during the construction of their autonomy, care based on learning and teaching for the family essentially restores the mothers’ self-esteem and transforms the newborn hospitalisation experience into a constructive exercise of self-achievement.

The study also shows that this education lacks any standardisation, which is a limitation in view of the specific contingencies of these users, and the recognition, in the family of the premature baby, of a partnership to achieve better quality care that can be extended to the home of each infant.

The findings of this study can provide new knowledge for nursing professionals and aid them in the standardisation of care and the learning of specialised methods to treat preterm babies and their families. It can also trigger reflection on ways to encourage mothers to accompany

their infants in the unit for as long as possible, not merely during temporary visit, with autonomy-generating active participation in the care of these babies.

We also believe that this study will add discussions to the body of nursing knowledge that support education and make future professionals more sensitive and capable of perceiving the needs of families during the hospital stay of preterm infants.

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