

## EXPERIENCES OF FAMILIES OF PREMATURE CHILDREN IN A NEONATAL INTENSIVE THERAPY UNIT

### VIVÊNCIA DOS FAMILIARES DE PREMATUROS INTERNADOS EM UNIDADE DE TERAPIA INTENSIVA NEONATAL

### EXPERIENCIA DE LOS FAMILIARES DE BEBÉS PREMATUROS HOSPITALIZADOS EN LA UNIDAD DE CUIDADOS INTENSIVOS NEONATALES

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## ABSTRACT

The objective of this study was to describe the experience of families of preterm neonates hospitalized in the Neonatal Intensive Care Unit. Exploratory research with qualitative approach performed at the Neonatal Intensive Care Unit of a teaching hospital in the state of Paraná, from April to June 2016, with 16 relatives of hospitalized premature infants. Among participants, 14 were mothers and two were fathers. A thematic analysis was carried out and the Interface Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires<sup>®</sup> was used to help organize the data. The study was approved by the Research Ethics Committee of the Health Sciences Sector of the Federal University of Paraná under the Opinion 1,170,956, CAEE 47561215.8.0000.0102, and by the Research Ethics Committee of the partner institution under Opinion 1,359.92 and CAEE 47561215.8.3001.0096. The study sought to follow the steps recommended by the Consolidated Criteria for Reporting Qualitative Research. The data showed that families live with the imminent risk of death without necessarily expressing this fear. They seek strength in situations worse than their children, in the spiritual dimension or even in resources whose origin they do not know how to explain, and this experience goes beyond the daily life and the biological dimension of care. We concluded that it is necessary to change the philosophy of professionals and institutions, from the point of view of caring for the family, so that this care may overcome the biological dimension, and open spaces for dialogue, so that the families may no longer mere spectators but become part of the care.

**Keywords:** Family; Premature; Neonatal Intensive Care Units; Neonatal Nursing; Child Care.

## RESUMO

O estudo teve como objetivo descrever a vivência dos familiares em relação ao internamento do prematuro em Unidade de Terapia Intensiva Neonatal. Pesquisa exploratória, com abordagem qualitativa, realizada na Unidade de Terapia Intensiva Neonatal de um hospital de ensino do estado do Paraná, de abril a junho de 2016, com 16 familiares de prematuros internados. Destes, 14 eram mães e dois eram pais. Foi realizada análise temática e utilizou-se o software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires<sup>®</sup> para auxiliar na organização dos dados. O estudo foi aprovado pelo Comitê de Ética em Pesquisa do Setor de Ciências da Saúde da Universidade Federal do Paraná sob o Parecer Consubstanciado 1.170.956, CAEE 47561215.8.0000.0102, e pelo Comitê de Ética em Pesquisa da instituição coparticipante, Parecer 1.359.92 e CAEE 47561215.8.3001.0096. O estudo procurou atender aos passos recomendados pelos Critérios Consolidados para Relatar uma Pesquisa Qualitativa. Os dados expressaram que a família vivencia de forma velada o risco iminente da morte sem necessariamente poder expressar esse medo. Buscam forças em situações piores que a de seu filho, na dimensão espiritual ou mesmo em recursos que não sabem explicar a origem, sendo que essa vivência extrapola o cotidiano e a dimensão biológica do cuidado. Concluiu-se que é necessário mudar a filosofia dos profissionais e das instituições, na perspectiva do cuidado à família, para que este possa ultrapassar a dimensão biológica, com espaços de diálogo, e para que essa família deixe de ser apenas expectadora e faça parte do cuidado.

**Palavras-chave:** Família; Prematuro; Unidades de Terapia Intensiva Neonatal; Enfermagem Neonatal; Cuidado da Criança.

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## RESUMEN

*El presente estudio tuvo como objetivo describir la experiencia de familiares de bebés prematuros internados en la unidad de cuidados intensivos neonatales. Investigación exploratoria cualitativa realizada en la unidad de cuidados intensivos neonatales de un hospital escuela del estado de Paraná, de abril a junio de 2016, con 16 familiares – 14 madres y dos padres – de bebés prematuros internados. Se realizó el análisis temático y se utilizó el software Interface de R pour les Analyses Multidimensionnelles de Textes et Questionnaires® para la organización de datos. El estudio fue aprobado por el Comité de Ética en Investigación del Sector de Ciencias de la Salud de la Universidad Federal de Paraná bajo el dictamen fundamentado 1.170.956, CAEE 47561215.8.00.00.0102 y por el Comité de Ética en Investigación de la institución coparticipante, dictamen 1.359.92, CAEE 47561215.8.3001.0096. El estudio siguió las etapas recomendadas por los criterios consolidados para la investigación cualitativa. Los datos expresaron que las familias viven de forma velada el riesgo inminente de muerte sin necesariamente poder expresar ese miedo. Buscan fuerzas en situaciones peores que la de su hijo, en la dimensión espiritual o incluso en algo que desconocen y no saben explicar su origen; esta vivencia va más allá de lo cotidiano y de la dimensión biológica del cuidado. Se llegó a la conclusión que la filosofía de las instituciones y de los profesionales debe cambiar, dentro de la perspectiva de cuidar a las familias, para que el cuidado supere la dimensión biológica, con espacios de diálogo, con miras a que estas familias dejen de ser apenas espectadoras y formen parte del propio cuidado.*

**Palabras clave:** Familia; Prematuro; Unidades de Cuidado Intensivo Neonatal; Enfermería Neonatal; Cuidado del Niño.

## INTRODUCTION

Prematurity is defined as any birth occurring before 37 weeks or 259 full days of gestational age.<sup>1</sup> Premature infants need adaptation to the extrauterine environment, which is related to their particular characteristics. These infants require specialized care, usually in Neonatal Intensive Care Units (NICU).<sup>2</sup>

The NICU is a sector that provides a differentiated care to newborns (NB) hospitalized with specific and appropriate physical, material and personal resources for this patients, thus contributing to the treatment of neonatal diseases and helping to reduce neonatal mortality.<sup>2</sup>

With the need for intensive treatment brought about by premature birth, preterm children and their families have to face an early and prolonged separation. The difficulties caused by this process of separation may influence the development of affective bond between the newborn and the family, especially in long hospitalization periods in the NICU.<sup>3</sup>

In these cases, families live an experience permeated by suffering, insecurity, frustration, disappointment, fear, sadness, anxiety, preoccupation and lack of confidence in the ability to care for their children<sup>4</sup>. Therefore, it is essential to provide care to all family members and not only to the hospitalized premature infants.<sup>2</sup>

The establishment of bond between parents and premature children is essential in the intensive unit, because the physical contact and interaction, through the listening of the parents' voice, by the NB, even in short moments, is beneficial for the child's growth and development.<sup>5</sup>

In order to provide care for the families of premature children, health professionals need to understand their needs so as to plan and promote effective assistance in the process of bonding between them. They should observe the singularity of each case, involving biopsychosocial and cultural aspects, since the reaction of each family member tends to be influenced by their culture and experiences.<sup>6</sup>

From the above, the following guiding question was set: what is the experience of families in relation to the hospitalization of

premature newborns in the NICU? In order to answer this question, the study had the objective to describe the families' experience regarding the hospitalization of premature infants in NICUs.

## METHODS

This is a descriptive study with qualitative approach taken from the monograph entitled "The experience of families of premature newborns admitted to Neonatal Intensive Care Units".<sup>7</sup> Qualitative research allows investigating a reality through several strategies,<sup>8</sup> while a descriptive study seeks to describe, as accurately as possible, the occurrence of a fact, its relation to other facts, its characteristics and its nature.<sup>9</sup> The research followed the steps recommended by the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>10</sup>

The study was carried out in the NICU of a teaching hospital in the state of Paraná, from April to June 2016, with 16 relatives of premature infants admitted to this sector, 14 of whom were mothers and two fathers (one interview was carried out mutually with the mother and the father), totaling 15 interviews. The inclusion criteria to participate in the study were: to be a relative of a premature neonate hospitalized for 10 days or more in the NICU and to be over 18 years old. The exclusion criterion was: to have communication difficulties that made it impossible to answer the questions.

Participants were invited through a personal approach and a pamphlet made available in the intensive care unit. Data were collected through interviews based on the guiding question: How do you feel about having your child in the NICU?

The data were submitted to the thematic analysis according to the steps proposed by Creswell,<sup>7</sup> which defines the analysis process as focused in the extraction of meaning from the text obtained in the interviews, and the researcher should reflect on these data and deepen the search of its significance. The steps of the analysis were: organization and

preparation of a verbatim transcription of the interviews, codification and arrangement of data in a textual *corpus* (cluster of texts that express a certain theme); reading of the data seeking a general perception of the ideas expressed by the interviewees; coding of data with organization of information in text segments (TS) (text division into the average size of three lines) with groupings into categories based on the similarity between the sentences (in this stage the *software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* – IRAMUTEQ® was used to help codifying, organizing and separating the information found); detailed description of the data using the codification previously assigned and, from this, creation of categories to reflect the main results of the study; representation of the analysis by means of categories, according to the statements of the interviewees, which emerged based on the classes coming from IRAMUTEQ®; and data interpretation, with details of the interviews and comparison with the literature.

Ethical recommendations were followed, and the approval of the Research Ethics Committee (REC) of the Health Sciences Sector of the Federal University of Paraná was obtained under the Opinion nº 1.170.956 and CAEE 47561215.8.0000.0102, as well as of the REC of the cooperating institution under Opinion 1,359.92 and CAEE 47561215.8.3001.0096. All participants signed the Informed Consent Form (ICF) after being clarified about the objectives of the study, the means of dissemination of the results and the rights of confidentiality of the obtained data, anonymity of participants and the voluntary nature of the participation in the study. In order to ensure the anonymity of the interviewees, the clippings of their speeches were identified by the “Int” coding followed by the interview numbering.

## RESULTS

The age of the participants varied between 18 and 47 years and the hospitalization time of the premature infants was between 10 and 86 days.

From the grouping of the data offered by the IRAMUTEQ® *software*, six classes were obtained. In these, the TS were interpreted and classes were then grouped into three categories: “feelings about the hospitalization”, “From the risk of loss to the expectation of life”, and “from the need for hospitalization to the desire to take the child home”. For the composition of these categories, the following order was followed: the first category emerged from class 6, the second from classes 1 and 3 and the third from the union of classes 2, 4 and 5, which are presented in the dendrogram, which is the graphic representation from the analysis made by the *software* (Figure 1), showing the percentage of TS per class.

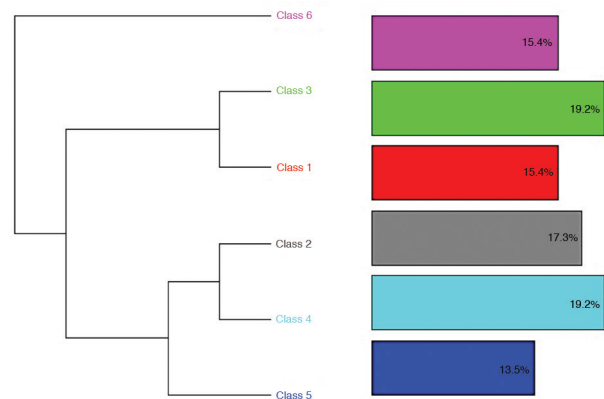


Figure 1 - CHD Dendrogram.

Source: Data processing in the IRAMUTEQ® *software*, 2016.

The thematic categories resulting from the analysis of the classes, as well as the speeches obtained in the interviewees, are presented below.

## FEELINGS ABOUT THE HOSPITALIZATION

In this category, we highlight the feelings experienced as a result of the hospitalization of the premature child in the NICU, which are portrayed only by the mothers participating in the study, since the discourses of the fathers were not used by the *software* in the class that gave rise to this category. These findings can be seen in the following statements:

*Hospitalization is a bit complicated, it causes me a lot of insecurity, when I see the other mothers with their babies hospitalized too [...] it's insecurity, you do not feel sure about anything, I have to wait and see what's going to happen. (Int03)*

*It's a feeling, we all feel it, really. It is anguish to have to leave my baby, but at the same time it is a security that I have. (Int11)*

*I imagined something totally different, now I feel anguish, because we get anxious. I want to leave soon, but I can't, I have no choice but wait. I have to be patient. (Int14)*

*It's deseperating, we can't do anything, just stare. I feel useless. (Int08).*

After the birth of the child, mothers experience a mixture of feelings, they are affected by insecurity, distress, anguish, impotence and uselessness. They expected full term births, staying next to the newborns in the rooming-in and hospital discharge in synchronous way. Instead of this, the child has to be in the NICU while they return home and, due to the condition

of the premature, they are prevented from performing the care in the way they intended, reinforcing the dependency on professionals for assistance and for reassurance.

### FROM THE RISK OF LOSING TO THE EXPECTATION OF LIFE

In this category, the relatives emphasized the instability of the condition of the newborn, which presents extreme situations ranging from the imminent risk of death to the hope of improvement and survival. Strength is necessary to face this moment.

The emotional instability of families allows us to see that coping is made difficult by the news of worsening of the clinical picture of the newborn, and enhanced by its improvement. Moreover, faith is expressed and hope is strengthened over time. This ambivalence of emotions can be observed in the following reports:

*I believe that mothers of premature babies lose heart, because every time we come here, we leave a piece of heart. And every day, a new hope arises. The baby losses a bit weight, about five grams, we promptly get afflicted. When all this began, my God, I would cry so much. (Int02).*

*We try to find strength but there is nowhere else to draw strength. I can only count on my strength! There's no other way, I have to live. (Int01).*

*It's not easy, I'm afraid, especially because I've lost another child. I am rather afraid that something will go wrong, but I need to have faith in God. (Int05).*

*Then he, [the great-grandfather of the NB] told me to be calm, that she was well, that nothing was going to happen. But it's different; I wanted to see her, to have her with me. I felt bad. Everyone was very tense, very apprehensive, very desperate. (Int13)*

Another relevant aspect is the comparison made by the relatives between the newborn and the other babies in the NICU, which they find somehow helpful, conferring a better acceptance of the condition experienced by the premature infant, and softening the negative feelings, as can be observed in the following reports:

*At first I was desperate. But then I knew my little girl had nothing serious. Later I learned that there were more serious babies, so I saw that my child was not so serious. We end up accepting it. (Int08).*

*It's very difficult, but on the one hand it's good. I mean, it's not good, it's never good, but what I want to say*

*is that of all the things the girl could have, she just needs to gain weight. Because we get very sad but we see worse cases here, we say thank God my daughter doesn't have any problem. You want to carry her, but you cannot get close to her in the first few days and I can only see her through that little door; oh, we suffer! (Int13).*

The attitude of family members to anchoring themselves in the more serious clinical conditions of other NBs helps them to face the present moment, since the ups and downs that the premature child experiences affects the family as a whole and reinforce the emotional instability and the difficulty to keep calm.

### FROM THE NEED FOR HOSPITALIZATION TO THE DESIRE TO TAKE THE CHILD HOME

In this category, the consequences of hospitalization were mentioned, including the abrupt separation suffered and the change in the family routine, and in order to support the situation in a less distressing way, the relatives rely on the care that the premature receives in the NICU.

The separation between the family and the premature child was emphasized, especially the one occurring shortly after delivery with the hospitalization of the neonate in the intensive care unit. This separation is intensified when the family returns home without the child, deconstructing the imagined picture during the gestational period in which the family would return home together. In these cases, the parents are taken over by contradictory feelings such as love and excitement arising from the birth of the child and pain and sadness caused by the necessary distance to assure the survival of the newborn. The difficulty that the family faces in coping with this situation can be observed in the following reports:

*I felt a very great pain, very deep, by the time I knew that my girl was going to the ICU, I was wasn't well because of my blood pressure, I was feeling a very great pain. (Int10).*

*It's horrible when you get home and everything is there, pretty, but without the child. When my baby was born the doctor put she on me, I felt so much love that one does not know where all that love came from, a great happiness, but then she is soon taken away to come to this place [...]. (Int13).*

*Having my son for some hours at my side and then seeing how they took him from me, to the NICU [...] it is very difficult. I feel sad because he is here. No mother wants that for her child, to stay in the hospital. Having my little boy and having to leave him here. (Int12).*

*You know how a mother is, the mother wants to take the child home, but it is difficult. It's very difficult to go home without the child. Very difficult! (Int02).*

Another particularity observed in this category was the influence caused by the hospitalization of the premature infant in the family routine. The patterns of feeding, sleep and rest are modified and the family tries to make adaptations to reconcile the daily life activities with the staying next to the premature child, according to the following reports:

*[...] He [father of the newborn] comes at night, then we take turns, sometimes when I am very tired, we make the change. Sometimes he comes by day and I come at night, but it has been complicated for us. (Int01).*

*[...] It is tiring, my God, it is stressful, distressing, everything you can imagine. Very difficult, three months ago, you get in the expectation, one day after other. (Int04).*

*[...] My mother was already tired, desperate, fighting with the waitress down there, she had already gone there three times to bring my food, and I told my mother, I eat anything to stay here, to enjoy being with my little girl. (Int13).*

*[...] I already have enough, my mother says it is a relapse, headache, I do not sleep well. It's too much concern. (Int15).*

In addition, in order to face and support in a less traumatic way the hospitalization of the premature infant in the NICU, the relatives seek comfort in the care given to him. They emphasize the well-being of the child and the care as a factor that stands out amid the difficulties faced at the moment. The following statements demonstrate these aspects:

*[...] Then I calmed down, knowing that here he was well taken care. (Int09).*

*[...] It is not easy for a mother, it is not easy. The important thing is that she is well cared for [...]. (Int10).*

*[...] Me, as a mother, I want to take her home soon, but I know she has to stay. So for me it's okay because I know she's okay, being taken care of, so I think it's okay. (Int11).*

*I know he's being taken care of here, but I wanted to be close to him. Then, it is very bad. (Int15).*

We observed that the family members cling to positive aspects to facilitate the experience of the hospitalization of the chil-

dren; in this case, the care is used for this purpose, as the unexpected separation and changed routine influence their emotional state.

## DISCUSSION

### FEELINGS ABOUT THE HOSPITALIZATION

The birth of a premature infant brings to the family an intense confrontation between the imaginary NB and the real NB.<sup>11</sup> The representations about the NB constructed in the gestation are gradually deconstructed and its image of newcomer is slowly assimilated.<sup>12</sup>

Premature birth ends up becoming complex for the family, especially for the mothers, who have to deal with a small, weak, fragile, and immature newborn, what is generally quite different from that imagined during pregnancy. Furthermore, when the last semester of pregnancy is interrupted, a moment when women could have been experiencing the greater growth of the belly, preparing commemorative events like the baby shower, finishing the organization of the room and the preparations for the arrival of the child, they feel frustrated and confused, making their interaction with the NB<sup>11</sup> even more difficult.

In many of these births, women are afflicted with feelings of sadness, suffering and fear, in the face of their inexperience and inability to provide maternal care for the fragile premature infant.<sup>13</sup> During the first weeks of admission of the premature infant, the mother also experiences the shock of the child's illness, their separation, and she still needs to take care of her own health, needing more support during this period.<sup>14</sup>

For women, being in the NICU with their child causes them to feel loss of their maternal function, thus having difficulty recognizing themselves as mothers. Instead, a team assumes the care that should be performed by them. The fact that the newborn is in an environment full of innumerable technological devices can reinforce the fear and insecurity they feel.<sup>15</sup>

This study showed that the insecurity and impotence in the face of the unchangeable situation can be aggravated by the position of observers of the care assumed by the mothers. In their point of view, they can do nothing to help the child, and should only accept reality, confirming the data found in the literature.

Families of premature infants face difficulties due to the frustration of their dream of having a healthy, full-term child that remains with the mother soon after birth.<sup>16</sup> At the beginning, the experience of having a child in the NICU generates a very difficult situation, prompting suffering, despair and insecurity in this new environment,<sup>17</sup> data that corroborate the findings found in this research.

Men and women may manifest a distinct confrontation with prematurity. For mothers, this period is marked by intense



emotional distress, fear of the loss of the child, and frustration before the difficulty of assuming the mother's role.<sup>11</sup> In the paternal perspective, the premature child is perceived as fragile, small and immature. In addition, the hospitalization in the NICU is a sad, complicated, difficult and painful experience, and parents are afraid to touch the premature infant and lose it.<sup>18</sup> The feelings portrayed by the parents participating in the study by Soares *et al.*<sup>18</sup> are similar to those experienced by mothers who represent this category in the present study.

Premature hospitalization affects the family as a whole.<sup>19</sup> In these statements feelings of sadness, fear, impotence, anguish and anxiety emerge, triggered by the impossibility of interacting with the child in the desired way.<sup>20</sup> Faced with this situation, characterized as difficult, the parents are hopeful of being discharged from hospital and of being able to have their child taken home.<sup>19</sup>

### FROM THE RISK OF LOSS TO THE EXPECTATION OF LIFE

The NICU represents an imminent threat of death for families of premature infants. When these families have their children hospitalized and requiring specialized care, they experience different feelings in the face of the uncertainty of life of the NB.<sup>21</sup> Even among relatives who report more tranquility with the recovery of the newborn, this statement is accompanied by the recognition that the initial moments were very difficult and painful.<sup>22</sup>

Initially, the family members live with anguish due to the instability of the clinical picture of prematurity and the unknown experience. Over time, the distancing of other relatives, the improvement and maintenance of the health status of the newborn for hospital discharge are reasons for parents' apprehension and stress.<sup>23</sup> In this study, some relatives reported that the initial situation of hospitalization was more difficult, corroborating the data obtained by the aforementioned authors. This is possibly due to the fact that at that moment, the fear of loss overrules hope, leading to the intense experience of negative feelings.

The impact of early birth causes a sense of incompleteness, especially on the part of the mother. The uncertainty regarding the risk of death and the severe condition of the child gradually causes her to bond to the NB. This initial bond takes time to be built and little by little the feeling of emptiness is filled by the feeling of belonging. This occurs mainly when the mother begins to interact with the neonate and perceives his responses.<sup>12</sup>

The relationship of parents of premature infants to other parents who have been in this condition for longer periods can be beneficial, since they can reassure them in this moment of apprehension and fear. For relatives whose prematurity is unknown, receiving information regarding the improvement of the NB brings with it a sense of comfort and strength in relation to the evolution of their children.<sup>19</sup>

However, in a study carried out with mothers of hospitalized premature infants, this comparison was experienced with sadness and concern, mainly due to the interurrences experienced by other neonates and witnessed by the new mothers, causing concern about what could happen to their child.<sup>22</sup>

On the other hand, the family members who participated in the present study described that seeing situations of other premature infants, in more complex clinical conditions, resulted in a positive feeling. The comparison with more difficult situations of other families, from the point of view of the interviewees, serves as a comfort in the process of accepting the condition of the child, characterizing this fact as a new finding in relation to the cited literature.

The family feels the imminent risk of death without necessarily expressing this fear. Therefore, they seek strength in situations worse than their own, in the spiritual dimension or even in resources whose origin cannot be explained. But they know that it is necessary to live in the fine line between life and death, between caring for the child and giving up that care, so that this experience goes beyond the daily life and the biological dimension of care. Thus, it is necessary to propose a family care that fits the instability that permeates this moment.

Another factor that assists in the transition of feelings is the provision of information by health professionals.<sup>19</sup> In such cases, it is fundamental to establish an effective communication channel between professionals and parents, so that this experience may bring less suffering and enhances the trust of the family in the individuals who provide assistance to the premature child.<sup>13</sup>

Research has found that parents are hopeful and less anxious when they receive the information that the child is in the NICU just to gain weight, having overcome the different complications associated with hospitalization. This means that the expectation is that the child will be discharged and go home soon.<sup>19</sup> These findings are confirmed by the data described in the present study in which family members demonstrated contentment after knowing that the premature child does not have serious diseases and that the cause of hospitalization comes only from low weight, anxiously awaiting the moment when the child reaches the weight determined to be discharged.

### FROM THE NEED FOR HOSPITALIZATION TO THE DESIRE TO TAKE THE CHILD HOME

The premature birth frustrates the expectation of being with the child after delivery, since the separation is imposed by the need of the neonate to stay hospitalized.<sup>13</sup> In these cases, the family shows anxiety to fulfill the desire to remain with their children, caring and protecting them.<sup>16</sup> These ideas are in line with what was seen in the present research, in which the interviewees emphasized the separation, characterizing this

moment as painful, sad and difficult, at the same time as the birth of the child brought the expression of love and emotion.

Because of the separation experienced and the short time that family and newborns have to get to know each other after childbirth, the visits and stay in the NICU become extremely relevant for family members who want to stay as long as possible beside the newborn.<sup>5</sup>

Besides the suffering from separation, the fragility of the premature baby and the family, the condition also imposes the need for availability to be next to the newborn. In order to be with them during hospitalization, relatives must give up part of their routine time in order to reconcile hospitalization with the family context<sup>21</sup> and be in good financial condition to pay for transportation, food and, in some cases, to pay a caregiver to stay with other children at home.<sup>24</sup>

This research indicated that changes in the sleep, rest and feeding patterns of the relatives of premature infants are constant. They take turns to be with the NB and also rest. This is because the routine and the long-term stay in the NICU is tiring, and also because the meals do not follow the usual times and are predetermined by the hospital institution. These data demonstrate that the families place their routine in the background, adapting to the purpose of being as close as possible to the newborn, as the findings in the cited literature.

Over time and with the reorganization of the routine, family members improve their perception and begin to notice the contradictory aspects that involve the intensive unit, namely: separation, negative feelings, risk of premature death, but also the possibility of that place provide care and saves lives.<sup>13</sup>

The family's understanding that the NICU is the appropriate environment for the care of the premature child is followed by the revelation of feelings of security and tranquility that overcome the episodes of fear and nervousness. The prevalence of positive feelings is attributed by the families to the attention provided by professionals to the child.<sup>13</sup> They feel content by seeing the dedication of the team, hosting the baby and giving them information about their child, clarifying doubts and minimizing their cravings and fears.<sup>25</sup>

The family then starts trusting in the team and this makes them believe that even in their absence the newborn will be promptly assisted with quality care. Although hospitalization is an experience of suffering, when it is perceived as part of the care by the team, the family has the opportunity to recover strength, feeling uplifted to fight for the expectation of being able to take the recovered premature child back home. These are in line with the present study, of the families who find in the care a source of support for NICU hospitalization; when they learned that the child was receiving quality care, the frustration resulting from the situation was minimized.

Therefore, encouraging family members to perform care, stimulating their independence and providing assistance to mothers during breastfeeding attenuates the temporarily lost

maternal and paternal role as a result of the fragile condition of premature infants and their hospitalization in the NICU.<sup>23</sup>

## CONCLUSION

The study revealed that the family experiences a turmoil of feelings and reactions when having a premature child hospitalized in the NICU, as well as difficulties in coping with such a situation. Although they report several negative feelings, characterizing themselves as impotent and frightened, the relatives demonstrate positive expectations, since they believe in the treatment and recovery of the health of the NB. Still, they appropriate means such as the comparison between the clinical condition of other hospitalized premature children, seeking to accept and face the current situation in a less traumatic way.

This ambiguity is due to the fact that the family suffers from the situation experienced, which does not correspond to the desired for that moment, at the same time that it looks for the strength to face it and to maintain the hope on the idea of taking the child home.

Thus, understanding the experience of family members in the intensive care environment can help health professionals reorient their practice and seek a care model that may stimulate the bond between family and premature baby, since in many NICUs parents stay with their children, although as participants and not as subjects of care.

Based on these findings, it is necessary to have a direct look at neonatal care, not only considering the psychobiological needs of the premature infant, but specifically, the emotional dimensions of the families weakened by the context of prematurity of their children. In order to do so, it is necessary to change the philosophy of the professionals and institutions that serve this public, so that a care that extrapolates the biological dimension be provided, including the instability of being or not being, having or losing, with spaces for dialogue to express anxieties and expectations, so that these families be, more than spectators, part of the care.

The limitations of the study were to interview only fathers and mothers of premature infants; it was not possible to describe the experience of other family members. Therefore, we suggest studies to verify the experience related to the hospitalization of prematurity in the perspective of all those involved in the family.

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