

## Maternal experiences in the first week of the premature hospitalization in intensive care

Experiências maternas na primeira semana de hospitalização do prematuro em cuidado intensivo

Las experiencias maternas en la primera semana de hospitalización del prematuro en cuidados intensivos

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**Abstract: Objective:** to describe the maternal experience in the first week of premature newborn hospitalization in the neonatal intensive care unit. **Method:** qualitative, descriptive and exploratory study. The data were collected through a semi-structured interview with ten mothers who had a premature delivery from July to November 2015. Thematic Analysis of Bardin was used. **Results:** five categories of analysis portrayed the maternal experience with moments marked by sadness in seeing the child in the unit researched, the fear of his death, the insecurity of maintaining contact and of participating in their care and, at last, the uncertainties in knowing when they could return home. **Conclusion:** the maternal experience in the first week of hospitalization of the premature newborn in the neonatal intensive care unit is marked by suffering and fear.

**Descriptors:** Neonatal Nursing; Hospitalization; Mothers; Infant, premature; Intensive care units, Neonatal

**Resumo: Objetivo:** descrever a experiência materna na primeira semana de hospitalização do recém-nascido prematuro na unidade de terapia intensiva neonatal. **Método:** estudo qualitativo, descritivo e exploratório. Os dados foram coletados por meio de entrevista semiestruturada, realizada com dez mães que tiveram parto prematuro no período de julho a novembro de 2015. Utilizou-se a Análise Temática de Bardin. **Resultados:** cinco categorias de análise retrataram a experiência materna com momentos marcados pela tristeza em ver o filho na unidade pesquisada, o medo de sua morte, a insegurança de manter contato e de participar de seu cuidado e, por fim, as

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incertezas em saber quando poderia retornar para casa. **Conclusão:** a experiência materna na primeira semana de hospitalização do recém-nascido prematuro na unidade de terapia intensiva neonatal é marcada pelo sofrimento e pelo medo.

**Descritores:** Enfermagem neonatal; Hospitalização; Mães; Recém-nascido prematuro; Unidades de terapia intensiva neonatal

**Resumen: Objetivo:** describir la experiencia materna en la primera semana de hospitalización del recién nacido prematuro en la unidad de cuidados intensivos neonatales. **Método:** estudio cualitativo, descriptivo y exploratorio. Los datos se reunieron mediante una entrevista semiestructurada con diez madres que tuvieron un parto prematuro entre julio y noviembre de 2015. Se utilizó el Análisis Temático de Bardin. **Resultados:** cinco categorías de análisis retrataron la experiencia materna con momentos marcados por la tristeza de ver al niño en la unidad investigada, el miedo a su muerte, la inseguridad de mantener el contacto y participar en su cuidado y, por último, la incertidumbre de saber cuándo podría volver a casa. **Conclusión:** la experiencia materna en la primera semana de hospitalización del recién nacido prematuro en la unidad de cuidados intensivos neonatales está marcada por el sufrimiento y el miedo.

**Descriptorios:** Enfermería neonatal; Hospitalización; Madres; Recién nacido prematuro; Unidades de cuidado intensivo neonatal.

## Introduction

The threat of premature labor is the most common indication for prenatal obstetric hospitalization.<sup>1-2</sup> It is an experience that can negatively impact the mental health of pregnant women.<sup>1</sup> Among the occurrences recorded at these times are stress, anxiety<sup>3</sup> and depression,<sup>3-4</sup> due to concerns and fears related to the baby's health, their own health, and uncertainty about the future.<sup>3</sup>

In addition, the news of the hospitalization of the newborn (NB) in the Neonatal Intensive Care Unit (NICU) undoes the maternal dreams and culminates with a feeling of frustration, unhappiness and guilt, being a difficult condition that ruptures the desired plans and impacts the loss of the motherhood dream, of the idealized child.<sup>5</sup> Having a baby hospitalized in the NICU is a distressing experience for mothers, being the result of exposure to different stressors related to the condition of the premature newborn (PNB), alteration in the maternal role, in the environment or in the team of the NICU. These factors potentialize

negative psychological effects, besides the interrupted development of adequate attachment between mother and child.<sup>6</sup>

In a previous study, the feelings experienced by mothers, related to their children's prematurity, also revealed anguish, fear and strangeness, when they had contact for the first time with the NICU. When looking at the baby, the mothers had to adapt to the real image, which, many times, was not similar to the one they fantasized about during pregnancy.<sup>7</sup>

Add to this, the environment of the NICU, considered hostile both to the hospitalized NB and to the mother, who perceives it as frightening and unpleasant,<sup>7</sup> especially during the first week of hospitalization in the NICU. In addition, other combinations of feelings experienced by mothers are observed, such as insecurity and impotence, because they expect to remain by the side of their children after childbirth and, in the face of this situation, they become expectators of care, reinforcing the dependence of the NB on the assistance of the NICU team.<sup>8</sup> In the first week of hospitalization of PNB in the NICU, puerperal women immerse themselves in an atmosphere of uncertainty, disorientation and inability to think clearly.<sup>9</sup>

Faced with such a situation, it becomes fundamental to look at mothers who are experiencing their children's prematurity and hospitalization and include their demands for care in the assistance plan. In the Brazilian context, however, the production of knowledge about the maternal experience in the first week of life of the PNB is still incipient. According to data from an integrative review conducted in 2016,<sup>10</sup> the studies published focus the experience in a broad way, which justified the realization of this research. Considering that this is the period in which rapid and profound cognitive, affective and behavioral changes can occur in the maternal experience, since this is the main family member that remains constantly in the NICU and acts as a link between the other family members and the PNB, it becomes necessary to understand how this experience is given in their perspective. Thus, this study seeks to answer the following question: How is the maternal experience during the first week of hospitalization

of the premature newborn in the NICU? This study aimed to describe the maternal experience in the first week of hospitalization of the PNB in the NICU.

## Method

This is a qualitative, descriptive and exploratory study, linked to a multicentric research, conducted in four Brazilian states: Rio Grande do Sul, Paraná, Bahia and Rio Grande do Norte. In this article, data collected in the NICUs of two public hospitals in the municipality of Feira de Santana, Bahia, are presented, included because they are the reference units in the PNB care in the region. In the units researched, the puerperal was the only member of the PNB family with free access to the NICU during the data collection period. The entry of the father and significant people to the family was possible in shifts and restricted hours and in a few days of the week.

Ten women participated (six interviewed in one hospital and four in the other) who followed the first week of hospitalization of the PNB in the NICU and had a premature delivery (<37 weeks). They were classified according to their Gestational Age (GA) obtained with the Date of Last Menstruation (DLM), or with echography done up to 20 weeks, or even by the Somatic Capurro method, in which<sup>11</sup> five physical characteristics of the NB are evaluated (shape of the ear, size of the mammary gland, formation of the mammary areola, texture of the skin and plantar folds) in order to identify the GA and the risk at birth.

Thus, they participated in the puerperal study chosen at random. Inclusion criteria were defined as: delivery between 20 and 36 weeks and 6 days of pregnancy and the concept weighing more than 500 grams; having the PNB hospitalized in the NICU for seven days or more; having followed the PNB hospitalization in the NICU; not presenting clinical and obstetric problems; and presenting psychological conditions to answer the interview.

The data collection was conducted from July to November 2015 through semi-structured interviews. Participants were encouraged to answer the following guiding questions: "How did

you feel knowing that your child would be hospitalized in the NICU?"; "How is/ or how was the experience for you in the first week of your child's hospitalization in the NICU?"

The interviews were conducted while the babies were hospitalized. However, some had already been discharged from the NICU and were transferred for weight gain follow-up at the Kangaroo Unit. Aiming not to disturb the routine of the participants, the interviews were scheduled according to their availability, in reserved places in the nurseries and counting only with the presence of the interviewer, after signing the Term of Free and Informed Consent (TFIC). A digital recorder was used to capture the statements of the interviewees.

The collection was closed when the saturation of the content of the statements was reached, that is, new information<sup>12</sup> possibly found in the interviews would not change in a relevant way the results already obtained, making the continuity of the collection unproductive.

The interviews were transcribed in full and received orthographic corrections, according to the consent of the interviewees. Initially, the collected material was organized in order to know its content. In the sequence, the empirical material was read in depth, identifying words or expressions that appeared in the texts frequently, which were grouped into 14 units of meaning that formed the basis for the elaboration of the units of meaning. These gave rise to the five categories of research to understand the object of the study. In the presentation of data, the most representative lines of each category were chosen, avoiding repetitions of common elements.

The analysis of the data was conducted through the thematic analysis of Bardin, in which the central concept is the theme, followed by the stages of pre-analysis (organization phase), exploration of the material, treatment of results obtained and interpretation.<sup>13</sup>

This study complied with the recommendations of Resolution 466/2012, with regard to ethics in research involving human beings. It was approved by the Ethics and Research Committee of the Universidade Estadual de Feira de Santana (CEP/UEFS), through Opinion No. 643.668, on May 12, 2014.

## Results

Among the ten mothers who participated in the survey, nine lived with their partner, five had more than one child who was at home under the care of other relatives and all found in the family a source of support during the hospitalization process.

The maternal experience in the first week of hospitalization of PNB in the NICU could be understood through the following categories, that emerged from the empirical material: An initially difficult experience; Suffering from seeing PNB in use of tubes and devices; Fear of the death of PNB; Not performing physical contact and care with PNB; Suffering from not knowing when PNB will leave the NICU.

### An initially difficult experience

Initially, the maternal experience was marked by intense suffering in front of the pre-term child and the consequent hospitalization in the NICU. This derives from the fact that prematurity breaks with the idealization of having a healthy baby and taking him home after delivery. Therefore, it is difficult for the mother to believe in the reality experienced, as evidenced by the following statements:

*[...] The experience of having my baby in the NICU [Neonatal Intensive Care Unit] is still a little hard to believe, because I expected to have it in January, only it happened before, three/four months before [...]. There is no explanation. I did not expect to have a premature child, and I did not expect it to ever happen to me, especially the first daughter. (I1)*

*[...] I don't wish for anyone to have a child hospitalized in the ICU [Intensive Care Unit] because it is difficult to know that you are not going to take them home, to know that they aren't well yet [...]. It's hard, because I don't take them with me at the moment I was born. (I2)*

*[...] had times I cried, asked God why, why this was happening to me [...].*  
(I7)

Add to this, the disturbance of the maternal cognitive domain in the first days of hospitalization, leading them in the direction of not understanding the information passed on by the team about the clinical status of the PNB. However, although they did not comprehend the situation experienced, the mothers wished to be present in the NICU.

*[...]we don't understand why it's there. The doctors explain, but we don't understand. Mom wants to be with her on her lap.* (I2)

In this sense, the experience in the first week of hospitalization of the PNB was considered difficult by the interviewees, for interrupting all the idealized plans and for triggering in the mother initial sources of suffering that were added to the peculiarities of hospitalization and the stress that the environment of the NICU causes.

### **Suffering from seeing PNB in use of tubes and devices**

As she enters the NICU and sees her premature child invaded by tubes, probes, catheters and surrounded by machines used as an unknown therapeutic support, the mother feels frightened.

*[...] I only got scared when I saw that she had the tube in her mouth.* (I2)

When witnessing the invasive procedures performed in the care of the PNB, mothers felt sad because they believed that their children were suffering.

*[...] sad to see her in the ICU[Intensive Care Unit], because every day she is punctured [referring to invasive procedures, such as venepuncture].* (I3)

*[...] he kept breathing by device. And then, when I went to see him, I felt that he was bothered, twisting all over there for me. It was all the more reason to be sad. (I4)*

As a consequence, one of the mothers adopted as an initial strategy the questioning of the members of the health team of the NICU about the situation of her child, in an attempt to become accustomed, understand the purpose of each device, get used to it and keep calm during the experience.

*[...] at the same time, it gave me agony to see those tubes in his mouth. Then I asked if those tubes wouldn't hurt his mouth. Then the nurse said no. It's so much that he had to be sedated a little, so he wouldn't move. (E8)*

Thus, the technologies and devices used to support the RNPT and the complexity of care impacted on the affective state of mothers, who experienced various feelings, such as the constant fear of losing their child.

### **Fear of the death of PNB**

The women interviewed perceived the NICU as a place where people are closer to death or in a critical state of health, which increased their fear of the loss of their premature child.

*[...] ICU [Intensive Care Unit] is a very heavy name and for a child born out of time. For me, there was already a risk to go to ICU, so it was strong. Because, when they say "go to ICU", the person thinks that it is already in serious case. (I1)*

This feeling was most intense when the women interviewed experienced clinical complications that demanded immediate interventions from health team members, such as neonatal resuscitation.



*[...] he even bled twice through the tube. I saw him totally stopped, almost dead. I saw there that my son was not well, it was that they [the team] were giving him a massage and I kept seeing everything. Then, when I got up here, I collapsed, I started crying [...]. I felt that I was going to lose my son, I was going to lose him. He stayed more than an hour, not awake, without breathing. (I4)*

Still during the PNB hospitalization experience, mothers experienced the constant fear of loss, due to their instability and clinical severity, thinking that at any time they would receive some bad news.

*[...] It was a desperation every time I arrived in the ICU [Intensive Care Unit] and had bad news. The desperation was because I was afraid of her dying. (I9)*

*[...] I cried for fear of that moment of her erasing. (I10)*

In this way, the constant pressure caused on the maternal figure, for being in an unknown place and perceived as a space of NB with unstable and increasingly serious clinical conditions, profoundly affected the cognitive condition of mothers, potentiating then, their initial distance from their child, evidenced by the insecurity in touching them.

### **Not performing physical contact and care with PNB**

Because she perceives the PNB as a small and fragile being, the mother initially felt fear of keeping in touch with her child. She postponed this care, believing that her touch could disconnect tubes, wires and devices and modify their clinical condition. Thus, for a moment, the technologies that guaranteed the life of the PNB were perceived, in the testimonies of the interviewees, as initial barriers in the approach between mother and child, interfering in the strengthening of the bond after birth.

[...] *but I get scared, because I'm scared to break down* [referring to causing clinical change]. *She's very fragile.* (I2)

[...] *I was afraid to catch her at first. I wouldn't even touch her because she was in the incubator. My mother would call me and ask me, and I'd say: Mom, I don't touch her. I'm afraid to disconnect something there. Then my mom would say, "It's gonna be okay. You have to move* [referring to touching the child]. (I6)

The decision not to touch the PNB, provoked by the belief that it would cause damage to their clinical condition, limited, in the first week, the maternal participation in less complex care, as for example, the change of diapers.

[...] *I haven't changed a diaper yet. I've seen changing, but I can't. I'm afraid of hurting. I touch like this: I open the little door* [of the incubator], *I straighten him, but even picking him up to change a diaper, it doesn't work. I've already changed two children, but they were nine months old. This is very fragile. He's not fully formed yet.* (I4)

The absence of physical contact and the fact that she could not breastfeed her child made the maternal experience even more difficult. Even though she wished to offer her milk as nutrition, this care occurred indirectly, through milking, in view of the clinical conditions of the NB and their lack of breastfeeding readiness. This initial impossibility made it difficult to strengthen the bond between mother and child.

[...] *I haven't held him since the day he was taken* [referring to the birth]. *Can't hold him yet, nor breastfeed him.* (I8)

[...] *difficult for not breastfeeding. We take the milk, but it's not the same as putting on your breast and feeling it. It's bad!* (I2)

*[...] he's on a zero diet. It's hard because there are some babies there in the ICU who can be breastfed, who are off a zero diet, and he's not. He's still on a zero diet. Then it's hard. (I5)*

*[...] First they [multiprofessional team] said they wouldn't be able to give the milk because she was on a zero diet and then she was taking it from the hospital. Now, every day 6 h, I take it for her. (I3)*

The absence of physical contact of the puerperal with her child, amidst the challenges faced during the first week of hospitalization in the NICU, associated with the uncertainties regarding the prognosis and discharge of the PNB, were additional sources of maternal anxiety and suffering because they did not know when they could return home, regain their routine and the conviviality with relatives.

### **Suffering from not knowing when PNB will leave the NICU**

Uncertainties about the child's future, the day of discharge from the NICU, and the return home intensified maternal suffering and the anxiety for information and answers that even the team could not give them.

*[...] It was a difficult experience because of the time she spent in the ICU [Intensive Care Unit]. I expected her to spend little time. The doctor told me that it was just because of the weight, at most 15 days she would be home and it did not happen. She spent 45 days. It was difficult, because she stayed longer than I imagined. The feeling of pain while she was in the ICU, was because I always asked her how long it was before she got out and she never had an answer, because they didn't know either. (I1)*

In addition, the full-time permanence in hospital to accompany the premature child, away from family and friends, also contributed to intense suffering, mobilizing the mother to wish to return to the normality that her life had before the experience of the premature birth and hospitalization of the child in neonatal intensive care.

[...] *I'm really missing my home, I really miss it [...]* (I10)

[...] *having to stay here in the hospital, a concern of having to stay here [...]*  
*The experience of having my baby in the ICU [Intensive Care Unit], I*  
*never thought I would pass in my life. It's hard to stay here, to stay away*  
*from everybody, away from home.* (I5)

Thus, the maternal will was to take the child home soon, in an attempt to end the suffering caused by hospitalization in the NICU.

[...] *makes you want to pick him up and take him home.* (I5)

## Discussion

The maternal experience in the first week of hospitalization of the PNB in the NICU was initially translated as very difficult, for breaking the idealization of a healthy child, generating sadness due to the impossibility of caring and taking him home after delivery.<sup>14</sup> Thus, the maternal experience was marked by intense suffering, difficulty to believe that the hospitalization was happening and profound cognitive and affective disturbance that had repercussions in the absence of understanding on the information that was passed on.

In this study, mothers suffered from seeing and following their children's hospitalization and had difficulties in accepting and understanding the reasons for their stay in the NICU. As already discussed in another study, the experience of experiencing hospitalization in the PNB is a torment, marked by tension and stress, which can interfere with the maternal physical and mental health.<sup>15</sup> In this scenario, the experience of maternity was marked by feelings of insecurity and fear about the survival of the child.<sup>5</sup>

It is therefore necessary that health professionals in the NICU identify, in the first days of hospitalization of the PNB, the support network and maternal social support used in difficult times and use them as strategies for their care. Furthermore, it is essential to offer emotional

support to these women, from the first moments of their entry into the NICU, by a duly qualified professional.

Besides the strangeness and impact caused by the NICU environment, the suffering when seeing the PNB in use of tubes and devices, was manifested by the maternal account of fear of these resources, for not knowing them. The use of these, although necessary to maintain the life support of the NB,<sup>5,14</sup> stimulates maternal questions and fear about the real chances of survival,<sup>5,9,16</sup> intensifying the stress<sup>17</sup> and suffering of the puerperal during the first days of hospitalization.<sup>14</sup>

Another source of maternal suffering revealed in this study, which made it difficult to experience the first week of hospitalization of the PNB in the NICU, was having witnessed invasive procedures. This vision generated sadness in the mothers, because they thought that the PNBs were suffering. To witness these procedures provides maternal apprehension, due to concern about the state of health of the PNB. O medo decorre da crença de que a utilização desses recursos se relaciona ao agravamento da condição clínica do NB, potencializando, assim, uma experiência muito dolorosa e de sofrimento para o filho, o que faz a mãe sentir-se ainda mais triste.<sup>14</sup>

Mothers of a research conducted in Ghana indicated that although they were often informed of the procedures to be performed on their babies, they were not explained. This, at times, made them anxious, especially when they assumed that the procedures were being performed because the clinical condition of the NB was deteriorating.<sup>18</sup>

Some national studies<sup>19-20</sup> conducted with parents of NB in NICU, through the application of the Brazilian version of the Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU), demonstrated that the change in the role of mother/father was the subscale in which the highest level of stress was obtained, which was also observed in research conducted in Turkey.<sup>17</sup> On this scale, one of the most frequently signaled items was feeling helpless and unable to protect the NB from pain and painful procedures.<sup>19</sup>

In that study, the subscale "Appearance and Baby Behavior" was considered more stressful situations: "When my baby seemed to be in pain" and "When my baby seemed sad".<sup>19</sup> In this subscale, the highest stress scores were identified in those interviewees who had no previous experience with prematurity.<sup>20</sup> In these, data related to "Sounds and Images", "Seeing a (breathing) machine breathe for my baby" and "The sudden noise of the monitors' alarm" were highlighted.<sup>19</sup>

In this sense, even in the face of intense fear and suffering, the strategy used by the interviewees was to seek information from health professionals about their child's conditions. The information provided by the health professionals, together with the progressive knowledge of the work protocols and the environment of the NICU, were essential to promote maternal tranquility.<sup>16</sup>

The fear of the PNB's death was a frequent theme in the interviewees' speeches. This fear was associated with the belief that the NICU would be a place for severe babies.<sup>5</sup> For the women interviewed, hospitalization in this unit happens because of the severe clinical conditions of PNB, having, thus, a higher probability of death than survival, which caused intense concern.<sup>14,16</sup> Thus, the NICU was perceived by the mothers as an enigmatic and threatening environment, which increased fear and prolonged their uncertainties<sup>16</sup> as to what would happen.

The fear of death also arose from the clinical instability of the PNB. Thus, the feeling of loss of the child was another element very present in the maternal experience during the first days of hospitalization in the NICU.<sup>5,21</sup> The fear of receiving some bad news at any moment was present in this experience. The information about the changes in the clinical picture made intense moments of apprehension, anguish, feeling of impotence and uncertainty about the future<sup>5</sup> of the PNB emerge due to its organic immaturity. The mothers felt that at any moment the clinical picture could worsen, emerging the fear of losing them.

Reinforcing these findings, in a similar research, several initial reactions to hospitalization were observed, such as feelings of despair and search for information on the clinical picture, as well as diagnosis, possible complications and prognosis.<sup>22</sup> Thus, to

strengthen the bond of trust between the team and the puerperal, it is necessary that professionals communicate effectively and constantly, and that they are sensitive and know how to choose the appropriate words, avoiding undoing the positive expectations created in relation to the evolution of the PNB.<sup>5</sup>

For this, it is important that health professionals orient puerperal women, already in the first days of hospitalization of the PNB in the NICU, about devices and devices used, clarifying that they are necessary as supports for their recovery and that they can also solve the doubts related to the belief of suffering associated with the use of these resources. For this purpose, several strategies can be used to help in the acquisition of the necessary knowledge, such as books, videos, photographs, leaflets or information booklets. It is also essential to provide clear information about the daily clinical evolution of the PNB.

The insecurity demonstrated also by the mothers in this study, to maintain contact with the PNB and participate in the less complex care, in the midst of the privations of not being able to care as they would like, derives from the way of seeing them as fragile beings. This fear also arose from the perception that touch could disconnect them from the apparatus and devices and cause clinical instability.

Research has shown that the first time mothers entered the NICU to see their children, they were shocked by their physical appearance and felt fear,<sup>16</sup> because of their tiny size<sup>5,9</sup> and vulnerability.<sup>14</sup> These are the visual impressions with the greatest impact on the maternal experience,<sup>5</sup> which further enhance their suffering<sup>14</sup> and accentuate doubts about the baby's real chances of survival.<sup>9</sup>

These findings corroborate those of another study, which revealed, in the mother's statements, feelings of impotence within the NICU, due to the impossibility of carrying out basic care with the babies, such as breast-feeding, picking up the lap and bathing.<sup>23</sup> Furthermore, the feeling of maternal fear of touching and caressing the children was explained

by the committed self-esteem, by the intensive care environment itself and also by the absence of self-confidence in feeling capable of caring for that being.<sup>24</sup>

In some studies, the NICU was perceived by babies as a threatening space for the mother-child relationship, as some initial barriers could prevent physical contact between them,<sup>14</sup> such as fear of interfering with technological support or transmitting infection,<sup>16</sup> which could cause further problems in their critical health status.<sup>9,14</sup> However, the first vision of babies was the starting point for mothers to deal with reality and accept them, regardless of their characteristics.<sup>18</sup>

Another factor that created suffering for the mother was the impossibility of breastfeeding her child, making it difficult to form the bond between them. Analogously, previous qualitative research revealed difficulties faced by mothers during hospitalization of their children, due to the distance and impossibility of providing direct care to them.<sup>25</sup> The small size and fragility of NTN, as well as the equipment and devices, can hinder the breastfeeding process.<sup>9</sup>

In this sense, the mothers in this research did not breastfeed their children in the first days of hospitalization in the NICU due to their clinical conditions, which was a source of maternal suffering. The emotional chaos experienced by mothers in the NICU diminishes their abilities to control the situation and has an unusual impact on the onset of lactation, through the use of a pump in their breast; however, the milk is configured as a strategy to remain emotionally connected to the baby.<sup>9</sup>

Mothers also revealed uncertainties in knowing the future of the PNB and when they could return to their homes and families, which contributed to anxiety in obtaining information and more suffering. Having a child in NICU and living motherhood in this scenario generates feelings of fear, insecurity, uncertainty<sup>5</sup> and constant concern about the survival of the NBR,<sup>5,14</sup> being this a very difficult situation.<sup>14</sup>



In addition, it was observed in this research that the detachment from the family also intensified maternal suffering and the desire to return home. In another study, when accompanying their children hospitalized in the NICU full time, the mothers reported a rupture of experiences and routines before hospitalization, in addition to the nostalgia of living with relatives.<sup>26</sup>

Thus, it is essential that health professionals in the NICU develop strategies and intervention programs that help mothers reduce the stress of their experience in the first week of hospitalization of the PNB and support them in coping with this situation.<sup>6</sup> For this, daily changes based on the effective reception of mothers in the PNB are necessary in the context researched, fulfilling their demands during hospitalization, as well as engaging them and including them in the care provided to their children,<sup>27</sup> considering them as a basic and fundamental unit of care for the new members of the family system and constant in their lives, even in the adverse context of the NICU.

In addition, it is necessary to insert the mother as early as possible in the care of the NB, encouraging and supporting her emotionally, so that the experience of accompanying the child in their first week of hospitalization in the NICU becomes less painful. In this way, she will contribute with her participation throughout the experience, in case of a prolonged stay in neonatal intensive care.

It is also essential to organize teams of qualified specialists to identify problems of a cognitive, affective and behavioral order in the first week of hospitalization of the PNB in the NICU, in addition to identifying its strengths and resources used in difficult times, which can be translated into interventions capable of promoting profound changes in the areas affected.

It is pointed out as a limitation of the study that the data are not generalizable, since they contemplate a single scenario of neonatal care and its singularities. However, considering the local particularities of the neonatal units of the hospitals in question and the social group interviewed, the possibility of their generalization to this context is considered.

In this way, research in other contexts of the national scenario may point out different elements on the maternal experience and other family members in the first week of hospitalization of the PNB in the NICU, contributing with possibilities of intervention and knowledge to sustain family health in difficult times. In addition, future researches can be carried out with greater extension of the collection time, because by using the theoretical saturation,<sup>12</sup> it cannot be stated with precision that other data will no longer be found.

## Conclusion

The strangeness of the new environment, the fear of the invasive care apparatus and the uncertainty about the outcome of the critical situation of the PNB caused maternal suffering and provided the constant feeling of fear of death.

This reinforces the importance of accompanying and supporting the mother during the first week of hospitalization of the PNB in the NICU, explaining her about the support devices and technologies and how she can participate in her care at that time, highlighting her presence for the recovery of her child, as well as the inclusion of other family members as social and constant supports in her life in neonatal intensive care.

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