Cadernos Brasileiros de Terapia Ocupacional
Brazilian Journal of Occupational Therapy

ISSN 2526-8910

Experience Report

Process of construction of the maternal occupational identity interrupted by the grief[1]

Processo de construção da identidade ocupacional materna interrompida pelo luto

Danusa Menegat[a], Daniel Ferreira Dahdah[a], Tatiana Barbieri Bombarda[a], Regina Helena Vitale Torkomian Joaquim[a]

[a]Universidade Federal de São Carlos – UFSCar, São Carlos, SP, Brasil.

How to cite: Menegat, D., Dahdah, D. F., Bombarda, T. B., & Joaquim, R. H. V. T. (2021). Process of construction of the maternal occupational identity interrupted by the grief. *Cadernos Brasileiros de Terapia Ocupacional*, *29*, e2134. https://doi.org/10.1590/2526-8910.ctoRE2134

Abstract

This study aims to investigate the occupation of a woman who became the mother of a preterm baby, experiencing the child's death one month after hospital discharge. It is a qualitative study, whose outline was the Case Study, anchored in the theoretical framework of the Human Occupation Model. Data were collected through the application of the Daily Occupations (DO) instrument and two semi-structured interviews, one conducted at the Neonatal Intermediate Care Unit and the other in the home context. The DO data were organized descriptively and the interviews were transcribed and subsequently analyzed using the Thematic Content Analysis. It is observed that the construction of maternal occupational identity occurred gradually and was related to the child's clinical condition. As analytical categories, two themes emerged: "Hospitalization of the preterm baby: a new, unknown and frightening context for the future and new mother" and "The death and the process of maternal mourning: how to continue to live after the child's death". It is argued that becoming a mother to a preterm baby reveals changes in the routine that demands staying in a hospital environment. Still, that the need to face the mourning was configured as a new and complex challenge since the maternal identity process was interrupted when experiencing the unexpected loss of the baby. Research that addresses the occupations of mothers of preterm babies is relevant to the practice of Occupational Therapy, as it allows knowing the construction of maternal identity in the context of risky birth, and also how to deal with the grief associated with maternal mourning.

[1]This article is part of the Doctoral Thesis developed at the Federal University of São Carlos/São Carlos - SP, entitled "Occupations of mothers of preterm babies during hospitalization and after hospital discharge", by Danusa Menegat. The current ethical procedures were followed, and the research was approved by the Human Research Ethics Committee of the Federal University of São Carlos (UFSCar), CAAE: 74765417.9.0000.5504 and opinion number 2,457,585.

Received on Aug. 6, 2020; 1st Revision on Oct. 7, 2020; 2nd Revision on Feb. 6, 2021; Accepted on Feb. 9, 2021.

Keywords: Activities of Daily Living, Maternity, Infant, Premature, Bereavement, Occupational Therapy.

Resumo

Este estudo objetivou investigar a ocupação de uma mulher que se tornou mãe de um bebê pré-termo, vivenciando, um mês após a alta hospitalar, o óbito do filho. Trata-se de um estudo qualitativo, cujo delineamento foi o Estudo de Caso, ancorado no referencial teórico do Modelo de Ocupação Humana. Os dados foram coletados por meio da aplicação do instrumento Diário de Ocupações (DO) e da realização de duas entrevistas semiestruturadas, uma delas realizada na Unidade de Cuidados Intermediários Neonatal e outra no contexto domiciliar. Os dados do DO foram organizados descritivamente e as entrevistas foram transcritas e, posteriormente, analisadas por meio da Análise de Conteúdo Temática. Observa-se que a construção da identidade ocupacional materna ocorreu de forma gradativa e relacionada à condição clínica do filho. Como categorias analíticas, emergiram dois temas: "Hospitalização do bebê pré-termo: um novo, desconhecido e amedrontador contexto para a futura e nova mãe" e "A morte e o processo de luto materno: como continuar a viver após o óbito do filho". Discute-se que se tornar mãe de um bebê pré-termo desvela mudanças na rotina que demanda a permanência em um ambiente hospitalar. Ademais, que a necessidade de enfrentar o luto se configurou como um novo e complexo desafio, uma vez que o processo da identidade materna foi interrompido ao vivenciar a perda inesperada do bebê. Pesquisas que abordem as ocupações de mães de bebês pré-termos são relevantes para a prática da terapia ocupacional, pois permitem conhecer a construção da identidade materna no contexto do nascimento de risco, e, ainda, como lidar com o pesar associado ao luto materno.

Palavras-chave: Atividades Cotidianas, Maternidades, Recém-Nascido Prematuro, Luto, Terapia Ocupacional.

Introduction

The term "occupation" is conceptualized as a habit or role composed of several activities related to an action or behavior (Kielhofner, 2008). Such a concept is addressed in the Human Occupation Model (HOM) developed by Kielhofner, in the 1970s, and considers that each individual reacts in different ways to everyday situations. Thus, we emphasize the importance of identifying occupations considered significant and satisfactory for a person, in addition to the environmental context to which they belong (Kielhofner, 2011).

According to the HOM, the concept of occupational identity is "who the person is" and "who wants to become an occupational being" (Kielhofner, 2008). Occupational identity is built on numerous characteristics such as the actions that individuals feel satisfaction in performing, the social roles involved, and what is expected from a given role (Taylor, 2017).

The construction of a person's identity is strictly related to the performance of occupations linked to occupational roles. Relationships with other people and the

intrinsic need to satisfy social expectations imposed on a given occupational role require the adaptation of behaviors that satisfy this requirement (Kielhofner, 2011).

When becoming a mother, women are encouraged to change their occupations to respond to changes resulting from motherhood, which will influence the construction of maternal occupational identity (Martins, 2017). Motherhood as an occupation and the implications of becoming a mother to a preterm baby, added to the context of the child's hospitalization, generate a significant impact on the woman's life, who forgo other occupational roles to be with the newborn during the hospitalization period (Dittz et al., 2006; Melo et al., 2016).

The construction process of maternal identity is perceived as complex and socially influenced, being susceptible to changes and resignifications experienced by the woman who became a mother (Behar, 2018). According to Stefana & Lavelli (2017), being the mother of a preterm baby requires adaptation, as the maternity exercised during the child's hospitalization may be affected by early separation, decreased possibility of postpartum contact, and the need to deal with the condition of prematurity.

As also mentioned by Joaquim et al. (2018), mothers of preterm infants report limited interactions due to physical separation and the lack of full opportunities for contact with the child, expressing feelings of anxiety, guilt, and insecurity to take care of the baby. Also, the mother constantly lives with the imminence of death and the uncertainty of the baby's clinical evolution (Baseggio et al., 2017).

When the baby's death occurs, there is a deconstruction of motherhood, that is, the loss of maternal identity. In this sense, the child's death may compromise the mother's behavior, potentiating mental suffering and impacting various spheres of life. In addition to losing their child, the mothers lose the life they planned with him (Freitas & Michel, 2014).

Despite the complexity of "becoming a mother to a preterm baby" (Joaquim et al., 2018), research has been dedicated to the construction of maternal occupational identity. However, there is a scarcity of studies that seek to understand the impact of grief over the death of the son (Dahdah et al., 2019). Thus, this study proposes to research the occupation of a woman who became the mother of a preterm baby in a hospital context and experienced the death of her child one month after discharge.

Method

This is a study with a qualitative approach, whose outline was the case study. The case study is considered a research method that investigates a phenomenon in-depth and in its real-world context (Yin, 2015). The qualitative approach allows to approach the meanings, reasons, beliefs, and interpretations related to how people live, feel, and think (Minayo, 2013).

We selected this case because we have the opportunity to research two complex realities experienced by a woman who became the mother of a preterm baby and, one month after hospital discharge, she experienced the death of her child.

We collected the data during the development of broader Doctoral research by the first author, with mothers of preterm babies before and after hospital discharge, submitted and approved by the Human Research Ethics Committee of the Federal University of São Carlos (UFSCar), according to Resolution 466 of the National Health

Council (CNS) and signature of the Informed Consent Term (ICF), with the researcher conducting the procedures.

We applied three instruments for data collection:

1 - **Identification Form (IF)** - one day after the mother's first contact with the researcher, in the NICU, for the characterization of the mother-baby dyad;

2 - **Occupation Diary (OD)** – It occurs in the first week and the second week of admission to the NICU. We adapted the instrument based on the study by Martins (2017). We instructed the mother to freely record the completion of the OD on two typical days of the week and on Saturdays, organized at intervals of time every two hours;

3 - **Semi-structured interview (SI)** - held after the application of the OD to deepen the activities considered significant and satisfactory in the mother's perception. The researchers developed this instrument from the concepts of the Human Occupation Model (HOM): Volition, Habituation, Performance capacity, and Environment (Kielhofner, 2011).

Data collection took place as follows (Figure 1):

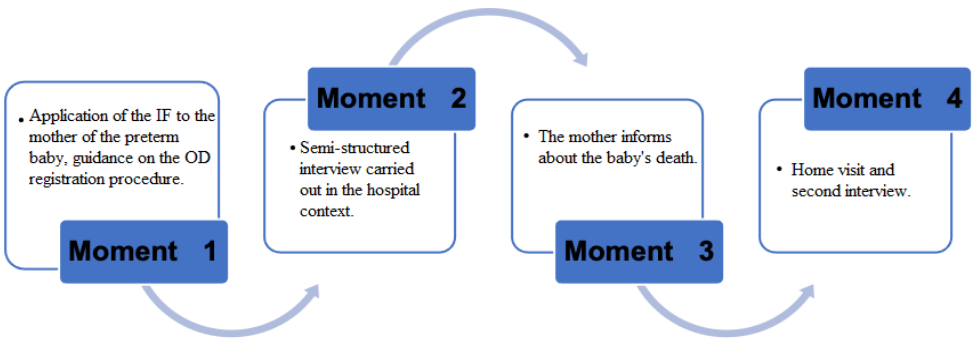

Figure 1. Data collection procedure. **Source:** The authors.

For the analysis, we descriptively analyzed the OD data. We recorded and transcribed in full the data obtained in the interviews for later analysis through the Thematic Content Analysis. The analysis technique allows describing the content reflected in the transcript objectively and systematically (Minayo, 2013).

Result

A 21-year-old mother, in a common-law marriage relationship for three years, participated in the study. She had completed high school and worked as a cashier at a supermarket, but at the moment, she was on maternity leave. The mother did not plan the pregnancy, referring to the desire to have her first child programmed, associating this desire with better stability of her socioeconomic condition.

The delivery was cesarean type due to severe maternal preeclampsia.

Her male baby was born preterm, with a gestational age of 27 weeks and a birth weight of 950 grams; and remained hospitalized for 14 days in the Neonatal Intermediate Care Unit (NICU).

Activities performed during the baby's hospitalization registered in the OD

The mother recorded in the OD, moments in which she dedicated to the occupation of a mother, taking care of the baby while she was in the hospital. Learning with the team was highlighted as a positive aspect in the process of becoming a mother, and also recorded the activities "changing the diaper" and "bathing the baby", as reported: "*I bath the baby twice because the bus was delayed, then I couldn't get there earlier. I changed the diaper; I already knew how to change it because I changed my cousins. Diaper was the simplest thing*". The institution followed a pre-established routine of care for babies, and the bath was carried out in the morning.

Initially, according to the service's procedure, breastfeeding was performed by gavage (administration of the syringe's milk through the tube), evolving to "the use of the bottle" and alternating with the stimulation of the mother's breast. The mother reported that the baby "got tired" when trying to suck the breast and that this condition interfered with weight gain.

The mother considered "breastfeeding" as a significant maternal activity in the two weeks of the child's hospitalization, according to her report: "*Breastfeeding helps in the child's development, gaining more weight and having more nutrients, breast milk, right*".

In the last week of hospitalization, the mother was happy with the child's clinical evolution associated with the transfer from the incubator to the crib, in which she could hold the baby more frequently, independently, and autonomously; and the baby's adaptation without the need for oxygen, which can be observed in her speech: "*Now that he is in the crib, I take him more, I don't need to be calling her* [nursing technician]*, he is also getting used to it without oxygen*". With the baby in the crib, the mother records the activities "holding the baby in her lap" and "changing clothes" and considered them satisfactory when performing them. According to her report: "*I was happy to see my son with the clothes that his grandmother gave him, I left the clothes here a long time ago, now when I have to change I change him, which makes me happy*".

With the baby in the crib, the activities related to mother-child interaction were recorded in the OD, such as: "pamper on the head" and "talking to the baby", and they were perceived as very significant in this period.

They also recorded domestic activities in the OD, such as "sweeping the house", "cleaning the house", "washing the dishes", "cleaning the stove", "preparing lunch" and "preparing dinner". As a leisure time, in a hospital environment, they recorded "talking to other mothers" and, at home, "watching television", an activity carried out at night together with the husband.

In the last days of the baby's admission to the NICU, the mother presented in the OD the activities associated with preparing for the child's discharge, such as "organizing the baby's closet", considered significant in this period, according to the statement: "*Soon he will go home, I need to organize his closet, there's a lot of clothes I got, his covers, but I still need to buy a bathtub, then there will be nothing more*".

Two thematic categories emerged from the interviews:

Category 1 - Hospitalization of the preterm baby: a new, unknown and frightening context for the future and the mother

This category refers to the construction of the maternal identity during the admission of the preterm baby to the NICU. The mother perceived the child's hospitalization period, shortly after birth as a difficult time. When she was discharged from the maternity ward, and the baby remained hospitalized, she reported the suffering she experienced on returning home, without the baby's physical presence. She said that this situation interfered with her quality of sleep, as we can see in the speech:

> *I missed him when I got home, at the hospital, I didn't feel much, but at home, I cried, I had nightmares, but when I wake up I know he is in the nursery, that everything is fine thanks to God, then I sleep again, but I'm always worried*.

The financial difficulties hindered to monitor of her son's hospitalization every day. This situation bothered her and she reported that she sought help from the hospital to use public transport more often. However, she was unsuccessful, as she reports:

> *Before I came in the afternoon because I could get a ride with the ambulance, but I had little time with him, so I tried help at the hospital for the bus ticket, but I couldn't. As I need two buses to go to the hospital and two more to return, I stay with him from twelve-thirty to two-thirty, I can't stay any longer or come every day*.

The mother reported that the team's professional asked her why she did not attend the unit regularly and she said that she felt uncomfortable explaining why, as follows: *"The girl* [nurse] *asked me why it took me sometimes, I spend four days without seeing my son, and I can't on weekends because there is no bus, so I explained the whole situation to her".*

The mother showed concern for the child's prematurity. Thus, she reported that she participated in a group, on the social network Facebook, created to share experiences, particularly of motherhood in the child's prematurity situation. Her report was:

> *I participate in a group on Facebook, I read the stories of mothers who also go through this, there was a mother with her son having pneumonia, after birth, and he was also born preterm. Some mothers say that they are afraid of getting pregnant again because we are really afraid*.

During hospitalization at the NICU, the mother reported that it was difficult to see the baby in the incubator, requiring monitoring of oxygen saturation, according to her report: *"It is difficult to see him in the incubator, I look, I don't want to move him too much, he still needs oxygen and he has a lot of "wires" around him*".

In the reports, the mother believed that she could only hold her child on her lap when he left the incubator: "*I thought I couldn't hold him because he was born premature and, therefore, I thought I couldn't get him out of the incubator*". At the NICU, the mother reported that she asked for help to hold the baby, after observing another mother requesting assistance with the nursing technician.

The mother described the sensations and perceptions when holding the child in her arms for the first time, like this: *"I felt the cold of my son close to me, I had only smelled him when he was born* [...] *He is already very "hairy".*

With the expectation of discharge, the mother was informed of the baby's need to undergo surgery, as she had a reducible right inguinal hernia since birth: *"I thought he would go home today. She* [nursing technician] *was bathing him, then she explained, and said that he was going to have the surgery and that she thought that the girls* [nursing technicians] *had explained it".* Regarding this situation, the report identifies the team's failure to communicate with the mother.

Category 2 - Death and the maternal grieving process: how to continue to live after the child's death

The category explains how the child's death occurred, the maternal experience after the loss, and the elaboration of the mourning, permeated by feelings of guilt and suffering.

The mother said how her son died and tried to save him, according to her account:

> *He was on my lap, I fell asleep and stayed with him until my husband returned from work. I don't know, I think he got the milk back, but it took me a while to understand. When I woke up, my husband had arrived, so I realized that the baby was very pale, we called him, then he wanted to cry but he didn't come out, I even blew his mouth, because sometimes, with mouth to mouth breathing, the milk could come back*.

When they realized that their son was not reacting, they went to the Emergency Care Unit (UPA). Afterward, the baby was referred directly to the Neonatal Intensive Care Unit (NICU) and underwent some tests that identified respiratory failure. Initially, the mother reported that she believed in the child's prompt recovery. However, after the transfer to the NICU, she realized the severity of the baby's condition since the feelings experienced during hospitalization and the imminence of death recede: "*He cried a little, so I was happy, but when he said it was necessary to be transferred to the NICU ... then ...*".

The mother reported how difficult it was to deal with her son's death, as follows:

> *My husband and I went to the funeral home to buy the coffin, I took his clothes. That tiny coffin ... I got home at midnight, my eyes were swollen from crying, the next day, crying again. It was hard to believe* [...].

She says that in the first days after the baby's death, she fell asleep with a piece of clothing belonging to her son or admired some photographs of him. *"It took me almost a week to sleep* [...] *the clothes I didn't even use on him are still folded, the covers he used too... Sometimes I sleep with a piece of clothing, I look at the pictures before I sleep ...*", she says.

The experience of the son's loss interfered with the organization of domestic activities: *"I solved things already, but tidying up the house ... in fact, I didn't even take it all, since the last time my mother came to help me with cleaning, I don't clean anymore".*

Regarding the grieving process, the mother reported: *"There are days when I have the feeling that half of the heart has gone away".* She also mentioned difficulties in dealing with guilt: *"I know I may have been wrong, but it is not easy to lose a child".*

The feeling of guilt was reinforced in the cycle of coexistence at work, as the mother witnessed comments from colleagues who blamed her for the death of her son. The mother said that she was considered negligent in the care for the baby, as she said*: "I heard comments at work that after breastfeeding I had laid him in bed, but that did not happen".*

At times, the mother seemed to feel guilty about her son's death, but she also looked to spirituality for a means of comfort:

> *Sometimes I feel guilty, even if God took him, he may have ended his mission here. Sometimes, I wonder about what happened, if it was my fault, but God knows the time, he could be here and go through more suffering. The doctor said that the milk could go to the lung, then he would undergo surgery, he could be hospitalized, I think he would not be able to handle it*.

The mother also perceived the involvement in the occupation of work positively, expressing the difficulty of accepting the loss, as she realized in her speech: "*I started working these days, talking to people, in the service I can still forget what happened, but when I'm at home I remember*".

The mother considered that the first experience of motherhood may have influenced the care for the child due to the difficulty in identifying the baby's needs: "*I don't know if it is because I am a mother for the first time if I could go back in time... because if a child cries you don't know if it's a diaper if it's milk if it's colic".*

After the loss, the mother reported not understanding the meaning of becoming a mother, showing fear of experiencing another pregnancy, and worrying about satisfying the baby's care in the best way:

> *Being a mother, I will only understand when I get pregnant again, the love will be double, but I will always remember that I had a son and I will be more careful. I am worried that everything can happen again, sometimes I am afraid, not of the pregnancy, but after the baby is born, I will remember what happened to him* [...].

Missing the deceased son, idealizing him alive, and recognizing that a second pregnancy would be accompanied by the memory of the death of the first baby, appear in the maternal report:

> *I see other children and I think it could be him. When I was pregnant, I imagined him big, running* [...] *People still say it will pass, it won't, I will always remember him, it will never be goodbye, and this longing hurt.*

Discussion

Our study is based on the theoretical reference of the Human Occupation Model (HOM), moving through the concepts of Volition, Habituation, Performance

Capacity, and Environment to investigate and learn about the occupation of a woman who became the mother of a preterm baby.

The results of this study showed the maternal fear and insecurity in the prematurity of the child and manifest changes in sleep and concern about being absent while the baby remained hospitalized. It is clear that Volition, an element of the HOM, was negatively impacted on the maternal role's capacity for engagement and performance (Lee & Kielhofner, 2017a), due to the restriction imposed by the specialized environment and the mother's financial conditions, that influenced the routine of daily visits to the Unit, and generated questions by the professionals.

The mother perceived the child's hospitalization as difficult due to fluctuations in the clinical condition. This context is configured as a daily challenge in dealing with the alternation of the baby's health status, from improvement to worsening (Gibbs et al., 2016). In the Habituation element (Lee & Kielhofner, 2017b), the mother strives to reconcile other occupational roles (of home and wife), external to the hospital environment, organizing her routine.

We observed in the reports that, during the hospitalization, the mother-child contact was established and that this positively interfered in the appropriation of the occupations performed and in the construction of the maternal identity. Melo et al. (2016) indicate that the mothers' involvement in the care of the baby is essential to the construction of the maternal identity.

Joaquim et al. (2018) consider that the new mother begins a period of learning in carrying out maternal care and experiences an adaptation process, anticipated by preterm birth. According to Lee & Kielhofner (2017a), Volição is shaped based on experiences, characterized as learning opportunities about what to do, allowing the discovery of what it likes to accomplish.

For Kielhofner (2011), the feeling of capacity and effectiveness (Volition) in the performance of a given role will occur from the resolution of the difficulties perceived during its performance to then adapt it. This favors the perception of activities as significant and/or satisfactory.

Throughout the hospitalization, the mother was happy to be involved in care activities, such as “breastfeeding”, “changing the diaper” and “bathing the baby”. Fraga et al. (2019) identified that allowing maternal involvement in caring for their preterm child enables ownership over time and mothers show satisfaction in exercising them. The role of the occupational therapist proves to be important in intervening in the environment and facilitating the person's participation in daily occupations (Fisher et al., 2017).

Breastfeeding was a significant activity performed by the mother. Studies show that the act of breastfeeding is related to the development of motherhood, in which being able to breastfeed is considered important for many mothers, as the progression in this occupation arouses the feeling of being a mother (Kronborg et al., 2015).

After the baby's death, the mother said she did not understand the true meaning of becoming a mother, as there was an interruption in the construction of identity as a mother. Maternal grief is a complex phenomenon, as it is seen as an inversion in the natural cycle of life and, despite changing with time, as the mother finds ways to deal with the child's absence, it is an experience that has never been overcome (Freitas & Michel, 2014; Brice, 1991).

The mother also reported changes in the organization of domestic activities. The child's death disrupted the element of habituation, negatively impacting the performance capacity of the maternal occupational role and maintaining the usual routine (Lee & Kielhofner, 2017b).

Maternal blame was also evident in the maternal report. Studies relate the mothers' feeling of guilt with the feeling of failure in the maternal function, which makes it impossible to ensure the child's life (Alarcão et al., 2008; Freitas & Michel, 2014).

Those who die are still present in memories, objects, photos, and other forms of presence (Forhan, 2010; Freitas, 2018). For Taylor (2017), the Environment composes the occupied spaces, the objects used, the interaction between people, and the existing meanings.

As evident in this study, Vidal (2010) and Muza et al. (2013) identified the maternal fear of experiencing a new pregnancy and reliving the loss of the child, given the impact of this situation on the mothers' lives. According to Mendonça (2018), occupational therapy seeks strategies that can help and facilitate the involvement of people in everyday occupations, as the loss of the baby can impact the occupations performed by the mother, and in the elaboration of the grieving process.

Conclusion

The results of this study met the proposed objectives enabling to the research of the occupation of a woman who became the mother of a preterm baby, experiencing the death of the child one month after hospital discharge.

Despite being restricted to a case study, the research emphasizes the importance of knowing the occupation of a woman who became the mother of a baby during intimidating situations that can limit occupational performance, as in the case of the hospitalized preterm child and the elaboration of maternal mourning. The importance of research focusing on the occupation of mothers of preterm babies is clear, and, given what has been exposed, the Human Occupation Model is an efficient theoretical approach for studies in this perspective.

References

Alarcão, A. C. J., Carvalho, M. D. B., & Pelloso, S. M. (2008). A morte de um filho jovem em circunstância violenta: compreendendo a vivência da mãe. *Revista Latino-Americana de Enfermagem*, *16*(3), 341-347.

Baseggio, D. B., Dias, M. P. S., Brusque, S. R., Donelli, T. M. S., & Mendes, P. (2017). Vivências de mães e bebês prematuros durante a internação neonatal. *Temas em Psicologia*, *25*(1), 153-167. http://dx.doi.org/10.9788/TP2017.1-10.

Behar, R. C. R. (2018). *A maternidade e seu impacto nos papéis ocupacionais de primíparas* (Monografia). Universidade Federal da Paraíba, João Pessoa.

Brice, C. W. (1991). What forever means: an empirical existential-phenomenological investigation of maternal mourning. *Journal of Phenomenological Psychology*, *22*(1), 16-38. http://dx.doi.org/10.1163/156916291X00028.

Dahdah, D. F., Bombarda, T. B., Frizzo, H. C. F., & Joaquim, R. H. V. T. (2019). Revisão sistemática sobre luto e terapia ocupacional. *Cadernos Brasileiros de Terapia Ocupacional*, *27*(1), 186-196. http://dx.doi.org/10.4322/2526-8910.ctoAR1079.

Dittz, E. S., Melo, D. C. C., & Pinheiro, Z. M. M. (2006). A terapia ocupacional no contexto da assistência à mãe e à família de recém-nascidos internados em unidade de terapia intensiva. *Revista de Terapia Ocupacional da Universidade de São Paulo*, *17*(1), 42-47. https://doi.org/10.11606/issn.2238-6149.v17i1p42-47

Fisher, G., Parkinson, S., & Haglund, L. (2017). The environment and human occupation. In R. Taylor (Ed.), *Kielhofner's model of human occupation* (pp. 91-106). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Fraga, E., Dittz, E. S., & Machado, L. G. (2019). A construção da co-ocupação materna na Unidade de Terapia Intensiva Neonatal. *Cadernos Brasileiros de Terapia Ocupacional*, *27*(1), 92-104. http://dx.doi.org/10.4322/2526-8910.ctoAO1125.

Freitas, J. L. (2018). Luto, pathos e clínica: uma leitura fenomenológica. *Psicologia USP*, *29*(1), 50-57. https://doi.org/10.1590/0103-656420160151

Freitas, J. L., & Michel, L. H. F. (2014). A maior dor do mundo: o luto materno em uma perspectiva fenomenológica. *Psicologia em Estudo*, *10*(2), 273-283. http://dx.doi.org/10.1590/1413-737222324010.

Forhan, F. (2010). Doing, being, and becoming: a family's journey through perinatal loss. *The American Journal of Occupational Therapy*, *64*(1), 142-151. http://dx.doi.org/10.5014/ajot.64.1.142.

Gibbs, D. P., Boshoff, K., & Stanley, M. J. (2016). The acquisition of parenting occupations in neonatal intensive care: a preliminar perspective. *Canadian Journal of Occupational Therapy*, *83*(2), 91-102. http://dx.doi.org/10.1177/0008417415625421.

Joaquim, R. H., Wernet, M., Leite, A., Fonseca, L., & Mello, D. (2018). Interações entre mães e bebês prematuros: enfoque nas necessidades essenciais. *Cadernos Brasileiros de Terapia Ocupacional*, *26*(3), 580-589. http://dx.doi.org/10.4322/2526-8910.ctoAO1051.

Kielhofner, G. (2011). *Modelo de la ocupacion humana: teoría y aplicación.* Espanha: Editoria Medica Panamericana.

Kielhofner, G. (2008). *Model of human occupation: theory and application.* Baltimore: Lippincott Williams & Wilkins.

Kronborg, H., Harder, I., & Hall, E. O. C. (2015). First time mothers'experiences of breastfeeding their newborn. *Sexual & Reproductive Healthcare : Official Journal of the Swedish Association of Midwives*, *6*(2), 82-87. http://dx.doi.org/10.1016/j.srhc.2014.08.004.

Lee, S. W., & Kielhofner, G. (2017a). Volition. In R. Taylor (Ed.), *Kielhofner's model of human occupation* (pp. 38-56). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Lee, S. W., & Kielhofner, G. (2017b). Habituation: patterns of daily occupation. In R. Taylor (Ed.), *Kielhofner's model of human occupation* (pp. 57-73). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Martins, S. (2017). *Gravidez nas adolescências: construções das identidades ocupacionais maternas durante a gestação* (Dissertação de mestrado). Universidade Federal de São Carlos, São Carlos.

Melo, R. A., Araújo, A. K. C., Marques, W. F., Santos, N. M., Fernandes, F. E. C. V., & Bezerra, C. R. (2016). Sentimentos de mães de recém-nascidos internados em uma unidade de terapia intensiva neonatal. *Revista Multidisciplinar e de Psicologia*, *10*(32), 88-103. http://dx.doi.org/10.14295/idonline.v10i32.569.

Mendonça, C. R. L. F. (2018). Sobre ocupar-se de cuidar do filho no hospital: o que dizem as mães de crianças cardiopatas? *Revista de Terapia Ocupacional da Universidade de São Paulo*, *29*(3), 263-269. http://dx.doi.org/10.11606/issn.2238-6149.v29i3p263-269.

Minayo, M. C. S. (2013). *O desafio do conhecimento: pesquisa qualitativa em saúde.* São Paulo: Hucitec.

Muza, J. C., Sousa, E. N., Arrais, A. R., & Iaconelli, V. (2013). Quando a morte visita a maternidade: atenção psicológica durante a perda perinatal. *Psicologia: Teoria e Prática*, *15*(3), 34-48.

Stefana, A., & Lavelli, M. (2017). Parental engagement and early interactions with preterm infants during the stay in the neonatal intensive care unit: protocol of a mixed-method and longitudinal study. *BMJ Open*, *7*(2), 1-7. http://dx.doi.org/10.1136/bmjopen-2016-013824.

Taylor, R. R. (2017). *Kielhofner's model of human occupation: theory and application.* Philadelphia: Wolters Kluwer.

Vidal, M. (2010). Gravidez após morte perinatal: sobre a relação da mãe com o bebê sobrevivente. *Ciência & Saúde Coletiva*, *15*(2), 3185-3190. http://dx.doi.org/10.1590/S1413-81232010000800023.

Yin, R. K. (2015). *Estudo de caso: planejamento e métodos.* Porto Alegre: Bookman.

Author's Contributions

Danusa Menegat and Daniel Ferreira Dahdah participated in the study design, analysis and interpretation of data, writing, and critical review of the manuscript. Tatiana Barbieri Bombarda and Regina Helena Vitale Torkomian Joaquim participated in the study design, analysis, and interpretation of data, writing, and critical review of the article. All authors approved the final version of the text.

Funding Source

CAPES – Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Code 001.

Corresponding author

Danusa Menegat
e-mail: danusamenegat@hotmail.com

Section editor

Prof. Dr. Milton Carlos Mariotti