


## TRIGGERING AND MITIGATING FACTORS OF MATERNAL OVERLOAD IN THE HOSPITAL ENVIRONMENT DURING CHILD HOSPITALIZATION

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### ABSTRACT

**Objective:** to identify factors that trigger and mitigate the burden faced by mothers of hospitalized children.

**Method:** exploratory descriptive research with a qualitative approach. Data were collected from July to August 2017, with semi-structured interviews with seven mothers accompanying children hospitalized in a ward in a public hospital in Campo Grande-MS. The data were analyzed by content analysis, generating two analytical categories: factors that trigger the overload and factors that mitigate maternal overload.

**Results:** the exhausting daily life, inadequate resting place and emotional factors such as feelings of fear and worry trigger maternal overload. Family and health professionals support alleviates mothers' burden.

**Conclusion:** mothers face overload, as they focus their strength on the sick child. Knowing the maternal experience during hospitalization allows nurses to identify their needs and include them in their care plan, seeking to perform interventions to better assist them.

**DESCRIPTORS:** Nursing; Hospitalization; Child; Mothers; Pediatrics.

### **FACTORES DESENCADENANTES Y ATENUANTES DE LA SOBRECARGA MATERNA EN EL ENTORNO HOSPITALARIO DURANTE LA HOSPITALIZACIÓN DEL NIÑO**

#### **RESUMEN:**

**Objetivo:** identificar los factores que desencadenan y mitigan la sobrecarga a la que se enfrentan las madres de niños hospitalizados. **Método:** investigación descriptiva exploratoria con enfoque cualitativo. Los datos se recopilaban de julio a agosto de 2017, con una entrevista semiestructurada con siete madres acompañantes de niños hospitalizados en enfermería, en un hospital público de Campo Grande-MS. Los datos se analizaron mediante un análisis de contenido, generando dos categorías analíticas: factores que desencadenan la sobrecarga y factores que amenazan la sobrecarga materna. **Resultados:** la vida cotidiana exhaustiva, lugar de descanso inadecuado y factores emocionales como sentimientos de miedo y preocupación desencadenan sobrecarga materna. El apoyo de los familiares y de los profesionales de la salud alivia la sobrecarga de las madres. **Conclusión:** las madres enfrentan sobrecarga, ya que centran sus fuerzas en el niño enfermo. Conocer la experiencia de las madres durante la hospitalización permite a las enfermeras identificar sus necesidades e incluirlas en su plan de cuidados, buscando realizar intervenciones para asistirlos mejor.

**DESCRIPTORES:** Enfermería; Hospitalización; Niño; Madres; Pediatría.

## INTRODUCTION

Child hospitalization is a stressful and traumatic event for the child, since, along with hospitalization, comes the rupture of the social environment and daily activities. The child needs to adapt to the new environment and its new routine, being repeatedly submitted to invasive and painful procedures<sup>(1)</sup>. They face a whirlwind of feelings due to the need for separation from loved ones and the limitations that the disease imposes on them<sup>(2)</sup>.

Families are impacted by hospitalization and this experience can trigger feelings of fear, guilt, anxiety, and helplessness about the child's illness. They experience crises related to conflicts and family disorganization, and the need to reorganize roles. At this moment, the family starts to prioritize the child's health<sup>(3)</sup>.

Commonly, the mother assumes the role of primary caregiver of the child, and they are the companions during hospitalization<sup>(4)</sup>. Whether for emotional, legal or moral reasons, mothers can set aside their personal needs for the sake of their child's recovery. They face changes in their health due to fatigue and exhausting routine, which, added to fears and lack of interest in their own care, cause a decrease in quality of life<sup>(5)</sup>. Families play a fundamental role in the child's recovery process and the way they deal with the stress of hospitalization affects the quality of life of both<sup>(6)</sup>.

Mothers are immersed in the hospital environment and need to learn the dynamics of the new scenario. Depending on the support and resilience they have, they may feel fear, insecurity, overload and loneliness<sup>(7)</sup>. The greater their involvement in the therapeutic plan, the greater their understanding and agreement with the proposed treatment. The mother plays an important role in the child's recovery process, because she provides support, attention and protection to her child<sup>(8)</sup>.

It is a fact that mothers, since they are the ones who usually stay with their children during hospitalization, need care, because during this process they are worn out and fear the breakdown of the family. One of the key elements for the attention to families is the recognition of their importance and their inclusion in care and decision making<sup>(6,9)</sup>.

In this sense, it is important that nurses have an open attitude toward the family and establish a bond and a relationship of trust with family members, so that their stories can be shared, and strengths and weaknesses can be identified. The sharing of information is fundamental for the elaboration of a care plan that involves the child and its family. The more attentive the listening and the welcoming posture of the professional, the better the quality of care provided, interfering in the child's response to treatment, in the length of hospital stay, and in the cost to the institution.

Identifying factors that trigger or mitigate maternal overload allows the establishment of actions to welcome the family, based on the pillars of Family-Centered Care: dignity and respect, participation, collaboration, and sharing of information. Thus, the question was asked, what has caused and/or mitigated the maternal overload during child hospitalization? To answer this question, this research went to the field with the objective of identifying the factors that trigger and those that mitigate the overload faced by mothers who accompany children.

## METHOD

Exploratory descriptive research with a qualitative approach. The philosophical framework of the Patient and Family-Centered Care was used.

The study was conducted in a pediatric ward of a public hospital in the city of Campo Grande-MS. Family members over the age of 18 years old who had been accompanying their children hospitalized for at least seven days were included, and family members who were accompanying the child for only a period or sporadic day were excluded.

The interviews were conducted by the lead researcher, who underwent training for the application of the questionnaire and deepened into the theme. The data were collected in July and August 2017.

To perform the data collection, the researcher contacted the technical nurse in charge and together they selected the participants who met the inclusion criteria; then, the families were individually invited to participate in the research, explaining the objectives of the study. After acceptance, the participants were taken to a room, without the presence and interference of other people, and they were also presented with the Informed Consent Form.

The data were obtained through a semi-structured interview, in which a questionnaire prepared by the researchers was applied. The first part contained questions about the characterization of the participants and the second questions related to the family member's burden during the child's hospitalization, the main question being: Tell me about how the hospitalization of (name of child) is going for you?

All interviews were recorded on digital media and transcribed in full by the researcher, with an average duration of 25 minutes. Then, each interview was read in its entirety, paying attention to the particularities of each answer, as well as all of them, following the method of Qualitative Content Analysis proposed by Morse and Field<sup>(10)</sup>, based on inductive analysis. After reading, the recommended steps for data identification, coding, and categorization were followed. The line-by-line coding gave sequence to the analysis and grouping into subcategories, provisionally named according to their similarities and divergences, this moment was performed by two researchers.

In order to preserve identity, the participants were identified with the letter "E" followed by the interview number, for example "E1".

The present research is in accordance with the ethical precepts of Resolution N°466/12 MS12<sup>(11)</sup> of the National Health Council and was approved on June 1, 2017 by the Research Ethics Committee of the Federal University of Mato Grosso do Sul with opinion N° 2,096,643.

## RESULTS

All participants included in the research were mothers, who were on average 30 years old, with a range of 20 to 53 years old. During the collection period, they did not have another family member accompanying the children (such as father, grandparents, etc.). Of these, four had left their jobs to take care of their sick child. Of those who did not quit their jobs: one was self-employed, one was a "housewife", and one was on medical leave. Of the seven mothers, five did not take turns with another person.

As for medical diagnosis, three children had chronic health situations (nephrotic syndrome and cerebral palsy), the others were hospitalized for acute situations without other associated pathologies (leishmaniasis, pneumonia, bronchiolitis, and septicemia). Four of them had been hospitalized previously. The average length of stay was 45 days, the shortest being nine days and the longest five months. Of the mothers interviewed, three lived in the study city, one lived in a neighboring state and was in town on a trip, and the others lived in the interior of the state.

Two categories emerged from the responses of the accompanying mothers who participated in the study: Factors that trigger mothers' burden and Factors that reduce mothers' overload.

### Factors that trigger mothers' overload

Among the triggering factors of overload reported by the mothers, the physical factors stand out, such as the ambience, the need to stay full time in the hospital without taking turns, the fatigue, and the desire to be at home. These factors potentiated stress, physical and emotional exhaustion.

The place for the companions to rest consists of an armchair next to the child's bed. The mothers reported that the armchairs caused body pain and triggered sleepless nights, they felt exhausted and attributed this to the fact that the chairs were old and small.

*I have been here for days, sleeping in that chair. Everyone is saying that I have eyesight. I am exhausted! I want to sleep.... I do not sleep well; I wake up several times. (E5)*

*I cannot sleep properly; the chair is horrible! (E1)*

The full-time stay in the hospital caused physical fatigue, as they were not able to bathe in the usual way, so their self-care was not considered satisfactory. Staying in an unattractive environment with stressful routines caused discouragement in the mothers.

*...this tiring place, no time to get ready, no time to even take a proper shower. I feel like being at home! It is very tiring. Because we stay here it seems that we are not doing anything, right? But every hour you get up, do this, do that... (E2)*

Mothers remained by their children's side all the time because they had no one to take turns with or because they were worried about leaving the child under someone else's care. Another reason was that they believe that it is part of their role as a mother to accompany their child during the hospitalization period. They perceived that their stay in the hospital contributed to the child's quick recovery.

*I would rather stay here. Because even if I leave, I will not be at peace, because I will be thinking here. Do you understand? So, if I went away, I would stay here with my head here. I would not turn off, I would not rest, I would not be able to stay there... In the beginning my mother stayed here, but then he did not eat, he started to fuss. Then I arrived and he changed totally, he started to eat, play... he needs me 100%. (E1)*

*It is bad to be hospitalized, right? But I must stay with him, I am his mother. There is no one who is better to stay than me... it is necessary that I stay by his side, he is my son, a little baby, it is bad to be in this situation of hospitalization, but this is bad for any mother. (E3)*

*It is an obligation of the mother, we have no choice, we did not want to be here, but we are... (E7)*

The mothers' emotional overload was evidenced when they expressed dissatisfaction with their self-esteem. They believed that they should not think about taking care of themselves while their child was sick. Thus, they put aside taking care of their physical appearance and hygiene. They mentioned that they were vain and liked to be neat but felt guilty about taking care of their appearance during the hospitalization period.

*It decreased a lot my self-esteem, because my daughter is in bad shape, I do not feel like getting ready... And I am super vain, I am a hairdresser and so on, in the salon I must be well groomed, well dressed, with make-up. But here I feel guilty. So, my daughter is sick, and I am going to get all dressed up? I washed my hair these days, I spent a long time without washing my head and I take care of myself, right? (E5)*

*When I am here, I do not even think about myself, or self-esteem... my self-esteem is superfluous. I am here to take care of her [the child]. (E7)*

The mothers remained concerned about the situation of their sick child. They often did not sleep to make sure that their child would be well. They remained alert and fearful that something might happen to their child if they slept.

*I am concerned, these days she said she was having pain in her little hand, so I do not sleep anymore, I watch her at night, seeing if she is well... I put the cell phone to wake up every hour, I am afraid of something happening and I do not see it. (E5)*

The concern with the other children, who stayed at home, also permeated the mothers' experiences during hospitalization. They understood that the hospitalized child required their stay at the hospital but being away from their other children made them think that they also needed care and missed them.

*It is bad because of my other daughter; I miss her more. Because she is like this, between my mother's house and my ex-husband's house... the other one missed school, because her father lives far away from the school, she did not study for a week. (E5)*

*It is just not good because I am far away from my other children. But it is good as far as possible, right?... I think about them all the time. (E1)*

They were shaken, because they felt they could not do anything about their sick child's situation, and when something happened that required some specific care for him, they got desperate and didn't know how to deal with it or how to help.

*When he went away for peritoneal dialysis, the machine beeped, he cried, I cried along with him, I did not know what to do! That despair! (E6)*

## **Factors that reduce the burden on mothers**

During the reports, it was possible to identify factors that reduced the maternal overload. Among them, family support was considered of great importance by the participating mothers, especially when family members helped with household chores and with the care of the children who stayed at home. In addition, taking turns among family members helped the mothers to rest, allowed them to leave the hospital environment for a few moments, perform household chores, and check on their other children.

*So, it helps me, right [the relay], I know that it is fine there and here it is fine too, because my husband, the only difference between me and him being with my son is that he breastfeeds and I have the breast, right? [laughs], but it is the only difference, my husband can supply a lot of things. (E3)*

*It [the rotation] helps me a lot because of the rest, so I can go home to sleep and because I can do something there, wash clothes, bring something that is needed, see my other son, help him with something, that he always needs. Because he is small. (E3)*

The support of the nursing professionals helped the mothers to feel confident in the task of caring for their child. They reported that they had someone to turn to when something happened that they did not have the knowledge to solve.

*No, it is tiring, but not difficult. Not difficult because the nurses help, right? There is all the support from the nurses. (E2)*

The experience of staying with the child in the hospital allowed the mothers to reflect and learn how to deal with the challenges of life and with the child's disease. They realized that they became stronger from the experience of being with their child in the hospital.

*At first, I was worried [about the child], gee, I almost died! I talked to God, because I am evangelical, I went to the chapel there, now I am well, thank God, I see differently, I feel stronger. (E5)*

*...he [the child] gives me strength every minute, every hour, every day. So, he strengthens me, I learn from that. (E1)*

With the child's hospitalization, the mothers began to value the help of people outside the family and to view the difficult situations experienced through a different prism.

*I learned a lot of things here that I did not value before, you know. Like, I was proud, I did not want anyone's help. Nowadays I need help from a lot of people. It is hard, but we must learn to leave our pride aside and live. My self-esteem has improved. I learned many things that I thought were not important in my life and today I know that it is, I see it from another angle. (E1)*

The support of the members of the health team was configured as an important factor for the feeling of well-being and relief of the accompanying mothers' emotional burden. The bond between the family and the team made the mothers' experience lighter and more positive.

*I feel good here, here I feel as if I were in my family too, because the love that I have here is very great for everyone, you know? The girls [nursing staff] themselves are like my family. (E4)*

## DISCUSSION

The results of this study point to situations that trigger maternal overload, especially because the mother is the main caregiver during the hospitalization period and because she does not share the care of the child with other family members. The hospital proves to be an uncomfortable environment, not offering conditions for them to rest, take care of themselves or distract themselves. On the other hand, the welcoming approach of the nursing staff makes these mothers' stay in the hospital more tranquil.

The participants of this study had similar characteristics to others, which also found a predominance of mothers who accompanied the children<sup>(12)</sup> with a mean age of 30 years and who often need to leave their jobs to dedicate themselves to the care of the child and accompany them in the treatment<sup>(13-14)</sup>.

The inadequate physical spaces and accommodations of the hospital for the proper rest of the accompanying mothers and the uninterrupted stay with the child caused fatigue and discouragement. This was evidenced in a research<sup>(15)</sup> conducted in a pediatric ward, which sought to describe the needs of the companion of the hospitalized child during his stay in the ward; the dissatisfaction of mothers about their condition of stay in the ward due to structural conditions, for not having a place to wash and dry their clothes and for not having an exclusive bathroom, among other aspects, was highlighted.

Therefore, it becomes necessary to reorganize the spaces in pediatric wards in order to allow the companion's stay that ensures the quality of sleep, rest, and well-being.

During the child's hospitalization, the companions experience situations that harm their physical health, such as lack of sleep and rest caused mainly by not having an adequate place to rest. Studies<sup>(16-17)</sup> point out the importance of sleep and rest, affected by the discomfort provided by hospital armchairs. It is evident the relevance of hospital preparation for the reception and stay of families, in order to welcome them properly.

Studies<sup>(17-18)</sup> discuss about the negative feelings of fear and insecurity that permeate the period of hospitalization and illness of the child, bringing up the importance of the nurse for the mitigation of these feelings. By staying longer in the ward, the nurse has the possibility of approaching the family, trying to clarify their doubts and alleviate the anguish that the experience of illness and hospitalization generates.

The low self-esteem of accompanying mothers was also highlighted, because they do not feel motivated and do not find conditions to do so. Actions should be proposed so that they are encouraged to devote time for self-care during their stay with their child in the hospital. The conditions offered by the hospital also directly affect the feeding, personal hygiene, and self-care of these mothers. When sleep and rest are affected, mothers show sadness, impotence, and fear before hospitalization<sup>(16)</sup>. Changes in the norms and routines of the unit and qualified assistance from professionals can help mothers to go through the challenges for which they do not always feel prepared.

In this study, three of the hospitalized children had chronic diseases, demanding more time and dedication from the mothers and representing a greater impact on the family. The context of chronic disease implies frequent hospitalizations and an increase in the overload and stress of all family members. This context requires more direct monitoring by nurses and other health professionals.

It is evident the need for appropriate space for the companions to stay with their children in the hospital environment and to be heard their doubts and anxieties. Other authors<sup>(15-16,19)</sup> point out the need for the health professional to have a holistic view, including the needs of companions who remain hospitalized with the child, providing greater well-being and a safe environment.

Taking turns with other family members is essential for mothers, reduces their burden during the child's hospitalization and relieves stress. The family support network is of great importance in this context, as there is often a need to redefine roles within the family. Mothers who stay with the child in the hospital need to feel secure about the continuity of the home routine and the care of the other children, and they should be encouraged to contact their support network to assist in the activities.

Despite the negative consequences that the child hospitalization caused to the mothers, it is possible to identify an acquired learning. The support of family, friends and the healthcare team help to enhance the resignification of the moment they are living, making the experience less traumatic<sup>(20)</sup>. Such factors that minimize the overload should be optimized by means of conversation groups that allow the exchange of experiences among mothers who experience similar situations, and the use of such spaces to solve doubts and understand the individual vision of each companion.

In this sense, the Institute for Patient-and Family-Centered Care proposes to health institutions a model of care in which the family is included in the whole care plan and proposes the incorporation of four central assumptions: dignity and respect, sharing of information, participation, and collaboration. These pillars need to be incorporated into the service in all spheres (administrative, supportive, and assistive), so that the family feels cared for and their needs are met. Moreover, it proposes an architectural structure shaped in this model of care<sup>(21)</sup>.

As limitations of this study, there are the inclusion of only one public hospital for data collection and the fact that it included mothers of children with chronic diseases, who have experience of long and recurrent hospitalizations. The apparent emotional fragility of the mothers in the interviews may also be a limitation. It is suggested that future investigations be carried out in other realities in order to identify differences and similarities of the reality experienced in other institutions.

## FINAL CONSIDERATIONS

The research showed that mothers of hospitalized children face situations that can trigger physical and emotional overload. The low self-esteem of the companions was evidenced and brings with it the feeling of guilt, since the child requires their total dedication during the hospitalization period. Another factor that contributes to low self-esteem is the non-availability of a space that ensures the mother's privacy and comfort for her hygiene and personal care.

Not having an appropriate place to rest, the difficulty in taking turns caring for the child, the isolation from other family members, and the feelings of sadness, fear, and worry about the sick child or the other children who remain at home, trigger a physical and emotional burden on the accompanying mother.

On the other hand, they find in the family support, the nursing team and the sick child itself the strength and motivation they need to continue. Feeling supported minimizes the emotional overload and suffering experienced in the context, favoring bonds of trust between them and the team.

Thus, it is necessary that nurses include mothers in their care process, creating opportunities for them to be heard. Hospitals need to favor the space for moments of therapeutic conversations in order to listen to their doubts and anxieties. In addition, they need to develop means to offer better conditions for the permanence of accompanying mothers and include them in their child's care process.

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