



## NURSING CARE FOR CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTH NEEDS

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### ABSTRACT

**Objective:** to investigate care demands of children and adolescents with special health care needs (CSHCN) hospitalized from the perspective of the nursing team. **Method:** descriptive, exploratory and qualitative research. Eleven 11 nursing professionals were interviewed, who work in a pediatric hospitalization unit of a hospital in the northwest region of Rio Grande do Sul, from November 2019 to February 2020. The statements were double transcribed and submitted to content analysis. **Results:** the professionals elucidated about the presence of family caregivers during hospitalization in the pediatric unit. The team expressed the importance of technical and scientific knowledge, as well as the potential and weaknesses in the work process with this specific population. **Final thoughts:** Nursing care with CRIANES requires technical and scientific skills, as well as the creation of the team-patient-family bond. Thus, it emphasizes the need for continuing education of professionals, to provide humanized and problem-solving assistance, reducing the rates of readmissions.

**Keywords:** Nursing. Child Health. Adolescent Health. Hospitalization.

### INTRODUCTION

Chronic childhood diseases are public health problems that can start gradually and progressively and are directly related to multiple causes, whether biological, psychological and/or cognitive<sup>(1)</sup>. In international literature, they are called Children With Special Health Care Needs (CSHCN), being translated into Portuguese as *Crianças com Necessidades Especiais de Saúde*, known by the acronym CRIANES. In this group, children and adolescents between 0 and 18 years of age<sup>(2)</sup>, who present several unique demands, which involve medicated, developmental, usual modified, technological or mixed care<sup>(2,3)</sup>.

Due to the complexity and fragility of CSHCN health demands, they are exposed to

longer and more frequent hospitalizations, with high rates of readmissions<sup>(4,5)</sup>. Thus, the need for professional training about the care of these patients as well as comprehensive care is emphasized so that the care required by this population contemplates their needs<sup>(3)</sup> and minimizes negative impacts of the hospitalization of children and adolescents<sup>(6)</sup>. Therefore, it is up to nursing professionals sensitivity to welcome them through scientific, continuous, proactive and problem-solving care<sup>(2)</sup>.

Since, in the hospital context, despite the presence of the family member/caregiver, the procedures and monitoring of the health conditions of these patients are the responsibility of the nursing team<sup>(7)</sup>, this should have

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knowledge about their work process and plan actions with an expanded look at the subjective needs of each child or adolescent hospitalized. It is also the responsibility of the team to provide care to the pediatric patient in a safe manner and to insert health promotion measures, from the creation of a bond with family members and quality care<sup>(8)</sup>. Thus, care during hospitalization should have its roots based on the interrelationship between team-family-child, so that it benefits the bond.

Thus, professionals should be able to transmit information about care and maintain special attention to the unique demands of families/caregivers and patients<sup>(9,10)</sup>. Likewise, it emphasizes the importance of nursing care in contributing to the insertion and inclusion of CSHCN in society, acting beyond practices and techniques, promoting the articulation of the care network, through education and health ensuring the full development of this CSHCN and enhancing the family's ability to articulate and promote comprehensive care<sup>(11,12)</sup>.

Given this context, it is important to know what are the demands of care required by CSHCN in the hospital environment, considering the specificities of this population, their daily care and family participation during hospitalization, care is humanized and resolved. This study is justified due to epidemiological transition, technological advances, reduction in infant mortality and improvement in quality of life, which led to an increase in survival and recurrence of hospitalizations of CSHCN, as well as the demand for care and specialized assistance by the nursing staff.

This article presents as a research question: "How are nursing care developed for children and adolescents with special health needs in the hospital environment?". Faced with these premises, the objective is to investigate the demands of care in children and adolescents with special health needs hospitalized from the perspective of the nursing team.

## METHOD

This is a descriptive, exploratory and qualitative approach. Data collection occurred in a Pediatric Hospitalization Unit (PHU) of a mid-sized hospital, located in the northwest region of

Rio Grande do Sul. The data collection process took place between November 2019 and February 2020.

Only health professionals were interviewed, whose inclusion criterion was being nurse, nursing technicians or assistants who worked there, at least six months with pediatric patients who had already developed care for the CSHCN at some point in their professional activity. Professionals who were on vacation and/or absent from their work activities were excluded.

Thus, data production was mediated by the main researcher and three nursing academics, one of them being a scholar of scientific initiation. A semi-structured interview script was used, previously tested, consisting of six questions regarding the development of nursing care, systematization of care, professional experiences with CSHCN, facilities and difficulties in the care process, and on family participation in pediatric hospitalization.

From the inclusion and exclusion criteria, 13 professionals were invited to participate in the research and there were no refusals. The interviews were conducted in a room attached to the PHU, individually and at the time it was feasible for the participants. Data collection was terminated when the collected data became recurrent, not adding new information, according to the criteria of data saturation<sup>(13)</sup>, totaling 11 nursing professionals.

The audios were recorded in digital media, lasting 14 to 25 minutes of statements. Subsequently, the transcription was carried out in the Microsoft® Word Program, in order to avoid inconsistencies, and the narratives, submitted to content analysis<sup>(14)</sup>, which provides rigor of objectivity and fecundity of subjectivity from the analysis of enunciations. This process was developed in different stages, composed by pre-analysis, exploration of the material and treatment of the results<sup>(14)</sup>.

It began by pre-analysis, through floating reading in order to systematize the initial ideas. In the exploration of the material, the analytical description of the most frequent discourses and categorization was carried out, where the representative enunciations were highlighted. For the treatment of results, inferences and interpretation, condensation and information highlighting were performed for analysis,

resulting in inferential interpretations and critical analysis of the research<sup>(14)</sup>.

The development of the study was supported by Resolution n. 466/2012 of the National Health Council<sup>(15)</sup>, it was approved by the Research Ethics Committee of the Federal University of Santa Maria through opinion N. 2.632.767 and received the Certificate of Presentation for Ethical Assessment N. 86186518.5.0000.5346. In order to preserve identity, the letter “P” referring to “participant” with a random ordinal number was used.

The manuscript met the standards established by the guidelines for health research production Enhancing the Quality and Transparency of Health Research Network (EQUATOR). Therefore, the instrument used to support this study was the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>(16)</sup>.

## RESULTS

The study consisted of 11 nursing professionals, all female, divided into: five nurses, five nursing technicians and one nursing assistant. These professionals have been working at the PHU for at least two years, and the maximum service time was 28 years. Regarding the age group of the participants, it varied from 25 to 62 years of age.

From the content analysis emerged two thematic categories: Care demands of hospitalized CSHCN and Family participation in the care of hospitalized CSHCN.

### Care demands of hospitalized CSHCN

The narratives of the nursing professionals emphasized on the care demands of the CSHCN during hospitalization in the PHU, highlighting who this child/adolescent is.

They depend on special care! They have some kind of disability or some chronic illness. (P1)

She has cerebral palsy, so she uses gastrostomy and diapers [...] It depends on all the care, so we have to do everything for her! (P3)

We aspired, often the child was hospitalized, was weakened, anyway, and we had to do everything with her [...] (P4)

The study participants brought in their

speeches about the need to know the care demands of the CSHCN, and the presence of drug care of this population when hospitalized in the PHU.

It's the extra care you have with this child, because of their own specialty, because of their disability. (P1)

The least you should know is what are the characteristics that the syndrome or disability can present, what are the limitations of this child! (P2)

We must have knowledge! You have to know all the techniques and care! (P3)

We ourselves are medication, when we have to puncture a vein [...] (P4)

This issue of venous medication, serum, these things are up to us! Someone has to be there twenty-four hours with them. I have no difficulty, we have to be with them more, they cannot be alone! (P5)

Some children are even more difficult, especially children with autism, very difficult to work with [...] (P6)

In the daily work of the pediatric hospitalization unit, there are facilities and difficulties that can be found when performing pediatric nursing care, especially to the group of children and adolescents who have chronic health demands. Thus, the performance of the nursing team should contemplate the uniqueness of each child and adolescent.

### Family participation in the care of hospitalized CSHCN

The statements of nursing professionals highlight the importance of the family caregiver during the hospitalization of CSHCN in the PHU, including why nursing often maintains the care that is already performed at home.

Mothers do everything, they are already well educated, they are already used to special children and adolescents [...]. (P4)

The family member, he practically does everything [...] they know a lot! (P5)

The mother who passes on to us what she was already doing at home. We try not to do anything different! (P8)

From the perspective of nursing

professionals, there are factors that hinder the care process, they also seek to include caregivers, family members and companions in pediatric care during hospitalization in the PHU.

It's not that easy, I'm a little afraid to work with this audience [...]. (P6)

It's hard to have to aspirate, but it's something necessary! I think there are some very painful things, for example a CSHCN that often pulls out the tube [...] I think it's a very painful thing, you know? (P7)

The nursing team also realizes the importance of humanized care. Although there is a diversity of demands for care and procedures, the team still denotes sensitivity to meet CSHCN.

The child comes to pediatrics, he is attended to, but he could receive even better assistance, due to his health condition [...] they are children! (P9)

Sometimes, we can't stay together with these children, but I try to bring them to the toy library and the family members accompany them [...]. (P10)

We tell the parents that they can take a walk there in the toy library, that they can sit with the child, play a little [...]. (P11)

From the perspective of nursing professionals, although there are difficulties to develop the demands of care presented by CSHCN, this process should be based on knowledge, family participation to ensure that CSHCN is cared for and that the family participates in all stages of hospitalization in the PHU, providing comfort and attention to children, adolescents and their families.

## DISCUSSION

It is notorious, given the enunciations of the participants, that these professionals often provide assistance to children and adolescents with special health needs, which indicates that this public needs hospital admissions because of their clinical condition. A study conducted in a Pediatric Hospitalization Unit (PHU) in Rio Grande do Sul, shows that, of 25 CSHCN hospitalized, only one of them had no history of readmissions<sup>(4)</sup>.

Therefore, for nursing professionals, knowledge about the subjective needs,

limitations and characteristics of chronic diseases that affect the CSHCN is essential for the performance of positive as well as a facilitator in the process of working with these. Therefore, it is emphasized that the care of the nursing team should not only be limited to the techniques to be developed, but also to develop other strategies that lead to rapprochement and the creation of bonds, to facilitate this contact<sup>(3,17)</sup>.

Among the care practices offered by the nursing team, it was identified that most CSHCN need modified usual care, since most of these children need help to perform common day-to-day tasks, such as hygiene, food and locomotion; drug care, related to its pathology and the diseases that usually result in new hospitalizations; those that present technological care, because it is necessary to maintain technologies such as colostomy bags, among others; and assistance in psychomotor and social rehabilitation, through multidisciplinary care. Furthermore, the nursing team is responsible for guiding family members and caregivers to provide adequate care after hospital discharge<sup>(4)</sup>.

The nursing team praises the difficulties present during the hospitalization of this population, when compared to children and adolescents living in other health conditions, because the CSHCN need more complex care. Professional unpreparedness, insecurity and fear when performing specific and complex activities, as well as the lack of a multidisciplinary team, directly influence the way assistance is developed<sup>(18)</sup>.

This emphasizes the importance of training and continuing education in health services for professionals who sometimes did not have access to information on techniques and singularities of this public. These gaps in knowledge about the care of CSHCN are also present in academic training, and the approach to the theme usually occurs only through participation in research groups, teaching or extension, which is not reality of all students<sup>(19)</sup>.

The complexity of care and the demand for time to perform a humanized work are also potential limiters during nursing work. The spaces present in the hospital, such as the toy library, are extremely relevant for the development of care and strongly contribute to

the creation of the team-family bond, showing a space for providing guidance and reducing the stress of hospitalization<sup>(20)</sup>, however, in the reports of this study, it is seen that professionals do not find time to use this space.

In the same way, the insertion of a multiprofessional work team in the PHU is an important instrument to provide extended and problem-solving care with the CSHCN. The care offered by a multiprofessional team collaborates with the guidelines about the limitations and subjective needs of each patient, contributing to health education and reducing the readmission rates of these patients<sup>(19)</sup>.

In contrast, some professionals do not see difficulties in working with this public, and emphasize, in their speeches, the need to see them as subjects who need care. It is necessary to prepare and train nursing teams to meet the demands of care of CSHCN and their families<sup>(18)</sup>. It is emphasized that, mainly, it is the role of nurses to mediate the process of training, adaptation and health education, on the management of care to CSHCN, instructing the family caregiver, since they are responsible for continuing the care process in the home context<sup>(21)</sup>.

The family is cited as a potential caregiver of the CSHCN. However, since they provide and have some knowledge of the necessary singular care, ends up sometimes intimidating the work of the professional. Nevertheless, in view of the above, the importance of working together with family members/caregivers and nursing staff is emphasized, since sharing of information and help of knowledge about the handling of technological devices and other singularities of clinical care, nursing, and the exchange of particular aspects of the patient, by family members, provides the best care for patients<sup>(19, 22)</sup>.

The development of the bond between family members/caregivers and health professionals is of paramount importance, since this relationship contributes positively to the care of CSHCN<sup>(23)</sup>. When there is trust in the bond, the dialogue becomes more accessible, and feels that it can express the demands, enabling a more comprehensive attention<sup>(24)</sup>. The presence of a professional-child-family bond helps in rehabilitation improves care, care delivery,

quality of care<sup>(18)</sup> and positive long-term results.

Thus, it emphasizes the importance of building a care network for their care, with specialized support from different health sectors. Since, when exposed to conditions of vulnerability, the chances of health problems of CSHCN increase<sup>(22)</sup>. The construction of this complex network would improve access to social services, showing better access to benefits and rights, contributing to the socioeconomic improvement of the family, reducing hospitalizations and burden on caregivers<sup>(10)</sup>.

The hospitalization process is challenging, both for children/adolescents and their family caregivers, as for the nursing professional, because sometimes these children/adolescents are removed from the home, school, their friends and family<sup>(25)</sup>. In daily work, the nursing team points out the numerous challenges they face, which are related to competence, assistance and effective care of the child, adolescent and family<sup>(18)</sup>. In this sense, it is observed that pediatric nursing care is complex, requires technical and scientific knowledge, should address the health needs of CSHCN in a comprehensive way.

An important limitation of the study was the fact that data collection was performed in characteristic vacation months of these workers and in a single PHU, and it is not possible to make generalizations.

## FINAL THOUGHTS

Given the above, nursing care to CSHCN is based mainly on the performance of complex technical care, and the assistance is challenging. For the team, there are still challenges about the complexity of the techniques that must be performed as well as skill, knowledge of the procedures, high time demands in this hospitalization process and the presence of the caregiver/family member, which can be challenging. Thus, the link between caregiver, patient and professional is a positive factor for the care to be performed in an integral way.

Moreover, there is need for permanent education actions in order to train health professionals, especially nursing professionals, to care for these children and adolescents, emphasizing the need for care based on

technical-scientific and humanized knowledge.

There should be training through extension actions and research with the current theme in other institutions, in order to know other realities. We conclude the need to improve the

nursing-family relationship so that emphasizes the importance of collective work in order to reduce frequent hospitalizations and improve the care of CSHCN in extra-hospital environments.

## CUIDADOS DE ENFERMAGEM A CRIANÇAS E ADOLESCENTES COM NECESSIDADES ESPECIAIS DE SAÚDE

### RESUMO

**Objetivo:** investigar as demandas de cuidados, na ótica da equipe de enfermagem, a crianças e adolescentes com necessidades especiais de saúde (CRIANES) hospitalizadas. **Método:** pesquisa descritiva, exploratória e de abordagem qualitativa. Foram entrevistados 11 profissionais de enfermagem que atuam em Unidade de internação pediátrica de um hospital da região noroeste do Rio Grande do Sul, nos meses de novembro de 2019 a fevereiro de 2020. As enunciações foram duplamente transcritas e submetidas à análise de conteúdo. **Resultados:** os profissionais elucidaram sobre a presença de familiares cuidadores durante a hospitalização em unidade pediátrica. A equipe manifestou a importância do conhecimento técnico-científico, bem como as potencialidades e fragilidades no processo de trabalho com essa população específica. **Considerações finais:** A assistência do cuidado de enfermagem com CRIANES exige habilidades técnico-científicas, assim como a criação do vínculo equipe-paciente-família. Desse modo, enfatiza-se a necessidade da educação continuada dos profissionais, para fornecer assistência humanizada e resolutive, diminuindo os índices de reinternações.

**Palavras-chave:** Enfermagem. Saúde da criança. Saúde do adolescente. Hospitalização.

## CUIDADOS DE ENFERMERÍA A NIÑOS Y ADOLESCENTES CON NECESIDADES ESPECIALES DE SALUD

### RESUMEN

**Objetivo:** investigar las demandas de atención, en la óptica del equipo de enfermería, a niños y adolescentes con necesidades especiales de salud (NINEAS) hospitalizadas. **Método:** investigación descriptiva, exploratoria y de abordaje cualitativo. Fueron entrevistados 11 profesionales de enfermería que actúan en Unidad de internación pediátrica de un hospital de la región noroeste de Rio Grande do Sul-Brasil, en los meses de noviembre de 2019 a febrero de 2020. Los relatos fueron doblemente transcritos y sometidos al análisis de contenido. **Resultados:** los profesionales aclararon sobre la presencia de familiares cuidadores durante la hospitalización en unidad pediátrica. El equipo relató la importancia del conocimiento técnico-científico, así como las potencialidades y fragilidades en el proceso de trabajo con esa población específica. **Consideraciones finales:** la asistencia del cuidado de enfermería a NINEAS exige habilidades técnico-científicas, así como la creación del vínculo equipo-paciente-familia. De ese modo, se enfatiza la necesidad de la educación continuada de los profesionales, para proporcionar asistencia humanizada y resolutive, disminuyendo los índices de reinternaciones.

**Palabras clave:** Enfermería. Salud del niño. Salud del adolescente. Hospitalización.

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