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Nursing's understanding of shared care for hospitalized children with a chronic condition

A compreensão da enfermagem acerca do cuidado compartilhado à criança com condição crônica hospitalizada

La comprensión de la enfermería sobre el cuidado compartido a niños hospitalizados con enfermedades crónicas

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ABSTRACT

Objective: to understand the Nursing profession's view of care shared between nursing teams and relatives/caregivers of children with a chronic condition. **Method**: this qualitative, descriptive, exploratory study involved 23 nursing personnel (5 nurses and 18 nursing technicians) in a pediatric unit of a state university hospital. Data were analyzed using Bardin thematic content analysis. **Results**: three categories were identified: Challenges in constructing shared care; Ways to promote shared care; and Benefits of shared care. They highlight both positive aspects to be improved so that shared care is effective and ways to achieve that. **Conclusion**: this study found positive aspects and challenges in the relationship between families and health personnel with a view to effective shared care. These can contribute to quality nursing care, highlight the educational aspect of care and favor interaction between health personnel and families.

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

RESUMO

Objetivo: compreender a visão do profissional de enfermagem sobre o cuidado compartilhado entre equipe de enfermagem e o familiar da criança com condição crônica. **Método: e**studo qualitativo, descritivo, exploratório realizado numa enfermaria de pediatria de um Hospital Estadual Universitário do Rio de Janeiro, com 23 profissionais de enfermagem, sendo 5 enfermeiras e 18 técnicas de enfermagem. Os dados foram analisados com base na técnica de análise de conteúdo temática segundo Bardin. **Resultados:** apreenderam-se três categorias: Desafios na construção do cuidado compartilhado; Maneiras de promover o cuidado compartilhado e Benefícios do cuidado compartilhado. Evidenciam aspectos positivos e que precisam ser melhorados para que o cuidado compartilhado seja efetivo e maneiras de realizá-lo. **Conclusão:** os resultados deste estudo evidenciaram aspectos positivos e desafios na relação profissional-familiar para efetivo cuidado compartilhado, estes poderão contribuir para assistência da enfermagem de qualidade, evidenciando o aspecto educativo do cuidado, favorecendo a interação entre profissional e familiares.

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

RESUMEN

Objetivo: comprender la perspectiva del profesional de enfermería acerca del cuidado compartido entre el equipo de enfermería y el familiar del niño con enfermedad crónica. **Método**: estudio cualitativo, descriptivo, exploratorio, realizado en una sala de enfermería pediátrica de un Hospital Universitario del Estado en Río de Janeiro, junto a 23 profesionales de enfermería: 5 enfermeros y 18 técnicos de enfermería. Los datos se analizaron mediante la técnica de análisis de contenido temático según Bardin. **Resultados**: se abordaron tres categorías: Desafíos en la construcción del cuidado compartido; Formas de promover la atención compartida y Beneficios de la atención compartida. Se presentan aspectos positivos que, sin embargo, necesitan mejoras para que el cuidado compartido sea eficaz y se muestran formas de hacerlo. **Conclusión**: los resultados de este estudio mostraron aspectos positivos y desafíos en la relación profesional-familia para un cuidado compartido eficaz, que pueden contribuir a una atención de enfermería de calidad, destacando el aspecto educativo del cuidado, favoreciendo la interacción entre el profesional y los familiares.

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

INTRODUCTION

Chronic conditions are problems that require continuous management over a long period, encompassing many aggravations[1]. Children with chronic conditions need some technology for survival, in addition to frequent hospitalizations and numerous procedures[2].

The treatment is generally long and complex, requiring constant care. Thus, it is important that the family is aware of the disease, its manifestations and complications, and is included and encouraged to participate in the care process[3].

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Family members play a fundamental role during this process not only for the child, but also for health professionals through the exchange of information about the child's condition, contributing to the care provided by the team[4].

Nursing is closer to the family and child, facilitating the creation of a bond with the subjects and providing greater visualization of the needs presented[5]. In addition, it becomes the point of reference and support for family members. Thus, nursing professionals are in a position of privilege to transform care, valuing the role of these family members and collaborating so that shared care is carried out in a responsible and respectable way[6].

In turn, shared care between the health team and the family involves developing a therapeutic project integrating the family and nursing, generating skills and capacity for communication, dialogue, acceptance and opportunities to be the protagonists of care[7]. Health professionals need to help, operationalize and empower these families to acquire care skills and competencies, making it safe and preserving their parenting[8].

Considering the importance of shared care in the development of family skills that encourage their role in quality care for children with chronic conditions, in addition to hospitalization, but also in the continuity of home care, it is believed that it is necessary to initially understand how the interaction between the professional and the family takes place and how this shared care process is carried out with the child with a chronic condition.

Thus, this study aimed to understand the view of nursing professionals on shared care between the nursing team and the family member of the child with a chronic condition.

METHOD

This is a qualitative, descriptive and exploratory study. The scenario was a pediatric ward of a State University Hospital in Rio de Janeiro. Inclusion criteria were: being a nurse or nursing technician; work in the referred unit and have experience in the area for at least three years[9]. Nursing residents were excluded due to the more restricted contact time in the unit and high turnover.

Data collection took place in July and August 2021 through semi-structured interviews in a single meeting, respecting the availability of each health professional. The main questions were: "What do you understand about shared care?"; "How does shared care happen in your clinical practice with families of children with chronic conditions?"; "What do you think of shared care in the hospital?"; "Would you change the way you carry out shared care?". In addition, an instrument was used to collect sociodemographic data to characterize the participants.

The interviews were audio recorded and later transcribed in full to preserve the original content. The interviews ended when they did not bring new elements to the study, adopting the criterion of theoretical data saturation. Data extracted from the interview were analyzed based on the thematic content analysis technique according to Bardin[10], being organized in three phases: pre-analysis, material exploration and treatment of the results. This manuscript was written according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The research protocol was approved by the Research Ethics Committee of the proposing institution on May 21, 2021. According to the norms of Resolution no. 466/2012[11], the dignity and autonomy of the interviewees were respected, recognizing their vulnerability and guaranteeing their willingness to continue participating in the study or not, compromising maximum benefits and ensuring that foreseeable risks are minimal.

Participants who agreed to participate in the study were included after signing the Informed Consent Form (ICF), which was available in two copies. Seeking to preserve the anonymity of the interviewees, the letter N for a nurse and the letter T for a nursing technician were used, followed by the ordinal number identifying the order of the interviews carried out.

RESULTS AND DISCUSSION

The study included 23 nursing professionals, five nurses and 18 nursing technicians, exclusively women, aged between 27 and 60 years. The length of experience varied between three and 27 years of experience in the pediatric area, with an average of 14 years. The working time in the field scenario of the research ranged from five months to 27 years.

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Data extracted from the interviews were organized into three categories: Challenges in building shared care; Ways to promote shared care; and Benefits of shared care, as presented below:

Category 1: Challenges in building shared care

This category represents all the difficulties and justifications found for the lack of shared care among the subjects in the hospital environment. The nursing professional identifies behaviors that may hinder performing shared care both by family members and by the nursing professionals themselves.

Subcategory 1.1: Aspects which hinder building shared care by family members

The professionals sometimes mentioned finding challenges in implementing shared care. Some of these include distancing from guardians during the child's hospitalization and the fear or insecurity of the family member in performing some care in the hospital.

Regarding separation from family members, although it is anticipated that children can have a companion 24 hours a day during hospitalization, some family members cannot be present during the entire hospitalization. This can happen for several reasons, including social, financial and/or family, but they have an impact on the participation in care.

> *Family members should be more present with the child. (T2)*
>
> *Mothers are not very present because they need to work, usually they have another child and stuff like that. (T12)*

According to the literature, children with chronic conditions are characterized by their fragile clinical condition, being subjected to frequent and/or prolonged hospitalizations and constant monitoring in health services[2], requiring adaptation on the part of family members.

Despite the participants' speeches indicating a greater need for the child to be accompanied by family members in the hospital, the literature shows that the mother, as the main caregiver, changes her routine to take care of the child, and in most cases abandons work and other activities of her daily life to dedicate themselves exclusively to child care, generating overload[12]. In addition to being an aspect that hinders shared care, it also affects the professional's relationship with the family.

> *Absence does this, this lack of trust, this lack of understanding of our care [...] When they are present, in addition to facilitating this (shared care), there is this issue of them having this trust with us. (T3)*

For this process to be started and built on a daily basis, it is necessary for the family member to be present at the health unit, considering that this absence weakens the relationship between child-family member-team in addition to hindering the construction of shared care.

However, it is necessary to understand the reason for the absence of this person in charge, understanding their social, financial and family context, seeking strategies to use when this family member returns to the hospitalization unit for a visit or follow-up for a period of time in order to invite this family member for care training.

A study points out that the presence of the family member during the child's hospitalization favors the child's emotional support, promoting safety, in addition to collaborating in the development of the nursing team's work, benefiting the construction of a relationship of closeness and trust between the family member and the professional[13].

Another point highlighted by the professionals was that the lack of information regarding the child's therapy, use of technological devices and the need for the procedures performed cause insecurity and fear on the part of the family member, directly influencing their participation.

> *I see insecurity. I see an initial rejection because of insecurity, not because they don't want to practice. (T8)*
>
> *They are really afraid of causing harm to the child when they are manipulating it (device) due to lack of knowledge. (T12)*

The scarcity of guidance and information about the diagnosis and the demand for procedures and the use of scientific terms lead to a feeling of unpreparedness on the part of family members, causing them to distance themselves from the care process for the child[14,15]. In addition, when communication between the team and the family member is not efficient, it causes the companion to withdraw, maintaining doubts about the pathology, treatment and even showing resistance to certain procedures[3]. With this, it is clear that non-participation of the family member may arise due to their own lack of knowledge about the diagnosis and treatment of the child, as well as the importance of their participation in care.

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In this perspective, the team must discuss participation in care with the companion for family-team integration to occur, providing training as well as theoretical and emotional support to care for their child at home[13]. Transmitting information and clarifying doubts values the participation of the responsible family member during this process and conveys security and tranquility to the family members, in addition to characterizing an attitude of respect[7].

Subcategory 1.2: Aspects which hinder building shared care by nursing professionals

It was possible to identify that although the interviewees identified the importance of family involvement in providing care of children hospitalized with a chronic condition, there are still those who prefer to work alone, without the presence of those responsible. Some justifications are because they have other demands, lack of time or even overload. Efficiency in completing activities faster seems to be prioritized by the professional in favor of the quality of individualized and empathetic care to that family.

> *I particularly prefer to do it alone, but I also have no problem doing it with them. We learn that we have to work as a team and include the family in the team. (T12)*
>
> *I'll tell you the truth, I don't like it. I like it when mom says to me "I do everything by myself" or I get there and do everything by myself [...] Because we do it faster, we don't waste time there, we think it's a waste of time, but in reality it's not true [...] but we think like this "wasting time teaching the mother, since there are other children for me to bathe, there is medication for me to administer". (T6)*
>
> *Sometimes you're already dealing with four children, you don't have time to stay there. (T7)*

It is understood that nursing is a great holder of specific technical-scientific knowledge for care, but the family member is the person who knows the child best and is able to identify small changes in the child's behavior, becoming a great collaborator during the treatment, providing essential information which contributes to the care[16].

Involving the family in care implies reviewing the ways in which nursing has outlined this process, considering that parental preferences for participation vary and it is necessary to be ready to support their participation at the level at which its members choose, leading to a satisfactory experience[7]. In addition, checking information about care provides an opportunity for this family member to share ideas and express feelings or doubts[17].

Overload of nursing professionals can directly affect the quality of care provided. Insufficient staff, extensive working hours and high work demands limit the professional's moments of interaction and attention to the companion's and patient's needs, focusing only on treatment and acting in a mechanized way[18,19]. Some participants pointed out that more complex care is not allowed to be performed by family members in the pediatric unit, being under the responsibility of nursing alone.

> *I see it as a matter of leadership. Because I've seen it prohibited here. "Oh, don't let the mother aspirate (her child)", but then the mother goes home, she will have to aspirate at home, do things at home. (T6)*

On the other hand, others claim that it can be performed by the family member as long as it is supervised by the nursing professional.

> *She (the nursing manager) does not let the companion administer the diet there alone and you are not around. She doesn't allow that. She says that from the moment the child is hospitalized, you have to do these things, you don't have to delegate to the companion. (T16)*

It is noted that despite the contradictions about what is allowed or not regarding the conducts for performing care, there is difficulty for the nursing professional to understand the real meaning of shared care. The speeches show that the professional still understands the family's participation in care as a way of compartmentalizing care instead of sharing, of dividing tasks instead of adding and exchanging knowledge.

Studies point out that care similar to that performed at home, such as cleaning and changing diapers, are determined by the nursing team as the role of the family member, with a delegation of care without co-participation[15,20], regardless of the clinical situation of the patient, not paying attention to the uniqueness of the child[14].

When there is a prediction of hospital discharge, family members begin to be more stimulated and allowed to carry out care, even the most complex procedures. There is a perception of the professionals themselves about the need for early guidance regarding the necessary care, considering that they will continue the care at home, but in practice this only occurs closer to discharge. According to the participants, this ends up causing the family member to not have enough time for training in care and to be able to externalize their doubts and anxieties, making them safer to perform at home.

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> *It's been a long time without knowing. Then they leave, two, three days to go, then it starts "oh mom, go home, you have to start this. [...] I realize that this is a care that has to be done from the beginning". (T18)*
>
> *For example, for glycemia, one day she starts measuring glycemia, at another time she already has to apply, at another time she already has to aspirate. I think it gets very confusing, too much information on the same day." (N1)*

It is necessary to understand that the guidelines are part of a process and that it is not seen as something specific, as this can generate doubts and possible harm to the child[15]. The process of autonomy becomes important for both the family member and the child, and should be started early, given that each individual requires different time and attention to develop the necessary skills and confidence to assume this responsibility[21].

The participants did not mention knowing if the family caregiver understands the knowledge or the forms of care they performed at home, especially in cases of readmissions, where the family member already provided specific care at home. Such an attitude hinders the partnership relationship in carrying out the procedures, making it a unilateral process. For there to be a successful relationship with the family, nursing professionals need to recognize and value the experience of those responsible for the child's condition and needs[6,17]. It is necessary to create spaces for communication and freedom so that the family can establish itself in the hospital environment. This exchange of experiences favors good coexistence of both, enriches their relationships and provides a more comprehensive and humanized care for the child[6].

Category 2: Ways to promote shared care

This category illustrates the promotion of shared care in the pediatric unit and the relationship between the nursing professional and the family caregiver. According to the participants, one of the ways shared care is promoted is through guidance. Thus, before carrying out child care or carrying out procedures involving a technological device, there is a prior explanation of the child's condition and the need to perform each procedure for the child's well-being.

> *We teach how to puff, the technique [...], the importance of using the puff [...] how to identify if the child is fine, or if it is out of normal parameters. (T11)*
>
> *We have to advise the mother about HGT, not only explain the method, but also the variations in the glycemic index, explain what insulins are, how they work, how to store them, all of this has to be guided [...] and encourage her to perform the care but always by her side. (N14)*

Approaching the real meaning of shared care, some spoke about understanding the family autonomy process as one of the examples. This was identified by the participants as 'doing-together', where the family member participates together with the professional about the child's demands, being an initial step in the construction of autonomy and security.

> *Usually she holds it for me, the person wants to participate. She holds the diet bottle, other times she prefers the child to be in her lap, understand? (T5)*

When care is initiated more actively by family members/caregivers, nursing has the role of guiding, supervising and assisting, ensuring that care is provided using the correct technique, however, respecting the uniqueness of each person and personal execution preferences of each person.

> *A condition that the child has developed, we start explaining, demonstrating, and then leave periods for this family to practice, perform under our supervision. (N22)*
>
> *We have to, in addition to teaching, set an example and supervise to see if the family member has the ability to do it. (T23)*

One of the main objectives when working with family members of children with chronic conditions is to support the family in coping with the disease and promote integration throughout the child's life. Long-term care establishes a partnership between parents and professionals, which can help this family adapt to changes that will be necessary throughout the course of the disease[17]. Family members feel involved in the care provided when they participate together with nursing, making it an interactive and cooperative process, enabling them to perform care[22].

It was identified that there are professionals who allow the family member to perform the care independently, not participating and supervising this care. This can have harmful consequences in care, which can be replicated in the home environment and cause some harm to the patient later on.

> *She does it alone and only communicates with me. We continue to observe and supervise, but then she does it alone and only communicates to us. (T8)*

Therefore, when the caregiver does not have the security or knowledge to perform the procedure, it may be putting the child's integrity at risk, which is a worrying factor on the part of professionals.

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> *If we don't train the father here, the child will be left unattended at home, so we have to try to involve them as much as possible, also respecting the responsible person's time. (N20)*

According to Article 92 present in the Code of Ethics for Nursing Professionals, it is prohibited for the professional to delegate attributions to companions and/or those responsible for the patient[23] considering that these are behaviors which require technical-scientific knowledge and it is the responsibility of nursing within the hospital environment. The family member needs to be supervised so that there is continuity of quality care, respecting their uniqueness.

The care provided to hospitalized children with chronic conditions differs from those performed at home, requiring specialized care supervised by the nursing team. So, delegating this care to the responsible person can cause harm to the child's health, in addition to the institutional and technical responsibility when there is hospitalization[15].

Category 3: Benefits of shared care in the hospital environment

This category shows the benefits identified by nursing professionals in sharing care in the hospital environment, allowing the family member to build autonomy and promote safety during hospitalization, and in turn contributing to building trust and equality between the family and nursing.

> *The more confidence the father has to take this child home, to take care of this child, the better it is for everyone. (N20)*

> *I find it interesting because this is where they will create security, they will learn from nursing to be able to take care and be able to go home and be discharged. (T9)*

The participation of the family member is important for the comprehensive care of the child with a chronic condition, contributing to establish a family-child bond and allowing conditions for physical and emotional well-being. In turn, it provides accountability and humanization of care.

> *It is also important due to the bond between the mother and the child. The child is often much better, calmer when the mother is doing the care. (T6)*

The family member, when confident, secure and autonomous in care, is more likely to perpetuate such behaviors at home. They become qualified to continue the care in a safe and adequate way. However, through the speeches of the participants, there is a concern with this to increasingly involve family members considering that they will need to perform care at home and will not have professionals around to help, unlike when they are in the hospital environment.

> *I always try to let the parents participate in the care. Yeah... many times I even prefer that they do it because it goes away... if the patient is chronic, they'll have to do it anyway. (N4)*

> *I feel calmer when she leaves because I know she will know how to take care of the child. (T18)*

One study showed that shared care helps build shared responsibility among those involved, including family members and professionals, benefiting the child with their particularity. This facilitates negotiating strategic actions capable of providing comprehensive and more humanized care for the sick child[8].

The learning opportunity enables developing knowledge and skills so that family members become able to deal with the complexity of the hospitalized child's health condition where they felt involved in the care provided. In addition, the importance of the nurse's partnership for building this knowledge is highlighted[21].

The family's mastery of reproducing some techniques related to the care of the child promotes a safe hospital discharge so that it is possible to continue the treatment at home, reinforcing the appreciation of the autonomy of this subject[4].

Study limitations

The limitations of this study are related to the impossibility of generalizing the data, since it was conducted in only one hospital in Rio de Janeiro. In addition, it was carried out in a pandemic period due to the Coronavirus, which could be a contributing factor to influence the responses of the participants due to the increase in hospitalizations and removal of professionals, consequently generating an increase in the demand for care and overload.

CONCLUSION

It was possible to understand the professional-family relationship during the process of building shared care through the results of this study, highlighting positive aspects that need to be improved so that it happens effectively and satisfactorily. The importance of the presence of the family member in the hospitalization unit is emphasized and that their participation in planning and implementing care is encouraged, beyond the home environment.

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A possible strategy for improving shared care could be periodic meetings between nurses and family members, providing clarification and training in care.

The results of this study may contribute to quality nursing care, highlighting the educational aspect of care, thereby favoring greater interaction and communication between professionals and family members.

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