

THE EXPERIENCE IN A NEONATAL INTENSIVE CARE UNIT: MOTHERS' POINT OF VIEW

A vivência em uma unidade de terapia intensiva neonatal: um olhar expresso pelas mães

La vivencia en una unidad de terapia neonatal intensiva: una mirada expresada por madres

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ABSTRACT

Objective: to explore the experience preterm infants' mothers of during hospitalization in a neonatal intensive care unit. **Methods:** a descriptive, exploratory study with a qualitative approach. Data were collected through a semi-structured interview, with puerperae whose children were hospitalized at a neonatal intensive care unit of a hospital in Southern Brazil. Data were analyzed by means of operative analysis. **Results:** the themes that emerged from the analysis were: mothers experience of hospitalized preterm children and mothers' perceptions regarding the care of preterm children in the intensive care unit. Mothers understand the need for hospitalization, however they are concerned, feel in difficulties and shock, fear and misinformation. **Conclusion:** despite the need for hospitalization and the emotional fragility caused by the separation of mother from her infant, there was no impairment in the development of the bonding.

Keywords: Nursing; Premature infant; Hospitalization; Critical care; Bonding

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RESUMO

Objetivo: conhecer a vivência das mães de bebês prematuros durante a hospitalização em unidade de terapia intensiva neonatal. **Métodos:** estudo descritivo, exploratório, com abordagem qualitativa. A coleta de dados foi realizada por meio de entrevista semiestruturada, com puérperas que tiveram seus filhos internados na unidade de terapia neonatal de um Hospital Escola do Sul do Brasil no período da coleta. Os dados foram analisados por meio de análise temática. **Resultados:** a vivência de mães de filhos prematuros hospitalizados e percepções de mães em relação aos cuidados de filhos prematuros na Unidade de Terapia Intensiva. As mães compreendem a necessidade de internação, mas esta gera preocupações, dificuldades e sentimentos de choque, medo e desinformação. **Conclusão:** apesar da necessidade de internação e da fragilidade emocional causada pela separação da mãe-bebê não houve comprometimento no desenvolvimento do vínculo da díade.

Descritores: Enfermagem; Recém-nascido prematuro; Hospitalização; Cuidados críticos; Vínculo.

RESUMÉN

Objetivo: conocer la vivencia de las madres de bebés prematuros durante la hospitalización en unidad de terapia intensiva neonatal. **Métodos:** se trata de un estudio descriptivo, exploratorio, con abordaje cualitativo. La recolección de datos fue realizada por medio de entrevista semiestructurada, con puérperas que tuvieron sus hijos internados en la unidad de terapia neonatal de un Hospital Escuela del Sur de Brasil. Los datos fueron analizados por medio de análisis temático. **Resultados:** las temáticas que surgieron del análisis fueron: la vivencia de madres de hijos prematuros hospitalizados y percepciones de madres en relación a los cuidados de hijos prematuros en la Unidad de Terapia Intensiva. Las madres comprenden la necesidad de internación, pero ésta genera preocupaciones, dificultades y sentimientos de choque, miedo y desinformación. **Conclusión:** a pesar de la necesidad de internación y de la fragilidad emocional causada por la separación de la madre-bebé no hubo compromiso en el desarrollo del vínculo de la díade.

Descriptorios: Enfermería; Recién nacido prematuro; hospitalización; Cuidados críticos; Vínculo.

INTRODUCTION

Family is an important and expressive social entity and the period of conception and birth of children is a remarkable stage in the shaping the family context. In this phase, the family goes through adaptations and feelings that emerge from the specificities and modifications that occur in the maternal body during pregnancy.¹

Pregnancy includes moments of expectation for the mother and her family, which prepare for the arrival of the baby in an environment full of expectations, beliefs, values and goals that will influence the formation of this developing human being. It is in this family context that the first relationships of the child that are important for their motor and psychosocial development will form. The development of affective bonds between parents and children influence healthy growth of the baby and determine positive modes of interaction, which allow the individual to adjust to the different environments that will be faced.²

The formation of the bond between mother and child occurs gradually, from the moment the pregnancy happens,

whether its planned or not, being influenced by several factors, including proximity, reciprocity, complicity and commitment between mother and baby that are necessary for the formation of the bond.³ The relationship between mother and baby begins to consolidate during the prenatal period, in an intimacy where those involved do not visually know each other. This leads to affinity based on expectations for imaginary baby figure.¹

The birth of a premature newborn may lead to the need for hospitalization in a neonatal intensive care unit. The hospitalization of a premature child in a neonatal intensive care unit and its consequent separation from the mother transforms the reality of the family, especially the mother, who begins to live with pain, sadness, anxiety, dysphoria and even depression.¹

The conditions of baby's physiological instability, low weight, the need for specialized medical care and numerous equipment needed in the context of the neonatal intensive care impact the parents and the entire family, and make the mother experience the separation from her premature baby, living with the uncertainty of his/her clinical evolution and, especially, of survival.⁴⁻⁵

This study is justified by the need to explore the experience of mothers of premature babies during hospitalization in a neonatal intensive care unit, as well as the need to contribute to the training of nursing professionals, so that they adopt a humanized approach focused on the real health needs of mothers and their families.

Given this context, the question that guided this study was: What is the experience of mothers of premature babies when they are hospitalized in a neonatal intensive care unit? Thus, the purpose of this publication was to explore the experience of mothers of premature babies when hospitalized in a neonatal intensive care unit.

METHODOLOGY

This is a qualitative, descriptive and exploratory study. The setting was the neonatal intensive care unit of the Teaching Hospital of the Federal University of Pelotas (UFPEL), in the city of Pelotas / RS. Data were collected through semi-structured interviews with five mothers who had their premature children admitted to the neonatal intensive care unit between November 2017 and January 2018. The end of the data collection phase was based on saturation information (repeating answers).⁶

The interviews were conducted in a private room near the unit. To ensure anonymity, the mothers were identified with the letter P followed by Arabic numbers according to the order of the interviews. The postpartum women were invited to participate in the study and, at that point, the objective and methodology of the study were explained. Those who accepted the invitation received the Informed Consent Form which was subsequently signed by the participants and the researcher. Inclusion criteria were: to be postpartum women between 72 hours up to 42 days postpartum, to be over 18 years old, with preterm infants hospitalized for more than

three days, to have physical and psychological conditions of verbal communication in Portuguese, allow the use of recorder and notes. Those who did not express interest in participating in the study or did not meet the inclusion criteria were excluded.

Data analysis was in accordance with the thematic analysis that recommends organizing, classifying and analyzing the obtained data, establishing links between these datasets, the literature and the researcher's reflections.⁷

The ethical principles of this article were based on Resolution No. 466/2012 and data collection began after approval by the Research Ethics Committee of The Faculty of Medicine of the Federal University of Pelotas, under to the Opinion of CAEE 80178417.7.0000.5317 on November 21, 2017.

RESULTS

The participants of the study were between 23 and 41 years old, most of them declared to be in a stable union and to live in the city of Pelotas / RS. Regarding the level of education, one has completed undergraduate school and one is enrolled in an undergraduate program, two have incomplete elementary school and one has completed high school. Family income was one to four minimum wages. Gestational age at delivery ranged from 28 to 35 weeks, with the predominant manner of birth being surgical delivery. For all interviewees, pregnancy was the first to be interrupted in advance, and the first time they had contact with the neonatal intensive care unit.

After analyzing the content of the semi-structured interviews, the themes that emerged were: The experience of mothers of premature children hospitalized in the neonatal intensive care unit and mothers' perceptions regarding the care of premature children in the neonatal intensive care unit.

The experience of mothers of premature children hospitalized in the neonatal intensive care unit

Regarding the experience of premature birth in the study scenario, the mothers stated:

It was very complicated, because it was all planned, her birth, everything right, it was very painful, because we did not imagine, it was a big scare for me and my husband we were a little lost, without reaction and in the hands of doctors, it was very sad, it was not what we imagined going through all this, I did not even imagine. It was something completely different from anything I had ever seen and experienced, a completely different experience, it is like having never had any children, first of all: first pregnancy of twins is as if it were the first pregnancy, not even speaking premature birth. (P4)

It was bad, because I did not expect, I was expecting everything right, complete, waiting to reach eight months

to organize baby shower, I was not expecting him to be born, when suddenly he came, very fast, did not really expect, it was very bad, sad it even seems like they were ripping our souls out, terrible, because you get that thing, you don't know if you will survive, if you won't, if you will keep going, then you can't stay here, you have to stay away, really terrible. (P5)

As for the feelings experienced at the first encounter with the baby, they reported:

It was kind of shocking when I saw him the other day, he was so tiny. (P3)

I had them one day, and went to see the other day alone, I could not get up, had to stay those 12 hours, then in the morning I did not get up, went to bed the other day, I did not see them or anything, they were born and gone, I didn't even see when they were born, little babies of 1.5 kilos, nor in the family we ever had, it was quite different. (P4)

When asked if they received guidance regarding the premature newborn's hospitalization, most mothers report that they did not obtain information from the professional team, except for what they were told at the time of the first visit to the neonatal intensive care unit:

He didn't go straight up, it just malfunctioned at birth, the breath caught, besides that I didn't know anything, my mother said once I got to the room. (P1)

[...] because you keep up, you don't know if you will survive, if you won't, if you will continue, keep up. (P2)

No. Not for me, they told my husband. My husband came in, watched the delivery together, then came here to see him, then we got to know his state the other day in the morning when we came to see him, everything happened at dawn, when he got worse, there we arrived and it was already clear, they told us everything. (P3)

I knew from my husband and my mother not from the team of doctors and nurses, no I got to know from family how they were, they let me take a little picture for me to see, and it was that I saw them like this, to find out only later when I talked with the pediatrician himself. (P4)

Yes, I was told that as he was young, his little lungs were not ready, he would be intubated, he would be in the incubator, but they would be there for whatever he needed. They told me more or less, except that I had no idea as I had never seen, especially when it's yours, which is a very different thing than the child of others. (P5)

Regarding the feelings regarding the newborn:

I was worried, I had the possibility and I didn't have to come to the unit, I was happy, but I was worried because here is always risky. (P1)

Yes, as much as I know you have to go home, you get calmer because you know you're well taken care of, every time I come and see him intubated it hurts my heart, but so, it's for him to get better. (P5)

As for the feelings experienced at the first visit to the intensive care unit, as well as on subsequent visits, the mothers said:

I was happy and sad at the same time knowing that you are leaving and he will have to stay. (P1)

I was very anxious, first had the contact with the pediatrician, she explained to me how was the situation, how would be the next days, the months too, it is probably about two months that she will be there, I was very sad to see her intubated, because she doesn't breathe alone. (P2)

For me it was exciting, because I was crazy to see him, I was shocked when I saw him, because he was full of braces, respirator, probe, with everything, to me it was kind of shocking when I saw him, he was very little one. (P3)

The first visit was terrifying, we had never seen, both were intubated, with respirator, they were making light. (P4)

It was like that, I cried a lot, because when you arrive, you see them intubated, it seems that I can't explain, it was very sad, there is no other word, then you get used to it, but every time I come and see him intubated it hurts my heart, but it is for him to improve. (P5)

They said they're fine, but if they're fine how come they are in the intensive care unit? I was able to stay near, but when I was farther it was harder (mother lives in Canguçu), but now it's ok, I come here 3 or 4 times a day because people can't always get in, not to be beating all the time at the door, and he's fine, sometimes is fine, sometimes are not fine. (P4)

I had never seen it. When my sister had her baby, he was not intubated because he was already older, but still he is yours, which is a very different thing than the child of others. (P5)

Mothers perceptions of the care received by the team in the neonatal intensive care unit

The mothers when asked if they felt cared for as mothers of hospitalized preterm infants, as well as regarding the care of their babies, said:

Yes, they are very attentive to me all are very attentive, they always seek to inform us, I find it very good there, I like that they are very attentive, are always around, to see that there is always an eye on him, taking care, monitoring. (P1)

They talk, give a lot of attention, they explain everything well, but when I was there in the hospital there was nothing, I had her and stayed in the room, the only function of nurses was with medication, signal verification, the care of nurses there (intensive care unit) is very good, helps us to compensate, the affection they have for us, and especially with her, it is a very good team, wonderful, I did not imagine how much care she has, we even notice in a simple gesture to put a dressing on her, or get some little thing, to cover her, the form of affection they express with her, incredible care, incredible, very good, gives us strengthened care that they have, all of them, without exception, wonderful. (P2)

Yes, because it's attention to him and also attention to me, but I try not to explain, that attention has to be more his, but I have a lot of attention too, from the people here, staff, doctors. (P5)

Regarding the perception of postpartum women after the visit, reports showed that mothers leave the visit with the feeling of security that their children will be well taken care of:

I think so, as I live away from here I always say, I'm going home calm, because he's being very well looked after, very well cared for, the girls have a huge dedication to him, all the information I ask them, they clarify, when they cannot, the pediatrician comes and talks, we are always well informed. (P3)

No words, very good, is any little thing, any questions I ask, they explain everything, they are always on top, every time I arrive they are with my baby, any little thing they find different they already communicate to me, very good, very good indeed, of all the hospitals you have, here is the best, as much as you know you have to go home, you go calmer because you know you are well taken care of. (P5)

Regarding the relationship with health professionals, the participants reported:

We are always in contact with the doctor, the care of the nurses there is very good, it is a force for us, when we go there

for support, which we need, because we come very down, and you enter there, and as much as it has something not so positive, on the other hand the affection they have for us and especially with her compensates this. (P2)

As I live away from here I always say, I'm going home calm, because he's being very well looked after, very well attended, the girls have a huge dedication to him. (P3)

Another point addressed was information about the support services available to mothers during their children's hospitalization. The answer was unanimous, they only knew the social worker:

No, we would like to have someone to talk to, to help in this moment of need, we feel very fragile. There was one day she was very sick, me and my husband, we left here very, very sad, we were trying to comfort each other, we cling to the faith and affection of friends and family. (P2)

Just the social worker. (P3)

The social worker. (P4)

The social worker talked to me. (P5)

DISCUSSION

Mothers of premature children hospitalized in the NICU feel concern, anxieties and fears are intensely as they realize their child's prematurity and see him being taken to the neonatal intensive care unit. A study conducted in a hospital in the interior of Rio Grande do Sul with three mothers of premature babies showed that hospitalization can represent a complicated and distressing period for parents, since the relationship and initial care that usually occur between parents and newborns are hampered by the environment of the neonatal intensive care unit and the procedures the baby undergoes during hospitalization.⁸

Another study conducted in an intensive care unit in a midwestern hospital in Rio Grande do Sul with seven mothers, pointed out that hospitalization can trigger the feelings of impotence in family members due to the distance from the baby, norms and routines of the neonatal intensive care unit, that generate concerns and difficulties, as mothers perceive this environment as frightening.⁹

The mothers in this study were frightened, probably due to the interruption of dreams and idealization regarding a term pregnancy. Premature birth and consequent hospitalization in a neonatal intensive care unit generate feelings of distress and despair that are reinforced by the fear and guilt for leaving the newborns, strengthening the feeling of helplessness in face of the situation that the

children are in.⁹ These feelings can change, and the bond built if pregnant women receive guidance during prenatal care and are informed of the conditions they may have to face if their children are preterm, preparing them for hospitalization of their children in a neonatal intensive care unit.^{8,10}

The findings of this study are similar to those of a study conducted with parents of newborns admitted to a neonatal intensive care unit, which show that physical characteristics of the newborn and the environment have an impact on the parents, as they were not prepared to confront this reality.¹¹

The mothers participating in this study reported the difficulty of finding a baby that does not meet the expectations created during pregnancy. The bad feelings prevailed before the dream of the healthy child and were expressed in the reports of the mothers with impactful mention of feelings such as pain, suffering, fright, anxiety, impotence and uncertainty of survival and development of children. Corroborating, a study of eight mothers of infants admitted to a NICU of a hospital in the interior of Paraná state indicates that the sight of a baby surrounded by appliances and specialized care can be painful for mothers, making them believe that their children are suffering, and with this, influencing the quality of the initial contact between them, making the support of the team to these mothers essential in order to overcome the initial difficulties.¹²

The authors, when conducting a study with ten mothers of newborns in the NICU of a referral hospital in Petrolina/PE state that the birth of a premature child is interspersed with feelings of insecurity, fears, and anguish over the unknown path ahead.¹³ These results are supported by another study conducted with seven mothers of premature infants admitted to a hospital in Southern Brazil, where the health team plays a unique role in building the link between the mother, father and child, in order to promote autonomy of care.^{5,13}

Similar to the present study, the clinical status of the baby is not usually explained to the mothers by the professional team before the first visit to the neonatal intensive care unit, and participants reported a lack of information prior to the visit to the neonatal intensive care unit.^{5,13} This lack of information about the unknown environment of the neonatal intensive care unit and the instability of the newborn are factors that contribute to the suffering, anguish and the perception of uncertainty in life.^{9,13}

The lack of knowledge of the mother ends up making her a supporting actor rather than the protagonist in the process of care for the newborn making it difficult to bond with the baby. It is essential that parents receive the support of health professionals responsible for the care of the newborn helping them to observe, recognize and understand the signs coming from the newborn.¹⁴

Studies with puerperal women with premature babies admitted to NICUs from different contexts in Brazil point to the need for the approach for construction of affective bonds between mother and baby.^{10,13} In the present study, mothers showed confidence in health professionals of the neonatal intensive care unit. Although they know the

problems arising from prematurity, they trust and believe in the professional care being provided to their children.

Corroborating, the health team should clarify the use of the equipment necessary for the maintenance of life support of newborns to the families, especially mothers, entering the NICU for the first time. They end up asking questions and feel anxious about the baby's real chances of survival, because the lack of understanding of what is happening can push the family away.⁵

Regarding the perceptions of mothers of the care received by the team in the neonatal intensive care unit, it is possible to infer that the mothers in this study feel cared for and acknowledge the team's effort in caring for their children. The care given to children and their care was also identified in the information about the condition of hospitalized children, their health conditions, as well as clinical evolution of their babies.

A study of 32 mothers and 7 fathers of infants admitted to NICUs from three different centers in south-east England indicates that neonatal intensive care teams should be aware not only of the newborn's clinical condition but also of the family's emotional state, mother's relationship, basing the relationship between the health team, family members and the mother on facilitating actions to reduce distress and strengthen maternal competence.¹⁴ Corroborating a study with three mothers of premature infants in a teaching hospital in southern Brazil, it highlights the importance of the mother's role in the neonatal care process, with the aim of reducing psychological distress and its consequences caused by the birth of a preterm child and their hospitalization in the neonatal intensive care unit.¹

This study demonstrated that the women know of the existence of support services in the hospital represented by the figure of the professional social worker and perceive social assistance as a real possibility of help. Although the mothers in the present study only identify the social worker as a support service, psychological care becomes essential so that they can talk about their feelings, giving new meanings to the moment they are living. The work of the psychologist in the context of the neonatal intensive care unit differs from the other forms of action of the hospital psychologist, as it focused on the psychological issues of both the mother and the baby.

In this sense, the work of the psychologist is to offer space for listening and welcoming as well as the possibility for identifying fears and worries that compromise the consolidation of the bond that is forming, improving family participation and awareness in the care of the newborn in the unit.¹⁵⁻¹⁶ It is important that the services are offered in a support network with multidisciplinary teams whose objective will be to minimize the suffering of mothers and families of newborns admitted to the neonatal intensive care unit, helping to cope with the emotional and structural difficulties faced by them.

It is feasible to implement strategies that mitigate the negative experience of newborn hospitalization in a neonatal intensive care unit, highlighting health education actions

and support groups. Support groups provide the opportunity for dialogue and the exchange in relation to the feelings and experiences, and can minimize suffering, increasing the possibilities of facing difficulties in the face of the process they underwent⁸. This study observed that the exchange of information with the team, the psychological and social support and the assistance provided by professionals to the hospitalized newborns are some of the positive strategies that mothers perceive in the care provided by the team.

FINAL CONSIDERATIONS

The results of the present study showed feelings such as bafflement with the new situation, shock, fear, misinformation. However, these feelings were softened by the good relationship and trust with the team of professionals stimulating the development of the mother-baby bond. Thus, despite the need for hospitalization and the emotional fragility caused by the separation of mother and baby, there was no impairment in the development of the bond between them. Understanding the experience and perception of mothers of premature newborns is important to improve the routine of intensive care units, encouraging the bond of mothers with their babies, and communication between staff and family.

The study is limited as the number of mothers was small. Further studies with a larger number of mothers are recommended to obtain a broader view of the maternal point of view in these units, thus qualifying the care provided.

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