

Original Article

# The importance of motherhood in the hospitalization of children with chronic diseases

Significado da maternidade frente às hospitalizações de filhos com doenças crônicas

Significado de la maternidad en la hospitalización de niños con enfermedades crónicas

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**Resume:** Objective: To describe the meanings of the experience of motherhood in the hospitalization of children with chronic disease. **Method:** exploratory field research with a qualitative approach, conducted with six mothers of children with chronic disease, in the Pediatric Intensive Care Unit of a teaching hospital. The collection took place from February to May 2017, through semi-structured interviews and we used content analysis in the thematic modality for data treatment. **Results:** three categories emerged: Ambivalent feelings expressed by mothers; Uncertainty of motherhood regarding hospitalized child with chronic disease; and Change in maternal routine regarding hospitalization of children with chronic disease. **Conclusion:** the study provided an opportunity to respond to the experience of motherhood of children with chronic illness manifested through feelings, uncertainties and changes in family routine, which allowed us to reflect on interventions that can alleviate the negative implications throughout the hospitalization period of these children.

Descriptors: Maternities; Hospitalization; Chronic Illness, Child

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**Resumo:** Objetivo: descrever os significados da experiência da maternidade frente às hospitalizações do filho com doença crônica. Método: pesquisa de campo, exploratória, de abordagem qualitativa, realizada com seis mães de crianças com doença crônica, na Unidade de Terapia Intensiva Pediátrica de um hospital de ensino. A coleta ocorreu nos meses de fevereiro a maio de 2017, por meio de entrevista semiestruturada e utilizou-se a análise de conteúdo na modalidade temática para tratamento dos dados. **Resultados:** emergiram três categorias: Sentimentos Ambivalentes manifestados pelas mães; Incertezas da maternidade diante do filho hospitalizado com doença crônica; e Mudança na rotina materna frente à hospitalização do filho com doença crônica. **Conclusão**: o estudo proporcionou responder a experiência da maternidade do filho com doença crônica manifestada por meio de sentimentos, incertezas e mudanças na rotina familiar, o que permitiu refletir sobre intervenções que possam amenizar as implicações negativas durante todo o período de internação dessas crianças.

Descritores: Maternidades; Hospitalização; Doença crônica, Criança

**Resumen: Objetivo:** Describir los significados de la experiencia de la maternidad en la hospitalización de niños con enfermedades crónicas. **Método:** una investigación de campo exploratoria con enfoque cualitativo, realizada con seis madres de niños con enfermedades crónicas, en la Unidad de Cuidados Intensivos Pediátricos de un hospital universitario. La recopilación de los datos se realizó de febrero a mayo de 2017, a través de entrevistas semiestructuradas y utilizamos análisis de contenido en modalidad temática para su tratamiento. **Resultados:** surgieron tres categorías: Sentimientos ambivalentes expresados por las madres; Incertidumbre de la maternidad con respecto al niño hospitalizado con enfermedades crónicas. **Conclusión:** el estudio brindó la oportunidad de responder a la experiencia de la maternidad de niños con enfermedades crónicas manifestada a través de sentimientos, incertidumbres y cambios en la rutina familiar.

Descriptores: Maternidades; Hospitalización; Enfermedad Crónica, Niño

# Introduction

The hospitalization of a child is considered a potentially traumatic situation, and when diagnosed with a chronic illness, her life and her family's is now guided by the disease and its treatment.<sup>1</sup> The triad of children, mothers and families may experience long periods of hospitalization, frequent readmissions, aggressive therapy, often with undesirable effects from their own treatment, difficulties caused by separation of family members, interruption of daily activities, limitations in understanding the diagnosis, anguish, suffering, pain and the constant fear of the possibility of death. The family may also experience financial mismatch as a result of the situation.<sup>2</sup>

Motherhood experienced with a child hospitalized for chronic illness is marked by

insecurity, overload and social isolation. The need to acquire knowledge and skills incorporated into the child's care routine can cause physical and psychological effects that directly influence maternal quality of life, and the apprehension of reality can be threatening and incomprehensible.<sup>3</sup>

The process of coping with the disease associated with all technological support to which this child will be subjected can generate distancing and feelings of exclusion on the part of mothers, since they feel deprived of fundamental and defining experiences of motherhood. The hospital routine has different dynamics and logic than the family routine, which makes the safe and necessary relationship between the binomial, the family and the health team difficult.<sup>3-4</sup>

The permanence of the mother, father or guardian in the hospital to accompany the child during hospitalization is guaranteed by the Child and Adolescent Statute,<sup>5</sup> but this living together has been a challenge. To minimize these impacts, it is necessary to include strategies that enable differentiated arrangements aimed at humanized therapeutic care to ensure the responsible maintenance of the relationships of all involved.<sup>2,4</sup>

The nursing staff contributes to making this process less traumatic and to favoring mothers' stay in the hospital, encouraging involvement in the child's health-care-health process. Actions of this nature constitute a source of protection, support and security for the child and the mother, which contributes to coping with the situation in a less suffered and supported and professionally supported manner.<sup>3-4</sup>

In this sense, in order to understand the experiences of mothers of children hospitalized with chronic diseases, so as to contribute to the care process and bring improvements to the planning and organization of care, the present study sought to answer the following questions: How does the woman experience motherhood when facing her child with chronic disease? What meanings are attributed to this experience? And aimed at describing the meanings of the experience of motherhood facing hospitalizations of children with chronic disease.

#### Method

A descriptive, exploratory research with a qualitative approach. This last one is based on the interpretative capacity of the observed reality to comprehend meanings that individuals build based on what they experience.<sup>6</sup>

Carried out with mothers during the hospitalization of their chronically ill child at the Pediatric Intensive Care Unit (PICU) of a teaching hospital in the interior of the state of Minas Gerais, Brazil.

The participants met the following inclusion criteria: mothers with children admitted to the PICU, for more than three months, with preventable diseases that have become chronic due to frequent reintegration, perinatal disorders, after intensive care, clinically fragile, dependent on ongoing health care and on health needs that affect their quality of life. Those with some symptoms of psychological discomfort and those under 18 years old were excluded.

The participants were approached in the unit under study, received a detailed explanation of the objectives, research procedures and were invited to participate. Upon their consent, the free and informed consent form was provided. The interviews were conducted from February to May 2017, according to the availability of the six participating mothers in a room that provided privacy and secrecy.

Data collection was performed through semi-structured interview in two stages. The first consisted of the sociodemographic data of the mothers: age, marital status, education, place of birth and occupation and of the children: age, length of stay and medical diagnosis. The second stage was guided by the following question: "Tell me what your experience of motherhood is like for your hospitalized children with chronic illness?"

At the end of her response, the following question was asked: "Would you like to say anything else?" The interviews were about 30 to 45 minutes long and ended when the data was saturated, that is, when the objective was answered and data redundancy was verified.<sup>7</sup> The interviews were recorded in audio, with prior authorization and, afterwards, were transcribed in full and stored in an electronic database for analysis and interpretation.

For the treatment of the narratives resulting from the interviews, we adopted content analysis, thematic modality, which consists of a grouping of techniques, going through the preanalysis, material exploration and treatment of results, inference and interpretation phases. Consecutive readings were performed to systematize the data. In the first reading, an exhaustive contact was made with the material signaling the points of interest. The important data were highlighted to ensure they were not discarded.<sup>8</sup>

In the following reading, data were coded and organized according to meaning units in order to visualize them in a grouped manner according to the research objectives. In the exploration phase the data were categorized. To guarantee the confidentiality of the mothers, it was decided to replace their names with the names of fruits (plum, pear, acerola...).

The development of the study met the national and international standards of Ethics in Research involving human beings, in compliance with Resolution MS/CNS 466/2012. The project was approved on May 3, 2016 by the Ethics Committee of Research (ECR) with human beings of the Federal University of Triângulo Mineiro under opinion No.: 1,527,742 and CAAE: 52981816.6.0000.5154.

#### Results

Six mothers aged 21 to 44 years old were interviewed, four were primiparous and two multiparous. As for schooling, two had completed higher education, three had completed elementary school and one had incomplete higher education. Regarding the profession, four were housewives, one student and one physiotherapist, three were single, two were in stable union and one was divorced. Regarding the characterization of the children, their ages ranged

from six months old to four years and eight months old, the length of stay from three months to three years and two months and the medical diagnoses were the following: three with Tetralogy of Fallot and the others with Werding-Hoffmann Syndrome, Adrenal hyperplasia and Esophageal Atrasia.

Three thematic categories emerged from the statements: Ambivalent feelings expressed by mothers, Uncertainty of motherhood regarding hospitalized children with chronic illness, Change in family routine regarding hospitalization of children with chronic illness.

#### Ambivalent feelings expressed by mothers

During pregnancy, mothers idealize that the child is born healthy and develops properly; however, due to the circumstances the child remains hospitalized, which causes a confrontation between the imaginary baby and the real one, which can impair the learning of maternal function and provide the experience of very intense contradictory and ambivalent feelings. The distancing of other family members is another source of concern for the mothers in this context. This can be illustrated by the following statements:

[...] no mother is happy[...] to have a child inside a hospital ICU[...]. (Plum)

[...] since she was born, she has always been hospitalized because of her problems [...] then she had breathing problems and needed to be intubated, but it is very bad to be there, we are always here [...]. (Apple)

[...] see your nephews, your friends, all the children at home, you see your only hospitalized child is not easy[...]. (Pear)

#### Uncertainty of motherhood regarding hospitalized children with chronic illness

Mothers of children requiring continued hospitalization demonstrate feelings of uncertainty about their children's future and often develop detachment. The uncertain prognosis, associated with the dependence on the technological devices, excludes the possibility of cure and may generate feelings of rejection and guilt. The following statements illustrate such aspects:

> [...] I saw K. in the state she was there I was rejecting her, I wasn't having her as a daughter anymore, I was having as a person I didn't know, then I was depressed[...] I wanted to give up on her[...]. (Mango)

> [...] I had given up on her so much that I told her father that I will not go to the hospital anymore, she is going to die... then I was distancing from her [...]. (Guava)

> [...] whether or not we know that a chronic child lives in the respirator, she will not have a life expectancy like a normal child [...]. (Pear)

#### Change in maternal routine regarding hospitalization of children with chronic illness

Maternity in the face of chronic illness and hospitalization abruptly changes the daily life of women. Having to manage the hospital routine with work, other children, domestic services is challenging, which can be exemplified in the following reports:

[...] *it's a very tiring routine, because you can never do anything, you can never have an appointment with anything serious, you must put it here in the middle*[...]. (Acerola)

[...] I have four more at home besides her [...] in the morning it's a rush because you go to school, you have to pick her up, you have to make lunch, leave everything tidy, after I finish organizing it at home, I come here [...]. (Guava) [...] it's like this, I come here every day three times a day, every day, J. is 6 years old, I didn't stay a day without seeing him, my husband comes in the morning to see him before we go to work, at lunch now we come back, and at the afternoon we come back again, weekend we don't work we stay longer with him [...]. (Pear)

### Discussion

Motherhood is a transformative experience in a woman's life; becoming a mother is preparing for a series of stages and challenges. From the planning or the confirmation of pregnancy the preparations begin, which involve prenatal, childbirth, postpartum, psychological approach, physical, financial economics, cultural and social issues. The follow-up performed during pregnancy should prepare them to assume this new responsibility through safe information and educational interventions that enable their active participation throughout the process.<sup>9</sup> In this context, the pregnant woman expects a healthy newborn (NB) who, after birth, she will take him home, perform first care, start breastfeeding and introduce him to other family members.<sup>9-10</sup>

In the postpartum mothers are fragile, any change that occurs and distances from the expected will cause changes in their emotional condition.<sup>10</sup> The experience of a child with chronic disease changes this dreamed perspective of motherhood; it implies adapting the new routine and coping with the child's health condition.<sup>4</sup> The need for hospitalization in a PICU represents a cause of suffering and death.<sup>3-4</sup>

Because this is an unexpected situation, concerns arise that provoke ambivalent feelings as well as situations of emotional inconstancy,<sup>4</sup> as found in the first category of this study. This evidences an approximation of the research results with the scientific production. The mother's psychic suffering and anxiety are expressed through crying and feelings of anguish that characterize the summation of the feelings experienced by her, due to the difficulty she faces when leaving a familiar environment in which she was adapted to a strange environment, both in relation to the physical structure and the established relationships, functioning as an outburst.<sup>11</sup>

The second category, Uncertainty of motherhood regarding hospitalized children with chronic illness, is related to the clinical condition and the severity of the child's health condition. Mothers feel unable and guilty for not having control of the situation, which makes them vulnerable. Associated with this, the distancing that occurs in long periods of hospitalization promotes the break of the link between the binomial and reestablishing this link is important for the continuity of treatment. Some conditions, such as congenital malformations, cause rejection because they do not resemble the idealized or considered natural. The numerous invasive procedures, multiple punctures, surgeries, and stoma needs also influence this perception. The first contacts are uncomfortable and impactful, because mothers are not familiar with the technological apparatuses and technical terms used by professionals, the delay to touch and pick up the child contributes to the removal.<sup>3</sup>

The aspects that permeate the child's health condition, the hospital setting, the procedures and therapeutic technologies compromise the proximity between mother and child, the fear of losing the child may lead mothers to distancing from their children, as an attempt to escape the possible loss. Prolonged hospitalizations limit the maintenance of the child's routine activities such as attending school and playing. Living with other family members is restricted to visits and depends on the child's clinical condition.<sup>10-12</sup> A number of studies indicate that when mothers are at home, anxious and apprehensive that something might happen in the hospital, there is a constant concern about their child's health situation.<sup>12</sup> In cases where hospitalization is required from birth, the relationship may be further tightened. Women who have other children experience a tiring daily life, trying to meet the demands of all; however, the chronic condition needs special dedication, which can impair the attention given to others.<sup>4,13</sup>

In this perspective, the change in the mother's daily routine due to the hospitalization of a child with a chronic disease, which emerged in the third thematic category, depends on the level of complexity and dependence of the disease, as well as on the existence of a support network. In this context, mothers assume most of the parental responsibilities in childcare and the father acts as home provider. The desire to be present in the care of the hospitalized child refers to the feeling of guilt, almost always present in the process of illness and the ability to perform motherhood. High dependence on care not only changes the routine but often prevents parents from resuming work or daily tasks, which directly interferes with the family's financial condition.<sup>4</sup> Those who live in other municipalities suffer with the displacement, stay and feeding.

Having a social support network helps the mother to keep accompanying the child in the hospital. The support network can be made up of family, friends, neighbors, institutions and health professionals. They provide material goods such as food and clothing to the family, as well as emotional support, comfort, motivation and help with household chores and care for other children.<sup>12</sup> The co-living environments within hospital institutions can minimize the limitations that hospitalization causes in the family routine and encourages mothers to spend more time near the child.<sup>14</sup>

Attending and valuing relationships and interactions with family members is part of the care. Health professionals need to devise strategies to minimize the impact of separation and to offer psychological and spiritual support. However, it is possible to identify teams that are not prepared to deal with families. An effective communication between the team and the mothers which values and respects each other's opinions and clarifies doubts contributes to the satisfaction and the building of a trusting relationship.<sup>13</sup> In a study conducted in southern Brazil, parents claimed attention from these professionals through listening.<sup>14</sup> A concern of

mothers and family members is whether the team has the technical and scientific knowledge to take care of their child, but providing affection, attention, solicitude and patience are also attributes observed by them and impact on the care relationship.<sup>15</sup> Here we see the need to invest not only in hard and light-hard technologies, but also in strengthening light technology as a crucial tool in humanized and dignified care.<sup>16-17</sup>

Allowing and inserting the mother into the child's care routine is essential to foster family bonding.<sup>18</sup> The nurse is responsible for preparing the patient care plan together with the other professionals of the multidisciplinary team. The plan must be prepared and executed from the time of diagnosis and admission to the unit. From the construction of this plan it is possible to prioritize the needs, meet the particularities and promote dehospitalization, so that the child can have family life reestablished, provided that their health condition allows.<sup>13,19</sup>

Given the imminent risk of death that these children face, addressing this issue with their mothers becomes necessary. The health professional should encourage them to talk about their anxieties, fears and concerns to minimize suffering.<sup>19</sup> Creating groups so mothers can share experiences with each other is a strategy for providing humane care.

# Conclusion

Through this study it was possible to identify the feelings and needs of mothers with children with chronic diseases admitted to the PICU, allowing to reflect on the meaning of this experience for each one of them, approximating their fears, expectations, pains and fears they experience. The results collaborate to rethink the practice of interventions, so that they can mitigate the negative implications during the entire period of hospitalization of children. It is also considered that the process of treatment, worsening, recovery and prognosis, surrounded by uncertainties, generates in these mothers a constant state of alert due to the lack of answers or perspectives regarding the condition and life span of the child. The process of building a membership in these cases, given the scenario of the hospital institution and being crossed by its apparatuses passes through the mediation of referral health professionals. The change in the maternal routine was determined by the chronic condition of the child.

As a limitation of the study, it is considered that it portrays a regional reality, so it should not be generalized. It is suggested that new research investigates the feelings and impressions of mothers through longitudinal follow-up to examine possible changes in their dynamics over time.

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