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**D**PPGSTEH

# Experiences of Mothers During The Hospitalizatrion of Their Children

Experiências de Mães Durante a Internação Hospitalar de Seus Filhos

Experiencias de Madres Durante la Interna Hospital de Sus Hijos

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## ABSTRACT

**Objective:** The study's purpose has been to know the experience of mothers during the hospitalization of their children. **Methods**: This is a descriptive-exploratory study with a qualitative approach in a pediatric clinic of a reference hospital in the northern region of *Ceará* State, Brazil, on November 2015. The research includes eight mothers with hospitalized children at least seven days. The information was collected through individual semi-structured interviews, which were organized through the thematic analysis. **Results**: Four thematic categories were configured: the experience of mothers with children in hospitalization; contributions of mothers in the recovery of their child; quality of nursing care in the mother's perception; feelings aroused by the mothers during the hospitalization of their child. **Conclusion**: It was evidenced the need for the health team to plan and implement qualified health care, furthermore, those professionals are imbued with humanization and a comprehensive care perspective.

Descriptors: Mothers, Hospitalized Child, Life Change Events, Nursing, Family.

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#### RESUMO

**Objetivo:** Conhecer a experiência de mães durante a internação hospitalar de seus filhos. **Métodos:** Estudo descritivo-exploratório, com abordagem qualitativa em uma clínica pediátrica de um Hospital de referência na região norte do Ceará, Brasil, em novembro de 2015, com oito mães com filhos internados há pelo menos sete dias. A coleta das informações ocorreu por meio de entrevistas semiestruturada individual, que foram organizadas por meio da análise temática. **Resultados:** Configuraram-se quatro categorias temáticas: experiência de mães com filhos em internação hospitalar; contribuições das mães na recuperação do filho; qualidade do atendimento de enfermagem na percepção das mães e; sentimentos despertados das mães durante a internação hospitalar do filho. **Conclusão:** Evidenciou-se a necessidade de a equipe de saúde planejar e implementar cuidados de saúde qualificados, e que esses estejam imbuídos de humanização e de uma perspectiva de atenção integral.

**Descritores:** Mães, Criança hospitalizada, Acontecimentos que mudam a vida, Enfermagem, Família.

#### RESUMEN

Objetivo: Conocer la experiencia de madres durante la internación hospitalaria de sus hijos. Método: Estudio descriptivo-exploratorio, con abordaje cualitativo en una clínica pediátrica de un Hospital de referencia en la región norte de Ceará, Brasil, en noviembre de 2015, con ocho madres con hijos internados hace al menos siete días. La recolección de las informaciones ocurrió por medio de entrevistas semiestructuradas individuales, que fueron organizadas por medio del análisis temático. Resultados: Se configuraron cuatro categorías temáticas: experiencia de madres con hijos en internación hospitalaria; las contribuciones de las madres en la recuperación del hijo; calidad de la atención de enfermería en la percepción de las madres y; sentimientos despertados de las madres durante la internación hospitalaria del hijo. Conclusión: Se evidenció la necesidad de que el equipo de salud planificar e implementar cuidados de salud calificados, y que éstos estén imbuidos de humanización y de una perspectiva de atención integral. Descriptores: Madres, Niño hospitalizado, Acontecimientos que cambian la vida, Enfermería, Familia.

# INTRODUCTION

Child development is recognized in the area of public health as an important indicator used to monitor the health and nutrition status of children, related to their intense link to environmental factors such as food, disease, general care, and hygiene, housing and sanitation conditions and access to health services.<sup>1</sup>

Concerning development, special attention should be given in the early years of life, as this period is critical for healthy growth and development, making them physically healthy, emotionally safe and respected as social subjects.<sup>2</sup> It can be seen that actions aimed at children's health must be associated not only with survival but especially with their integral development as a person.

However, the processes of illness and hospitalization can interfere with the healthy development of the child, causing the removal of family, school, and friends, preventing the execution of daily activities. The entrance into a completely different space, with unknown individuals, subjected to a routine of others and therapeutic devices, whose scope is unknown to them, cause negative feelings, as well as stress.<sup>3</sup>

Nevertheless, child hospitalization has repercussions not only on the child's life, but on the whole family, implying the need for support, attention, guidance and permanent care for the companion, such as the mother, since she is closely linked to the child and she is usually the one who most longs for healing and discharge, and suffers the emotional effects of hospital stay.

Therefore, we seek to know the experience of mother-companions during hospitalization to unveil the fears, anguishes, and challenges of this involvement in the process of illness and care plan for their children. Besides, it is intended to answer the following question: What are the experiences of mothers during their children's hospitalization and their involvement in the child care plan in a hospital setting?

# **METHODS**

This is a descriptive-exploratory research with a qualitative approach, developed in a pediatric clinic of a referral hospital for 55 Cities in the northern region of *Ceará* State, Brazil, during 2015.

This research included eight mothers with hospitalized children, adopting as inclusion criteria: hospitalization of the child for at least seven days, and mothers, over 18 years old. The criterion of the number of hospitalization days was established because it was considered sufficient for the mothers to have some perception of the experience of being with the hospitalized child.

For the collection of the narratives, information was collected through medical records to identify the accompanying mothers who fit the research profile. The collection took place through individual semi-structured interviews, as configured in a strategy used in the fieldwork process and by the combination of closed and open questions.

The interviews were recorded with the help of an electronic recorder, with the participants' authorization for greater reliability of the information obtained, later transcribed in full and organized through thematic analysis<sup>4</sup> operationally divided into three stages: Pre-analysis; Exploration of the material; Treatment of results obtained and interpretation.

Note that the study complied with the principles and guidelines of the Resolution No. 466/12 of the National Health Council.<sup>5</sup> The anonymity of participants was preserved through the use of codenames of roses to identify mothers. The research was approved by the Research Ethics Committee (REC), according to the No. 1,318,813.

# **RESULTS AND DISCUSSION**

Considering the eight mothers participating in the study, it was found that the ages ranged from 19 to 32 years old. Concerning the level of education, one had incomplete

primary education; four had completed elementary school; and three, complete high school. Regarding marital status, three were married; two in a stable union; one was divorced and two were single.

Regarding the number of previous pregnancies, it was possible to identify variations from one to five pregnancies per woman and no history of abortion. Seven claimed to be catholic and one is evangelical. Among these eight, only one said to use medicines, in this case, the contraceptive.

After analyzing the information obtained, four thematic categories were elaborated: experience of mothers with children in hospitalization; contributions of mothers to their child's recovery; quality of nursing care in the perception of mothers and; feelings aroused from mothers during the hospitalization of their child.

### Experience of mothers with hospitalization

The woman is configured as an important member of the family, since she develops different activities in care during the health-disease process. However, in addition to the development of family activities, such as taking care of the house, children, husband, and other family members, it is emphasized that it also incorporates various roles in society, such as insertion in the labor market, which implies an overload of activities to be performed.

She is also involved in providing care as an important member of the family nucleus in hospitalization situations<sup>6</sup>, and distances herself from her other duties. In situations of hospitalization of the child, she becomes almost exclusively the mother of a sick child who needs hospital care<sup>7</sup>, adapting to changes in personal, professional and social routine.<sup>6</sup>

At seven days old I took him [son] to the hospital vomiting a lot. Then, the doctor who was there transferred him (...). I was very worried but at the same time quiet because the doctor said he was going to be accompanied, but I had a lot of difficult times with him. (CACTUS)

Yes, with my mother. I don't remember the period, but I think it was last year. She was hospitalized with stomach pain. It was good because she left well. (SUNFLOWER)

The findings show that the investigated patients' hospitalization experience is not restricted to their children, but also to other family members, expanding the focus of women's responsibility beyond their offspring, including other family members.

In addition, the hospitalizations of children commonly fall to the mother, as the speeches point out:

Very difficult, because by the time I spent here thinking it was going soon, is already five months in here and there is still no expectation and no prediction of hospital discharge. (HORTENSE) It's horrible because spending several days in hospital with my child, we are out of the house. (DAHLIA)

Difficult, because, for example, he is my first child, then being hospitalized with him. At home, I always have the help of a family member, my husband. So, to be with him alone is very difficult. (LILY)

However, although the time is difficult and very worrying, there are still those mothers who can have the strength to keep positive thoughts about their child's recovery:

*I am calm, I already know his problem, I think it is God who gives strength (laughs). There is no use complaining, if God wanted we just have to accept it. (CACTUS)* 

*Difficult, but we believe he will recover.* (CHRYSAN-THEMUM)

The maternal tranquility expressed by mothers is related to previous experiences. They already know the pathological process of the child and can recognize the signs of improvement, which makes them more confident.

Also, religion and spirituality are tools for coping and resilience of mothers to deal with this difficult situation, such as the mission of monitoring the hospital stay of children, permeated by stressful events.

Thus, from the testimonies, it can be seen that trust in God, that is, faith a in divine power is a resource used by the companions in coping with the situation<sup>6-8</sup>, placing in it their hopes for the recovery and healing of the child.<sup>8</sup>

### Difficulties faced during child hospitalization

It is clear from the reports of the investigated that one of the difficulties experienced during the hospital stay of the child, is related to food, which is not available by the hospital as the need of companions:

I think the worst difficulty was feeding, because I only breastfeed right? Then on the first day here I got sick. Because here, we have to choose if it comes breakfast, lunch and dinner, there is no snack, and I wanted to, because I only breastfeeding, right? (...) And I don't go out to leave my son here alone, because he already ripped the access several times his hand was swollen, the health team tried several times, sticking to find his vein, so I didn't want to leave anymore, I preferred to be alone with the three meals. (LILY)

Just the matter of food, that I do not go out to eat and leave him alone here, then I get hungry many times, I have said this to them several times, but if my lunch does not come today, I will leave with my son. (ORCHID) Regarding compliance with the rules and routines assigned by the hospital institution, a relationship of obedience and utility was observed, aiming at their constant subjection to the instituted and, the imposition to them can generate conflicts, compromising the dedication to the hospitalized child and the caregiver of the fragile child.<sup>9</sup>

Considering this discussion, it is important to enabling the family to live harmoniously with the norms and routines, making them more flexible when imperative. Therefore, it is necessary to rethink whether this family member who cares for and lives with the hospital's rules and routines is satisfied with what is imposed, otherwise, it is essential to allow them to adapt rules and routines that fully meet their needs, providing them comfort and support.<sup>10</sup>

The purpose is not to promote extreme changes in the rules and routines of hospital institutions, but to adapt them based on the particular needs of family members, as a strategy of humanization, respect and attention to their individualities, with a view to a good interpersonal relationship between health professionals, family and patients, as well as comfort in the hospital environment.

Moreover, geographical distance, financial conditions, and increased expenses during the hospitalization period were other elements highlighted in the study, which means that probably the hospitalization of a child is also aggravated by the socioeconomic context:

*There are several, one of them is that I live very far from here, but a matter of spending.* (CHRYSANTHEMUM)

Lack of money, because my husband can't work outside, just for ourselves, and we get the family grant. (SUN-FLOWER)

According to the speeches, this is a challenge for women, with physical and emotional distress<sup>11</sup> generating doubts and uncertainties, due to dissatisfaction with the permanence in the hospital environment, recovery and the distance from home and family, such as the husband, who subsidizes in the care of the child.<sup>7</sup>

Also, another factor that was unfavorable to the families during the hospitalization of the child was verified, such as the increase in expenses with communication, mobility, food, among others.<sup>12,14</sup>

Financial difficulties, added to the expenses that involve a prolonged hospital stay and distance from home, trigger concerns<sup>12</sup>, besides discomfort<sup>6,12</sup>, overload<sup>6</sup>, especially for the mother<sup>15,16</sup> who, particularly, in most cases, accompanies the child during the entire stay in the hospital unit.<sup>16</sup>

### Mothers' contributions to child recovery

The presence of a family member during hospitalization is characterized as a way to bring benefits to the child's recovery and the minimization of stressful events associated with the hospital stay.

*Always by his side giving strength when needed.* (HORT-ENSE)

I think this way I contributed, right? With the doctors, everything they asked me to do, for example, wash his nose with serum, I washed, if he has a fever, I will give shower him. I followed all the recommendations of the doctor and the nurse. (LILY)

I calm him down, say he'll be fine soon so we can go home. (ORCHID)

The interviewed mothers presented in their speeches the attention to the child through dialogue, as a strategy to give confidence about recovery and return home, as well as the implementation of complementary care, based on the recommendations of the health team.

Because of the bond that mother and child establish between themselves, since pregnancy, and concerning the rooted knowledge that they have about their preferences and behavior, it is common to be mothers, the people selected for the monitoring of children in their hospitalization experience.<sup>17</sup>

The mother is also characterized as an important element during the hospitalization process, because, besides representing the fulfillment of legal issues and advances regarding the quality and humanization<sup>18,9</sup>, it can contribute to the recovery, treatment and emotional support of their child<sup>20</sup> and the development of other functions, such as monitoring<sup>12</sup> and the performance of some direct care activities.<sup>21,22</sup>

Thus, it is configured as a human resource and facilitator of the work of health professionals<sup>23,24</sup>, because the production of care, which was previously performed only by the health team, has been shared with the family, often being delegated to a family member<sup>23</sup>, usually the mother, for playing the role of caregiver in the context of child hospitalization.

# Quality of care by the health team in the perception of mothers

Regarding the assistance of health team professionals, the testimonies of the mothers identified satisfaction with the care provided to children and the care and availability of professionals during hospitalization:

*They are very good; I have nothing to say. (CHRYSAN-THEMUM)* 

*Ah, I think they answer well, give the medication at the right time, they are always alert when we call, they come* 

to answer. (DAHLIA)

Here, the service is very good. (FLEUR-DU-LIS)

To tell the truth I think (...) to tell the truth I don't know because what I saw is that they do everything. They are not yet 100% but they are in the way (...). (LILY)

The attention given to the child and the companion by the health team makes the mothers have a good impression of the health professionals of the hospital unit.<sup>25</sup> Moreover, just knowing that the child is receiving quality care leaves the less apprehensive mothers.<sup>16</sup>

In contrast to previous reports, some mothers pointed out that not all health team professionals are sensitive to their children's treatment and illness:

There are some, who know that they are dealing with children, they had to be more sensitive, it is not all, but you know, they are very insensitive, they do not know. It seems that they do not realize that they are dealing with children, sometimes the child cries they think it is bad, if the person complains, for example, I said that the hand of my son was swollen they did not like. (LILY)

In this investigation, the dissatisfaction of the interviewed mother regarding the procedure performed by the health team to the child was verified. In this sense, it is pointed out that technical procedures, when painful, can trigger negative repercussions on children, such as withdrawal, negative emotions, limitations and restrictions in the child's life during the hospital stay.<sup>26</sup>

These feelings in their different magnitudes cannot be ignored, but confronted and considered through dialogue and constant support from the health team. It is in this process of coping and adaptation that it becomes possible to build strategies that enable mothers and patients to withstand the difficulties of this experience.<sup>6</sup>

Therefore, health professionals need to be aware of the particularities of children and, in the case of peripheral puncture, put in place methods that reduce pain, such as previous use of anesthetic cream to soften the painful sensation during the invasive procedure<sup>27</sup>, and pass along information about the procedure to be performed with the child in the hospital unit, as this approach will result in cooperation and trust, supporting the conduct of the health professional and the diagnostic evolution.<sup>28</sup>

In this sense, it is understood that the attention and care offered to patients and caregivers during hospitalization by health professionals are characterized as essential elements for the understanding of quality care and, it is up to the health professional, the operationalization of care that fully addresses the users of the health service, focusing on humanized, welcoming, dialogic and attentive care.

# Feelings aroused in mothers during the hospitalization of their child

The aggravation to the child's state of health and the referral to the hospital unit is characterized as a singular moment in the mother's life, since it arouses negative feelings, such as anxiety and fear of the imminent loss of the child:

I'm afraid when these crises, there won't be time, because once I get here his problem gets worse. I'm afraid of losing him. (CACTUS)

In the maternal discourses, the psychic suffering expressed through crying and the feeling of sadness regarding the hospital stay of the child and the distance from home are verified:

Sadly, when it was said that he was going to be hospitalized I just did cry. (FLEUR-DE-LIS)

Sadness, not only because of the fact of hospitalization, but because I had no idea of the seriousness of what he had, then when they said he was going to be hospitalized I thought if it was necessary, I was very sad because we want to stay home. (LILY)

Sadness, right? Because he cannot leave, he will have to go to Fortaleza to have surgery, I'm afraid because they have discovered so much disease in him here. (SUNFLOWER)

Child hospitalization is a difficult situation that interferes with the emotional state of the accompanying mothers, unleashing and subjecting them to negative feelings, such as sadness for the child's health.

It was also evidenced physical tiredness, related to the stay in the hospital unit:

*With eight days I'm not going home, I cannot sleep here, I'm very tired. (LILY)* 

During the hospitalization process, mothers may be vulnerable, showing physical and psychological tiredness. Physical tiredness is mainly due to the lack of infrastructure of the unit, since most hospitals do not have functional and physical resources that contribute to the presence of the family member.<sup>29</sup>

# CONCLUSIONS

Maternal reports showed that the hospitalization of the child is characterized as a moment permeated by suffering and negative feelings, regarding the child's health, financial difficulties, compliance with norms and routines of the hospital, distance from home and family members.

The presence of a family member, especially the mother, during such a difficult time for the child, is *sine qua non* for

the operationalization of benefits, as it provides support, attention, and protection to the child to cope with suffering caused by hospitalization, besides the implementation of instrumented care and encouraged by the health team professionals.

The study revealed that some mothers are satisfied with the care the health team has been providing to their children, although child health care is still in the process of germination, along with full care.

Empirical data reveal that mothers are impacted by the hospitalization process, as there is disorganization in the family's daily life, physical and emotional well-being, which are worn out during this painful moment, generating a family breakdown added to feelings such as fear, sadness, and insecurity.

Limitations of this study are the small number of participants who contributed to the investigation, which does not allow the generalization of the information collected and discussed. The study will serve as a subsidy for the qualification of care in hospitals, given the challenges faced by mothers during their children's hospitalization.

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