

The needs of parents of hospitalized children: evidence for care

Necessidades dos pais de crianças hospitalizadas: evidências para o cuidado

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ABSTRACT

Hospitalization has its benefits when treating sick children, but it can also cause negative impacts. Although it is essential and beneficial to the child, parental presence in the hospital ward destabilizes the family routine and generates new needs. The objective of this study was to search for evidence in the literature and identify, gather, and synthesize the knowledge that has been produced about the needs of parents of hospitalized children via an integrative literature review. The article search was conducted in the PubMed, CINAHL, PsycINFO, Scopus, Web of Science, and LILACS databases between 2002 and 2014 and resulted in 17 articles that met the established criteria. The parental needs found in these studies were grouped into three categories: the needs related to parents themselves, needs related to the health team's actions, and those related to organizational structure and resources. These needs were intimately interconnected, which means that accessing, assessing, and satisfying them must occur simultaneously, thus providing quality care to children and their families.

Descriptors: Parents; Child, Hospitalized; Hospitalization; Needs Assessment; Pediatric Nursing.

RESUMO

A hospitalização traz benefícios para o tratamento da criança doente, mas também implica em impactos. Embora essencial e benéfica à criança, a presença dos pais na enfermaria desestabiliza suas rotinas e desencadeia necessidades. O objetivo deste estudo foi buscar evidências na literatura, para identificar, reunir e sintetizar o conhecimento produzido acerca das necessidades dos pais de crianças hospitalizadas, por meio de revisão integrativa da literatura. A busca das referências foi realizada nas bases PubMed, CINAHL, PsycINFO, Scopus, *Web of Science* e LILACS, entre 2002 a 2014, identificando 17 artigos que se adequaram aos critérios estabelecidos. As necessidades encontradas foram agrupadas em três categorias: necessidades dos próprios pais, necessidades relacionadas às ações da equipe de saúde e necessidades ligadas à estrutura e recursos organizacionais. Estas necessidades estão intimamente interligadas, de modo que o acesso, avaliação e sua satisfação devam ser realizados em conjunto, qualificando a assistência à criança e sua família.

Descritores: Pais; Criança Hospitalizada; Hospitalização; Determinação de Necessidades de Cuidados de Saúde; Enfermagem Pediátrica.

INTRODUCTION

Since the 19th century, the value of having parents present at all times during their child's hospitalization and the dynamics and organization of work processes in pediatric wards have undergone significant changes. These changes have resulted in advancements and challenges, both for health teams and for the families of pediatric patients⁽¹⁾.

Several historical milestones have contributed to these advancements, such as the publication of a report on maternal deprivation as an etiological disturbing factor of mental health by the World Health Organization (WHO) in 1951; the publication of the Platt Report⁽²⁾ in 1959 in England; the Nordic Charter for Children and Youth in Health and Hospital Care created by the European Association for Children (EACH) in Hospital in 1988; and the ratification of the United Nations Convention on the Rights of the Child in the United Kingdom, in consonance with most of the world, in 1991⁽¹⁾. Finally, in Brazil, the enactment of Law no. 8069 in 1990 regulated the Statute of the Child and Adolescent and began enforcing the right of patient companions to be present in pediatric wards⁽³⁾.

Certainly such accomplishments result in benefits for both children and parents. Since their implementation, parents have become agents and participants in the hospital care of their children. However, usually neither child nor parents are prepared to face hospitalization. While for the sick child this process can represent the fear of the unknown, physical suffering related to painful procedures, and psychological suffering, for the parents it can mean loss of normality, insecurity in their parental roles, financial instability, and pain for their child's suffering⁽⁴⁾.

A study among family members of hospitalized children found that high levels of stress and anxiety among parents tend to be more associated with the hospitalization than with the child's illness per se⁽⁵⁾. Accompanying a hospitalized child leads to difficulties in reconciling work outside of the home, household chores, hospital stays, and caring for other children. Furthermore,

there are economic repercussions, such as reduced family income and expenses related to transportation, medication, and food⁽⁶⁻⁷⁾.

Parental presence during child hospitalization is of crucial importance, as it provides children with a safe and familiar environment, meeting their needs, helping them be more collaborative, and minimizing negative repercussions. It contributes to bringing the child-companion pair closer together, reducing emotional stress for both and strengthening bonds⁽⁸⁻¹⁰⁾. Despite the recognition of such benefits of formalizing the presence of parents in pediatric wards, most healthcare professionals are unfortunately not only unaware of them but are not prepared to care for parents and meet their needs as well. Their attention is directed to the child's physical illness, and thus issues related to the emotions, insecurities, and doubts of parents are frequently neglected⁽¹¹⁾.

This distance between professionals and parents can make it difficult to recognize and satisfy the needs that arise from the process of child hospitalization. Therefore, efforts aimed at synthesizing the knowledge that has been produced about the needs of parents of hospitalized children can help raise the awareness of health professionals on the topic. Furthermore, such a review can bring to light and put into context needs that have already been identified in the literature and thus contribute to planning nursing care for children and their parents. In this sense, the present study aimed to conduct a search of the evidence available in the literature in order to identify, gather, and summarize the knowledge that has been produced about the needs presented by parents of hospitalized children, subsidizing clinical practice and directing future research. Furthermore, it assessed the methodological quality of the references included in the review.

METHODS

Integrative literature reviews, which consist of a wide-reaching analysis of the literature and a summary of

the knowledge on a given topic, provide support for decisions and can help improve clinical practice⁽¹²⁾. The present study was developed according to the following steps: identifying the theme and formulating the guiding research question; setting inclusion and exclusion criteria for the studies and literature search; defining the information to be extracted from the selected articles and categorization of studies; assessing the studies included in the review (detailed data analysis); interpreting and discussing results; and synthesizing the findings⁽¹²⁾.

Considering that child hospitalization brings with it positive and negative repercussions for both children and their families, that this process unleashes various needs, including parental ones, and that, for the most part, health professionals are not prepared to identify and meet such needs, we proposed the following question: "What scientific knowledge has been produced about the needs presented by parents of hospitalized children?"

The literature search was undertaken using the following databases: PubMed, a digital archive produced by the National Library of Medicine (USA) in the area of biosciences; CINAHL (Cumulative Index of Nursing and Allied Health Literature), which encompasses the main scientific productions in the field of nursing; PsycINFO, a reference in the areas of psychology, behavioral sciences, and education; Web of Science, which refers to a set of databases (Science Citation Index, Social Science Citation Index, Arts and Humanities Citation Index, Current Chemical Reactions, and Index Chemicus) compiled by the ISI (Institute for Scientific Information); LILACS, which gathers scientific publications in the health area produced in Latin America and the Caribbean; and Scopus, a multidisciplinary database produced by the publishing house Elsevier.

The keywords and descriptors used were extracted from the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MESH) and were used in many different combinations: hospitalized child; parents; needs assessments; and NOT newborns. In order to guarantee the reliability of the study, the Kappa test was conducted

with $K=0.82$ in order to verify the level of agreement among the researchers who searched for the articles that were selected from the databases and included in the review.

Inclusion criteria were: articles that originate from primary studies regardless of methodological approach; available in Portuguese, English, or Spanish; published between January 1, 2002 and December 31, 2014 and whose abstracts were indexed in the databases mentioned above; whose studied population included parents of children or adolescents; and whose objectives focused on the needs of parents with hospitalized children from the parental perspective.

Exclusion criteria for articles were: those that considered needs only from the point of view of healthcare professionals; articles whose primary purpose was not directed at parental needs; and studies conducted with the parents of children hospitalized in intensive care units and in emergency, psychiatric, outpatient, and perioperative services. During the selection process of the review sample, we also excluded duplicate studies and those aimed at comparing parental needs as perceived by parents and those perceived by the health team, because even though they addressed the focus of the review, they did not allow us to extract results that only refer to needs from the parents' point of view.

We selected publications after carefully reading titles and abstracts to verify that they addressed the guiding research question and met the pre-defined inclusion and exclusion criteria. In the event of doubt about the inclusion of a given study, we selected the article and made the final decision after reading the full article and discussion among the members of our research group.

The strategy employed for the study search resulted in 575 articles; after removing duplicate studies, this total was 364. Of this subset, 321 were excluded for the following reasons: 12 involved non-hospitalized children; 23 referred to children in intensive care or neonatal units; 13 were for children in psychiatric services; 26 were in reference to children in perioperative care; 17 were

literature reviews; 25 used different research subjects; and 205 had different objectives. Thus, 43 full articles were read and then discussed among the researchers. The final sample consisted of 17 articles. Of the 26 studies excluded after being read fully, 11 were excluded for not addressing the needs of parents; six for involving children in emergency, perioperative, or intensive care units; one

because the parents did not accompany their children during hospitalization; seven for presenting parental needs according to perspective of the health team or another population; and one because the full text was in French. Figure 1 shows the flowchart created by the authors of the present study detailing the steps taken to reach the final sample of articles included in the review.

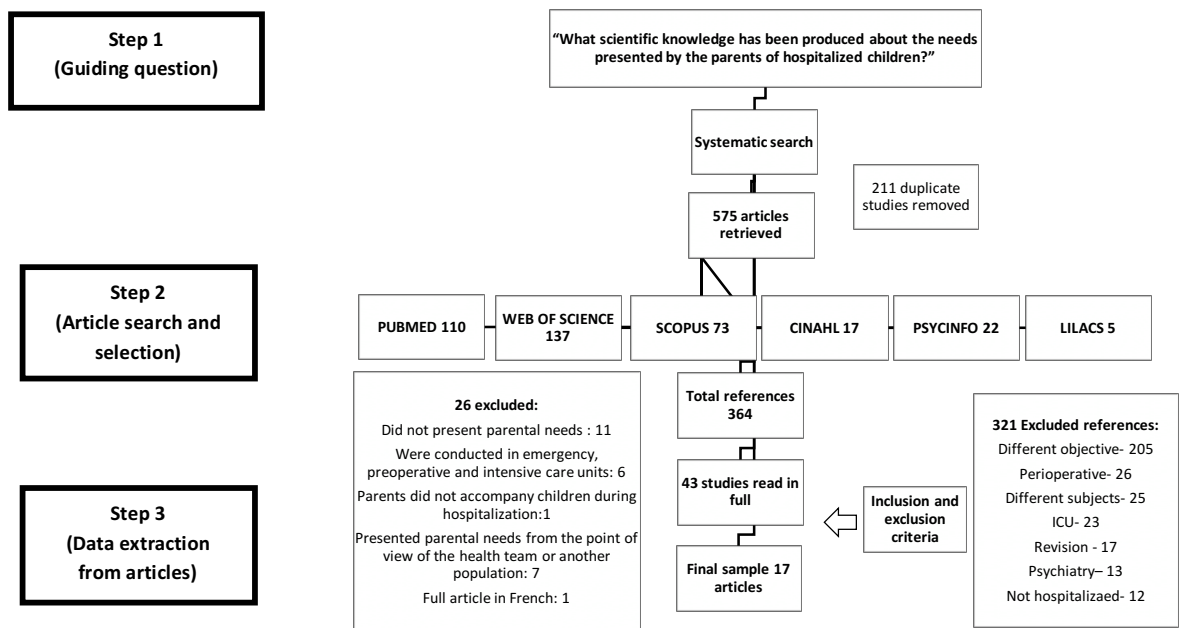


Figure 1: Flowchart for selection of studies.

Data extraction and analysis were conducted with the help of an instrument created by the researchers that contained the following indicators: researchers' field of work; year and country of publication; location of the study; objective; design as stated by the authors of the article; participants; methodological procedures; and results regarding parental needs. Each researcher analyzed the selected articles independently. After consolidating the results, thematic content analysis was conducted⁽¹³⁾. Throughout this process, we classified the textual information, reducing it into data that were relevant and easily manageable by the researchers. The data were then classified and grouped into categories

with common themes, allowing us to reach the objective of the study⁽¹³⁻¹⁴⁾.

Given the heterogeneity of the methods employed in the reviewed studies, the methodological quality of the quantitative studies was assessed according to the criteria established by Malhotra and Grover⁽¹⁵⁾. In turn, the methodological quality of the qualitative studies was assessed according to the criteria defined by Clark⁽¹⁶⁾. Based on these criteria, we developed an instrument for extracting data to identify the presence or absence of important methodological points. With this strategy, we critically analyzed each study in terms of its conception,

ethics, population, data collection procedures, and analytical approach.

RESULTS

Characterization and methodological analysis of selected studies

Of the 17 studies selected for analysis, 16 were conducted by researchers in the field of nursing and one by social workers; 15 articles were published in English and two in Portuguese; 11 results were published in specific nursing periodicals and six in periodicals in the field of pediatrics. Moreover, five were quantitative studies conducted with surveys and 12 adopted a qualitative approach. Charts 1 and 2 presents the information extracted from the original articles included in the review and synthesizes the parental needs found.

Table 1: Characteristics of qualitative studies included in the review

Author / Year / Country of origin	Objective	Design/Procedure	Parental needs
Stratton/2004/United States	To explore the experience of parents with the care provided to their children during hospitalization	<ul style="list-style-type: none"> • Descriptive qualitative study • Grounded theory • Three fathers and three mothers of children between the ages of 0 and 18 years • Interviews 	<ul style="list-style-type: none"> • Ask questions about the professionals' skills and how they carry out procedures; be informed • Receive explanations about procedures • Experience well being • Cope with uncertainty • Monitor care and stay with their children • Interact and establish clear and comprehensible communication with teams • Be recognized and receive comfort, concern, and compassion from the team
Dudley, Carr/2004/ United States	To explore the monitoring experience and investigate the meanings, patterns, and daily routine of parents of hospitalized children	<ul style="list-style-type: none"> • Ethnographic study • 10 parents of children between the ages of 7 and 16 • Interviews 	<ul style="list-style-type: none"> • Maintain perseverance, hope, and self-care activities • Develop global resilience • Keep control and adapt to the new environment • Receive comfort regarding basic needs, such as hygiene, sleep, and rest
Lam, Chang, Morrissey/2006/ China	To explore the experiences and perception of Chinese parents participating in their child's care	<ul style="list-style-type: none"> • Exploratory qualitative study • 19 parents of children between the ages of six months and 11 years • Interviews • Four pediatric wards and one regional hospital in Hong Kong 	<ul style="list-style-type: none"> • Remain at child's side and ensure their safety • Accompany child during procedures • Participate in the child's care • Receive emotional support; reorganize family routines • Receive help with child's care from nurses • Information (test results, care, child's evolution) • Hear words of comfort from nurses • Receive comfort, quiet, and good hygiene conditions; rest and food provided by the hospital
Reeves, Timmons, Dampier/2006/UK	To understand the negotiation experience of parents of technology-dependent hospitalized children	<ul style="list-style-type: none"> • Exploratory quantitative study • Six parents of children dependent on high-technology • Interviews 	<ul style="list-style-type: none"> • Feel like parents and not just nursing aids • Know that the child is being cared for by competent and experienced nurses • Know that their opinion is heard and respected • Have autonomy to care for child as if at home, although other parents prefer to just accompany the child • Trust professionals and have good support systems in the hospital • Have emotional support to take on their child's care and responsibility

Author / Year / Country of origin	Objective	Design/Procedure	Parental needs
Jackson, Stewart, O'Toole, Tokatlian, Enderby, Miller, et al./2007/Australia	To assess the coping mechanisms, hope, support, stress, and adaptation of parents of hospitalized children	<ul style="list-style-type: none"> • Prospective study • 73 parents of children under the age of 18 with brain tumors • Interviews, in person or over the phone, at four points: diagnosis; six months; one year; and two years post-diagnosis 	<ul style="list-style-type: none"> • Constant, clear, and appropriate information • Honesty and compassion; good communication with and trust in the team • Understanding of the hospital system • Continuity of care; inclusion in decisions regarding the child's treatment • Emotional and financial support • Comfort for parents who sleep at the hospital
Chan, Leung, Chui, Tiwari, Wong, Wong, et al./2007/China	To identify the needs and experiences of parents during the hospitalization of children with highly suspected Severe Acute Respiratory Syndrome; describe parental perception of the care provided; and identify ways to improve communication between health professionals, children, and parents during strict isolation	<ul style="list-style-type: none"> • Descriptive qualitative study • Eight parents of seven children with a suspected diagnosis of Severe Acute Respiratory Syndrome • Interviews 	<ul style="list-style-type: none"> • Spend more time with child before isolation • Be better informed about the causes of their child's isolation • Reconcile household chores and daily routines • Be familiar with and constantly updated on their child's condition
Avis, Reardon/2008/UK	To explore the perception of parents regarding how their special needs children have been treated by professionals	<ul style="list-style-type: none"> • Exploratory qualitative study • 12 parents • Interviews 	<ul style="list-style-type: none"> • Adequate communication with the team • Trust in the team • Emotional support • Understanding information received
Lee, Lau/2012/China	To examine the experience of Chinese mothers regarding the overall pediatric care of their hospitalized child	<ul style="list-style-type: none"> • Phenomenological study • 15 mothers of children between the ages of one month and one year • Interviews 	<ul style="list-style-type: none"> • Information • Communication with the team • Adequate emotional support • Be at the child's side • Be included in planning their child's care
Kopacz, Predeger, Kelley/2013/United States	To learn from the experience of Alaskan parents with children infected with respiratory syncytial virus and contribute with knowledge on the impact of this disease on families	<ul style="list-style-type: none"> • Descriptive study • Six accompanying mothers • Semi-structured interviews 	<ul style="list-style-type: none"> • Manage emotions • Comfort • Adaptation • Be at the child's side • Receive information about diagnosis, signs and symptoms of the disease
Salmani, Abbaszadeh, Rassouli/2014/Iran	To express factors that affect how mothers of hospitalized children develop trust in nurses	<ul style="list-style-type: none"> • Descriptive study • 14 accompanying mothers • Semi-structured interviews 	<ul style="list-style-type: none"> • Support; managing feelings • Quality of care • Participate in the child's care • Be informed about the treatment and reasons for procedures • Effective, clear, and understandable communication • Interact with the health team

Author / Year / Country of origin	Objective	Design/Procedure	Parental needs
Melo, Ferreira, Lima, Mello/2014/Portugal	To analyze the opinions of parents/caregivers and health professionals about parental involvement in the care provided to hospitalized children in Portuguese hospitals	<ul style="list-style-type: none"> • Exploratory study • 660 parents or caregivers • Questionnaire with open-ended questions 	<ul style="list-style-type: none"> • Interact with health team • Comfort (adequate environment for their needs) • Information on the child's condition • Be at the child's side • Participate in the child's care • Support from the team • Communication and negotiation of care
Giambro, Sabourin, Broome, Buelow/2014/United States	To determine the process of communication between parents and nurses, from the point of view of parents of hospitalized technology-dependent children	<ul style="list-style-type: none"> • Grounded theory • 11 parents of hospitalized children • Semi-structured interviews 	<ul style="list-style-type: none"> • Information • Communication and understanding the information given • Interact with the team • Participate and be included in the care plan • Understand their role in the ward • Negotiate care • Quality of care and trust in professionals • Monitor the hospitalized child

Table 2: Characteristics of quantitative studies included in the review

Author / Year / Country of origin	Objective	Design/Procedures	Parental needs
Sabatés, Borba/2005/Brazil	To become familiar with the perception of parents regarding the type of information received by nurses during the child's hospitalization	<ul style="list-style-type: none"> Descriptive-exploratory, cross-sectional, quantitative 50 parents of children between the ages of one month and six years Structured interviews 	<ul style="list-style-type: none"> Understand the situation and the child's treatment Receive precise and consistent information on the child's diagnosis, treatment, and specific care and the parents' role in the hospital
Kyritsi, Matiziou, Perdikaris, Evagelou/2005/Greece	To investigate what specific needs are important to parents during the hospitalization of their children and the level of importance attributed to each need	<ul style="list-style-type: none"> Cross-sectional descriptive study 103 parents of children between the ages of two months and 14 years Needs of Parents Questionnaire 	<ul style="list-style-type: none"> Receive information on what is happening to the child, their condition, and prognosis Trust the health team Communicate with the team Receive emotional and financial support Participate in the child's care
Öjmyr-Joelsson, Nisell, Fremckner, Rydelius, Christensoon/2006/Sweden	To assess the experiences of parents with the care given to children with high and intermediate imperforate anus, specifically regarding the child's care, information received by parents and children, and involvement in care	<ul style="list-style-type: none"> Descriptive, comparative and retrospective study <u>Study group</u>: parents of 25 children with high and intermediate imperforate anus <u>Control group I</u>: parents of 30 children with juvenile idiopathic arthritis <u>Control group II</u>: parents of 32 healthy children Questionnaire with 59 items, individually answered by fathers and mothers (analogic visual scale) 	<ul style="list-style-type: none"> Understand the treatment: mothers in the study group demonstrated lower comprehension of the importance of the child's treatment; Information: fathers in the study group displayed lower satisfaction with the information received about the child's care Involvement in care: mothers and fathers displayed high level of involvement with the child's care
McCann/2008/Australia	To describe the sleep experience of parents who accompany their hospitalized children and identify variables that can influence the duration and quality of sleep	<ul style="list-style-type: none"> Descriptive, cross-sectional, and survey study 120 parents/responsible for children, between the ages of 10 days and 15 years VSH Sleep Scale (Verran, Snyder-Halpern; 1987) and open-ended question about the experience of accompanying child during hospital stay 	<ul style="list-style-type: none"> Be with the child Receive support from professionals Comfort, especially in terms of environmental factors that affect sleep (sleeping cots, temperature of air conditioning, noise at night)
Söderbäck, Christensson/2008/Mozambique	To investigate the needs, experiences, and expectations of adults accompanying hospitalized children with regard to the care provided	<ul style="list-style-type: none"> Descriptive cross-sectional study 100 primary family caregivers (89% mothers) Questionnaire based on the Needs of Parents Questionnaire (NPQ), adapted to Mozambiquian culture 	<ul style="list-style-type: none"> Offer primary care to their child Receive information on the child's condition Receive religious support; participate in decisions regarding the child; be taught to perform more complex care Participate in situations that are painful or frightening for the child That doctors are able to provide a diagnosis, and care and attention to the child; that nurses offer safe treatment, have a good relationship with the child and family, and have time available for them That nursing aides help, provide guidance, keep the ward clean, and offer assistance

- Quantitative studies:** All five studies⁽¹⁷⁻²¹⁾ were conducted with the help of surveys, which included structured questionnaires to determine the experience of parents during the child's hospital stay^(17-19,21) and the information received by parents throughout this period⁽²⁰⁾. Of all the studies, two⁽¹⁷⁻²¹⁾ conducted interviews with parents, one⁽¹⁹⁾ interviewed parents and children, another⁽²⁰⁾ interviewed parents and the health team, and one interviewed the child's primary caregivers⁽¹⁸⁾. The sample size ranged from 62 to 152 respondents, with a response rate greater than 85% in all cases. All five studies^(17-19,21) performed a pilot test before applying the questionnaires. None of them provided information about the reliability of the measures used, and three^(18-19,21) did not provide information about their validity. All five⁽¹⁷⁻²¹⁾ clearly defined their unit of analysis, and the consistency of the instrument reflected the unit of analysis. Furthermore, the chosen respondents were adequate for the research question. Only one of the studies⁽¹⁹⁾ assessed the content validity of the measures. Three of the studies did not describe construct validity^(18,19,21). Furthermore, sampling was defined and justified in three of the studies^(17,18,20).
- Qualitative studies:** Of the 12 qualitative studies, only seven presented the research question⁽²²⁻²⁸⁾ and eight^(22-25,27-28,30-31) a description of the methodological design. Seven investigations^(22-24,26-28) gave details on how participants were selected; five^(22,24-28,30,32) presented information on how participants were recruited and by whom; three studies^(22,29,33) partially provided this information; and one⁽³¹⁾ provided no information on the topic. None of the studies provided the reasons given by parents who did not wish to participate in the study, and eight⁽²²⁻³¹⁾ contained methodological information, such as the interview questions used. Five of the studies^(23-25,27-28) had a study group and clearly defined scenarios and seven^(22,26,29-33)

reported only part of this data. In only one study⁽²⁴⁾ did researchers report taking on two roles, and in three of them^(24-25,30) the ethics of such a decision was discussed, wherein the researchers critically analyzed their own influence in formulating the research question and collecting and interpreting data. All eight studies^(22-25,30-33) expressed concerns with ethical issues; however, three^(22,29-30) made no mention of being approved by an ethics committee. Two⁽²⁸⁻²⁹⁾ described and justified their methods and two⁽³²⁻³³⁾ gave partial emphasis to them. In seven of the studies^(22-25,27-29) the analytical approach was described and justified at length; the authors of three of them^(24,30-31) determined the end of data collection; and only one⁽³¹⁾ did not present the results with reference to preexisting literature. Only three studies⁽²³⁻²⁵⁾ described and discussed their strengths and limitations.

Based on this analysis, we observed that some studies included in the review lacked greater methodological detailing, as the absence of information does not imply absence of rigor in the study's conduction. Nonetheless, we considered it best to maintain the group of included studies intact, given the contribution of their findings to knowledge on pediatric nursing. However, we emphasize the need for studies with greater methodological rigor and description, to increase the validity and reliability of their results.

The analysis of the selected publications allowed us to organize the results into three categories: the needs of parents; needs related to the health team's actions; and needs related to organizational structure and resources.

The needs of parents

Among the numerous needs reported by the parents in the studies, the need to *stay at the child's side during hospitalization* was the most frequently mentioned. This need was indicated in several different ways and contexts^(17-18,23,25-28,30,32,33), frequently characterized as "monitoring," that is, aimed at accompanying the child

and ensuring the child's wellbeing and feeling of safety throughout the entire time in the hospital^(23,27-28,30). While some parents only wanted to be at their child's side as a way of keeping some control over the situation, others simply wanted to be present^(26-27,30). Many parents revealed this wish in terms of the child's own wellbeing, as they were calmer and felt safer with their parents⁽¹⁷⁻³³⁾. Others wanted to be with their children during procedures and painful and frightening situations⁽¹⁸⁾.

By staying at their child's side during hospitalization, parents wish to maintain their parental role, taking on care activities the same way as at home⁽³⁰⁾. In this context, the needs that emerged were related to *participating in the children's care*^(18,21,23,25,28-29,31-32), in that many parents wanted to be more involved in the child's assistance and daily care so that they could be part of the care plan^(23, 28). Other parents were interested in being involved in decisions regarding their child's treatment^(18,27,31).

However, at the same time that they wished to participate in the child's care, parents also seemed confused and disoriented with regard to the role they were supposed to play^(20,23,30). Many of them did not know what the nursing team expected of them and what they could expect from the team⁽²³⁾, expressing the need to *know what their role in the hospital is* and *negotiating their children's care with professionals*⁽²⁷⁻²⁸⁾.

When parents were at their children's side and participated in their care, they felt safer and more secure, as if they were able, in such an unstable and threatening setting, to *keep control* over the situation. This was also a need indicated by some of the studies⁽²²⁻³⁰⁾. Furthermore, there was the need for *safety*^(17,23,29), as many parents only felt safe when they knew that their children were also safe, a feeling conveyed via the presence⁽¹⁷⁾ and confidence of the professionals^(18,24,28-32).

While in the hospital, parents still had their daily activities and commitment. They had to reconcile household work, family routines, work, and other tasks in order to adapt to the new and hostile hospital environment^(22-23,26,33). The need for *adapting* to this

situation was defined by some researchers as resilience⁽²²⁾. The parents stated that they faced constant challenges in their daily routine and that they were always trying to regain a sense of normality within their family^(24,26).

In addition to this adaptation, parents had to cope with a number of emotions, such as love, responsibility, defense, involvement, zeal, concern, fear, anxiety⁽²²⁾, stress, guilt⁽²⁶⁾, resentment, sadness, nervousness, impotence and helplessness⁽²⁵⁾, uncertainty regarding the evolution of the child's condition⁽³⁰⁾, and maintaining hope⁽²⁹⁾ and perseverance in care⁽²²⁾. *Managing these feelings* was also indicated by the studies as a parental need.

Needs related to the health team's actions

Most of the analyzed studies reported the need for *information*⁽¹⁸⁻³³⁾. In some of them, parents made reference to this need generically, not specifying the type of information they wished to receive^(18,24,30-31). In other studies, parents expressed what knowledge they considered most important or necessary in this context. The topic that most interested parents was related to the evolution of their child's care. They appreciated being informed about the diagnosis, treatment and prognosis^(19-21,23,25,29-30,33), in addition to the child's condition during hospitalization^(18,21,27,33). They also wished to receive explanations about their child's pathology and the child's main signs and symptoms⁽²⁶⁾, in addition to the types and reasons for procedures performed on the child⁽²⁹⁻³⁰⁾. Another type of information requested by the parents was with regard to their role in the child's care, as many parents did not know what type of participation was expected from them during the hospital stay^(20,23,32) and with regard to the child's care after discharge⁽²⁷⁾.

Parallel to this need for information, the studies also indicated a need to *communicate* with the health team^(21,24-25,27-30,31). Many parents emphasized the importance of establishing good communication with health professionals^(25,29,31). The parents also presented

the need to *understand* the information received^(19-20,24,28-29,31). Not only did they want to receive information about their children, but this information had to be clear⁽²⁹⁻³⁰⁾ so that they could understand the situation⁽²⁰⁾ and the importance of the child's treatment⁽¹⁹⁾. They also had a need to understand the hospital system⁽³¹⁾.

Still on this topic, many parents expressed wanting the health team to establish better *interaction* with the child and family^(25,27-28,31). Some parents wanted this interaction to lead to more information about the child's condition, care, and recovery⁽³¹⁾, while others wanted professionals to build a good relationship with the child and the family by being friendlier and closer⁽²⁹⁾ and having time available for them⁽²³⁾.

This search for interaction with the team went together with the need to *receive emotional support*, as parents usually like to rely on the team to help them manage their emotions and deal with the several difficulties^(17,21,23-25,29-32). Such support could be expressed through words of comfort⁽²⁹⁾, recognition, concern, and solidarity⁽³⁰⁾, or by demonstrating compassion for parents and the hospitalized child⁽²³⁻³¹⁾. For many parents, the presence of a nursing professional or doctor helped them feel safer⁽¹⁷⁾. In addition to emotional support, some studies also indicated the need for financial⁽²¹⁻³¹⁾ and spiritual support⁽¹⁸⁾.

Parents also expressed a strong need to *trust the health team* caring for their children^(18,21,24,28-32), valuing honesty as an essential characteristic of these professionals⁽³¹⁾. This need was frequently associated with the need to *guarantee quality of care*^(18,28-30,32). Many parents liked to check that their children were being cared for by competent and experienced nurses^(29,32), sometimes questioning their skills and how they performed procedures^(28,30) to ensure that these professionals would offer their children safe treatment⁽¹⁸⁾.

Needs related to organizational structure and resources

In addition to all the needs mentioned above, the parents also presented some basic ones, such as the need for food, sleep, and hygiene. Most parents declared that they considered it important to have *comfort* in meeting these needs^(22-23,26-27,31,33). They needed bathrooms in good conditions in order to take baths and perform other hygiene activities^(23,27). Many parents appreciated it when the hospital offered meals to companions so that they did not have to leave their child alone in the ward to look for a place to eat⁽²³⁾. They also said they needed silence at night to sleep, in addition to comfortable chairs or beds in which to spend the night^(23,27). One study⁽¹⁷⁾ focused on the quality of the sleep of parents accompanying their children during hospitalization found that there were many environmental factors in the hospital that affected their quality of sleep. Many parents complained of uncomfortable chairs offered for sleeping, air conditioning that was always very cold, and the loud noise level in the hospital at night.

DISCUSSION

The synthesis of the articles included in this review incorporated three themes that presented interactions between components related to the parents' needs, those related to the health team's actions, and those related to organizational structure. The needs indicated by the studies were intimately interconnected in such a way that one did not exclude the others, but strengthened their relevance.

The findings of a literature review that assessed the attitudes and experiences of parents with regard to family-centered care during child hospitalization⁽⁶⁾ corroborated those of the present study. In terms of the need for adaptation, these researchers found that accompanying a hospitalized child can unleash a number of difficulties for parents and that they need to find a balance between family, work, and household chores that can cause exhaustion and isolation. A study conducted in England⁽³⁵⁾ showed that accompanying a child in the hospital could imply social and personal costs, such as

isolation, hindered relationships, and changes in the parental role. Some parents even lose their jobs while caring for a sick child.

Prior to so many challenges and difficulties, the support of the health team is essential in helping parents handle their emotions and directing them through their professional conduct. A study in Finland⁽³⁶⁾ found that parents appreciated being supported by health professionals when they listened to them, had time available for them, provided adequate information, and held positive attitudes.

In one of these studies⁽³⁰⁾, the parents used their relationship with the team as a way to better understand the issues surrounding them, deal with uncertainty, and seek tranquility with regard to their child's condition. The same study⁽³⁰⁾ also revealed that parents sought to establish an interactive relationship with the health team that not only consisted in receiving information related to the child's care but also involved compassion, comprehension, and sensitivity from professionals with regard to the parents' and child's needs.

Another study analyzed in this review⁽¹⁸⁾ indicated that parents had their own needs and expectations with regard to the hospital. Therefore, lack of information about their child's health condition made it difficult for these parents to understand and commit to the care provided, making them feel neglected and abandoned.

The synthesis of the review also showed us that parents manifest a significant desire to be included in the child's care plan⁽⁷⁾. Many of them reported feeling excluded from care, complaining that they did not receive adequate information about what health professionals expected of them, or not being invited to discuss their child's condition⁽²⁵⁾. Parents frequently reported thinking that nurses did not understand their experience of grief and sadness, which made them feel diminished and inclined to trust the team less and less. This can indicate that the needs of these parents were not adequately identified by these professionals⁽³²⁾. The attitudes of health professionals involved in a child's hospitalization

can also influence the entire family's emotional health⁽³⁴⁾. If, on the one hand, effective communication with children and their families minimizes uncertainty and anxiety⁽²⁵⁾, on the other, lack of discussion and clarification helps make them even more anxious⁽²⁴⁾.

Communication is one of the most important factors to be considered in hospital admission⁽⁶⁾. It must be present in all of the moments involving the child-family-professional triad. However, what we found in this synthesis is that, for the most part, good communication is not present. For example, we cited aspects regarding the negotiation of care and clarification of the parental role during the hospital stay. Corroborating our findings, one study⁽⁶⁾ found that parents face many challenges, such as confusion regarding their role in the hospital and not knowing what is expected of them during this period. We must also consider that many parents try to adjust their role to meet the expectations of the health professionals in order to ensure their child's care.

The presence of parents in the hospital is a good opportunity for nurses to involve them in their child's care. However, due to lack of human resources and time, professionals end up gradually delegating some aspects of nursing care to parents in order to reduce their own workload⁽¹⁰⁾. Parents tend to feel lost in such a situation, for even though they want to be at their child's side to provide support and comfort, they are afraid of taking on some of the responsibilities of care. They want to provide the same care they provided at home, but do not want to be seen as nursing professionals and take on care they are not trained to perform⁽³⁰⁾.

Nevertheless, parents do not give up their right to stay by the child's side during hospitalization, whether for the child's comfort and support⁽¹⁷⁾, to maintain control of the situation⁽¹⁷⁾, or even ensure their safety⁽⁷⁾, as was mentioned in one of the studies⁽³⁰⁾. This study identified that parents felt the need to remain at the child's side or to monitor as a way of "trying to protect" the child. This study⁽³⁰⁾ found that parents were afraid that something could go wrong with the child, many times based on

previous care experiences provided upon admission or at the beginning of the hospitalization period.

Despite this need for monitoring, the same study⁽³⁰⁾ found that parents concerned themselves with the technical skills of the professionals only when a specific incident occurred or when the child experienced discomfort, distress, or pain. Parents are extremely surprised or incredulous when something happens that can traumatize the child. This shows that the trust of parents has to be earned, especially through the quality of care provided by the team and, that for parents, this quality manifests itself as “not making the child suffer” or “being aware of their emotions and needs.”

However, even if the health team strives to answer the questions and meet the needs of parents and child, they do not always find mechanisms to help them reach this goal. Often, lack of support, communication, and interaction between the health team and parents are consequences of scarce resources in the institution in which the child is hospitalized. Due to reduced staff and overcrowded wards, professionals do not have enough time to develop significant relationship with parents⁽³⁷⁾.

CONCLUSION

The search for evidence conducted by this study through identifying, gathering, and synthesizing knowledge showed that parents present numerous needs during their child's hospitalization. These needs can be related to the parents themselves, the health team, or the institution in which the child is hospitalized. These findings indicate that accessing, evaluating, and meeting the needs of parents in this context is a group task, mobilizing spheres at the level of the health institution and requiring integrated action between professionals and even the parents that are with their children during this period. To this end, investment must be made by health services to improve infrastructure, providing resources that at minimum meet the basic needs of parents, such as sleep, food, and hygiene. Furthermore, it is important to invest in health teams, hiring human

resources proportional to the number of patients cared for by the service and providing the staff with training and qualifications in order to improve assistance.

Within the health team, professionals must be able to identify the needs of parents and direct actions in order to meet such needs. Communication must be used as an interaction tool between the child-family-team triad by transmitting clear and reliable information that answers the main questions of parents and provides the information requested by them. The team should also aim to make time to listen to parents and support them, caring and sympathizing with their emotions and yearnings.

Even though shared care is important and essential, it must be done responsibly and in partnership so that parents do not feel overloaded, but understand and carry out their role of caring for the child with safety and satisfaction. Furthermore, professionals must seek to keep updated and improve their abilities, earning the family's trust and ensuring the quality of care and assistance given to the hospitalized child.

Nurses should present themselves as the child's and family's partner during the hospitalization process, developing a comprehensive and human perspective on this pair. Both must be seen as the target of nursing care, in such a way that care is thought about and planned together with parents, qualifying them to make decisions. Unfortunately, there are still many barriers that make such professional practice difficult and prevent these parental needs from being met. Further studies should be conducted to identify such barriers and to propose interventions to overcome them and direct the actions of health teams.

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