

BONDING IN NEONATAL INTENSIVE CARE UNITS: EXPERIENCES OF EXTREMELY PRETERM INFANTS' MOTHERS.

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ABSTRACT

Background: The birth of an extremely preterm infant can disrupt normal mother-infant physical contact and the care provided by the mother. This situation has an impact on the process of bonding between the mother and the child.

Aim: The objective of this study was to describe and understand the experiences of mothers who have extremely preterm infants admitted in Neonatal Intensive Care Units with regard to their bonding process.

Methods: An interpretive, qualitative research methodology using Gadamer's philosophical hermeneutics was carried out. A focus group and eleven in-depth, semi-structured interviews were conducted. Data were collected between June and September of 2016.

Findings: Sixteen women with a mean age of 34.4 years participated in the study. Two themes emerged from the data analysis: (1) Premature labour and technological environment, a distorted motherhood, with the subthemes 'feeling of emptiness and emotional crisis' and 'the complexity of the environment and care generate an emotional swing; (2) Learning to be the mother of an extremely preterm infant, with the subthemes 'the difficulty of relating to a stranger' and 'forming the bond in spite of difficulties'.

Conclusions: The bonding with extremely preterm infants is interrupted after giving birth. The maternal emotional state and the environment of the neonatal intensive care unit limit its development. Nursing care can facilitate mother-infant bonding by encouraging communication, participation in care, massaging or breastfeeding.

Key words: preterm infant, neonatal intensive care units, mother-child relationship, bonding, attachment, qualitative research.

Summary of relevance

Problem

Studies on mother-infant bonding have focused on the premature infant in general, however, the bonding process in extremely preterm infants has not been clearly explored.

What is already known

The quality of postnatal bonding is influenced by a variety of factors, mother-child interaction being one of these. The premature birth and the consequent hospitalization of the child interfere with the normal bonding process.

What this paper adds

This paper shows the obstacles that mothers find to be connected to their extremely preterm infant as well as the elements that help them develop their bonding.

1. Introduction

A preterm birth, which refers to births before 37 weeks of gestation, is the most prevalent health problem among infants in industrialised countries.¹ The worldwide incidence of neonates born prematurely is estimated to be around 11.1%.² Extremely preterm infants (< 28 weeks of gestation - WG) are the group with the highest risk of motor, cognitive and behavioural problems.³ Physiological immaturity and low weight of neonates born prematurely require admission to Neonatal Intensive Care Units (NICU) for vital signs and nutrition control⁴. A preterm birth is a situation for which parents are not prepared,⁵ experiencing emotional shock, fear, anxiety, depression and post-traumatic stress.^{6,7} Although neonate admission in NICU reduces mortality, parental separation alters parental interaction and roles.^{8,9} Prematurity increases the risk of psychopathology in the child,¹⁰ as parents may suffer denial, impotence, uncertainty, guilt and bonding deficiencies.^{11,12}

Attachment is the emotional bond that the child develops with their parents (or caregivers). According to the Theory of Attachment,¹³ the framework of our research, the safety, anxiety or fear of a child is determined by the accessibility and responsiveness of their parent (or caretaker), with whom they establish the bond. Mother-child bonding begins between the second and third trimester of pregnancy, extends to the postpartum and neonatal period and contributes to the physical, psychological and emotional development of neonates born prematurely.^{14,15} In addition to the pathophysiological problems, the premature birth affects the role of motherhood,^{16,17} and together with the mother-child interaction deficiency in the NICU, generates stress, loneliness, fear of loss and risk of insecure attachment.^{18,19} Several studies have highlighted the importance of emotional support, paternal involvement, and physical contact with neonate born prematurely in the NICU.^{15,20} Hermeneutics is the methodology of interpretation concerned with problems that arise when dealing with meaningful human actions; as a methodological discipline, it offers a toolbox for efficiently treating problems of the interpretation of human actions. The bonding process in NICU has been studied in neonatal nurses,^{15,21-25} however greater understanding is needed from the point of view of mothers who have extremely preterm infants.⁸ The aim of this study is to explore, describe and understand the experiences of mothers who have extremely preterm infants admitted to the NICU with regards to the bonding process.

2. Method

A qualitative approach based on Gadamer's hermeneutic phenomenology was employed in the processes of data interpretation and analysis.²⁶

2.1 Participants and setting

Through convenience sampling, mothers of extremely preterm infants admitted to NICU from a specialized hospital with 15 modules (12 for neonates and 3 individual modules for children up to 14 years of age) were selected. It is a traditional NICU (Level III) model, with all newborns in a common ward, without restricted visiting hours, where maternal participation is limited to breastfeeding and skin-to-skin contact. Inclusion criteria were: female gender, over 18 years old and to be the mother of an extremely preterm infant (<28 WG and <1000g) hospitalized in NICU for at least 30 days. The exclusion criteria were: refusal to participate in the study, being the mother of an infant with congenital pathology, sepsis, neural tube defects or death. A total of 18 women agreed to participate, although two abandoned the data collection, one due to physical problems, the other, for declining to discuss the issue. A total of 16 women participated in the study, 5 formed a focus group (FG) and 11 participated in in-depth interviews (DI) (Table 1). The mean age of participants was 34.4 (SD=4.6). 75% of the women had a single gestation, the rest being multiple; 68.7% of births were by caesarean section and the rest were vaginal (Table-1). The mean gestational age was 25.9 weeks (SD=0.9), the mean birth weight was 793.1g (SD=152.5) and the mean stay in the NICU was 51.5 days (SD=12).

2.2 Data collection

The data collection was carried out between June and September 2016, in a hospital in the southeast of Spain equipped with a NICU. The focus group, with a duration of 87 minutes, was carried out in the local university's premises; the in-depth interviews, with an average duration of 35 minutes, were conducted at the interviewee's home. The focus group was conducted first and it informed some of the topics later addressed in the in-depth interviews. The FG can foster the interaction among the participants and facilitate the emergence of relevant themes; however, intimate experiences and feelings can be difficult to explore in such contexts. For example, some comments about the mothers'

feeling of guilt for ‘making bad choices’ arose in the FG but not in enough depth, hence why this theme was also explored during the DI by asking specific questions such as “please, talk to me about what you think the relationship between mothers’ lifestyle and giving birth to a preterm child may be”. Data collection was stopped after data saturation was reached, having collected sociodemographic data of the participants as well. Both were recorded and transcribed, creating a hermeneutic unit analysed with Atlas-ti 7.0.

2.3 Data analysis

According to Gadamerian hermeneutics, a modified form of the steps developed by V. Fleming was used.²⁷ The first step was to decide if the research question was relevant in relation to the methodological assumptions; the researchers decided it was. In the second step, the researchers reflected upon the topic, to identify any pre-conceived notions derived from our research and experiences of therapy and care of extremely preterm infants in NICU. The third step aimed to achieve an in-depth understanding of the phenomenon through dialogue between the researcher and the participants. New questions arose during this stage, *how do the complications of extremely preterm infant affect the mother-child affective relationship?* The fourth step aimed to comprehend the phenomenon through dialogue with the text. After reading the transcriptions, the participants’ experiences were re-examined and new questions emerged: *how does the NICU environment influence the bonding process? And what role do professionals play?* Examining each sentence allowed us to identify units of meaning, subthemes, and themes (Table 2). The fifth step established reliability of the qualitative data. To increase reliability, triangulation between researchers was performed; three researchers analysed the data separately, discussing any differences until an agreement was reached. An independent researcher read the interview transcripts to confirm their agreement with the stated findings (themes and subthemes) and that all of the participants’ perspectives were taken into account. To maximize reliability, a clear description of the context, of the data collection and of the analysis was given. To ensure confirmability, the participants verified the results.

The study was approved by the Ethics and Research Committee of the Department of Nursing, Physical Therapy and Medicine of the University of Almeria (EFM-11/2016), 27 May 2016. Participants were informed about the study's aim, participated voluntarily and signed an informed consent form. The authors declare no conflict of interest.

3. Findings

Results were organized into units of meaning, four sub-themes and two main themes.

3.1. Premature labour and technological environment, a distorted motherhood.

The sudden onset of labour was described as an unreal situation by the participants, accompanied by dread, anxiety and fear of the loss of the newborn. This category shows the emotional impact of the birth of an extremely preterm infant, an unexpected feeling of emptiness in a technological environment such as the NICU, which leaves women bewildered.

3.1.1 Feeling of emptiness and emotional crisis.

These women would never have imagined a birth like this after preparing to meet their child, then to fear losing them, not finding them or not seeing them. Even refusing general anaesthesia during labour, to not lose consciousness and find out upon awakening that the child is dead. The first moments after childbirth were defined as a period of emotional shock; a feeling that they had lost control of their lives; were not able to manage their emotions; and not knowing how to react. Immersed in a mental confusion that lasts more than a month, some participants expressed not having truly experienced the birth of their child.

I did not expect it, I had severe preeclampsia, suddenly, and I could not meet my little girl, I did not have the feeling of having given birth...it was very strange (DIW8).

Fear and uncertainty over what they might find took over for the women, who did not even dare to visit their child in the NICU. As one participant said, family support at this stage is critical, but they perceived it as ineffective because of their own distrust.

Your family supports you... but you don't know if they are telling the truth. (DIW3)

Other participants experienced feeling of emptiness after childbirth, as they could no longer feel their child inside their belly. They felt hollow; empty because they suddenly stopped feeling them, because they could not be with them and went home without them. The connection with their child broke down at a time of the pregnancy in which a complete mental image of the child had not yet been established.

I felt that my belly had been stolen because I was convinced that I had three months left to have her. How I missed her.... (FG).

3.1.2 The complexity of the environment and care generate an emotional swing.

The fear of losing their child is evident especially in the first visit to the NICU, considered the worst and most difficult. While some participants were anxious to get to know their child, others avoided or delayed this moment, they did not want to see the infant or touch it because, essentially, they believed that in the end they were going to die. The environment and machines surrounding extremely preterm infant in the NICU contributes to this feeling, perceived by mothers as an enigmatic and threatening environment that increases fear and prolongs uncertainty.

I was overwhelmed by seeing the NICU, so many tubes, respirators, full of small cables. It took me two days to go back... I was paralyzed by the fear! (DIW6).

In spite of the steps taken to promote mother-infant bonding, such as the reduction of noise, the creation of semi-private spaces or family-centred nursing care, being unfamiliar with the NICU's technology and work routine, alarms and movement of healthcare professionals were identified as the main environmental stressors. This could influence the bonding process since most participants reported being more focused on the NICU context than on getting to know their child.

During the visits, the continuous sound of the monitors, the coming and going of the staff to check that everything was going well, scared me a lot. (DIW11).

Some participants reported feelings of joy, excitement, love and tenderness, but mixed with anxiety, fear, anguish, grief, pain, frustration, shame, worry and impotence. Nevertheless, as one participant relates, the strongest feeling during the hospital process at the NICU, even after discharge, was guilt.

I felt guilty about everything he was going through. I would ask, why does he have to suffer so much? Why couldn't my body keep him inside me longer? (DIW5).

Women come to connect their own physical health with information received about the health of their child in the NICU. However, they connected their psychological and emotional health as well, which they associated with other children's declining health and death, or other parents' emotional state. For the participants, the information provided by healthcare professionals, together with the progressive knowledge of the working protocols and the NICU environment, is the key to their tranquillity.

You go through the "all new" stage but...then you start asking questions and you become an expert in something that had never occurred to you (FG).

3.2 Learning to be the mother of an extremely preterm infant.

This category reflects the experiences of the participants about the loss and reconstruction of the emotional bond to the extremely preterm infant admitted in the NICU.

3.2.1 The difficulty of relating to "a stranger".

During the first days in the NICU the physiological instability of extremely preterm infant, together with the physical and emotional instability of the mother hinders the bonding process. Mothers hardly touch the newborn, go home without them and do not participate in their care, making it difficult to recognize their child as their own. They cannot feel like mothers because they do not have a child to care for, they cannot make decisions without the consent of healthcare professionals and they feel excluded.

You can't pick it up, give it a bottle, bathe it, give it a kiss whenever you want...it's like it's not your child, as if you're introduced to a stranger. (FG).

Women focus on the uniqueness of the extremely preterm infant's physical appearance, their small size, the translucency of their skin, their degree of prematurity. While most want to touch and support their child, whose perceived vulnerability and fragility make them hesitant or fearful. The fear of interfering with technological support or transmitting an infection, delays and limits physical contact. However, some of the participants did not want to touch their child because they were afraid of initiating a bond with a newborn they could lose.

Every time I opened the door (to the incubator) I was afraid to hurt her, but my biggest fear was to touch her, to get attached to then have her leave...(DIW2).

Physical contact is described as the most important element in establishing the bond broken after childbirth. For mothers, touching their child mitigated the anguish and distress of separation.

...the emotional bond was created from the moment I could touch her, as the days went by it got stronger and stronger, you can feel your child again (DIW1).

3.2.2 Forming the bond in spite of difficulties

The participants expressed that the incubator, the machines, the design of the ward, the schedules and the lack of information, constitute serious obstacles to developing a relationship with their child. However, they especially emphasized the lack of intimacy, interrupted continuously by the alarms or the visits of other relatives to other babies in the NICU.

I can't ask that all the parents leave and that the NICU be only for me, but there is a lack of privacy created by the beeping, by the voice of whoever is next to me...(FG).

The unrestricted access of the mothers in the NICU favours the bonding and it is the Kangaroo Mother Care that reinforces the bond most. This is how it was defined by one of the participants:

It is in that first complete contact you can feel close to your baby, his heartbeat, his breathing, to transmit his feelings to him and to see how, little by little, he recognizes you by your voice or by smell. (DIW9).

Engaging in extremely preterm infant care helps mothers feel useful. For example, involving mothers in extracting their own milk was seen as the only and best thing they could do for their child. However, the absence of breast milk increases stress, guilt and detachment. For our participants, healthcare-related information is key to the success of the process.

...they say go to the milk bank and express milk, but I don't know how to do that. And as I did not have a single drop, I felt I was a bad mother, the worst. (FG).

Participants stressed that their participation in interventions such as massage could be beneficial for the child. The tactile experience, which differs from that of professionals, has a potential effect on the development of mother-child attachment behaviour that reduces stress and anxiety, an opportunity to get to know each other better, provide comfort and feel useful.

... it would favour the bond with the child very much, it is not the same way of touching the mother as the physical therapist. The mother gives them something else, it's returning to your smell, to feel... (DIW3).

Severe pathologies that threaten the life of an extremely preterm infant, such as respiratory distress syndrome or necrotizing enterocolitis, means that the participants did not want to become attached when faced with the possible loss, so they distanced themselves emotionally and the bonding weakened. However, pathologies such as infection, bronchopulmonary dysplasia or retinopathy, helped the mothers form a stronger bond with their child.

...you feel part of their battle, I was always there to encourage her, to tell her how strong she was and the bond was going to strengthen (DIW7).

Faced with these difficulties, nurses promote mother-infant bonding through family-centred care, early skin-to-skin contact and the mother's involvement in the basic care of the newborn. The

mother-nurse relationship also arises as a need derived from their own separation, a close collaboration that facilitates their involvement in the care of the extremely preterm infant. Our participants felt more relaxed, informed and confident when they felt empathy from the nurse who cared for their child, valued as enablers of bonding.

The nurses always tried to create as much of a bond as possible between my daughter and I, they were our confidants, they gave us courage, strength to continue ... (DIW3).

Although the support of the nurses diminished the stress and anxiety of the mothers, the most effective emotional support was provided by other mothers of preterm infants. For the participants, only a person in their situation can understand the experience.

No one understands you, except a person who has gone through the same thing ... (FG).

Discussion

The objective of this study was to describe and understand the experiences of mothers who have extremely preterm infant admitted in the NICU with regard to the bonding process. The premature labour and separation of the newborn abruptly interrupt the mother-child bond, causing an emotional crisis and negative feelings in a woman who is not prepared.^{10, 28} Given the vulnerability, dependence and need for protection of the preterm infant, the separation generates fear, uncertainty and distrust in the mother,⁶ an abstraction of reality that may explain the rupture of the emotional bond.⁹ According to other studies, the NICU is a complex technological context that interferes with the mother-preterm infant relationship,¹⁶ possibly undermining maternal feelings of bonding. After preterm labour and separation, mothers perceive the NICU as an unknown, confusing and threatening environment,^{23, 28} with negative effects on interaction.¹⁰ Concurring with other studies,¹⁹ our results suggest that the NICU's design, amplitude, illumination, noise and alarms compromise privacy and the bonding process. Mothers require a family-centered care unit that takes care that the environment has specific spaces for the visit, and elements that can facilitate bonding.^{8,17} The mothers' feeling of guilt is associated in our study with their behaviour during pregnancy,^{12,18} and together with other factors such as the child's weight or developmental deficiency, may predict insecure bonding in preterm

infant. Similar to other research,^{22,24} the information and assistance required and received by parents from healthcare professionals is key to bearing this worry, anxiety or anticipatory grief experiences.¹² Our participants alluded to the necessary mother-child interaction and physical contact to maintain postpartum bonding, which coincides with other studies and our theoretical framework links the development of the maternal role to emotional bonding.^{8,13} Separation from preterm infant reduces and delays the mother's responsibility for her infant's care; anxiety then arises from not feeling motherly enough and the risk of insecure bonding increases.^{7,9} Our participants talk about learning to be mothers to a stranger, an extremely preterm infant whose appearance, skin colour or low weight, already described in other studies,¹¹ generates fear, rejection or estrangement. These feelings, exacerbated by the possible loss, generate negative emotions from the first visit to the NICU.¹⁸ There, the woman lacks comfort and freedom to develop her maternal role,⁸ with negative consequences for the development and health of the child.¹⁵ As in other studies, participants require physical contact in order to feel useful,¹⁹ and they need support programs focused on fostering feelings of closeness and trust.^{12,28} Prolonging mother-child physical contact in family rooms or Kangaroo Mother Care,²⁴ can improve safety and strengthen the mother-preterm infant relationship.^{14,15,24} Involving mothers in care, breastfeeding or massage programmes can reduce insecurity and guilt,²⁹ thus restoring motherhood and the bonding process.⁸ Fathers' participation and commitment also positively influence emotional bonding, physical proximity, and communication toward premature infants. Exploring and understanding the fathers' experiences could help neonatal nurses to develop and implement interventions that are specifically adapted to their needs in a NICU.²¹ Our results also point to the mother-nurse interaction in the promotion of secure bonding.¹⁷ Nurses can provide information, support and guidance,^{18,25} fostering confidence and security in the interaction with the preterm infant.¹¹ Although for the neonatal nurses the quality of life of preterm infants and family are an important consideration,⁴ it remains difficult to implement. As in our study, mothers require help to adapt and develop their maternal competencies,^{16,17,23} foster closeness and facilitate the bonding process.^{15,20} Sharing their experiences with nurses or other mothers in the NICU,¹⁶ is found to be fundamental. Early detection of risks during the prenatal stage could allow midwives and neonatal nurses to give

expert advice, support and education on what to do in case of giving birth to a preterm child, improving both the experience in the NICU and the bonding process with their child.³⁰

This study is not without limitations. Our results help to understand the experiences of mothers who have an extremely preterm infant in NICU with regards to the bonding process. The inclusion of parents or participants from other ethnic minorities, may have changed the results. In the NICU where the study was performed extremely preterm infants, preterm infant, newborn term and children up to 14 years share a physical space, and may have influenced the experience of the participants.

Conclusions

This qualitative research highlights the complex nature of the bonding process in extremely preterm infants admitted to the NICU, broken by the premature separation from the mother in a hostile technological environment. The feeling of emptiness and the emotional crisis of the mothers compromise the establishment of a secure bonding and the processes of adaptation. Women have told us that, in the NICU environment, guilt and fear mediate the process of bonding to their children. Mothers need the support and understanding of healthcare professionals, pointing to nurses as facilitators of the secure bonding process. Neonatal nurses are in a unique position to guide women toward regulating their own emotions, promote positive adaptation to the context of the NICU, therapeutic communication and encourage contact through Kangaroo Mother Care, breastfeeding or massage. Further research is required to explore factors that facilitate both physical and emotional closeness to ensure an adequate bonding process in preterm infants at NICU.

Authors' contributions

IF, JG and ML made significant contributions to the conception and design of the study, interpretation of data and drafting the manuscript. IF, MC and JH were involved in the acquisition, analysis and interpretation of data, JG and ML were involved in data analysis and drafting the manuscript, CF, MC and JH were involved in the interpretation of data and the critical revision of the manuscript for important content.

Competing interests

None.

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Table 1. Socio-Demographic Data of the Participants (N=16).

Participant	Age	Marital status	Level of education	Parity	GW	Type of birth	Multiple birth	Birth weight	Days NICU
FGW1	35	Married	Higher	2	25	Vaginal	No	800	62
FGW2	37	Married	Higher	1	26	Caesarean	No	800	58
FGW3	38	Married	Higher	1	27	Vaginal	No	840	65
FGW4	36	Married	Higher	1	27	Vaginal	Yes	940	54
								970	50
FGW5	27	Living with partner	Medium	3	26	Caesarean	No	830	32
DIW1	35	Married	Medium	4	27+2	Caesarean	No	970	37
DIW2	28	Married	Basic	1	27	Vaginal	No	875	33
DIW3	31	Married	Higher	1	26+4	Caesarean	No	950	35
DIW4	30	Married	Higher	1	25	Caesarean	Yes	575	66
								520	63
DIW5	32	Separated	Medium	2	24+5	Caesarean	Yes	560	52
								525	55
DIW6	36	Married	Higher	1	26	Caesarean	Yes	940	52
								820	60
DIW7	32	Separated	Medium	1	25+3	Caesarean	No	840	63
DIW8	33	Married	Basic	2	25	Vaginal	No	607	58
DIW9	41	Separated	Higher	3	26	Caesarean	No	740	34
DIW10	34	Separated	Medium	3	27+1	Caesarean	No	900	38
DIW11	45	Married	Higher	1	26	Caesarean	No	810	62

Note. FGW=focus group women. DIW=in-depth interview woman. GW= Gestational weeks

Table 2. Themes, Subthemes and Units of Meaning.

Theme	Subtheme	Units of meaning
1. Premature labour and technological environment, a distorted motherhood.	1.1 Feelings of emptiness and emotional crisis 1.2. The complexity of the environment and care generate an emotional swing.	Emotional shock, Post-partum feelings, Family support Lack of awareness, NICU stressors, Emotional ambivalence, Guilt, Reaction to information, Influence on maternal emotions, Influence on physical health.
2. Learning to be the mother of an extremely preterm infant	2.1 The difficulty of relating to a “stranger.” 2.2 Forming the bond in spite of difficulties.	Absence of maternal feelings, Separation, Bond rupture. Physical contact, Attachment obstacles, Kangaroo care, Breast milk, Complications, Nursing Massage.