

Perception of preterm mothers about prematurity: subsidy for nursing care in neonatology*Percepción de las madres prematuras sobre la prematuridad: subsidio a la atención de enfermería en neonatología**Percepção de mães de prematuro acerca da prematuridade: subsídio para o cuidado de enfermagem em neonatologia***Viviane Barbosa Martins¹**

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Abstract

The aim was to describe the perception of mothers of preterm infants about prematurity and to analyze how this perception reflects the nursing care provided. This is a descriptive study with a qualitative approach. The setting was a Neonatal Intensive Care Unit, located in the city of Cabo Frio, in the State of Rio de Janeiro. The subjects were 8 mothers of newborns hospitalized at the institution. The analytical categories from the analysis were: Feelings that guide mothers of premature babies; challenges of mothers of premature babies facing the care of their child; factors that promote better coping by mothers of premature babies in the face of adversities experienced in their daily lives, and the role of nursing in the experience of mothers of premature babies. It was attested that these women go through many emotions, face challenges, and make use of strategies to care for their child. All these aspects, most of the time, go unnoticed by the health team, however, nursing has emerged as an essential element in this difficult trajectory. This study reinforced the idea that the focus of nursing care should be on the assisted subject and not just on the technical part involved in care.

Descriptors: Infant, Premature; Neonatology; Perception; Mother-Child Relations; Nursing.**Resumen**

El objetivo fue describir la percepción de las madres de prematuros sobre la prematuridad y analizar cómo esta percepción refleja los cuidados de enfermería brindados. Se trata de un estudio descriptivo con enfoque cualitativo. El escenario fue una Unidad de Cuidados Intensivos Neonatales, ubicada en la ciudad de Cabo Frio, en el Estado de Río de Janeiro. Los sujetos fueron 8 madres de recién nacidos hospitalizados en la institución. Las categorías analíticas del análisis fueron: Sentimientos que guían a las madres de bebés prematuros; desafíos de las madres de bebés prematuros que enfrentan el cuidado de su hijo; factores que promueven un mejor afrontamiento por parte de las madres de prematuros frente a las adversidades vividas en su vida diaria, y el papel de la lactancia en la vivencia de las madres de prematuros. Se constató que estas mujeres atraviesan muchas emociones, enfrentan desafíos y hacen uso de estrategias para cuidar a su hijo. Todos estos aspectos, la mayoría de las veces, pasan desapercibidos para el equipo de salud, sin embargo, la enfermería se ha perfilado como un elemento esencial en esta difícil trayectoria. Este estudio reforzó la idea de que el enfoque del cuidado de enfermería debe estar en el sujeto asistido y no solo en la parte técnica involucrada en el cuidado.

Descriptores: Recien Nacido Prematuro; Neonatología; Percepción; Relaciones Madre-Hijo; Enfermería.**Resumo**

Objetivou-se descrever a percepção de mães de prematuros acerca da prematuridade e analisar de que forma esta percepção reflete o cuidado de enfermagem prestado. Trata-se de um estudo descritivo, com abordagem qualitativa. O cenário foi uma Unidade de Terapia Intensiva Neonatal, localizada no município de Cabo Frio, no Estado do Rio de Janeiro. Os sujeitos foram 8 mães de recém-nascidos hospitalizados na instituição. As categorias analíticas provenientes da análise foram: Sentimentos que norteiam as mães de bebês prematuros; desafios de mães de prematuros frente ao cuidado de seu filho; fatores que promovem um melhor enfrentamento das mães de bebês prematuros diante das adversidades vivenciadas em seu cotidiano, e o papel da enfermagem na vivência de mães de bebês prematuros. Foi atestado que estas mulheres passam por muitas emoções, enfrentam desafios e lançam mão de estratégias para o cuidado de seu filho. Todos estes aspectos, na maior parte das vezes, passam despercebidos pela equipe de saúde, no entanto, a enfermagem emergiu como um elemento essencial nessa dura trajetória vivida. Este estudo permitiu reforçar a ideia de que o foco da assistência de enfermagem deve estar no sujeito assistido e não apenas na parte técnica envolvida no cuidar.

Descriptores: Recém-Nascido Prematuro; Neonatologia; Percepção, Relações Mãe-Filho; Enfermagem.

Introduction

According to the Ministry of Health, are considered premature neonates who have not completed a gestational age equal to 37 weeks, that is, up to 36 weeks and six days or 259 days, counted from the first day of the last menstrual period. Newborns weighing less than 2,500 grams, considered to be of low birth weight, also fall into the risk group, being susceptible to admission to the neonatal Intensive Care Unit (ICU)¹.

The rate of prematurity in Brazil (11.5%) is almost twice that observed in European countries, with 74% of these being late preterm (34 to 36 weeks of gestation). Many cases can result from iatrogenic prematurity, that is, removed without indication, in women with scheduled cesarean sections or incorrect assessment of gestational age².

The World Health Organization (WHO) considers prematurity as a worldwide problem, mainly because of its relationship with neonatal mortality. Brazil is among the ten countries with the highest rates, which are responsible for 60% of premature births in the world. Currently, neonatal mortality in the country is responsible for almost 70% of deaths in the first year of life, and adequate care for the newborn has been one of the challenges to reduce infant mortality rates³.

Still on Brazil, data reveal that in 2010, 7.2% of all live births were preterm. It has also been registered an increase in the incidence of prematurity and low birth weight in capitals and larger cities in the country, such as Rio de Janeiro (12%) and Pelotas (16%), which has been a source of great concern⁴.

The increase in the incidence and prevalence of prematurity is an event that concerns health managers across the country, constituting a complex public health problem, as it is a multifactorial issue that is interrelated and can vary in different populations³.

Given the alarming number of cases of prematurity in the country and its impact on the health system, it is necessary to carry out research on this topic to improve the management of this situation. The investigations carried out should focus on the statistical and epidemiological nature, but they also need to discuss the psychological and social issues surrounding this child and his family, as everyone is affected by this condition, and therefore need to know how to deal with it.

In this context, the position of the mother of a preterm newborn regarding prematurity is considered. This is because, with the early birth of the baby and the need for prolonged hospitalization in a neonatal ICU, this woman experiences a reality far from what was expected, and her feelings may fluctuate according to the child's evolution.

In association, this premature birth leads to the separation of the mother-infant affective bond, in addition to generating fear and anxiety due to the uncertainty of the newborn's clinical evolution. The mother can also blame herself for the impossibility of caring for her own child, which is not possible due to the fragility that surrounds this child, which requires specialized care from the health team. Furthermore, the environment itself, made up of so many

Prematurity and hospitalization, which follow childbirth, become an anxiogenic and distressing phase for the whole family. The mother, father and baby triad are shaken by the forced separation, which can lead to serious problems, resulting from fundamental processes that should happen in the beginning of the child's life⁵.

As it is the team that spends the most time with the clientele, nursing plays a decisive role in the quality of care for premature infants and their families. Establishing care flows and consolidating the therapeutic bond from admission to discharge provide support and balance in maintaining the newborn and family's needs. Such attitudes aim at the conjunction of a harmonious environment, which promotes safety and humanization¹.

Bearing in mind the importance of nursing for care in front of prematurity and considering that the mother represents the family member who spends the most time hospitalized with the newborn, discussions about the mother's conceptions about all aspects become significant. Involved in prematurity. By knowing the real needs of this woman, the nursing team, especially the nurse, acquires conditions to intervene in a targeted way, making care more directive and, therefore, effective.

Through the above, the objective was to describe the perception of mothers of preterm infants about prematurity and to analyze how this perception reflects the nursing care provided.

Methodology

This is a descriptive study with a qualitative approach. Descriptive research aims to identify, record and analyze characteristics that relate to the process. The qualitative approach is characterized by not being concerned with numerical representation, with in-depth results being obtained by investigating the expectations of the study subjects⁶.

The study setting was a small-sized, 13-bed Neonatal Intensive Care Unit, privately administered, but with some beds intended for care by the Unified Health System, is in the municipality of Cabo Frio, in the state of Rio de Janeiro.

The research subjects were 8 mothers of newborns hospitalized at the institution, who met the following inclusion criteria for the study: being over 18 years old and having a premature newborn. Mothers of premature babies over 30 days old were excluded from the research.

The number of research participants met the data saturation criterion, which refers to the guiding principle of ceasing data collection when no new information is obtained and redundancy is reached, which occurred when the above-mentioned number of subjects was reached⁷.

Data collection took place through interviews based on a semi-structured instrument designed for this study, which was audio-recorded and later transcribed for analysis. This step took place in September and November 2018. After



"[...] with me it was fear because I didn't know if he would survive [...]" [ACACIA].

"[...] but when he was serious I went home to sleep afraid the phone would ring [...] the fear is that something will happen" [JASMINE].

Seeing your child so small, fragile, and requiring so much care, this concern increases, because the pregnancy did not go until the moment of completion of training.

Restlessness is usually present after the birth of a premature child, extending during hospitalization due to insecurity in its survival. After hospital discharge, this feeling is reinforced by the incessant search for answers that improve their development¹⁰.

Another feeling identified in the testimonies was the sadness the participants experience because of their life situation, as pointed out below:

"[...] I only knew how to cry, from Tuesday to Thursday, I used to talk about this girl I opened my mouth to cry [...]" [DAISY].

"[...] I was sad because I saw him like this [...] I only knew how to cry" [VIOLET].

The sadness that affects these women comes from the feeling of impotence they experience, who see so many problems around their baby and cannot do anything to change the situation. In addition, this mother idealizes her baby, who will take him home with her and, in view of this situation, she is forced to move away and leave him in the care of others.

Prematurity influences the mother's interaction with her baby, as this is hospitalized while the mother is forced to go home alone. This generates in this woman a strong feeling of frustration and the fantasy of not having been able to complete the pregnancy, having given birth to an unfinished baby.¹¹

All fear and sadness shown above are linked to a greater feeling of these mothers, which is the love for their children. The following statements demonstrate that the affection and zeal they feel for their babies cause all this anguish and concern, which are consequences of the uncertainties surrounding the prematurity situation.

"[...] an emotion, at the same time a concern, all together...when I got here I couldn't even touch it, just look, but I was relieved to see she was here [...]" [AZALEA].

"[...] It was very difficult, but now I'm better, happier, to see that he's reacting better" [ACACIA].

"[...] emotion, at the same time a concern, all together" [DAISY].

Even in the face of the exhausting routine of coming and going to the hospital, or the full-time stay with premature babies, the mothers showed that the affection and affection resulting from love, overcome the feelings of fear, insecurity, and sadness.

Taking care of these children is directly linked to love and care, elements that constitute the central nucleus of social representations that reflect maternal care in the face of premature children. Love is related to the role of a

collection, the data were analyzed using the Bardin Content Analysis method⁸, a strategy that can be defined as a set of communication analysis techniques aimed at obtaining, by systematic procedures and objectives of description of the content of the messages, indicators that allow the inference of knowledge related to the conditions of production and reception of these messages.

Content analysis took place in the thematic modality, following the steps pre-established by the adopted methodological framework, namely: pre-analysis, material exploration and data processing.

The pre-analysis contemplated the organization of the material to be used, arising from the transcription of the interviews, with the aim of making it operational, systematizing the initial ideas. Then, the empirical material was briefly read, with an initial identification of relevant aspects that met the objectives of the study.

In the material exploration stage, meaning units relevant to the research context were identified, which were codified and grouped thematically, giving rise to previous analytical categories.

In the third and final stage, data processing, there was the inference and interpretation of the established categories, based on a critical and reflective analysis, based on relevant and significant theoretical references.

In this study, all ethical aspects provided for in Resolution No. CNS-466/12, of the Ministry of Health, which establishes the guidelines and regulatory standards for research involving human beings, were respected⁹. The research was approved by the Research Ethics Committee of the Universidade Veiga de Almeida, under the embodied opinion nº 2.907,198, of September 20, 2018.

Results and Discussion

Eight mothers of premature babies who met the inclusion criteria defined for this research participated in the study. The age group of these women was between 30 and 36 years old, with premature children hospitalized for about 3 months.

The data showed that there are countless circumstances and countless obstacles experienced by mothers who have premature babies.

The testimonies allowed, after carrying out the content analysis in all the steps described above, the elaboration of the following analytical categories, which will be presented and discussed below: feelings that guide mothers of premature babies; challenges of mothers of premature babies facing the care of their child; factors that promote better coping by mothers of premature babies in the face of adversities experienced in their daily lives, and the role of nursing in the experience of mothers of premature babies.

Feelings that guide mothers of premature babies

The study pointed out that there are many feelings experienced by research participants, with the fear of the baby's death being the most widely indicated. This data is shown in the lines below.



mother in her life with her child, and care represents the attitude regarding the desire to see her child improve every day⁵.

Challenges of mothers of premature babies facing the care of their child

The daily lives of mothers of premature babies are surrounded by obligations and responsibilities that are imposed on them, affecting their daily lives. Such assignments result from the demand for care that these babies require due to their health condition. The research demonstrated the consequences of this care routine caused in the study participants and that they represent significant challenges that they overcome each day.

The testimonies elucidated that mothers feel intense physical wear and tear caused by this routine, as shown in the statements below:

"[...] I'm more tired [...] the body, the mind is worn out [...]" [JASMINE].

"[...] tiring, I'm operated on, I caught the flu there so it all accumulates" [ROSE].

When analyzing these mothers, tiredness can be seen on their faces, many lose weight faster, as they stop eating, and the vast majority have more children, having to share the attention with others, which leads to physical wear and tear. intense emotional.

All this exhaustion is associated with the reality of the newborn, who is in a state of absolute dependence, requiring the other to fully donate to their self-conservative and affective care, making all the necessary connections between them and their world⁵.

Another situation identified in the speeches of the participants, which arises from the daily routine of caring for their children, is the insecurity they feel to take on the care that their baby needs, as shown below:

"[...] I'm afraid, at home there will be no way to see saturation, to know if the heart is racing, especially when he feels short of breath [...]" [JASMINE]

"[...] I think I'm unprepared, there's a lot of care [...]" [AZALEA].

"[...] I believe he needs more specific care that I can't give [...]" [VIOLET].

Preterm mothers are experiencing a new moment. Seeing small babies, non-standard, and with care from medications in pump, monitors, and a whole team participating in such care, this ends up making these mothers feel unprepared for their baby's care.

The need for babies to remain in incubators, monitored by different equipment, prevents, or at least makes it difficult for the mother to start caring for her child. Faced with this impossibility of taking care of her own child, the mother is affected by extreme insecurity and anxiety, which makes it even more difficult to contact the baby, who does not respond satisfactorily to the mother's stimuli at that time⁵.

Factors that promote better coping for mothers of premature babies in the face of adversities experienced

In the face of difficulties, people make use, even if unconsciously, of ways to better face difficult situations. The mothers interviewed revealed some of these ways, which help them to accept the condition of prematurity in a better way.

Faith in God represents one of these coping mechanisms, as illustrated in the statements below:

"[...] in my head I have to find some way to repay all that God has done for me, for other people" [DAISY].

"[...] he tiny there, and I thought my God in heaven does he have a chance? [...] I ask God to help me, give me direction [...]" [JASMINE].

Religiosity can be understood as the individual's relationship with a religious institution or church or by other religious understandings, which obeys a belief or practice of some public religious rituals, proposed by a certain religion. Spirituality is defined as a characteristic of the individual, which may include belief in a God, and establish a spiritual link between the being and the cosmos and with other people. Thus, spirituality involves questions and reflections on the meaning and purpose of life, which transcends religion or religiosity¹².

Religiosity is used to encourage the hope of a cure and structure life during treatment. The possible benefits achieved by religious beliefs, in some situations experienced in the expectation of death, are relief from fear and uncertainty, coping and emotional comfort¹³.

Brazil is a country descended from multinationals, which reflects a nation with different religions, where a good part of the people put their problems in God's hands, placing their faith in Him. In God individuals seek the resolution of their problems and find in Him strength to continue fighting.

It was also clear in the study that the participants use their own internal mechanisms to face the adversities arising from prematurity. This inner strength can be understood as a set of internal stimuli that the individual has that helps them to better adapt to the situations they experience. This statement is proven in the following statements:

"It was very tense, I thought I couldn't stand it, I thought I was going to die, I didn't think I would have this structure" [VIOLET].

"[...] The day is every day a day, not thinking about tomorrow is thinking about each day winning" [ORCHID].

"[...] but the strength comes and the thought that is ending, a daily struggle [...]" [JASMIM].

The excerpts above reveal that mothers of preterm infants, despite the weakness and tiredness felt, are strong women, who believe in their child's recovery and fight for this to happen, striving to be present at the hospital and at every stage of the baby, learning to deal with them to take care of them and see the expected improvement.

As already pointed out, there are internal stimuli that represent true adaptation mechanisms. The stimulus is



identified as an element that provokes a response, it can be internal or external, and includes all the conditions, circumstances, and influences around the person, which affect their development and behavior considering the circumstances they face¹⁴.

The role of nursing in the experience of mothers of premature babies

The reports showed that the nursing team plays an extremely important role for mothers of preterm infants in terms of the experience of prematurity.

The testimonies attest that nursing care for these women permeates the technical part of care, reaching a welcoming and humanized level.

"The (nursing) team, I have nothing to complain about, it is essential, as it plays our role as a mother, which is to care, be with the child, give affection" [DAISY].

"[...] they do (nursing) in the sense of taking care of him, take care of us like a mother [...] words of comfort and explanation, so in addition to giving that feeling that my son is well cared for [...]" [JASMINE].

"The nursing team is very blessed, very good, not only with him" [LILY].

As seen, mothers find a support network in the nursing team. Mothers observe these professionals constantly taking care of their baby and want to learn from them the care, depositing in this team the hope of adequate assistance, which promotes the improvement of the newborn.

Given the importance of the nursing team, it is worth noting that these professionals must also accompany mothers to prepare them for home care, equipping them to deal with possible complications. It is essential to reassure these women about the development of their child, making them understand that, although the responsibility for care at home is predominantly hers, her love, effort, and dedication will allow for effective care¹⁰.

Thus, it is necessary to understand that the nursing team must involve not only the newborn in the care during their hospitalization, but also gather their universe of relationships, considering that the family and the child become a single client. From this conduct, the focus of care will be centered on humanization and will make the family also feel welcomed and valued¹⁰.

Final Considerations

This study achieved the proposed objectives, identifying the main perceptions of mothers about prematurity, confirming the reflection of the nursing care experienced by them.

In this context, it was attested that these women go through a range of emotions, face challenges and make use of numerous strategies in their daily care of their child. All these aspects, most of the time, go unnoticed by the members of the health team, however, nursing was represented by the participants, as an essential element in this difficult trajectory.

These data prove the importance of nurses being able to recognize the undisclosed indicatives that surround their patients, as only the proper care of subjective aspects promotes complete care. Taking care of the inner needs of the clientele is as important as assisting the technical and clinical aspects.

The role of nursing is of paramount importance in the entire process of understanding and coping, making it necessary to plan assistance that favors the quality of care and promotes maternal well-being, preparing and strengthening the emotional bonds between mother and baby.

Thus, this study contributed to the identification of the needs of these mothers and framed the nursing team as an important support network, reinforcing the idea that the focus of care should be on the assisted subject and not just on the technical part involved in the care. Only in this way, the mother, the premature baby, and other family members will be welcomed effectively and will have a truly humanized care reflected in them.

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