THE DISEASE AND THE CHILDISH HOSPITALIZATION: UNDERSTANDING THE IMPACT ON FAMILY DYNAMICS

ABSTRACT

Objective: to analyze the impact of childhood hospitalization in the family routine. Method: exploratory study, descriptive with qualitative approach, performed with 10 caregivers of hospitalized children in pediatric unit of a hospital of the city of Cuité/PB/Brazil, by means of semi-structured interview. Data collection was conducted between November 2011 and January 2012. The interviews were analyzed with support of the technical of content analysis, in category of thematic analysis, after approval of the research project by the Ethics Research Committee of the Faculdades de Enfermagem e Medicina Nova Esperança, Protocol nº 192/11. Results: three categories were identified: "Changes in daily family life", "Maternal overload in the care for hospitalized child" and "The Family as important support network". Conclusion: hospitalization entails not only the emotional and physical weakness of the child, but also affects the everyday and the internal organization of the family. Some of its members contribute significantly to the needs and situations.

Descriptors: Hospitalization; Child; Family Relationships.

RESUMO


Descritores: Hospitalização; Criança; Relações Familiares.

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The disease and the childish hospitalization…
INTRODUCTION

The hospitalization process translates itself as a very hard and stressful experience for any individual, especially for the child, due to the intense (re)adaptation, not only for it, but also of the whole family that experiences significant changes in the inter-relationships between its members and in daily routine. 1,2

The impact caused by the illness of a child in family life, alone, is already too significant. When linked to this condition, we find the need for hospitalization of a child, feelings of anguish, fear and anxiety occur in even more intense proportions.3

As well as a child, the family also goes through hard times of conflict. The emergence of a disease in any family member causes devastating outcomes, destabilizing any family core, because its members are interconnected and when one gets sick all of it is affected.4 5

This event is potentially stressful for the family, because inserts it in an environment that often threatens the sense of security and competence, generating feelings of powerlessness and helplessness. A child that experiences a process of hospitalization not only takes a sick body to the hospital environment, but takes its family, besides all the experiences lived until that time. The child’s family is directly linked to this health-disease process; this means that the care must be expanded and singular, including the demands of family.5 6

Despite the illness constitutes itself, in most cases, as a moment of crisis in the family, the restructuring, the formulation and the strengthening of bonds can also happen during illness. At that time, values and forms of relationships within the family may be reconsidered and, with that, conflicts can be solved with mutual help and unity, strengthening the love, bonds and the care among its members.4

Anyway, the family tries to adapt to the changes caused by the illness and the hospitalization of the child. The effective coping and adjustment to the changes arising from hospitalization requires from the family new forms of organization and also the development of skills in dealing with the pressures, difficulties and uncertainties which are existing in the family life divided between home and hospital, as well as to maintain the welfare of the family situation.7

The parents comprise a large proportion of individuals who accompany their children and who live next to them the reality of the hospitalization process and other aspects related to it.8 In this sense, they may offer important contribution in identifying conflicts and changes experienced by the family during the hospitalization of the child.

Given this dimension, the aim of this paper is analyzing the impact of infant hospitalization in the family routine. It is hoped, with the execution of this study, understand and discuss the changes and implications that the process disease/hospitalization of the child may bring about in family dynamics, in order to contribute to the elaboration of strategies which assist the coping of this process.

METHOD

This is an exploratory and descriptive study, with qualitative approach, developed in a Pediatric Unit of a Municipal Hospital of the city of Cuité, State of Paraíba, Brazil, between November 2011 and January 2012. This is a reference hospital in the city, the only one that meets the demands of the local population.

The participants were 10 caregivers of hospitalized children, specifically, mothers, randomly chosen, regardless of the clinical diagnosis. For the selection of the subjects, we listed were the following inclusion criteria: caregivers of children younger than 10 years old and be in follow-up with the child for a minimum period of seventy-two hours. We excluded the caregivers who presented some cognitive impairment.

The determination of the number of participants is related to the criterion of data saturation, which occurs when the data collection stops of producing new information or they are redundant.

The delineation of this treatment time was due to the need of the caregiver for knowing the service and the health practices, developed in this monitoring, to better reflect on the impacts that the process of infant hospitalization can cause in the family routine. It should also be noted that the criterion “childish age” was related to the characterization of the age group studied, based on the definition of the World Health Organization (WHO), which considers like child a person younger than 10 years old.

Data collection was performed through individual semi-structured interviews, which were recorded and transcribed by prior permission of the participants. Two guiding questions were formulated that were used for the apprehension of reality, namely: what has changed in the family since the child's...
hospitalization? And how do you realize the family involvement in the division of tasks before the hospitalization process of the child?

The empirical data generated in this study followed the steps recommended by the qualitative method of content analysis in the category of thematic analysis.9 The conduction of this type of analysis involves systematic steps, namely: the encoding of data; the categorization of data and the interaction of the thematic cores. Thus, the analysis began with reading and re-reading of the interviews, seeking the identification of the focus of concern or family difficulty, as well as the skills learned. So, it was possible to identify the categories and integrating them into the thematic core.

Because it is an investigation on human beings, the project was submitted to the Ethics Research Committee of the Faculdade de Enfermagem e Medicina Nova Esperança (CEP / PB) under the Protocol with number 192/11 and CAAE 0192.0.351.00011, as prescribed by Resolution 196 / 96 Brazilian National Health Council. The participants signed a Free and Informed Consent Form, in two copies, staying with one of them and letting the other one in the possession of the researcher responsible. In order to meet the ethical principles, the subjects involved in the study were informed and clarified about the objectives of it. During the presentation of the results, we used the letters "AC" to identify the caregiver, followed by Arabic numerals that represent the sequence of the interviews.

RESULTS AND DISCUSSION

The caregivers of children admitted to the Pediatric Unit of a reference hospital in the municipality of Cuiaté-PB, Brazil, had ages ranging from 19 to 37 years old. Regarding the level of schooling and exercise of work outside the home, it was found that all of them had completed primary school, while two reported not exercising labor activities. About seven had stable marital relationships, presenting family income less than one minimum wage.

Regarding the hospitalized children, it was found that the age group of these was between one and eight years old, five females and five males. The hospitalization period showed variation between three and ten days, whose clinical diagnoses identified included asthma, intestinal infection, dehydration and diarrhea.

A content analysis of the interviews allowed the grouping of participants' perceptions regarding the implications suffered by the family regarding changes in daily routine, comprising three categories: “Changes in daily family life”; Maternal overload in the care for hospitalized child and “The Family as important support network”.

♦ Changes in daily family life

The illness and the hospitalization process constitute a critical situation for human beings, and even having more specificity when it comes to the child audience, because it involves changes and disruptions in their daily lives, as well as the whole family. We observed significant changes in daily routine, requiring rearrangements, adjustments and reorganization of the structure of family dynamics.

The difficulty in managing personal and family obligations with the care required for the hospitalized child is one of the critical aspects indicated by the caregivers of this and of another similar study.10 The disruption of daily life was clarified by caregivers. According to these, the constant stay in the hospital generates imbalance and hinders the maintenance of their daily routine, because the caregiver member, usually the mother, prioritizes assistance to the sick child at the expense of their personal commitments and family demands.

Among the main aspects highlighted by the caregivers regarding the interference of the hospitalization on the family routine is the inability to reconcile the domestic obligations, labor activities outside the home and those ones related to the other children, due to the responsibility be imbued to the primary caregiver.

The remoteness of the home and the concern with the inability to continue the daily activities at home was one of the repercussions reported by participants with regard to the interference in the routine process, due to the hospitalization process of the child. According to them, the decision to stop the domestic activities because their stay in hospital to care for the child was necessary, but it was also very hard and troubled.

[...] It interferes because have to drop out the things at home. You have to come here [...] and the house gets lonely, with nobody (AC3).

[...] It interferes because the house is a mess, for caring. It messed up a lot because just the mother can care (AC6).

[...] It interferes too much. I had to drop out everything at home to be with her. It was hard; it is being very difficult because I had to leave the house services and all. I cannot
Corroborating findings of other research, caregivers of hospitalized children also clarified the interference and disruption in family routine. According to them, the perceived changes in the lives of family members marked this period intensely and the everyday had to be planned according to the child’s treatment. Even performing and recognizing the need of (re) adaptations, which are generated from the new situation, there was a significant commitment in the family habits.

The illness and hospitalization also reflect several feelings in the family, especially among parents who are usually ahead of that process in the role of primary caregivers. The fear of the unknown and, mainly, of the death of their child are feelings experienced by parents who are blaming themselves, believing that somehow could have prevented such condition.

The absence of the home environment for a prolonged period emerge feelings of concern for the other children, who feel abandoned when hospitalized brother/sister. Research shows that the feeling of jealousy generated in the other children, who feel abandoned when they realized the profound dedication and concern for the sick sibling; it is a common situation when a hospitalized child becomes the priority of the family, especially for the parents.

The routine changes because I have not just her. I have two at home and I cannot take care of them right, the other two, because I have to stay here watching her and it worries me very much (AC1).

Oh, my God! It is difficult to understand. I am here concerned with my girl, but I cannot stop thinking about my two boys who are at home. I'm so worried about my boys (AC4).

I have another, but he's thirteen, he knows taking care himself a little, but I'm worried about him because he cannot cook. I get stressed calling to know if he has eaten something (AC10).

A mother’s concern is related to the fragility caused in the family coexistence and limited attention, especially to other children due to the need for continuing monitoring to the child. In this sense, it is clear that, when this type of situation develops itself, as shown in this study, parents experience conflicts and feelings of anguish, suffering and worry; because they become steady presence for the hospitalized child and even perceive themselves like distant people for the other children.

The reports show a sense of impotence about all that is happening in the environment outside the hospital, as the care of the domestic tasks and their children, i.e., the maternal feelings are ambiguous: on the one hand the mother feels the need to accompany the hospitalized child; on the other hand, she resents not being able to assist the others children who stayed at home.

Even recognizing the need for adaptations, which are generated from the new situation, it is understood that there is a mobilization of most family members, however, the centrality of care falls upon, especially, on one of its members - the primary caregiver - usually represented in other studies, as well as in this, by the mother figure, for who is imbued the responsibility for providing physical, financial, emotional and affective assistance.

Despite important changes and achievements of the feminine being in society in recent decades, including in the labor market and as the holder of the financial support of the family, the historical-cultural construct established by society still preserves to the maternal figure the responsibility for the care of the hospitalized child. To her is targeted the role of being main teacher, socializing and caregiver of the offspring. Added to this social context, some authors explain further the maternal empowerment in the act of caring, due to the bonding and the solid relationship established between the binomial mother-child during the pregnancy and the childbirth.

Mothers find themselves interned with the child; remain away from their other children and of the work, exposed to fatigue, to family breakdown and still having their feelings often not prioritized, or even not considered.

Mother overload in the care for hospitalized child

The inclusion of maternal care in case of hospitalization of the child is something noticeable and also identified in other studies. It is understood that the presence of the mother in this circumstance, as well as during painful procedures should be valued, because at this time, child under stress searches in the maternal figure the sensation of security and comfort.

Nevertheless, often, the centralization of
assistance and care directed to the child by the mother causes him/her significant overload of activities and responsibilities. Her attention and integral dedication as the main caregiver compromise the performance of other functions, besides resulting in considerable physical and emotional repercussions.

[…] I have to do everything. […] Here is in the hospital and at home […] I don't stop even for one minute […]. Sometimes I think that I will not get […] without me for everything (AC3).

[…] To be here with her all the time is something necessary, but I know that it is heavy […]. I'm very tired, my back hurts, and I do not know if I can take […] there are times when I get too stressed (AC5).

[…] There are times when I do not think I can take, you know. I cannot think because it is not joke; it is too tiring to stay here day and night (AC8).

Depending on the type of disease, like the chronic illnesses, and the length of hospitalization, the centralization of care can lead to serious health problems to the main caregiver. The joint pain, such as neck pain and back pain, as well as the clinical pictures of insomnia, anxiety, fatigue and depression are some of the complaints most evident among the primary caregivers.16

Besides the aforementioned disorders and motor repercussions, the restraint and social isolation caused due to lack of time for resolution of personal tasks may also contribute to the occurrence of emotional and psychological disorders among the primary caregivers.17

A favorable factor for the occurrence of maternal overload, observed in this study, and also approached by another author16 in relation to the care of the sick child refers to its centralization by the mother in this role. The mother, often, does not see the opportunity to share activities of caring with others people or relatives, because, for many of them, the lack of confidence in delegating child care to another person and the conception that only the mother can take care is quite consolidated between them:

[…] I do not trust leaving him with someone else […] only I know what he wants. Only I have patience with him […] I do not trust at all (AC4).

[…] I have to take care of him, because his father does not know or care as the mother does, right? So, she really has to stay (AC6).

[…] I am the mother. The mother really is who that has to stay […] only the mother cares right. I do not trust leaving her with another person in any way. I'd rather stay here (AC9).

The hospitalization of a child is also aggravated by social and economic context, i.e., when a family member needs to leave, or even, leave the job to accompany the little patient during the hospitalization time. Corroborating the findings of this study, an author16 focuses on that caregivers, commonly represented by the maternal and paternal figures, complain about having to reconcile their stay in hospital, care provided to the child and the work.

Although mothers feel themselves overloaded, they recognize the importance of their presence beside the child during the hospitalization time, which creates in the child a sensation of protection and maintenance of the link with the external environment and family. Such monitoring leads to feelings of worry, fear and insecurity in relation to not carrying out the daily obligations, like the work activities outside the home, which may contribute to even more intense structural problems of family order.

[…] I'm just going home once a day, at night and take a bath and back then […] and that ends up hindering my work (AC1).

[…] It interferes so you know, because, for example, I work, I can no longer go to the service because I'm with her assisting her. The main problem is because I work and I cannot go to work and it will hurt me (AC5).

[…] It very interferes, changes everything. It changes my routine and I cannot work, changes everything (AC8).

[…] It changes because I need to work. Everything is late and I'm worried about it […] I'm afraid of losing my job […] (AC10).

According to other researches,19-20 among the most important changes brought about by the process of hospitalization in the family life of a child are the absence from work, due to the fact that parents prefer to follow up directly the admission of these infants, which in turn, can cause difficulties and financial implications which also bring worry and further intensify conflicts in the family.

♦ The Family as important support network

The families of hospitalized children seek directions to facilitate the coping of disease. It should be noted the importance of support networks as strategies of overcoming or adaptation to the complex and stressful situations. In this context, the help of family and close friends, community, professionals and associations are considered as important support networks in coping with this process.16

Social support includes the support offered by family, as well as other people who are willing
to help, whether through educative, spiritual, social and / or health support.\textsuperscript{15}

The social support offered to the mothers who participated in this study came from close family members, and their maternal grandmothers, were the more participative and active in the division of tasks. It is important, however, noting that the presence of members in coping with family problem was directed to the collaboration of assistance for the healthy children, excluding them from the care of hospitalized child, which remained in the continuing maternal cares.

One way seen as a strategy launched by the mother was related to the search for the participation of other family members in the division of tasks regarding the domestic activities, specifically the contribution of care to the other children. This type of support is configured as an essential help so that they can tackle the problem, by minimizing the emotional distress arising from multiple responsibilities taken on their daily lives.

Close relatives were placed by interviewees as important sources of support in coping with illness and hospitalization of their children. The active participation of these subjects minimized the maternal suffering and consolidated the importance of family bond in this process. However, the concern, by the part of mothers, in relation to the interference in routine of supportive member was also noticeable in their testimonies:

\textit{[...] I have three and they overload my mother who is taking care of them [...] ends up to hamper the work of my mother and it ends up worrying me (AC1).}

\textit{[...] I have a girl who stays with my sister-in-law and I'm worried because I know that it interferes with the routine, it is difficult (AC3).}

\textit{[...] I'm so worried about my three children [...] who gives the food is the aunt [...] the aunt is the one who gets there and here, carrying out food to them three (AC4).}

\textit{[...] The other child is with her grandmother, but still remain that concern [...] I'm calling to know if they have the foods in the correct times (AC7).}

\textit{[...] I have another child who stays with its grandmother; at least she looks good, right? It is better that we [...] but I do not like worry about others (AC8).}

The contribution of support networks is necessary and needs to be strengthened, in order to minimize overload and driving for coping with family breakdown occasioned by the illness of the child or another member who compose it.\textsuperscript{16} The social support networks constitute themselves as strong allies in overcoming the difficulties that can arise throughout the treatment process.\textsuperscript{16}

The family is still the closest support network of the human being and it is characterized by the care of its members, which is considered one of its main functions. Thus, families have assumed a portion of the responsibilities in the care and division of tasks.\textsuperscript{21-22}

\textbf{CONCLUSION}

In the everyday life of families, spaces for illness or hospitalization of any of its members are not usually planned. When it occurs, shows a significant disruption in family dynamics.

It is noticed among the family members a reversal of roles, the need for adjustments to the rules and hospital routines, besides an important social and psychological adjustment, especially by parents, when this process involves a child. The role played by them is very intense, requiring the search for strategies to balance the demands of family and not just of the sick child.

From this perspective, the maternal figure takes on the responsibility of care in a more intense and forceful manner than the other members. It emerges from them the centralizing feeling. But, despite the need for the continuing presence along with the sick child, the mother also understands that this decision brings important physical, emotional and financial repercussions, such interference in domestic routine, work and, especially, in relationships with other children.

The impossibility of balancing the demands of the sick child and the family itself consists in the more worrying conflict for the mother, who experiences a set of feelings of guilt, inadequacy, anxiety and unhappiness.

It is noteworthy to note, however, as a relevant factor to the discussion that family participation, especially of maternal grandmothers, was perceived as an important support network in domestic demands. Usually, when the couple finds difficulties, for minimizing changes caused by the process of hospitalization of a child, they both seek help from relatives, neighbors or friends so they can face the moment of fragility of the family unit.

Even with an understanding of the need of the support from other members of the family, sum up the feelings experienced and mentioned by the mother to the concern about overload of tasks, even though, in most cases, it is like an agreement among its members.
Hospitalization entails not only the emotional and physical weakness of the child, but also affects the everyday and the internal organization of the family. It is essential, therefore, that health professionals involved in the care of children and, especially, the nursing, for being routinely close to that reality, promote the help and necessary support for that moment become less painful and traumatic for the family and the small patient.

REFERENCES


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