NURSING CARE FOR THE FAMILIES OF HOSPITALIZED CHILDREN AND ADOLESCENTS

CUIDAR DE ENFERMAGEM ÀS FAMÍLIAS DE CRIANÇAS E ADOLESCENTES HOSPITALIZADOS ATENCIÓN DE ENFERMERÍA A LAS FAMILIAS DE NIÑOS Y ADOLESCENTES HOSPITALIZADOS

Lucas Batista Ferreira¹, Jonas Sâmia Albuquerque de Oliveira², Rafaella Guilherme Gonçalves³, Tatiana Maria Nóbrega Elias⁴, Soraya Maria de Medeiros⁵, Deborah Dinorah de Sá Mororó⁶

ABSTRACT

Objective: to describe the strategies adopted by nurses in order to provide the families of hospitalized children and adolescents with care. **Method:** this is a qualitative study, guided by thematic oral history, conducted with 12 nurses at a pediatric hospital. A semi-structured interview script was used to collect data. Data was organized and codified by using the software *Atlas.ti 7.0 (Qualitative Research and Solutions)*, obtaining the categories: The family from nurses' viewpoint: conceptual perspective; and Nurses providing the families of hospitalized children with care. **Results:** it was revealed that nurses turn the establishment of bonds, communication, health education, and search for support from the multiprofessional team, as well as a qualified listening and a calm professional attitude, into strategies to provide the families of hospitalized children and adolescents with care. **Conclusion:** the strategies used by nurses take place in the subjective dimension, and, in the essence, they are of great importance, by contributing to a better coping with the hard experience that hospitalization represents for the binomial family/child; these nurses also have a closer relationship with both the family and the child, getting to know their needs better. **Descriptors:** Nursing Care; Family; Child, Hospitalized; Adolescent; Hospitalization; Pediatric Nursing.

RESUMO

Objetivo: descrever as estratégias adotadas pelos enfermeiros para o cuidado de famílias de crianças e adolescentes hospitalizados. **Método:** trata-se de um estudo qualitativo, norteado pela história oral temática, realizado com 12 enfermeiros em um hospital pediátrico. Utilizou-se um roteiro de entrevista semiestruturado para a coleta de dados. Organizaram-se e codificaram-se os dados por meio do programa computacional *Atlas.ti 7.0 (Qualitative Research and Solutions)*, obtendo-se as categorias: A família na visão de enfermeiros: perspectiva conceitual; e Os enfermeiros cuidando de famílias de crianças hospitalizadas. **Resultados:** revelou-se que os enfermeiros fazem do estabelecimento do vínculo, da comunicação, da educação em saúde e da busca por suporte da equipe multiprofissional, bem como da escuta qualificada e da postura profissional tranquila, estratégias para o cuidado de famílias de crianças e adolescentes hospitalizados. **Conclusão:** dão-se na dimensão subjetiva as estratégias utilizadas pelos enfermeiros, que, em sua essência, têm grande relevância, pois contribuem com um melhor enfrentamento da experiência difícil que a hospitalização representa para o binômio família/criança; esses enfermeiros também têm uma relação mais próxima tanto com a família como com a criança, conhecendo melhor suas necessidades. **Descritores:** Cuidado de Enfermagem; Família; Criança Hospitalizada; Adolescente; Hospitalização; Enfermagem Pediátrica.

RESUMEN

Objetivo: describir las estrategias adoptadas por los enfermeros para brindar atención a familias de niños y adolescentes hospitalizados. **Método:** este es un estudio cualitativo, guiado por la historia oral temática, realizado con 12 enfermeros en un hospital pediátrico. Se utilizó un guión de entrevista semi-estructurado para recoger datos. Los datos se organizaron y codificaron utilizando el software *Atlas.ti 7.0 (Qualitative Research and Solutions)*, obteniendo las categorías: La familia desde el punto de vista de enfermeros: perspectiva conceptual; y Los enfermeros que brindan atención a familias de niños hospitalizados. **Resultados:** se reveló que los enfermeros convierten el establecimiento del vínculo, de la comunicación, la educación para salud y la búsqueda de soporte del equipo multiprofesional, así como de la escucha calificada y la actitud profesional tranquila, en estrategias para brindar atención a familias de niños y adolescentes hospitalizados. **Conclusión:** las estrategias utilizadas por los enfermeros tienen lugar en la dimensión subjetiva y, en esencia, son de gran importancia, contribuyendo a hacer frente a la experiencia difícil que representa la hospitalización para el binomio familia/niño; esos enfermeros también tienen una relación más cercana tanto con la familia como con el niño, conociendo mejor sus necesidades. **Descriptor:** Atención de Enfermería; Familia; Niño Hospitalizado; Adolescente; Hospitalización; Enfermería Pediátrica.

¹Nurse, Federal University of Rio Grande do Norte (UFRN). Natal (RN), Brazil. Email: lucas08batista@gmail.com ORCID iD: <https://orcid.org/0000-0003-0539-9121>; ²Ph.D., UFRN. Natal (RN), Brazil. Email: jonassamiufrn@yahoo.com.br ORCID iD: <https://orcid.org/0000-0003-0303-409X>; ³MS student, UFRN. Natal (RN), Brazil. Email: goncalvesraffaella@gmail.com ORCID iD: <https://orcid.org/0000-0001-8006-8061>; ⁴MS, Universidade Potiguar (UnP). Natal (RN), Brazil. Email: tatianaelias@gmail.com ORCID iD: <https://orcid.org/0000-0001-9104-3716>; ⁵Ph.D., University of São Paulo (USP). Natal (RN), Brazil. Email: sorayamaria_ufrn@hotmail.com ORCID iD: <https://orcid.org/0000-0003-2833-9762>; ⁶Ph.D., UFRN. Natal (RN), Brazil. Email: deborahsa1@hotmail.com ORCID iD: <https://orcid.org/0000-0002-0936-0761>

INTRODUCTION

Since the advent of the Brazilian Child and Teenager Statute (Estatuto da Criança e do Adolescente - ECA), children and adolescents' rights have been legally conquered, which were previously not guaranteed, including the right to life and health. It has been reported that the ECA lists the duties to be fulfilled by health facilities, to provide comprehensive child and adolescent care, among them enabling proper conditions for the permanence of a parent or guardian if the child or adolescent is hospitalized.¹

Children's hospitalization usually leads to disorganization of daily life and family environments, and family members set the child's health and well-being as a priority.² It is shown that this daily life change may be, intensely, considered a hard time for the whole family group and this tends to generate distress.³

Nursing professionals are required, due to the fact that hospitalization is regarded as a hard experience, to take actions that reduce the child and family's anguish, and this is key to comprehensive care.⁴ It is understood that actions towards solidarity, closeness, affinity, bonding, accountability, and support are tools that can help the family feeling more safe and strong in the face of child hospitalization.⁵

It is known that patient-and family-centered care (PFCC) is an approach that recognizes family significance as a healthcare user, by ensuring its participation in the planning of actions and taking into account that it has influence on patient's health and it must be seen as a partner in improving practices and the healthcare system.⁶⁻⁷

The PFCC implementation seeks to meet not only clinical, but also emotional, affective, and social needs, enabling a more comprehensive care, which requires a change in the ways of providing hospitalized children and adolescents with care.⁶

The concept of this philosophy of healthcare has been advocated for a number of years by pediatric nursing, however, the detachment between the nursing work process and the hospitalization experience from the family viewpoint has been observed.² It is clearly common, in hospital everyday life, a healthcare centered only on hospitalized children. It is known that this scenario is contrary to the discussion and publication of the main studies that indicate the use of healthcare strategies along with families that go through such a distressing experience.⁸

It becomes a challenge faced by pediatric nursing to be capable of assisting the child and her/his family in various healthcare contexts, by recognizing the family as a complex system with a heterogeneous structure, peculiar functioning, dynamic and changeable roles, and multiple and individual needs, especially in health-disease situations.⁹

By means of research, the significance and benefits of the therapeutic interaction between the child, the family, and nursing are demonstrated, and this can contribute to the autonomy of those involved, less work overload, greater satisfaction with the healthcare provided, decreased number of adverse events, comfort, and family embracement in this traumatic time and decreased length of hospital stay.^{5,10-2}

This research is justified by the relevance of the theme, the lack of studies related to family-centered care strategies, and the findings in the practical field of nursing care deficits centered on the family approach to hospitalized children and adolescents, by exploring the possibilities of family care on the part of nurses.

OBJECTIVE

- To describe the strategies adopted by nurses to provide the families of hospitalized children and adolescents with care.

METHOD

This is a qualitative, descriptive study, guided by thematic oral history, conducted at a pediatric philanthropic hospital in Natal, Rio Grande do Norte, Brazil.

Twelve nurses were selected as research participants, according to these inclusion criteria: having an employment agreement with the study site; and voluntarily agreeing to participate in the study. The exclusion criteria were: being on vacation or on work leave within the data collection period and refusing to participate.

A semi-structured interview was adopted for data collection, guided by a script, divided into two parts: the first with close-ended questions about the socio-demographic variables related to respondents, such as age, sex, marital status, weekly workload, and specialization in Child Health; and the second with topics and open-ended questions related to nursing care for the families of children undergoing the hospitalization process. It is reported that, in order to register the data collected at each interview, a digital recorder was used after written permission by participants.

Participants were interviewed at the workplace, with meetings previously scheduled via telephone, depending on their availability. It is pointed out that the interviews were converted into written documents. In this process, three steps were accomplished: 1) the initial transcript, i.e. the conversion of oral content into written content; 2) the textualization, i.e. correction of spelling and grammar errors, as well as the elimination of sounds or noise and the adaptation of meaningless words in the context at stake, in order to make the text comprehensible; and 3) the final transcript, which consists in the wording of the whole text with authorial intervention.¹³

Data were organized and codified by using the software *Atlas.ti 7.0 (Qualitative Research and Solutions)* for qualitative analysis. It is noticed at the material exploration stage that the codification of information contained in the material seeks to reach the text sense nucleus. *Quotations* or *quotes* were made, citations of the primary documents, i.e. in the particular case of this research, consisted in selected fragments of respondents' speeches. Then, the *codes* were assigned, just after the *quotations*, represented by the codification, through typing by a word or a set of words of each *quotation* pre-established in pre-analysis.

Finally, these *codes* were classified in thematic categories (*families*), which are the sets of primary documents, *codes* or *memos* grouped by convenience or by theoretical closeness. Next, the thematic axes that favor highlighting the main healthcare strategies adopted by nurses along with the families of hospitalized children and adolescents were developed. In this method, raw data is emphasized, having empirical research as a basis, which underwent the steps of: a) pre-analysis; b) material exploration; c) processing of data obtained; and d) interpretation of results.¹⁴

Two categories were obtained in this study: 1) The family from nurses' viewpoint: conceptual perspective; and 2) Nurses providing the families of hospitalized children with care. In the processing of results and interpretation, "the analyst, having at his disposal significant and faithful results, may then propose inferences and advance interpretations in relation to the intended purposes, or other unexpected discoveries."¹³

At this stage, the software made it easier to organize networks for visualization of the main results, which were interpreted taking into account the theorization of the child and

family-centered care model, as well as Neuman's Systems Theory.

Next, in data evaluation, thematic oral history took place, which presupposes narratives with direct objectivity based on a specific subject and selected in advance. Thus, the study assumes to clarify or assess the interviewer on a particular case.¹³ The reports by nurses from the pediatric hospital were systematized according to the main information observed in respondents' speeches, in order to identify the most significant themes that represent the healthcare provided to the families of hospitalized children and adolescents.

RESULTS

Twelve nurses, 11 women and 1 man, aged between 24 and 59 years old, were selected for the study, 8 of them single and 4 married. It is shown that the participants' length of time working in the institution ranged between less than 6 months and more than 10 years and the participants' weekly workload was between 30 and 48 hours a week. It is defined that, in relation to having a graduate degree in Child Health, only 4 out of the 12 participants had a specialization certificate: 3 in Neonatal and Pediatric Intensive Care Unit; and 1 in Child Health. The results are presented in a descriptive way, into 2 categories of analysis.

♦ The family from nurses' viewpoint: conceptual perspective

This analytical category was included in the study regarding the search for the concept of family presented by participants considering their vocational education, life history, and experience in the context of pediatric hospitalization, having in mind that the concept of family can influence the healthcare for family members of children and adolescents undergoing the hospitalization process.

The study participants described a family, according to the profile of its members, which shows to be relevant in the construction of a citizen's personality, character, and principles, as illustrated in the following lines:

For me, it is the basis of everything. Family is the foundation, there are principles to develop the character, personality of any citizen. (N10)

A family, in fact, means a base that comes from the beginning and this lasts a whole lifetime. Family is very important! (N4)

It is a structural base in the development of any human being. It is a reference between healthcare, bases, values, ethical issues aimed at the social environment. So, for the

sake of inclusion, I believe we have this whole set in the family as a subject. (N11)

It has been highlighted in the discourse of some research participants that the family shows itself in the sacred dimension, with features referring to religiosity, as expressed in the speech below:

It is a divine institution for me. It is something that God has created, very important. (N8)

In addition to this sacred dimension, the family has been described by nurses as a space where we can find safety, in situations of daily life routine or in solving problems, as described in the following speeches:

Family means everything, it's our safe harbor. (N7)

Family is very important, because it is the child's comfort when hospitalized here. (N8)

In terms of the concept of family described by nurses, the dimensions of foundation and base of the structure and development of the human being were pointed out. Besides, the divine creation was related to the family dimension and the family relationship was depicted as a safe harbor in situations of adversity.

♦ Nursing care for the families of hospitalized children

In this category of analysis, the dimensions of care provided by nurses to the families of hospitalized children and adolescents are discussed. It is stated that these professionals, who experience daily life work in a pediatric hospital unit, highlighted six main healthcare strategies adopted by them along with the families of hospitalized children and adolescents (Figure 1).

Figure 1. Healthcare strategies adopted by nurses along with the families of hospitalized children and adolescents. Natal, 2016.

It is shown by the findings of this study that these professionals, when establishing bonds with families, insert the communication dimension in the healthcare provided, as observed in the speeches below:

We go on with our visit and they start talking, we discover things they tell only due to that strong bond. (N1)

I try to stay closer to the family; we know that the bond ends up taking place [...] we know that the bond is very significant, due to the confidence that nurse conveys to the family. (N4)

Communication was reported by nurses as a major factor for the credibility of healthcare and routine hospitalization of children and adolescents. Another healthcare dimension that these professionals reported to adopt refers to specific competence nuclei of other professionals belonging to the

multiprofessional team, especially psychologists, social workers, and nutritionists.

It is added that by means of the communication and bonding established with families, nurses can have a closer relationship with families, getting to know their needs better and gaining their trust. This identification is used, nurses indicate to the professionals mentioned above their attempt to seek support for families. This scenario is depicted in the reports below:

As a nurse, we talk and, if needed, we call for these practitioners, psychology, social service, in order to talk, too, so that we work together. (N10)

The healthcare actions we take are, for instance, when the mother is going through a hard time, we should call the psychologist. As for food, we call the

nutritionist. We call the social worker to deal with any social issue, this is our duty. (N9)

It was registered that another way described by nurses when providing the families of hospitalized children and adolescents with care concerns health education measures in the hospital environment. It is worth emphasizing that this refers to the institutional routine, the functioning of sectors, the hygiene and infection prevention measures, as well as the maximum information about the invasive care that hospitalized children and adolescents need:

[...] in relation to the procedures, I always explain what I am doing and why I am doing it. This is what I do in relation to the family and I provide guidance, in case they have any questions. (N3)

When they arrive, the relatives of children who are already here and the others who are going to visit, I always talk to them, I tell what the ICU is like and I explain them what the place is, that this setting is predisposed to infections, I explain the status of protection, handwashing. (N4)

I try to advise on the significance of hygiene in the environment to provide their children with care, both their own and the others'. (N6)

Qualified listening was also constituted as a healthcare way on the part of nurses towards families. They have reported that, on many occasions, they make available the tool for listening and grasping doubts, anxieties, denials, affirmations, and disappointments as a possibility to provide families with care, such as:

We, as a nurse, we talk. (N10)

Well, in order to minimize it all, such a distress, this hospitalization time, we have to listen. We also give our shoulder, but leaving the boundaries there, all right. I am a nurse, I can listen to you, try to solve something. (N12)

In addition to listening and availability, the nurses pointed out a calm professional attitude, along with the understanding of what the child hospitalization experience is, as something important to be considered when providing families with care. We can observe this in the speeches below:

[...] I explain the status of protection, handwashing, sometimes some people even think it is strange, sometimes they get irritated, but we take it right and explain so that they are careful, [...] and we come to a consensus, we are always talking. (N4)

[...] thus, I try to be as calm as possible, so that I can deal with them, even because they are mothers who spend a lot of time

here, they are already stressed, thus, it is a drop of water leading them to get even more stressed. (N6)

DISCUSSION

It is possible to interfere, by means of the idea that each nursing team member has about the family of a hospitalized child, in the healthcare practice, in the sense of including or not the family in practical activities.¹⁵

It was indicated, by the findings of this study, that the family was seen, by most of the participants, as an element of the structure and social development of a human being. It is linked to family creation and relationship as a safe harbor in situations of adversity.

It is inferred that family is a crucial concept of analysis, since it defines the initial and primary structure for the interrelation between individuals and their space with the social environment, and the family is in charge of establishing the standards and values, constituting itself as a group located in a shared space-time where each individual has a defined role (sexuality, reproduction, socialization, and healthcare) that derives from the unfolding of social life.¹⁶

It is observed, in the context of child growth, that the family is key, because its members play a role in the process of social, emotional, and biological existence, in all contexts where the child is in and especially in the hospital environment, where the child finds, in family members, the strength and safety needed to face the painful and unknown processes and, therefore, the presence of a family representative is key.¹⁷

It is exposed that, in this way, nurses from pediatric units deal directly with the family of hospitalized children and adolescents. It is demonstrated that, as these families are seen by healthcare practitioners as a healthcare user, considering the PFCC, healthcare strategies should be prepared to serve them. It is stated that the child's illness and hospitalization are hard and stressful situations for the binomial family/child. It is understood that supporting the ill child and her/his parents is an indispensable element to provide ill children with care.

It is reported, in the case of the support offered in nursing care for the parents of hospitalized children, that Margaret Miles has developed an evaluation model based on four elements: emotional support; evaluation support; information support; and instrumental support.¹⁸

It is understood that it is crucial to establish a bond in the interrelationship of the triad (patient/family/team). It is revealed that sincere and true attitudes are the keys for success in the relationship between the nursing team and the companion.¹⁹

The affective bond established in the care for some children and their families, stimulating them to stay longer with the child and to give their affection and attention, going beyond the technical care.¹⁵

It is allowed, through communication between the nurse and the family of a hospitalized child, to make the meeting of the triad (patient/family/team) easier, when it becomes possible to consolidate bonds by fostering actions based on respect and observing the needs and peculiarities of each family.^{4,20}

It is considered that, in order to be effective, this communication needs to reach the family and be understood, it must be horizontal, generate bonds, accountability, and autonomy of those involved, thus, there must be an exchange of knowledge, with a view to adapting the family to the reality of hospitalization and contributing to recover the child's health.²

Nursing education is put into practice through clarification of issues involving child hospitalization, doubts about procedures, risks of infection within the hospital environment, proper hygiene measures, and the functioning of sectors.

It is noticed that, as the information about the child's health and the procedures needed are made available and clarified to the parents, they become more capable of overcoming the hospitalization experience, being closer to children and asking more questions about diseases and procedures.²⁰

It is clarified that parents are eager for information, they appreciate all questions related to the child's health, as well as the possible consequences that the disease can cause to her/his life in the future.^{7,21}

It is understood that nurses show concern by identifying conflicting situations in families, which can make the hospitalization experience harder for the binomial family/child, thus, they ask for the contribution of other healthcare team members in the face of problems identified. Continuing care provided by the multiprofessional team to existing family conflict situations becomes a must, in order to adopt effective ways to meet urgent stress-related needs that illness can cause.²²

On the other hand, it is confirmed by the study, by claiming that nurses ask for a colleague when they need help regarding mental health issues of the patient/family. It is indicated that these healthcare practitioners should participate in training sessions to improve management in the face of established relationships with patients and their family members. It is highlighted that the patient/family, regarded as difficult to contact, may be going through a period of anxiety or conflict due to hospitalization, and understanding this aspect allows health practitioners to resort to embracement.⁴

It is revealed that the nursing practitioner does not play the role of psychologist, however, it is noticed that, when listening to the family, the latter feels embraced and respected as for its emotional needs.¹⁵

It has been found that qualified listening by nurses demonstrates the attention and interest in what the families express, not neglecting the feelings that surround them in face of hospitalization and observing their needs. It is pointed out that the companions of hospitalized children need to talk about their problems, anxieties, fears, doubts, and experiences in the current hospitalization, therefore, they demand attention and recognition as patients on the part of healthcare practitioners.²

It is emphasized that, by taking a calm and embracing professional attitude, nurses aim not to be another stressor for families of children and adolescents who already undergo the distressing and hard hospitalization experience. It is shown through small gestures, friendly gaze, quiet voice, the relationships that are consolidated between health professionals and their families²³, thus contributing to a better coping of the period in which the family remains in the hospital.

It may be indicated that Neuman's Systems Theory provides care for the child and her/his family with a basis and that the user (individual/family/community) is considered as an exposed system that responds to stressors (of intra-, inter-, and extra-personal origin) existing in the environment. It may be claimed that its responses are influenced by physiological, psychological, sociocultural, developmental, and spiritual variables. It is demonstrated that nursing care actions should occur in order to help users resorting to their ability to respond to stressors. Based on this theory, it is sought to reduce the variables that influence the system's reactions to stressors.²⁴

In some countries, family-centered care has evolved to varying magnitudes. It is

pointed out that patients and their families, besides playing an active role in healthcare and decision making, became recognized as advisors and collaborators in teaching, contributing to a better quality and a redesign of the healthcare system.²⁵

However, it was found by a study carried out in Poland, assessing the perception of parents of hospitalized children about the nursing care provided to them, that the family members considered the instrumental support given by nurses as unsatisfactory.²⁶

It is warned that, in Brazil, there is family-centered care in pediatric health institutions, but lacking major expression, so, in the hospital environment, there is a predominance of isolated actions taken by practitioners who give attention to the family because they are emotionally moved by its situation.²⁵

Thus, the family-centered care approach shows to be needed in vocational education courses, either at High School technical education, undergraduate, and graduate levels, and/or in refresher courses, offering curricular components on the theme and presenting the positive impacts that this knowledge brings to professional practice.¹⁵

CONCLUSION

In this study, six main healthcare strategies adopted by nurses along with the families of hospitalized children and adolescents were identified: embracement; communication; health education; search for support from the multiprofessional team; qualified listening; and calm professional attitude. It is demonstrated that apparently simple healthcare actions, in fact, take major relevance, as they contribute to a better coping with the hard experience that hospitalization represents for the binomial family/child.

It is worth emphasizing the significance of using Neuman's Systems Theory to provide the healthcare for the families of hospitalized children and adolescents with a basis, as it aims to reduce the variables that influence the system's (family's) responses to stressors existing in the environment (hospital).

To do this, the need for healthcare actions aimed at a paradigm shift of healthcare models focused on children's illnesses or the child itself is highlighted, considering her/his growth and development process, as it is commonly seen in pediatric hospitals, in order to take a child- and family-centered approach, which, in turn, is regarded as a routine in children and adolescents' lives.

The study was conducted in only one pediatric hospital, a fact that constitutes a limitation of this research.

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Corresponding Address

Jonas Sâmi Albuquerque de Oliveira

Rua Goianinha, 22 / Ap, 103

Nova Parnamirim

CEP: 59150-480 — Parnamirim (RN), Brazil