The construction of maternal co-occupation in the Neonatal Intensive Care Unit

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Abstract: Introduction: The term co-occupation has been used by occupational therapists to define the implicit involvement of two or more individuals in an occupation. In this perspective, maternal care is considered a co-occupation, and occupational therapists seek to promote the insertion of the mother in the Neonatal Intensive Care Unit (NICU), maternal guaranteeing autonomy and independence in the care of the baby. Objective: To analyze how the construction of maternal co-occupation in the NICU takes place. Method: A qualitative, multiple-case study conducted at a philanthropic hospital in Belo Horizonte, Minas Gerais, Brazil, and attended by six mothers of infants admitted to the NICU. Semi-structured interviews and the participant’s diary were used as instruments of data collection. The data were submitted to content analysis in thematic modality with the use of MAXQDA software. The themes were grouped giving rise to two categories with their respective subcategories. Results: It was verified that the mothers experience different feelings related to the baby’s hospitalization in the NICU, and their involvement in co-occupations in this context happens gradually, intensifying from the clinical improvement of the baby. Conclusion: The way mothers construct co-occupation during the infant’s hospitalization in the NICU is based on their understanding and previous experience about motherhood, as well as on aspects related to the context of the NICU. It is necessary that occupational therapists know the expectations of mothers in order to build with them possibilities of involvement in co-occupations that meets their expectations.

Keywords: Occupational Therapy, Mothers, Intensive Care Units Neonatal, Infant Care.

A construção da co-ocupação materna na Unidade de Terapia Intensiva Neonatal

Resumo: Introdução: O termo co-ocupação tem sido utilizado por terapeutas ocupacionais para definir o envolvimento implícito de dois ou mais indivíduos em uma ocupação. Nessa perspectiva, o cuidado materno é considerado uma co-ocupação, sendo que os terapeutas ocupacionais buscam promover a inserção da mãe na Unidade de Terapia Intensiva Neonatal (UTIN), garantindo a autonomia e independência materna nos cuidados do bebê. Objetivo: Analisar como se dá a construção da co-ocupação materna na UTIN. Método: Estudo de caso múltiplo, descritivo-exploratório de abordagem qualitativa, realizado em um Hospital filantrópico de Belo Horizonte, Minas Gerais e que teve como participantes seis mães de bebês internados na UTIN. Utilizou-se como instrumentos de coleta de dados a entrevista semiestruturada e o diário da participante. Os dados foram submetidos à análise de conteúdo na modalidade temática com a utilização do software MAXQDA. Resultados: Verificou-se que as mães vivenciam diferentes sentimentos relacionados à internação do bebê na UTIN, sendo que seu envolvimento em co-ocupações, nesse contexto, acontece de forma gradativa, se intensificando a partir da melhora clínica do bebê. Conclusão: O modo como as mães constroem a co-ocupação durante a internação do bebê na UTIN baseia-se no seu entendimento e na sua vivência prévia acerca da maternidade, bem como nos aspectos relacionados ao contexto da UTIN. Faz-se necessário que os terapeutas ocupacionais conheçam as expectativas das mães, a fim de construir com elas possibilidades de envolvimento nas co-ocupações que venham ao encontro de seus anseios.

Palavras-chave: Terapia ocupacional, Mães, Unidades de Terapia Intensiva Neonatal, Cuidado do Lactente.
1 Introduction

The term co-occupation has been used by the Occupational Therapy professionals to define the implicit involvement of two or more individuals in an occupation, so each person influences the other (PIERCE, 2009). Thus, academics show mothers’ care as a co-occupation process, since there is a dyad between the mother’s and the child’s occupations (DALVAND et al., 2015).

Especially in the national literature, this terminology has not been widely adopted because other authors have used terms such as participation or involvement in maternal care (JOAQUIM; SILVESTRINI; MARINI, 2014; DITTZ et al., 2011; MORENO; JORGE, 2005). The term co-occupation is an original concept to occupational science, well grounded in interdisciplinary theories, but there is still a need for more research on this perspective (PIERCE, 2009). Other authors say that despite the history and consistency of co-occupations, there is still a shortage of understanding of Occupational Therapy professionals on this topic. Thus, researchers propose the development of qualitative studies to explore the nature of co-occupations, as well as to improve the quality of their work (DALVAND et al., 2015).

In this study, the term co-occupation was chosen when addressing the mother’s involvement in the care of the hospitalized baby in the Neonatal Intensive Care Unit (NICU), understanding that it is a situation that demands interaction between the mother and the child, and the mother and the baby learn with each other, providing feelings of satisfaction and maternal competence (NUGENT, 2015).

Maternal engagement in co-occupations related to the care of children with disabilities has been widely discussed. The study by Dalvand et al. (2015) shows that the mothers of children with cerebral palsy play an important role in the care of their children, which requires considerable time by the mothers. Most daily activities of these children require the engagement of mothers, facilitating participation and providing better performance of children in daily activities.

Maternal demands and responsibilities in the care of their children with disabilities challenge the constant presence of mothers as well as their efforts to meet the medical, educational and recreational needs of their children, and it is necessary to give up the professional career plan to become a mother full-time (SMITH, 2004). When intervening with this group, occupational therapists offer opportunity for maternal engagement in co-occupations as one of the purposes to be achieved, even if the child has serious impairments (PRICE; MINER, 2009).

In the neonatology context, it is possible to identify that the mothers live a similar situation. The need for hospitalization of the baby in a NICU has repercussions on the family daily life, in which the woman often abdicates from her other occupational roles to accompany the child during hospitalization (DITTZ; MELO; PINHEIRO, 2006). Also, studies show that hospitalization arouses different feelings in the woman, such as the fear of the unknown and the frustration of not having the baby in the family (DITTZ; MELO; PINHEIRO, 2006; MORENO; JORGE, 2005).

Regarding the care of newborns hospitalized at the NICU, mothers are offered the opportunity to perform diaper changes in situations in which the baby is stable and the mother is able to carry out this care. Mothers are also stimulated to touch their babies and guided over their behavioral signals during their touch (DITTZ et al., 2011). Besides, there is the incentive to Kangaroo care and to breastfeeding and/or the administration of the newborn’s diet when the baby does not suck the breast (MALAKOUTI et al., 2013; DITTZ; MELO; PINHEIRO, 2006).

There are some limitations found on the participation of the mother in the care of the baby in the NICU, such as the resistance of the professionals in inserting the mother in the care activities, the lack of planning by the professional in the routine activities, the difficulty of the team in dealing with the emotions of this mother facing the hospitalization of the baby, the difficulty of the professional to consider the singularity of each woman and the inadequacy of the physical space to accommodate the mother and the family of the newborn (DITTZ et al., 2011; MOLINA et al., 2007). The clinical conditions of the baby and the personal availability of the mother for the care activities interfere in this participation (DITTZ et al., 2011). Thus, it is important to emphasize that the dialogue between professionals and mothers is an important instrument to enable maternal care participation (DITTZ et al., 2011).

The presence of the mother in the NICU and her participation in the care are very important for the recovery of the baby (MORENO; JORGE, 2005) and to promote human development (JOAQUIM et al., 2018). The involvement of the mother in the direct care of the newborn is better with the care provided by the health team, a better performance of the woman in the care of the child after discharge, and a reduction in the need for re-hospitalization (DITTZ; MELO; PINHEIRO, 2015).
As a member of the team, the occupational therapist is recommended to assist the newborn and the family, seeking to promote, support and facilitate the process of insertion of the mother into the NICU, guaranteeing autonomy and maternal independence in care activities (DITTZ; MELO; PINHEIRO, 2006; VERGARA et al., 2006).

The discussions about the engagement of the baby mothers in the co-occupations in the context of the NICU is emphasized considering that each human being is unique, with its rights, duties, and values. Each mother should be recognized in her singularity, as well as her feelings regarding the current experiences (MORENO; JORGE, 2005).

In this context, the concept of mothering is necessary to be understood as something that is not only related to the child’s need to receive basic care but also to the psychic availability of the mother to her baby (STELLIN et al., 2011). In this way, a woman is not characterized primarily as a mother, but the mother’s role is a process of construction, and this understanding could be also as the conception of co-occupations. Therefore, since co-occupation is an object of study of Occupational Therapy, it becomes imperative to produce knowledge about this topic in the neonatology field.

Thus, this study aims to analyze how the construction of maternal co-occupation occurs in the Neonatal Intensive Care Unit.

2 Method

This is a descriptive-exploratory study with a qualitative approach, using the multiple case study as a research modality. Through the study of one or a few objects of study, this study allows a broad and detailed knowledge in which several studies are conducted (several individuals, several organizations) usually using four to ten cases (GIL, 2002).

The study was conducted at a philanthropic institution in Belo Horizonte, Minas Gerais, specialized in maternal and child care and exclusively assisting patients of the Unified Health System (SUS).

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The following criteria were adopted to include the mothers: primiparous, literate women who remained in hospital full time during the baby’s hospitalization and whose newborns had a gestational age at birth greater or equal to 28 weeks and were clinically stable and hospitalized at the NICU for at least four days. The abovementioned period was determined aiming at the need of a time for adaptation of the mother to the hospital routine (DITTZ, 2009). The exclusion criteria of the mothers were: Alcohol and illicit drugs users; women with psychic disorders and emotional instability. The individuals eligible to participate were identified from the daily census conducted in the Espaço de Sofias, which is a unit for the mother’s stay during the hospitalization of the child in the NICU, regarding the length of stay of the mothers. Then, the records of the newborns admitted to the NICU were consulted to obtain information about the gestational age, clinical evolution and date of the baby’s hospitalization, as well as to collect information about the maternal history.

The data collection was from August 18 to November 20, 2016, and began after the approval of the Ethics Committee in Human Beings of the Hospital Sofia Feldman (CAAE: 55375416.5.0000.5132), according to Resolution 466/2012 of the National Health Council. Participants were informed about the purpose and characteristics of the study, guaranteeing the confidentiality and integrity of the study. They were asked to sign the Informed Consent Term (TCLE) and the Free and Informed Consent Form in the case of a participant under 18 years old. All the mothers who were approached by the researcher accepted to participate in the research.

A semi-structured interview and a participant’s diary were used as instruments for data collection. A pilot test was carried out in the period from July 12 to 17, 2016 to validate and adapt the instruments of data collection, indicating the adequacy of the guiding questions of the interviews. The semi-structured interviews with the study participants were performed at different times, one after four days of hospitalization of the baby in the NICU (initial interview) and the other immediately after the discharge of the newborn from the NICU (final interview). A script was drawn up for each interview, as presented in Table 1. The interviews were recorded and later transcribed by the researcher.

The participant’s diary was a penciled and paginated notebook, for individual use (Figure 1). All the participants in the study received the diary after agreeing to participate in the study and were instructed to record everyday events, perceptions, feelings and what they wanted most. Thus, this instrument enabled to understand the participants’ reactions and perspectives to their experiences (ZACCARELLI; GODOY, 2010). By closing the data collection, the participants provided the diary to copy it and then it was returned to the mothers.

The saturation criterion was considered to close the data collection when the themes in the interviews and participants’ diary were repeated (MINAYO, 2013).
The data obtained through interviews and diaries were transcribed in full by the researcher, constituting a single text referring to each of the participants. The participants were identified with the letter “M”, followed by the numerical code of the inclusion order in the research to preserve their anonymity. The data obtained through the initial interview were identified with the letters “II”, the final interview with the letters “FI” and the field diary with the letters “FD”. For the analysis of the data, the professional software MAXQDA was used and the content analysis guidelines were met in thematic analysis modality to reveal the sense cores (MINAYO, 2013). The most recurrent and relevant themes were identified for the purpose of the study and the discourses were cut. Thus, the themes were grouped in two categories sown in the results.

The long-term approximation of the object and scenario of research, the persistent observation and the triangulation of analysts were sought to guarantee the credibility and confirmability of the data (LINCOLN; GUBA, 1985). For this procedure, the researcher used the available literature and also was inserted in the field so she could know the relationships established between the mothers and their babies and between the mothers and the health professionals. It was also possible to know the routines of the NICU and the daily life experienced by the mother during her stay in the NICU. Due to the fact that the researcher acted in the research scenario during the data collection period, she did not follow up in the Units in which the babies of the mothers participating in the study were hospitalized, avoiding possible bias. To meet the validity criterion, two other researchers with experience in a qualitative approach and with the thematic of the study participated in the process of analysis of the results, and one of them carried out the first analysis together with the main researcher. In another moment, the second researcher verified and confirmed the results obtained in the analysis of the data.

**3 Results and Discussion**

Six mothers aged between 17 and 29 years old participated in the study, all of them attended school for 10 years or more. Among the newborns, the mean gestational age was 32.16 weeks and the weight ranged...
from 690 grams to 3,340 grams. Regarding infant feeding, all had breast milk. In Table 2, there is a more detailed characterization of each participant.

The analysis allowed grouping the data into empirical categories and subcategories presented in Table 3.

3.1 Maternity from the perspective of mothers of the babies hospitalized at the Neonatal Intensive Care Unit

3.1.1 Mothers’ conceptions on their motherhood

At the same time that motherhood is highlighted with a sense of joy, it is also a situation with fear and insecurity, since considering all the demands of the practice of motherhood, the mothers fear not being able to take care of their child:

*Being a mother is something indescribable; it is a love different from everyone I know. God really is wonderful!* (M1 – FD).

*Being a mother to me, I think being a mother is the word fear. Afraid of everything! I think it's insecurity!* (M5 – II).

Motherhood is a unique experience in the life of the woman, demanding changes and adaptations from the redefinition of the new roles assumed by her. The mothers experience different feelings and emotions associated with the baby’s birth as a result of the reorganization of the occupational role (ZANATTA; PEREIRA, 2015).

Therefore, there is a need to provide listening spaces for the women, contributing to the elaboration and organization of their new role in society. The occupational therapist can contribute to this process through guidance on the care of the baby and the reception of the doubts and insecurities of the mothers, contributing to the empowerment of women for their motherhood.

Motherhood is understood by the study participants as a gift that demands affection, dedication, love, and responsibility. The birth of the baby is understood as a milestone in a woman’s life, a time to make choices and changes to include the baby:

*Being a mother is a gift from God, it is a gift!* (M2 – FD).

Table 2. Characterization of the mothers and newborns participants of the study.

<table>
<thead>
<tr>
<th>Mother</th>
<th>Mother’s age</th>
<th>Mother’s education level (years)</th>
<th>Gestational age of the NB (weeks)</th>
<th>NB weight when was born (grams)</th>
<th>Type of diet received</th>
<th>Hospitalization time in NICU (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>28</td>
<td>11 years</td>
<td>34 weeks</td>
<td>1355 g</td>
<td>Breast milk extracted manually</td>
<td>18 days</td>
</tr>
<tr>
<td>M2</td>
<td>20</td>
<td>10 years</td>
<td>39 weeks</td>
<td>3340 g</td>
<td>Breast milk extracted manually</td>
<td>10 days</td>
</tr>
<tr>
<td>M3</td>
<td>19</td>
<td>12 years</td>
<td>28 weeks and 6 days</td>
<td>1280 g</td>
<td>Breast milk extracted manually + baby formula</td>
<td>41 days</td>
</tr>
<tr>
<td>M4</td>
<td>17</td>
<td>11 years</td>
<td>29 weeks and 1 day</td>
<td>690 g</td>
<td>Breast milk extracted manually + Pasteurized Human milk</td>
<td>74 days</td>
</tr>
<tr>
<td>M5</td>
<td>29</td>
<td>11 years</td>
<td>34 weeks</td>
<td>1790 g</td>
<td>Breast milk extracted manually</td>
<td>12 days</td>
</tr>
<tr>
<td>M6</td>
<td>21</td>
<td>12 years</td>
<td>29 weeks and 5 days</td>
<td>1565 g</td>
<td>Breast milk extracted manually</td>
<td>25 days</td>
</tr>
</tbody>
</table>

Table 3. Categories and Subcategories.

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternity from the perspective of mothers of infants hospitalized at the Neonatal Intensive Care Unit</td>
<td>- Conceptions about motherhood.</td>
</tr>
<tr>
<td></td>
<td>- Maternity in the context of the Neonatal Intensive Care Unit.</td>
</tr>
</tbody>
</table>

The construction of maternity as a co-occupation in the context of the Neonatal Intensive Care Unit.
For me, it is to dedicate the love, the affection, the emotion. All the feeling you have for your child (M3 – II).

I think it's the basis of everything: education and care, lots of love (M5 – II).

Being a mother and put the child in the world are two completely different things!

Being a mother is not putting a child in the world and pushing the responsibility for another person to take care just to continue hanging out. To be a mother is to give up things that one likes to do, but will not be able to do so after the baby's arrival, like going out the whole night, sleeping through the night and waking up later. It is to change the previous plans and make new ones where the baby is included (M2 – FD).

In this context, the gift is nothing more than the alliances formed between the mother and the baby, linking them simultaneously with pleasure, interest, obligation, and donation. The gift is not about rituals expressed by feelings of generosity, but it is related to the spontaneity existing in the relationship between mother and child, and the gift is to establish and value relationships (ALVES, 2013; CAILLÉ, 1998).

The concept of gift becomes important as we seek to understand the relationship built between the mother-baby. From this recognition, it is imperative to say how important is the elaboration of strategies for the establishment or strengthening of the bond between the dyad. The participation of the mother in the care of the child favors the affective bond (BARROSO; PONTES; ROLIM, 2015).

This finding reinforces the importance of the occupational therapist to promote independence and maternal autonomy in the care of the newborn. By guidelines for the signs and behaviors of the baby, opportunities are created for the mother to participate directly in the care of activities such as bathing and feeding.

The reports show that motherhood is not something defined a priori, being built from previous experiences and the relationship that the mother establishes with the child. It is also noticed an availability of the mothers to learn with the baby and to transform from this learning:

I got [the baby] on Monday. Being a mom is something I've always wanted to be, but I've never tried to create a concept because I think we'll find out together, both her and a daughter when she grows up, as me as a mother when she grows up. Because every mother is one way, just like every child is in a way. So I always tried not to base as a mother should be when I had a child. I do not know her yet, I do not know her, she's just born, nor does she know who she is. So, I do not have a concept formed, like: the mother is this! So, I'm discovering myself as a mother every day and I think that being a mother is that. It is you to discover yourself with your baby (M6 – II).

Trying to make it what we are, but a little better. We have to try to improve on everything! My mother was a good mother and I'm going to take the good things what she did for me and do it for my son, but always trying to improve. I think that's it! (M5 – II).

Studies indicate that the relationship established with the mother is one of the references for the daughters in the conceptions of motherhood since mothers often repeat what they lived as daughters (KREUTZ, 2001; BADINTER, 1985). The construction of motherhood is also influenced by mother-child coexistence and the availability of the mother to the baby, and the so-called maternal instinct is questioned (BADINTER, 1985).

The care of the newborn is perceived by four of the participating mothers as something inherent to motherhood, related both to the actions of feeding and hygiene the baby and to education and orientation to life:

The child is totally dependent on us. Without us, the child does not eat, does not bathe, does nothing. So that's it, it's doing a lot of things for us to get rewarding improvements (M2 – II).

Give education, respect, love, affection, incentives, right? Show how life is (M4 – II).

But I think a woman, for her to be a mother, has to know how to educate, guide, care, right! (M5 – II).

Therefore, participants’ understanding of motherhood has multiple intertwined aspects. The feelings experienced by them are influenced by the care given to the child, by the exchanges or relationships previously established as daughters and now as mothers and by the elaboration of the change of occupational role, which makes the construction of motherhood a unique process.
3.1.2 Motherhood in the context of the Neonatal Intensive Care Unit

The data show feelings experienced by the mothers when facing the need for hospitalization of the baby in the NICU. All participants report experiencing feelings such as fear, worry, anguish, apprehension, frustration, sadness and impotence in the reality experienced. The feelings are related to having given birth to a premature newborn and the unpredictability of the baby’s clinical condition due to prematurity:

I went to my daughter’s house soon after [coming back home], when I saw her, I had a feeling of failure, but when she looked at me and gave me a half smile, I calmed down a bit (M4 – FD).

[...] It is a very fearful feeling we felt. Until we see that he [baby] is well stabilized, then we get scared. Every day we are getting scared at the time of the news, to see some bad news, but thanks to God everything worked out (M1 – FI).

On Saturday, we woke up and came to the hospital and she [baby] was at CPAP! it was a shock. A person who was well and suddenly felt my daughter tired... On Sunday, we came early, she was in the tube. When I saw her, I just cried, there were no words, nothing to reassure me (M4 – FD).

However, the close relationship between the mother’s feelings and the child’s clinical condition can be seen, and feelings such as joy and hope are indicative of the baby’s recovery and achievement during the NICU admission:

Today I went to visit my son and I had the news that they intubated him and now he is in the CPAP. My day got better (M3 – FD).

[...] the days are long, taking milk is boring and sometimes painful, but I rejoice in every evolution. I am glad when the diet increases, after all, she is gaining weight, I am happy with every positive test result and every time my touch calms her when she holds my finger and I concentrate on believing she knows I am there. I’m glad when the nurses say she’s not quiet and just lies the way she wants (M6 – FD).

With a premature birth or other health conditions of the baby, the mothers face the need for the child’s hospitalization in the NICU. This environment is totally unknown by the mothers, as they are faced with the presence of technological equipment, excessive light and noise, constant movement of people and invasive procedures the newborns are subjected. All of these factors can raise distressing feelings during the baby’s hospitalization in the NICU (QUERALT, 2016).

Thus, adequate guidance on unit care routines may contribute to minimize the emotional impacts of mothers on the infant’s hospitalization (AL MAGHAIREH et al., 2016).

The need for hospitalization of the baby in the NICU and the demand for specialized care make maternal closeness difficult and impose limits on women to experience motherhood. In this situation, mothers have difficulty recognizing themselves as mothers, especially because they cannot perform the child’s care, which they consider to be maternal attributions:

I have not been a mother yet! I did not get my son on my lap, I still did not change his diaper, I still did not nurse him, the most I did was touch him.

Yes, because I have not really figured out myself as a mother. I gave birth to a baby that is here in the ICU and, for example, I did not even take him. There are many things that characterize the daily life of a mother that I have not yet been able to live (M6 – II).

There is a close relationship between the mother’s involvement in the care of the baby and the fact that they recognize themselves as mothers. For this reason, the influence of the NICU context on maternity practice should be considered. The term context refers to everything that composes or encircles a subject, exerting a strong influence on their occupational performance (ASSOCIAÇÃO..., 2015). The occupational function of a person is shaped by contextual factors, such physical, cultural, social or personal (RADOMSKI, 2007). Thus, understanding the context of the occupations, providing occupational therapists with knowledge about the extent and influence on occupational involvement (ASSOCIAÇÃO..., 2015).

In the context of the NICU, the care of the baby has been historically centered on the health professional predominating the hierarchical medical model of care. Although it is necessary, this approach may jeopardize the development of the mother-to-baby care relationship (QUERALT, 2016; CARDIN, 2015). Thus, recognition of the maternal role by the professionals in the NICU is essential. From
a practice focusing on the relationship between the mother-baby, it is possible to make the mother partners in the care process, offering a humanized and quality assistance to the baby and her family (AL MAGHAIREH et al., 2016).

The mothers allow knowing that their daily life during the NICU stay is highlighted by tiredness due to the routine of caring for the child and the preoccupations with the baby and other family members who are at home. Mothers seek to be organized with the child and to be involved in his care, recognizing that the baby is the priority of their lives at that moment:

*It is very tiring [the routine]. It was very tiring, it's being very tiring yet. So, I know that what we are going through is still going to be very tired, but it is the same concern that we get when he is in this situation* (M1 – FI).

*Ah! It is too hard. Wow... tiresome. Because, when he started to breastfeed, the girl [nurse] asked me if I could go down all the time, even at dawn, because otherwise, I would give her milk in the cup, but I would rather breastfed than it would be tiring, I preferred. But it is very tiring* (M2 – FI).

*There were stressful days because it was a problem here with him, there was trouble at home that I had to leave to solve it. Sometimes I had to go home and solve problems there and leave him, which for me was also very difficult, but had days too which was very good* (M3 – FI).

A study by Ribeiro et al. (2014) considers that the estrangement between the mother and the baby shortly after birth and the estrangement of the mother from other family members were the main factors that caused them feelings such as fear, anguish, and impotence, as well as the stress caused by the baby hospitalization.

All the factors mentioned in this context can change the maternal role, compromising the mothers’ engagement in the care of the baby (CARDIN, 2015).

During the hospitalization of the newborn in the NICU, the mothers identify the companion as a source of support. Faith and the possibility of expressing their feelings in the diary seem to contribute to the confrontation of the situation experienced by them:

*Thank God my husband is with me always, he gives me a lot of strength, especially on days like today that, once again, we have not heard from pediatricians, it’s already 2 days without news [...] (M6 – FD).*

I went to see her and I saw my heart in that moment accelerating and my faith shout to God to leave her with me. At that moment I did the last prayer of the day: do the best for her, my God (M4 – FD).

*And at that moment, at 09h30, I’m here writing to be calm and waiting for the news schedule (M4 – FD).*

The practice of spirituality in the neonatal context contributes to the humanization of care, strengthening the bond between the mother, the baby, the family, and the health team. This spirituality is shown as one of the primary sources of hope, helping mothers to overcome and understand the process of hospitalization of the baby. Thus, the creation of spaces for the expression of spirituality becomes important to assist mothers in coping with the child’s hospitalization process (VERAS; VIEIRA; MORAIS, 2010).

A study by Macnab et al. (1998) used diary writing as a strategy for parents of preterm infants, identifying that 73% of them felt that writing in the diary significantly helped reduce stress, and 68% used it to address the most stressful experiences.

The activity groups were used as a resource by the occupational therapist supporting the mothers in facing the situation experienced. The groups enable a rescue of subjective questions, producing an extended care in the physical, contextual, personal aspects of each one (JOAQUIM; SILVESTRINI; MARINI, 2014). Also, it favors the formation of a support network with other mothers in the same situation (DUARTE et al., 2013). They also provide mechanisms for families to discuss and share their concerns (BALBINHO et al., 2015) and contributes to the reduction of stress (MOURADIAN; DEGRACE; THOMPSON, 2013).

The data show that the hospitalization of the newborn in the NICU is highlighted by the fragility and unpredictability of the baby’s clinical condition, the presence of trained professionals and technological equipment aimed at improving or guaranteeing health. This situation may lead mothers to experience conflicts regarding the maternal role since this context has limits for the construction of the mother-baby relationship and the mother’s engagement in care. Even if these limits are evident to the participants, they maintain the desire to take care and make themselves present in the baby’s life, anchored in the understanding that he is the priority of her life at that moment.
3.2 The construction of motherhood as a co-occupation during the hospitalization of the baby in the NICU

The data show that the experience of motherhood in the context of the NICU is permeated by the desire of mothers to participate in the care of the baby. However, most of this care is restricted to health professionals due to the clinical condition of the newborns, generating frustration in the mothers:

I wanted to give him the bath, but it was not possible because he was very young and being underweight and breastfeeding there [in the NICU] was not possible (M2 – FI).

I wish I could take him, take a shower, feed him, right! [...] I hope God will help him recover quickly so I can have more contact with him (M3 – II).

I wish I had made the Kangaroo with her, but there, it was already scheduled. It was a couple of times that the [nurses] girls schedule it for me, except that she was giving apnea during the week and the pediatrician thought it best not to do it (M4 – II).

It’s the main thing that makes me... that I really miss her, to be able to get her and that, because the most we can do is to take her little hands in the incubator (M6 – II).

I can no longer see my son in the ICU and cannot take care of him the way I want: to bathe, to put on clothes, to change diapers, among others (M2 – FD).

According to Pierce (2014), co-occupations are those that mothers say they are or wish to do. They are personally constructed, presenting a form, a rhythm, a beginning, and an end, with a cultural meaning, and they can include activities that are not directly observable by external caregivers such as warmth, play, sanitize, look, talk, read, protect, touch, hold or record moments.

This data is in line with the discussions held by Pickens and Barnekow (2009) who consider that maternal care is a co-occupation since it occurs when the mother and baby perform an occupation in a mutually responsive and interconnected manner, requiring aspects of physicality, emotionality and shared intentionality. The shared physicality occurs when two or more people engage in reciprocal motor behavior. The shared emotionality occurs when one person is reciprocally sensitive to the emotional tone of the other. In shared intentionality, there is an understanding of the role and purpose of each one during the co-occupation engagement (PICKENS; BARNEKOW, 2009).

Occupational therapists can act as interlocutors between the other professionals of the health team and the family, contributing to the establishment of mutual trust. In addition to promoting maternal occupational performance by supporting and inserting mothers into co-occupations during the infant’s hospitalization in the NICU (CARDIN, 2015), it is possible to expand care and interaction through actions not yet performed by the mothers, such as the act of talking and singing to the child (DITTZ; ROCHA, 2018).

In the initial moments of hospitalization, the mothers identify the adequate hygiene of the hands as an important action in the care of the child, recognizing that this care is essential to reduce the risk of infection of the baby in the NICU:

So for now, there are few. There’s a lot of hygiene we have to have. Lots of care for the fact that he is premature, it is very dangerous to get infection, these things. What I have experienced at the moment is this (M3 – II).

The hygiene. In the ICU, we used to do not have a habit of doing it straight, which is fast, usually you go to the bathroom and wash your hand, but you do not have that habit of all time to wash your hand and alcohol in your hands, because in the ICU any little thing can bring worsening to the baby. And that’s it, hygiene. Hygiene increased significantly (M5 – II).

When mothers show the hand hygiene as a care to be performed, reflection in this situation becomes necessary. The hand hygiene is part of the routine in the NICU, being performed by all the people that circulate in this space. The recognition of hygiene by some mothers as a form of care may be related to the fact that in the initial moments, mothers did not have the opportunity to identify other ways to get involved in the care of the baby. Therefore, the importance of implementing actions, even in the initial moments of hospitalization, must be considered to build with the mothers the possibilities for engagement in the co-occupations that they wish to participate in the context of the NICU.

All mothers participating in the study performed the manual extraction of breast milk, and two of them also offered the force-feeding for the baby. It is evident that the manual extraction of milk is considered by the mothers as something far from
the act of breastfeeding the child in the breast and sometimes as a tiring and exhausting activity. However, for mothers, this was one of the main ways to take care of the child in the NICU:

Yeah, and I was going to get some milk, but when he started breastfeeding I stopped taking milk, I was just in that routine. All the time! (M2 – FI).

Taking milk is essential, right. That’s what we can do while she’s in the ICU. Make the maximum effort to maintain the milk, because it does not have the breastfeeding stimulus, so we have to control to go every 3 hours to take it, otherwise the milk will decrease. So it’s waking up at dawn to go into the milk room. Because it’s not good to extract milk. It is not the same [breastfeeding] and it is tiring. And it’s not that magical moment of breastfeeding, it’s you taking your milk there and that’s it (M6 – FI).

The above discourse allows considering the importance of identifying elements that allow other forms of mothers’ involvement in feeding the baby, especially when they cannot suck the breast. Intervening for mothers to establish face-to-face contact, touching or holding the child in the lap during dietary management may be strategies that favor mother involvement. It is recommended that occupational therapists contribute to this approach to promote meaningful and reciprocal involvement of the mother and baby in this co-occupation (CARDIN, 2015).

Holding the baby in the lap, caressing and performing the Kangaroo task were activities performed by the mothers during their child’s hospitalization at the NICU. The involvement of the mother in the care activities occurs gradually, intensifying as the length of hospital stay. It is noticed that the mothers feel satisfied and fulfilled before the opportunities to take care of the child in the NICU:

In the ICU, I could not do much about the devices. So the only thing I could really do was watching him and, from time to time, passing my hand through him. The last day he stayed in the ICU, they took him out of the light, I did the kangaroo with him, it was very good! But, I did not have many things to do there (M5 – FI).

Today, we had no news in her clinical condition, we continued in the light, but they let me do Kangaroo. I got my baby on my lap for the first time, I was extremely happy and she was quiet, cuddled all the time. It gave me hope that soon she goes home. It was difficult to put her back in the incubator, but now she and I know the feeling of the warmth we can find in each other (M6 – FD).

Then I managed to take two baths inside her [of the NICU], although she began to take a bath also towards the end, a bucket and a bathtub (M6 – FI).

The presence of co-occupational aspects during the hospitalization of the baby in the NICU is highlighted, presenting it as an essential way. Essential co-occupations are those necessary to sustain life or growth and development and are characterized by one of three aspects of co-occupation. Although all co-occupations have physical, emotional and intentional aspects that are shared, one aspect may have a stronger presence than others (PICKENS; BARNEKOW, 2009).

From the data presented, it can be seen that the aspect of shared physicality is more strongly presented than the other aspects in the co-occupation in the NICU. However, the other aspects of co-occupation in this unit cannot be disregarded. In Kangaroo care, for example, there is the presence of shared emotionality, and among the many benefits of Kangaroo care, there are the strengthening of the mother-baby bond, the reduction of the psychological and physical stress of the baby and greater incentive and maintenance of breastfeeding (SARPARAST et al., 2015).

Based on this understanding, it is possible to consider that the incentive to Kangaroo care, besides presenting several benefits for the development of the newborn, is also of extreme importance for the process of construction of the maternal co-occupation in a NICU. The Occupational Therapist can act together with the other professionals in the actions to raise awareness and training for Kangaroo care and to provide spaces for discussion about this practice, such as conversation wheels or groups of orientations for mothers (FREIRE et al., 2014).

By sharing their experiences with newborn hospitalized at the NICU, the participants allow knowing the situations that enabled them to perceive themselves as mothers. Holding the child in the lap, touching, breastfeeding and realizing that the baby recognizes the mother’s voice were experiences that contributed to the materialization of motherhood:

Then I went to the ICU and I talked to her and asked her to shake my hand. Then she squeezed my little finger. She was pretty bad. It was because she listened to me (M4 – FI).

In the ICU, I think it was the day I did the kangaroo. There, it was the first time I said: Wow,
The construction of maternal co-occupation in the NICU is directly related to the recognition of the mother in relation to motherhood. Thus, occupational therapists favor co-occupation, supporting the engagement of mothers in the care of their babies, based on a practice centered on the relation between the mother-baby dyad and her family (CARDIN, 2015), considering the variability of behavior the expectations of the parents and how they experience the condition of having a baby in the NICU (DITTZ; ROCHA, 2018).

4 Conclusion

When becoming a mother, the woman experiences different feelings and emotions, as well as the need to reorganize her occupational roles. The construction of motherhood is a unique process, being influenced by the previous experiences of the woman as a daughter and through the relationships, she establishes with the baby after birth. With the need for the baby to be admitted to the NICU, mothers experience negative feelings due to the unpredictability of the baby’s clinical conditions and the limits imposed by the context of the NICU.

This study allows knowing how the process of constructing the maternal co-occupation in the NICU occurs. Despite the limits imposed by the context of the NICU, the mothers feed the desire to participate in the care of the child and they do it gradually, as the improvement of the clinical conditions of the baby occurs.

The fulfillment of the expectations of the mother regarding the care of the baby, which she considers to be inherent in motherhood, is fundamental for her to be recognized as a mother, observing the co-occupational aspects, especially in shared physicality and emotionality. Therefore, it is necessary for occupational therapists to know the expectations of mothers to build with them possibilities of involvement in the co-occupations that meet their expectations, but also in accordance with the clinical conditions of the baby and the context of the NICU.

The recognition of these aspects as part of the occupational therapist's clinical practice in this context can be a way to plan and implement care practices that consider the uniqueness of the mother, the baby, and her family, promoting maternal engagement in co-occupations.

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