SUBJETIVIDADES

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Relatos de Pesquisa

The experiences of mothers of extremely premature babies with the “glass womb”

As experiências de mães de bebês prematuros extremos junto ao “ventre de vidro”

Las experiencias de madres de bebés prematuros extremos junto al “vientre de vidrio”

Les expériences des mères de bébés extrêmement prématurés chez “l’utérus de verre”

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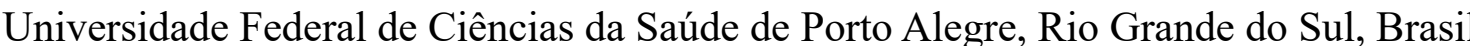

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Abstract

The mother and baby relationship, their bonds and emotional aspects, have been fertile ground for studies in the field of psychology. Motherhood usually brings to women both physical and emotional changes, awakened during pregnancy. However, the interruption of pregnancy due to a premature birth can be accompanied by adverse feelings, when faced with the fragility of the baby, since prematurity can endanger the life of the preterm. The present study aimed to understand the maternal experience of having an extremely premature baby hospitalized in a Neonatal Intensive Care Unit (NICU). A qualitative, exploratory and transversal design was chosen. The research participants were four mothers of extremely premature babies admitted to a NICU of a hospital in the city of Porto Alegre, in the state of Rio Grande do Sul. The instrument used in this research was a semi-structured interview, guided by a pre-established script containing sociodemographic questions and questions about maternal experiences that aimed to respond to the objectives of this study. For the data analysis, the interviews were transcribed and the data collected were worked from the content analysis, in the thematic modality. This study confirmed that, in the face of extreme prematurity, mothers experience a mix of emotions, such as anguish, guilt, despair, the main one being the fear of losing their babies. It was found that the incubator is considered by the mothers of this study as a great ally for the survival and development of their children.

Keywords: *mother-infant relationship, prematurity, premature birth, Neonatal ICU*

Resumo

A relação mãe e bebê, seus vínculos e aspectos emocionais têm sido terreno fértil para estudos no campo da psicologia. A maternidade, geralmente, traz à mulher mudanças tanto físicas como emocionais, despertadas ainda na gestação. Entretanto, a interrupção da gestação em virtude de um parto prematuro, pode vir acompanhada por sentimentos adversos, ao se deparar com a fragilidade do bebê, visto que a prematuridade pode colocar em risco a vida do pré-termo. O presente estudo teve por objetivo compreender as experiências maternas de ter um bebê prematuro extremo internado em uma Unidade de Tratamento Intensivo Neonatal (UTIN). Optou-se por um delineamento qualitativo, exploratório e de caráter transversal. As participantes da pesquisa foram quatro mães de bebês prematuros extremos internados em uma UTIN de um hospital da cidade de Porto Alegre, no estado do Rio Grande do Sul. O instrumento utilizado nessa pesquisa foi uma entrevista semiestruturada, guiada por um roteiro preestabelecido, contendo perguntas sociodemográficas e perguntas sobre as vivências maternas que visaram responder aos objetivos desse estudo. Para a análise de dados foi realizada a transcrição das entrevistas e os dados coletados foram trabalhados a partir da análise de conteúdo, na modalidade temática. Este estudo confirmou que, diante da prematuridade extrema, as mães experimentam um misto de emoções, como angústia, culpa, desespero, sendo a principal delas o

medo da perda de seus bebês. Constatou-se que a incubadora foi considerada pelas mães deste estudo como uma grande aliada para a sobrevivência e o desenvolvimento dos seus filhos.

Palavras-chave: relação mãe-bebê, prematuridade, nascimento prematuro, UTI Neonatal

Resumen

La relación madre-bebé, sus vínculos y aspectos afectivos, han sido terreno fértil para los estudios en el campo de la Psicología. La maternidad suele traer a la mujer cambios tanto físicos como emocionales, despertados durante el embarazo. Sin embargo, la interrupción del embarazo por parto prematuro puede estar acompañada de sentimientos adversos, ante la fragilidad del bebé, ya que la prematuridad puede poner en riesgo la vida del prematuro. El presente estudio tuvo como objetivo comprender la experiencia materna de tener un bebé extremadamente prematuro internado en una Unidad de Cuidados Intensivos Neonatales (UCIN). Se optó por un diseño cualitativo, exploratorio y transversal. Los participantes de la investigación fueron cuatro madres de prematuros extremos hospitalizados en una UCIN de un hospital de la ciudad de Porto Alegre, en el estado de Rio Grande do Sul. El instrumento utilizado en esta investigación fue una entrevista semiestructurada, guiada por un guión preestablecido que contenía preguntas sociodemográficas y sobre experiencias maternas que pretendían responder a los objetivos de este estudio. Para el análisis de los datos, se transcribieron las entrevistas y los datos recolectados se procesaron a partir del análisis de contenido, en la modalidad temática. Este estudio confirmó que, ante la prematuridad extrema, las madres experimentan una mezcla de emociones, como angustia, culpa, desesperación, siendo la principal el miedo a perder a sus bebés. Se constató que la incubadora fue considerada por las madres de este estudio como un gran aliado para la supervivencia y desarrollo de sus hijos.

Palabras clave: *relación madre-hijo, precocidade, nacimiento prematuro, UCI neonatal*

Résumé

La relation mère-enfant, leurs liens et leurs aspects émotionnels, ont été un terrain fertile pour les études dans le domaine de la psychologie. La maternité apporte généralement aux femmes des changements physiques et émotionnels, réveillés pendant la grossesse. Cependant, l'interruption de grossesse due à un accouchement prématuré peut s'accompagner de sentiments négatifs, face à la fragilité du bébé, car la prématurité peut mettre en danger la vie du prématuré. La présente étude visait à comprendre l'expérience maternelle d'avoir un bébé extrêmement prématuré hospitalisé dans une unité de soins intensifs néonatals (USIN). Une conception qualitative, exploratoire et transversale a été choisie. Les participants à la recherche étaient quatre mères de bébés extrêmement prématurés hospitalisés dans une USIN d'un hôpital de la ville de Porto Alegre, dans l'État de Rio Grande do Sul. L'instrument utilisé dans cette recherche était un entretien semi-structuré, guidé par un scénario préétabli contenant des questions sociodémographiques et des questions sur les expériences maternelles visant à répondre aux objectifs de cette étude. Pour l'analyse des données, les entretiens ont été transcrits et les données recueillies ont été traitées à partir des analyse de contenu, dans la modalité thématique. Cette étude a confirmé que, face à l'extrême prématurité, les mères éprouvent un mélange d'émotions, telles que l'angoisse, la culpabilité, le désespoir, la principale étant la peur de perdre leur bébé. Il a été constaté que la couveuse était considérée par les mères de cette étude comme un grand allié pour la survie et le développement de leurs enfants.

Mots clés : *relation mère-enfant, prématurité, naissance prématuré, USI néonatale*

The maternal experience and the mother-baby relationship have aroused interest in studies in the field of psychology. The subjective experience of motherhood brings both physical and emotional changes to women, starting from pregnancy. When carrying her baby, the mother creates an imaginary baby, in which she deposits her dreams and fantasies of a perfect child (Lebovici, 1987). However, the interruption of pregnancy due to premature birth may be accompanied by adverse feelings, when faced with the image of the real and fragile baby.

Prematurity is defined as any baby born alive before completing 37 weeks of gestation, mostly accompanied by low weight, in addition to other health factors, which can put the life of the preterm infant at risk (MS, 2020). Furthermore, for prematurity, a classification is established as follows: extremely premature, born before 28 weeks of gestation; very premature, from 28 to less than 32 weeks; moderately preterm, from 32 to less than 34 weeks; and late premature, from 34 to less than 37 weeks (Brazilian Society of Pediatrics [ABP], 2019).

In Brazil, approximately 340,000 premature births were recorded in 2019, accounting for 12% of births before 37 weeks of gestation in the country. In the global context, this number reaches 15 million premature babies per year. The

importance of this data is such that, in 2008, World Prematurity Day was established on November 17, with the purpose of increasing attention to the issue (Ministério da Saúde [MS], 2020).

Among the most common characteristics of premature babies, the fragility of the organs, especially the brain, stands out, in addition to low weight, especially when below 1500g, which requires greater care with nutritional recovery (Zelkowitz, 2017). In extremely premature babies, the baby's weight at birth is usually below 1000g, highlighting the thin skin, visible veins, little fat under the skin and a head disproportionate to the size of the body (MS, 2020). Another aspect that can generate clinical complications in premature babies is pulmonary immaturity. Friedrich et al. (2005) highlight that premature babies are exposed to factors that can harm their immature lungs. Respiratory and cardiac complications are among the main causes of hospitalizations of premature babies in Neonatal ICUs (Nascimento et al., 2019).

The Neonatal Intensive Care Unit (NICU) is a place created to care for preterm babies, with minimal harm after early exit from the mother's womb, with the incubator being the main instrument (Carvalho & Pereira, 2017). However, seeing their child in the incubator can cause suffering to mothers, since, at first, the incubator may have a negative effect as it is a substitute for maternal care (Esteves, 2017).

Coming across a premature baby can awaken a harsh reality for the mother, having given birth to an unfinished child, different from the image she had during her pregnancy (Lebovici, 1987). A mother who gives birth to a premature baby experiences the disruption not only of the pregnancy, but of her expectations regarding her child, as well as developing adverse feelings such as anguish, incompetence, fear and guilt. Such feelings can be intensified by hospitalization in the NICU. The hospital routine, the separation from family life and the fragile condition of the premature baby are some factors that can favor the awakening of intense emotions that can lead to suffering, such as anguish, anxiety and fear (Souza et al., 2009).

Mothers with babies hospitalized in the NICU feel fragile and experience feelings of frustration and guilt, reducing their ability to develop the conditions for caring for and mothering their children, putting emotional bonds at risk (Bragheto & Jacob, 2011). Emotional aspects can harm the mother-baby relationship, compromising the mental health of both. In fact, these feelings are fueled by the fragile health condition of the baby hospitalized in the NICU, where there is a team that provides the necessary care and treatment, thus making it impossible for the mother to fully perform her maternal role.

In a longitudinal study involving three pairs of mothers and their babies, Bortolin and Donelli (2019) emphasize that the mothers reported that the period of their babies' hospitalization in the NICU was a traumatic period, in addition to experiencing great suffering due to not being able to hold their babies immediately after birth. It can be inferred that there is a rupture in the mother's relationship with her baby. By holding the baby, the mother acts as an auxiliary ego, integrating and giving meaning to the bodily experiences that pass through the newborn, adapting to the basic needs of her child (Winnicott, 1999).

Thus, considering the importance of understanding mothers' feelings and expectations about their children, with the aim of thinking of solutions that aim to bring the dyad closer together, This study aimed to understand the maternal experience of having an extremely premature baby admitted to a Neonatal Intensive Care Unit.

Method

Outline

This is a qualitative, cross-sectional study with an exploratory design that aims to provide greater insight into the problem, potentially making it more explicit. Exploratory studies aim to gain greater familiarity with a given problem and data collection can be carried out through interviews (Gil, 2010).

Participants

The participants were four mothers of extremely premature babies admitted to a NICU in a hospital in Porto Alegre, in the state of Rio Grande do Sul. The research participants were selected through convenience and intentional sampling, "in which individuals are selected based on certain characteristics considered relevant by the researchers and participants" (Gil, 2010, p. 153).

The mothers in this study were identified with fictitious names such as Jasmine, Tulip, Magnolia and Orchid, respecting the confidentiality, reliability and ethics that the research proposes. The flower names were thought of based on the narrative of one of the mothers, when she said that "I can't wait to take my little flower home" (*sic*).

All participants were primiparous, that is, mothers who experienced pregnancy for the first time. The participants' educational level, with incomplete or complete higher education, stood out; their marital status, married or in a stable union; and their age over 30 years old, at the time of the baby's birth.

Table 1

Characteristics of Study Participants

Participant	Age	Education	Profession	State civil	Time of gestation	Baby birth weight in grams	Time of hospitalization in days (at the time of the interview)
Jasmine	38	Superior Full	Businesswoman	Unity Stable	24 Weeks and 6 days	545	81
Tulip	32	Superior Incomplete	Assistant Legal	Unity Stable	23 Weeks and 2 Days	480	78
Magnolia	35	Superior Full	Student of Psychology	Unity Stable	24 Weeks and 4 Days	619	44
Orchid	32	Postgraduate studies Incomplete (PhD student)	Information Technology Area	Married	26 Weeks and 4 Days	932	22

Instrument

The instrument used in the research was a semi-structured interview. The main objective of the interview is to obtain information from the interviewee regarding a subject or problem, and it is an important work tool in several fields of social sciences, including psychology (Marconi & Lakatos, 2003).

To this end, the guiding questions of the individual interview sought to understand the subjective experience of each participant. The questions began by asking about how the mothers were on the day of the interview, as well as the condition of the babies. Next, questions related to sociodemographic data, to better understand the profile of each participant. Subsequently, a sequence of questions about pregnancy, the arrival of the baby, complications due to extreme prematurity, the challenges of breastfeeding, the hospital routine, the support network and, in each of these, the feelings in these experiences.

Data Collection and Analysis Procedures

The research was conducted in person at a hospital in the city of Porto Alegre, in the state of Rio Grande do Sul, after approval by the Ethics Committee of the Universidade do Vale do Rio dos Sinos and the Ethics Committee of the partner hospital. The study followed the ethical recommendations for conducting studies with human beings, in accordance with *Resolution No. 510* (MS, 2016b) of the National Health Council.

The invitation to participate in the research was mediated by the psychology team of the NICU sector. All participants were informed about the purposes of the research and signed the Free and Informed Consent Form (FICF) in two copies, one for the participant and one for the researcher.

Data collection, based on semi-structured interviews, was carried out individually, in the hospital itself, in a room inside the NICU. The collection period took place between March and April of 2022, with an average duration of one hour. The interviews were recorded with prior authorization from the participants.

For data analysis, the interviews were transcribed, and the collected data were processed using content analysis, in the thematic modality. For better organization, the analysis takes place in three stages: pre-analysis, with the organization and reading of the material; exploration of the material, organizing it into categories; and processing of the results, which allows the information obtained to be highlighted (Bardin, 1979).

Results and Discussion

From the analysis of the transcripts of the interviews conducted with mothers of extremely premature babies admitted to the NICU, it was possible to identify two categories to compose the results and discussion of this work, namely: *prematurity* and the *Neonatal ICU.* Furthermore, to better understand maternal experiences, two subcategories were established for each category, identified as *maternal feelings regarding prematurity* and *maternal experiences and expectations.*

Prematurity

Prematurity is considered a clinical syndrome of complex conditions that needs to be treated with multiple strategies. The degree of prematurity is determined by gestational age and, in most cases, is accompanied by low birth weight (Brazilian Society of Pediatrics, 2019).

In this study, all participants were mothers of extremely premature babies, with a gestational age between 23 and 26 weeks, and a birth weight between 480g and 932g. Due to the gestational age and the extremely low birth weight, these babies are considered extremely fragile due to their physical condition. Premature babies require care that is appropriate to their needs and, therefore, are classified based on neonatal risk, with the risk being directly linked to infant mortality. Extremely premature babies are classified as high risk and require specific care and procedures (MS, 2014).

For an extremely premature newborn, the respiratory system is extremely immature and respiratory capacity during extrauterine life needs to be mediated by procedures and equipment, such as intubation and ventilation with a face mask, which may be temporary or prolonged. In addition, other organs are delicate and fragile, such as the skin, which is very thin and gelatinous, with a transparent appearance, where the veins are more visible. The head of an extremely premature baby is disproportionate to the size of the body and may present temporary deformities depending on the conditions of birth (MS, 2014).

These characteristics create a shocking image of the extremely premature baby, especially due to the tubes and devices connected to ensure the newborn's survival. Furthermore, it is observed that extremely premature babies tend to be lethargic and apathetic, reacting very little to stimulation. This less rewarding image of the baby, with whom communication is almost non-existent, can generate a variety of feelings in mothers, such as fear, anguish and guilt (Lebovici, 1987).

Maternal feelings towards prematurity

The birth of a premature baby usually generates negative feelings in mothers such as fear, despair and guilt (Cunha et al., 2009). In fact, one of the most common feelings in the reports of the mothers in this study was fear. For them, the fear of losing their children is the most intense, since extremely premature babies have one of the most fragile conditions of prematurity. This feeling was expressed in the following statement:

> I was scared, because then I realized that she really might not survive. When I saw how fragile she was. Her skin is transparent, you could practically see all her organs. (...) I cried for fear of losing her. (Tulip)

Even though extreme prematurity is not accompanied by a pathology per se, some mothers and fathers are subjected to the anguish of the baby's death (Lebovici, 1987). In addition to the fear of loss, the mothers also reported a fear of not having a mother-baby bond. For two of them (Jasmim and Tulipa), the development of the pregnancy was too short, from the discovery of the pregnancy to the extreme premature birth, and they were unable to establish a connection with the belly, the baby or the layette for the newborn. So when the extreme newborn is born in critical conditions, the mother cannot exercise maternal care for her child, such as holding the baby in her arms or breastfeeding him. Thus, she cannot touch her baby without gloves, nor kiss him. This issue can be evidenced from the following statements:

> When she was born, I was very afraid of not having that bond with her. At first, I was very afraid of not feeling anything for her, because of the shock, the condition, the fragility, because it's scary. She's a 500g baby, she's not a cute baby with rosy cheeks, she's another baby. (Jasmine)
>
> It seemed like I still couldn't touch her, that I had to wait, so much so that I said that my biggest fear was that she wouldn't like me, that she wouldn't recognize me as her mother, for me it was a long time. (Tulip)

Bowlby (1982, p. 123) explains that "the threat of loss generates anxiety and actual loss produces sadness, while each of these situations can arouse anger". The author highlights that affective bonds and the most intense emotions in subjective states tend to occur together, with the bond between mother and baby being one of the most important and persistent.

The mother who leaves the hospital and suffers the anguish of not taking her baby home, nor experiencing the first moments as a family with her child, feels frustrated, because "the mother is equally exposed to feeling hurt in her narcissism for not having been able to carry her pregnancy to term" (Lebovici, 1987, p. 190). The author emphasizes that there is also a feeling of guilt, due to the maternal fantasy of having given birth to an incomplete baby, which can also install an idea of inability to exercise her role as a mother (Lebovici, 1987). This mix of emotions can be identified in the following statements: "*I feel guilty: what did I do for them to leave here? What could I have done differently? To this day I think: what could I have done differently?* " (Orchid). Furthermore,

> When I looked at all that, with them hooked up to a bunch of machines, I wanted to say, "Put them inside me again, for the love of God!" But I couldn't. So it was a mixture of emotion, love and fear, worry and, at the same time, frustration because

I wanted to have won and for them to stay with me. They were close and yet so far away! Far from skin to skin, from smell, from contact. The fear is the fear of loss. (Magnolia)

In this last statement, it is possible to identify an ambivalence of emotions presented by the mother. This ambivalence is commonly experienced by mothers of premature babies, who are happy about the birth of the baby, but are frustrated and suffer due to the unstable condition and the complications to which the premature baby is subjected, thus causing negative feelings (Neves et al., 2021).

Mourning is also a characteristic present in the narratives of the mothers in this study. First, it is mourning for a short pregnancy, without any arrangements or preparations for the baby's layette items, without validation of the belly, or rather the "big belly" (*sic*). The second trimester of pregnancy is a moment understood as a "double advertisement", where the baby presents itself to the mother, moving more in the belly, just as the mother shows herself to others as a pregnant woman (Santos et al., 2010), which does not occur in the context of extreme prematurity. There is also mourning for not having the sensations of the child in the belly, with movements and kicks, nor the much-dreamed pregnancy *book* or the baby shower. About this, the mothers said:

We think about the grieving process, about a pregnancy that was designed in a way that most of the time happens, right? And we start to accept another format of pregnancy, where we lose some things. I didn't have a belly, my belly was going to start growing, so I lost some moments and gained others, but it's a feeling of adequacy. I hadn't been validated as pregnant in front of people. (Jasmine)

I didn't have time to have a baby shower or take a picture. I don't even know how much I weighed, and I don't know what my belly looks like. Because I was hospitalized for 18 days, on complete bed rest, without setting foot on the floor. I don't know how big I got, I have no idea. I lost all sense of my body. I would do it all over again. Today I said to my husband: I wish I was still in that room. I would stay for 50, 60 days. As many days as I needed, just to have them inside me. (Orchid)

Furthermore, there is also a mourning of a real baby that differs greatly from the baby dreamed of and imagined by the mother (Lebovici, 1987). Mourning can also be a coping process, a resource to overcome the trials of having an extremely premature baby. Kaplan and Mason (1960) propose that mothers of premature babies need to go through four psychological tasks: anticipatory mourning, understanding the possibility of losing such a fragile baby; recognizing the failure of having given birth to a preterm child, which, although difficult, is considered a healthy process; resuming active activities with the baby, when it is already possible for the mother to perform some acts of care, such as bathing, changing diapers and breastfeeding; and, finally, realizing that prematurity was a temporary state, which gives way to normality.

Maternal experiences and expectations regarding prematurity

Unlike a full-term baby, the birth of a premature newborn "stops being a meeting between parents and children and becomes a succession of missed encounters, which begin postpartum, when the newborn is separated from its mother and immediately admitted to the ICU" (Braga & Morsch, 2003a, p. 54). Due to the critical condition of the babies at birth, none of them were placed in skin-to-skin contact with their mothers. Immediately after birth, the babies are wrapped in a plastic bag, like cling film, to immediately retain the premature baby's body temperature. This first image may be considered frightening by the mothers, although they report that they received information about these procedures before birth. Then, the baby is taken to the incubator for initial care, and it is in this glass womb that the mother sees her child for the first time:

I couldn't hold her. They told me that they might be able to show her to me, but it would depend on the condition she was born in. She was going to be evaluated. They brought her to me, to see her as soon as they took her out. She was wrapped in a bag to preserve her and then they brought her back into the incubator so I could see her a little before they brought her here for ICU. (Jasmine)

Mothers report that their desire to have initial contact with and care for their children was frustrated by premature birth. In general, at the end of pregnancy, the mother prepares herself to meet the needs of her baby, dedicating herself to her maternal role to meet the demands of the newborn, which Winnicott (1956) called "primary maternal concern." The needs of an extremely premature baby are different, which requires the mother to adapt her relationship with her child. Sometimes, what the mother can offer is her presence, as stated in the narrative below:

I make a point of telling her every day that I love her, I come here to tell her that I love her. That's what I come here to do, since I can't do much for her other than tell her that I love her. I tell her that I love her, that I'm here, that I miss her, that I'm waiting for her to go home. (Tulip)

The bond that is established between mother and baby during breastfeeding is the most powerful thing in human relationships (Winnicott, 2017). However, breastfeeding an extremely premature newborn has its own processes and challenges. Premature

babies have difficulty sucking and swallowing and are less tolerant to food. Their nutritional needs are also greater than those of full-term babies, and the mother's own milk is the best choice for premature newborns (MS, 2020).

The premature newborn initially receives feeding through a vein, and after an assessment of the newborn's condition, he or she receives feeding through a tube that goes from the mouth to the stomach (Rocha, 2003). Thus, the experience of the babies of the mothers in this study happened as follows: from parenteral nutrition, that is, that which is received through an intravenous procedure, with the nutrients that the preterm infant needs; and, later, they began to be fed with breast milk through a tube that passes through the newborn 's mouth and goes to the stomach. To this end, the mothers were encouraged to stimulate the expression of breast milk. This process is called milking and is carried out in a specific sector of the hospital, which is called the exhaust: "Manual milking is defined as a technique of extracting breast milk, using hands or pumps to facilitate the extraction of milk" (Faleiro, 2021, p. 14).

It is important to highlight that these mothers are emotionally exhausted when they perform the milking process. Thus, the volume of milk extracted is small and needs to be stimulated with medications that increase production. The participants reported that the team that monitors the milking process in the partner hospital's *milking room* is very welcoming and helped them to understand that the volume of milk is not the most important thing, but rather the intention of the act, which is symbolic but also reveals the concreteness of a maternal act. When a premature baby is born, there is also a premature mother (Lebovici, 1987). These reflections can be seen in the narratives below:

> From the first day, they stimulated my milk production with medication, because I don't have the ability to suck, so my body, like all premature babies, is also premature. I haven't reached my full gestation yet. (Magnolia)
>
> Emotions seem to be closely linked to milk. Anxiety, distress, all these feelings that are experienced here are directly related to milk (...). The people there don't charge us anything, there's even a poem that says: "love is not measured in milliliters". So, each drop is extremely important and is a tremendous dose of love. (Orchid)

Given the baby's fragility, a feeling of helplessness can be established, making breastfeeding even more difficult (Rodrigues et al., 2013). Breastfeeding establishes an important bond between the mother and her baby, even if the premature baby cannot yet effectively breastfeed, the skin-to-skin proximity, olfactory stimulation and talking to the baby help in milk production (Gomes, 2018).

Another procedure performed on premature babies is colostrum therapy, which is "a practice that can bring many benefits, with the development of the newborn's immunity and microbiota, through the stimulation of the lymphatic tissues associated with the oropharynx, in addition to strengthening the bond between mother and baby" (Santos, 2021, p. 11). Colostrum is rich in nutrients, in addition to being considered a natural vaccine, and can be used daily as a therapeutic option for premature newborns. The procedure is explained by the narrative of a mother:

> The only contact he has with my milk is colostrum. It's with a little syringe, put on the side of the cheek, 3 drops at first, then increase to 0.1ml in the syringe, so they have this contact with breast milk. (Magnolia)

All the mothers in this study reported that they are committed to maintaining breast milk production, as they know how important this food is for their babies. They comment that they are waiting for the moment when they can, in fact, breastfeed their children, as "breastfeeding is the realization of motherhood" (Jasmim). They also know that premature babies have a different time frame and that it is necessary to reach certain milestones related to the newborn 's weight, thus allowing for some new achievements:

> He still can't breastfeed, especially because he can't latch on. Today he weighs 1,180 kg. We count every gram, so we joke that even his poop makes a difference, because if he poops before weighing himself, the grams decrease. So all the weights are counted so that we can reach the milestones. There's the 1 kg milestone, which he took a while to reach, which is when you can touch him without gloves, so you take the gloves off, and the contact is direct to the skin. And we wait a long time to reach this breastfeeding milestone. (Magnolia)

In addition to the milestones related to the baby's weight, another practice is adopted as a philosophy for premature babies. This is the corrected age, which, according to the Ministry of Health (MS, 2016a), would be the monitoring of the growth and development of a premature baby based on the corrected gestational age. This means that, when born, the premature baby needs to be seen not at its usual chronological age (such as 1 month, 2 months, 3 months of life), but rather the time remaining to complete its intrauterine life should be considered.

This practice makes it easier for mothers to understand that their children do not perform behaviors expected in the development of a full-term baby. In fact, it helps them understand that an extremely premature baby has its own time, with a body still growing and developing basic functions and that it will exhibit reactions typical of prematurity, such as apneas. Apneas occur when "the baby's heart rate slows down and stops breathing and may also present cyanosis around the lips and extremities" (Moreira & Rodrigues, 2013, p. 43). Even with this information, when a child stops breathing, it awakens in the mother despair at the possibility of losing her baby:

> It's very intense, just like when we come in here and everything is fine, then it's not fine at all, and there are things we have to learn that are very difficult here. Here, babies will have apnea, and we have to learn that it's normal for prematurity, but a mother never learns that stopping breathing is normal. It's total despair! It's very surreal because we're experiencing things that a normal baby often wouldn't experience. We have to deal with it. (Magnolia)

For some families, despair sets in, especially when their baby is about to die. In these cases, it is recommended that parents stay close to their baby, even though they know it is not easy, and that each family should decide how to deal with this suffering (Braga & Morsch, 2003b). Two mothers in this study (Magnólia and Orquídea) had the experience of giving birth to extremely premature twins, and in both cases, one of the siblings died. Mothers reported that losing a child is like losing their own breath. They describe a pain so intense that it is impossible to express it in words and, although they were devastated inside, they needed to regain their strength to care for the baby who remained there. This suffering can be evidenced in the following narrative:

> He was very weak. Very debilitated. His oxygen saturation was no longer rising, it was falling. It was kind of a milestone. Then at 3 in the morning there was a very strong storm, with lightning, it rained a lot, *a gray day* (our emphasis). It was the 30th. I knew it wasn't going to be a normal day. I knew it was going to be different. Somehow, something was telling me what was going to happen. And we came here. And it happened: throughout the day, his blood pressure was getting lower and lower. The guys made skin-to-skin contact with us, he went to his husband's chest, who cried a lot. He still had hope. I felt he was going. The feeling I had was that he was saying goodbye. He cried a little in my husband's arms and when I picked him up, he was gone. It was the worst day of our lives. It was the day that destroyed me. (Orchid)

Immediately after the loss of a baby, a pain that initially seems to have no end arises. However, in cases of twins, where one of the siblings survive, energy and efforts are focused on this baby, allowing the suffering of the loss of one to change and hope for the life of the other to be established (Braga & Morsch, 2003b). This happened with Magnolia and Orquídea, who needed to process the grief of one of their children in order to focus on the health of the surviving sibling.

The Neonatal ICU

ICUs have a set of resources for treating serious or potentially serious patients who require specialized care with a higher frequency of procedures. A neonatal ICU is made up of a multidisciplinary team that, in addition to treating the baby's health, also needs to be attentive to encouraging emotional bonds between the baby and its parents (Souza & Pegoraro, 2017). The NICU of the partner hospital of this study was completely renovated and redesigned a few years ago. The new facilities were also equipped with the most modern technologies for treating newborn babies who need it.

Maternal feelings towards the Neonatal ICU

The hospitalization of a newborn child, especially in extreme conditions of prematurity, brings about equally extreme feelings. Therefore, parents may normally feel inadequate, presenting feelings of guilt, sadness or resentment when they realize the needs of their child who needs to remain in the neonatal unit (MS, 2017).

The mothers in this study remained in the NICU with their babies for a period of time that varied from 6 to 12 hours a day, including a relatively organized routine of tasks. During this routine, they followed the procedures and exams performed on their children, performed milk expression in the drainage area, talked to the team and, as the newborn's milestones progressed, they were allowed to make some advances in caring for the premature baby, such as holding the baby in their arms, helping with bathing, changing diapers and participating in colostrum therapy.

The main piece of equipment used to care for newborns in the NICU is the incubator. Extremely premature babies spend a long time in the incubator, which is a warm, safe environment that is suitable for their development. Mothers report that the incubator is a great partner in the process of hospitalizing their babies, as can be seen from the following statements: "*The incubator is life! For an extremely premature baby, it is a form of security"* (Jasmine); "*It is an imitation of my belly. I started to see that it is a different place, I imagine that I am having an ultrasound every day, because I saw her developing in there"* (Tulip); "*It is my transparent belly. Because he is there, so much so that we count the weeks as the gestational period. So, he is 31 weeks old. Of course, he will be 2 months old, but what counts here is his development"* (Magnolia); and "*It is like a vase. He is a little plant, you have the soil, you are going to water that little vase. The incubator is like a little vase to me and my little seed is there, and it is growing"* (Orchid).

In light of these reports, the researcher named the incubator "*glass womb.*" This is because, in fact, this equipment, which is actually made of acrylic, works like a uterus, providing the conditions for the baby's survival and development.

Another important observation is how these mothers inform themselves and learn about medical terms regarding the health status of their newborns and the procedures their children undergo. In this NICU, the entire team communicates

horizontally with the mothers, answering their questions throughout the hospitalization process. In this way, the mothers realize that they become more involved and have a better understanding of care practices, in addition to acquiring vocabulary to understand conversations among the team, and they become spokespeople for the extended family about their children's health conditions. Here are some examples:

> They had to change the oxygen tube because he had grown, and I needed to change it because it was not as effective. It is intubation through the mouth, the same as intubation for adults. They tried to change the type of respirator, which is the CPAP, which provides a continuous, mechanical, more stable flow. These are things I didn't know, these are things that the staff explains. This helps to understand everything that is happening. (Orchid)
>
> There are many little cables connected to it. It's a blood pressure monitor, a temperature monitor, a saturation monitor, and all the other related devices there. There's an oxygen tube, a feeding tube, a direct gastroenterology tube. There are a lot of wires, and we respect all of that. At first, I was shocked. You see your child in that situation. You don't prepare yourself to have a child in that condition. But you develop respect. (Orchid)

This maternal interest was called "primary medical concern" by Agman et al. (1999), explaining that mothers of premature babies admitted to the NICU, deprived of their maternal functions and care for their babies, approach clinical information about their children's health. Thus, mothers can, at least, get closer to them and even feel safer when it is necessary to discuss the conduct and therapeutic procedures of preterm babies.

Distancing, understood here as safety and care for the baby's fragile state, also brings the feeling that the baby does not yet truly belong to that mother. Lebovici (1987) argues that mother-baby interaction occurs in processes in which the mother sends "messages" to her baby, who "responds" by promoting maternal satisfaction. For the author, this wordless conversation establishes an emotional exchange, through gestures, smiles and babbling. During hospitalization in the NICU, this interaction is impaired, especially for extremely premature newborns, because neither the mother is able to send these signals and messages to her baby, nor is the pre-term baby able to respond to them. Faced with this difficulty, the mother perceives a child who is not yet hers, as explained in the following statement:

> The child is mine, but it's as if he wasn't. Because in order to touch him, I have to ask. In order to hold him, I have to ask. Many times, I hear that it's not possible, or that I can't hold him now, or that I can't put my hand on him now because his temperature isn't right yet. So we have to ask permission to touch our child. (Magnolia)

Experiences and expectations regarding admission to the Neonatal ICU

The experiences of mothers in the NICU are very difficult and cause a real physical distance from their babies, especially when the baby is extremely preterm. Mothers become identified with their babies through the interaction between the two, which occurs when they hold the baby in their arms, caress him/her and breastfeed him/her (Winnicott, 1983). The mothers in this study describe that the exercise of interaction with their babies takes longer, because they are extremely premature.

One of the most anticipated moments for a mother of a premature newborn is the moment of holding her child in her arms. To do so, the baby must have reached the necessary weight milestone, around 1 kg, and be in a clinical condition that allows contact with the mother outside the incubator. The Ministry of Health (MS, 2016a) promotes the *Policy of Humanized Care for Newborns* and considers the *Kangaroo Method* as the most appropriate way for mothers to approach low-weight preterm infants. "Skin-to-skin contact, in the Kangaroo Method, begins with parents touching their babies from the first moments of hospitalization, progressing to the kangaroo position" (MS, 2016a, p. 9).

The *kangaroo position* consists of holding the child upright next to the mother or father's chest. The baby should only be wearing diapers, and the mother should be without a bra, thus favoring skin-to-skin contact (MS, 2016a). In the NICU in question, this moment of holding is called simply "skin-to-skin" and is performed as soon as the baby's health conditions allow. Mothers reported this moment as an important event in the relationship with their children, although the first contacts are permeated by insecurity, due to the tubes connected to the baby, as reported by the mother:

> When I held her for the first time, I felt a difference in my process of connecting with her. I think it materialized a little more the motherhood that, until then, we had touch, but it was a different touch, it was touching and letting go of the weight of the hand on the baby. Holding her at 12 days old, even though the baby is intubated, is very difficult, but it is the first contact. It was actually quite quick, because she still weighed 800g. Now it is a different connection, because when they are very small, we hold them skin to skin, placing them on the chest. (Jasmine)

The emotional relationship between a mother and her baby does not occur instantly at birth but is established in an ongoing process based on interaction. When a baby needs to be admitted to the NICU, certain deprivations occur, such as restrictions on physical contact, such as skin-to-skin contact with the mother and even breastfeeding (Castro et al*.,* 2020). Therefore, it is important to encourage the dyad to get closer as quickly as possible, and to do so, NICU professionals need to be sensitive to each mother-baby pair. Mothers recognize when the team helps to alleviate the effects of hospitalization:

> The sense of humanity here is very great. Sensitivity and the way people treat you, the openness that people give you. People connect with you and that's what's above. They're always paying attention to you. It's continuous. My mother works in a hospital and it's not like that. Here things are different. (Orchid)

Still about the NICU, the mothers were asked what being a NICU mother is like. These mothers understand that being a mother to an extremely premature baby who is hospitalized means experiencing ambiguous feelings, of great anguish due to the newborn 's fragility, but also of small joys that, when added together, build the relationship between the dyad. So, the NICU mothers define themselves as: "*First, she is a mother with no ground or roof. Who is placed in an environment that you don't know. And then, the mother becomes resilient, so she knows, that she is patient"* (Tulipa). Furthermore,

> A newborn mother is someone who has her heart in her hand. There are days when our hearts are vibrating and other days when our hearts are heavy. It seems like we don't know where we're going to get the energy and strength from. It's a roller coaster ride. (Magnolia)

The mothers' experience of premature babies facing the hospitalization of their children entails a series of losses, from the idealized child, still in pregnancy, to the impossibility of taking the child home after birth. In addition, the encounter with the baby is permeated by therapeutic behaviors that restrict the maternal role (Neves et al., 2021). In this sense, promoting humanized care by the team is essential to minimize the impact that mothers may experience during the process of hospitalizing their babies.

Final Considerations

The objective of this exploratory study was to understand the maternal experience of having an extremely premature baby admitted to a NICU. To this end, semi-structured interviews were conducted to understand the mothers' feelings, experiences and expectations.

Among the main findings, it is worth highlighting that the birth of an extremely premature baby is accompanied by issues not previously thought about by the mothers in this study. Among them, the invalidation of the belly due to the short gestation period, the birth without much contact with the baby, the impossibility of touching the baby due to the very low weight, the challenges of maintaining the flow of breast milk without the initial possibility of breastfeeding, the real grief when there is the loss of a child and the hope of keeping the other alive, in cases of twins.

This study also identified a positive relationship between mothers and the Neonatal ICU team and the incubator. The Neonatal ICU becomes a second home for these mothers, as it is, in fact, the best place to welcome and care for extremely premature babies. As the main piece of equipment for this care, the incubator is seen by mothers as an ally in the treatment. Thus, the incubator, which the researcher calls a "*glass womb*", in addition to its fundamental role in the survival of premature babies, is also responsible for the baby's development, even in the most extreme conditions, and for this reason, it is grateful to these mothers.

This study confirmed that, when faced with extreme prematurity, mothers experience a mix of emotions, such as anguish, guilt, and despair, the main one being the fear of losing their babies. The fear arises from the fragile figure of a premature baby, especially extremely premature babies with very low birth weight.

These mothers also fear not being able to establish a bond with their baby. This seems to be a genuine fear, due to the successive mismatches in the relationship between the two, from the impossibility of touching their children's hands, to the delay in cuddling them in their arms, to the skin-to-skin kangaroo position, and even to the long-awaited moment of breastfeeding.

The limitations of this study include the fact that the research was conducted in only one hospital in the private health network in a single city, and it would be interesting to learn about the reality of hospitals in the public health network, as well as the reality of other regions of Brazil. It is also important to highlight that the data collected relate to the experience of mothers of extremely premature babies, and it would be interesting to expand the range of information to include mothers of very premature, moderately premature and late premature babies.

It can be stated, however, that this study contributed to the recognition of some of the maternal experiences regarding the hospitalization of their extremely premature children. In this way, it was possible to present the main challenges, as well as the potential that these mothers go through. Given all of the above, it is suggested that studies on the relationship between the dyad be expanded, in cases of hospitalization in the NICU due to prematurity, with the aim of understanding other processes, also disseminating good practices that favor the mother-baby relationship.

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