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Children with special health care needs in a pediatric emergency service: a cross-sectional study*

Crianças com necessidades de saúde especiais em um serviço de pronto atendimento pediátrico: estudo transversal*

Niños con necesidades especiales de salud en un servicio de urgencias pediátricas: estudio transversal

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Abstract

Objectives: to screen children with special health needs in a pediatric emergency service and analyze their care demands. **Method:** a cross-sectional study, carried out from March to June 2019, in a children's emergency hospital service, in the municipality of Rio das Ostras, Rio de Janeiro, Brazil. The Brazilian version of the *Children with Special Health Care Needs Screener* (CSHCN *Screener*®) and the instrument characterizing demands with family caregivers of children were applied. Descriptive statistics were used. **Results:** children with special health needs corresponded to 5.1% of the 235 families screened. The main domains of health needs were greater use of services and dependence on medicines. Among the care demands, the modified usual care stood out. **Bottom line:** the six care demands were identified among the screened children. The adoption of the CSHCN *Screener*® is recommended to increase visibility and indicate assistance strategies for this population group.

Descriptors: Child Health; Pediatric Nursing; Chronic Disease; Health Profile; Emergency Service, Hospital

Resumo

Objetivos: rastrear crianças com necessidades de saúde especiais em um serviço de pronto atendimento pediátrico e analisar suas demandas de cuidado. **Método:** estudo transversal, desenvolvido de março a junho de 2019, em serviço hospitalar de emergência infantil, no município de Rio das Ostras, Rio de

Janeiro, Brasil. Aplicaram-se a versão brasileira do *Children with Special Health Care Needs Screener* (CSHCN *Screener*®) e o instrumento caracterizador de demandas com familiares cuidadores de crianças. Utilizou-se a estatística descritiva. **Resultados:** crianças com necessidades de saúde especiais corresponderam a 5,1%, dentre 235 famílias rastreadas. Os principais domínios de necessidades de saúde foram maior utilização de serviços e dependência de medicamentos. Dentre as demandas de cuidados, destacaram-se os cuidados habituais modificados. **Conclusão:** as seis demandas de cuidados foram identificadas entre as crianças rastreadas. Recomenda-se a adoção do CSHCN *Screener*® para ampliar a visibilidade e indicar estratégias assistenciais a esse grupo populacional.

Descritores: Saúde da Criança; Enfermagem Pediátrica; Doença Crônica; Perfil de Saúde; Serviço Hospitalar de Emergência

Resumen

Objetivos: buscar los niños con necesidades especiales de salud en un servicio de urgencias pediátricas y analizar sus demandas de cuidado. **Método:** estudio transversal, conducido de marzo a junio de 2019, en un servicio de emergencia hospitalaria infantil, en el ayuntamiento de Rio das Ostras, Rio de Janeiro, Brasil. Se aplicó la versión brasileña del *Children with Special Health Care Needs Screener* (CSHCN *Screener*®) y el instrumento de caracterización de demandas con parientes que cuidan a sus niños. Se utilizó estadística descriptiva. **Resultados:** los niños con necesidades especiales de salud correspondieron al 5,1% de las 235 familias procuradas. Los principales dominios de las necesidades de salud fueron el mayor uso de los servicios y la dependencia de medicamentos. Entre las demandas de cuidado, se destacaron los cuidados habituales alterados. **Conclusión:** las seis demandas de cuidado fueron identificadas entre los niños evaluados. Se recomienda la adopción del CSHCN *Screener*® para aumentar la visibilidad e indicar estrategias de atención a este grupo poblacional.

Descriptores: Salud del Niño; Enfermería Pediátrica; Enfermedad Crónica; Perfil de Salud; Servicio de Urgencia en Hospital

Introduction

Children who use health and related services, with a frequency higher than that required by the child population in general, were named, in 1998, as *Children with Special Health Care Needs* (CSHCN), by the *Maternal Child Bureau* of the United States of America (USA). This comprehensive definition includes a group of children who have or are at increased risk of having a chronic physical, developmental, behavioral and/or emotional condition.¹ These are clinically fragile children who are more likely to be exposed to individual, programmatic and social vulnerabilities, whose health problems manifest themselves over time with increasing levels of functional limitations, comorbidities, complexity, and the need for specific health services.¹⁻²

Among the many challenges for health systems is the importance of monitoring health needs and the types of care needed in order to adequately adapt policies and programs to ensure access to necessary health services and care for these children.³ To this end, an instrument was required to operationalize this definition, which led to the creation of the *Children with Special Health Care Needs Screener* (CSHCN *Screener*®), which allows

defining their prevalence and identifying the domains of health needs. In this way, it becomes possible to assess the conditions of access to the service network, plan the offer of care and expand the coverage and resolution of the demands presented by this population group.³⁻⁶

The CSHCN *Screener*® has been applied in prevalence studies since 2001 in the USA. Instead of focusing on the diagnosis of the disease, this instrument establishes a set of health needs that are specialized and specific. Thus, the CSHCN *Screener*®, composed of five structured questions, includes three definition domains, which are not mutually exclusive categories. In the same child, one or more of the three domains of health needs can be identified: 1) dependence on prescription drugs for a certain clinical condition; 2) use of services above what is considered normal; 3) presence of functional limitations.³⁻⁶

In Brazil, since 2004, the expression CSHCN has been freely translated as children with special health care needs (CSHCN) and, later, a typology of care demands associated with them was defined.² However, more recently, in the literature, this same children's group has been called children with special health needs, despite the use of the same acronym,⁷ insofar as they have unique and differentiated health needs, therefore, special, needing organized and articulated care in a network, being, therefore, this the term adopted in the current research.

From a global health perspective, these children are challenging for families, health professionals and health care networks. Thus, their identification is the first step in supporting the elaboration and development of specific public policies to meet their particular demands and improve access to the health system. In this directive, in the USA, the CSHCN *Screener*® was applied in three national surveys (2001, 2005–2006 and 2009–2010), with versions available in English, Spanish, Chinese, Japanese, Korean and Russian, on behalf of immigrants living in in the country.⁴⁻⁹ It has also been used in other English-speaking countries for tracking and determining the prevalence of CSHCN, such as Australia¹⁰ and the United Kingdom¹¹ and translated and culturally adapted in Switzerland,¹² Brazil,⁴ and Egypt.⁶

It is noteworthy that, from the domains of the CSHCN *Screener*®, when tracking and studying the health profile of these children, it is possible to recognize the demands of care for family caregivers and health professionals into six groups: developmental care related to the constant need for functional stimulation; technological care for the use of devices such as gastrostomy, tracheostomy, colostomy, among others; medicine care to the continuous use of drugs, such as cardiotonics, anticonvulsants, for example; customary care modified to the use of adaptive technologies in daily care and activities of daily living to get around, eat, get

dressed, use the toilet, among others; mixed care for the combination of demands, excluding the technological one; and, clinically complex care combined with all of the above.²

Due to their fragile underlying condition, CSHCN are vulnerable to health fluctuations and may often require emergency hospital care. The literature points out that clinical severity, the number of biomedical tests and hospitalization rates are higher among these children than in the general pediatric population. Thus, health professionals working in pediatric emergency care units need to know how to recognize them in the set of others, through careful and effective screening, in order to adequately meet their particular demands.¹

However, although the CSHCN *Screeener*[®] is widely applied in population surveys to screen these children in other countries, in Brazil, its use has so far been restricted to primary care services in isolated municipalities in some states,¹³ which has been constituted a knowledge gap at the national level. Therefore, it is necessary to expand the application scenarios of this instrument to track them in the most varied services of the care networks in the Brazilian context, including urgent and emergency environments.

In addition, applying it to the Brazilian child population, associated with other tools, can increase the visibility of both special health care needs and specific care demands, which contributes to the formulation of public policies and assistance strategies for care of those needs. Therefore, the following research question was elaborated: What are the care demands of children with special health care needs screened by the CSHCN *Screeener*[®] in a pediatric emergency service?

Therefore, the objective was to screen children with special health needs in a pediatric emergency service and analyze their care demands.

Method

Cross-sectional and descriptive research, developed in a children's emergency hospital service in the city of Rio das Ostras, in the coastal lowland region of the state of Rio de Janeiro (RJ), Brazil. It is one of the services of the urgent and emergency care network, of the Unified Health System (SUS), which serves children from the municipality itself and neighboring cities, performing an average of 160 daily services. Children and their families wait at the reception located at the entrance of the hospital, to obtain the first care from the nurse who performs the reception with risk classification, with subsequent referral to medical care according to the required needs of each case. To describe the research, the *Strengthening the Reporting of*

Observational Studies in Epidemiology (STROBE) guidelines were followed.

The study population comprised children treated at the urgency and emergency service. Sampling was by simple convenience, with a confidence interval of 95%, a sampling error of 5% and an expected prevalence of 15%, considering an average among the prevalence found in international surveys to identify children with special health care needs in the general population.^{6,10-12,14} In Brazil, the investigations found are in specific scenarios and not population-based. The minimum number of participants was 196 family caregivers of children, however, an addition of 20% to the sample was considered to control losses, totaling 235 participants. In the selection of participants, the following inclusion criteria were considered: family caregiver (over 18 years old) of a child up to 12 years old. The exclusion criterion: family caregiver who was unaware of the child's birth and health conditions.

Data were collected between March and June 2019, by a team, composed of the first author and two research assistants, all nursing students from the last period of the undergraduate course at a Federal University, on weekdays, until the sample was reached. All of them were trained to apply the data collection instruments and were supervised by the guiding professor, PhD in nursing. A pilot test was carried out with 20 family caregivers to verify the applicability of the two forms; however, adjustments were not necessary. Therefore, these participants were included in the sample. There was no abandonment regarding participation.

Initially, through a structured face-to-face interview, in a reserved way, in the service's waiting room, the CSHCN *Screener*[®] was applied before or after the child was evaluated in the risk classification room, with an average duration of 5 minutes. The first part of each CSHCN *Screener*[®] question, translated and culturally adapted to the Brazilian reality,⁴ explores five different life and health conditions. The first condition refers to the need or use of prescription drugs other than vitamins. The second is the need or use of medical, psychosocial or educational services more than other children of the same age. The third, the limitation or inability to perform daily activities, compared to other children of the same age. The fourth, needing or receiving specialized physiotherapy, occupational therapy or speech therapy treatments. The last one, to the need or performance of treatment or follow-up for emotional, developmental or behavioral problems. All answer options are yes or no.⁴⁻⁵

In the second and third parts of the CSHCN *Screener*[®], each question is answered only by obtaining affirmative (yes) answers for any condition described in the first part of the instrument. In these statements, relationships between these answers are sought with any health problems

whose actual or expected duration is at least 12 months. Any question with an affirmative answer, in any part of the instrument, already determines that the child has some domain of health need that requires special and specialized care from health and educational services.^{4,5}

For family caregivers whose children were screened with special health needs, then, on the same day and place, a second instrument characterizing demands was applied, already used in another research with this population group,¹⁵ which also proved to be adequate for use in this study through the pilot test performed. The first part contained sociodemographic variables related to the child and the family: child's sex (female; male); child's ethnicity (black; brown; white; indigenous); child's age (in years); caregiver (mother; father; grandmother; grandfather; siblings; others); caregiver age group (up to 19 years old; 20 to 24 years old; 25 to 35 years old; more than 35 years old); caregiver's marital status (married; stable union; living with a partner; separated; widowed; single); caregiver's level of education (total illiterate; functionally illiterate; complete elementary school; incomplete elementary school; complete high school; incomplete high school; complete higher education; incomplete higher education); origin: (Municipality of Rio das Ostras; others); family income (no income; up to 1 minimum wage; 1 to 2 minimum wages; 2 to 3 minimum wages; 3 to 4 minimum wages; 4 minimum wages or more); housing: (masonry; others); electricity (yes; no); origin of drinking water (public network; well; does not have it); disposal of waste (public network; open sky; septic tank; other).

The second part covered the conditions of pregnancy, delivery and birth: prenatal care (yes; no); number of appointments (quantity); risk pregnancy: (yes; type; no); gestational age at birth (preterm, term, post term); type of delivery (vaginal; cesarean section; forceps); birth weight (value); weight for gestational age (small for gestational age; adequate for gestational age; large for gestational age); need for respiratory resuscitation (yes; no); feeding at hospital discharge (breast; mixed; artificial).

And the third part, the origin of special health needs and care demands: acquired cause (yes; type; no); congenital cause (yes; type; no); medical diagnosis (type); demand for medication care (yes; type; no); technological care (yes; type; no); modified usual care (yes; type; no); developmental care (physiotherapy; speech therapy; nutrition; others; periodicity). The interview time for CSHCN family members, in the application of the profile assessment instrument, was on average 15 minutes.

Data were entered by two people independently and submitted to descriptive statistical

analysis with measures of absolute and relative frequency, central tendency (mean, median) and dispersion (standard deviation) using the *Statistical Package for the Social Sciences* software from *International Business Machines Corporation* (IBM® SPSS), version 20.0.

Study approved by the Research Ethics Committee, opinion 3,196,393, on March 13, 2019. The research was conducted in accordance with Resolutions 466/2012, 510/2016 and 580/2018 of the Ministry of Health. Participants signed the Informed Consent Term.

Results

Among the 235 children whose family members participated in the study, 12 were identified by the CSHCN *Screener*® with at least one domain of special health needs, which is equivalent to a relative frequency of 5.1% in the sample. Regarding the domains, among the CSHCN screened, it was found that the need or use of medical, psychosocial or educational services more than other children of the same age (91.7%) and dependence on prescription drugs (83, 3%) were the most prevalent (Table 1).

Table 1 - Distribution of CSHCN* screened according to health needs domains. Rio das Ostras, RJ, Brazil, 2019 (n=12)

Health needs domains	n	% among CSHCN* (n=12)	% among the children (n=235)
Use of services above what is considered normal	11	91.7	4.7
Dependence on prescription drugs	10	83.3	4.3
Presence of functional limitations	7	58.3	3.0

*CSHCN = Children with special health care needs

More than half of the CSHCN (58.3%; n=07) had three combined domains of health needs and two of them (16.7%) had two domains. For all of these children, the reason was a medical, behavioral, or health condition and the condition continued or is expected to continue for at least 12 months. The need for or receiving specialized physiotherapy, occupational therapy or speech therapy treatments was equivalent to ten children (83.3%) and emotional, developmental or behavioral problems determined the need for treatment or follow-up for seven (58.3%).

Table 2 shows the distribution of children screened by their family characteristics. The twelve family caregivers were mothers, 58.3% lived with their spouse, the most frequent age group was between 25 and 35 years old (66.7%) and 41.7% of the participants had completed high school. Most families lived in the municipality of Rio das Ostras (91.7%), all in masonry

houses with electricity, with most consuming treated water from the public network (83.3%) and with access to sanitary sewage (66.7%). It is noteworthy that eight family members lived with a family income of up to two monthly minimum wages (66.7%).

Table 2 - Distribution of CSHCN* screened according to family characteristics. Rio das Ostras-RJ, Rio das Ostras-RJ, 2019 (n=12)

Variables	n	% among CSHCN*
Main caregiver		
Mother	12	100.0
Age Group		
20 to 24 years old	1	8.3
25 to 35 years old	8	66.7
Over 35 years old	3	25.0
Caregiver's marital status		
Married	7	58.3
Separated	2	16.7
Single	3	25.0
Caregiver's Education Level		
Complete Elementary School	2	16.7
Complete High School	5	41.7
Incomplete High School	3	25.0
Complete higher education	1	8.3
Incomplete higher education	1	8.3
Family's origin (city)		
Rio das Ostras	11	91.7
Others	1	8.3
Family Income		
Up to 1 minimum wage	2	16.7
From 1 to 2 minimum wages	6	50.0
From 3 to 4 minimum wages	2	16.7
4 minimum wage or more	2	16.7
Housing conditions		
Masonry	12	100.0
Electricity	12	100.0
Consumption Water		
Public network	10	83.3
From well	2	16.7
Waste destination		
Public network	8	66.7
Septic Tank	4	33.3

*CSHCN = Children with special health care needs

The data on the CSHCN'S personal characteristics and the conditions of pregnancy, delivery and birth are presented in Table 3. Regarding sex of the children, there was a ratio of boys to girls of 1.4:1; the majority (58.3%) were preschoolers, with a mean age of 5.75 (SD \pm 3.646; median of 5.5). Regarding ethnicity, 50% of the interviewees declared that the child was white, while 41.7% were brown. Regarding the

conditions of pregnancy, all of them reported having had prenatal care, most with more than six appointments (91.7%) and low-risk pregnancies (66.7%). Most CSHCN were born by cesarean section (75.0%) in good birth conditions, both in terms of gestational age, since 75.0% were at term, and regarding weight, since among 66.7% of children the same was suitable for gestational age. Mean birth weight was 3,549g (SD± 1,360.13g and median of 3,327.5g), with a minimum birth weight of 1,980g and a maximum of 5,500g.

Table 3 - Distribution of CSHCN* screened according to personal characteristics and conditions of pregnancy, delivery and birth. Rio das Ostras-RJ, Rio das Ostras-RJ, 2019 (n=12)

Variables	n	% among CSHCN*
Child's sex		
Male	7	58.3
Female	5	41.7
Child's Age Group		
Preschool (2 to 6 years old exclusive)	7	58.3
School (6 to 10 years old exclusive)	3	25.0
Pre-teenager (10 to 12 years old exclusive)	2	16.7
Ethnicity		
White	6	50.0
Brown	5	41.7
Black	1	8.3
Prenatal		
Yes	12	100.0
Number of appointments		
Up to six appointments	1	8.3
Six or more appointments	11	91.7
Risk pregnancy		
Yes	8	66.7
No	4	33.3
Type of delivery		
Caesarean section	9	75.0
Normal	3	25.0
Gestational age at birth		
At term	9	75.0
Pre-term	3	25.0
Weight for gestational age		
Proper for gestational age	8	66.7
Small for gestational age	2	16.7
Large for gestational age	2	16.7

*CSHCN = Children with special health care needs

It is worth mentioning that there were high-risk pregnancies due to hypertension (8.3%; n=01), preeclampsia (8.3%; n=01), oligohydramnios (8.3%; n=01) and placental displacement (8.3%; n=01). However, only one child (8.3%) had complications at birth, requiring the use of inhaled O₂ and medications for resuscitation. Most children (75%; n=09) were exclusively

breastfed at discharge from the maternity hospital, while three (25%) were using artificial milk.

The origin of special health needs in the child's life was due to congenital (83.3%; n=10) and acquired (16.7%; n=02) causes. According to the mothers, the children were diagnosed with the following diseases: asthma (16.7%; n=02), allergy (16.7%; n=02), low immunity (16.7%; n=02), asthmatic bronchitis (16.7%; n=02), contact dermatitis (16.7%; n=02), hydrocephalus (16.7%; n=02) and myelomeningocele (16.7%; n=02). They also highlighted that they were also undergoing medical follow-up for: chronic pulmonary obstruction, cerebral palsy, blindness, learning deficit, bone fracture, gastroesophageal reflux, Attention Deficit Disorder (ADD) and Down Syndrome, with one (8.3%) child for each of these diagnoses. Many children (41.7%; n=05) had more than one diagnosis, initial or current, that could be associated with their special health needs.

The six care demands for family caregivers and health professionals were identified among CSHCN, with emphasis on modified usual care (91.7%), followed by medicine care (83.3%), (Table 4).

Table 4 - Distribution of CSHCN* screened according to types of care demands. Rio das Ostras, RJ, Brazil, 2019 (n=12)

Care demands	n	% among CSHCN*
Modified usual care	11	91.7
Daily medication use	10	83.3
Infection prevention	3	25.0
Prevention of bronchoaspiration	2	16.7
Vital signs monitoring	2	16.7
Gastrostomy feeding	1	8.3
Saturation monitoring	1	8.3
Monitoring of seizures	1	8.3
Medicine care	10	83.3
Corticosteroid	5	41.7
Bronchodilator	3	25.0
Anti-reflux	2	16.7
Analgesic	1	8.3
Antihistamine	1	8.3
Urinary antispasmodic	1	8.3
Cardiogenic	1	8.3
Eye drops	1	8.3
Psychotropic	1	8.3
Mixed care	9	75.0
Medicine care + modified usual care + developmental care	4	33.3
Medicine care + modified usual care	4	33.3
Medicine care + developmental care	1	8.3
Developmental care	7	58.3
Physiotherapy	5	41.7
Speech Therapy	4	33.3
Occupational Therapy	1	8.3
Technological care	3	25.0

Urethral relief tube	2	16.7
Gastrostomy	1	8.3
Tracheotomy	1	8.3
Clinically complex care	2	16.7

*CSHCN = Children with special health care needs

The modified usual care demands included different restrictions and adaptations in the activities of daily living of the CSHCN and their families. Among children who use medication continuously at home, four (40%) of them make continuous use of more than one type of medication per day. Also, among those with mixed care demands, by the combination of one or more demands, some that present developmental care demands are already being followed up by speech therapy (33.3%; n=04) and occupational therapy (8.3 %; n=01).

However, it is noteworthy that although ten children (83.3%) need physical therapy intervention, only five (41.7%) are followed up in this specialty, so five (41.7%) do not have access to this type of service. Also according to the mothers, these CSHCN have been accompanied by other specialties, according to the nature of their needs, such as immunology (33.3%; n=04), psychology (25.0%; n=03), homeopathy (16.7%; n=02), nutrition (16.7%), ophthalmology (8.3%; n=01) and pulmonology (8.3%; n=01).

Discussion

The current study identified that 5.1% of the children who sought the service of the urgency and emergency care network of the SUS, in the inland of the state of RJ, had special health needs. The rate found is close to that obtained among the child population in the United Kingdom of 7.3%.¹¹ The CSHCN *Screener*® applied in primary care in Egypt⁶ and Hawaii⁹ had a prevalence of 12%. In Switzerland¹² and Australia¹⁰ the rates were even higher, 18% and 24%, respectively. In the study that applied the instrument for the first time in the Brazilian context, the rate found was 36%,⁴ and in primary care in two Brazilian municipalities it was 29%¹³.

The difference in findings between the studies carried out in the city of Rio Grande do Sul and in Rio das Ostras can be explained by the difference in scenarios. The first was developed in a specialized outpatient clinic of a teaching hospital, therefore, children with diagnoses of disease or conditions previously defined were already being followed up. The second is a service of the urgency and emergency care network that serves children in general and does not have a local network of specialized services,

which reinforces the need to screen CSHCN also in pediatric emergency care services for the timely care of children of their specific demands.¹

The need or use of services beyond what was expected for children in general was the most common domain of health needs among CSHCN, followed by dependence on prescription drugs. In some cases, the combination of more than one or even all three domains affected the same child continuously for at least 12 months. On the one hand, the results found differ from other research that revealed a higher percentage of drug dependence.⁹ On the other hand, they corroborate the results of an Egyptian study, in which in almost all children, the reason was a clinical, behavioral or health condition and the condition continued or was expected to continue for at least 12 months. In addition, most also presented a combination of three domains,⁶ which reinforces the complexity of the care that these children need to maintain their survival.

The need for or receiving specialized treatments was also relevant, however, not all CSHCN screened had access to the necessary services in the municipality, such as physiotherapy. It is noteworthy, however, that the city of Rio das Ostras is located approximately 170 km from the capital of RJ, where most of the state's specialized services are available. In this directive, a Brazilian study points out that it is common for families of CSHCN to resort to the judicial system to guarantee the minimum necessary care at home, which is not always met.¹⁶

Similar results were identified in a survey carried out in a pediatric hospital in the city of Rio de Janeiro, in which it was identified that families live a constant pilgrimage to large urban centers in search of multidisciplinary and specialized care.¹⁵ Generally, these children are more welcomed by the large referral hospitals for their continued treatment than in the health services available in their territory.²

An international study carried out in Switzerland draws attention to the role of clinical complexity itself as a potential determinant of health inequities, reflecting, for example, in reduced access to different services when compared to other children.¹² Australian research also points out that although access to health services is vital for the development and well-being of all children, those in need of various types of health care are precisely the most vulnerable to the weaknesses of health systems.³

Regarding the profile of these children, the mothers were the primary caregivers who accompanied the CSHCN in the emergency service. A significant portion of these

women did not have the support of a partner, either because they were separated or single. Such data reaffirm that the family care network for these children is reduced to the main caregivers of the family nucleus and the female sex, usually mothers, who are fully dedicated to their care.¹³

Most families live in the municipality with a variable income between one and two Brazilian minimum wages and two families live on less than one minimum wage, therefore, they are low-income, belonging to social class E. Therefore, financial vulnerability is a common reality among these family members. Investigations show that the medical expenses of these children are two to three times higher compared to those without special health needs.^{1,13}

Regarding the conditions of pregnancy, in Brazil, it is recommended to carry out at least six prenatal appointments,¹⁷ which was contemplated by all mothers in the present study. Regarding birth conditions, another study pointed out that the majority of CSHCN was also born by cesarean section, at term, with physical parameters within the appropriate range and without complications during delivery and, likewise, only one child required respiratory resuscitation maneuvers,¹⁵ corroborating with current findings.

In respect to the individual characteristics of the CSHCN, the male gender and the age of early childhood predominated, with a significant portion in the preschool age. Other studies also showed a higher prevalence in male children.⁵⁻⁶ The origin of children's special health needs was due to a congenital cause, with a minority having prematurity and low birth weight. Such data reinforce the importance of advance planning for the birth of babies with congenital diseases in institutions that offer adequate support, including so that new special health needs are not generated beyond the expected domains. It should be noted that adequate knowledge of the factors associated with congenital malformations contributes to the planning of actions in maternal and child health aimed at improving diagnostic methods, specialized monitoring with measures that improve quality of life, which contributes to increased survival and, consequently, the reduction of infant mortality.¹⁸

Six care demands were identified, with emphasis on modified usual care, which represented adaptations in the way of caring for children, transforming the life habits of CSHCN and their families. Adaptations depend directly on learning new care that is also

the responsibility of nursing, even requiring the role of nurses in counseling/teaching families, as it is an integral part of nursing care.²

Regarding medication care, ten children used drugs continuously at home and some used more than one medication for daily use. Therefore, families need to incorporate a range of actions to ensure the correct administration of the drug, such as paying attention to the expiration date, dosage, fractionation, storage and adverse effects, which also implies a correct reading of the prescription.¹⁵ Thus, this type of demand requires the coordinated action of different professionals, including the doctor (prescription), nurse (administration and nursing guidelines) and pharmacist (pharmaceutical guidelines) and other health professionals involved in care, thus aiming at safe handling and with quality care for these children.

Three families in the study needed to learn to manipulate different technological devices to maintain life. For example, a child had the way of receiving food replaced, with the transition from the oral route to the gastrostomy, as well as breathing with the help of the tracheostomy, which altered the spontaneous breathing mechanism. In addition, two needed technological support for bladder emptying. In this logic, a child with technological dependence requires, from their family caregivers, the acquisition of interdisciplinary knowledge and the adequacy of daily care, in order to meet the essential needs for their survival.¹⁹

It is known that home care services should be applied to CSHCN, in order to prevent exacerbations and avoid hospitalizations for preventable causes, through continuous care over time by a multidisciplinary team. In the case of these children, the care provided by these services in Paraná includes surveys, medication administration, dressings and guidance for aspiration and diet administration.²⁰ However, due to the scarcity of this type of home care service in the studied municipality, families need to learn to perform different technological care alone, for example, prepare and administer enteral diets, change tracheostomy cannula, aspirate the airways and perform vesical catheterization.

Therefore, learning to perform the modified technological, drug, developmental and habitual care of CSHCN is a reality and a challenge for Brazilian families.²¹ Faced with changes in the functioning of their children's bodies, caregivers are faced with an innovative care, replacing and/or modifying the daily and usual care of maintaining life,

which makes a previous way of caring different, so that the lives of their children at home are ensured. Therefore, the need to learn in the management of different instruments and medications emerges. However, as this care is not transmitted by cultural heritage, it is necessary to learn from health professionals, especially nurses, the procedures for the safe and quality management of these technologies.²

Although children have different care demands, including mixed and clinically complex ones, which require a range of guidelines from pediatric nursing with families, this was not a self-reported demand by the mothers interviewed. However, a study indicated that the participation of nurses in coordinating CSHCN care at home can potentially reduce the use of urgent and emergency appointments and specialties, in addition to hospital admissions.²² In addition, nursing professionals help to overcome daily difficulties, providing comprehensive and cost-effective care at home, specialty clinics, and in hospital settings, with better health outcomes and greater family satisfaction²³

In this directive, the participation of the multidisciplinary team in primary care, with the nurse as the care coordinator for CSHCN, favors a humanized and comprehensive care for these children and their families. However, the literature points out that the health care network for these children is considered fragile and disjointed, and that urgent and emergency services and tertiary level services are accessed preferentially to the detriment of primary level services.²⁴ In this directive, research developed in a teaching hospital in Rio Grande do Sul, revealed a high demand for urgency and emergency services among adolescents with diabetes mellitus,²⁵ who are part of the group of CSHCN. Thus, the application of the CSHCN Screener® in emergency care services for the screening of these children is essential, in order to increase the visibility of this group and direct public policies that overcome the hospital-centered model and guarantee the effective participation of primary care in the lives of CSHCN and their families.

The research is limited by the information self-declared by family members about the health conditions of their children, as some CSHCN may not have been screened in the research, especially when their condition does not result in activity limitation. Also, the health network of the municipality in question does not cover the more specific needs of these children, which includes the scarcity of services and specialists, directly reflecting the number of CSHCN in the emergency service. As the results are limited to

the child population of a municipality, it is necessary to carry out further research in the urgent and emergency care network.

Conclusion

It was evidenced that among the children, in urgent and emergency situations, attended in an emergency service, 5.1% were identified with special health needs through the application of the CSHCN *Screener*[®].

The need or use of different specialized services above what was considered usual or routine in relation to other children was the most common domain of health needs, isolated or combined, for these CSHCN. In addition, the six care demands for family caregivers and health professionals were identified among CSHCN, with emphasis on modified usual care. It is noteworthy that flaws in the network of specialized care for these children in the municipality were identified.

Health needs are special and specific and require a better organization of the child's health care network. Therefore, the adoption of the CSHCN *Screener*[®] in emergency services is recommended, due to its practicality in tracking this group of children, to increase visibility and indicate care strategies.

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