



ORIGINAL ARTICLE

MATERNAL REPRESENTATIONS BEFORE THE BIRTH AND HOSPITALIZATION OF THE PREMATURE CHILD IN NEONATAL ICU

REPRESENTAÇÕES MATERNAS FRENTE AO NASCIMENTO E HOSPITALIZAÇÃO DO FILHO PREMATURO NA UTI NEONATAL

REPRESENTACIONES MATERNAS ANTE AL NACIMIENTO Y LA HOSPITALIZACIÓN DEL NIÑO PREMATURO EN LA UCI NEONATAL

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ABSTRACT

Objective: describing the feelings experienced by the mother who has a premature newborn hospitalized in a Neonatal Intensive Care Unit. **Method:** a descriptive study with a qualitative approach conducted with 15 mothers, in the period from March to May 2013. The study had the research project approved by the Research Ethics Committee, CAAE 0203.0.268.093-11. **Results:** the central ideas found were: Happiness before birth; Suffering before the premature birth; Fear of the unexpected; Hope before uncertainty; Fears and beliefs facing the premature birth; Uncertainty in the face of the labor birth and Hope of survival. **Conclusion:** the feelings of the mothers are very complex due to various factors involved during hospitalization of their child, their treatment and possible sequels, but the happiness of mothers with the continuity of her family surpasses all negative feelings. **Descriptors:** Premature Birth; Neonatal Intensive Care Units; Newborn.

RESUMO

Objetivo: descrever os sentimentos vivenciados pela mãe que possui um recém-nascido prematuro hospitalizado em uma Unidade de Terapia Intensiva Neonatal. **Método:** estudo descritivo com abordagem qualitativa realizado com 15 mães, no período de março a maio de 2013. O estudo teve aprovado o projeto de pesquisa pelo Comitê de Ética em Pesquisa, CAAE 0203.0.268.093-11. **Resultados:** as ideias centrais encontradas foram: Felicidade frente o nascimento; Sofrimento diante do nascimento prematuro; Medo do inesperado; Esperança frente à incerteza; Temores e crenças frente ao nascimento prematuro; Incerteza frente ao parto e Esperança de sobrevivência. **Conclusão:** os sentimentos das mães são muito complexos devido aos diversos fatores envolvidos durante a hospitalização de seu filho, seu tratamento e possíveis sequelas, porém a felicidade das mães com a continuidade de sua família supera todos os sentimentos negativos. **Descritores:** Nascimento Prematuro; Unidades de Terapia Intensiva Neonatal; Recém-Nascido.

RESUMEN

Objetivo: describir los sentimientos experimentados por la madre que tiene un recién nacido prematuro hospitalizado en una Unidad de Cuidados Intensivos Neonatales. **Método:** un estudio descriptivo con abordaje cualitativo realizado con 15 madres en el período de marzo a mayo de 2013. El estudio tuvo el proyecto de investigación aprobado por el Comité de Ética en la Investigación, CAAE 0203.0.268.093-11. **Resultados:** las ideas centrales encontradas fueron: La felicidad ante el nacimiento; El sufrimiento ante el nacimiento prematuro; El miedo a lo inesperado; La esperanza ante la incertidumbre; Los miedos y las creencias ante el nacimiento prematuro; La incertidumbre frente al parto y La Esperanza de la supervivencia. **Conclusión:** los sentimientos de las madres son muy complejos debido a diversos factores que intervienen durante la hospitalización de su hijo, su tratamiento y las posibles secuelas, pero la felicidad de las madres con la continuidad de su familia supera todos los sentimientos negativos. **Descriptores:** El Nacimiento Prematuro; Unidades de Cuidados Intensivos Neonatales; Recién Nacido.

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INTRODUCTION

Birth is a physiological and natural phenomenon; like a single moment of great significance for the mother and the son, and the whole family awaits the arrival of the newborn (NB).¹ Emotional ties begin to develop during pregnancy, still before birth. So, parents build dreams around the newborn, idealizing it as the most perfect way possible. When there is the birth of a newborn outside the expected perfection, there are feelings like disappointment, failure, guilt and fear of loss and may lead to estrangement between parents and children.²

The postpartum period is commonly called postpartum, already characterized as a time of crisis for most women who have experienced it, making it even more delicate with such problems.³

This unexpected separation can cause the emergence of feelings and emotions that interfere with mother-infant bonding and family relationship, generating different and unpredictable reactions.⁴ Premature birth, major diseases and congenital malformations endanger life outside the womb baby, due to the immaturity of organs and weakness of the immune system. These children need adequate support to survive, offered by a Neonatal Intensive Care Unit (NICU). Although it constitutes in therapeutic environment for care of high-risk patients, using the latest technology and a body of relevant scientific knowledge, as well as a skilled healthcare team, the infant experiences a lonely time, needing to fight for survival.⁵

During hospitalization of NB in the NICU is the disruption of the binomial of the bond, which often compromises the affection between parents and children. Physical contact between the two becomes sporadic and at a distance, in a cold and hostile environment.⁶

In addition to the suffering caused by the disease itself, hospitalization is itself considered fatiguing and causing changes in most aspects of family life, including the separation of parents, especially when they live in another city, and one of them needs to be away for long indeterminate to monitor the treatment of her son. So fear, worry and feelings of loneliness affect the balance and the roles held by each of them, which can precipitate family breakdown.⁷ Existing routine smash associated with the break with the everyday,¹ so the need arises awareness of professionals regarding the importance of parental presence during times of crisis such as hospitalization of premature child,

promoting the sharing of feelings, concepts, values and attitudes that prioritize support for parents and the needs for assistance to hospitalized children.⁸

OBJECTIVE

- Describing the feelings experienced by the mother who has a premature newborn hospitalized in a Neonatal Intensive Care Unit.

METHODOLOGY

This study is part of the doctoral thesis << Care for the newborn with very low birth weight: representations of the family and nurses >>.

This is a descriptive study with a qualitative approach⁹ developed in the NICU of the hospital/ school located in Londrina (PR), accredited by the National Health System (SUS). This hospital engaged in the provision of health care services in virtually all medical specialties, human resources training, continuing education, and research and technology development, technical and scientific cooperation with the network services. It has in its structure, medical-surgical inpatient units, pediatric, maternity, surgical center, emergency room and ICU adult, pediatric and neonatal. The NICU has 8 beds and 05 pediatric ICU beds each.

Data collection was conducted through semi-structured interviews applied to mothers in the period from March to May 2013. This type of interview allows the informant speak about their experiences from the main focus proposed by the researcher at the same time that it allows free and spontaneous responses.¹⁰ The guiding questions of the study were: "How are you experiencing the birth of your child's situation" "How was the birthday of his son" "How did know that her son was a newborn born prematurely and with a considered risk?".

Integrated this study 15 mothers in the period March-May 2013; had their children admitted to the neonatal intensive care unit of the hospital with a diagnosis of prematurity. Mothers were interviewed between the 7th and 15th day of admission of children in the NICU.

The theoretical basis adopted for the construction of the interview scripts were the assumptions of the Social Representations Theory, interpretation of reality that assumes that there is no distinction between subject and object of research, since all reality is represented by the individual.¹¹

Social representations are a number of opinions, explanations and statements made

from the daily life of the groups, communication key element in this process. Considered theory of common sense, because they are created by groups as a way of explanation of reality, social representation formalizes a particular knowledge modality that has the function of the development of behaviors and communication among individuals.¹¹

The data was worked according to the methodological framework of the Collective Subject Discourse (CSD). The CSD proposal basically consists in analyzing the collected verbal material, extracting from the speeches four methodological figures to organizing, presenting and analyzing the data obtained in the interviews. The **key phrases** are comprised of verbatim transcripts of some of the statements that allow the rescue of what is essential in the discursive content; the **central idea (CI)** of a speech can be understood as the statements that convey the essence of discursive content; **DSC** seeks to rebuild, with significant fragments of individual speeches as a puzzle, so many synthetic discourses as is considered necessary to express the thought or social representation of a group of people about a particular subject and is built in the first person singular; **anchoring** is explicit linguistic manifestation of a given theory, ideology or belief that the author of speech and may declare that, as a general statement, is being used by the enunciator to "frame" a specific situation.¹² In this study, we developed the first three figures.

The survey was conducted with the assent of the research project by the Ethics Committee of the State University of Londrina/CEP/UEL under Protocol 228/2011. To ensure the anonymity of the individuals, the names of the mothers interviewed were replaced by the letter M followed by numeric sequence.

RESULTS AND DISCUSSION

A brief characterization of the participating mothers shows that the age group of the same ranged from 19 to 43 years old. Regarding the marital status eight were married, five singles and two maintains a consensual union. In respect of the occupation nine had regular job and six were housewives. Regarding education, two mothers had primary school, seven not completed high school, four completed high school, one higher incomplete and another complete college. Family income varied from one to five wages. Of these, six were experiencing for the first time motherhood nine already had other children.

During pregnancy, the main complications found were urinary tract infection (UTI), pre eclampsia (PE) and gestational diabetes (GD).

The urinary tract infection is the most common urinary problem during pregnancy. It occurs in 17-20% of pregnancies and is associated with complications such as premature rupture of membranes, preterm labor, chorioamnionitis, postpartum fever, maternal and neonatal sepsis infection.¹³

The PE is high blood pressure that occurs after 20 weeks of pregnancy (or sooner in cases of gestational trophoblastic disease or fetal hydrops) accompanied by proteinuria, disappeared before 12 weeks postpartum. In the absence of proteinuria, suspicion is strengthened when increased pressure appears accompanied by headache, visual disturbances, abdominal pain, thrombocytopenia and elevated liver enzymes.¹³

The GD is defined as "carbohydrate intolerance of varying degrees of intensity, first diagnosed during pregnancy, may or may not persist after childbirth".¹³

They emerged from the maternal discourse seven IC: Happiness before birth; Suffering before the premature birth; Fear of the unexpected; Hope the face of uncertainty; Fears and beliefs before the premature birth; Uncertainty facing the birth and Hope of survival.

Having a premature newborn admitted to the NICU has generated mixed feelings of happiness and suffering among mothers as shown below:

♦ IC1 - Happiness facing birth

DSC1 -Oh, it's an unexplained happiness, not like say, have no words! Very happy, I really wanted to, I've had two miscarriages, I wanted very much. Happy because she was born and is alive to this day. It was a well-planned pregnancy then came like that to mess with the whole family. First granddaughter, first daughter, then inexplicable joy, not even how to speak. A wonderful time; without explanation. (M7, M8, M9, M11, M13, M14, M15)

Note in this speech that, regardless of the conditions of birth and consequences of it, the fact that the child was born alive, makes for some time mothers refer to the moment of birth with feelings that reflect positive aspects. Birth is considered a unique and special time in a woman's life, bringing her numerous demonstrations and changes in their daily day⁵, so even with the experience of having the child admitted to the NICU, happiness turns out to overcome the problems as evidenced in the following speech:

DSC2 -*At first it was hard, but now everything is fine. At first it was hard recognizing she was going to stay in the ICU, because I was waiting for her for eight months, which would be scheduled the C-section for eight, but she arrived with six, but this being good. She's right, it's all good! Oh they (ICU team) are doing well, everything they are able to do, they are doing. I have nothing to complain about. It's sad for her being here, but as soon as we get more comfortable because she needs attention, but everyone is quite happy, anxious, but it's cool. (M1, M3, M5)*

It is evident that prematurity and hospitalization of the NB cause great concern and fear among mothers. However, technological advances culminated today with a technology capable of ensuring the survival of extremely preterm infants and very low birth weight. Safety in new technologies within the NICU generates a sense of relief, knowing that care is being carried out in full and innovative way, and that everything will be done to the continuity of life.¹⁴

Preparing to deal not only with the technical performed with the NB, but also to relieve the mother's suffering generates security and bond formation between the NICU team and the family. With this treatment it becomes more effective, and all come in line for the improvement of the NB.

It is known that premature newborn care not only in advanced technological level. Nowadays professionals in general, seek centered care also in the family, and as a result the effective participation in the hospitalization of their children. This time to generate many feelings of distress as referred to in the following speech:

♦ IC2 - Suffering before the premature birth

DSC3 - *It's bad, because I won't be able to take her home, she will have to stay in the ICU. At first I was without understanding right, never happened to me, I was scared and anxious. It was very bad. It was nerve-racking, because I didn't know if she was going to live. (M3, M9, M10)*

When the newborn is hospitalized in the NICU parents face the fear of disease and the unknown; feelings of guilt and insecurity; lack of control over the hospital environment; change in routine life; insecurity about the child's behavior; lack of procedures regarding their recovery; financial, social and emotional problems linked to illness and hospitalization of the child; different behavioral patterns of the usual.¹⁵

A study related to the mother's perception in the care of newborns hospitalized points

out that more than half of mothers do not receive guidance on equipment placed on his son, and come to the NICU frightened. Often guidelines are passed from scientific mode to the families, thus causing misunderstanding of the case and the suffering. It emphasizes the importance of developing continuous and permanent education for professionals are able to assist with completeness considering the binomial mother/son. Professionals need to develop activities that aim not only to procedures which are indispensable to the survival of the infant, but also taking the time to provide the mother and the baby strengthen the love between them.¹⁵

The immediate misunderstanding of the child's health status generates feelings of fear and failure on this new situation, as can be seen below:

♦ IC3- Fear of the unexpected

DSC4- *Look, at first I was scared, worried, for he was born too small was horrible, without words, is being very difficult, too much risk to survive. That insecurity, will it be fine tomorrow? (M2, M6, M12, M15)*

It becomes evident in the speech that the experience of giving birth to a baby who requires hospitalization triggers negative feelings, such as: disappointment, low self-esteem, sadness, guilt, hostility, despair and grief. But what bothers the parents is the fact that they are separated from their babies, feeling unable to protect them from pain and discomfort.¹⁶

The birth of a premature child and the need for hospitalization in a unit of high complexity as the NICU generates in the family and particularly the mother feelings of inadequacy and uncertainty about the future of his son and about their own future, but the hope of survival is expected and demonstrated, as reported below:

♦ IC4 - Hope in face of uncertainty

DSC5 - *I honestly don't know if it will survive. I'm worried. Of course, what mother wouldn't? But I'm hoping it survives. I'm more optimistic, more confident that he will get out of this. (M2, M12)*

Having a child in the ICU is an unexpected experience that triggers shock reaction, disbelief, grief and deep sorrow. Can reveal the fear of losing the child, because the ICU environment still carries the stigma of a place to die.¹⁶

Some mothers over time become more confident in the recovery of the hospitalized child and feel more comfortable in the hospital because they realize the need for child treatment, and the fact that he is alive is a great victory. However, some of them

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show also the sense of concern, because they fear the unstable picture of the baby and your future.¹⁶

Family support is very important for the mother to continue believing in the recovery of your child, creating comfort at risk. The religion and faith are also highlighted as major allies in the health-disease process as shown below:

♦ IC5 - Fears and beliefs before premature birth

DSC6 -It was actually a fright, knowing that my son could leave the table with life or not. I was very surprised, I was nervous; my husband supported me as well as my family. And then, when he was born, went straight to the ICU, I was terrified. I felt fear, I thought he was going to die, but was born, thank God, very well! Only premature. I'm glad he was born, was a wonderful moment in my life. It was a miracle of God. (M1, M2, M3, M4, M5, M7, M8, M11)

When a family member gets sick, the whole family structure is affected, especially if a child because everyone is involved in this. With the hospitalization of the child, no matter how structured it is the family, always there is a destabilization of its dynamics.¹⁶ Therefore as reported in discourse family support is very important for the mother to restore and see the birth of his son as a time unique and wonderful.

With the admission of the baby in the NICU, parents begin a career marked by painful and stressful moments and also the separation of the child's household. World's hospital and in particular the ICU is different and full of technological devices. In this environment, the parents begin to initially live with anxiety by the stabilization of the clinical picture, with the gain and weight maintenance and, finally, with the period before hospital discharge. The families of these children, more specifically parents, are considered risk groups.¹⁷

The family support for parents and newborns becomes essential for the relief of suffering. So religion arises as a great ally to cope the situation.

Religious beliefs are mediators in the health-disease process in that it allows the development of cognitive schemes that could expand personal coping resources, promoting a sense of control and increased self-esteem, favoring the attribution of meaning to stressful events. Faith is referenced as support for coping with the result of his son's hospitalization anguish, while God is always associated with the feeling of strength, safety

and comfort to overcome the situation of suffering and probation.¹⁸

Even with this support, it can be seen that fear by premature birth and the newborn's vitality conditions after birth are contained in the speeches. This set of factors makes the doubt NB survival to risk conditions remain as reported below:

♦ IC6 - Uncertainty facing childbirth

DSC7 - I was very surprised, because I didn't expect, I thought I was going to hold out until the nine months because everything was going well. By the time I got to the hospital, I was bleeding and swelling, but had no pain. I went to an ultrasound and the doctor said I'd have to do a C-section risk, because the test was altered. Al was complicated, because the doctors said he could be born with lung problem, that my son could leave the table with life or not. When I got off the stretcher, the water broke, and then they told me I was going to have to do an emergency C-section. The contractions, pain when he was born, were terrible. It was gone, painful and disturbing, because I didn't know if the baby was going to get out alive. (M1, M3, M4, M5, M8, M9, M10, M11, M12, M13)

Preterm labor (TPP) accounts for 75% of births before 37 weeks of gestation. The prevention during prenatal care is rarely possible, because usually has a multifactorial etiology or unknown.¹⁹ Among the clinical factors present some substantial risks, such as premature birth story, twin pregnancy and vaginal bleeding in the second quarter.²⁰

The identification of some modifiable risk factors before conception or early in pregnancy can prevent this. However, most spontaneous preterm births occur in women without any risk factors. Although the survival of premature infants has improved in recent years, prematurity is still the leading cause of neonatal morbidity and mortality.²⁰

The confidence shown by mothers on assistance provided by the staff of the NICU causes great hope of the NB survival, identified as follows:

♦ IC7 - Hope of survival

DSC8 -She's reacting very well, had no problem after that came to the ICU, and started to breathe better, there've been more carefree. I wasn't very surprised, because I had a premature child. But thank God she's fine! At least there's a place that can treat, I was more relaxed. (M1, M3, M4, M5, M9, M10, M13, M14)

With the development of technological resources, the main concern of professionals working in the NICU back to the maintenance of life of newborns increasingly premature. For this, prioritizes the quality of care

provided in hospitals, through trained professionals and the latest equipment. Gradually, with the success of interventions, it is increasing the survival of premature infants egress NICU.²¹

The child's survival at first is what mothers want most; however, over the first impact other anxieties emerge as fear of possible consequences, and how they and their families will drive this as shown below:

DSC9 -I was desperate, crying day and night thinking he was going to die. To the heart a thousand heads explode, because time passes a lot of thing, what it is going to be and whether it will survive. We had a very hard time with the baby here because he stayed 12 days intubated. I thought it was going to take away, we'd win and lead. I didn't think I'd be here. My main fear was he didn't resist, because we have already loved the baby inside the belly. Now here in the hospital, but if escape as it will be life out there? Will have to take medication for the rest of your life, you will have to do some treatment, I don't know; only time will tell. But I'm thinking the thousand, won't have that mother who speaks well, everything will be fine, there are a lot of questions, a lot of questioning, that there's no way anyone respond. Just surviving. And living to learn. So, only time will tell how it's going to be. Have to wait. It was very sad, but what can I say, you have to accept. (M1, M2, M4, M5, M6, M7, M11, M12, M14, M15)

The separation at birth as well as the child's hospitalization causes different and unpredictable reactions, as commonly, premature birth or illness trigger sadness and insecurity, which affect the bonding and attachment.²²

In fact, we see the complexity of emotions and feelings of mothers, when the birth of the child requires hospitalization in the NICU, which means life-threatening. Thus, fear of impending loss and the unknown becomes probably the joy in doubt and uncertainty about the near future.²²

Watching them connected to high-tech equipment, mothers express sadness at the conditions that children face. Mechanical ventilation is a therapy that apparently distance the child's mother, as well as the subtle characteristics of premature newborns.²²

Uncertainty regarding the RN survival after hospital discharge is a factor that worries the mothers, in the same way that the possibility of staying in any sequel after treatment is great source of suffering. Despite the need for hospitalization of infants, the acceptance of it by mothers is always very difficult to understand.

CONCLUSION

At the end of the study we found the multiplicity of feelings experienced by mothers going through fears, anguish, suffering, disability and uncertainties along with happiness at birth and the newborn's survival hopes. Besides the family support it is observed religiosity as great ally to face the adverse circumstances.

Technological advances and confidence in the NICU team provide care for the safety mothers about the best treatment for the continued life of their child.

Even with the treatments and commitment of professionals, the survival of the newborn is a major doubt for mothers. The idealization of the perfect child, created during pregnancy, at the moment is destroyed by the consequences of stay of uncertainty after discharge and over the years.

Through the present reports in this study, it can be seen that there is a huge range of feelings and emotions involved from the beginning of pregnancy to premature birth and hospitalization of infants in the NICU.

The difficulty of understanding the mother's part for hospitalization often derives from the shock of having their first contact with the child broken by his premature birth, after months of anxiety and idealization.

Despite the complexity of the analysis of the feelings of mothers due to various factors involved, from the RN entry in the NICU, its treatment and possible future sequels, the study also showed hope of improvement, making the happiness of mothers front of continuity his family overcome all complications.

It is believed that this study will contribute to the reflection and understanding of the range of feelings presented by mothers, seeking integral and humanized care is the right of every citizen.

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