

## NURSING MOTHERS' PERCEPTIONS WHEN EXPERIENCING PREMATURE IN THE NEONATAL INTENSIVE CARE UNIT

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### ABSTRACT

**Objective:** to understand the nursing mothers' perception when experiencing the hospitalization of their premature neonates in an intensive care unit of a public hospital from Distrito Federal, Brazil. **Method:** a qualitative research study involving 11 nursing mothers and 24 medical records of those women and their neonates, including two twins. The data were collected between September 2019 and April 2020. The quantitative and qualitative data data were analyzed by means of descriptive statistics and through content analysis, respectively. **Results:** three categories emerged, which involved the hospital routine and the psychosocial and family impacts. Fear of complications and death, insecurity, anguish and changes in the social and family routine were evidenced. The support mechanisms involved psychological appointments, visits to the infant, family support and interaction with the team. **Conclusion:** the findings contribute to maternal and neonatal care by providing professionals and managers with an understanding of aspects inherent to human subjectivity that can exert an influence on care.

**DESCRIPTORS:** Hospitalization; Neonatal Nursing; Premature Newborn; Mother-Child Relationships; Health Care.

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## INTRODUCTION

Preterm birth persists worldwide as a worrying issue, which exerts direct impacts on infant morbidity and mortality and on the quality of the maternal and neonatal care offered. According to the World Health Organization (WHO), 15 million infants are born prematurely in the world each year<sup>1</sup>. In 2017, around 2.5 million newborns died in the first 28 days of life, most of them due to preventable causes<sup>2</sup>. More than 60% of the preterm births occur in Africa and in Southern Asia. In general, in low-income countries the mean percentage of preterm births is 12%, when compared to 9% in high-income countries<sup>1</sup>.

Prematurity often requires treatment in Neonatal Intensive Care Units (NICUs). In this context, a research study conducted with 126 neonates hospitalized in NICUs in southern Brazil revealed that they were born with a mean of 33 gestational weeks, and that 78.4% were premature. In 26.1% of the cases, the reason for preterm delivery was preeclampsia, followed by urinary tract infection (15.9%), preterm labor (14.5%), membrane rupture (14.5%) and oligohydramnios (11.6%). Prematurity was the main reason for hospitalization (69.6%), followed by hyaline membrane disease (41.3%), respiratory dysfunction (11.2%) and transient tachypnea in the newborn (10.4%)<sup>3</sup>.

Preterm birth can cause numerous short- and long-term complications for the neonate, such as brain injury, severe bacterial infection, jaundice and/or congenital conditions<sup>4</sup>, as well as it can also affect school-age children for being at an increased risk of presenting learning difficulties<sup>5</sup>.

In relation to the mothers, prematurity is more frequent among women with multiple pregnancies, inadequate prenatal care, and who had already undergone induced deliveries and C-sections<sup>6</sup>. Extending beyond the neonatal complications, a mother who has a premature infant is at risk of developing long-term conditions such as hypertension and kidney and cardiovascular diseases, as well as complications in subsequent pregnancies<sup>4</sup>.

In relation to the consequences of prematurity for the family, it was found that health problems, anxiety and fatigue were more common in mothers of preterm infants, and that the women who had less early contact with their newborns presented a higher risk of health problems and negative feelings in relation to their children and made lesser use of postnatal services and support than other mothers<sup>7</sup>. In addition to that, the impact of prematurity entails financial and psychological costs for the families, with detrimental effects on the child's cognitive and emotional development<sup>8</sup>.

Having a child hospitalized in an NICU is a stressful experience for parents<sup>9</sup>. Thus, a family-centered intervention is necessary to improve parents' involvement in the care of their infants, as well as to increase their awareness regarding the fact that they can play an active role in their children's development<sup>10</sup>.

In this context, it is observed that nurses who are part of an NICU team need diverse scientific technical knowledge, as well as to be trained to provide quality care to this clientele and their families. In the act of care, it is essential that the professionals consider and respect the mother-infant bond as something beneficial in maintenance and recovery of the newborn's (NB) health<sup>11</sup>. Consequently, it becomes essential that the professionals understand the perceptions experienced by the mother, so that they can offer more targeted and humanized care.

Considering the nonexistence of similar studies in the unit where the research was carried out and the scarcity of studies on the theme in Brazil, the intention was to elucidate this knowledge gap in order to understand the nursing mothers' perceptions when experiencing the hospitalization of their preterm infants in the intensive care unit of a public hospital from Distrito Federal, Brazil.

## METHOD

A descriptive and exploratory study with a qualitative approach. This type of research presents the subjective aspects and allows prioritizing the social subjects that hold diverse information and interpretations about their social reality<sup>12</sup>. It was developed between the second week of September 2019 and April 2020 in the Maternity sector, Nursing Mother's Ward and Neonatal Intensive Care Unit (NICU) of a public teaching hospital from Distrito Federal. The population consisted of 11 women (nursing mothers) and was delimited after reaching saturation of the testimonies obtained<sup>13</sup>. A documentary research was also carried out in the medical records of the mothers and of their respective neonates admitted to the NICU, totaling 24 documents including two mothers with twins, in order to obtain data on the obstetric and neonatal characterization of those involved.

The inclusion criteria involved women aged 18 years old and over who were in the Nursing Mother's ward and their medical records, as well as those of their respective premature neonates, with or without associated comorbidities, admitted to the NICU. Women with mental or physiological disorders that prevented them from speaking and interacting with the researchers were excluded, as well as those who refused to participate in the research and/or did not sign the Free and Informed Consent Form and the Authorization Form for the Use of Voice Sound for research purposes.

For data collection, an instrument divided into two parts was used: the first with structured questions referring to the characterization of maternal and neonatal profiles; and the second, with subjective and open information regarding the mothers' perceptions about prematurity. The second instrument was previously tested by two of the study researchers with two nursing mothers, and it was readapted to ensure greater understanding in the participants.

The interviews were recorded and transcribed in full, and the transcribed data were checked with those collected by the two researchers, one being a Nursing student with a Scientific Initiation scholarship and the other a professor, advisor and researcher in charge of a public Higher Education Institution. It is noted that the student underwent previous training for data collection and was supervised in all the stages, including data analysis and coding.

A field diary was used to capture impressions about the setting and about the participants. The women were approached in the Nursing Mother's ward during the rest intervals and invited to participate in the study in a private room. Each interview lasted a mean of 30 minutes. The letter "M" was used to ensure anonymity, followed by the subsequent numbers corresponding to the interviews. The data were processed based on reading and interpretation through content analysis<sup>13</sup>. The following stages were conducted: organization of the testimonies, categories, comparison of the analysis, reading, data classification and coding, identification of the analysis units; grouping of the data obtained, interpretation of these results, and elaboration of the syntheses that emerged from the interviews. According to the recommendations for methodological rigor, it was decided to use the list of consolidated criteria for qualitative research studies<sup>14</sup>.

The study was approved by the Research Ethics Committee of the Health Sciences School of the University of Brasília, under opinion No. 3,467,635.

## RESULTS

The mean age of the nursing mothers participating in the research was 28 years old. Their gestational age at birth varied from 24 to 36 weeks. The maternal diagnoses

corresponded to: premature rupture of the ovular membranes, urinary tract infection, pregnancy-specific hypertensive disease, twin pregnancy with fetal-fetal transfusion, gestational diabetes, chorioamnionitis and uterine prolapse. In relation to schooling, four had incomplete High School, five had completed High School and two had graduated from Higher Education courses. Regarding marital status, seven participants were married, three were single, and one was in a stable union. In relation to their occupations, five mothers reported being unemployed and there was a housewife, two clerk assistants, a butcher, a businesswoman and a physiotherapist. Regarding monthly income, seven mothers earned between two and three minimum wages, two earned more than three wages and another two earned up to one minimum wage.

In relation to the neonatal characterization, it is worth noting that there were 13 neonates, nine from single pregnancies and four from two twin pregnancies. All the infants were in the NICU, with five to 29 hospitalization days. Seven neonates were born through C-sections and four in normal deliveries. The prevalent diagnoses were as follows: respiratory distress, presumed early sepsis, intrauterine growth restriction, Down Syndrome, heart disease, fetal-fetal transfusion, anemia and pulmonary hemorrhage. All presented neonatal complications: one required mechanical ventilation, four were on continuous positive air pressure, and eight were subjected to catheterized oxygen therapy at the moment of the interviews.

Three analytical categories emerged, namely: Perceptions and experiences of the nursing mothers regarding the impact of the hospital routine; Psychosocial and family impact on the nursing mother's perception; and Multiprofessional support for the nursing mothers when their infants were hospitalized. The following was evidenced: satisfaction with the care offered, fear of complications and death of the infant, insecurity, anguish, general fear and changes in the social and family routine. The mothers' support mechanisms involved the following: psychological appointments, visits to the infant, family support and interaction with the multidisciplinary teams of the NICU and of the Nursing Mother's ward.

### **Perceptions and experiences of the nursing mothers regarding the impact of the hospital routine**

This category reflected the nursing mothers' perception, their feelings and their thoughts about their experiences in the hospital environment, their routines in relation to the assistance provided by the multidisciplinary team, and their roles in monitoring their neonates hospitalized in the NICU.

The participants reported fear of the unknown and yearning for their children's improvement; they externalized the challenges of hospital stay, impaired self-care, and daily fatigue related to constant milking for their newborns, affecting rest. Some reported a sensation of imprisonment and relegation of self-care to the background, given that their presence is a priority for the recovery of their infants. The subcategories found were as follows: hospital routine, powerlessness, impaired mother-child bond, and self-care. The reports are presented below:

*Staying close to the baby is the best thing for me, but it's tiring. I can't rest... I have to go downstairs to get the milk, every three hours, and I'm worried about being close... to see what they're doing (M2).*

*I don't feel so much of a mother with my son in the ICU, because I don't have this whole thing of bathing him, dressing him, taking care of him, those things... The environment is heavy... Sometimes you just want to run away, leave everything behind and escape (M3).*

*You'll only find desperate mothers here... You see your child suffering, being punctured all the time... and you can't do a single thing, so it hurts so much... And in relation to taking care of myself, I don't even want to know a thing about my health. Because my priority is his health (M5).*

*It's kind of that I still don't feel like a full mother because I haven't even been able to take the baby yet... I feel powerless... But my presence here... I think that it must help him, somehow (M6).*

*I can't take care of myself here, just the basics. Now, now it has to be her first, then me (M8).*

*As for me, it has changed. It changed in all senses, kind of... Hair, I'm not in the mood for that, now I'm just thinking about him and then I end up forgetting about myself a little bit (M9).*

## **Psychosocial and family impact on the nursing mother's perception**

Through social and family arrangements set up to deal with the changes caused and the full demand of the nursing mothers as part of the treatment instituted for the neonates, the women brought up reflections on the importance of the support network, mostly represented by close family members such as their partners, aunts, mother, father, mother-in-law and siblings. All of them recognized the network as fundamental in the face of the hospital stay and monitoring of their infants in the NICU. Due to the changes imposed on the social and family routine, the conflicting perception of the role of being a mother and wife and the concern for other children was verified in the reports presented. The subcategories identified were the following: support network, family, and home.

*There were moments when the other [daughter] at home started to feel sad, and then I feel... I'm not taking care of the one there, nor the one here... Since I came in here, I haven't been home... I even forgot that my house was colorful (M3).*

*I do have my family. My husband actually, just him. He comes to visit them. But it's only us (M4).*

*I have. My husband, my mother and my sister. They all help me. They even stay at home with my other daughter because, as my husband works during the day, my mother and sister take turns (M2).*

*If you see how I am with my kids, I call them my life, my love. I even blocked him [husband] on my cell phone... because I need some time for myself... my issue, no one is feeling my pain. I'm sad. No way for me to be happy (M5).*

*Me but he [husband] is closer and my family too... it changes everything... my job: the hell with it. Life outside, I don't care. I think that it's just him now. Then my husband asked: "Are you coming home?" But what am I going to do there? My life is here now. It's kind of like that (M6).*

## **Multiprofessional support for the nursing mothers when their infants were hospitalized**

This category is related to the recommendations, guidelines and emotional support provided by the health team to the mothers. Most of them showed to be satisfied for receiving guidelines from the health team referring to how to manage the neonate's care, reporting that they felt confident and able to perform it. They also underwent follow-up with a psychologist. Some of them highlighted the importance of searching psychological support, anguish relief and better preparation to deal with the situation. They also mentioned that the daily guidelines provided by the professionals helped them improve their emotional aspects. The subcategories were multiprofessional support and mental health, according to the following reports:

*They [professionals] were always really available to give information. I have nothing to complain about. But then the psychologist's guidelines end up helping, it brings some*

*relief, I managed to let some steam off. I have nothing to complain about the team, the technicians, the nurses. I lack nothing. I received so much help, the entire medical team knows my whole story (M3).*

*[Psychologist] He was good, not only with me, but also with the other mothers, right? Because sometimes there are people who are psychologically weaker than others. Just like now in this moment, that I feel alone. You have your child, you have your family, but you feel alone (M5).*

*The psychologist comes, talks a little with me and asks me if I need to talk, it's just looking for them, I go to a reserved place and that's it. It makes me vent a little (M6).*

*I already went to a psychologist. It was good for me because I was crying too much. She talked to me and my husband and solved a lot of things, I was really relieved, because I was crying too much... It made a big difference for me (M8).*

*So, at the moment I'm pretty shaken by everything that's going on. In relation to the service they're providing to the baby, I'm really satisfied (M9).*

## DISCUSSION

Referring to the findings of the sociodemographic and obstetric characterization, a study conducted in Brazil obtained similar results, related to age group, maternal diagnoses that caused the preterm births, occupation and schooling. Diverse evidence points out that low schooling can be associated with neonatal mortality<sup>15</sup>.

It is indispensable to consider the social determinants that interfere in the occurrence of prematurity and, consequently, in the higher risk of neonatal deaths. A study carried out in Jordan and that evaluated the incidence, risk factors and mortality of preterm infants describes lower levels of maternal schooling, together with low socioeconomic status, as an independent causal factor for preterm births and increased neonatal morbidity<sup>16</sup>.

In relation to the first category, Perceptions and experiences of the nursing mothers regarding the impact of the hospital routine, a Brazilian research study evidenced that premature births implied changes such as reconstruction of the formation of the mother-child bond, demand for intensive care, interventions in the reestablishment of breastfeeding, and the possibility of compromising the future quality of life of the newborns, their mothers and their families<sup>17</sup>. In this study, the impact caused by the sudden change in the social and family routine when experiencing the treatment of their hospitalized infant was observed, corroborating the findings.

Another research study, conducted in a Brazilian NICU, revealed that the mother-infant relationship was impaired due to the premature separation and to the hospitalization of the neonate. A number of barriers represented by the incubators and by several devices were also identified, hindering natural bonding<sup>18</sup>. Likewise, the findings reveal such barriers, in addition to distancing from the women's maternal role as the care under their responsibility was delegated to the health professionals.

The emotional impact of preterm birth was verified in another study conducted with 16 mothers of critically-ill neonates, resulting from their stay in the NICU, which led the women to feel anxiety, a sense of loss of control and fear of fatal complications in their children<sup>19</sup>, as verified in this study. Other results point to the nursing mothers' difficulty when they see themselves totally focused and involved in their infants' care routine and distanced from reality, where everything revolved around hospitalization. As well as in this study, in most of the cases the mothers renounced to their social freedom to stay close to their infants<sup>20</sup>.

Regarding the second category, a study conducted in Brazil involving mothers of neonates in a critical condition revealed difficulties dealing with the hospital environment and with being distanced from the infants, verifying the need to maintain a support network. The main support sources verified were family members and close friends<sup>21</sup>, similarly to the findings related to family assistance as a support network.

Similar findings from other evidence show that the experience of having a premature infant can be painful for the mother, due to uncertainty regarding the child's survival. Therefore, admission of the premature neonate to the NICU interrupts the bond that is established between the binomial since pregnancy, generating in the mother a mixture of joy for the child's survival and anguish and sadness for the separation<sup>22</sup>. In the results presented, the mothers also mentioned the issue of emotional pain due to the situation experienced.

Regarding the third category, the results of a study conducted with mothers of premature infants pointed out that the presence of a multiprofessional team that supports the women during their own and their infants' stay in the NICU is of paramount importance, providing them with clear guidelines regarding the care to be provided to the child<sup>22</sup>. Similarly to this study, the mothers reported satisfaction and relevance regarding the professionals' guidelines to safely perform their roles in the treatment and recovery of their infants.

Another Brazilian research study verified the need for the multiprofessional health team to welcome the family, encouraging adherence to the care measures. The mothers of premature infants presented feelings of incompetence in caring for their children. The stress experienced remains for an extended period of time, until they feel confident in relation to their children's health<sup>23</sup>.

Other findings showed that the experience with the infant was fundamental for the mothers to develop self-confidence and the maternal role. The mothers' gradual inclusion fostered by the team made them consider themselves more competent in caring for their children. It also pointed to the role of the professional nurse as a mediator in the process of developing maternal autonomy for care<sup>24</sup>.

In relation to mental health, corroborating the results presented, other findings indicated that, for nursing mothers, feelings such as concern, insecurity, sadness, fear, despair and guilt were verified with the birth and hospitalization of their premature infants. In the participants' testimonies, psychological support was essential to face the situation and develop the so much yearned family bond<sup>25</sup>.

The limitations of this study are based on the specific aspects inherent to qualitative research, which allows for an in-depth understanding of the subjectivity of the research participants' reports, not allowing to verify analytical associations and generalizations that point to possible replications of the results. In addition to the limitation of the method, the sample size indicated the researchers' difficulties recruiting participants, with a limited representation of the target population, reaching a minimum number in which saturation of the testimonies was reached.

## CONCLUSION

The study allowed an in-depth understanding of the nursing mothers' experiences when faced with prematurity of their neonates hospitalized in the NICU. The qualitative analysis approach allowed evidencing their routines, fears, anguish, weaknesses, insecurities and coping strategies in the face of the dissociated role of being a mother. It was possible to learn details about the necessary support network for them to stay strong and resilient

during the entire process, as well as about the support mechanisms in order to preserve their mental health.

The findings should be strongly considered and they evidence implications for the professional practice, as they corroborate other studies and contribute to guiding care from the understanding of the universe of nursing mothers and their demands, which exert a significant impact on quality of life and can affect the entire neonatal care process. The results revealed the importance of an ongoing process for monitoring, welcoming and guiding the mothers, and can contribute to qualifying the professionals who work in neonatal care, based on the understanding of the demands of mothers who are in a situation of distress and vulnerability.

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