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EXPERIÊNCIAS FAMILIARES DURANTE A HOSPITALIZAÇÃO INFANTIL: UMA REVISÃO INTEGRATIVA

Family experiences during child hospitalization: an integrative review

Experiencias familiares durante la hospitalización infantil: una revisión integrativa

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ABSTRACT

Objective: The study's purpose has been to unveil what has been produced by nursing professionals concerning the experiences faced by hospitalized children family members. **Methods**: It is an integrative literature review, which was performed in January 2018 based on the search in the PubMed, *LILACS* and SciELO databases, using the descriptors: hospitalized child, family, nursing. The selected studies were published from 2011 to 2017 in English, Portuguese, and Spanish languages. After data analysis, 31 studies were selected. **Results**: The following categories were elaborated: adaptation of the family routine, withdrawing away from the rest of the family and healthy children; maladaptation due to physical structure and lack of hospital comfort; medical procedures, nursing and strict rules/routines. **Conclusion**: Children hospitalization impacts significantly on their family life, affecting their family relationships, their physical and mental health, and the maintenance of their social network.
Descriptors: Hospitalized children, family, nursing, family experience, pediatrics.

RESUMO

Objetivo: Desvelar o que vem sendo produzido pela enfermagem sobre as experiências enfrentadas pelos familiares de crianças hospitalizadas. **Método:** Revisão integrativa a partir da busca nas bases PubMed, LILACS e na biblioteca Virtual SciELO, utilizando os descritores: *hospitalized child, family, nursing,* durante o mês de janeiro de 2018. Selecionaram-se estudos publicados entre 2011 e 2017, nos idiomas inglês, português e espanhol. Após a análise dos dados, foram selecionados 31 estudos; **Resultados:** Elaborou-se as categorias: adaptação da rotina familiar; afastamento do restante da família e dos filhos sadios; desajuste diante da estrutura física e falta

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de conforto hospitalar; procedimentos médicos, enfermagem e normas/rotinas rígidas. **Conclusão:** A hospitalização de uma criança interfere significativamente na vida dos familiares, afetando seu relacionamento familiar, sua saúde física e mental e a manutenção de sua rede social.
Descritores: Criança hospitalizada; Família; Enfermagem; Experiência familiar; Pediatria.

RESUMEN

Objetivo: Desvelar lo que viene siendo producido por la enfermería sobre las experiencias enfrentadas por los familiares de niños hospitalizados. **Método**: Revisión integrativa a partir de la búsqueda en las bases PubMed, LILACS y en la biblioteca Virtual SciELO, utilizando los descriptores: hospitalized child, family, health, durante el mes de enero de 2018. Se seleccionaron estudios publicados entre 2011 y 2017, en los idiomas Inglés, portugués y español. Después del análisis de los datos, se seleccionaron 31 estudios; **Resultados:** Se elaboraron las categorías: adaptación de la rutina familiar; alejamiento del resto de la familia y de los hijos sanos; desajuste ante la estructura física y falta de confort hospitalario; procedimientos médicos, enfermería y normas / rutinas rígidas. **Conclusión**: La hospitalización de un niño interfiere significativamente en la vida de los familiares, afectando su relación familiar, su salud física y mental y el mantenimiento de su red social.
Descriptores: Niño hospitalizado; La familia; Enfermería; Experiencia familiar; Pediatría.

INTRODUCTION

The child's need for hospitalization generally presents itself as a time of difficulties and vulnerabilities for both the child and their family, who now need help to adapt to the situation experienced.[1-2] This is configured as a potentially traumatic experience, which can experience fear and insecurity in the process of illness and hospitalization of a child, requiring health professionals the ability and humanization to make it possible to minimize suffering during this process.[3]

The family is understood as a unit that must be integrated into childcare, especially in hospitalization situations due to the child's ability to generate stability and balance in the face of changing environments. Therefore, including the family in childcare is a way to humanize the hospital environment, helping them to accept and adapt the condition to which the child is being subjected, reducing their feeling of abandonment concerning other family members and facilitating their relationship with the health team.[4]

The participation of parents in the health care of hospitalized children is essential, highlighting the hospital as an unfamiliar environment and that brings changes in parental roles.[5] Despite the knowledge regarding the need for the family to remain fully in the hospital, daily professional actions, combined with hospital rules and routines, have removed the family from the health/disease and childcare process, given the insufficient conditions that are offered in the hospital institutions for family members.[6]

Accordingly, the role of the nursing team is important to recognize parents as a constant in the child's life, so that they support, respect, and encourage their active participation in the hospitalization process, relating sensitivity to theoretical knowledge, with the purpose to offer qualified and humanized assistance.[7]

The nursing team must pay attention to the experiences faced by family members of hospitalized children to improve the care directed to them during the process. So, the guiding question was defined: What does nursing have been producing about the experiences faced by family members of hospitalized children? Hence, this article means to unveil what has been produced by nursing professionals concerning the experiences faced by hospitalized children family members.

METHODS

It is an Integrative literature review, with a broad methodology that allows the search, critical evaluation, and synthesis of evidence that aims to promote an impact on clinical practice. Thus, different research and methods can be included simultaneously, allowing the researcher to have an understanding of the phenomenon studied and identify aspects that require further research.[8]

In its development, six steps were followed: definition of the theme and elaboration of the guiding question, establishment of criteria for inclusion and exclusion of studies, search in the literature; definition of the information to be extracted from the selected studies and their categorization, evaluation of the included studies; interpretation of results and presentation of the review and synthesis of knowledge.[9]

To lead the study, the guiding question was defined as: what has nursing been producing about the experience of family members of hospitalized children? The integrative review included studies carried out with human beings, published in full between the years 2011 and 2017, in English, Portuguese, and Spanish, and which, regardless of the outline, addressed the highlighted topic, with abstracts available in the following databases: the *Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS)* [Latin American and Caribbean Literature in Health Sciences]; the National Library of Medicine (PubMed); and the Scientific Electronic Library Online (SciELO). Literature reviews, letters to the editor and opinion of authorities, and expert committee reports were excluded.

For the articles' selection, the following descriptors were used: hospitalized, children, family, and nursing; such descriptors were previously consulted in the dictionaries Medical Subject Headings (MeSH) and Descriptors in Health Sciences (DeCS). It is noteworthy that "AND" was used between the descriptors as a Boolean operator. Only articles produced by nurses were selected.

The databases were consulted in January 2018. Studies were read and analyzed by two reviewers, with a third being consulted for cases in which doubts regarding the inclusion of studies arose. And, to identify other related studies, a manual search of articles was carried out in the references of the studies selected for full analysis.

It was classified for a better understanding of the integrative review, aspects considered relevant as the type of publication; methodological details, sample, year of publication and results, and level of evidence. This made it possible to individually evaluate the studies and making it possible to identify similarities and differences between them.

After combining the descriptors, 13 articles emerged from the SciELO database, nine of which were included (two were excluded because they did not address the proposed theme; two, because in their results show the perspective of professionals and not family members), from *LILACS* emerged 133 articles of which 14 included (81 were excluded for not having been published in the last five years, 10 for presenting in their results the perspective of nursing professionals and 18 for not covering the proposed theme), and from PubMed emerged 121 articles, of which eight were included, six were excluded due to duplication with the other databases, 77 for not covering the proposed theme, 13 for presenting clinical data in the results, and 12 for presenting the perspective of the professionals, two for being integrative reviews. Thus, a total of 31 articles were included.

To assess the level of scientific evidence of the selected articles, the following aspects were considered: level 1 studies with methodological design for meta-analysis or systematic reviews, level 2 randomized controlled clinical trials, level 3 non-randomization clinical trials, level 4 cohort and case-control, level 5 systematic reviews of descriptive and qualitative studies, level 6 descriptive or qualitative studies and level 7 expert opinion.[10]

RESULTS

Table 1 - Articles published in 2011.

Study identification	Journal	Research design and approach method	Sample, study location, and year	Level of evidence[10]
The vulnerability experienced by the family of children hospitalized in a Pediatric Intensive Care Unit.[11]	*Revista Escola de Enfermagem.*	Qualitative study. Direct approach.	11 mothers, five fathers, a grandmother and two uncles, totaling 19 family members, 2011.	VI
Maternal satisfaction with care provided to hospitalized children.[12]	*Revista Aquichan.*	Qualitative study of the descriptive correlational type. Direct Approach.	127 mothers, 2011.	VI
The routine of relative/companion to the child with cancer during hospitalization.[13]	*Revista Rene.*	Qualitative study. Direct approach.	Seven family members, 2011.	VI
Being the mother of a child with cancer: a phenomenological investigation.[14]	*Revista enfermagem Universidade Estadual Rio de Janeiro.*	Qualitative descriptive exploratory study of the phenomenological type. Direct Approach.	Eight mothers, 2011.	VI
Social support for family caregivers during the child's hospitalization.[15]	*Rev Enferm Universidade Estadual do Rio de Janeiro.*	Qualitative study. Indirect approach.	15 family members, 2011.	VI
The experiences of relatives of children hospitalized in an Emergency Care Service.[16]	*Rev Esc de Enferm da Universidade de São Paulo.*	Descriptive qualitative study. Direct approach.	10 family members, 2011.	V

Table 2 - Articles published in 2012.

Study identification	Journal	Research design and approach method	Sample and year	Level of evidence[10]
The daily routine of parents of children hospitalized with cancer: nursing challenges.[7]	*Revista Gaúcha de Enfermagem.*	Qualitative descriptive exploratory study. Direct approach.	Nine mothers, two fathers and a couple, 2012.	VI
Safety of pediatric intensive care inpatients: understanding adverse events from the companion's perspective.[17]	*Revista Eletrônica de Enfermagem.*	Qualitative descriptive exploratory study. Direct Approach.	13 family members, 12 mothers and one father, 2012.	VI
Family experience in the hospital during child hospitalization.[18]	*Revista Gaúcha de Enfermagem.*	Qualitative descriptive exploratory study. Direct approach.	12 mothers, 2012.	VI
An interpretive phenomenological study of Chinese mothers' experiences of constant vigilance in caring for a hospitalized sick child.[19]	J Adv Nurs.	Qualitative phenomenological study. Direct Approach.	15 mothers, 2012.	VI
Parent's perceptions of health care providers actions around child ICU death: what helped, what did not.[20]	Am J Hosp Palliat Care.	Qualitative study. Direct Approach.	63 responsible, 2012.	VI
Parental perceptions of care of children at end of life.[21]	Am J Hosp Palliat Care.	Qualitative and quantitative study. Direct and indirect approach.	21 parents, 2012.	IV e VI
An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit.[22]	J Child Health Care.	Qualitative study. Direct Approach.	18 families, 17 mothers and 11 fathers, 2012.	VI

Table 3 - Articles published in 2013.

Study identification	Journal	Research design and approach method	Sample and year	Level of evidence[10]
Interaction between the nursing staff and family from the family's perspective.[4]	*Escola Anna Nery Revista de enfermagem*	Qualitative study, Direct Approach.	Seven family members, 2013.	VI
Reflections of child hospitalization in the life of the familiar attender.[23]	*Revista Brasileira de Enfermagem*	Qualitative study. Direct approach.	34 family members, 2013.	VI
Designing a hosting area as an advanced nursing care strategy in a pediatric nursing ward.[24]	*Revista Biomédica Revisada por Pares*	Quantitative study. Indirect approach.	51 family members, 2013.	IV
The family revealing itself as a being of rights during hospitalization of the child.[25]	*Revisão Brasileira de Enfermagem*	Descriptive qualitative study. Direct approach.	15 family members, 2013.	VI
Experiences of Alaskan parents with children hospitalized for respiratory syncytial virus treatment.[26]	J Pediatr Nurs	Descriptive qualitative study. Direct approach.	Six mothers, 2013.	VI

Table 4 - Articles published in 2014.

Study identification	Journal	Research design and approach method	Sample and year	Level of evidence[10]
The involvement of parents in the healthcare provided to hospitalized children.[27]	*Revista Latina americana*	Qualitative exploratory study. Direct approach.	660 parents and 95 health professionals, 2014.	VI
Applicability of theoretical model to families of children with chronic disease in intensive care.[6]	*Revista Brasileira de Enfermagem*	Descriptive qualitative study. Direct approach.	Seven mothers and four fathers, 2014.	VI
The family living the time during the hospitalization of the child: contributions for nursing.[28]	*Escola Anna Nery Revista Anna nery*	Descriptive, exploratory qualitative study. Direct approach.	15 family members, 2014.	VI

Study identification	Journal	Research design and approach method	Sample and year	Level of evidence[10]
The family caregiver during the hospitalization of the child: coexisting with rules and routines.[29]	*Escola Anna Nery Revista de Enfermagem*	Qualitative study. Direct Approach.	18 family members, 2014.	VI
Experience of mothers on having a child diagnosed and hospitalized by the virus Influenza A (H1N1).[30]	*Revista Brasileira de Enfermagem*	Qualitative study. Direct Approach.	Five mothers, 2014.	VI
Are parents doing what they want to do? Congruency between parents' actual and desired participation in the care of their hospitalized child.[31]	Issues Compr Pediatr Nurs	Quantitative study. Direct and indirect approach.	191 fathers, 2014.	IV

Table 5 - Articles published in 2015 and 2017.

Study identification	Journal	Research design and approach method	Sample and year	Level of evidence[10]
Hospitalized child and the nursing team: opinion of caregivers.[32]	*Revista de Enfermagem UFPEL online*	Qualitative, descriptive and exploratory study.	17 companions of hospitalized children, 2017.	VI
Meaning given by family to caring for the hospitalized child.[33]	*Avances en Enfermeria*	Qualitative research with methodological framework of Grounded Theory.	15 family members, 2017.	VI
Social, demographic, and hospital factors related to anxiety levels in relatives of pediatric patients.[34]	Revista Enfermería universitaria	Quantitative, descriptive and cross-sectional study. Indirect approach.	34 family members, 2015.	IV
The (dis)satisfaction of the companions about their condition of staying in the pediatric ward.[35]	*Escola Anna Nery Revista de enfermagem*	Qualitative study. Indirect approach.	11 companions, 2015.	VI
Meanings attributed by family members in pediatrics regarding their interactions with nursing professionals.[3]	*Revista Escola de Enfermagem da Univ. de São Paulo*	Qualitative, descriptive, exploratory study. Direct approach.	15 family members, 2015.	VI
Parents' experiences of their child's admission to paediatric intensive care.[36]	Nurs Child Young People.	Qualitative study. Direct approach.	Five mothers and a couple (mother and father), 2015.	VI
Hispanic parents' experiences of the process of caring for a child undergoing routine surgery: a focus on pain and pain management.[37]	J Spec Pediatr Nurs	Qualitative study. Direct Approach.	60 mothers and fathers, 2015.	VI

The countries where the studies were carried out were Canada (n=2), United Kingdom (n=1), Colombia (n=1), China (n=1); Brazil (n=18), Mexico (n=1), Chile (n=1), Portugal (n=1), United States of America (n=3), and China (n=1). Most of the studies were developed with qualitative (n=27) and quantitative (n=3) research. Direct, face-to-face interviews to search for information were more frequent in 27 studies, the indirect approach occurred in 4 studies.

Concerning the year of publication of the studies, 18 were published between 2011 and 2013 and 11 between 2014 and 2015 and 2 in 2017. All studies aimed, in essence, to assess the difficulties encountered by family members of hospitalized children.

During the analysis, four categories have arisen: adaptation of the family routine, withdrawing away from the rest of the family and healthy children; maladaptation due to physical structure and lack of hospital comfort; medical procedures, nursing and strict rules/routines.

DISCUSSION

The analysis of the studies allowed us to perceive a diversity of situations experienced during this period and how they influence their daily lives.

Adaptation of the family routine, withdrawing away from the rest of the family and healthy children

The family organization changes according to the level of complexity of the child's illness. The family adapts itself to

each situation that arises; develops strategies to face adverse conditions and learns ways to face the situation, establishing new roles and obligations that are to be shared, and other forms of relationship with each other and with the social environment appear.[6]

Family disorganization causes not only changes in daily activities and the function of members within the family routine, but also the impacts reach extreme dimensions in the emotional, social, and financial spheres. At home, the extended family assists in coping with the daily routine of hospitalization, they assume the house cleaning, the washing of clothes, financial support, and also the care for other children.[15] The adaptation of the family routine also impacts on the withdrawal from the rest of the family due to this reorganization that family members are obliged to carry out due to the child's hospitalization, the withdrawal occurs specifically from healthy siblings, who are temporarily left aside and cared for by other family members.

It is noteworthy that because the hospitalized child demands more frequent care, parents impair the care of other children, as long as they need to stay in the hospital for the treatment of the sick child.[6] The longer the child's hospitalization period, the longer the family member will be away from home and, consequently, the more difficult it will become to caring for the children who stayed at home. In some cases, the children may show sadness and jealousy towards the hospitalized child and also cause the same feeling in the hospitalized child when the relative (caregiver) returns home.[23]

In the hospital experience, it is noticed that the mother is the main caregiver, often, the act of caring reduces the feeling of guilt for hospitalization.[38] It is emphasized that the mother may feel guilty about the child's illness and hospitalization, however, in most cases, the illness process is inherent to the care offered.

Another point that deserves to be highlighted is the feeling of abandonment on the part of the family experienced by some family members who take care of the hospitalized child, many times, the person who accompanies the child in the hospital needs to face alone, the difficulties arising from this experience.[2]

The importance of building support networks is evident to subtract the concern with the children who stayed at home and increasing their support so that the adaptation process is effective and meaningful during the hospitalization period.

Maladaptation due to physical structure and lack of hospital comfort

The hospital is described by family members as a different environment, a place with many sounds, lights, and people in continuous movement. This causes them to have a very big impact, they have to learn to deal with all these stressors, since there is no other way, and she will need to remain in that place until the child recovers.[11]

It appears that the places available to family members do not offer comfort or are in poor condition.[23] In the hospital infrastructure, the child's housing conditions and privacy are considered to be inadequate by the parents, as these aspects do not cover the needs of the child and the accompanying person.[27]

Family members say that comfort is one of their main needs, so the ideal would be to improve living conditions.[24] As, for instance, the existence of more comfortable waiting rooms, respect for privacy, a place to sleep, a bathroom with shower, food for the companion and a safe place to store their belongings, as this would provide a welcoming space and facilitate the work process, promoting well-being, demystifying the hospital environment as an unpleasant place and exercising the valorization of politics of humanization in the hospital setting.[39]

A research on the structure for family members' rest shows that the use of a recliner, the padding is hard, and the surface is not linear. When the companions are financial stable, they use it at their disposal. For instance, the use of the comforter or mat to minimize discomfort, however, because they stay for long periods in the hospital and the fact that the furniture is not a bed, the discomfort always appears as a complaint.[35]

Therefore, institutions must carry out the necessary adjustments to guarantee the ambience guidelines of the *Política Nacional de Humanização (PNH)* [National Humanization Policy][40] that refers to a welcoming environment that allows comfort, individuality, and privacy, as well as areas of "living rooms" for companions, to provide a more comfortable stay.

Medical procedures, nursing and strict rules/routines

The accomplishment of medical and nursing procedures during the admission of the hospitalized child is shown as a difficulty to the point that the situation worsens in the face of the impotence of the family member when having to leave the environment to perform clinical procedures and wait for the end of care performed by the team. In this perception, such procedures are exemplified, for instance, repeated peripheral punctures and the administration of drugs with immediate reactions, catheterizations, and aspirations.[6]

The family ends up feeling powerless and at the mercy of the professionals' decision, as they do not obtain the necessary clarifications on why they are developing a certain action or procedure with the child.[13] The fact that the family members need to be absent during the shift change, rounds and procedures, makes them angry and frustrated, they cannot understand the reason for this attitude of the professionals, of not wanting to share the discussion of the child's health status and of not explaining the reason for such an attitude.[17]

Another weakness found is the rigid rules and routines that can lead the family to feel vulnerable and helpless, presenting difficulties in adapting and acquiring skills for childcare, making the pediatric care environment dehumanized. Nonetheless, families recognize the need for rules and routines to favor the smooth running of the sector, as they are part of the hospital culture, organizing the work process of professionals, and optimizing patient care.[29]

Norms and routines, although difficult to accept by family members, are important for the proper functioning of the services provided to patients; since care requires a process of organizing the service offered, to ensure better recovery and good service. It is understood that the care provided by the team and their sensitivity is essential to recognize the family's moments of fragility and respect their space, maintaining their privacy and avoiding greater wear and tear during hospitalization.

It is believed that they should be adapted to meet the unique needs of children and family members.[29] However, because of the imposition of norms and routines, it was seen that families resist, either by explicitly refusing to comply with them when they disagree with them, circumventing them without the knowledge of team members, such as, for example, bringing hidden food from home to the hospital, or complying with the rules, but protesting about having to do it.[29]

Norms and routines are important for hospital organization and assistance, on the other hand, professionals need to have the sensitivity to perceive and understand the situations in which it is necessary to make these norms and routines more flexible, since during a child's hospitalization what is sought is the care and clinical improvement.

CONCLUSIONS

The results of this investigation demonstrate that the hospitalization of a child significantly interferes in the lives of all family members and, in a special way, the mother's, who is the person that, in most cases, accompanies the child throughout their hospitalization. Almost consensually, it was found that this situation significantly affects their family relationship, physical, and mental health. Tiredness is accentuated by the lack of an adequate physical structure for their rest and by the need to continually remain alert to any change in the child's clinical condition in addition to meeting specific care demands.

It is important to note that during the process of children's hospitalization, family members identify their weaknesses, highlighting the difficulty in adapting to the new daily life, which manifests itself due to the parents or guardians withdrawing from their home and works to contemplate the care towards the hospitalized child, then causing difficulties for normal family functioning.

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