

ORIGINAL ARTICLE

CHILDREN'S EXPERIENCE ON HOSPITALIZATION: SOCIOLOGY OF CHILDHOOD APPROACH

Enoque de Oliveira Carvalho¹, Luana Nunes Lima², Manuela Costa Melo³, Lara Mabelle Milfont Boeckmann⁴, Valéria Batista da Silva⁵

ABSTRACT

Objective: to gain insight into the experience of hospitalization from the children's perspective.

Methods: Qualitative study with 16 hospitalized children conducted between March and July 2018. Individual interviews and notes from the field diary were used for data collection. The narratives were coded and grouped by similarity, and content analysis was used. The study was carried out in a pediatric unit of a general hospital from Distrito Federal.


Results: Three themes that expressed children's knowledge about the understanding of the disease, the daily routine of hospitalization, the experience related to the procedures undergone by the children and the recognition of the importance of the activities developed in the playroom emerged.


Conclusion: The children described an environment that differs from their family routine and with several stressors inherent to hospital care. Thus, reflections on the performance of health professionals can be made and the scope of potential interventions can be maximized, from the perspective of comprehensive care centered on the children and their families.


DESCRIPTORS: Pediatric Nursing; Child Care; Child Health; Qualitative research; Hospitalized Child.


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¹Nurse. Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

²Nurse. Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

³Nurse. PhD, Nursing. Nursing Professor from Escola Superior de Ciências da Saúde. Brasília, DF, Brazil. 

⁴Nurse. PhD, Nursing. Nursing Professor from Universidade de Brasília. Brasília, DF, Brazil. 

⁵Nurse. Master degree in Nursing. Nurse in direct patient care from Secretaria de Estado de Saúde do Distrito Federal. Brasília, DF, Brazil. 

EXPERIÊNCIA DA CRIANÇA SOBRE A HOSPITALIZAÇÃO: ABORDAGEM DA SOCIOLOGIA DA INFÂNCIA

RESUMO

Objetivo: conhecer a experiência da hospitalização na perspectiva da criança.

Métodos: estudo qualitativo, realizado entre março e julho de 2018, com 16 crianças hospitalizadas. Para coleta, utilizou-se entrevista individual e anotações do diário de campo. As narrativas foram codificadas e agrupadas por similaridade, empregou-se análise de conteúdo. Realizado em unidade pediátrica de um hospital geral do Distrito Federal.

Resultados: emergiram três temáticas que evidenciaram o conhecimento das crianças acerca do entendimento da doença, o cotidiano da hospitalização, a experiência com os procedimentos aos quais foram submetidas, e a valorização das atividades desenvolvidas na brinquedoteca.

Conclusão: as crianças narraram ambiente diferente de seu cotidiano familiar e com diversos fatores estressores inerentes ao cuidado hospitalar. Dessa maneira, pode-se gerar reflexões sobre a atuação e aumentar o escopo de possibilidades de intervenções, na perspectiva do cuidado integral centrado na criança e sua família.

DESCRITORES: Enfermagem Pediátrica; Cuidado da Criança; Saúde da Criança; Pesquisa Qualitativa; Criança Hospitalizada.

EXPERIENCIA DEL NIÑO ACERCA DE LA HOSPITALIZACIÓN: ABORDAJE DE LA SOCIOLOGÍA DE LA INFANCIA

RESUMEN:

Objetivo: conocer la experiencia de la hospitalización en la perspectiva del niño.

Métodos: estudio cualitativo, que se realizó entre marzo y julio de 2018, con 16 niños hospitalizados en una unidad pediátrica de un hospital general de Distrito Federal. Para la obtención de los datos, se utilizó entrevista individual y apuntes del diario de campo. Se codificaron las narrativas y se las agruparon por semejanza, empleándose el análisis de contenido.

Resultados: resultaron tres temáticas que evidenciaron el conocimiento de los niños acerca del entendimiento de la enfermedad: el cotidiano de la hospitalización, la experiencia con los procedimientos a los cuales fueron sometidos, y la valoración de las actividades desarrolladas en la ludoteca.

Conclusión: los niños relataron ambiente diferente de su cotidiano familiar y con diversos factores de estrés inherentes al cuidado hospitalario. Así, se pueden generar reflexiones sobre la actuación y ampliar el alcance de posibilidades de intervenciones, en la perspectiva del cuidado integral centrado en el niño y su familia.

DESCRIPTORES: Enfermería Pediátrica; Cuidado del Niño; Salud del Niño; Investigación Cualitativa; Niño Hospitalizado.

INTRODUCTION

Hospitalization of children may be an adverse, stressful and frightening experience for them and for their families, which can alter their physical, mental, moral, spiritual and will impact their adulthood⁽¹⁾.

It is one of the first crises to be faced by children, given their limited defense mechanism. It is believed that health professionals can provide care focused on the needs of the children and their families, so that they could learn to deal with all the possible changes caused by disease and hospitalization⁽¹⁻³⁾.

There are approximately 35.5 million children in Brazil. Over the past five years, there were 9,049,042 hospitalizations of children between zero and 14 years of age in the country, considering all causes, including multiple hospitalizations of the same child. In the Distrito Federal alone there were 239,689 hospitalizations, which accounts approximately for 23.14% of the total hospitalizations in the referred period^(4,5). The relevance of these data reinforces the fact that the hospital scenario impacts the children's experiences, since the hospitalization itself and the various interventions to which these patients are submitted abruptly lead to a sudden change in their routine.

A review of the Brazilian literature on the topic, including studies published over 16 years on indicators of hospital stress in pediatric care, highlighted the need for interventions that improve communication and quality of life in the hospital environment, focusing on the needs of the families, offering psychological support and encouraging games for children, due to its beneficial effect. The research also suggested that further studies on hospitalization and its consequences for children are needed, in order to develop appropriate strategies⁽⁶⁾.

Studies on the hospitalization of children involve the impacts caused by their removal from the family environment, living in an unknown environment, the lack of recreational activities they are used to and having to undergo invasive procedures. The studies highlight the biological effects - changes in brain development and functioning, and increased risk of developing chronic diseases, such as hypertension and diabetes mellitus; the psychological effects - development of anxiety, depression and disorders such as mood, panic, separation anxiety, post-traumatic and obsessive compulsive disorders; the social effects - a developmental regression in the way children relate and develop their skills of interaction and belonging to a social network; and cultural effects.

The complexity of the hospital environment and the knowledge gaps in the theme^(7,8) justify the need to gain insight into the hospitalization experience from the children's perspective, in an attempt to mitigate the effects of hospitalization and promote comprehensive care. Therefore, the study aims to know the experience of hospitalization from the children's perspective.

METHOD

Exploratory descriptive study with a qualitative approach that uses the Sociology of Childhood⁽⁹⁾ as a theoretical framework and the Technique of Narrative⁽¹⁰⁾ as methodology, and favors "learning" to "listening" to children.

Sociology of Childhood⁽⁹⁾ is a movement of Social and Human Sciences that values children as a central object of their research. In Brazil, this movement started in the 20th century and contributes to the perception of children as social actors, through the development of studies on childhood, from the perspective of children, not adults.

The study was carried out in a pediatric unit of a general hospital linked to the State Department of Health of Distrito Federal, which belongs to the Coordination of the Regional Health Service and assists in average 90 children per month. This health unit is intended for the care of children and adolescents from zero to 12 years of age, with clinical diseases, especially those involving respiratory and gastrointestinal problems, and also those with special health needs.

The selection of the participants was made by intentional sampling during the time of data collection. The inclusion criteria were children hospitalized for more than three days, aged between four and 12 years old, as in this age group children are able to make correlations between what they experience and their reality⁽¹¹⁾. Exclusion criteria were children with unstable and or severe clinical status.

The study was carried out between March and July 2018. Individual interviews and field notes were used in data collection. To enhance the children's verbal narrative, the researchers developed an interview guide containing a semi-structured and an unstructured part with open-ended and subjective questions. The structured guide covered the children's socio-demographic and psychosocial aspects: age, sex, date of hospitalization, length of hospitalization, diagnosis or diagnostic hypothesis, child's education, place of residence. The unstructured part of the interview contemplated the central question about the children's experiences during hospitalization, which answers the following questions: how do you feel here in this hospital? What has changed in your life with the hospitalization?

To ensure anonymity, the children were identified by the names of children's characters, chosen by each of them, followed by their ages. The interviews lasted approximately 15 minutes, were recorded and transcribed, and field notes were enclosed in parentheses. During the interviews, there was little variation in the narratives, which resulted in data saturation⁽¹²⁾. Therefore, there was no need for other interactions with the participants.

It should be noted that the interviews and field notes were conducted by two students who received Scientific Initiation scholarships and accompanied by researchers with experience in qualitative research. For the development of the study, the students were trained for the two meetings, which addressed the reception, the interviews with the children and their respective family members, the formulation of the guiding questions, the relevance and the completion of the field diary.

After the data were transcribed, the narratives were grouped, read, reread and reorganized, and then the data was classified and analyzed according to the thematic modality, based on Content Analysis⁽¹³⁾. The analysis consisted of three steps: pre-analysis; exploration of the material, coding, classification and categorization; and finally, the treatment of results and interpretations. The peculiarities of care for hospitalized children were identified as pre-categories. Subsequently, the data was cross-checked to ensure the reliability of the process of emergence of the thematic categories.

The research project was approved by the Research Ethics Committee of the Teaching and Research Foundation in Health Sciences of Distrito Federal, under protocol No. 2,514,332. All children signed the assent form, and their parents signed the free and informed consent form.

The Standards for Reporting Qualitative Research (SRQR)⁽¹⁴⁾ was used to ensure the scientific rigor of the research.

RESULTS

Sixteen (16) participants were interviewed, with ages ranging from four and 12 years. Of these, 10 (62.5%) were female and six (37.5%) were male individuals. Regarding the cause

of hospitalization, diagnosis by body system: endocrine system (two/12.5%), respiratory (four/25%), neurological (two/12.5%), integumentary (one/6.25%) and gastrointestinal (two/ 12.5%); or the causes were related to surgery (one/6.25%), neoplasms (one/6.25%) and others (three/18.75%) that included a diagnosis to be clarified: unspecified fever, diagnostic hypothesis of idiopathic thrombocytopenic purpura, and unknown diagnosis. Of the total participants, 10 (62.5%) lived in administrative regions of the Distrito Federal (DF); six (37.5%) lived in the Economic Development Integrated Region of the DF and Surroundings (RIDE). All children attended school.

The narratives were analyzed and organized according to three thematic categories: Moment of hospitalization; Hospital dynamics; and Going back home.

Moment of Hospitalization

This first thematic category allowed the identification of two subcategories: pre-hospital and hospital experience. The first category depicts the children's experiences of the events that preceded their hospitalization. These are narratives about the expectation of their experiences, reports of hospitalizations of people they know and the process of falling ill, explaining the cause of hospitalization.

I came here to the hospital because my mom brought me. Because I was sick. I can't remember feeling pain. I don't know what my illness is. (Magali, 4 years old)

My friend was operated on the stomach, she said it was very bad. Because nobody treated her properly, she was treated like an animal. She said it sucked. (Buttercup, 8 years old)

I thought that being hospitalized was worse. That I was going to be full of holes in my body (Brave, 10 years old)

Regarding the second subcategory, hospital experience, feelings about hospitalization were reported, according to the following units of significance: negative feelings and positive feelings. The feeling was defined as the sensations perceived by the children regarding hospitalization.

I was afraid of I don't know, of being poorly treated. (Buttercup, 8 years old)

I was afraid to die without being able to speak to my mother. (Casper, 10 years old)

[When I arrived] I thought I was dying, then I felt better. (Iron man, 6 years old)

Now I'm fine, when I arrived here I felt bad, I was sick. (Spider-Man, 8 years old)

Hospital dynamics

In this second thematic category, the hospital dynamics of the children's experiences with the relationships built during hospitalization and the activities developed are presented. Thus, three subcategories were identified: the care provided by the multidisciplinary team, the presence of other people in the ward, and the activities performed by the children during hospitalization.

In the first subcategory "relationship established between the professionals and the child", the unit of significance called affection, which refers to feelings of satisfaction and dissatisfaction, was identified.

The people who work here are nice. There's nobody boring here. The professionals give us the medicines and talk about the pain. The nurse gives the medicine and the doctor talks about the pain. The nurse is annoying when she tells us not to eat, not to eat anything today. There are more doctors here than nurses. (Flash, 10 years old)

What makes it bad to stay here is the needle. This is already my third hole. (...) I say it hurts, and they look into my eye and inject that stuff even faster. Then I move my eyes to the side, they pierce me with the needle and I cry. (Brave, 10 years old)

The second subcategory concerns the presence of other people in the ward, such as the companion of the hospitalized child and the other children who share the same space.

Here I play, have dinner, I can take the things that are on my bed, in the same room where other children and my father are. If my dad didn't stay with me, I wouldn't go to sleep, I would be walking. Since I arrived at the hospital, my father has taken care of me. (Spider-Man, 8 years old)

I didn't become friends with any other children here, because I didn't want to. I already have friends outside the hospital. I don't want to make friends here. (Buttercup, 8 years old)

Regarding the third subcategory, the activities performed by the children involved the procedures to which they were subjected, as well as the activities developed in the playroom. Regarding the procedures, the narratives expressed the influence of the environment on the participants, particularly the learning of the terminology and jargon used in the health care environment, as well as their routine and standardizations.

People come and say that they will listen to my heart. This is to hear the heartbeat. (...) This is called serum and is used to apply the medication on my body. (Ant-Man, 10 years old)

They put a drain on me and it can't be moved. It has a tap and a place to store what comes out of the hose I had to sleep for them to put the drain on me, and when I woke up I had the drain on the bed. Nobody told me they were going to put the drain on me. (Iron man, 6 years old)

These clothes I'm wearing are from the hospital, and the doctor lent them to me. [...] When we get sick, we have to wear hospital clothes. I don't like them, because they are ugly, I like mine. (Mulan, 5 years old)

In the playroom, children played and also performed school tasks with the school pedagogue. When they played, the children were immersed in their playful world, as a natural way of detaching themselves from their condition and the hospital environment. The narratives throughout the games showed the need for some children to control that environment, and the games revealed a high degree of importance for their social life.

Let's make a tower, shall we? This game is very cool! (Popeye, 4 years old)

I love to play cooking. [...] I'm going to do a lot today, heat the oven. Take the chocolate icing, you make the icing. [...] I have to do the dishes. I have to do everything. I love to play, but now I have a lot of things to do. (Magali, 4 years old)

Going back home

Children are sensitive to sudden changes in the environment during the hospitalization process, and reports have shown that they do not completely disconnect from their daily lives outside the hospital environment and wish to go back home. This subcategory comprises the family system, domestic animals and the family routine, as well as narratives about friends and hobbies.

At home I have my toys, my clothes. (Spider-Man, 8 years old)

I miss my grandmother. (Little Red Riding Hood, 5 years old)

Mom also takes care of me at home. [...] I have a cat, his name is cute. My cat did not come here because he is not sick. (Magali, 4 years old)

I want to go home because I'm staying here all the time. (Popeye, 4 years old)

I like to play and go to the library and fight karate, I achieved the gray belt. (Flash, 10 years old)

DISCUSSION

The mechanisms for coping with stressful situations are acquired after experiences of crisis⁽¹⁵⁾. Repeated exposure to stress can cause structural changes in the prefrontal cortex and cause problems in the processes of attention and memory, as well as emotional disorders during childhood and, consequently, in adulthood⁽¹⁶⁾. Therefore, the Sociology of Childhood reinforces children's reports, by valuing them as a central object of research, i.e., not only talking about them, but above all, talking to them.

In some cases, children do not understand the reason for hospitalization, because of their degree of development, limited perception of the disease, or because they have received little information on the subject⁽¹⁷⁾. However, it is known that the more information children have, the lower their stress and fear, and the greater their ability to face hospitalization in a positive way⁽¹⁸⁻²⁰⁾.

In the first thematic category corresponding to the "moment of hospitalization", the children reported their expectations about hospitalization based on what they had already heard about the hospitalization experience. It is known that throughout the child's development, their activities take on their own meanings in a system of social behavior and, when these activities concern one particular object, they are modified by someone else's view⁽²¹⁾.

Regarding the health-disease process, it should be said that it is not uncommon for children to reveal feelings of apprehension and uncertainty⁽²⁰⁾. They are presented in the subcategory "hospital experience". However, children's development, whose processes operate from the children's interaction with people in their environment, is based on learning. Therefore, the associations of the disease process made by children are intrinsically linked to their environment and to the interpretations of the reality of the people with whom they live.

Children associate hospitalization to a treatment they need, which despite being unwanted, generates the hope of going back home⁽¹⁵⁾, and the feelings expressed by the children are positively revealed. However, negative feelings are more frequent in the narratives. Fear, as a negative feeling present in this first category, besides its ability to modulate and interfere with painful sensations, affects quality of life, due to the constant fear of the unknown, the lack of social interaction, the procedures performed, and even death.

In the second thematic category on "hospital dynamics", the daily life and the relationships built by the children, during their hospitalization, together with their companions, other hospitalized children and health professionals, are shown. When children are hospitalized, they leave their family context and are subjected to the routine of the health team. In this context, communication - verbal, non-verbal and abstract - is inserted as the basis of the relationship between the child and the professional, and gestures that demonstrate empathy and affection are used in the health service as a strategy to establish trust and make the children happy.

Furthermore, some relationships are perceived as unsatisfactory when, for example, the children believe that health professionals feel pleasure in performing invasive and painful procedures on them⁽¹⁷⁾. Thus, health professionals must explain in accessible and clear language the need to perform that procedure, and how it will be performed, so that

the children do not develop negative feelings regarding hospitalization.

The hospital routine often proposes exposure to invasive and painful procedures - puncture of venous access, insertion of drains, among others, which trigger stress reactions and feelings of helplessness, strangeness, fear and loss of control. Therefore, activities that reduce stress and suffering must be developed, as well as assessment methods and intervention strategies to prevent the aggravation of pain and anxiety in subsequent procedures⁽¹⁶⁾. Some intervention strategies include visit during free time and performing diversified activities in the playroom.

For children, playing is more than seeking an occupation; it is a necessity, it is their work, the means by which they develop physically, emotionally, cognitively and socially⁽¹⁹⁾. Playing is inserted in this context: the narratives showed playing as a possibility to exercise control of the situation, since hospitalization can cause a sense of loss in the children and generate stress⁽¹⁵⁾.

The greater the children's understanding of the situations experienced, the less the suffering and, consequently, the better they will cope with this situation. So, other interventions, such as the use of therapeutic toys, may be useful, and health professionals must explain to the children the procedures before they are performed, to relieve their anxiety and stimulate their collaboration^(19,20).

The therapeutic toy is a structured intervention that can help children deal with the fear of the unknown caused by the hospitalization experience and cope with this situation. It has the following modalities: to instruct, to dramatize and to enable physiological functions. Its purpose is to prepare and inform the children about procedures to be submitted; it allows them to express their feelings and overcome unpleasant situations. Furthermore, in situations of permanent changes in prolonged treatments, it allows children to be trained in their new life conditions⁽¹⁹⁾. Therapeutic toys can be used by any child, especially at preschool and school age, and the nursing team of the pediatric area that assists hospitalized children and their families is responsible for providing children's access to these toys⁽²²⁾.

In addition to factors related to the illness process itself, hospitalized children undergo a sudden change, as they are removed from their families, friends and hobbies. Therefore, this phenomenon generates states of crisis, stress, with moments of homesickness⁽¹⁴⁾. The thematic category "going back home" emerged in this context.

The feeling of homesickness, very common in the narratives, arose because the children were removed from their usual environment and taken to an environment where they are isolated from the outside world and inserted in a scenario full of routines, which they may or may not be able to understand⁽¹⁵⁾. Finally, there were feelings of sadness, lack of courage and unwillingness to face hospitalization, which can be maximized by a feeling of helplessness and lack of control.

During hospitalization, it is not uncommon for children to transfer their emotional needs to the professionals who work there. Thus, special attention and active listening are essential, so that the impact of negative emotions is minimized⁽²³⁾. Therefore, the aspects that pervade the children's universe during the hospital routine must be known by health professionals, so that they are able to develop an assertive and accurate communication, using language accessible to children, to reduce their anxiety⁽²⁰⁾.

This study has two limitations. The first is the fact that it was performed in a single inpatient unit, a public hospital, which may not be representative of a wider reality. Therefore, the study cannot be generalized and must be replicated in other pediatric inpatient units, to learn the experience of other participants. The second limitation is the broad age range of the participants (between four and 12 years of age), who, therefore, are at different stages of cognitive development. However, despite the children's different age groups, their perceptions of the hospitalization experience were similar.

FINAL CONSIDERATIONS

Understanding the phenomenon of hospitalization, from the perspective of pediatric clients, allowed us to highlight the negative aspects that impact their lives, when these individuals deal with an environment different from their daily lives and with several stress factors inherent to hospital care, and the results obtained must be considered by health professionals. The positive aspects were also revealed, such as games, visits, affection and adequate communication to minimize children's suffering and thus promote strategies based on their needs.

These findings demonstrate that children are attentive to all the processes to which they are submitted, seek to understand and explain the experience lived and that their daily routine prior to hospitalization interferes, above all, with their hospital experiences. Therefore, health professionals must pay attention to these changes, so that children and their families can receive comprehensive care that takes into consideration their expectations and desires.

The findings of this study contribute to the understanding of the children's universe during the experience of hospitalization, particularly by considering strategies that minimize the negative impact and promote an assertive communication between health professionals and children. Such findings can significantly contribute to the clinical practice of nurses, by allowing reflections on their performance and increasing the scope of intervention possibilities from the perspective of comprehensive care centered on the children and their families.

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Corresponding author:

Manuela Costa Melo

Escola Superior de Ciências da Saúde

Conjunto A Bloco 01 - 70710-100 – Brasília, DF, Brasil

E-mail: melomanuela91@gmail.com

Role of Authors:

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