

## Preparation for the care of children with chronic diseases: the perception of caregivers

Preparação para o cuidar de crianças com doenças crônicas: a percepção dos cuidadores

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### ABSTRACT

**Objective:** to describe the caregivers' perception of preparation to care for children with chronic diseases. **Methods:** qualitative research, carried out with nine caregivers in a home transition unit in a tertiary hospital. Semi-structured interviews were used to obtain the data, and the content analysis technique was used to describe the results. **Results:** with the qualitative material analysis process, the main perceptions of the reported care were obtained: Knowing the Care Unit; Training, learning and guidance and Difficulties faced. **Conclusion:** the preparation for the care of children with chronic diseases is complex and was perceived as a fundamental step towards leaving hospital, requiring from these caregivers donation and effort to face this process.

**Descriptors:** Nursing Care; Pediatric Nursing; Chronic Disease.

### RESUMO

**Objetivo:** descrever a percepção dos cuidadores da preparação para o cuidar de crianças com doenças crônicas. **Métodos:** pesquisa qualitativa, realizada com nove cuidadores em uma unidade de transição domiciliar de um hospital terciário. Utilizaram-se a entrevista semiestruturada, para obtenção dos dados, e a técnica de análise de conteúdo, para descrição dos resultados. **Resultados:** com o processo de análise do material qualitativo, obtiveram-se as principais percepções dos cuidados relatados: Conhecendo a Unidade de Cuidados; Treinamento, aprendizagem e orientações e Dificuldades enfrentadas. **Conclusão:** a preparação para os cuidados com as crianças com doenças crônicas é complexa e foi percebida como etapa fundamental para a desospitalização, exigindo desses cuidadores doação e empenho para enfrentar tal processo.

**Descritores:** Cuidados de Enfermagem; Enfermagem Pediátrica; Doença Crônica.

## Introduction

Chronic conditions in childhood are characterized by being long-lasting, usually causing sequelae and limitations to the patient and also subjecting the child to perform invasive procedures and to remain hospitalized for extended periods<sup>(1)</sup>. Due to the health-disease process, these patients often need new hospitalizations and, in some cases, remain dependent on technologies to survive<sup>(2)</sup>.

Chronic illnesses arising in childhood affect both the child and his family. This diagnosis may not be expected and generates physical and emotional stress<sup>(3)</sup>. Thus, when the family is surprised by the need to provide special care for the child, an adaptation to this new reality is essential<sup>(4)</sup>.

In this sense, it is interesting that health professionals embrace these families and seek to understand the impacts of children's hospitalization, aiming to reduce anxiety and contribute to the provision of comprehensive care<sup>(5)</sup>. Thus, it is essential that the professional nurse, a member of the health team, enhances the family's skills regarding the care demanded by the child, promoting support for the development of skills, with regard to the practice of procedures and techniques that these patients need in their day-to-day home care<sup>(6)</sup>.

In this context, the National Policy for Comprehensive Child Health Care considers as strategic actions the care of children with chronic diseases and conditions in childhood, the development of guidelines and lines of care directed at this population and also the improvement of care and home care<sup>(7)</sup>.

To know the caregivers' view of preparing for the care of these patients is essential to stimulate a broader view of the health team, contributing to the creation of strategies that facilitate the process, the provision of orientations directed to this audience and the promotion of assistance holistic, appropriate to the family reality promoting quality of life for the patient and his family. Thus, aiming at providing comprehensive care, the question was asked: How do

caregivers perceive their preparation for caring for children with chronic diseases who need special care?

This study aimed to describe the caregivers' perception of preparation to care for children with chronic diseases.

## Methods

This is a qualitative study carried out at the Special Patients Unit of a tertiary pediatric reference hospital in the State of Ceará, in the Northeast Region of Brazil. This unit receives chronic patients on mechanical ventilation who have a stable clinical picture, not requiring intensive care, and are being prepared for home care. There are also, in this sector, outpatients who have complications in their homes and need to return to the unit for conduct assessment and stabilization.

We chose to use convenience sampling, using the theoretical exhaustion method to aid in the definition of the sample<sup>(8)</sup>. Nine family members of children with chronic illnesses hospitalized in the sector participated in the study, including caregivers who had been in the unit for at least 2 months and those who had previously trained at the unit and remained there due to complications in the patient's health status.

The participants were approached by one of the authors of the study, who assumed the role of interviewer, in the unit itself, before the start of the collection, for a brief explanation of the research and verification of the opportune time for its realization, clarifying that the interviews would take place in a meeting room available in the sector, in the previously scheduled period, and the child would remain in the care of a health professional at the unit during the interview. Since it was impossible to be absent from the proximity of the patient's bed, a period was waited during which the other caregivers would leave the infirmary to proceed with the interview. Only one interviewer performed the collection and prior training was not necessary.

To obtain the information, a semi-structured script was prepared by the authors, containing sociodemographic data of the caregiver, such as, for example, sex, age, place of birth, marital status, among others; and the hospitalized child, such as age, medical diagnosis, among others. This script contained the following guiding question: How is the training for child care going? The following complementary questions were also included: How did the patient's illness process take place? ; What do you understand about the care the patient needs? ; How do you feel about knowing that you will have to take care of the child at home? The interviews were conducted between September and November 2019, with an average duration of 31 minutes. After the participant's authorization, a voice recorder was used to record the narratives and later transcription.

To analyze the information, the content analysis technique was used<sup>(9)</sup>. Then, the most representative speeches were selected to substantiate the study. The data were analyzed using the qualitative theoretical framework, in order to understand the phenomenon within its context<sup>(10)</sup>. The study was approved by the Research Ethics Committee in the Health Area of the referred hospital and had a favorable opinion, under No. 3,501,127/2019, and Presentation Certificate for Ethical Appreciation No. 17608819.1.0000.5042. Participants signed the Free and Informed Consent Form and, in order to maintain the anonymity of the interviewees, their real names were omitted and names of flowers were given to represent them in a fictitious way.

## Results

Nine caregivers participated in the research, all female. Eight were mothers of patients and one was a grandmother. The age range was 23 to 41 years. As for marital status, five women were single, three were married and one maintained a stable relationship. Most had completed high school and came from the interior of Ceará, Brazil. All of them interrupted their

work activities for the exclusive dedication of the children, and the majority received help from family members and spouses. Regarding the number of children, four had one child, another four had two children and one had three children.

The diagnoses of the participating patients were spinal amyotrophic, hydrocephalus, myelomeningocele, Moebius syndrome, congenital heart disease and syndromes to be clarified. These patients were children and aged between 1 and 5 years. The length of hospital stay ranged from 3 months to 2 years and 3 months, and all children were dependent on mechanical ventilation.

With the qualitative material analysis process, the main perceptions regarding the reported care were obtained: Knowing the Care Unit; Training, learning and guidance and Difficulties faced.

### Getting to Know the Care Unit

During hospitalization in the Care Unit, the caregiver understood and adapted to his new role and reality. The family members' speeches reflect the perception of care for these children and the training that was offered to them.

In the speeches, family members showed eagerness and desire to learn the procedures, as they understood that this was a transition sector for home care, and also valued the service, as it is a unique sector and that contributed to the children's hospitalization: *When we go up to the Unit, you are always in that of learning, because here is a transition unit, this is where you have to learn to take it home. But when I came up here, I was so thirsty to learn (Rose). It is the only unit that can assist special children. It is the only one and it is not everywhere you have it, so try to value what we have (Daisy).*

The interviewees showed interest in caring due to the possibility of being closer to their children, strengthening the affective bond, and for playing a role that made them feel useful in the service: *I preferred to bathe her (patient) because I to get in touch with her, it was so long ago that I didn't touch my daughter, that I didn't have this physical contact with her, I preferred to bathe (Orchid). Here (Care*

Unit) *it is better because we spend more time taking care. Time passes faster. There (intensive care unit) we cannot do anything (Camellia).*

It can also be observed that mothers were concerned about the waiting time for a bed in the Care Unit, and this had negative consequences for other patients: *He (patient) stayed 8 months in the intensive care unit to be able to come up here ... there was no vacancy here (Lilly). ... she was there (intensive care unit) only, she stayed for almost 3 months, waiting only for a place for the Special Patients Unit. Then she was occupying a bed of a very serious child exclusively to go up (Orchid).*

### Training, learning and guidance

During the training at this unit, the understanding by the caregivers of how the training took place in the sector was fundamental. The interviewees whose children had been hospitalized for a longer time demonstrated a greater understanding of how training works: *Because this is a transition, you are learning little by little, you are not here and you already have someone to train you, it is not like that. You will learn according to your need. ... No, you learn slowly. Why? Because you don't have to be in a hurry, I tell all mothers that come from the intensive care unit, you don't have to be in a hurry with anything, you have to do it little by little, you have to be calm. Why when you go home, you have to know what? Security (pause) so you can do it (Rose).*

At the unit, there was a range of care to be provided by caregivers, such as bed bathing, care for maintaining skin integrity, hygiene and care for the tracheostomy stoma, replacement of the tracheostomy cannula, aspiration of airways, cleaning and care with gastrostomy, exchange of gastrostomy tube, installation of diet by tube, intermittent bladder catheterization and administration of medication by tube when close to hospital discharge, in addition to first aid care. Most of the interviewees, when asked about care, made a point of reporting the procedures they had the skills to do, showing feelings of satisfaction and personal fulfillment when practicing them for the benefit of their children and loved ones. They also exposed seeking autonomy to perform this care: *Vacuuming, you have to vacuum, you have to take care of this baby (laughs),*

*although he (patient) doesn't like to be vacuumed ... we do everything, we bathe, we just do not take the medication (Violet). Today, I don't know (laughs), I think people feel so good when we know how to do it. I know, bathe her (patient), I know how to clean the tracheostomy, the gastrostomy, I know how to suck, I know how to do the catheterization, I know how to put the medication in the gastrostomy, I know the basics (laughs). I know what she needs; thank Go ... (Sunflower). I was always like this, wanting to learn soon, because it sucks that you have to keep calling people (professionals) directly ... And then, we were like: No, I will soon learn so I don't have to be calling people to do it anymore things (Tulip).*

The speeches of the participants demonstrated the importance of the guidance provided by health professionals during training at the unit for the learning process, highlighting the way they received these teachings and emphasizing that the nursing team maintained this function: *I learned the care here at the unit with nurses, with the unit nurse, she taught me a lot. And I also learned from the nursing resident. He taught me everything about gastrostomy, everything. ... So, he did dynamics with us, and one of those dynamics he did, he took a class on gastrostomy, on how to remove and put it on (Rose). The bath, the training was with the girls, the nursing techniques. They always help us, even if we just want to do it (laughs), they kept looking the nurse to vacuum, which also nurses always observe the way we take the gloves, because every life we have to be very careful, because it is the one who puts and uses it to go to vacuum, cannot touch anything. So, it was already a process that we needed to learn and people looked to see if we know. The same way concerning catheterization, I had to see catheterization all my life when I was going to do it and then, then they gave me the opportunity and I knew how to do it (Sunflower).*

Still in relation to the training provided by the nurses, the caregivers highlighted an important point, by emphasizing that the nurses' lack of time and a tiring workday could hinder the realization of the nursing guidelines: *Then the nurse at the unit went and said: I don't have much time to teach, but I'll teach ... because there isn't enough time, I'm racing for everything in the world here (Carnation). There was a time when she (eldest daughter) spent one week in hospital, I stayed in another hospital and came here. I stayed there and came here. Every day, every day. I almost can't take it. At that time, I imagined how a technician and a nurse feel (Daisy). Even though they*

(nursing technicians) are going home, I see that there are technicians who come every day, almost every day to work, every other day, it is tiring too. So, I think so, that what they do helps us a lot (Sunflower).

### Difficulties faced

One of the difficulties reported in the testimonies of caregivers in relation to training was the feeling of fear in carrying out the procedures at the beginning of the training and insecurity in the face of the patients' demands: *One of the difficulties reported in the testimonies of caregivers in relation to training was the feeling of fear in carrying out the procedures at the beginning of the training and insecurity in the face of the patients' demands: I did not have the security to do things, but in the intensive care unit we were not safe. When I came up here I saw that, you living with these children like that, you lose your fear, with others who already do, you lose the fear of doing things (Tulip). When I saw my son with a tracheostomy, I got scared, I was scared, I said: I won't be able to get close to him. But little by little you get close; you keep imagining that it hurts ... (Daisy).*

During the interviews, the theme of the support network was also widely cited, mainly its absence or the fact that the support network is restricted, which, according to the interviewees, created an overload for them, because, in most cases, there was no rotation among caregivers: *Only those who have love are left to care, and sometimes the mother has no help and is forced to stay, it is very tiring (Carnation). It makes you want to leave. Because, in itself, you get a lot of money, you have to do it, you have to be there with him, but the person doesn't stop and think about how you are (Daisy).*

### Discussion

The study presented as a limitation the data collection in only one hospital institution, which makes it impossible to compare it with other services that provide training for caregivers for home care and the generalization of the information obtained. Thus, new research on the caregiver's view in this process is potential to analyze the strategies in use, such as proposing new care paths and knowledge related to the theme.

The results obtained in the present study contributed to the understanding of health professionals about the caregivers' perception of the preparation for the care of children with chronic diseases, enabling the team to be sensitized to carry out quality training, which considered the particularities of each family and the difficulties presented in the process, making it possible to outline strategies and care plans for the care of such patients and their families. In addition, the study showed the role of nurses and their limitations in this process, addressing a relevant issue for providing quality care and promoting a safe care environment.

According to the characterization of the participants, it was shown that maternal care is still the most prevalent when it comes to the care of children with chronic diseases. It was also possible to note the abdication of the caregivers' personal and employment activities to dedicate themselves exclusively to children. Such data corroborate research carried out with technology-dependent children, in which the mother was the main caregiver and, therefore, needed to acquire new skills and knowledge for this care<sup>(11)</sup>.

Another important point was the various diagnoses found in this unit, which ranged from neurodegenerative diseases and malformations, as well as rare syndromes. Due to its complexity, patients with chronic diseases generally use some technology, such as mechanical ventilation, tracheal aspiration, bladder and gastric catheterization, in addition to dressing and medication administration, requiring the assistance of a multidisciplinary team and routine care in health services<sup>(2)</sup>.

The pediatric units that host these patients maintain characteristics that make them different from the others, as they have a higher level of complexity, a long period of stay, a re-qualified environment and trained multi-professional teams<sup>(2)</sup>. This is, then, a period of adaptation of the family member/caregiver and the child to the new reality, as well as the moment of understanding how these units work and how the training takes place.

The interviewees realized that it was a transition unit for home care and, therefore, they valued the sector and donated themselves entirely to training, understanding care as a way of learning techniques and procedures, as well as a way to be more close to their children. Thus, one of the most reported issues was the delay in accessing beds in the Care Unit, which would delay the long-awaited home care. It is essential that hospital institutions have a transition unit for children with chronic diseases, to favor leaving hospital through educational care techniques, promoting safety and autonomy for caregivers and thus reducing hospital costs and risk of infections<sup>(2)</sup>.

Such preparation is a process that takes place individually, taking into account the caregiver's level of education and their safety in carrying out the care. Therefore, it is essential that health professionals assist caregivers during this period, for better coping and understanding of the situation<sup>(12)</sup>. Providing a teaching-learning process that suits the caregiver is a way to promote comprehensive patient care, and it is important that the services provide educational materials to be used by health professionals during the training.

Helping and encouraging the participation of caregivers in this process is essential, as they encourage protagonism and responsibility in the process. During hospitalization, the caregiver also plays an important role for health professionals, as it is to him that the team is directed to resolve questions about patient care and the child's health status, making the caregiver a key part of care for chronic patients<sup>(13)</sup>.

Regarding the care demanded, such patients needed procedures such as decubitus changes, tube feeding, administration of diets, bladder catheterization, and aspiration of the airways, among others. These data corroborate studies carried out with children with chronic diseases that identified, in addition to the reported care, the administration of medications, the management of stomas and the handling of nebulizers and aspirators<sup>(3,12)</sup>. This routine of performing procedures involves learning new ways of hygiene,

food and medication administration, which requires extra attention and, sometimes, the use of some technologies, considering the particularity of each child<sup>(13)</sup>.

During the training, doubts must be resolved and the family's fear and insecurity in relation to the procedures must be addressed, always giving a chance to perform the care even in the hospital environment, when they feel able to do so<sup>(14)</sup>. In this context, the multi professional team has the function of guiding and training these caregivers and family members to provide adequate assistance<sup>(12)</sup>. Among the professionals that make up this team, the nurse has the role of promoting an educational practice that generates a better understanding of the patient's chronic condition, providing guidance on the handling of devices, the use of diets and medications<sup>(15)</sup>, as also providing support and holistic assistance through informative, technical and emotional help<sup>(16)</sup>.

During the interviews, the caregivers' perception of the workload of the nursing team in the service was often cited and that, because of this, there was little time available for carrying out the guidelines. The professional nurse is fundamental for the planning and development of health actions and the organization of the health work process, being important the recognition of their professional practice<sup>(17)</sup>.

After experiencing the perceptions about the training, it is important to observe the difficulties faced in the process, in order to understand the feelings experienced and seek ways to remedy these issues. The difficulty in accepting the condition of patients, on the part of caregivers, was one of the problems mentioned, as well as the dependence on some technologies for the survival of these children. Such a process needs time and progresses from the moment the caregiver understands the patient's real health condition<sup>(12)</sup>.

The action of assuming the provision of care for a chronic patient, in most cases, demands from the main caregivers maturation, so that this new reality can be faced<sup>(12)</sup>. Therefore, it is important to have a support network to assist caregivers in this delicate

process. Thus, the support network, made up of family and friends, is fundamental for coping with the situation, helping to reduce the burden on caregivers<sup>(18)</sup>.

In this context, the realization of therapeutic groups for caregivers is important to understand how the process occurs, aiming to contribute to the continuity of training and generating an environment of safety, support and growth. Not only does the child with a chronic disease demand care, but also the whole family and, for this, health professionals must welcome these caregivers, being attentive to their needs and respecting their particularities, in order to form a wide support network for these families<sup>(19)</sup>.

Caregivers go through a complex process in preparing to care for children, which requires an understanding of training, availability to learn the procedures and coping with the difficulties presented. In this context, the professional nurse stands out as an advisor and facilitator of the process, although there are obstacles to his professional performance.

## Conclusion

It is concluded that the preparation for the care of children with chronic diseases is complex and required from caregivers donation, effort and willingness to face this process. Understanding the importance of the Care Unit was fundamental, in order to have a fruitful partnership between the caregivers and the unit's health team, which is a differentiated sector, which has a care and pedagogical dimension.

## Collaborations

Torquato RC and Santos LKX contributed to the design of the project, analysis and interpretation of data and writing of the article. Rovere GP, Pitombeira MG and Pereira AS contributed to the relevant critical review of the intellectual content and to the approval of the final version to be published.

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