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FAMILY VIEW ON THE SHARED CARE OF HOSPITALIZED CHILDREN WITH CHRONIC CONDITION

VISÃO DE FAMILIARES SOBRE O CUIDADO COMPARTILHADO DA CRIANÇA COM CONDIÇÃO CRÔNICA HOSPITALIZADA

VISIÓN FAMILIAR SOBRE EL CUIDADO COMPARTIDO DE NIÑOS CON CONDICIÓN CRÓNICA HOSPITALIZADA

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Objective: to understand the view of family members of children with chronic hospitalized conditions about shared care with the nursing team. Method: qualitative, exploratory and descriptive study, conducted with ten relatives of children with chronic conditions hospitalized in the clinical, surgical and pediatric intensive wards of a University Hospital in Rio de Janeiro, Brazil. Data collection occurred through the application of semi-structured interviews. The data were analyzed by content analysis. Results: four categories were identified: Seeking a definition for shared care; Helping and learning during hospitalization; Exemplifying the ways to perform shared care in the hospital environment; Sensations experienced by shared care. Final considerations: in the view of caregivers of children in chronic conditions, the sharing of care in hospitalizations is perceived as the help of companions to professionals, and not as part of care. Moments of exchange and learning were identified, but care seemed to be more compartmentalized than shared.

Descriptors: Family. Child, Hospitalized. Chronic Disease. Professional-Family Relations. Nursing.

Objetivo: compreender a visão dos familiares de criança com condição crônica hospitalizada sobre o cuidado compartilhado com a equipe de enfermagem. Método: estudo qualitativo, exploratório e descritivo, realizado com dez familiares de crianças com condições crônicas internadas nas enfermarias clínica, cirúrgica e intensiva pediátrica de um Hospital Universitário no Rio de Janeiro, Brasil. A coleta de dados ocorreu mediante aplicação de entrevista

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semiestruturada. Os dados foram analisados pela análise de conteúdo. Resultados: identificou-se quatro categorias: Buscando uma definição para cuidado compartilhado; Ajudando e aprendendo durante a hospitalização; Exemplificando as formas de realizar cuidado compartilhado no ambiente hospitalar; Sensações vivenciadas pelos cuidados compartilhados. Considerações Finais: na visão dos cuidadores de crianças em condição crônica, o compartilhamento do cuidado nas hospitalizações é percebido como ajuda dos acompanhantes aos profissionais, e não como parte do cuidado. Foram identificados momentos de troca e aprendizado, porém o cuidado pareceu ser mais compartimentado do que compartilhado.

Descritores: Família. Criança Hospitalizada. Doença Crônica. Relações Profissional-Família. Enfermagem.

Objetivo: comprender la visión de los familiares de niños con enfermedades crónicas hospitalizadas sobre la atención compartida con el equipo de enfermería. Método: estudio cualitativo, exploratorio y descriptivo, realizado con diez familiares de niños con enfermedades crónicas hospitalizados en las salas intensivas clínicas, quirúrgicas y pediátricas de un Hospital Universitario de Río de Janeiro, Brasil. La recolección de datos se produjo mediante la aplicación de entrevistas semiestructuradas. Los datos fueron analizados por análisis de contenido. Resultados: se identificaron cuatro categorías: Búsqueda de una definición de atención compartida; Ayudar y aprender durante la hospitalización; Ejemplificar las formas de realizar la atención compartida en el ámbito hospitalario; Sensaciones experimentadas por el cuidado compartido. Consideraciones finales: en opinión de los cuidadores de niños en condiciones crónicas, el reparto de cuidados en las hospitalizaciones se percibe como la ayuda de los acompañantes a los profesionales, y no como parte de los cuidados. Se identificaron momentos de intercambio y aprendizaje, pero el cuidado parecía estar más compartimentado que compartido.

Descriptores: Familia. Niño Hospitalizado. Enfermedad Crónica. Relaciones Profesional-Familia. Enfermería.

Introduction

Chronic health conditions are situations that require continuous and long-term treatments that require long-term care. They comprise both chronic and infectious diseases, since they are health situations that require continuous, long-term treatments that require care continuity, interruption and incorporation of life routines[1]. In children, chronic conditions may be related to physical conditions, mental illnesses, developmental and learning disabilities. Among the many chronic childhood diseases, cystic fibrosis, congenital heart diseases, cerebral paralysis and cancer stand out[2].

The chronic condition for children and their family means life changes that require adaptations and strategies to cope with the diagnosis and support their needs. It is then essential to follow the child and family during the entire treatment, as well as the creation of bonds of trust and safety with the health team[2]. Among Brazilians, in the infant population, 9.1% of children aged 0 to 5 years, 9.7% from 6 to 13 years and 11% of adolescents aged 14 to 19 years have chronic disease[3].

The chronic condition of a child is responsible for the large number of hospital admissions, which require continuous care and do not always lead to cure[4]. One cannot think of child hospitalization without linking the family to this process. According to the Byelaw of the Child and Adolescent, it is children's right that health care facilities provide conditions for full-time companion[5]. During hospitalization, the child's family becomes intercessory and co-responsible for the child in the hospital[6].

The role of nurses in the process of adapting families to the disease is fundamental to help them find the best way to face this mission[7]. The care of hospitalized children with chronic conditions implies recognizing both the child and the family as multidimensional beings and that must have their values identified. This offers nurses the opportunity of numerous interactions, since a pathology-centered approach is not enough to assist the child and his/her family in their complexity[8].

Child care requires not only technical knowledge, but a set of actions that involve both

their family member and nursing professional. It means respecting, embracing, understanding and meeting the needs of infant patients, seeking to minimize suffering through humanized and comprehensive care[9].

It is extremely important to hear the family and encourage them to expose their doubts and opinions throughout the care process, as they are essential for health promotion during hospitalization. Thus, nurses should stimulate the family's participation in this care, considering them a partner[10].

The implementation of shared care during hospitalizations has been increasingly stimulated. Shared care can be defined as the elaboration of a therapeutic project that involves the family and nursing, thus motivating the skills and abilities to develop communication, embracement and dialogue, giving opportunities to place the family member as the protagonist of care[11-12].

The family feels safer and more confident in the care received by the child, when interacting and sharing care with nursing professional and team. When family caregivers are heard and their claims are met, they recognize that the interactions with the team are positive and feel part of the routine, when taking part in the child's care[13].

Given the above and the restlessness of the researchers to understand how the shared care between the professional and the family member occurs, this study is significant and considerable, as it intends to give voice to family members, so that they can describe how shared care happens in their own vision.

Thus, the aim of this study was to understand the view of family members of hospitalized children with chronic condition about shared care with the nursing team.

Method

This is a qualitative, descriptive and exploratory study conducted in the pediatric and surgical clinic wards and in the pediatric intensive care unit (PICU) of a State University Hospital in the city of Rio de Janeiro.

The participants were relatives of children with chronic conditions hospitalized in the aforementioned wards, of both sexes, aged over 18 years. The inclusion criteria were: being the main caregiver in the hospital context; have a diagnosis of the child's chronic condition of at least three months; have undergone at least one hospitalization prior to the current one. These criteria are justified by the greater proximity of this caregiver to the care performed in the hospital, understanding that a minimum of three months since the beginning of the diagnosis allows him/her to understand this process.

Visiting relatives or sporadic caregiver and family caregiver of children hospitalized in the final phase of life were excluded. This decision was justified by the fragility and vulnerability in which these people are at that time.

The present study followed the determinations of Resolution n. 466/2012 of the National Health Council. The dignity and autonomy of the interviewees were respected, recognizing their vulnerability and guaranteeing them the will to continue or not participating in the research. The expected risks and benefits were considered, with impairment of maximum benefits and ensuring that predictable risks were avoided[14].

Data collection began after the approval of the study by the Human Research Ethics Committee of the institution of the study field, State University of Rio de Janeiro, under Opinion n. 4.631.805.

The family members who agreed to participate in the study signed the Informed Consent Form (ICF) and were informed about the objectives of the research, confidentiality and anonymity of the participants and destination of the results obtained. Any doubts that arose during the application were answered. To respect the anonymity of the participants, the letter "F" (family member) was used to identify them in this text, followed by the number referring to the order of the interviews. In addition to the interview, to characterize the participants, an instrument was used to collect sociodemographic data, containing the following items: kinship, date of birth, gender, skin color, occupation and education.

Data collection occurred through a semi-structured interview in a single meeting between interviewer and interviewee, from July to November 2021, in places reserved in the institution's own sector where the child was hospitalized. The interviews were audio recorded on a smartphone's voice recorder. The trigger questions were, "Have you ever heard of shared care?", "What is shared care for you?", "How does care happen together with the nursing team?", "What is the care you perform together with the nursing team when you are in the hospital?". It should be noted that, even if the first answer was negative, the other triggering questions were asked in order to understand the interviewee's previous knowledge about the theme. In addition to these, other questions were asked, according to the participants' answers. The interviews were closed when they did not bring new elements to the study, adopting the criterion of theoretical saturation of the data.

Data were analyzed by thematic content analysis, according to Bardin[15]. For this, the interviews were transcribed and analyzed thoroughly, following the steps: in first one, floating reading was made, choosing the corpus documents of the content analysis, formulation of hypotheses and objectives, reference of the indexes and elaboration of indicators and preparation of the material; in the second one, the material was exploited; and in the third one, the results obtained were treated and interpreted. This manuscript was written according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Results

Ten family members participated in the study: eight mothers, one father and one grandmother. Among the participants, 90% (n=9) were female. Age ranged from 22 to 45 years, with a mean of 32 years. About the occupation of the participants, 40% (n=4) were unemployed, 20% (n=2) were housekeepers, another 20% (n=2) were administrative assistants, and 10% (n=1) worked as manicures. Among the interviewees, 70% (n=7) had completed high school, 20% (n=2) completed elementary school and one participant (10%) reported having incomplete elementary school.

Based on the results obtained, it was possible to identify four categories: Seeking a definition for shared care; Helping and learning during hospitalization; Exemplifying the ways to perform shared care in the hospital environment; and Sensations experienced by shared care. The category "Helping and learning during hospitalization" was divided into two subcategories: Being supportive and Exchanging learning.

Seeking a definition for shared care

This category addresses how family caregivers defined the concept of shared care during the child's hospitalization, seeking a meaning for the term. The expression shared care, because it is something new and little spoken in health units, still causes doubts about its definition. In this research, many still did not know how to identify it, others reported having heard or at least knew of its existence.

> *For me, care is care* [laughs]. *I do not know that much. Shared care... I do not have much idea. Actually, I have already heard about this word. But I do not know what it is.* (F4).

> *I have no idea* [...] *For me, everything is new. I had to learn, I have learned very quickly.* (F7).

Some caregivers understood the term as an exchange of care between family and professional, more closely of what would be the real meaning of the subject in question.

> *Shared care is about parents with the professional, right? I guess it is a joint work, of parents and professional* [...] *the routine, that moment, you with the professional, treating and taking care of the patient, and us, as parents, observing, watching, learning and doing what we can do.* (F8).

> *Here in the ward, with the nurses, reconciling the patient's care with the nurses, is that it?* (F1).

The expression could be perceived as a division of care, a breakdown of the tasks that needed to be performed among people, as in the following statement:

> *It is to share the care with another person, right?* [share the care with] *my son.* (F2).

Helping and learning during hospitalization

This category shows how shared care was seen in their practice by family members within hospitalization units. At certain times, this care was seen as a collaborative form among the subjects; in others, as a form of teaching-learning, that is, an exchange of knowledge between professional and family. Thus, two subcategories emerged: Being supportive and Exchanging learning.

Being supportive

The care shared between nursing professionals and family members was mentioned by most participants as a form of help that the family member offered the professional. For some participants, care appeared collaboratively, being a support of the guardian for the professional, a solidarity act, helping those who were taking professional care of the child.

> *But I am paying attention to help, I see how they do it, so that, if another nurse comes and does not do it like the other, I say: "whatshername did it like that, it is how you do it". So, I try to participate in everything. I ask if I can do it, if I can help. They usually let me help.* (F2).

> *I know you cannot do it, because, if someone sees, the nurse can be reprehended, but I have to help. I cannot stand still, watching the person trying to do everything alone, with me just watching. As I am not holding the child, in my view, I think there is no problem in helping him.* (F6).

> *At bath's time, I hold him while she is doing the bed. Sometimes, they bathe him, and I help them with the water. Because she does it alone, it is too much for a single person, so I end up helping everyone.* (F7).

> *I think it is good, sharing, helping the nursing whenever they need. I think it is important for the companion to be together, also helping* [...] *because I guess I am being useful both for my daughter as for the nursing personnel. Because, sometimes, in case she is in pain, or something, I go and talk to the nursing.* (F10).

Exchanging learning

Often, sharing care was seen as a form of teaching and learning. An exchange of knowledge between professional and family, mixing scientific knowledge on the part of professionals and experiences about the child by caregivers.

> *I am watching the good care the team is offering, and I have to deepen more and more, got it?* [...] *see some things that, perhaps, I am not used to do at home, but I am doing here* [...] *So, I am getting more experience. I have already learned many things I did not know at home.* (F4).

> *I exchange, then they keep paying attention at what I am doing, then they ask, they keep asking me, how I do to exchange, the products I use for him, his hygiene* [...] *it is experience we keep exchanging. The nursing personnel sometimes does not know what I know and vice-versa.* (F6).

Exemplifying the ways to perform shared care in the hospital environment

This study unveiled that shared care occurred through various forms and at various times of hospitalization, according to family members. Thus, this category shows at what point this care was performed in the family caregiver's view.

Most of the family members saw shared care happening during the most basic procedures of daily life, such as hygiene, diaper change, feeding, even the most complex care, such as aspiration of secretion in tracheostomy.

> *In the morning, when he wakes up, we bathe him, exchange his clothes, make the dressings with the tracheum, nebulization, aspiration, gastric dressing. The following is the diet* [...] *Once in a while, while he is sleeping, I prefer giving him. When he is awake, they are responsible for it.* (F1).

> *I participate 24 hours. My dedication is 24 hours, the most I can, got it?* [...] *I exchange his clothes, when it is time to diaper him, whenever I can, I feed him, whenever I can, I bathe him, kind of it.* (F4).

> *For example, when it is time to change his ileo bag* [ileostomy bag] *I am the one who changes it, I am responsible for cleaning it, I put his bath things on the bed, I diaper him* [...] *I diaper him, I drain the bag, then the nursing personnel asks if have already diapered him, if he is already clean, then I say I have. Then I keep his diaper for them to weigh it.* (F6).

> *I help her eat, when she has difficult. I offer her food in her mouth, I ask her to hold the liquid, juices, milk. I offer in her hand* [...] *I used to accompany her in the bathroom, sometimes helped her in the bath too, in case she felt dizzy and fell. I held her, got it? Took her to the bed. Always accompanying her, in case she felt something and passed out, I would be with her.* (F10).

Shared care was also observed by caregivers as a way to support the child in difficult situations and be attentive to avoid complications or act quickly whenever they can happen.

> *We are always paying attention, in case of any reaction, in case he is not feeling well, or something, you are always there, you do not leave us until the chemotherapy is over. You are always observing and watching, in case of any event, you are there to help him right away. So am I, I am close, but supporting him, as a mother supporting him.* (F5).

> *During hygiene, when I have to hold her, who is a bit agitated, I held her hands. Talking to her for her to get calmer, bathing her and sometimes, when they had to collect her blood, to venipuncture her, to be easier. Also talking to her, to facilitate both sides.* (F9).

> *Because, suddenly, let us suppose, he feels sick, the nursing is already doing something else, I go there quickly and call for them. I guess it is important! It is important to have a companion too.* (F10).

Sensations experienced by shared care

This category shows the feeling that shared care generated in caregivers and how they demonstrated this in the care process, pointing out experiences.

The child's chronic condition often required specialized and complex care that family members were unaware of or afraid to perform. In addition, hospitalization and the devices that the child needed, such as venous access, for example, aroused extra insecurity and concern.

> *I mean, whenever I can do something, I do, without harming him, got it? Maybe something, I can do something harmful to him, so I prefer leaving for the team. Harming him losing an access, without being able to handle it, got it? So I feel more secure if the team does it, if the team is with me.* (F4).

> *Many things I am not able to do* [...] *usually, when he is with an access, I let most things for the nursing, because I am afraid of being helping and losing the access.* (F6).

> *How to deal? How to treat? Got it? And, I mean, I was very scared at the beginning, because those things are very delicate, it is a matter of a lot of care, a lot indeed.* (F9).

The family members identified the importance of the affection of the professionals for the children, showing security to rely on the team at all times, due to their attention and dedication. This was expressed by the participants by the feeling of gratitude and affection for the care provided to the child.

> *Whenever I need, they are ready to help me. If I call for them, they are willing to help me. They treat my grandson with kindness. I have nothing to complaint about. All I have is gratitude.* (F2).

> *I feel well. More so when you do it with kindness, as you always do, I feel calm. I like being able to do everything with my son.* (F4).

In addition, they identified the nursing team as part of their support network, since hospitalization brings distance from daily life not only for the child, but also for the family member.

> *Here in the hospital, you, nurses, end up being our backup. I do not know if all mothers feel like this. But I can say that, here, you end up being my backup. Because I am far from my family, so not always someone can talk with us. So, he feels sick and you see it right away. So you are always ready and end up being our backup.* (F5).

Finally, the family members pointed out some reasons for the importance of performing shared care for both the family member and the child during hospitalization:

> *And the nursing letting us be part in anyway, the least we can, is very important and calms us down, because they are things we lack in the routine, being close and the child feeling it, not only being beside him, but touching, helping, calming him down; So this openness for us to help in the care is extremely important.* (F9).

Discussion

The results presented allowed realizing that the family member has difficulty defining shared care, and identifies it as helping the health professional and as the exchange of experiences. However, he/she is able to exemplify the care shared through experiences lived during hospitalization of children with chronic conditions.

Studies on the sharing of care[12,16-17] highlight the importance of its performance between the nursing team and health users or their families, but do not bring the perception or understanding of those involved about the meaning of the theme studied, showing that the subject can still be little addressed with the subjects, bringing a great damage to care and patients.

The present study identified that the concept of shared care generates doubts among family members regarding its real meaning. Although some participants expressed a more similar idea, the statements still indicated doubts.

Studies indicate that shared care can be defined as that which occurs between patient, family and nursing, in a horizontal and reciprocal way, in which the subjects involved can share their knowledge, so that there is success in the care process, adding professional knowledge and experiences lived by patients and their families.

Thinking about care together provides that there is a critical analysis of care by the professional and a closer look on the part of family members. This generates changes in favor of the patient himself, bringing benefits during hospitalization and post-hospitalization[12,18].

Most participants saw shared care as a way to assist the work of the nursing team during routine procedures and care, participating from bathing to supporting more complex procedures. The exchange of experiences between family and professional, when performing daily care with the child, appeared as something important when talking about shared care, because the family caregiver, besides realizing that he was being heard, felt important in the process of caring for the child.

Even if nursing professionals have specific scientific knowledge for care, it is the family member who captures the changes that can occur with the child. Thus, the family member can be a great collaborator for the treatment of infant patients, when it gives essential information that helps in care. These, however, should not be devalued by the nursing professional[19].

This study did not identify joint care planning, but only the performance of some of them by the family member. However, another study indicated that parents of children with special needs value decision-making in partnership, as this facilitates family members to play their parental role[20].

It is evident that the nursing professional constitutes a link of informative and formative support. With this, the care shared during the hospitalization of a child with chronic conditions often generates the teaching-learning process between family and professional, especially in the first hospitalizations, soon after the discovery of the diagnosis. Thus, providing information about the child's clinical picture to family members should be a process repeated by the health team, allowing them to clarify any doubts and to obtain more information[21].

The transfer of knowledge between nursing and caregiver causes the caregiver to expose his/her points of view, in order to obtain the best care for the child, either by the scientific knowledge that nursing brings about care, or by the caregiver's life experience with the child. A study[16] states that, by sharing information, nurses and clients are able, together, to reflect on a given reality and analyze the importance of established practices. When they realize that they become inadequate, they both are willing to change.

The literature indicates that, by including the companion in care, the nursing team provides greater embracement and the family member feels more comfortable in interpersonal interaction. This occurrence provides the sharing of important information in child care[22].

Participants in this research considered that most of care provided by the nursing team during care could be shared with them, such as basic procedures from day to day to day life until more complex procedures, which involved technological devices. Shared care also emerges as support in more complicated situations that children go through during hospitalizations, as well as in moments of complications, in which companions need to be attentive to request interventions from the health team.

According to a study, families avoid depriving themselves of the role of caregivers during hospitalization, seeking to perform the child's comprehensive care and satisfying their demands, such as food, hygiene, and diaper change. They also strive to meet their needs, giving them attention and affection, besides being sentinels in the evolution of their child's health condition[17].

According to the literature, hospitalization in childhood can break routines in family relationships and, with this, often, the family member often gives nursing a reference role of support, thus contributing to the role of the family member in care and to shared care[12].

In hospitalization units, there is care close to that performed at home, which, even looking simple, appears as a new characteristic when using technological devices, making it complex[17]. Thus, some family members demonstrated fear and insecurity when this more complicated care sat, adopting a position of mere helpers, distancing themselves from their main role

in care. This appeared as a nuisance in the participants, because they did not act effectively in the care of their children, because of the child's clinical condition or simply because they did not have the knowledge of the specific demands presented.

This fact becomes alarming, considering that the lack of participation and construction of autonomy in care in the hospital environment can have harmful consequences in the continuity of home care with the child. The nursing professional need to act in the necessary orientations, in order to train this family member in care, respecting the singularity of the subject. A study points out that, as mothers learn techniques related to care, they achieve more autonomy, allowing them to gradually increase their responsibility in child care and, consequently, making them safer and committed to the child's condition[23].

As nursing becomes the point of reference and support for family members, the nursing professional is put in a privileged position to transform care, evidencing and valuing the role of these and collaborating for a responsible and respectable care[11].

The limitations of this study are related to the impossibility of generalizing the conclusions since it was carried out in only one hospital in Rio de Janeiro.

This study may contribute to clinical practice regarding care humanization, through shared care with the family caregiver of the infant patient. Concerning teaching and research, the development of this work contributes to a greater discussion in the area on the subject addressed, encouraging future research and sensitizing to a reflection on the theme in graduate and postgraduate studies.

Final considerations

It was possible to understand that caregivers' view on children in chronic condition about the sharing of care in hospitalizations often related it with the help of companions to professionals and not as part of care. Furthermore, many times, care was more compartmentalized or divided than shared and added together.

There was lack of information on the subject, since most of the participants in the research had a different view of what the real meaning of shared care was.

However, even though the statements distanced from the true concept, shared care occurred in the hospitalization units, when they mentioned that there was an exchange of learning during the daily care of the nursing team. This was due to the fact that some professionals put the caregiver in the care process, taking into account their experiences about the child, and because the family members themselves mentioned how much they learned from nursing during hospital admissions. Moreover, even with doubts, caregivers, together with the nursing team, exercised something of shared care during hospitalizations.

In addition, shared care, in the view of family members, went beyond daily procedures, such as hygiene, eating and even more complex procedures. They mentioned that they saw the sharing of care when, together with nursing professionals, they were able to provide emotional support to the children.

Thus, the nursing team needs to be attentive to the demands, in a unique way, respecting the individual process of each child and his/her family member when going through hospitalization.

Collaborations:

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2 – analysis and interpretation of data: Letícia Silva da Rocha, Michelle Darezzo Rodrigues Nunes, Isabella Fornerolli de Macedo and Letícia Guimarães Fassarella;

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4 – approval of the final version: Letícia Silva da Rocha, Michelle Darezzo Rodrigues Nunes, Isabella Fornerolli de Macedo, Letícia Guimarães Fassarella, Sandra Teixeira de Araújo Pacheco and Thais Alves Reis Evangelista.

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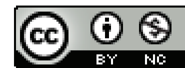

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