



# Maternal feelings about the hospitalization of the premature child: content analysis

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# ABSTRACT

Aim: understand the feelings experienced by the mother when having her premature child hospitalized in the Neonatal Intensive Care Unit (NICU). **Method:** descriptive research of a qualitative nature, performed with 11 mothers, through a semi-structured interview. The Content Analysis framework was adopted. **Results:** three thematic categories were identified: Suffering from the hospitalization of the premature child; Premature child care: trust in the team; Experiencing the impact of the neonatal intensive care environment. **Discussion:** mothers were faced with feelings such as fear, guilt over suffering and possible loss of the child, and reported feeling powerless and unable to care for the child at this time, which increased their anguish. **Conclusion:** mothers, when faced with the premature child in the NICU, experienced different feelings, feeling incapable and, often, moving away from the newborn. However, they reported confidence and security in the care of professionals with their children, valuing both technical aspects and interpersonal relationships.

Descriptors: Mother-Child Relations; Intensive Care Units, Neonatal; Infant, Premature.

### INTRODUCTION

When a woman becomes a mother, she has an immeasurable capacity to form lasting bonds with her children, an emotional situation called attachment, which encourages the mother to offer conditions that are conducive to the child's growth and development, with physical and emotional implications throughout life<sup>(1)</sup>.

The onset of attachment to the child occurs during pregnancy and continues and intensifies after birth and throughout all interactions that will occur. Generally, mothers expect to feel naturally bonded to babies soon after birth. However, this is not automatic, and to encourage its occurrence, there must be opportunities for the mother to contact the child, avoiding situations that limit or interfere in this process<sup>(2)</sup>.

Gestation is an important period of preparation for the arrival of the baby, part of an experience full of intense feelings and physical and emotional changes. It is also a moment of regression to dependence, in which the mother begins to develop the process of identification with the child to be born. She becomes the host of a new human being and needs to receive it without knowing how it will be, as it is an unknown baby. Thus, they usually generate expectations about the child<sup>(3)</sup>.

In situations where the arrival of the child is anticipated, not happening as dreamed by the mother and her family, many feelings are raised. Normally, preterm birth occurs urgently, which leads the mother to not be psychologically prepared, also feeling as a premature and often unprepared mother to take care of her child, tending to react in different ways to this situation. Fear of the disease, the unknown, the hospital environment and uncertainty in terms of the present and the future of the family member, i.e., the clinical evolution of the baby and its survival, arise<sup>(4)</sup>. When the preterm newborn needs care in the Neonatal Intensive Care Unit (NICU), which often occurs, the situation is even more complex. This is because the mother becomes a mere spectator of the specialized care provided by the health team to her child, which can cause the feeling of loss of her maternal function and generate difficulty in recognizing herself as a mother. The unknown environment of the NICU, which is surrounded by technology, with stateof-the-art devices, can increase the mother's fear and insecurity<sup>(5)</sup>.

In preterm births, sometimes the newborn needs immediate care in the delivery room before being referred to the NICU, and extrauterine contact with the mother is delayed because of its conditions and institutional norms/routines. In the case of preterm birth, due to the condition of biological immaturity, the unborn baby is fragile, drowsy, unpredictable and immature, and it is necessary to refer it immediately to the NICU and, therefore, this separation is usually total on the first day and partial on subsequent days<sup>(6)</sup>.

Therefore, premature birth is an unexpected event in the life of the family, forming as a stressful event, which generates, especially for parents, different types of emotions and feelings, such as anxiety, anguish, guilt and disappointment. The arrival of a small and fragile baby leaves a gap between the expectation of the imaginary baby, that is, the one imagined during pregnancy, with healthy physical characteristics, and the real baby present in the NICU. This fact leads the majority of mothers to feel insecure about their ability to care, to mother and to interact with the baby<sup>(7)</sup>.

Aiming to better understand the reality experienced and the feelings of the mother in a situation of separation from the child after childbirth, the present study, which aims to understand the feelings experienced by the mother

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when having her premature child hospitalized in NICU, was proposed.

# METHOD

The qualitative approach was used, adopting the content analysis framework according to Bardin<sup>(8)</sup>. Qualitative research is understood as one involving subjective questions, which is not concerned with quantifying, but rather with understanding and explaining the dynamics of social relations. It works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which cannot be reduced to the operationalization of variables<sup>(9)</sup>. The content analysis makes it possible to unveil what is behind the words, enabling interpretation<sup>(8)</sup>.

The study was based on a NICU located in a hospital accredited by the *Sistema Único de Saúde* (SUS - Unified Health System), a public service considered as a Regional Reference Center, with a model of care directed to high-risk pregnant women. It is a large hospital, which serves patients from approximately 250 municipalities in Paraná and more than 100 municipalities in other states, and is a member of the state health network<sup>(10)</sup>.

Eleven mothers, whose premature children were hospitalized in the NICU, participated in this study. Inclusion criteria were: mothers of newborns with gestational age less than 37 weeks and whose children required hospitalization in the NICU. Mothers whose children died at the time of collection and/or had malformations were excluded.

When the mothers were personally invited to participate in the study, they were informed about the study's objectives, ensuring confidentiality of information, spontaneous participation and freedom to withdraw from the research at any time. On that occasion, authorization was also requested for recording the interview. Participation was agreed through the signing of a free and informed consent form.

Data collection was performed from August to September 2013, through a semi-structured interview, understood as a process of social interaction, in which the interviewer seeks information about the interviewee, from a script containing topics around a central problem. In addition, it privileges the acquisition of information by individual speech, revealing structural conditions, value systems, norms and symbols, and conveys representations about certain groups from a spokesperson<sup>(11)</sup>.

The question used to guide the interview was: What does it mean for you to have your premature child hospitalized at the NICU?

In addition to the recording, field notes were used to record speech synthesis. At the end of the interview, the mother listened to the recording and the researcher read the synthesis done, for validation or alteration of the information. The interviews were individual and carried out in a reserved space of the NICU. The average duration of the researchers' meeting with the mothers was 45 minutes, considering the initial interaction and the interview itself. The number of mothers was not defined a priori: the data collection was closed at the moment the concerns were answered and the purpose of the study was reached.

After data collection, the interviews were transcribed and the material was explored, identifying the thematic nuclei, according to the method of content analysis proposed by Bardin<sup>(8)</sup>. To preserve the anonymity of the participating mothers, they were identified by the letter M, followed by the number corresponding to the order of the interview.

This research was carried out with the favorable opinion of the Research Ethics Committee of the State University of Londrina (UEL), under No. CEP 331/2011.

#### RESULTS

Brief characterization of the 11 mothers participating in the study shows that, in relation to the number of pregnancies, six were primiparous. The age ranged from 17 to 41 years. As for the marital situation, nine were married and two lived in consensual union. Family income ranged from one to five minimum wages. Five performed vaginal delivery and six underwent cesarean section, presenting gestational age ranging from 24 to 35 weeks. The birth weight of newborns ranged from 560 to 2,190 grams.

In analyzing the information obtained during the interviews, it was possible to organize them into three thematic categories: Suffering against the hospitalization of the premature child; Premarital child care: trust in the team; Experiencing the impact of the neonatal intensive care environment.

# Suffering from the hospitalization of the premature child

Mothers, when they encountered their child in the NICU, experienced different feelings, such as: fear, sadness at not being able to hold the child in the lap, guilt and longing for closeness, which is frustrating for the mother.

> I was a little afraid [...] to come home without him (crying) [...], I missed him; I wanted to be with him; I planned the little room, his little things, and I couldn't take him home [...]. I always imagined going to the maternity home to have the baby, bath him and to take him away [...]. (M5)

Ah, I felt a weight and sorrow; I wish I had taken her with me. I wish I'd had her and gone home with her, but it's her nature, what can I do, right? (M8)

[...] It was hard; I had a sense of guilt and impotence in the early hours [...]. Because I had never seen it; not even by video... anything [...] a premature child. So I was caught by surprised at first, but then I accepted it. (M7)

The mothers of the study reported that, when faced with the fragility of their children, who were being monitored with unknown devices, they experienced feelings of suffering, helplessness, and insecurity to touch or care for them. They felt incapable and, in many cases, moved away from the newborn.

> It is very small and a little fragile; breathing; you put your hand and feel the beat of the heart; it seems like it's all superficial [...] in the head you feel the circulation, everything so thin, it looks like an egg shell. (M1)

> I never imagined seeing him that size [...] very small; so it's a surprise to see that she's perfect, you know? She has hair, nails, eyelashes, has everything. She was there only to grow up; everything was in the right place. (M6)

> The situation of the child so small, weighing grams, is hard; in the beginning I feel fear, despair. (M2)

> [...] I found Rafaela very strange. I still didn't believe I had gotten pregnant, that I had had her [...] she was not my

little girl; she looked like a Japanese girl; her eyes were slant and her cap was not on her head [...]. (M8)

[...] My ultrasound showed 500 grams [...], and 500 grams is not even a packet of beans. I knew he wasn't going to be a big kid. [...] First, I waited 25 days to hold my son for the first time, so I started to feel a taste of being a mother, because until then, I could not even touch him, because the oximetry would decrease if I just looked at him, because he was very small. (M5)

#### Care for the premature child: trust in the team

It is possible to observe the confidence and safety of the mothers in relation to health professionals. The clarification, attention and reception of the health team to the family of the newborn, in addition to daily living, strengthen this relationship of trust.

> And they [the professionals] explain, you know, any questions [...] they don't do anything without telling me, and I know they're treating her well. (M4)

> Everyone is great, so I think they are to be congratulated. [...] There is a meeting every Friday in which we choose a topic to clear doubts, because the baby goes through several procedures that, for us, are from another world, but which are simple for them; so they explain the procedures and we get more relaxed about it. (M3)

> Their service is very good! This makes us feel safe because we know that the

child is being well assisted. We see the child developing every day [...] every day we can see that the child is better, looking healthier, gaining a few pounds, increasing the amount of milk [...]; this brings more hope. [...]. (M7)

According to the mothers' statements, their recognition regarding the health team and the feeling that they are valued by health professionals is evident.

## *Experiencing the impact of the neonatal intensive care environment*

The environment of the NICU, surrounded by technological devices, qualified professionals, special care and technical terms, contributes to the increase of anxiety and the tension of mothers facing the unknown. This can be seen in the following statements:

> When we get there, we see all those tubes, full of those things and it looks like they're hurting her [...]. When I got to the ICU it made me feel like getting her and running away. (M4)

> It took us twelve hours to get down and when we got there, we saw him with several tubes in his nose, so I cried... [...]. But then the nurse came and talked to us; but it's awful... because, [...] everybody thinks that the baby is going to die. Actually, it's not quite like that, but I always had that impression: 'Oh, he's in the NICU, so he's going to die'. (M3)

> [...] I thought he was here because he would not survive, you know? [...] oh, but seeing the competence of the doctors and nurses, and with the testimony

of the other mothers, I gained strength and courage [...]. (M6)

[...] she was born well, breathing alone; after three days she was intubated [...]; it's scary to see all that stuff in a baby [...]. The place, I had never seen it, I didn't even imagine it existed; a child in an incubator; a children's ICU... Especially at the beginning, the equipment, the place... everything is very complicated. (M2)

For mothers it is difficult to see their children in the NICU connected to wires and tubes, surrounded by care and devices, as presented in some of the statements.

# DISCUSSION

The present study allowed identifying and understanding the variety of feelings experienced by the mother when having her premature child hospitalized in NICU, related to the suffering before hospitalization, trust in the care team and the impact of the neonatal intensive care environment.

Mothers were faced with feelings such as fear, guilt over suffering and possible loss of the child, and reported feeling powerless and unable to care for the child at this time, which increased their anguish.

These feelings corroborate with those evidenced in another study<sup>(12)</sup>, whose objective was to identify, through the scientific literature, feelings experienced by the family of newborns at risk and their relationship with health professionals. It was identified that most of the articles referred to feelings of suffering, such as fear of losing the child, guilt and insecurity towards the child considered to be at risk due to prematurity and the need for hospitalization in an intensive care unit.

The experience of the hospitalization of a child in the NICU is known to be a stressful experience for the parents. While advances in science and technology have helped to improve the quality of neonatal care, allowing premature infants and critically ill infants to survive, this does not diminish the negative emotional and psychological experiences that parents endure. The complexities of the NICU environment and the child's appearance are potential stressors for parents<sup>(13)</sup>.

These factors may negatively influence parents' ability to learn about their children's care, generating feelings of inadequacy and frustration<sup>(14)</sup>.

Mothers' feelings should be valued and accompanied by a humane and welcoming care, noting that by delaying contact between the mother and the preterm baby, the situation worsens for both, as the mother may not feel safe enough to take care of the her baby at home, and the infant may require recurrent post-discharge hospitalizations<sup>(7)</sup>.

For the proper development of the baby, the balance between biological, environmental and family needs is needed. Therefore, the adequacy of the technical approach and the postures that imply environmental and behavioral changes with a view to greater humanization of care is essential<sup>(15)</sup>. Thus, the team was valued by mothers, not only for its technical competence, but also for interpersonal relations established and resulting, for example, the valorization of the maternal presence, respect for their doubts and guidelines on the procedures to be performed.

Knowing the importance of the early bond between parents and their preterm and/ or hospitalized children in intensive care units, the Ministry of Health implemented guidelines to guide the team to facilitate the formation of affective bonds, such as: free access of parents to NICU; the right to have a professional to provide all the necessary information about the baby; stimulation to the touch and affection to the baby; make the NICU environment welcoming for them; allow them to participate in the care of their babies; and listen carefully to what they have to say and clarify their doubts<sup>(15)</sup>.

It could be observed in this study that the mothers relied on the NICU team that assisted their child, which may favor parents to develop early bond with their children, because they feel security in the team in order to help them overcome the fears in the face of the situations experienced <sup>(16)</sup>.

Thus, the communication of professionals with the family favors the emergence of a bond of trust and respect, contributing to the quality of care provided to the newborn. It is important for providers to provide family support in order to reduce the anxiety and fear experienced by the parents of the newborn by providing comfort, addressing concerns and providing information on the child's health status, treatment and equipment used<sup>(16)</sup>.

The impact on parents of the technological apparatus of an NICU environment is frightening. In general, parents are unaware of this environment and, at first, have a sense of suffering by noting that all of this technology may be generating pain and suffering in their child. When parents step into unity and see their small, fragile child, connected to various circuits and tubes, they feel powerless because they cannot reverse this situation<sup>(12)</sup>.

In a study<sup>(17)</sup> regarding the experience of mothers of premature babies hospitalized in intensive care units, similar results were obtained when considering the impact of the hospital environment, since the main feelings revealed were fear and stress caused by the lack of knowledge of the environment.

The stress that results from premature birth, the need for intensive care and prolonged physical separation due to the need for hospitalization in the NICU can cause physiological and psychological adverse effects for both the baby and the mother. The hospital environment and this new situation compromise the establishment and maintenance of the mother-baby relationship and may have repercussions on the child's later development and on the emotional well-being of the mother. Therefore, proficient communication, good information provision and sensitive and emotional support are important in order to overcome or reduce the effects of the hospitalization impact and the technological devices used<sup>(18-19)</sup>.

The NICU team should welcome parents so that they feel integrated into the environment, providing empathy, clarification about the child's clinical conditions, guidance on the procedures and devices present in the environment, thus reducing the view of a hostile and frightening environment<sup>(20)</sup>.

# CONCLUSION

The results revealed that when mothers encountered the child in the NICU, they experienced different feelings, such as fear, sadness, guilt and longing to be with the child and to be able to hold him or her on her lap. These sensations of impotence and insecurity to perform a touch or care contributed to the feeling of incapacity, and, often, to the withdrawal from them in relation to the newborn. However, mothers reported confidence and security in the care of professionals with their children.

Mothers' anxiety, caused by premature birth and need for NICU admission, should be tempered by the humanized care and guidance of the health team, as the mother's understand-

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ing of the baby's real situation may aid in therapy and make it possible to take the baby home safely to perform the necessary care, avoiding recurrent hospitalizations.

Thus, the awareness of health team professionals in the NICU, through workshops, is important to develop a differentiated view on the mother-child binomial, helping them to form an affective bond and providing more humane and holistic care in the neonatal hospitalization process.

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