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## THE EXPERIENCE OF MATERNITY TO THE BABY HOSPITALIZATION IN THE ICU: A ROLLER COASTER OF EMOTIONS

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**ABSTRACT.** In this study, we sought to know the experience of mothers of babies hospitalized in a Neonatal or Pediatric Intensive Care Unit. This was a qualitative, exploratory-descriptive study. Nine mothers of infants admitted to six different Neonatal or Pediatric Intensive Care Units, located in five cities in the State of Rio Grande do Sul, participated in the study. A sociodemographic questionnaire and a semi-structured interview were applied to collect the empirical material. The interviews were transcribed and subjected to content analysis. Three categories emerged from this analysis. The results reveal that it is difficult for mothers not being able to take their babies home after birth. They revealed feelings such as fear, insecurity, fear of the baby's death, impotence and guilt. The mothers experienced a sense of loss of control, concern for other children and the need for support from the mother and husband. The health team can alleviate the suffering of mothers by means of simple initiatives with a view to a better reception to mothers and family.

**Keywords:** Maternity; intensive care unit; new born.

## A EXPERIÊNCIA DA MATERNIDADE DIANTE DA INTERNAÇÃO DO BEBÊ EM UTI: UMA MONTANHA RUSSA DE SENTIMENTOS

**RESUMO.** Nesta pesquisa buscou-se conhecer a experiência de mães que tiveram seus bebês hospitalizados em uma Unidade de Terapia Intensiva Neonatal ou Pediátrica. O estudo se caracterizou como qualitativo, de caráter exploratório-descritivo. Participaram nove mães de bebês internados em seis diferentes Unidades de Terapia Intensiva Neonatal ou Pediátrica, localizadas em cinco cidades do Estado do Rio Grande do Sul. Para a apreensão do material empírico foi utilizado um questionário sociodemográfico e uma entrevista semiestruturada. As entrevistas foram transcritas e submetidas à análise de conteúdo. Desta análise emergiram três categorias. Os resultados revelam que é difícil para as mães não poder levar seus bebês para casa após o nascimento. Elas revelaram sentimentos como medo, insegurança, temor da morte do bebê, impotência e culpa. As mães vivenciaram a sensação de perda de controle da situação, preocupação com os outros filhos e a necessidade de apoio da mãe e do marido. Foi possível elucidar que a equipe de saúde pode minimizar o sofrimento das mães por meio de iniciativas simples com vistas a um maior acolhimento às mães e aos familiares.

**Palavras-chave:** Maternidade; unidade de terapia intensiva; recém-nascido.

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## LA EXPERIENCIA DE LA MATERNIDAD FRENTE LA HOSPITALIZACIÓN DEL BEBÉ EN LA UCI: UNA MONTAÑA RUSA DE SENTIMIENTOS

**RESUMEN.** En esta investigación se buscó conocer la experiencia de las madres que tuvieron a sus bebés hospitalizados en una Unidad de Cuidados Intensivos Neonatal y Pediátrica. El estudio se caracteriza por ser de carácter cualitativo, exploratorio y descriptivo. Participaron nueve madres de niños hospitalizados en seis distintas Unidades de Cuidados Intensivos Neonatales o Pediátricos ubicadas en cinco ciudades del estado de Rio Grande do Sul. Para la aprehensión del material empírico se utilizó un cuestionario sociodemográfico y una entrevista semiestructurada. Las entrevistas fueron transcritas y se sometieron a análisis de contenido. De este análisis surgieron tres categorías. Los resultados apuntan que es difícil para las madres no ser capaz de llevar a sus bebés a casa después del nacimiento. Revelaron sentimientos como el miedo, la inseguridad, el miedo a la muerte del bebé, la impotencia y la culpa. Las madres experimentaron la sensación de pérdida de control de la situación, la preocupación por los demás niños y la necesidad de apoyo de la madre y el marido. Fue posible dilucidar que el equipo de salud puede reducir al mínimo el sufrimiento de las madres por intermedio de iniciativas sencillas con mirada a una mayor atención a las madres y familiares.

**Palabras clave:** Maternidad; unidad de terapia intensiva; recién nacido.

### Introduction

The experience of hospitalization of a baby in an Intensive Care Unit (ICU) is a hard time for mothers and their families, which can result in a crisis, since it imposes to the caregiver of the baby, usually the mother, limitations, impediments and situations that change the relationship with work, with their relatives, friends and partners. This situation often causes in the family the need for reorganization to meet the new routine (Viera, Mello, Oliveira, & Furtado, 2012).

Some current studies have presented contributions regarding the scenario of this episode (Hagen, Iversen, & Svindseth, 2016; Lara & Kind, 2014; Vivian et al., 2013). However, this study advances by presenting and discussing experiences of mothers of babies hospitalized in ICU, living in small towns in the interior of the State of Rio Grande do Sul.

The understanding of the health professionals about the maternal experience, during the hospitalization of their infants in ICUs, favors the proposal of strategies with a view to minimizing the difficulties and suffering generated by the hospitalization. Thus, this study aimed to know the experience of mothers during the hospitalization of their infants in an Intensive Care Unit in the interior of the State of Rio Grande do Sul.

### Method

#### Design

This is a qualitative, exploratory-descriptive study that allows a greater approximation to the daily life and the experiences lived by the subjects (Minayo, 2011).

## Participants

The research was carried out with nine mothers who experienced the hospitalization of their babies in some Pediatric or Neonatal Intensive Care Unit. To identify the participants, the snowball sampling was used. In this technique, the initial participants of a study indicate new participants who in turn indicate new participants and so on, until the proposed goal is reached (Biernarcki & Waldorf, 1981). In order to determine the number of participants, the data saturation criterion was used, that is, the saturation is reached when the new interviewees begin to repeat the contents already obtained in previous interviews, without adding new information relevant to the research (Fontanella et al., 2011).

To choose the participants, the following inclusion criteria were considered: have a baby with up to 24 months of hospitalization in Pediatric or Neonatal ICU; have accompanied the child's hospitalization; have an age of 18 years or more. The nine mothers interviewed were aged between 23 and 40. The characteristics are listed in Table 1.

Mothers were referred to by the letter M followed by a number from 1 to 9, at random, as shown in Table 1. The research was performed at the place that the mother preferred, but all places had adequate conditions, such as silence and privacy.

**Table 1.** Characterization of the interviewees

Mother	Age	Marital status	Schooling	Occupation	Family income	Number of previous pregnancies
M 1	36	Married	Higher education	Physical therapist	6 thousand	0
M 2	30	Married	Higher education	Administrator	10 thousand	0
M 3	37	Married	Higher education	Physician	15 thousand	2 abortions +1
M 4	30	Married	Incomplete elementary school	School bus driver assistant	1,500	2
M 5	32	Married	Higher education	Housewife	15 thousand	1
M 6	40	Married	Complete Elementary school	Housewife	1,500	1 abortion+2
M 7	36	Married	Incomplete High School	Housewife	2 thousand	1
M 8	23	Common-law marriage	High school	Caregiver	900	0
M 9	27	Married	High school	Housewife	900	0

Source: The authors

The hospitalizations occurred in six different Pediatric and Neonatal ICUs, located in five cities in the State of Rio Grande do Sul. The ages of the babies ranged from 0 to 38 days, and the babies were referred to by the numbers, from 1 to 9, according to the number

corresponding to its mother. Characteristics of infants and hospitalizations are described in Table 2.

**Table 2.** Characterization of infants and hospitalizations

Baby	Curr ent Age	Age at hospita lization time (Days)	Birth	Diagnosis/	ICU	City	Length of stay
<b>Baby 1</b>	1y9m	38	Term	Undefined	PED	Santa Maria	3 days
<b>Baby 2</b>	11m	1	Premature	Respiratory Insufficiency	NEO	Santa Maria	9 days
<b>Baby 3</b>	1y4m	0	Premature	Respiratory Insufficiency	NEO	Santa Maria	8 days
<b>Baby 4</b>	10m	0	Premature	Low weight	NEO	Alegrete	22 days
<b>Baby 5</b>	1y5m	1	Premature	Cardiopathy	NEO	Porto Alegre	1 month
<b>Baby 6</b>	1y3m	0	Premature	Brain Injury	NEO	Santa Maria	1 month
<b>Baby 7</b>	1y5m	7	Premature	Cardiopathy	NEO	Porto Alegre	18 days
<b>Baby 8</b>	3m	0	Term	Pneumonia	NEO	Santa Rosa	15days
<b>Baby 9</b>	1y9m	0	Premature	Pneumonia	NEO	Estrela	84days

Source: The authors

## Data collection

Data collection took place from June to September 2016, after approval by the Research Ethics Committee of Franciscan University (Universidade Franciscana - UFN), through the opinion number 1,559,142, dated May, 2016.

A first telephone contact was made with each mother, in which the research proposal was presented and the invitation to participate was made. After the acceptance, it was combined date and place. On the day of data collection, the researcher clarified doubts and obtained the signature of the Informed Consent Term. Subsequently, to collect the empirical material, we used a sociodemographic questionnaire and a semi-structured interview, which was recorded in audio for later transcription. The questionnaire was applied to characterize the participants, containing information such as age, marital status, schooling, city, occupation, number of children, length of stay in the ICU, among others.

In turn, the interview followed a semi-structured script composed of open and closed questions regarding the experience of the baby's hospitalization, the mother-baby bond and the feelings experienced. The preparation of the interview was based on Minayo (2011).

## Data analysis

All interviews were transcribed and printed to facilitate floating readings. Firstly, the corpus of analysis was constructed, composed by transcripts of the interviews. For data analysis, content analysis was selected, because it is a technique that allows the inference of knowledge regarding the conditions of message production and consequent inferential interpretation (Bardin, 2011; Minayo, 1993, 2011).

## Results and discussion

### The mother faced with the need for hospitalization of the baby in the ICU

During gestation, mothers construct the image of the ideal child through unconscious fantasies. After birth, they need to adapt to the image of the real baby, but when the baby is born with some health complication and needs hospitalization, this emotional adaptation becomes even more difficult. Birth is the moment when the family idealizes the child that is to come, being, almost always, cause for joy and satisfaction. However, for the mothers participating in this study, the reality turned out to be different from the planned ones, they had interrupted the plan to go home with their babies. The frustration with this reality is expressed in their lines:

I wanted to go home with her, as I had dreamed, I did not want to stay there, my plan was to get the baby right and go home the other day with her (M2); I felt a great pain, I wanted to take her home, I did not want to believe that this was happening to her (M6); I had to go home without him, I was supposed to stay for two days, but I asked to stay three, because I expected he would be discharged from the hospital with me, but he did not, he had to go to the ICU. When we got home, we both collapsed, because it was not what we had planned, we were very sad (M3).

The study by Lara and Kind (2014) revealed that maternal discharge not associated with the discharge of the baby causes fear and pain in the mother, since the mother's desire to take the child home, to her welcoming and familiar environment, is present since gestation, accompanying dreams and fantasies. Thus, mothers in general feel insecure and worried, even though they understand the clinical need for hospitalization.

The hospitalization of the woman, for the arrival of a new member in the family system, changes the dynamics of the family. When added to the news that the baby will need an Intensive Care Unit, the impact is even stronger, as evidenced by the study participants:

It was the worst pain I ever felt in my life, because when the doctor said that he was going to the ICU, I was in shock, you know, when you do not know where to go, I felt lost (M8); It was a shock to me to know that she was going to the ICU, I would never expect that to happen, I was so fine, then suddenly she is born and this all happened (M6); It was very distressing, we were not expecting him to need an ICU because I was already at the end of gestation, maybe because I was from the health area, I already knew everything that could happen (M3).

Although Mother 9 was previously advised of the possibility of her child after birth needing ICU admission, she also revealed that she had suffered an intense impact: "They had already told me that when he was born he would have to go to the ICU, I tried to get prepared, but when I saw him with all those tubes, I went into despair, it was horrible".

The difficulty to be prepared may be related to low schooling and family income, poor access to quality information through the internet and print media. In addition, according to Maldonado (1997), during gestation several emotional reactions are triggered by the

woman, and in thinking that the baby can be born with health problems, strategies of defenses are activated to minimize the suffering.

One of the strategies of defense that can be activated by the woman during the gestation is the negation, she denies the reality to not accept the loss of the ideal, as illustrated in the speech of Mother 2:

I had read a book on gestation, and had a part that was about premature and ICU, I skipped it, I thought she was not going to be premature and much less that she would go to an ICU, I regretted not having read, if I had read it would not have been so shocking.

Pediatric and Neonatal Intensive Care Units were created with the objective of saving the lives of infants and children, and with the advancement of technology this has happened successfully, but there is still an association between ICU and the proximity of death, as was referred to by them:

I thought that the patient going to the ICU, it would be between life and death, it was not pleasant at all (M7); I did not even know what ICU was, I just knew it was a bad thing, that people would go there when they were dying (M8); I thought somebody was going to the ICU when dying, that going to the ICU was death. The doctor could have said, explained, because I did not know, you'll only know just in time (M2).

The environment of ICU is formed by a scenario of technologies, many devices, intense movement of professionals, with a dynamic and logical organization different from the routine of the mother. In agreement with the results of the study by Favaro, Peres and Santos (2012), it was possible to verify from this study that the first maternal visit to this hostile environment produces suffering. They described it as a difficult experience:

The first time I went into the ICU I had a bad time in there, that place is horrible (M9); Until I went to see her, I was calm, I did not cry, I slept well, I rested. Then the first sensation when I came in was a shock, she was on the ventilator, with a feeding tube, horrible to see (M2); Arriving there was horrible, because you enter, you do not expect to see your son that way, he was intubated, with a pee-tube, a feeding tube, full of needle pricks, it was horrible (M5).

However, Mother 1 mentioned that the first moment she arrived at the ICU she felt safe seeing the possibility of elucidating the diagnosis of her baby: "Arriving at the ICU, I even calmed down, I thought: well, now at least, let's go find out what's happening to him". Importantly, this mother was the only one who had already taken her baby home, and only on the 38<sup>th</sup> day of life he presented the symptoms requiring hospitalization. All other babies in this study remained hospitalized after birth.

### **The exchange of lullaby by a roller coaster of emotions**

Many feelings are experienced by the mothers during the period of ICU hospitalization. In the study by Vivian et al. (2013), the most mentioned feeling was fear. In the same way, in the present study, when asked about their feelings, the mothers reported having had much suffering, worry and fear. Eight of the mothers reported fear of the unknown, fear of what could happen and, mainly, fear of losing the child, as expressed in the speeches:

A mixture of feelings, the worst was fear, fear of something happening, fear of not knowing what was happening, no diagnosis, fear of how I was going to deal, fear of loss, thought he was going to die (M1); Everything went through my head, afraid of losing after delivering, afraid that he would die (M5);

I saw her full of apparatus, full of things, I was afraid of losing her (M6); I was afraid of losing him, since I was pregnant, I always had a lot of bleeding, and there, I was afraid he would die (M9).

Still on the emotions experienced in the period of hospitalization, it is possible to perceive through the mothers' speeches that it was a period of much suffering, besides the fear of losing the child, they experienced negative emotions like anguish and sadness, as evidenced by the words:

A mixture of feelings, sadness to see him there, a very great despair (M1); Anguish is the first feeling that comes to my mind, sadness of having to leave him there alone (M3); I felt a great pain, an emptiness, a sadness (M6).

According to Guidolin and Célia (2011), the appearance of ambivalent feelings of happiness/sadness, hope/hopelessness, separation/attachment, is due to the various doubts that arise regarding the baby, as a mother. In this study, some mothers also reported ambivalent emotions as sadness and happiness, as seen in the speech:

It was a mixture of feelings, anguish, a bad feeling, sadness that she was not with me, but I felt happiness because she was born. (M2); Sadness, anguish, fear, I was very sad because I could not take him, but the first lap was only happiness (M9).

Babies' hospitalization ranged from three to 84 days, during which time the mothers were focused on the babies, everything revolved around the hospital stay, they were emotionally distant from real life:

That was a parallel life, what was out here did not interest me, did not know if there was sun, not even looked at my phone, I just wanted to know about her (M2); I was always expecting, on alert, every day that passed I wanted him to react (M4).

According to Winnicott (1988), in puerperal stage there is an emotional alteration, essential and provisional, which allows mothers to intensely bind to the newborns, adapting to them and seeking to meet all their basic needs. What in another period would be pathological, in the puerperium is considered natural, the fact that the mother does not give importance to self-care and devote all her attention to the baby. However, in view of the need for the child to remain in the ICU, it is possible to observe that the self-care of the participating mothers was further impaired, and the baby became the center of maternal care even more intensely.

If you do not eat, do not sleep, whatever, I just thought about him, wanted to take care of him, heal, treat him the best (M1); I did not eat right, I did not sleep properly, I took naps, I woke up and seemed like a nightmare, I did not have relapse and depression I don't know how (M5); I lost weight at that time, I did not eat, I did not sleep, I came home, but I wanted to go back, always in that wait (M6).

The unconditional surrender of the mother for the care of the baby is also justified by the impossibility of shifts with the father, since the Brazilian legislation grants the father only five days of paternity leave, which in the case of hospitalization of a newborn does not allow the father to be able to follow the hospitalization full time. Although Law 8069, of 1990, established the Statute of the Child and Adolescent, which establishes in its article 12 that hospitals must provide conditions for the full-time stay of one of the parents, or guardian, in cases of hospitalization of children (Brasil, 1990).

However, the father is often prevented from remaining in the ICU due to employment legislation, as exemplified in Mother 7 speech: "My husband had to work, when he could he stayed there for a while and then went back to the work". This makes the stay of the mother



next to the hospitalized baby occur more frequently than in relation to the father, in the case of the study participants, the majority was the main caretaker during the hospitalization of the child. "I missed my husband spending more time there with me, it was not that he did not want to, but he had to work" (M9).

These results are in agreement with the findings of Hayakawa, Marcon and Higarashi (2009). The authors emphasize in their study that fathers of hospitalized children hardly can closely follow the evolution of their children, which generates the feelings of sadness and impotence, alternated with periods of resignation. On the other hand, the study by Deeney, Lohan, Spence and Parkes (2012) showed that fathers with a higher socioeconomic class showed greater freedom to be present at the hospital because of their financial security and their opportunities to negotiate working hours more flexible than the fathers of lower economic class.

Regarding the role of the father in this scenario, it can be seen from the report of the participants of this study that, often when present, the fathers exerted a protective role to the mother, assuming the function of reassuring them.

The one who supported me was my husband, he said that we were going to get it, that we were going to win, we were going to try to do everything. He gave me a fundamental support (M1); But the most important thing was my husband, always, because we felt together, we had planned everything together, he gave me everything I needed (M3).

It is noteworthy that in these two cases, the fathers exercised their professional functions with flexibility in the organization of work.

From the speech of Mother 2, it can be observed that, at moments when the husband had to leave, she felt insecure:

The day he had to travel, that day I felt insecure, I was alone there, that day she didn't want to nurse, I don't know if I did not give her the insecurity. When he was with me, I felt stronger, I do not know if it is a dependency on the husband, I thought that if something happened, he was there, and he would solve.

Corroborating the findings of this study, in the study by Deeney et al. (2012), fathers referred to the need to be strong, to be the protector, the father involved, the mainstay of the family. The role of the father is necessary, according to Winnicott (1988), because mothers are in helplessness due to their state of primary maternal concern. In this study, mothers who did not have the participation and presence of the companion felt alone, overwhelmed, helpless as evidenced in Mother 6 speech:

I missed the support of my husband, it was so difficult to listen to all that of the doctors alone, I listened and kept crying alone there, and he said he did not go because he did not like to see her like that, I felt devastated, I wanted his support, and he did not support me.

However, Mother 8 was the only participant in this study who, even with the presence of the husband, felt alone because the husband did not provide her with a space in which she could talk about her feelings, did not allow her to express her emotions, so that she did not feel comforted:

I felt very alone, even with my husband by my side, I felt very alone, I cried all the time, but I could not cry on my husband's side, when I wanted to talk he just said I had to stay strong, then I had to hold back the tears, then I had to hold back, I was holding back, holding back [...].

According to Hagen et al. (2016), mothers who are not accompanied by the baby's fathers may have more coping difficulties compared to those who are accompanied. Besides

that, they presented more stress when accompanying the child without parental involvement. In addition to appreciating the presence of the partner, the presence of their mothers, grandmothers of the babies, was also extremely important for the participants, as evidenced in Mother 2 speech:

The person I wanted was my mother, I did not want my mother-in-law, sister-in-law, nothing, because who gave me comfort was my mother, she did not ask for anything, she knew just looking at me. Many afternoons the mother did not even talk to me, just stayed by my side, kept me company, respecting my silence.

The fact is that the grandmothers are, in general, the main caretakers of the baby's mother, that is, they take care of the one who cares. And since the mothers of the study were in a time of great fragility, anguish and fear, the presence of the grandmothers of the babies worked as an important support for the participants to face the situation. In the absence of the mother, the baby's grandmother, one can perceive the lack of her, since there was a need to feel supported and protected by the mother. In the case of Mother 1, her sister covered the absence of the mother:

I think if I had my mother present there, it would have been easier, I could not count on her ever, it always hurt me. Thank God at that moment my sister replaced the mother, my sister replaced her, because the mother is missing a lot (crying).

However, Mother 8, whose mother is already dead, cannot count on her sister's support:

I really wanted a mother, a father, something I never had, I never had them by my side. My mother died, my father I did not know, who raised me was my grandfather. I wish I had my sister around, that she had not abandoned me, because she was the only example of a woman I had.

The visit of grandparents to infants hospitalized at NICUs is already a practice recommended by the Ministry of Health in relation to humanization in NICU, and has shown to be an important instrument for strengthening the support network for the mother and for the inclusion of the baby in the family (Brasil, 2011).

The suffering of mothers is not only due to the hospitalization of the child, but also is due to all the changes in their daily life. According to Costa, Mombelli and Marcon (2009), the reality experienced by mothers is characterized by a constant struggle between health and the illness of the child, conditions in which mothers have other children at home, employment, husband, financial difficulties, and frequently hospitalization occurs in another city. In this study, five of the participating mothers had their baby hospitalized in another city, which made the presence of the husband and other relatives even more difficult, as evidenced by Mothers 5 and 7.

Husband, mother, my brothers, could not be there, because hospital was far away (M5); I had no ground, I do not know what to do. There was a day when I could not talk to my husband, he was out working, my parents were away (M7).

When the mother has other children, and she needs to stay in the hospital taking care of the hospitalized child, there are concerns about the children who are at home, as exemplified in Mother 7 speech: "I worried about him being alone, I was afraid, but, I knew that his grandmother was taking care of him, if he needed something he would call his uncles, but I worried the same way". Mother 5 mentioned that one of the most difficult things was to stay away from the other son: "I missed him so much, when I spoke to him it was

very difficult, I suffered from being far away, he stayed with my employee who is like a grandmother”.

It is noticed the fact that the failure to give assistance to the child at home can trigger guilt, as if exchanging a child for the other.

With the second child, we feel as if we were betraying the first, feeling that you were doing something wrong, when in fact it is not, but it was difficult for him to understand why the little brother did not go home and Mother had to stand there with him (M3).

In a similar way, Santos et al. (2013) emphasized in their study that mothers who had other children triggered the feeling of impotence because they were between the need to accompany their hospitalized child and the fact that they could not care for the children who were at home.

### **What can alleviate the strong emotions of the roller coaster? The importance of support**

It is perceived that this scenario affects and changes the whole family routine, generating in the mother the sense of loss of control in the functioning of the family, of the insecurities regarding the ability to regain balance and the doubts related to the situation experienced. Thus, mothers need permanent support, guidance and care (Hayakawa, Marcon, Higarashi, & Waidman, 2010).

It is possible to observe that in the face of the suffering, the uncertainties and changes in the mother's daily life, besides the support of the companion and the mother, the support of other family members was also of paramount importance. “My father was there in the visiting hours, my sister was there so I could go home, they helped me and supported me a lot” (M6); “My uncle and my sister-in-law were always there to help me” (M7).

In addition to the support of close relatives, some of the participating mothers also received support from not-so-close relatives, who mobilized and approached offering help, which resulted in the creation and strengthening of bonds, as observed in the report of Mother 5: “I had the support of a cousin of mine who until then was distant, but he lives in Porto Alegre with his wife, and we have created a huge bond, so huge that they are his godparents, it was an outstanding support”.

Although face-to-face support is essential, the results of this study revealed that digital social networks also served as a support. As an example, mothers connected via Facebook, managed to express, shared their pain with others, felt support through expressions of affection and messages from relatives, friends and even unknown people. It should be noted that the support received was not only the emotional, but also the material, as shown in the following speeches.

In the Facebook, I shared, I posted many pictures of him, because a lot of people wanted to know about him, and I even had support from people I did not know, they made chains of prayers, they sent me messages of support (M5); We posted in the social network, and a lot of people helped, everyone who helped were humble people, deposited money (M8); Many have heard from the Facebook. I got a lot of help from a lot of people, we got a sheep and an iron from a store, to organize a raffle, because we need money to get people transportation (M9).

Bouso, Ramos, Frizzo, Santos and Bouso (2014), in agreement with this thought, affirmed that social networks provide an important space in the construction of support networks, since they drive the manifestation of feelings and the speed in which the

comments flow, resulting in an almost immediate support, providing a coping context to those who experience a moment of illness or mourning.

Besides the use of social networks as a form of coping, some mothers used the comparison, because when they observed the health status of their babies in relation to the other patients hospitalized in the ICU, they perceived more serious cases, and they felt strengthened.

Comparisons gave me strength, I saw that my problem was so small, some had already had surgery in the heart, and my daughter just had to suck, in a few days she was leaving (M2); There, I saw horrible cases, which made me think that the problem of my son was nothing, it seems selfish, but I listened and thought that the case of my baby was nothing, I felt stronger (M8).

According to the findings of Hayakawa et al. (2009), in the hospitalization of the child, the mother seeks answers to her insecurities and the mechanism of this search is usually the comparison with the state of the other hospitalized children, through which she elucidates her doubts and renews her strength to continue.

The presence of the mother in the ICU for the baby is fundamental, not only the physical presence, but also the emotional involvement, because there is a unique style of interaction in the mother-baby relationship. However, hospitalization of the infant in the ICU may introduce cuts in this relationship and the mother may be prevented from providing and living the sensations for which she has been prepared. Some mothers reported that they had not received encouragement from the team regarding the bonding and care of their baby, as exemplified in the Mother 3 report:

When I arrived, they had already changed the diaper, they did everything, the team never stimulated the care, I wish they had let me have him on my lap more time, to have had more physical contact with him. There, nothing happens, I wanted to have been more mother and less spectator, I was there just to look.

However, mothers 5 and 7 reported that the team stimulated their contact with the baby, it should be noted that their babies were admitted to the same ICU: "I asked them to take the baby on my lap and they permitted me, they were always telling me to take and touch it". "They always said I could pick her up when I wanted to". According to Scochi, Gavia, Melo and Mello (2000), the mother's lack of opportunity to interact with her hospitalized child can lead to impairment in the formation and development of attachment. This impairment may influence the prognosis of the hospitalized baby and the mother's attitude toward hospitalization.

The mother must be perceived by the team in its particular characteristics and needs. This favors the adaptation of the mothers, since at that moment they are anxious, fragile, with feelings of loss and without control of the situation. Nevertheless, in the present study, some participants pointed out that they did not feel cared for and that their needs, most of the time, were not met by the team, as can be seen in the following statements.

It seems that no one on the team cared what I felt (M2); No one on the team ever asked how I was, whether bad or not, it made no difference to them (M3); But no one on the team cared much for me there (M6).

In this perspective, it is important that the team establish with the mothers of the infants an empathic and intersubjective relationship, facilitating their participation in the care of the child. Thus, health professionals can contribute to the mother's search for coping strategies to alleviate her suffering and emotional stress from a perspective of caring for the family as a means of caring for the baby (Freitas, Menezes, & Mussi, 2012).

## Final considerations

Knowing the experience of mothers who had their babies admitted to a Neonatal or Pediatric Intensive Care Unit allows to reflect on the changes and difficulties they face. This theme has to be addressed by health professionals during prenatal care, so that the ICU-death relationship is demystified. In addition, it would be interesting if the professional who receives the baby has the possibility to explain to the mother about the operation of the ICU and to ask questions about the environment.

Regarding father participation, it is important to note that the presence of the partner generates safety and comfort for the mothers. However, in some situations, father involvement is limited due to the need to return to work. Among the results, it is emphasized that the father has few days of paternity leave, which physically and emotionally burden the mother.

When mothers receive the support and care from the family, especially through the presence of her mother and the baby's father, they can face the situation with more security, confidence and tranquility. Thus, there is a need for greater acceptance and affectionate treatment to families within ICUs, not as a result of the imposition of laws, but rather as a need felt and interpreted by the health team.

It is necessary to improve the physical environment, offering more comfort for mothers, so that they can sleep and eat better, perform personal hygiene, as well as moments of relaxation, which could be offered through spaces such as living room, availability of materials for reading, drawing, handiwork, films. In addition, it is imperative that all hospitals, whether public or private, make available to mothers and their families the hospital psychology service. Among the participants of this study, only three mothers could count on this specialized care.

Support for mothers also happens at a distance, through social networks, so it is suggested that Intensive Care Units can provide free Wi-Fi to the accompanying mothers and relatives, collaborating to bring them closer to people who are not allowed to enter the ICU, such as friends and relatives. The social network may allow them to communicate more with people who work as affective references and who do not live in the same city, providing the possibility to follow the state of health of the baby and comfort the mother during the period of hospitalization of the baby.

In this way, it is essential to have a committed, sensitive and well-prepared health team, always ready to reflect on their practice and manage not only to direct their care to the baby but also to mothers and their families.

In view of the above, it is possible to verify that the hospital itself as a health institution and the team can make use of tools and devices with a view to alleviating the suffering of the maternal experience during the ICU hospitalization. Therefore, within this theme, new studies involving the participation of hospital management, health staff and family members, especially those that promote listening to the father and the grandmother, were suggested, as they were characters that appeared prominently in this study.

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