

Experience and perception of family members on child's hospitalization in pediatric unit

Vivências e percepções de familiares sobre a hospitalização da criança em unidade pediátrica

Experiencias y percepción de familiares sobre la hospitalización del niño en unidad pediátrica

Tayane Próspero Cardoso^I, Pâmela Roberta de Oliveira^{II}, Rosa Jacinto Volpato^{III}
Vagner Ferreira do Nascimento^{IV}, Elias Marcelino da Rocha^V, Alisséia Guimarães Lemes^{VI}

Abstract: **Aim:** to identify the perceptions experienced by accompanying relatives of children during hospitalization. **Method:** exploratory, qualitative research carried out in a pediatric sector in the interior of Mato Grosso from May to June 2015. Data was obtained through semi-structured interviews with the relatives of hospitalized children and submitted to thematic analysis. **Results:** the mothers were more present as companions during the hospitalization and, in some cases, were the first contact with the pediatrics sector. The physical structure was considered satisfactory. Some of the feelings and attitudes expressed were despair, fear, impotence/helplessness, longing, and hope. **Final considerations:** the study pointed out the need for reception of family members by the entire health team during the hospitalization of the child, while including them in the

^I Enfermeira na Secretaria Municipal de Saúde de Barra do Garças-MT. Pós-Graduada em Saúde Pública com ênfase em saúde mental pelo Centro Universitário do Vale do Araguaia (UNIVAR). Colaboradora no projeto de pesquisa em Saúde Mental da Universidade Federal de Mato Grosso (UFMT), Campus Universitário do Araguaia (CUA). Barra do Garças, Mato Grosso, Brasil. E-mail: tayanepc@gmail.com ORCID ID: <https://orcid.org/0000-0003-2800-7573>

^{II} Enfermeira. Doutoranda no Programa de Pós-Graduação em Enfermagem pela Universidade Federal de Goiás (UFG). Professora Adjunta II no Curso de Enfermagem da Universidade Federal de Mato Grosso (UFMT), Campus Universitário do Araguaia (CUA). Colaboradora no projeto de pesquisa em Saúde Mental da UFMT/CUA. Barra do Garças, Mato Grosso, Brasil. E-mail: pamelaveira@yahoo.com.br ORCID ID: <https://orcid.org/0000-0003-0497-6548>

^{III} Enfermeira. Mestra em Enfermagem pela Universidade Federal de São Carlos (UFSCar). Colaboradora no projeto de pesquisa em Saúde Mental da UFMT/CUA. Barra do Garças, Mato Grosso, Brasil. E-mail: rosamjacinto@hotmail.com ORCID ID: <https://orcid.org/0000-0001-5709-7008>

^{IV} Enfermeiro. Doutor em Bioética pelo Centro Universitário São Camilo (CUSC). Professor Adjunto II no Departamento de Enfermagem da Universidade Estadual de Mato Grosso (UNEMAT), Campus Tangará da Serra. Colaborador no projeto de pesquisa em Saúde Mental da UFMT/CUA. Tangará da Serra, Mato Grosso, Brasil. E-mail: vagnerschon@hotmail.com. ORCID ID: <https://orcid.org/0000-0002-3355-163X>

^V Enfermeiro. Mestre em Ciências da Saúde pela Universidade de Brasília (UnB). Professor Assistente I no Curso de Enfermagem da Universidade Federal de Mato Grosso (UFMT), Campus Universitário do Araguaia (CUA). Colaborador no projeto de pesquisa em Saúde Mental da UFMT/CUA. Barra do Garças, Mato Grosso, Brasil. E-mail: elefamoso@hotmail.com ORCID ID: <https://orcid.org/0000-0002-0086-8286>

^{VI} Enfermeira. Doutoranda em Enfermagem Psiquiátrica pela Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP-USP). Professora Assistente II no Curso de Enfermagem da Universidade Federal de Mato Grosso (UFMT), Campus Universitário do Araguaia (CUA). Coordenadora do projeto de pesquisa em Saúde Mental da UFMT/CUA. Barra do Garças, Mato Grosso, Brasil. E-mail: alisseia@hotmail.com ORCID ID: <http://orcid.org/0000-0001-6155-6473>

treatment process, attending to their physical and psychological needs, and thus contributing to an improvement in the quality of childcare.

Descriptors: Convalescence; Child hospitalized; Pediatric nursing; Family; Pediatrics

Resumo: Objetivo: identificar as percepções vivenciadas por familiares acompanhantes de crianças durante a hospitalização. **Método:** pesquisa exploratória, qualitativa, realizada em um setor pediátrico no interior de Mato Grosso, de maio a junho de 2015. Os dados foram obtidos por meio de entrevistas semiestruturadas com os familiares de crianças hospitalizadas e submetidos à análise temática. **Resultados:** as mães estavam mais presentes como acompanhantes durante a hospitalização e que, em alguns casos, aquele foi o primeiro contato com o setor de pediatria. A estrutura física foi considerada satisfatória. Alguns dos sentimentos e atitudes expressados foram desespero, medo, impotência/incapacidade, saudade e esperança. **Considerações finais:** o estudo apontou a necessidade de acolhimento dos familiares durante a internação da criança por parte de toda a equipe de saúde, incluindo-os no processo de tratamento, atendendo suas necessidades físicas e psicológicas, contribuindo, desse modo, para a melhoria da assistência à criança.

Descritores: Convalescência; Criança hospitalizada; Enfermagem pediátrica; Família; Pediatria

Resumen: Objetivo: identificar las percepciones experimentadas por familiares acompañantes de niños durante la hospitalización. **Método:** pesquisa exploratoria, cualitativa, realizada en un sector pediátrico en el interior de Mato Grosso, de mayo a junio de 2015. Los datos fueron obtenidos por medio de entrevistas semi estructuradas con los familiares de niños hospitalizados y sometidos al análisis temático. **Resultados:** las madres estaban más presentes como acompañantes durante la hospitalización y que, en algunos casos, aquel fue el primer contacto con el sector de pediatria. La estructura física fue considerada satisfactoria. Algunos de los sentimientos y actitudes expresados fueron desesperación, miedo, impotencia/incapacidad, anhelo y esperanza. **Consideraciones finales:** el estudio señaló la necesidad de acogimiento de los familiares durante la ingreso del niño por parte de todo el equipo de salud, incluyéndolos en el proceso de tratamiento, atendiendo sus necesidades físicas y psicológicas, contribuyendo, de ese modo, para la mejoría de la asistencia al niño.

Descriptor: Convalecencia; Niño hospitalizado; Enfermería pediátrica; Familia; Pediatría

Introduction

The pediatric population of the hospital has changed over the past few decades. With the increase in surgeries and outpatient care, a large percentage of children today have more serious and complex problems than those hospitalized in the past. Consequently, these children are subjected to a greater number of invasive and traumatic procedures while hospitalized.¹ In this sense, special attention is necessary for the psychosocial and developmental needs of the child, integrating their family into the care process, since the effects of hospitalization can affect both parties, generating in the children attitudes that see an initial separation of parents, as well as negative behavior and dependence.¹

The presence of an accompanying relative during hospitalization is the child's right, as established by Law 8.069 1990, in the Statute of the Child and Adolescent (ECA), and corroborates to a positive evolution of physical and emotional reactions.² A study showed that the group of children accompanied during hospitalization presented a lower frequency of crying, vomiting, diarrhea, tachycardia, loss of appetite, insomnia, nocturnal enuresis, as well as a lower frequency of indifference, fear, apathy, aggression and irritability when compared to a group of children unaccompanied during hospitalization.³

Although the presence of a family member is essential to accompany the child during hospitalization, it is necessary to emphasize that the family member may experience emotional upheavals during this process. This leads to a disorganization of their biopsychosocial aspects, since hospitalization changes both the child's life and family dynamics, especially the life of the mother who, in most cases, accompanies the child throughout their hospitalization.⁴ Common themes identified as stress factors and causing reactions among the parents whose children were hospitalized, include: feelings of helplessness; a need to receive explanatory information in simple language; and emotional support to deal with fear, face uncertainty and to reestablish their confidence with positive thinking.¹

It should be pointed out that these factors can negatively influence the quality of life of these relatives and also their capacity to provide support and respond to the child's needs during treatment, which can interfere adversely with the hospitalization.⁵

In addition, during hospitalization, there is a rupture in family ties, since the family may not know exactly how to act in an environment with different rules to meet the needs of their sick child, which increases their level of anxiety.⁶ To minimize the stressful effects of hospitalization at patient admission, guidance should be given regarding what is happening with the patient and the required treatment.⁷

Providing information is one of the most important nursing interventions and contributes to reduce anxiety.¹ The family requires clear explanations and guidelines in simple

and understandable language appropriate to their cultural and religious beliefs, including guidance on the normal behavioral reactions of children during hospitalization such as separation, regression, aggression and hostility. In addition, there is a need for information and clarification on hospital rules. Therefore, it is fundamental that the health professionals seek new strategies of action and invest in the provision of guidelines and the clarification of the accompanying relatives' questions, with the objective of minimizing their suffering.⁴

It is important to recognize the essential role of support networks for families during hospitalization and the importance of valuing each of these elements (family, team and spirituality) for the success and optimization of the family coping process.⁸

In this way, the family should be seen as a secondary patient / client, because the accompanying relative feels suspicious and insecure about the reality experienced during the hospitalization and lacks opportunities to talk about the illness, fears, death and, above all, to express their emotions.⁷ Listening in a welcoming and humane way to family members who accompany the hospitalized child maximizes the potential benefits from hospitalization and is an important and fundamental step in planning family-centered nursing care.

The rationale for this study is based on research^{3-5,7-8} which reinforces the essential importance of support networks for families during the child's hospitalization, meeting the demands not only of the patient, but also of the relatives, thereby valorizing an understanding of the subjective experience with effective integral and humane reception of both child and family.^{3-5,7-8}

Scientific evidence indicates that it is the duty of nursing professionals to attend to the biopsychosocial and spiritual demands of the child and family as caused by the disease and hospitalization, in order to strengthen the sense of competence and autonomy of both.^{1,6,9} Hence, the need to develop studies such as this to generate improvements in the quality of care provided, together with dignity and respect for the hospitalized child and family.

Thus, the research question of this study was: how do the family members accompanying children admitted to the pediatric unit perceive and experience hospitalization? The study was designed in accordance with the main objective: to identify the perceptions experienced by relatives of children during hospitalization.

Method

This is an exploratory study with a qualitative approach. The investigation was carried out in the pediatrics sector of a public hospital located in the interior of Mato Grosso State, Brazil.

The hospital unit where this study was performed, attends 100% through the Unified Health System (SUS) and is composed of six sectors, divided into emergency/first aid with 12 beds, hospitalization with 32 beds, maternity with 18 beds, pediatrics with 12 beds, surgical center with three rooms and adult Intensive Care Unit (ICU) with six beds.

All family members who were accompanying children hospitalized in the pediatrics sector from May 1 to June 30, 2015 were invited to participate in the study. After excluding 2 relatives, a total of 10 relatives met the eligibility criteria, namely: 18 years of age or over; to have a family relationship with the child who was hospitalized in the pediatrics sector; and to accompany the child for more than 24 hours after admission. Exclusion criteria were: family members accompanying indigenous children who could only speak their indigenous mother tongue, since the inability to communicate in Portuguese would impede an exchange of information between researcher and participant.

Data collection was performed through semi-structured interviews, composed of questions that included sociodemographic aspects (gender, relationship, age, schooling, marital status, family income and religion), as well as the family's perception of the hospital environment, their expectations regarding the child's prognosis and the feelings they experienced during the hospitalization period.

The interviews were individual, performed in a calm and quiet environment in the pediatric unit, recorded on digital media (voice) and with a mean duration of 40 minutes. The data were transcribed in full by forming a database in Microsoft Word 2010 and stored with a cloud backup system in order to ensure security. These data were submitted to analysis of content and thematic modality, because the set of relations can be graphically presented by means of a phrase whose theme is the unit of meaning that is naturally extracted from an analyzed text.¹⁰

Firstly, the interviews were submitted to several readings with formulation and reformulation of hypotheses and objectives, the parameter being exhaustive reading of the material and initial indications. Secondly, exploration of the material was performed to reach the nucleus of understanding the text, or that is, to find the categories that are organized around significant expressions or words, in function of which the content of a discourse is organized.

During the data analysis, four categories were identified through repetition and relevance criteria, namely: family members' perception related to the hospital environment; feelings and expectations of the family in relation to the child's prognosis; strategies to cope with adversities related to the hospitalization of the child; and changes in the family's roles and lifestyle during the hospitalization.

To guarantee anonymity of the participants, in the reports the letter "F" was used for family members, followed by the Arabic number corresponding to the order interviewed (F1 to F10).

The research complied with the recommendations in Decree 466/2012 of the National Health Council regarding the guidelines and regulatory norms for research involving human beings and was approved, on January 27, 2014, through Resolution 515/705, by the Ethics in Research Committee at the Federal University of Mato Grosso / University Campus of Araguaia.

Results and discussion

Chart 1 shows the characteristics of the children at the time of the interview. The majority of the children were accompanied by their mothers, hospitalized as a result of physical conditions, and presented a mean hospitalization stay of 5.1 days.

Description	Age at admission	Motive for hospitalization	Hospital Stay (days)	Participant: relative interviewed / Code designated
Child 1	3 years	Fractured femur	05	Mother (F1)
Child 2	13 days	Hypoxia	13	Maternal grandmother (F2)
Child 3	7 years	Tonsillitis	02	Mother (F3)
Child 4	5 years	Acute gastroenteritis	03	Mother (F4)
Child 5	9 months	Hydrocephalus	07	Mother (F5)
Child 6	7 months	Pneumonia	02	Mother (F6)
Child 7	6 years	Acute gastroenteritis	03	Mother (F7)
Child 8	6 days	Congenital syphilis	06	Mother (F8)
Child 9	6 years	Pneumonia	05	Mother (F9)
Child 10	8 years	Severe anemia	05	Mother (F10)

Chart 1 - Characteristics of the children hospitalized in the pediatrics sector of a public hospital in the interior of Mato Grosso State, Brazil.

In relation to sociodemographic characteristics of the family members who accompanied the children, it is noteworthy that women (n = 10) were responsible for accompanying hospitalized children, with ages ranging from 23 to 39 years old, educational level from degree to secondary and uncompleted secondary (20%, respectively), married (80%), family income between one and two minimum wages (40%) and ≥ 3 minimum wages (40%), and who declared themselves to be evangelical (60%) or Catholic (20%).

Ruptures in the family bonds and changes in the family role patterns played by the parents can occur during hospitalization of the child.^{1,6} A study¹¹ has reported that a (re)

organization of the family occurs during hospitalization, demonstrating that the woman is assigned to caring for the children, while men, often not presenting the same facility in child care as the mother, assume the role of providing for the family's daily needs.¹²

This fact was also verified in an integrative review¹¹ that identified a certain homogeneity regarding the inclusion of family members who were accompanying the child during hospitalization, comprising samples constituted, mostly, by mothers.

Regarding the presence of mothers accompanying the child during the hospitalization process, the literature indicates that when they stay with their children during hospitalization, they act with the objective of minimizing the child's suffering, by preparing them to undergo the health procedures, in order to prevent trauma. To do this, they bring a pacifier, provide proximity, comfort their children after stress, resist repetitive and often painful procedures, and insist on reporting information about the child. Faced with these attitudes, these children usually cry less, become calmer, improve faster, and feel protected.¹³

From the discourse of the women in this study, it was observed that those with a higher level of schooling demonstrated knowledge of the legal rights conceded to users of the Unified Health System regarding hospitalization of children. Research suggests that the level of schooling correlates with the degree of the family's ability to access and understand information and to acquire new knowledge. In this sense, it is important for the family "to be able to understand the processes of illness and hospitalization through which their loved one is passing, as well as to create appropriate coping mechanisms".^{14: 639} Conversely, it should be emphasized that a low level of education impairs understanding of the preventive or curative actions of the health care.¹⁵

Finally, in this study, there was a prevalence of married women, as was also identified in a cross-sectional study conducted with relatives of in-patients at a university hospital in Pelotas,

Rio Grande do Sul State, Brazil, and predominately with a monthly income of one to two minimum wages.¹⁶

Perception of family regarding the hospital environment

Hospital units, especially in public hospitals, present some singularities that can generate (dis)comfort. Lack of knowledge about the hospital environment engenders fear and anxiety in the companion, causing new social, physical and affective needs and, however simple the motive, hospitalization tends to lead to a negative experience.¹¹ In terms of prior knowledge of a pediatric unit, half of the accompanying relatives reported it was their first experience in the pediatric unit. Regarding the physical structure of the pediatrics sector, differences emerged between the experiences reported. For most of the accompanying relatives, the physical structure offered was evaluated in a positive way, with emphasis on the reception and the care, which, according to their perception, attended the needs of the children; nevertheless, there were also some negative evaluations.

The physical structure is not very good, no. It is leaving much to be desired, as does every public hospital, which attends via SUS. (F1)

Here there is shade and fresh water, a cooling fan day and night, I sleep well! What do I have to complain about? Nothing [...]. (F2)

I like it here, I like it [...] Here it is good, I was well attended. He was very poorly, after he arrived, he took the medicine, became much calmer. (F6)

Well, I had a different impression. When I arrived, I was scared, because I was down there [referring to the emergency department] and there are a lot of people, very busy, very little space, so I thought: Is this the pediatrics here? Then two days later, I was sent here, [...] to pediatrics, when I arrived, I looked at the environment, I said: Wow! Completely different, I liked it very much, I was very well treated, I am really enjoying it, the care rates ten out of ten [...]. (F9)

A study¹⁷ performed in a university hospital in Natal, Rio Grande do Norte State with seventy accompanying relatives of hospitalized children revealed that 45.7% reported a relative delay in care during the hospitalization of the child. However, there was satisfaction regarding the transfer of information about the patient (88.6%), the visiting time (75.7%) and cleanliness of the installations (75.7%). Besides this, 65.7% did not know where to make complaints or suggestions and 44.3% did not know the names of the professional staff who directly attended their child.¹⁷

Furthermore, regarding the impact of the physical structure, research⁴ carried out in Goiás State, described that increased fatigue was related to a lack of adequate physical space for the accompanying relatives to rest, since the mothers need to be continuously alert to any change in the child's clinical condition, in addition to meeting their specific demands for care.

Likewise, a study pointed out that the family should be offered a structure favorable to daily contact with their loved one and the health team, humanizing the hospitalization through participation of the family in caring for the child and minimizing the changes in their daily life.¹⁸ It is also emphasized that an appropriate, humanized and welcoming environment contributes to alleviation of the infants' pain and suffering through all the technological, psychological and recreational resources made available during their care.¹³

Feelings and expectations of family members regarding the child's prognosis

Among the feelings expressed by accompanying relatives related to the child's prognosis, fear was the most often cited by the companions (80%).

I was scared because he was in the incubator four days. I've never been through these experiences. He would stay in the incubator and I would be afraid to take him out of there and he would run out of oxygen and I would lose him. (F2)

Fear can be observed in the accompanying relative's discourse, caused by a lack of understanding of the diagnosis, by the unknown environment, by the need for invasive procedures, by the probability of worsening clinical evolution and even by the possibility of the child's death.

Such feelings were also similar among relatives of in-patients in a pediatric Intensive Care Unit (ICU),¹⁹ and among relatives of children with chronic diseases hospitalized in the pediatrics sector in the South of Brazil.²⁰

It can be seen that when a child is hospitalized, several factors affect the accompanying relatives, causing despair. They describe the circumstance as a very difficult, horrifying and terrifying moment, capable of generating a state of intermittent anxiety.

It is a very great despair. I was desperate when I saw my daughter in this situation, when you get the X-ray result and the doctor tells you that your daughter's leg is fractured, that the bone has split, that this bone has split into two parts. (F1)

Another study explains that the changes presented in the dynamics of families accompanying hospitalized relatives are due to internal needs, emotional balance and external pressures (breakdown of work routine and financial difficulties). All of this interferes with self-care and quality of life and can also generate feelings of depression, anguish, anger, sadness, fear, guilt, and frustration.²¹

Another feeling also verified in this study was confidence, indicated by half of the accompanying relatives. Confidence is represented by trust in the treatment and by the use of various health technologies that aid in the children's recovery. Mothers are confident, especially because they believe that all of this is essential for improving the health of their sick child. However, this confidence is felt together with a certain anxiety, generated by the hospitalization process.

[...] I had a lot of information about the treatment received, the team that takes care of him [...] That`s what gives more confidence because, even though my son's problem was serious, they managed to transmit confidence to me. (F10)

Feelings of confidence, hope and strength were also found among relatives of children attending a rehabilitation institution in São José dos Campos, São Paulo State.²² These feelings become predictors, which seek to alleviate the pain and suffering of family members, while also contributing to their confidence in an improvement in the clinical prognosis of the sick child.¹⁹

Strategies to cope with adversity related to hospitalization of the child

In search of strategies that allow obstacles to be overcome during hospitalization, the role of support providers takes on a primordial condition. In this sense, a study pointed to three main segments as sources of support for mothers in the process of coping with neonatal hospitalization: the health team, the family and spirituality.⁸

The women participating in this research stated that they believed and trusted in God. Religious belief and spirituality have helped family members find peace and comfort in the face of the anxiety and anguish that permeates hospitalization, thereby contributing to overcoming suffering.

I think it's a struggle, but with God's strength, it's the only force I have to be breaking and thinking that the best will always happen. It`s only by believing in God, because the way he was [...]. (F4)

It's a phase that will pass. I believe in God and the God I follow is a living God and I know He will help her to pass this test. (F7)

When a person becomes ill, the family organizes itself and uses differentiated strategies to deal with suffering, among which is spirituality. In this perspective, being associated to a religion seems to represent a support structure for people in coping with their daily problems,

contributing to greater satisfaction with life and the absence of feelings of helplessness and hopelessness.²³

Research⁵ has shown that there are significant differences between non-practicing and practicing participants regarding greater use of the “accountability” coping strategy, which refers to the attitude of blaming oneself for the child`s adverse situation.

Thus, belief and spirituality give meaning to life and those events present in it, reducing the conflicts and feelings of guilt that arise in the face of an unexpected situation and suffering.⁵

It was observed that the accompanying relatives, for the most part, declared themselves to be religious and used their faith in God as a possibility for refuge, focusing on positive thoughts that comforted them and maintaining confidence in a clinical improvement for their children.

Nothing, just faith in God. (F3)

[Crying] [...] Only God and, looking to him, just looking to him I know it's going to be all right, it's already all right, just because I'm seeing that he's alive, that he's well, it's great. (F8)

I pray, right! I pray every day, I place all in the presence of God. My brothers in the church have been coming, praying too. (F9)

Faith in God. I have no religion, but I believe in a living God, a healing God, a God who can do all things. So, regardless of religion, I have my God, I know He hears my prayers and I know He has already healed him. (F10)

A study⁵ carried out with family members of children with leukemia undergoing treatment in the interior of São Paulo State indicated results similar to this, since most participants highlighted spirituality as a crucial tool to assist them in coping with problems. In this way, it can be seen that caregivers have in their spirituality a relief for the suffering caused by their children's illness and, in it, they seek the strength to face the situation and continue to provide care.^{5,11}

Changes in the family's roles and lifestyle during hospitalization

This research has shown that there were modifications in the family routine to adapt to the hospitalization process of the child. These changes in family routine have also been pointed out in other studies, since the presence of a full-time family member in the hospital environment disorganizes and adds difficulties to the management of daily tasks at home or at work.^{4,11,19,21}

From the day he was born, I'm here for him. I left everything behind and came here, thirteen days here and I`ll go many more if I have to. (F2)

My time now is just for him, I'm not working and spend all my time with him, the important thing is his health. (F4)

The narratives confirm that there was a temporary disorganization in the family routine , similar to that observed in other studies,^{4,19-20} which reinforce that after hospitalization of a family member, there is a commitment focused exclusively on the clinical improvement of the child, starting to rely on other family members or their confidence to reorganize their daily tasks and thus facilitate adaptations to the new routine.^{4,19-20}

In the case of mothers, this situation affects their family relationship, their physical and mental health and maintenance of their social network.

[Crying] [...] My husband stays with my other son, I never stayed away, you know, from my other son, my job, my family. (F6)

[...] I no longer see my family, I am always anxious about everything [...]. (F10)

In addition, the lack of support from other family members aggravates the suffering and highlights the social isolation to which these mothers are subjected.^{4,11} In this sense, a feeling mentioned by relatives concerning the altered family role was homesickness for members of the

family, either because they do not live in the same city or because they cannot be present in the hospital environment.

I can't stay calm. I'm very sorry for him and the other, who stayed at home, it's difficult! The other is three years and four months, this one is seven months old
[Crying]. (F6)

[...] I no longer see my husband, I hardly go home anymore, I live here in the hospital. Even when I leave, some phone rings, you already think of the worst and I'll only leave here when he leaves. (F10)

In this form, concerns related to the new routine established causes disorientation among the family members, who are surrounded by doubts due to a lack of understanding about what is happening with other family members. This situation gives rise to feelings of missing loved ones, sadness and anxiety.

Similar data were found in the discourses of other mothers / accompanying relatives who experienced concern for their other children at home, together with tiredness, emotional exhaustion, lack of time for self-care, sadness, anguish, and even blame for their child's illness.^{4,23} Thus, emotional exhaustion and distance from relatives compromises the necessary rest at night, since normal life outside the hospital is in a suspended state.²¹

Accompanying relatives are more likely to become ill than other family members and friends, due to permanence in the hospital environment, denial of self-care, and direct contact with the person requiring care mobilizes inner tensions and leads to psychological suffering.¹¹

Furthermore in this context, it is relevant to consider that children necessitating hospitalization also undergo changes in their routine, since they experience organic and psychological limitations in an unknown environment. Distance from their home and exposure to multiple technical procedures makes hospitalization a time of significant emotional conflict.¹⁸

Thus, the hospitalization of a child translates into a difficult and agitated experience, involving both child and family, who experience significant modifications in their daily routine and interrelationships between relatives.¹⁸

It should be understood that each family develops a unique way of facing hospitalization, leaving no room for standardization or generalization. Hence the need and importance of seeking strategies to enhance knowledge of family dynamics and to understand their behavior and feelings, since this enables the promotion of extensive care to include the family as a whole and not merely the sick child.¹¹

Thus, health professionals should recognize the family member as an integral component in the recovery process and their importance for the child's well-being; thereby offering a more humanized service, capable of supporting the family and including them in the therapeutic plan for each hospitalized child.

Final Considerations

This study showed that mothers are more often the accompanying relative during hospitalization and that in some cases, this was their first contact with the pediatrics sector.

According to the perception of the majority of relatives, the physical structure was considered satisfactory. This is important, since it is necessary for the structure to be planned and well organized in order to ensure the environment is as quiet and welcoming as possible for the child and accompanying relative to live the moments of deep physical and emotional stress generated during hospitalization.

A nuance in the family members' feelings and attitudes towards hospitalization of the child was observed. Negative feelings were translated into despair, fear, and impotence / helplessness. This was to be expected, faced with a sick family member in a situation of delicate vulnerability. At the same time, relatives expressed positive feelings and attitudes such as faith,

trust and hope, showing strength in the face of adversity and conviction in the clinical improvement of the child, even if they find themselves momentarily in a place that causes anxiety and fear. In addition, they stated that they felt confident regarding the care provided for the hospitalized child.

The study also revealed a change in the routine of children and their families during the hospitalization process, which could provoke negative feelings (homesickness, sadness and tension) in the accompanying relatives that can in turn influence the recovery of the sick child.

Thus, the results point to the need for global and humanized reception of the family during the hospitalization process of the child, with the participation of the various members of the multidisciplinary health team in the work of including family in the therapeutic process of treatment, attending to their biopsychosocial and spiritual needs; thus enhancing the benefits of hospitalization and the systematization of nursing care for children and their families.

Finally, as a limitation of the study, it is considered that it portrays only a specific regional reality, and as such it should not be generalized. Therefore, it is necessary to carry out further studies of this nature in other realities of pediatric units on a national and international basis.

It can be affirmed that discussions on this subject are indispensable for the production of knowledge about nursing performance in the care of hospitalized children and their families, in order to provide subsidies for the development of a care model that contemplates, with respect and dignity, those subjectivities and individualities in the broad spectrum of human experiences and responses arising from the hospitalization process.

As an implication for nursing practice, from the realization of this study, it is possible to favor the promotion of a caring, welcoming and humanized care relationship, centered on the hospitalized children and their accompanying relatives, and facilitating and promoting healing, health and quality of life.

References

1. Sanders J. Cuidado centrado na família da criança durante a doença e a hospitalização. In: Hockenberry MJ, Wilson D. Wong, Fundamentos da enfermagem pediátrica. Rio de Janeiro: Elsevier; 2011. p. 675-702.
2. Centro de Defesa dos Direitos da Criança e do Adolescente (CEDECA). ECA 2017 Estatuto da Criança e do Adolescente [cartilha]. Rio de Janeiro: CEDECA; 2017. p. 24-78.
3. Oliveira GF, Dantas FDC, Fonsêca PN. O impacto da hospitalização em crianças de 1 a 5 anos de idade. Rev SBPH [Internet]. 2004 [acesso em 2018 jan 13];7(2):37-54. Disponível em: <http://pepsic.bvsalud.org/pdf/rsbph/v7n2/v7n2a05.pdf>.
4. Santos LF, Oliveira LMAC, Barbosa MA, Siqueira KM, Peixoto MKAV. Reflexos da hospitalização da criança na vida do familiar acompanhante. Rev Bras Enferm [Internet]. 2013 [acesso em 2018 mar 16];66(4):473-78. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672013000400002&lng=pt.
5. Faria AMDB, Cardoso CL. Aspectos psicossociais de acompanhantes cuidadores de crianças com câncer: stress e enfrentamento. Estud Psicol (Campinas, Online) [Internet]. 2010 [acesso em 2018 jan 17];27(1):13-20. Disponível em: <http://www.scielo.br/pdf/estpsi/v27n1/v27n1a02>.
6. Sabatés AL. Reações da criança ou do adolescente e de sua família relacionadas à doença e à hospitalização. In: Almeida FA, Sabatés AL. Enfermagem pediátrica: a criança, o adolescente e sua família no hospital. Barueri: Manole; 2008. p. 49-56.
7. Ferreira PD, Mendes TN. Família em UTI: importância do suporte psicológico diante da iminência de morte. Rev SBPH [Internet]. 2013 [acesso em 2017 out 13];16(1):88-112. Disponível em: <http://pepsic.bvsalud.org/pdf/rsbph/v16n1/v16n1a06.pdf>.
8. Oliveira K, Veronez M, Higarashi IH, Corrêa DAM. Vivências de familiares no processo de nascimento e internação de seus filhos em UTI neonatal. Esc Anna Nery Rev Enferm [Internet]. 2013 [acesso em 2018 mar 16];17(1):46-53. Disponível em: <http://www.redalyc.org/pdf/1277/127728366007.pdf>.
9. Bowden VR, Grennberg CS. Princípios do cuidado centrado na família. In: Bowden VR, Grennberg CS. Procedimentos de enfermagem pediátrica. Rio de Janeiro: Guanabara Koogan; 2017. p. 3-5.
10. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.
11. Albuquerque DB, Morais RCM, Macedo IF, Vieira RFC, Souza TV. A família no cenário hospitalar pediátrico a partir da década de 1990: uma revisão integrativa. Cogitare Enferm [Internet]. 2013 [acesso em 2018 mar 16];18(4):789-95. Disponível em: <http://www.redalyc.org/articulo.oa?id=483649282024>.
12. Nascimento VF, Maciel MM, Lemes AG, Borges AP, Terças ACP, Hattori TY. Percepções de familiares sobre hospitalização no ambiente intensivo. Rev Enferm UFPI [Internet]. 2015 [acesso em 2018 fev 08];4(2):92-9. Disponível em: <http://www.ojs.ufpi.br/index.php/reufpi/article/view/3402/pdf>.

13. Gomes GC, Leite FLLM, Souza NZ, Xavier DM, Cunha JC, Pasini D. Estratégias utilizadas pela família para cuidar a criança no hospital. *Rev Eletrônica Enferm* [Internet]. 2014 [acesso em 2017 fev 05];16(2):434-42. Disponível em: <https://www.fen.ufg.br/revista/v16/n2/pdf/v16n2a21.pdf>.
14. Maruiti MR, Galdeano LE, Farah OGD. Ansiedade e depressão em familiares de pacientes internados em unidade de cuidados intensivos. *Acta Paul Enferm* [Internet]. 2008 [acesso em 2018 jan 05];21(4):636-42. Disponível em: <http://www.scielo.br/pdf/ape/v21n4/a16v21n4.pdf>.
15. Freitas KS, Kimura M, Ferreira KASL. Necessidades de familiares de pacientes em unidades de terapia intensiva: análise comparativa entre hospital público e privado. *Rev Latinoam Enferm* [Internet]. 2007 [acesso em 2018 jan 05];15(1):1-9. Disponível em: http://www.scielo.br/pdf/rlae/v15n1/pt_v15n1a13.pdf.
16. Granzotto JA, Mota DM, Vecchi AA, Santos EO, Gonçalves ER, Silva JBY, et al. Características sociodemográficas maternas e perfil das crianças internadas em um hospital do Sul do Brasil. *Rev Enferm UFSM* [Internet]. 2014 [acesso em 2018 jan 13];4(1):97-104. Disponível em: <https://periodicos.ufsm.br/reufsm/article/view/8466/pdf>.
17. Medeiros YKF, Mororó DDS, Pinto JTJM, Rocha NSPD, Fonseca GS. Quality of care provided to the hospitalized child from the perspective of the companion. *Rev Rene* [Internet]. 2017 [acesso em 2018 mar 17];18(4):499-506. Disponível em: <http://periodicos.ufc.br/rene/article/view/20236/30794>.
18. Nascimento VF, Maciel MM, Terças ACP, Lemes AG, Hattori TY, Demarchi RF, et al. Apreensões e sentimento de fé de familiares no ambiente de cuidado intensivo. *Rev Gest Saúde* [Internet]. 2015 [acesso em 2018 fev 03];6(3):2639-55. Disponível em: <http://periodicos.unb.br/index.php/rgs/article/view/22406>.
19. Pêgo CO, Barros MMA. Unidade de terapia intensiva pediátrica: expectativas e sentimentos dos pais da criança gravemente enferma. *Rev Bras Ciênc Saúde* [Internet]. 2017 [acesso em 2018 fev 03];21(1):11-20. Disponível em: <http://periodicos.ufpb.br/ojs/index.php/rbcs/article/view/23827/16430>.
20. Gomes GC, Mota MS, Moreira MAJ, Jung BC, Xavier DM, Silva CD. (Des)preparation of family member for the care of children with chronic illness. *Rev Enferm UFPI* [Internet]. 2017 [acesso em 2018 jan 08];6(1):47-53. Disponível em: <http://www.ojs.ufpi.br/index.php/reufpi/article/view/5737/pdf>.
21. Passos SSS, Pereira Á, Nitschke RG. Cotidiano do familiar acompanhante durante a hospitalização de um membro da família. *Acta Paul Enferm* [Internet]. 2015 [acesso em 2018 mar17];28(6):539-45. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002015000600539&lng=en.
22. Silva CCB, Ramos LZ. Reações dos familiares frente à descoberta da deficiência dos filhos. *Cad Ter Ocup UFSCar* [Internet]. 2014 [acesso em 2017 dez 09];22(1):15-23. Disponível em: <http://www.cadernosdeterapiaocupacional.ufscar.br/index.php/cadernos/article/view/537/483>.
23. Medrado EDD, Whitaker MCO. Experiências de familiares durante a hospitalização de sua criança/adolescente em uma unidade pediátrica. *Rev Soc Bras Enferm Ped* [Internet]. 2012 [acesso em 2018 jan 13];12(2):123-30. Disponível em: https://sobep.org.br/revista/images/stories/pdf-revista/vol12-n2/Art_4_Experiencias_Evelin.pdf.

Contributions of the Authors:

1 – Tayane Próspero Cardoso

Concept and project; analysis and interpretation of data; writing of article and critical review of intellectual content; and final approval of the version to be published.

2 – Pâmela Roberta de Oliveira

Analysis and interpretation of data; writing of article and critical review of intellectual content.

3 – Rosa Jacinto Volpato

Analysis and interpretation of data; and writing of article.

4 – Vagner Ferreira do Nascimento

Analysis and interpretation of data; writing of article; and critical review of intellectual content.

5 – Elias Marcelino da Rocha

Analysis and interpretation of data and writing of article.

6 – Alisséia Guimarães Lemes

Concept and project; analysis and interpretation of data; writing of article and critical review of intellectual content; and final approval of the version to be published.

How to cite this article

Cardoso TP, Oliviera PR, Volpato RJ, Nascimento VF, Rocha EM, Lemes AG. Experience and perception of family members on child's hospitalization in pediatric unit. Rev. Enferm. UFSM. 2019 [Access at: 2019 jun 15];vol ex:1-21. DOI: <https://doi.org/10.5902/2179769231304>