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## Maternal representations about the provision of care to newborns at risk: a collective discourse

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### ABSTRACT

**Aim:** To capture maternal representations about the provision of care to newborns with very low birth weight in neonatal hospital units. **Method:** A qualitative study involving 41 mothers interviewed between November 2011 and July 2012. For analysis, we used the Social Representations framework, following the Collective Subject Discourse (CSD) method. **Results:** Nine central ideas emerged: fear of the unknown, difficulty in accepting being apart from the baby, difficulty in talking about the baby, real possibility of death, feeling of helplessness with regard to their child's hospitalization, feeling of guilt for failing to care for the child, the wait for a miracle, feelings of confidence with regard to the team, and the satisfaction that proximity to the newborn brings to the mother. **Conclusion:** We identified a number of negative aspects such as fear of the unknown separation from the child. On the other hand, the proximity to the newborn was identified as a facilitating aspect. We emphasize the need for intervention aimed at using the mother as a support and the gradual integration of the mother into the care provision process.

**Descriptors:** Mother-Child Relations; Infant, Newborn; Infant, Very Low Birth Weight.

## INTRODUCTION

The process of providing care for preterm infants with low birth weight or any other complication considered to be risky, has advanced greatly in recent years as a result of scientific and technological advances. This allows improved survival rates in terms of very low birth weight (VLBW) infants in both developed and developing countries, and has resulted in a change of profile and fall in infant mortality rates<sup>(1-2)</sup>.

The Neonatal Intensive Care Units (NICU), equipped with the latest technology and staffed with highly skilled professionals, contribute to the increased survival of VLBW infants. But they focus primarily on biological aspects, favoring automated behaviors due to the ongoing emergencies, disease severity and the fast dynamics of the service provided, in which dialogue and critical reflection find no space. This subject has been discussed, especially by nurses who work directly with VLBW, in order to transform this reality, expanding the care process to other dimensions and inserting family care<sup>(2)</sup>.

One of the stages of the family cycle that can cause deep changes or significant challenges for the family, is the birth of a baby. In the case of the birth of a neonate at risk, the family is faced with an exhausting and challenging experience, which leads to profound changes in family dynamics and extends to the hospitalization of the infant<sup>(3-4)</sup>.

The hospitalization of VLBW infants in the NICU can last for several months. In the scenario of long hospitalization, a sudden change occurs in the life of the family - especially in that of the mother who, in a short space of time, becomes a companion to the child without being prepared for this change and finds that the period is often permeated by much suffering.

In a recent study conducted in the city of Maringá (PR), Brazil, referring to the perception of adolescent mothers regarding newborns at risk, it is evident that, culturally, the child's weight is a major factor when it comes to the family considering them healthy or not<sup>(5)</sup>.

The complexity of events involving a woman during pregnancy and the puerperal period implies knowing not only physical, but several other conditions that may be directly or indirectly related to the status of members of the family as woman/mother and man/father, and the psychological changes as they affect the couple<sup>(6)</sup>. During a wanted or unwanted pregnancy, the family expects a healthy birth. But when a child with abnormal conditions is born, this unexpected event might generate negative feelings such as frustration, and might mean that the birth is transformed into a difficult and sometimes conflicted phase, mainly because it removes the chance of a healthy motherhood.

The birth, in normal conditions, has its own natural difficulties attributed to several factors involving the care of the newborn. In a way, the classic and basic cultural ritual of care itself must be developed, with the interaction and binding of the mother, her child and the family, a process influenced by beliefs, values and past experiences. On the other hand, it requires the baby's adaptation to its own family and environment<sup>(7)</sup>.

In a situation of prematurity, the child, in addition to emerging unexpectedly in the life of the family, is perceived by the family as being an unfinished being, which can even lead to it being rejected. This way of perceiving the premature child generates insecurity, and triggers intense changes and transformations in the lives of each of the family member. This can cause emotional damage for the whole family, especially for the parents<sup>(7-8)</sup>. If the baby is of a very low weight, it

is assumed that the feelings and attitudes can become even more negative.

From early on, parents feel responsible for their child's life. Upon discovering the pregnancy, the mother tends to change her routine, directing her focus to the welfare and health of the baby. When something goes wrong (e.g., the need for the termination of pregnancy due to maternal complications or fetal distress), many women feel guilty about the failure to achieve a healthy pregnancy and birth<sup>(8)</sup>.

The family expects a perfect child and gets worried about it. Thus, most mothers giving birth ask questions of the health care team in the delivery room, in order to know if their children have been born healthy, its weight, if it cried, and its physical characteristics. These questions are asked by the mother in order to verify if the child has been born without complications or malformations. However, if delivery is anticipated and leads to the birth of a premature baby with low birth weight, and who may develop severe complications, the mother's dreams and desires are modified, and a new stage in the life of the woman and her family begins<sup>(4)</sup>. In this case, among the feelings experienced, anxiety, depression and fear on the part of mothers facing this situation stand out<sup>(9)</sup>.

Besides such feelings, other difficulties are reported in scientific studies on the involvement of parents in the provision of care of the child admitted in NICU<sup>(2,3,6,7,8,9)</sup>, including the contradiction between the interest of health professionals in promoting this participation and in maintaining the care provision routines and technical procedures. Therefore, the following concerns have guided this study: how do mothers experience the moment of hospitalization of VLBW infants in the NICU? What are their needs at these moments?

In addition, in the case of the realities of intensive neonatal care, unveiling the ex-

periences of women in these circumstances becomes an essential condition to the pursuit of appropriate tools and strategies, guided by a dynamic planning process geared to meeting the needs of these mothers/caregivers, focusing on minimizing the trauma that can be caused by the hospitalization experience associated with premature children since their birth.

In this sense, the present study aimed to consider maternal representations about the care provision to newborns with very low birth weight in neonatal hospitalization situations.

## METHOD

We used a qualitative approach to this study. Qualitative research provides knowledge about the meaning of a particular problem in an individual's life. It consists of a set of interpretive and material practices that demonstrate a world, turning it into a series of representations, in order to understand or interpret the phenomena under consideration<sup>(10)</sup>.

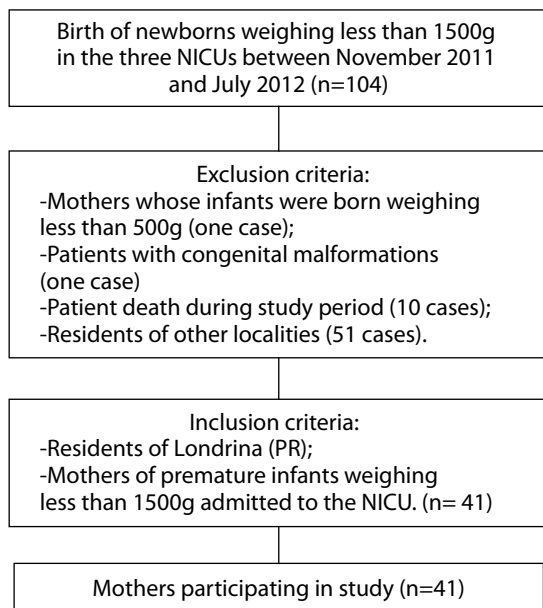
As a research scenario, three NICU located in hospitals accredited by the Government Health System (SUS) and considered to be Regional Reference public service Centers and two charity institutions – one seen as a model of care provision for high-risk pregnancies, and the that focuses on attending to different health plans.

The survey was conducted with the assent of the State University of Londrina (UEL) Research Ethics Committee, under register number CEP 228/2011; and the Santa Casa de Londrina Research Ethics Committee (ISCAL) under register number 393/201. To ensure anonymity, the name of the interviewees was replaced by the letter M, followed by a numerical sequence.

During the period of data collection (from November 2011 to July 2012) the mothers were selected for inclusion in our sample, according

to the following recruitment flowchart. By the end of this period, the survey included 41 participants.

#### Recruitment flowchart



Data collection was conducted with mothers through the use of semi-structured interviews, between the third and seventh day of hospitalization. From the empirical material analyzed, nine central ideas emerged (based on the Collective Subject Discourse - CSD) based on the responses of the study participants to the following guiding questions: how are you experiencing the situation of your child's birth? How did it feel knowing that your child had a very low birth weight?

It is noteworthy that more than one CSD emerged with regard to some central ideas.

The theoretical framework adopted for data analysis was the Theory of Social Representations, considered as an interpretation of reality that assumes that there is no distinction between the subject and the object of the research: since all reality is represented by the individual, every representation is therefore a form of the global and unitary view of an object. In order for the subject to form this global vision, she uses

everyday facts and knowledge based on common sense elements<sup>(11-12)</sup>.

The social representation enables the integration of implicit and explicit aspects of individual behavior resulting from social interaction. This leads us to an understanding of reality and human phenomena from the collective perspective, without losing the point of view of individual aspects.<sup>(12)</sup>

Thus, the representation is a global and unique view of an object and, in order to form this global vision, we use elements of everyday facts and common sense knowledge<sup>(10)</sup>, in which the research subjects give meaning to the objects, starting from their own reality and/or experiences<sup>(10)</sup>. It is a philosophical expression that means the reproduction of a previous perception of the reality or content of thought. Social representations have two functions: 1) create a conventional view of objects, people or events, providing a definite perspective with regard to them; 2) representations are "prescriptive". In other words, they impose themselves on the individual with an irresistible force. This force is a combination of a structure present even before we start thinking, and a tradition that postulates what is to be thought<sup>(12)</sup>. The representations are generated by common sense knowledge, acquired spontaneously and used by people for understanding and controlling everyday facts and life itself. They are called social representations because they belong to the group, but they express individual thinking at the same time.

The data was processed with the use of the methodological framework of the CSD. The purpose of this method is basically to analyze the verbal material collected by extracting four speeches in terms of methodological approaches (key expressions, central ideas, CSD, and anchoring) to organize, display and analyze data obtained through interviews<sup>(13)</sup>.

The key expressions consist of a literal transcription of the interviews. These allow the recovery of what is essential in the discursive content; the central idea (CI) of a speech can be understood as the sentences that allow us to translate the essence of the discursive content; CSD is built in the first person, and tries to reconstruct, with significant fragments of individual speeches (like in a puzzle) as many synthetic discourses as necessary, to express the thought or social representation of a group of people about a particular theme; the anchoring is the explicit manifestation of a given linguistic theory, ideology or belief that the author of the speech can declare and, as a general statement, is being used by the enunciator to demonstrate a specific situation<sup>(15)</sup>. An anchoring figure was not designed in this study, since the respondents did not use general statements to fit particular situations. It is known that the anchor is a particular type of CI in which there is not an exact idea evident, but an explicit statement of a value of a belief or ideology<sup>(13)</sup>.

## RESULTS

The mothers' age varied between 15 and 40 years. In terms of their marital status, 23 reported as being married, 12 were in a common-law union, five were single and one was divorced. Of these, 25 were experiencing motherhood for the first time and 16 had already had other children.

Using the CSD technique, the data collected was analyzed. This allowed the researchers to obtain the central ideas and their corresponding key expressions that, in turn, were grouped according to their similarity, composing the synthetic discourses in the first person singular – the collective speeches, representatives of the reality that was intended to be studied.

Therefore, the results revealed negative feelings and difficulties when facing the situation, as shown in CIs 1-5:

### CI1- Fear of the unknown

**CSD1-** *It's been hard. I'm afraid, because he's a really little baby, you know? The first time I entered the ICU I was very scared. I looked at him, so tiny, so fragile ... Oh, it gives me a pain in the heart just to remember! It is very difficult to have a baby in this situation, so you get that feeling, wondering if he'll be fine, or if he would get worse. You always keep thinking... It's really challenging! I'm afraid something will happen to him.*  
**(M1, M2, M3, M4, M5, M6)**

### CI2- Problem of accepting being apart

**CSD2-** *It's hard, because I was hoping that when he was born, he could just go home with me, and now he has to stay here as long as he should have been in my belly. I wish I could take him home. It's sad to leave and to leave him here... What I really want is to see him at home.*  
**(M1, M2, M3, M5, M7, M8, M9, M10)**

### CI3- Problems of talking about the baby

**CSD3-** *No one in my family expected this to happen, and they ask and ask... and you try to escape from this, because it is bad. Because coming here every day is very hard and distressing. You run away from everything and everyone just to avoid from having to keep answering things you don't know. Or things you know but make you suffer... And the others keep asking and insisting that they*

want to know. It's too hard... (M2, M3, M4, M5, M11, M14, M34, M37, M39)

#### CI4- The real possibility of death

**CSD4-** The doctors and nurses warn you of everything that will happen. So you already get scared, because you don't expect this, but you know that everything is a risk to the baby, risk of a bacterial infection – the baby is exposed whether you expect it or not. I already knew he was a baby at risk, and his chances of survival were small. First, because he is so tiny; and then because he's more likely to get infections and I knew it increases the chance of him dying. (M1, M2, M3, M5, M7, M8, M9, M10, M11, M21, M30)

#### CI5- Feelings of helplessness about the child's hospitalization

**CSD5-** It's so hard to look at him so tiny and fragile. Every day I come here I can receive bad or good news, and I can't do anything to protect him, cuddle him or take him away. I'm terrified to touch and hurt him. I feel useless and I have to agree with everything the doctors say, because what can I do? I can just pray and ask God to guide the hands of these professionals, because I do not know anything, but they do. (M1, M2, M3, M4, M5, M7, M10, M14, M16, M17)

**CSD6-** That was a day that I felt very guilty. He had spent all morning in the ICU and I insisted that the girls put the baby in my lap. They said it was not prudent, because he had just come out of the machine that helped him breathe, but I kept insisting... So they put him on my lap, but

in less than half an hour he started to get purple, so they had to quickly put him in the incubator to give him oxygen. It was horrible, I was so scared that I spent many days without wanting to touch him, because I was afraid that he might get worse. (M12, M30, M31, M38)

#### CI6- Feelings of guilt for being unable to take care of the child

**DSC7-** Sometimes I have no desire to return to the hospital because I can't do anything. I am unable to provide any care; it looks like he will break. I dreamed so much about this pregnancy, about the day of his birth, oh... And he has so many clothes that I can barely touch him; just his diapers cover all his body. I feel useless. (M26, M27, M33, M34, M37)

On the other hand, we observed positive feelings emerging, as demonstrated in the CIs 7 to 9:

#### CI7- The waiting for a miracle

**CSD8-** I'm sure God will do a miracle, and I pray every day that He lets my son survive. And this is what keeps me steady. Before entering the ICU, I always ask: "God, do a miracle. Allow my son to live and go home with me." (M5, M12, M13, M22, M25, M40, M41)

**DSC9-** You know, every day I listen to the doctors, nurses and the entire staff talking to me and to most other mothers that our children are babies who are at risk of dying or suffering any permanent abnormality. But when we are here, in our little room, waiting to see them, we comment that nothing is impossible to

God, and He has done so many miracles... The Bible is proof of that. So even when they say "Only a miracle will make your child get better", we'll go after this miracle. (M24, M25, M28, M31, M33, M35, M38, M41).

#### CI8- Trust in the team

**CSD10-** The first time I went to the ICU, the nurse who was with me opened the little door of the incubator and said I could touch him gently. At the time I was scared and said no. She insisted, held my hand and did it with me. It was wonderful, but I confess it took a while for me to get used to touching my child without fear. (M1, M3, M4, M6, M10, M13, M25, M28, M31, M36, M38, M40, M41)

**CSD11-** I know my son's situation is serious. He may die. But I also know that the team that is taking care of him is very competent, and I have great confidence in them. They care enough to tell me what is happening. They call me when he gets worse, and they ask me to stay longer in the hospital. So I have faith that he will survive because I trust the professionals and know that God is guiding their hands and thoughts to look after my child and that of other mothers as well. (M13, M15, M18, M19, M20, M23, M26, M27, M29, M32, M36, M37, M39)

#### CI9 - The contact with baby that brings satisfaction to the mother

**CSD12-** Today I realize that my presence here (in NICU) is very important for my son. When I arrive and start talking to

him, I look at the monitor and see that his heart beat increases... Wow, it's a thrill! The girls always say that he knows I arrived, because he's like a "little puppy" in the incubator: he doesn't get quiet until I get him. It's very good. (M15, M18, M19, M21, M36).

**CSD13-** Oh, that was an unforgettable moment... One day, I arrived at the hospital and one of the nurses asked if I wanted to take my baby on my lap. I trembled, I was afraid but desperate to hold him. Then, at the moment they put him in my lap, Oh my! What a joy to see him in my arms! I'll never forget that day... I left there (NICU) so happy that night I could not sleep, just kept remembering him in my arms. (M22, M24, M26, M27, M32, M35, M36, M38)

**CSD14-** You know, when I looked at my baby for the first time, it was a mix of feelings. First I was happy, because despite everything, he was alive. But there was also fear and disappointment, because he was so tiny (even a little ugly), and I thought he would be born chubby, fluffy and hairy like normal babies. So looking at him on the first day was strange, but when the nurse opened the little door of the incubator and I could touch him, oh my God, it was magic! He is so soft, now I think he's gorgeous. (M14, M16, M17, M20, M21, M23, M29, M39)

## DISCUSSION

The results revealed that mothers who have their children admitted in NICU fear for



their lives. They try to be hopeful, but from the beginning they are informed about the gravity of the situation, and this generates an intense fear of the unknown.

This observation corroborates the findings of a study<sup>(14)</sup> in which the parents said that having a premature baby in a NICU led to feelings of insecurity, arising from the fragile condition of the newborn, as well as the possibility of him not surviving.

Thus, we see in the reports of the mothers interviewed, the fear of imminent loss and of the unknown, can transform a moment that could be one of joy, the birth of a child, to an episode made up of anxiety, doubts and uncertainties about the future. The experience of facing the infant's hospitalization process is a stressful one for parents, and the separation from the child can be very difficult, triggering many feelings and emotions such as sadness, fear, shame, helplessness, sense of loss, frustration, emptiness, hope and others<sup>(15)</sup>.

It appears as a difficult situation for the families and especially for the mothers, who generally remain for a longer time in the hospital environment to the detriment of other members of the family. Many feel alone and helpless, especially when they do not have family and/or partner support. In this study, the need to provide information on the situation of the child to others is also configured as a stressful factor to mothers because, in many situations, these women did not possess enough knowledge to elucidate those who ask.

Parents often isolate themselves from other members of the family during the hospitalization of their child when difficulties expressing themselves on the successes and failures of the hospitalization arise. In the case of hospitalization of the newborn, the separation between mother/family and child/relatives occurs at a moment when contact is fundamental for the

development of the maternal/familial role. Regarding the mothers, they tend to feel unable to meet the needs of their children, and struggle to cope with their feelings and family demands<sup>(16)</sup>.

Accepting that the child, when born, cannot be taken home and shown to the family, generates maternal frustration and a sense of removal of the child. This reality sometimes makes mothers feel powerless and without control of the situation, and may even trigger a maternal depressive state<sup>(7)</sup>.

In fact, the impotence in the face of the unknown was strongly emphasized by the participants in this research. They want to help in their child's recovery, but due to the severity of the situation and their lack of knowledge, they feel in the hands of the health team. This situation could be improved through careful and continued inclusion of mothers in the provision of care to newborns as part of the NICU plan, and should not, to be viable, depend on the goodwill of each professional<sup>(17)</sup>. At the same time, it is necessary that the team is prepared to deal with the anxiety of mothers and their families, yet not yielding to the will of these at the expense of the health of the baby.

In general, parents want to be constantly informed about the status of their baby; however, if the approach is inadequate, this information may reflect negatively: they suddenly realize the severity of the situation and risk of death of the child. These factors raise the level of stress<sup>(18)</sup>.

The experience of becoming mothers of infants at risk triggers ambivalent feelings. Alongside the barriers faced and already described, this study also showed as a positive side in terms of the search for support in religion to accept the children and keep believing in their recovery<sup>(19)</sup>.

The religiosity of many families favors mothers in terms of providing them with the necessary strength, and allows them to continue to fight for their child since, due to the

complexity of the treatment, these newborns are hospitalized for prolonged periods, causing the problems discussed above. We observed that, independent of maternal religious orientation, they find support in their faith in God to overcome the adversities experienced. Religious and spiritual beliefs provide meaning and offer possible answers to the existential questions that arise concerning the illness and possibility of death of their child<sup>(20)</sup>.

Another positive aspect apprehended in relation to maternal experience was concerning health teams, with the recognition of their fundamental role regarding the involvement of parents in the NICU activities, primarily from the guidance provided during the first visit. These professionals must provide ways to reduce the anxiety and fear that the parents of newborns feel, offering comforting conditions, trying to respond to their concerns, and providing information on the health status of the child, their treatment, and the equipment used<sup>(3)</sup>.

It is important to emphasize that communication between professionals and families favors a bond of trust and respect, contributing to the quality of the care provided to the newborn. The received attention, the interpersonal relationship between the health staff and parents, the fact of being allowed to have contact with the children, and being informed about their condition, generate comfort and a feeling of security and confidence<sup>(3)</sup>.

The scientific literature suggests that the approach to the mother/father provides positive incentives for clinical stability and evolution of the premature baby, a reduction in hospitalization time, and reduced readmissions of children<sup>(19)</sup>. However, an analysis of the overall results of this study revealed that the mothers are far removed from the care provision process during the hospitalization of very low birth weight infants in the NICU.

Family-centered care allows mothers and other family members to feel important in terms of the recovery of the child in such conditions. Actions to allow a stable baby to be placed in their lap contribute to making the mothers truly share in the responsibility for the child's care. Even when cuddling is not possible, it is up to the team to identify possible activities to be performed by mothers and other members of the family, encouraging them to assist in building bonds and in the recovery of the newborns. We stress that tactile (touch and caresses) and auditory stimuli (speech and singing), are important for the establishment of the mother-infant bond<sup>(20)</sup>.

## CONCLUSION

We consider that the objectives of the study were achieved by revealing, through the maternal representations, aspects of their experience during the hospitalization of their children at risk, as infants with very low birth weight in this case. Among the difficulties we highlight the fear of the unknown, the separation from the child, the need for providing information to family on aspects over which they had no control or knowledge, the real possibility of death of the child and the feeling of impotence related to the situation experienced. On the other hand, the faith in God, trust in the health team, and the proximity to the newborn, were perceived as facilitating factors related to this experience.

Thus, the study demonstrates the need for interventions aimed at mothers with babies admitted to intensive care units, such as allowing careful integration in terms of their child's care, with the support of a multidisciplinary team; and allowing the presence of other family members who can help mothers in this situation.

The understanding by health professionals, particularly nurses of the NICU, may lead them to consider that there is no unidirectional care when it comes to newborns, but a context of shared actions between staff and mother/family.

We hope that the results of this research encourage new studies that emphasize other possible perspectives to address the context of care actions, seeking constant thinking and rethinking about interventions that facilitate relationships between the different subjects involved, with a view to valuing integral and humanized care in these institutional healthcare spaces.

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