DAILY ROUTINE OF ACCOMPANYING MOTHERS IN THE NEONATAL INTENSIVE CARE UNIT

COTIDIANO DE MÃES ACOMPANHANTES NA UNIDADE DE TERAPIA INTENSIVA NEONATAL
COTIDIANO DE MADRES ACOMPAÑANTES EN LA UNIDAD DE TERAPIA INTENSIVA NEONATAL

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ABSTRACT
Objective: to analyze the daily life of accompanying mothers whose children are hospitalized in the Neonatal Intensive Care Unit. Method: qualitative, descriptive and exploratory study, carried out in the Puerperal Rooming-in of a public maternity. The data were produced through a semi-structured interview with five mothers and then analyzed by the Content Analysis Technique in the Categorical Analysis modality. Results: three categories emerged: << Being a companion: changes in daily life and coping with hospitalization >>; << Occupation with the child and idleness: the antagonism of daily life >>; << Social support network in the daily hospitalization >>. Conclusion: during their stay in the hospital, mothers live in an environment that is strange to them, being away from their daily lives and having to live with a new daily life. It is important to extend care beyond the hospitalized newborn, establishing a cozy relationship with the mothers, perceiving them as an active subject that requires care and sensitive listening. Descriptors: Maternal behavior; Rooming-in; Neonatal Intensive Care Units; Mothers; Mother-Child Relationships; Maternal-Child Nursing.

RESUMO
Objetivo: analisar o cotidiano das mães acompanhantes cujos filhos estão internados na Unidade de Terapia Intensiva Neonatal. Método: estudo qualitativo, descritivo e exploratório, realizado na Casa da Puérpera de uma maternidade pública. Os dados foram produzidos por meio de entrevista semiestruturada, com cinco mães; em seguida, analisada pela Técnica de Análise de Conteúdo na modalidade Análise Categorial. Resultados: emergiram três categorias: << Estar acompanhante: mudanças no cotidiano e o enfrentamento da hospitalização >>; << Ocupação com o filho e ociosidade: o antagonismo do cotidiano >>; << Rede de apoio social no cotidiano da hospitalização >>. Conclusão: durante a permanência no hospital, as mães passam a conviver em um ambiente que lhes é estranho, afastando-se de seu cotidiano, tendo que conviver com uma nova cotidianidade. Ressalta-se a importância de estender a assistência para além do recém-nascido hospitalizado, estabelecendo uma relação acolhedora com as mães, percebendo-as como sujeito ativo e que necessita de cuidado e escuta sensível. Descriptores: Comportamento Materno; Alojamento; Unidades de Terapia Intensiva Neonatal; Mães; Relações Mãe-Filho; Enfermagem Materno-Infantil.

RESUMEN
Objetivo: analizar el cotidiano de las madres acompañantes cuyos hijos están internados en la Unidad de Terapia Intensiva Neonatal. Método: estudio cualitativo, descriptivo y exploratorio, realizado en la Casa de la Puérpera de una maternidad pública. Los datos fueron producidos por medio de entrevista semi-estructurada, con cinco madres; en seguida, analizada por la Técnica de Análisis de Contenido en la modalidad Análisis Categorial. Resultados: surgieron tres categorías: << Estar acompañante: cambios en el cotidiano y el enfrentamiento de la hospitalización >>; << Ocupación con el hijo y ociosidad: el antagonismo del cotidiano >>; << Red de apoyo social en el cotidiano de la hospitalización >>. Conclusión: durante su estadía en el hospital, las madres pasan a convivir en un ambiente que les es extraño, alejándose de su cotidiano, teniendo que convivir con una nueva cotidianidad. Se resalta la importancia de extender la asistencia para más allá del recién nacido hospitalizado, estableciendo una relación acogedora con las madres, notándose como sujeto activo y que necesita de cuidado y escucha sensible. Descriptores: Conducta Materna; Alojamiento; Unidades de Cuidado Intensivo Neonatal; Madres; Relaciones Madre-Hijo; Enfermería Materno-Infantil.

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Pregnancy - for most women - is a time marked by expectations about the developing fetus. Added to this, the arrival of a child is also the beginning of a cascade of changes that will occur in the family environment, either by the emergence of new roles of the family members, or by the anguish and fear that something may happen different from that idealized, especially when there is a birth of a premature and/or at-risk child.1

For several reasons, some newborns (NB), soon after birth, require special care in Neonatal Intensive Care Units (NICUs), without which their survival would not be possible. Faced with the hospitalization of the child and the risk of death, parents develop a series of feelings of guilt, anxiety, worry and confusion.2

The NICU is a frightening environment for the family, as they are confronted with several unknown technologies and devices, which exposes the newborn to stressful situations, manipulations and constant procedures, for the sake of their recovery.3 Especially for the mother, this situation is more difficult because she becomes the companion of the hospitalized child and this condition is full of doubts, uncertainties and sufferings, since she often enters the hospital environment and must face the child’s hospitalization alone.4

During this process, the mother - now as a companion - does everything she can to cope with this difficult time, thus remaining ever present. Despite all the suffering experienced, they often renounce their desires and abandon their routine to experience together with the child the hospitalization in search of recovery of the child’s health.5

In an attempt to follow the Child and Adolescent Statute (ECA in Portuguese)6, some hospital institutions have adopted strategies to facilitate the mother’s stay as companion creating “spaces” called “Mother’s Home”, “Puerperal Home”, “Maternal Rooming-in”, among others.

As a companion, the daily life of these women changes considerably, since they start to face the condition of hospitalization of the child, added to the condition of remaining in an institutionalized and therefore depersonalized space.

It should be emphasized that, for this research, we have adopted as daily routine the ways of behaving that are natural and common to the individual but which, at the same time, are unique.7

Having said that, the following question aroused: how is the routine of accompanying mothers in the NICU?

**OBJECTIVES**

- To analyze the daily life of the accompanying mothers whose children are hospitalized in the NICU.
- To describe the aspects of the daily life of accompanying mothers in the NICU; to identify the social support network of the accompanying mothers during the hospitalization of their child in the NICU.

**METHOD**

This is a qualitative, descriptive and exploratory study carried out at the Puerperal Rooming-in in a public maternity hospital in the interior of the state of Bahia.

The Puerperal Rooming-in is a place for mothers who have already been discharged from hospital, whose children are hospitalized in the neonatal units. It has twelve beds, divided into two infirmaries, where the mothers can stay until the hospital discharge of the NB to home or transfer to the Kangaroo Method.

Five mothers participated in this study. The inclusion criteria were: having a child hospitalized in the NICU; and having been in the Puerperal Rooming-in for at least five days (considering a minimum time interval for the mother to have adopted new routines in her daily life). The exclusion criteria were: mothers of newborns with congenital malformations (condition that would change the experience of the accompanying mother); being deaf and/or mute, considering the limitations of the collection technique itself and/or of the researcher.

The research was approved by the Research Ethics Committee (approval number 53558216.4.0000.0053). The data collection took place in the months of May to June 2016 through a semi-structured interview. It was guaranteed the confidentiality and anonymity of the participants, who only participated after signing the Informed Consent Form, being referenced by names of flowers (chosen by them, without any repetition).

We used the Bardin Content Analysis8, which made it possible to establish three thematic categories, namely Being a companion: changes in daily life and coping with hospitalization; Occupation with the child and idleness: the antagonism of daily life; Social support network in the daily hospitalization.
RESULTS AND DISCUSSION

Knowing the accompanying mothers and their newborns in the Neonatal Intensive Care Unit

The length of stay of the mothers in the Puerperal Rooming-in ranged from eight to 92 days. Their age ranged from 15 to 24 years. All of them were from other municipalities. Four said they were students and one was a housewife. The declared family income ranged from less than one minimum wage to one minimum wage. About the marital status, two were in stable union, one was married and two were single. Two of the interviewees had more than one child and the other three had only one.

As for the hospitalized NBs, the length of stay in the NICU ranged from five to 92 days. Two were full-term newborns and three preterm infants weighing at birth between 1130g and 3644g. Regarding the medical diagnosis, there were differences between clinical problems, such as perinatal asphyxia, respiratory failure, respiratory distress and extreme and surgical prematurity, such as complex cardiopathy.

Be a companion: changes in daily life and coping with hospitalization

Mothers have reported a breakdown of what was common to each of them, their experiences, habits and routines, and they start to miss their lives prior to hospitalization, thus having difficulties and some resistance in adapting to the new routine.

I have already adapted; we get used to it with so many things, don’t we? (Lily).

The mother’s ability to accept her status as a companion and the new reality in which she is goes through conformism determined by the desire to contribute to the survival of the child. 10

It is perceived that in order to fulfill her role as mother, to protect and care for her child, the mother temporarily interrupts her routine and dedicates herself entirely to the child.

I am not in here because I am forced to, but at the same time, because there is an angel that forces me to be here, because if it was not for the love of my life, I would not be here (Rose).

The decision to stay in the hospital to accompany the hospitalized child is linked to the desire to fulfill the role of mother that is inherent in her. This constant presence represents the bond of love built during gestation, which does not allow them to leave the hospital without taking their children in their arms. 11

It becomes more difficult to adapt to the environment as the mother begins to feel distant from what she was used to prior to hospitalization.

The environment is not the same. You have your room just for you, here we have to divide, we have to interact with other people, but it is just not the same thing as our home. I miss home, I miss cooking my food, cleaning my house, all of it (Rose).

The condition of being a companion subjects the mother to the hospital routine and to family and social separation, which generates negative effects. 10 In addition, in the daily life of the hospital environment, the daily tasks that the mothers used to perform before the hospitalization situation can be interrupted unexpectedly, causing suffering experiences. 9

Also, due to the long stay in the hospital at full time, a common feeling that arises between the mothers is the longing for the conviviality with the relatives.

Staying away from the family is even worse. When they call to know how we are, they cry over there and we cry over here and it only makes the situation worse; the longing becomes even more intense (Rose).

It is even worse [staying away from the family], because we already have the conviviality, the custom (Lily).

As a companion, the mother is divided by the desire to dedicate herself to the child hospitalized in the NICU and to rest of the family that she left at home. 11
For mothers who have other children that are at home under the care of others, it becomes even more difficult to cope with the hospitalization process, because homesickness and the inability to care for them become strong.

It is even harder, because I miss them, I start to cry, it is even harder when I think about the family, especially my daughter (Jasmine).

It is not easy, no. Even more for those who have a child outside; in this case, our thought is here inside and at the same time outside (Daisy).

The condition of accompanying mothers becomes even more conflicting when they have other children, because due to her absence at home and the need to remain in the hospital they end up transferring to other family members the responsibility of caring for the healthy children, which generates feelings of neglect of maternal care.  

In addition, they also suffer because of the health condition of the NB, the hospitalization in the NICU and the rupture of idealizations generated during pregnancy.

He was born prematurely. […] Then he went immediately to the ICU, so I get desperate. So I think that's what changes, we get more worried. […] He was all intubated, I was in desperate, in panic; I think that changes it all. […] I must be a responsible mother, even though I have fifteen (Lily).

This statement reinforces that after the hospitalization of the premature newborn in the NICU several feelings appear in mothers, such as sadness, guilt, fear, hope and frustration. These mothers experience an intense moment of crisis because they had expected throughout the gestation the birth of a healthy child.  

In a similar study, the mothers referred the birth and hospitalization of the baby as a drastic moment of change, characterizing the experience as stressful, anxiety-generating and frustrating in having to deal with the uncertainties and improbabilities intrinsic to the situation.  

The condition of being a companion makes it possible for these women to be resilient in the context of coping with an adverse situation, as seen in the following statements. 

My daughter showed me how strong I am. Because having stayed here for 42 days is not easy (Daisy).

I have learned to have more responsibility in life. It made me appreciate life more, because it has been very difficult what I am going through, very, very difficult (Jasmine).

A study carried out in Argentina also revealed that some mothers reported accepting the situation of hospitalization of the child that life imposed on them, feeling stronger, tolerant and patient, overcoming the fears they used to have before maternity.  

 Occupation with the child and idleness: the antagonism of daily life

As the mother starts to follow and collaborate with less complex care and breastfeeding of the child, she spends most of her time in the NICU, following the routine of this unit, without having time for herself.

It's a rush [daily routine], because every three and three hours … I stay here, and every three hours I have to go to the ICU. So I do not even have the time to stay here talking to the girls (Sunflower).

The exhausting routine of mothers includes having to, at fixed times, usually every three hours, milk and stay in the NICU with their child. For this reason, they end up with little time to rest and recover from everyday wear and tear.  

Added to this, the restrictions imposed in relation to care with the newborn are frustrating for the mothers.

We cannot take them and take a shower. We must watch others bathe [the baby]. I could not hold him, but now she has given me to hold him. I could not giving him milk, I would take the milk and give it to him through the syringe, but now he has started to take [the breast] […]. I look like at him, I want to hold him but I cannot (Lily).

It was noticed that although the mothers were very participative in the care of the NB, at times, they experienced conflicts about their role within the NICU.  

A study carried out in England also revealed that some mothers felt suppressed of rights and impotent in their relations with the health team and this resulted in a difficulty in forming bonds with their children.  

The health team must insert mothers as soon as possible in the care of the child so that they feel responsible and participating in the care of the child and also for the improvement of the baby.

The daily care provided to infants in the NICU favored a greater interaction and recovery of the mother-child bond, besides allowing the mothers to practice what was taught to them in this unit.  

Amid the tiresome and rushed routine, the mother experiences idleness in the hospital environment. It is noticed that mothers do not enjoy any form of leisure or occupation in the free moments.
Here we have nothing to spend time, you know, most of us keep laid here or in the ICU. […] Here you just need something for the mothers to do, for the time to run fast because there is not, there is nothing to do here (Jasmine).

In similar studies, the mothers judged the maternal rooming-in as an unfamiliar environment, with deprivations of leisure activities and also said that the hospital infrastructure, the lack of privacy and leisure programs make it difficult to overcome family distancing, social contact and, consequently, adaptation to the new daily life.

◆ Social support network in the daily hospitalization

The family caregiver inserted in the hospital environment needs support to experience the hospitalization of the child positively and, thus, to enjoy an interactive process with exchanges of experience and recovery of his/her humanity.18

One of the main forms of support was the support of the family members by staying present in the visits, phone calls and words of comfort and prayers, strengthening the mothers in the hospitalization process:

I get a lot of support from my mother and father, […] we all the time on the cell phone, communicating […]. They talk to me a lot, he asks me not to be sad because it transmits to the baby, and that I should hand it over to God, be calm, pray a lot, that everything has already worked out right (Rose).

My family gives me support […] When they come to see me, they call, they try to find out how I am, […] they are worrying, making a chain of prayer for God to help her to go out of here soon (Sunflower).

These situations show that family support is crucial, capable of sustaining them, and renew their strength to continue to fight for the recovery of their children.4 They also reveal how the family represents an emotional, spiritual and even financial support for these mothers, constituting an important support to deal with the adverse situations that hospitalization causes.

A healthy and harmonious family environment makes it possible to understand the difficulties experienced and the participation in the care of members in various care situations.19

Only Daisy emphasized the figure of her husband as a partner who helps her, inasmuch as he takes care of the other child who is at home, in addition to encouraging her to continue with the hospitalized daughter.

[My husband] has given me strength to this day to stay here with the girl. He is taking care of the boy. When he needs to work, he is unemployed, so when he does some odd job, he leaves her with my sister. […] He is by my side (Margarida).

When accompanying husbands participate actively, from the parturition process to the concern for the well-being of the woman and the child, they are a source of crucial support during the hospitalization of an infant.1

Another support is deriving from the friends who provide the accompanying mother with a distraction amidst the daily afflictions of hospitalization.

My friends outside too, my colleagues. They talk to me, they try to find out how she is doing and they tell me to think positively (Sunflower).

In another study, the presence of friends became beneficial to the mothers, since many did not receive support from their relatives.9 In the same way, the friendships built with the roommates, because they are experiencing the same situation, provoke mutual help, establishing a network of solidarity.

I have met new people, several cases; because we think our problem is worse than the others, but when we sit down to talk, we find out that there are worse cases. […] My roommates give me much support (Sunflower).

I met people, I made friends, it was good, because we have met different people, different friends. (Jasmine)

These discourses express that this reciprocal relationship of support built with the other accompanying mothers invigorates hope daily, as they share positive experiences, establishing strong bonds of friendship.2

In addition, only one interviewee mentioned the hospital psychology team as a source of support, which was present, making daily visits, being always available when she needed to talk.

From the psychologists; the girls come up here every day to talk to us. Everything we need from their support, they are always there, you know? We talk when you have something to talk offload (Jasmine).

The performance of the psychologist is essential to assist the mother at this time. However, it is worth mentioning that every multidisciplinary team involved in the care of the newborn needs to feel responsible in welcoming this mother and perceiving her individualities.

A similar study revealed that the accompanying mothers considered the health team as a support, since they were welcomed even before birth and throughout the
hospitalization of the child. This welcome took place in the form of guidelines, specialized monitoring, supplying the care demands of the binomial and thus reducing anxiety and promoting well-being and comfort. Only one interviewee cited the hospital and the Puerperal Rooming-in as another source of support, since it would become impossible for her to stay full-time with the hospitalized NB if there was no such support. Here the hospital, which also welcomed me, because I was already wondering how I would manage to go to my town; I did not even know that there was the puerperal rooming-in (Daisy).

Despite the suffering experienced, the maternal rooming-in was seen by the mothers as an innovative initiative of the hospital, as it enhances their presence, enabling them to stay full-time with the hospitalized child. Oddly in this research, only one interviewee pointed to the maternal rooming-in as a support network. Since it is one of the main supports for mothers, this situation leads us to question about the care developed in this sector, the reception that the mothers have received and whether the NICU team has perceived them as active and suffering subjects, and whether they have developed sensitive listening with these accompanying mothers.

This research is limited to the extent that an observational study has not been performed, and it has emerged the gap and, at the same time, the possibility of future investigations that may include observations of the daily life of the accompanying mothers, as well as ethnographic and/or long-term follow-up.

**CONCLUSION**

During their stay in the hospital, mothers come to live in an environment that is strange to them, being away from their daily life, having to live with a new daily life, creating new habits and routines.

The nurse - as a manager of the sector - needs to develop plans of care for the accompanying mothers, since this mother can become a participant in the care of the child, inasmuch as she is welcomed, inserted in the process of hospitalization of the child and as she can also express their anguish and/or difficulties of adaptation.

Another suggestion that emerges from the results is the need to encourage the mother in prolonged hospitalizations to visit her home, family and friends whenever possible in order to alleviate the longing felt for her habitual reality.

It is also suggested that, in the training of health professionals, emphasis should be given on the approach to the companion, who should be included in the systematization of care, since they may positively contribute to the hospitalization process if due care is provided to them.

The need to provide mothers with daily activities and environments as routine during their stay at the Puerperal Rooming-in is also emphasized so that they can occupy themselves and relax in the face of the suffering experienced and thus make the experience easier. In this way, the creation of spaces that allow creative group activities, such as rounds of conversation, handicrafts, music therapy, workshops focused on baby care, beauty days and others should be encouraged.

It is important to extend the care beyond the hospitalized NB, establishing a warm and trusting relationship, perceiving these women in their individualities, and not just as 'a mother accompanying the child', since they also need care, sensitive listening, and to be an active subject during all hospitalization so that they can understand and accept this new reality.

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