







Original article

Experiences of mothers of untimely babies: from pregnancy to home care

Vivências de mães de bebês prematuros: da gestação aos cuidados no domicílio

Experiencias de madres de bebés prematuros: desde el embarazo hasta la atención domiciliaria

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Abstract

Objective: recognizing the experiences of mothers of untimely babies from pregnancy to home, after hospital discharge. **Method:** a qualitative, descriptive and exploratory study developed with 16 puerperal women in a Children's Polyclinic, in December 2020, through semi-structured interviews, submitted to Thematic Content Analysis. **Results:** the experiences of pregnancy involved both the absence and the presence of risk factors. At birth, it was observed the separation of the mother and the baby, with few orientations on the reasons for their stay in the Neonatal Intensive Care Unit. In hospitalization, the mothers showed emotional and physical exhaustion in the face of changes in routine. At home, they sought to keep the care developed in the hospital environment. **Conclusion:** it is fundamental the sensitive and attentive look of health professionals regarding the orientations provided to women and their families, allowing greater understanding of issues related to prematurity.

Descriptors: Neonatal Nursing; Premature Labor; Premature Birth; Premature Newborn; Intensive Care Units

Resumo

Objetivo: conhecer as vivências de mães de bebês prematuros da gestação até o domicílio, após a alta hospitalar. **Método:** estudo qualitativo, descritivo e exploratório, desenvolvido com 16 puérperas em uma Policlínica Infantil, em dezembro de 2020, por meio de entrevistas semiestruturadas, submetidas à análise de conteúdo temática. **Resultados:** as vivências da gestação envolveram tanto a ausência como a presença de fatores de risco. No nascimento, observou-se a separação da mãe e do bebê, com poucas orientações sobre as razões da permanência deste na Unidade de Terapia Intensiva Neonatal. Na internação, as mães demonstraram desgaste emocional e físico diante das mudanças na rotina. Já no domicílio, elas buscaram a manutenção dos cuidados desenvolvidos no ambiente hospitalar. **Conclusão:** é fundamental o olhar sensível e atento dos profissionais de saúde quanto às orientações fornecidas à mulher e sua família, permitindo maior compreensão sobre as questões ligadas à prematuridade.

Descritores: Enfermagem Neonatal; Trabalho de Parto Prematuro; Nascimento Prematuro; Recém-Nascido Prematuro; Unidades de Terapia Intensiva

Resumen

Objetivo: conocer las experiencias de las madres de bebés prematuros desde el embarazo hasta el domicilio, tras el alta hospitalaria. **Método:** un estudio cualitativo, descriptivo y exploratorio desarrollado con 16 mujeres puerperales en un Policlínico Child, en diciembre de 2020, a través de entrevistas semiestruturadas, sometido a análisis de contenido temático. **Resultados:** las experiencias de embarazo implicaron tanto la ausencia como la presencia de factores de riesgo. Al nacer, se observó la separación de la madre y el bebé, con pocas orientaciones acerca de los motivos de su estancia en la Unidad de Cuidados Intensivos Neonatales. En la hospitalización, las madres mostraron agotamiento emocional y físico ante los cambios en la rutina. En casa, buscaban mantener la atención desarrollada en el ámbito hospitalario. **Conclusión:** es fundamental la mirada sensible y atenta de los profesionales de la salud en respecto a las orientaciones brindadas a las mujeres y sus familias, permitiendo una mayor comprensión de los temas relacionados con la prematuridad.

Descriptores: Enfermería Neonatal; Parto Prematuro; Nacimiento Prematuro; Recién Nacido Prematuro; Unidades de Cuidados Intensivos

Introduction

Birth labor (BL), childbirth and birth consist of unique experiences in women's lives. They can be permeated by countless feelings, which are perceived differently by each subject. This is a moment of transition, in which the woman experiences physiological and psychological changes, which enable the arrival of a child into the world.¹

However, complications may arise during the gestational period, causing preterm labor (PL).¹ This is defined by the presence of uterine contractions between 22 and 37 weeks of gestation, being related to several risk factors. Diagnosis involves the presence of contractions every five and eight minutes and dilation equal to or greater than two centimeters.² According to clinical evolution, preterm birth can be classified as elective or spontaneous. The elective

occurs, in large part, due to maternal complications, while spontaneous has multifactorial causes.¹

When a PL occurs, that is, the early interruption of the gestational period, the woman experiences changes in the natural rhythm of birth, which can be impacting due to the imposed condition of prematurity. For the newborn (NB), birth before time provides risks for life, due to impairment in development.³

Preterm birth is one of the main risk factors for mortality and morbidity early in life.³ According to the World Health Organization, there are about 15 million untimely births per year worldwide. In this context, it should be highlighted that prematurity has become the leading cause of death in children under five years of age.⁴ In the national scenario, Brazil has shown high rates of prematurity, representing one of the countries with the highest number of registered cases, around 319,000 untimely births.⁵

Considering that prematurity has become a public health problem, it is necessary to highlight that most infant deaths are concentrated in the first year of life, and prematurity is one of the causes for this event.³ Thus, the importance of the care developed during pregnancy, childbirth and postpartum is highlighted, so that preventable complications and comorbidities are identified. It is necessary to offer quality assistance, guaranteed by public policies, which contribute to lower infant mortality levels.⁶

Considering prematurity as a factor that contributes to the high rate of infant morbidity and mortality, we can see the need for advanced care for the neonatal population, as well as the use of technologies and higher professional qualification.⁷ Through the use of these resources, we seek to help in the survival and development of untimely babies.³ In view of this, care and care involve a higher level of complexity, and it is often necessary a period of hospitalization in the Neonatal Intensive Care Unit (NICU).^{3,6}

A literature review indicated the separation that occurs soon after birth between mother and untimely infant, highlighting that the broken tie in the pilot stages hinders the formation of attachment that is important for the child's healthy development. In addition, it was observed that hospitalization in the NICU generated negative feelings in mothers regarding the clinical status of the baby.³

Thus, it is perceived that untimely birth can involve a traumatizing event, capable of shaking the expectations of a mother. A study conducted with mothers of extreme preterm

infants, hospitalized in a NICU of a hospital located in southwestern Spain, revealed that untimely birth and separation of the baby weakens the process of mother and child bonding, which can cause emotional crisis, in addition to psychological distress.⁸

Thus, it is recognized that preterm birth demands complex care directed to the NB, but also implies special attention to the puerperal woman, who may find herself weakened in this process.⁵ Thus, it is considered essential to give voice to the puerperal women who experienced untimely birth, valuing their feelings, the practices of care for the baby and the difficulties faced. In this sense, the present study aimed to know the experiences of mothers of untimely babies from pregnancy to home, after hospital discharge.

Method

This is a qualitative, descriptive and exploratory study conducted through field research.⁹ Data collection was developed at the Child Polyclinic, in a city located on the Western Border of Rio Grande do Sul.

The Child Polyclinic is a public service in this city and develops care for children from zero to 24 months considered "risk", in the context of post-discharge from the NICU. On site, multiprofessional care is offered, performed by five pediatricians, a nurse, a nutritionist, a speech therapist, three nursing technicians and a hygienist. The average monthly service attendance is around 1000 consultations.¹⁰

Prior to the beginning of data collection, the principal researcher presented the research project to the team of the Children's Polyclinic. At the time, the dates, times and place for data collection were combined.

The participants were captured by the main researcher in the waiting room of this Children's Polyclinic, where they were waiting for scheduled follow-up consultations. The interviews were developed after the researcher's verbal invitation and before the child's consultation. Upon acceptance, the participant was taken, along with the baby, to a reserved room, to ensure her privacy and anonymity.

The participants of the research were 16 puerperals, invited intentionally, individually and personally. The eligibility criteria were to have experienced vaginal birth or cesarean section, when she had gestational age below 37 weeks; regardless of age group and parity; and

have a child under follow-up at the Polyclinic of the city. The inclusion of new participants was terminated when the data saturation criterion was reached.⁹ It is noteworthy that there were no refusals or give-ups during the data collection procedure. Data collection occurred in December 2020, through an individual semi-structured interview conducted by the principal researcher, who had experience with this technique. It should be noted that no pilot test was performed.

The interview involved closed questions related to the characterization of the population surveyed, as well as open questions focused on the objective of the study. The closed questions included the date of birth, schooling, marital status, religion, occupation/profession, family income, obstetric history, complications and/or injuries in the experience of the last pregnancy, date of birth of the baby, gestational age of the mother on the day of birth, weight and length. The open questions were: Tell me how the pregnancy went; Tell me how the baby was born. If the baby went to the NICU: tell me how it was during your baby's stay in the NICU; Tell me about the care practices you develop with your untimely baby; Did you take any particular care with him? Have you faced any difficulties since the baby was born? (If so, what were the difficulties? For you, how does it feel/how do you feel having/caring for a untimely baby? What have you done/done to deal with these feelings?

During data collection, prevention measures were taken due to the COVID-19 pandemic, according to the recommendations of the Ministry of Health.¹¹ The researcher and the participants used a mask, as well as gel alcohol. A safe distance between participant and researcher was kept. Disinfected pens were offered for the signature of the terms, and, after each interview, the chair, table and doorknobs were disinfected. The data production process was recorded audio with the authorization of the participants and lasted an average of 10 minutes.

The interviews were transcribed, and the data were submitted to thematic content analysis.⁹ To perform the pre-analysis stage, the interviews were reproduced in the Microsoft Word program, to use the available tools to highlight words, terms and/or meaningful expressions in the exploration stage of the material. From this, it was possible to identify the units of meaning and categories. From this, it was possible to identify the units of meaning and categories. At the end, the results obtained and interpreted from theoretical references in the maternal-child area were treated.

The research was approved by the Research Ethics Committee on July 1, 2020, under CAAE 24860619.0.0000.5323, Opinion N 4.128.128. The study was developed respecting the standards contained in Resolution N 466/12 of the National Health Council of the Ministry of Health. Mothers over 18 years of age and those responsible for minors signed the Free and Informed Consent Form. Participants under 18 years of age also signed the Free and Informed Consent Term. To preserve the identity of women, the letter "P" was used because it is the letter of the word puerperal, followed by a numeral.

Results

The participants of the study were 16 women, aged between 17 and 43. Six had incomplete elementary school and two had completed elementary school; one had incomplete high school and two had completed and four had incomplete higher education and one had complete higher education. Six were single, five had a stable relationship and the others were married. Four were Catholic, six were evangelical, three were Spiritists, three others reported not following any religion. Seven reported being "from home", four had paid fixed work, three were students, one was autonomous and the other had a possible paid work. Most lived with children and partners, with a family income between R\$800.00 and R\$2,600.00 reais.

Six were primiparous, three had already experienced abortions and twelve had undergone cesarean section in some of their previous pregnancies, and in the last pregnancy, ten participants reported cesarean birth. Women mentioned complications and/or injuries in the experience of the last pregnancy, such as untimely amniorrhexis, pregnancy-specific hypertensive diseases, untimely placental detachment, bleeding, oligohydramnio, multiparity and early (under 15) or late (over 35) pregnancy).²

Among the participants, a total of 18 children were identified, with two cases of twinning. These babies were born when their mothers were between 28 weeks and 36 weeks and six days of gestation. Their weight at birth was 1180 to 2940 grams, and the length from 36 to 48.5 centimeters. Of the total, 15 required hospitalization in the NICU and this ranged from five days to two months.

Following the data analysis, the first category entitled "The experience of pregnancy of mothers of untimely babies" was obtained. This category presents the complications that occurred during the gestational period and that influenced untimely birth, as well as other experiences marked by the absence of gestational risk. The second category addresses the

moment of birth, the trajectory of the NB in the intensive care unit and the repercussions of this hospitalization for mothers and was named "From birth to hospitalization in the Neonatal Intensive Care Unit: what do mothers have to say?".

The experience of pregnancy of mothers of premature babies

Often, prematurity is tied to the presence of risk factors identified in pregnancy. In this sense, the participants reported complications that contributed to the occurrence of untimely birth of their children. Among the interurrences mentioned, there was the loss of amniotic fluid untimely, preeclampsia and eclampsia.

I've had a lot of complications. I was threatened with an abortion. I had to take care of myself, until I started to lose fluid and got into the maternity ward. (P1)

I lost a lot of liquid. (P5)

I did the ultrasound at five months and found that I had little liquid, then already began to complicate. (P14)

I had a purse on my cervix punctured. I've been losing liquid for a long time. (P16)

When we arrived in the room, I was already convulsing on the floor, because of the very high blood pressure. (P2)

I had hypertension [...] I couldn't take the pain in my stomach anymore, I went to the hospital, I was giving myself eclampsia. (P3)

On the other hand, other puerperal women reported that they had a calm and quiet pregnancy, without complications. Nevertheless, there was a need for one participant to remain at rest due to medical guidance and another had to ask for leave from work due to the Covid-19 pandemic.

The pregnancy was quiet [...] I didn't have any sickness, I didn't have to take medicine. (P9)

The pregnancy was very quiet [...] had a little bit of blood in the placenta, in the cervix I think, then not to lose them [twins], I had to rest. (P10)

It was quiet. I had nothing, I just stopped working when this coronavirus came, then I stopped working. (P15)

Thus, it is verified that, even in situations where birth occurs untimely, the course of pregnancy can take place uneventfully. In these cases, the gestational experience is like that of other pregnant women at usual risk. However, for those who presented risk factors, there was concern about the gestational outcome, depending on the information provided by health professionals.

They were keeping me there [in the hospital], trying to hold her, until the day came that if I didn't win, I would lose her. (P1)

We got scared when the doctor said he wouldn't know if he was saving my life or the baby's.. (P2)

I was a little worried about the other time I lived it all, afraid to live it all over again [referring to the loss of one of her children who was born untimely]. (P4)

They told me it was risky, or it was me who could save it, or it was him. (P5)

Faced with the fear of losing their child, some women resorted to spiritual support. Health professionals encouraged them to seek faith and perform prayers.

The nurse herself commented there at the time, that if I had faith, regardless of any saint, I was supposed to start praying. It was only for God's sake. (P16)

I didn't know if he was going to save himself, but they were going to do everything they could to save him. I said, whatever God wants to save him. (P5)

All week I listened: Mommy prays, because at any time he can die. (P14)

From the statements, it is possible to observe the meaning attributed to spirituality. For some, the positive outcome of pregnancy was tied to a higher deity. With this, they used prayers as comfort and hope during the experience of this process.

From birth to hospitalization in the Neonatal Intensive Care Unit: what do mothers have to say?

Added to the uncertainties of pregnancy, the birth of the untimely baby was an experience marked by the separation of the mother-baby binomial and its immediate hospitalization in the NICU. Even in cases where babies presented stable clinical conditions at birth, participants reported that they could not see them.

When she was born, they [health professionals] had to take her because she didn't cry, but then she recovered well. (P1)

She was born and went straight to the ICU. (P2)

At birth, I didn't see him, because by the time they did the C-section they already picked him up and rolled him up, because he didn't cry. It seems that they called the pediatrician [...] how do you say? He'd come out dead, then the doctor saved him and took him straight to the ICU.(P3).

The birth was very quiet. I just didn't see her when she was born, because they took her straight, but when they passed her in the incubator, I could see her. (P8)

By the time she was born, I didn't see her, I only heard her cry, because they rushed to take her to the NICU.. (P16)

It is observed that the participants know little about the conditions of the baby at birth, but just said that they did not cry, that the birth was peaceful or that they could hear their crying. They do not mention having received guidance from health professionals before they took them to admission to the NICU.

On the other hand, during the untimely infant's stay in the NICU, the participants demonstrate knowledge about the complications their children went through. The reports show that, after birth, the untimely infant needed particular care, because in some cases he presented respiratory distress, neonatal jaundice, circulatory and urological problems.

In the ICU, they did some tests on her, gave her an injection to mature her lungs, because since she didn't get any treatment. She took medication, I think seven days in the serum with antibiotic and stayed on oxygen [...] gave the paleness in her, she did not get to stay a whole day in the light. (P2)

He was hospitalized for eight days because he was born without breathing, was born purple, tried to revive. Then gave the paleness and stayed eight days to do the photo [phototherapy]. (P7)

She was there for thirteen days. They did tests on her, because she had that paleness and stood in the light, doing the procedure. (P9)

It was horrible. He had a trivial problem in the pee, it was horrible, I was very nervous. He had a detour in the urethra, which was thinner and did not come out the pee. He didn't pee for two days. They probed. Then when they went to do the tests, they think they opened the urethra channel again. (P15)

She had a cardiac arrest [...] she was born with heart puff; she was not with a well-made heart. (P16)

Given the prolonged period of stay in the NICU, the stigma of prematurity generated concerns in mothers, causing them to be afraid that there would be some harm with their children. With this, fear analyzed in the participants due to the permanence of their children in the NICU or soon after the mother's hospital discharge, without one of the children who remained hospitalized.

In the ICU, I was very worried, because as prematurity must be attention. I was worried that he would be born with an organ without developing, with some problem. (P6)

It was hard because we're afraid to lose. I didn't want to, but after seeing the baby, you moved. (P13)

It was horrible to me. The day I left the hospital without him in my arms, it was horrible. It was very difficult [referring to the fact that he was discharged from the hospital with only one of the children and that the other twin remained hospitalized in the NICU. (P14)

Hospitalization in the NICU required changes in the daily life of mothers, who needed to travel daily to the hospital. The reports address the period in which the COVID-19 pandemic occurred in Brazil. Thus, in addition to the restrictions imposed by the pandemic, mothers also faced difficulties related to emotional and physical exhaustion.

There could only be one person in case I had to stay because of him. I was right in the hospital, I practically lived there. (P5)

It was pulled hard. It's a well-pulled thing, because you spend all day in the hospital, you don't eat right, you don't drink water, you just sit there waiting, have the nervousness when you enter, because it's a little demo ... it was quite

distressing, because we wanted to take her home at once, but we had to wait until she regains the weight. (P8)

I couldn't see her, because of the pandemic, I couldn't. My husband was in isolation, they wouldn't let him see it, because he couldn't have contact. So, I didn't go to see her until after she left the ICU. (P9)

He went to the NICU. I had to go all morning there to see him. (P12)

Every day, I went in the morning and afternoon to the NICU to see him. The first time I saw him, I died crying because I'd never had a premature child.. (P14)

It was horrible, she left with five days, and he stayed another ten days [twins], and I had to come home and go, because it was three times a day that we could visit them. (P15)

The women also reported the routine of going to the hospital to breastfeed their children. This displacement was repeated several times a day, depending on the demand and need of the baby.

The other day at 7:00 a.m. I had to be there to breast-suck him.. (P5)

I went to the hospital six times a day to breastfeed every day for eight days. I discharged on the second day, and the other days I had to go. (P7)

I went twice a day and stayed three hours there to breast. (P15)

Given the extended stay of the untimely infant in the NICU, the mothers reported the continuation of some care after the discharge of the untimely infant. For one participant, the bottle became essential due to the difficulty of breastfeeding, while for another the use of alcohol became a routine care at home.

When I managed to give her breast, she was already used to the bottle and the probe, yet she gave a little pull, but she was very angry. (P2)

We use alcohol with it because we've gotten used to the NICU. There they had a whole routine with her and the care for her is totally different. (P16)

It is possible to observe the involvement of mothers in the care of untimely infants, from the moment of hospitalization in the NICU until hospital discharge. At home, they seek the maintenance of the care developed in the hospital environment.

Discussion

Complications during the gestational period may contribute to PL and, in turn, to prematurity. These are related to untimely amniorrhexis, hypertensive diseases, gestational diabetes, bleeding, untimely placental detachment, infections, among other complications that may lead to untimely birth.¹²

In the present study, four puerperal women reported having presented fluid loss untimely, which can be considered as an obstetric complication, capable of resulting in untimely

birth. Untimely amniorrhexis, or rota pouch, consists of untimely rupture of membranes before the onset of PD. When its outcomes are negative, it is related to maternal and neonatal morbidity. In this context, the lower the gestational age of the pregnant woman, the greater the risk for women and their newborns.¹³ A study conducted from the analysis of 300 medical records of women who had a preterm birth in a public maternity hospital in the state of Piauí pointed to untimely amniorrhexis as the second largest cause of untimely birth, with a percentage of 17.26%, representing 53 women affected by this complication.¹²

Another disease experienced by the participants involved hypertensive syndromes during the gestational period, with emphasis on preeclampsia and eclampsia. Preeclampsia is defined as a pregnancy-specific hypertensive disease and is related to the presence of arterial hypertension associated with proteinuria and/or edema after the 20th week of gestation. This disease can evolve to a more severe condition, eclampsia, capable of generating unfavorable complications for the mother-baby dyad. Symptomatic symptoms involve seizures, headache, changes in mental status and vision, diastolic blood pressure greater than 120 mmHg, vomiting, and pain in the right hypochondrium.²

In this sense, the importance of qualified prenatal care, as indicated by the Ministry of Health, is emphasized, with the performance of at least six consultations, laboratory tests and immunizations.² From this follow-up, it is often possible to identify some of the risk factors early and, when necessary, to treat certain diseases in a timely manner, and may reduce maternal and fetal risks.¹⁴

It was also verified that some participants did not present complications during the gestational period. A case-control study conducted in the maternity of a tertiary referral hospital for the care of high-risk pregnancies in the state of Santa Catarina found a similar result. In this study, there was a prevalence of spontaneous preterm birth (53.2%), with no association with complications and complications during pregnancy, corroborating the results of this study.¹⁵

In the on-screen study, we also identified a participant who experienced twin pregnancy and who needed to be at rest. Another moved away from her work activities due to the pandemic context of COVID-19. Authors state that multiple pregnancies present significantly more risks when compared to those with a single fetus. The risks affect both the mother and the baby and involve a higher chance of stillbirth and neonatal mortality, increasing its

incidence when there is an association with prematurity.¹⁶ In relation to the need to leave the work environment, this can be justified by the fact that, in the context of pandemic, pregnant women were classified as a risk group. In such cases, there is a recommendation to restrict its movement.¹⁷

One of the participants, who had twin pregnancy, also cited the occurrence of "blood in the placenta", which consists of the condition of placenta previa. In this case, it is known that twinning consists of a risk factor for this disease. If maternal bleeding is mild and the patient is already at the 37th gestational week, there is a need for obstetric evaluation and, possible, guidance regarding relative rest,² which corroborates the testimony presented by the participant.

In view of these experiences, the participants showed concern about the gestational outcome, added to the possibility of anticipating the baby's birth and the probability of him being admitted to the NICU. This concern emerged after the information provided by health professionals regarding fetal prognosis. They also mentioned the concern about frailty related to the condition of prematurity, and this feeling generated fear about the outcome of untimely birth. The communication of shocking news to the family of a child in critical condition is not an easy occasion to report, due to the way it is communicated, it can cause hopelessness in the face of the welfare of the untimely infant.¹⁸

A study conducted in a Ghana hospital with mothers of untimely infants also revealed feelings of concern about prematurity. In this research, it was found that negative emotions were related to the fear of the baby's death or injuries in its clinical condition.¹⁹ In this sense, authors⁸ affirm the importance of the role of the health professional in the context of NICU, as a facilitator of the interaction between mother and baby to promote a positive adaptation in this hospital environment.

With this, spiritual support often becomes the foundation for coping with fear. The act of believing and having faith, regardless of religion, brings hope and expectation swells in situations such as prematurity.²⁰⁻²¹ A study conducted in Cape Town, with mothers of untimely infants hospitalized in the NICU, emphasizes the importance of spiritual support as a way of coping, highlighting prayer as an essential strategy to intervene and thank for the health of their children.²² Thus, spiritual support is a form of comfort and, at the same time, comfort during neonatal hospitalization.²³

It is considered that health professionals play an essential role in welcoming the mother and family of the untimely infant. Welcoming contributes to effective communication and understanding of the child's clinical condition, providing fruitful situations to clarify doubts and meet the demands of these individuals.²³ Therefore, professionals inserted in the NICU are responsible for providing information and offering support to family members, based on their singularities.¹⁹

The separation of the mother and baby marked the participants' experience, soon after birth, and the hospitalization of the NB in the NICU. They mentioned that they could not even see the NB, even those who presented stable clinical conditions at birth. This situation was reported, even when the untimely infant did not need hospitalization in the NICU.

A study that analyzed the profile and experience of birth of 555 women considered the separation of mother and baby immediately after birth (29.9%) and in the first hour of life (42.7%) as obstetric violence.²⁴ It is understood that skin-to-skin contact between mother and baby triggers a series of beneficial events for both, which are not allowed when separating them.^{8,24} A systematic review that analyzed studies between 2010 and 2017, affirms the importance of this practice with untimely babies and how it helps in the prevention of acute pain before procedures performed in the NICU. In addition, this review showed the relevance of this contact for the construction of bonds between mother and baby, and in helping to promote breastfeeding.²⁵

The NICU involves a hospital wing designed to care for NUs that are most vulnerable due to critical health status. During hospitalization in the NICU, specialized assistance is offered with the use of technologies aimed at avoiding the mortality of the newborn.²⁶ In view of this fact, authors²⁵⁻²⁶ affirm the importance of the family member's participation during care in the unit, aiming at helping the recovery of the baby and keeping the bond between mother and child. However, these aspects were not observed in the findings of the present study, because in the NICU, routines and norms are often kept that hinder the involvement of the family in care during the hospitalization of untimely infants.

During their stay in the NICU, the hospitalized preterm infants presented conditions related to prematurity. Among the injuries presented, respiratory distress, neonatal jaundice, circulatory and urological problems were identified. An epidemiological clinical study pointed to respiratory distress, prematurity, neonatal jaundice, low birth weight, congenital syphilis, neonatal infection and heart diseases as the main causes of hospitalizations in a NICU.²⁷ In view

of these conditions, there is a need to inform the child's clinical condition to family members, based on accessible and effective communication that allows the family to understand the general dimension of this situation.¹⁸

In addition, it is necessary to consider the care demanded by prematurity, encompassing all technical and technological support focused on the needs of the child. Thus, the use of equipment and the performance of specific procedures are necessary for the maintenance of the physiological state of untimely infants and their extrauterine development.⁷⁻⁸

Faced with this scenario of separation and introduction of the baby in a strange place, where they are exposed to stress and, in some cases, to pain resulting from invasive procedures, studies report that family members experience several sensations, including uncertainty, anguish and fear about the survival of untimely infants.^{18,20-21} These negative feelings compromise the establishment of the bond and the adaptation process in this technological and hostile environment.⁸

Tied to the hospitalization of babies in the NICU, the mothers faced another challenge, the context of the pandemic. Authors¹⁷ also address this pandemic scenario, in which precautionary measures were imposed to avoid contamination with the SARS-COV-2 virus, and its relationship with the daily life of mothers of babies hospitalized in a NICU.

In the present study, precautionary measures involved behavioral changes of mothers, as well as restriction in the circulation of several caregivers, imposed by the health institution. In addition to the concerns related to the baby's health, the pandemic contributed to the exacerbation of feelings, resulting from the change in people's daily lives.

Other changes experienced by mothers in their daily lives involved the daily displacement of their residence to the hospital. This period proved distressing for the participants and generated emotional and physical exhaustion in them. Authors¹⁸ consider that visits to the baby become desired moments. However, then, mothers experience suffering because they need to say goodbye to the baby, looking forward to the day when they can take him home.

After the hospital discharge of the children, the mothers reported the continuity of the care performed in the NICU at home. This care included the use of alcohol to manage the child and the supply of the bottle due to the difficulty in the breastfeeding process. From the arrival of the child at home, the routine of the family nucleus undergoes changes. In this sense, by

following the dynamics of care in the care of children in the NICU, mothers seek to reproduce the same actions in the home environment.²⁰

The care involved with babies in a NICU, especially in times of pandemic, intensified. In this sense, the use of alcohol is related to the insertion of prevention and care measures established in the NICU. These measures became routine in the families' homes.¹⁷

It was observed that breastfeeding was affected due to the separation of the mother and baby at the time of birth, but also due to the period of hospitalization of the NICU. These aspects, linked to the lack of guidance of health professionals, may impair the establishment of breastfeeding for mothers of untimely infants,²³⁻²⁴ as verified in the study, generating, for example, the need for bottle introduction.

Such maternal care involves the NB after hospital discharge, it is noted the importance of a support network attention not only to the care of the newborn, but also to the postpartum care. It should be emphasized that the guidelines should be transmitted from prenatal care being extended to other family members, in order to cover the care of the NB, self-care in relation to the puerperium and the challenges to be faced.²⁸ Thus, the strengthening of a support network and professional support must continue at home so that the orientations and care involving the untimely neonate and the puerperal woman are valid, transforming this moment into a pleasurable experience for mother, child and family.²⁹

Moreover, it is emphasized that, although the study did not focus on the COVID-19 pandemic, it still allowed us to understand the experiences of the mothers of untimely babies in this context, demonstrating the situations of physical and emotional exhaustion, commonly observed in the face of hospitalization, and which were exacerbated at the present time. This aspect can be considered as a contribution to the construction of knowledge, as well as pointing to the need for research that can effectively address the experiences and difficulties experienced in this pandemic scenario by mothers and families of untimely babies. Another point to be considered involves the need for studies from the perspective of other caregivers, such as the father and grandparents, who are also involved in the care of the baby, in a situation of prematurity.

It is assumed that the findings of this study may contribute to the practice of health professionals regarding the care provided from pregnancy to the puerperium. From the understanding of the experiences and difficulties faced by mothers of untimely babies during the gestational period until the hospital discharge of the untimely infant, the health

professional can become more sensitive and able to offer effective support to the mother and family.

Conclusion

The findings of this study made it possible to know the experiences of mothers of untimely babies, noting that these were marked by moments of emotional instability, represented by anguish and fear in relation to prematurity. During pregnancy, there were complications that caused untimely birth. At the same time, for some women, the pregnancy went unchanged. However, when they learned about the possibility of anticipating birth, fear surfaced in the face of the gestational outcome. Thus, spiritual support became fundamental in this time of uncertainty in which mothers were experiencing.

At the birth of the untimely baby, there was the separation of the mother and the baby and then the hospitalization in the NICU. At that moment, it was observed the absence of guidance from health professionals regarding the clinical conditions of the baby and the justification for hospitalization in the intensive care environment. However, upon arriving at the NICU, the mothers were welcomed by health professionals working in the sector. From this, they began to demonstrate knowledge about the child's clinical conditions and perceived the need for specific care due to prematurity and immature physiological development. Hospitalization involved altering the mothers' daily life, demanding daily displacement and care in the face of the COVID-19 pandemic.

The experience in the home portrayed the continuity of the care developed during hospitalization. It was verified the need for bottle use due to the difficulties faced during the breastfeeding process in the NICU and the use of alcohol for the handling of the child as necessary elements in the care developed at home, highlighting that the latter intensified due to the pandemic. In addition, the mother's fundamental role was observed, looking at the care developed with her child during hospitalization, aiming to keep them after hospital discharge.

It can be inferred that the study contributed to the identification of feelings and difficulties that permeate the experiences of mothers of untimely babies. In addition, the research also allows to assume a gap in relation to the care provided in the gestational period and at the time of birth. Therefore, it signals the need to look sensitively and attentively from health professionals regarding the orientations provided to the woman and her family.

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