

CHILD WITH SPECIAL HEALTH NEEDS AT ONE HOSPITAL OF THE BRAZILIAN UNIFIED HEALTH SYSTEM

Criança com necessidades de saúde especiais de um hospital do sistema único de saúde

Niño con necesidades especiales de atención en salud de uno hospital del sistema único de salud brasileño

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ABSTRACT

Objective: To determine and analyze special healthcare needs among children hospitalized in a highly complex hospital in Rio de Janeiro. **Method:** cross-sectional and descriptive study carried out with family members of children hospitalized in an intensive care and acute care units of one highly complex healthcare network. In 2019, a tool “children with special healthcare needs Screener (CS Screener®) – Brazilian version” was applied in the interview with 21 family members. **Results:** hospitalized children (76.19%) had needs and demands for health services related to diseases and behavioral conditions. The care for these children was depended on the Unified Health and Social Security Systems. Four had technological devices in place; eight were accompanied by specialists in psychosocial health services and special education. **Conclusion:** these children were readmitted frequently, occupying most hospital beds in the Health System, which was the main reference for the continuity of nursing care and the continuous use of medications.

Descriptors: Child care, Unified health system, Child health, Health services needs and demand, Nursing care.

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RESUMO

Objetivo: Determinar e analisar necessidades de saúde especiais entre crianças hospitalizadas em hospital de alta complexidade, no Rio de Janeiro.

Método: estudo transversal e descritivo desenvolvido com familiares de crianças hospitalizadas em unidade intensiva e enfermarias de cuidados agudos, na rede de atenção de alta complexidade. Em 2019, aplicou-se o *children with special healthcare needs Screener (CS Screener)* - versão brasileira na entrevista com 21 familiares. **Resultados:** as crianças hospitalizadas (21/36) apresentaram necessidades e demandas de serviços de saúde relacionadas à doenças e transtornos comportamentais correspondendo a 76,19%. O cuidado da criança dependia do Sistema Único de Saúde e de Assistência social. Quatro possuíam dispositivos tecnológicos implantados; oito eram acompanhadas por especialistas na atenção psicossocial e educação especial. **Conclusão:** essas crianças se reinternavam frequentemente, ocupando a maioria dos leitos hospitalares do Sistema Único de Saúde, principal referência para a continuidade dos cuidados de enfermagem e uso contínuo de medicamentos.

Descritores: Cuidado da criança, Sistema único de saúde, Saúde da criança, Necessidades e demandas de serviços de saúde, Cuidados de enfermagem.

RESUMEN

Objetivo: Determinar y analizar las necesidades especiales de atención en salud entre los niños hospitalizados en un hospital de nivel tres en Río de Janeiro. **Método:** estudio transversal y descriptivo desarrollado con familiares de niños hospitalizados en unidades de internamiento (cuidados intensivos y agudos), en la red de salud del Sistema Único de Salud. En el año de 2019 se aplicó la herramienta *“children with special healthcare needs Screener (CS Screener)”* - versión brasileña en la entrevista con familiares. **Resultados:** los niños hospitalizados (76,91%) tenían necesidades y demandas de servicios de salud relacionados con enfermedades y trastornos de conducta. El cuidado dependía de los Sistemas públicos (Salud y Seguridad Social). Cuatro tenían dispositivos tecnológicos en su cuerpo; ocho fueron acompañados por especialistas en atención psicossocial y educación especial. **Conclusión:** estos niños fueron readmitidos con frecuencia, ocupando la mayoría de las camas; la principal referencia para la continuidad de la atención de enfermería y el uso continuo de medicamentos.

Descriptores: Cuidado del niño, Sistema único de salud, Salud del niño, Necesidades y demandas de servicios de salud, Atención de enfermería.

INTRODUCTION

Children with special healthcare needs (CSHCN) is an expression that has been adopted in the United States since 1998 to designate children who have or are at increased risk due to a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.^{1,138}

Childhood and adolescence (from 12 months to 17 years old) correspond to the age of coverage of this child group, and since then, the international literature has been investigating the clinical, epidemiological, family, demographic, economic and socio-cultural conditions of this child group in different contexts of life.²⁻⁶

In Brazil, the expression CSHCN was loosely translated

as Children with Special Health Needs (CRIANES) and defined as “those who have or are with greater physical, developmental, behavioral, or emotional conditions, and who require related health services to a type, or quantity far beyond what children normally demand”.^{7:35}

The research on increasing the survival rate of these children, in international and national contexts, covers a set of complex, technological conditions, disabilities and deficiencies that favor the transition of age. In this sense, the expression and definition of Youth with special healthcare needs (YSHCN) gives more visibility to young people who have or are at risk of having a chronic condition or physical, developmental, emotional or emotional impairment beyond young people in general.⁸

In the United States, the Children with Special Health Care Needs Screener (CS[®] Screener) instrument was developed in 2001 to identify these children and young people in general.² Because it is a culturally diverse country, the instrument was presented in a multilingual format, with questions in English and answers in Western (English, Spanish, Russian) and Eastern (Chinese, Japanese) languages, for example. Screener has already been applied in other countries (Australia, United Kingdom) and culturally adapted to the languages spoken in Switzerland, Egypt and Brazil.⁹⁻¹⁴

The CS[®] Screener consists of five structured questions, which must be answered by those who care for children and know their birth and health history, whether they are family members or not. It allows the identification of the prevalence of CRIANES and the assessment of the areas of special health needs that generate demands for long-term, continuous and complex care in the hospital-home transition, homecare services and in the primary care. These areas are: (a) limited or compromised ability to perform activities that most children of the same age are able to perform; (b) use or need for continuous use of prescription drugs (c) specialized (physical, occupational, speech) therapy (d), special health services (in general), mental and educational health, on a continuous and prolonged basis ; and (e) treatment or counseling therapy for an emotional, behavioral or developmental problem.² These are areas of more frequent needs among CRIANES than children in general that pose challenges for different systems (health, education, transportation, housing, etc.) .

In Brazil, the CS[®] Screener has been applied in studies of the prevalence of CRIANES in primary care services in some municipalities. The results of these studies point to an invisibility of care to CRIANES in settings of basic health units, which determines fragmentation of service offerings and little dialogue between the care networks (medium/high complexity and basic).¹⁴⁻¹⁶

For greater visibility of this group in different health care contexts, there is a need to expand the application environments of the instrument, as is the case of hospitalization units for the treatment of acute and critical

cases. Therefore, we questioned what is the prevalence and areas of needs of CRIANES hospitalized in clinical wards and intensive care unit of a hospital of high complexity in the city of Rio de Janeiro? The objective was to determine and analyze special health needs among children hospitalized in a high complexity hospital in Rio de Janeiro.

METHODS

This is a cross-sectional and descriptive study whose source of data was the application of the Brazilian version of the CS[®] Screener, only by a field researcher, during a period of 10 days, five in the first sector (October 2019) and five in the second (December 2019), with an interval of one month between the two applications.

Answers obtained with the application of the Brazilian version of the CS[®] Screener, ^{2,14} structured in five domains distributed in six sections, totaling 63 questions. A section with information about the child and family: identification of the caregiver and child; data on the child's health, birth; data related to caregivers, data related to family (sociodemographic and economic). Five sections include variables related to the areas of special health needs: use of prescribed medications, clinical condition (pre-existence and duration), use of specialized health services, limitation of common activities for the age, need for specialized professional monitoring.¹⁴

The sectors of hospitalization where the research participants were approached to answer the instrument were the acute care units (ACU) and pediatric intensive care units (PICU). The ACU is the pediatric hospitalization sector with six wards in full activity. The wards are divided according to patient profile, that is, A and B for infants, C and E for mixed ages, D for patients who undergo surgical interventions with short stay and H for patients with hematological diseases. Wards A, B, C, D and E have eight beds each, and ward H, six beds.

The PICU consists of six pediatric beds, four neonatal hospital beds and one isolation bed. At the moment, the isolation bed and two neonatal beds are disabled, totaling eight active beds. Both children admitted to the ACU and to the PICU remain with family members for 24 hours.

Regarding the profile of the population hospitalized at the ACU, hospitalizations of children with acute and chronic cases for respiratory problems, encephalopathies, metabolic diseases, gastrointestinal disorders and hematological diseases stand out. In the PICU, severe patients are admitted, with the need for continuous monitoring, infusions of highly supervised and / or controlled medications, the need for mechanical ventilation, invasive procedures, among other demands, as well as post-surgical patients who require admission to the PICU. It is the sector with patients who are more dependent on care by the Nursing team.

The number of participants was defined based on

selection criteria established a priori by the researchers according to the guidelines of the intentional non-probabilistic sample. In this type of sampling, there is a deliberate choice of sample elements, depending on the researcher's criteria and judgment.¹⁷

The sampling composition criteria were family members over 18 years of age, who were caregivers of hospitalized children and knew the child's health history, from birth.

During the two periods of data collection, in the acute care unit (ACU) there were eight family caregivers of eight (08) children in early childhood (ward A and B), who met the inclusion criteria. Five family members participated in the interviews.

Two (02) family members of eight (08) children, in the second age group and hospitalized in ward C participated, as well as two (02) family members of four (04) children in ward D, three (03) of eight (08) children hospitalized in ward E while in ward H relatives of all hospitalized children participated (n = 4 interviews).

Figure 1. Sample distribution according to the number of beds, hospitalized children and Family members interviewed at ACU and PICU. Rio de Janeiro, 2019

ACU						PICU
Ward A* (nursing)	Ward B (nursing)	Ward C (Pre-scho ol/ school)	Ward D (surgery)	Ward E* (Mixed)	Ward H (hematology)	
L-08 CH-04 FA-03 FE-03	L-08 CH-04 FA-04 FE-02	L-08 CH-08 FA-08 FE-02	L-08 CH-04 FA-04 FE-02	L-08 CH-08 FA-07 FE-03	L-06 CH-04 FA-04 FE-04	L-08 CH-06 FA-06 FE-05
TOTAL: L - 54 CH - 38 FA - 36 FE - 21						
Legend: L-Beds; CH - Hospitalized Child; FA. Family caregiver; F.E - Family member interviewed; ACU - Acute Care Unit; PICU - Pediatric Intensive Care Unit.						
Note: *Two children lived in the hospital for over a year without Family caregiver, therefore they were not included in the study.						

Of the total of 36 people (ACU + PICU) who met the selection criteria, 21 agreed to participate in the survey by answering the instrument on 21 children, 16 of whom were interviewed at ACU and five (05) at PICU.

The data were organized in Word tables, version 2016 (Microsoft Office Professional Plus 2016). Descriptive statistics were applied, in absolute and relative frequencies, and the result presented in the form of tables. The tables were organized according to the study variables in rows and scenarios in columns.

Research corresponds to one of the objectives of the project appreciated and approved by the Research Ethics Committees of the proposing institutions (CAAE n° 79107417.1.0000.5238, Opinion n° 2.360.481, October 31, 2017) and co-participants (CAAE n° 79107417.1.3001.5264, Opinion No. 2420864, December 7, 2017).

The interviewees received the Free and Informed Consent Form, and the objectives of the research were explained to them by the interviewer. Then they signed the document and received one of the two copies with the researchers' signature.

RESULTS AND DISCUSSION

The majority (90.47%) of family caregiving participants who answered the CS[®] Screener were women (mothers and grandmothers). There were two male interviewees (fathers). As for the place of residence, most participants live in municipalities in the metropolitan region of Rio de Janeiro; nine residents of the city of Rio de Janeiro. Twelve participants live in municipalities in the same region (Nilópolis, Duque de Caxias, São João de Meriti, Nova Iguaçu, Belford Roxo, São Gonçalo), in the mountain region (Petrópolis and Magé), in the north of Rio de Janeiro (Bom Jardim) and in the vale do café (Pinheiral, Barra Mansa, Vassouras). None reside in another state in the country.

Education varied: 10 had completed high school, totaling 11 years of study; four completed elementary school only.

Regarding monitoring of pregnancy and delivery conditions, 18 (90%) women had more than six prenatal consultations and the types of delivery (normal and cesarean) did not vary statistically between respondents (Table 1). Only two women reported complications related to birth, namely one triple umbilical cord wrap-around and one resuscitation.

Table 1- Children with special health needs according to the prenatal variables, delivery and birth conditions (type of delivery, gestational age, birth weight) and child's age. High complexity hospital. Rio de Janeiro, 2019

Variables	N=21
Pre-natal consultation	
Yes	20(95,2%)
No	01(4,8%)
Number of prenatal consultations (n=20)	
< 06	02(10%)
06 or more	18(90%)
Type of birth	
Cesarean	10(47,6%)
Normal	11(52,4%)
Gestational age	
Premature	03(14,2%)
Term	17(81%)
Late	01(4,8%)
Weight at birth	
Low weight (<2,5kg)	5(23,8%)
Normal weight(2,5kg-3,9kg)	15(71,4%)
Overweight(>4kg)	01(4,8%)
Age of the child	
> 02 years (nursing)	07(33,3%)
02-05 years (pre-school)	06(28,6%)
06-09 years (school)	06(28,6%)
10-17 years (adolescent)*	02(9,5%)

Source: Elaborated by the authors.

As for the gender of the children, there is no statistically significant difference, as 11 were boys and 10 girls. The same is observed in relation to the race / skin color components declared by the interviewees, since 11 were white and 10 children were black and brown. Regarding the children's age, at the moment of the application of the instrument,

13 were in early childhood, and eight in childhood and adolescence, at the age of attending a regular school.

Among the birth conditions, the majority (81%) of the children were born at term gestational age and with appropriate weight for their age (71%). Almost a quarter (23.8%) of children were born with low weight. (Table 1)

Table 2. Children with special health needs hospitalized according to the disease, health / behavior problems that influence the performance of activities of daily living. High complexity hospital. Rio de Janeiro, 2019
*2/21 were dependent on mechanical ventilation (MV) coupled to tracheostomy (TQT)

Health/ Behaviour problems	N (21)	Technological devices		Long-term use catheters
		Tracheostomy	Gastrostomy	
NEUROLOGICAL SYSTEM (n=7)				
Epilepsy	01	No	No	No
Autistic Spectrum Disorder	01	No	No	No
Chronic encephalopathy	03	Yes*	Yes	No
Neuropathy after appendectomy	01	Yes	Yes	No
Microcephaly	01	Yes	Yes	No
RESPIRATORY SYSTEM (n=5)				
Bronchiolitis	03	No	No	No
Pneumonia	02	No	No	No
GASTROINTESTINAL SYSTEM (N=4)				
Intestinal malrotation	01	No	No	No
Short bowel syndrome	02	No	No	No
Crohn's disease	01	No	No	No
HEMATOLOGICAL SYSTEM (n=4)				
Acute lymphoid leukemia	04	No	No	Yes
IMUNOLOGICAL SYSTEM (n=1)				
Immunodeficiency	01	No	No	No

*2/21 were dependent on mechanical ventilation (MV) coupled to tracheostomy (TQT)

Source: Prepared by the authors.

76.19% of the children whose family members answered the Screener had illnesses and behavioral problems in the area of special health needs. This group of children compared to the total of those who were hospitalized represents 42.1%. Approximately 23.8% of the children had neurological problems (encephalopathy, neuropathy and microcephaly) and needed tracheostomy and gastrostomy. Four children diagnosed with acute lymphoid leukemia had a semi-implanted catheter for prolonged chemotherapy treatment. (Chart 2)

Table 3. Children with special health needs hospitalized according to specialist monitoring, hospitalizations and use of health services. High complexity hospital. Rio de Janeiro, 2019

Variables	N (=21)
Monitoring by specialists	
Yes	17(81%)
No	04(19%)
Number of hospitalizations	
01 time	06(28,6%)
02-03	08(38%)
04-05	01(4,8%)
05-10	04(19%)
>10	01(4,8%)
Since birth	01(4,8%)
Use of health services	
SUS*	18(85,7%)
Mixed	03(14,3%)

SUS - Unified Health System. Source: Prepared by the authors.

The majority (81%) of the children were continuously monitored by specialists and those who were readmitted more than twice corresponded to 71.4%, and one of them had been hospitalized since birth. All children depend exclusively on the Unified Health System (SUS) to meet their health needs, with 85.7% using the public health system exclusively. (Table 2)

Table 4. Children with special health needs hospitalized, according to the areas of their needs (use of medication, health condition, duration and intensity of clinical care, specialized health services, performance of activities, and school and psychosocial monitoring). High complexity hospital. Rio de Janeiro, 2019

Variables	N
Continuous use of medication (n=21)	
Yes	17(81%)
No	04(19%)
Types of medication (n=17)	
Corticosteroids	01(5,8%)
Immunosuppressants	01(5,8%)
Corticosteroids + bronchodilators	03(17,6%)
Antibiotic	04(23,6%)
Anticonvulsants	07(41,4%)
Anti-psychotic	01(5,8%)
Duration of health problem (n=21)	
< 01 year	09(42,9%)
> 01 year	12(57,1%)
Medical assistance to children in general (n=21)	
Yes	17(81%)
No	04(19%)
Special educational support (n=21)	
Yes	07(33,3%)
No	11(52,4%)
Don't know	03(14,3%)
Psychosocial support (n=21)	
Yes	07(33,3%)
No	10(47,7%)
Don't know	4(19%)
Difficulty in conducting daily life activities	
Yes	08(38%)
No	13(62%)

Source: Prepared by the authors.

Regarding the areas of special health needs, the majority of respondents reported that 81% (n = 17) of the children needed medication for continuous use, in the “a” area. Among these drugs, seven children needed anticonvulsants, four needed antibiotics. In addition, 57.1% had a need for professional care superior to children in general, referring to area “b”, health problem lasting more than 12 months.

Children who had greater difficulty in performing activities of daily living than children in general were mainly those with diseases related to the neurological (38%) and respiratory systems (area c). The need for special education and psychosocial support (areas “d” and “e”, respectively) corresponded to 33.3% of responses. (Table 3)

Almost half of the hospitalized children had some recurrent special health need in the 12 months preceding the application of the Screener, a prevalence of 42.1%. The most recurrent areas of special health needs among hospitalized children were continuous use of prescription medication (81%); follow-up with specialists (81%) for chronic conditions, use of technological devices and behavioral disorders. There are needs that determine a high demand for care for the services of the Unified Health System at a much higher level than other children of the same age (81%) due to the greater number of hospitalizations (71.4%) and psychosocial care (33.3 %). The need for special educational support (33.3%) and commitment to the performance of activities of daily living (38%) are also

highlighted. These needs and demands for services are of a prolonged, continuous and complex nature, determining a challenging daily care for health professionals and family caregivers, most of them women, who accompany children during hospitalization. These needs are associated with the problem of living in municipalities far from the high complexity hospital, a reference for the care for children in the Unified Health System. In this context of vulnerabilities, the process of health care further complicates the care required of women. CRIANES, in addition to representing a challenge for hospital discharge and the hospital-home transition.¹⁸⁻²⁰

Children with the neurological system diseases had the need to use technological devices (gastrostomy and tracheostomy). All of them presented difficulties in carrying out activities of daily living, which indicates a close relationship between health problems, activities and technological devices. The lower the child’s performance in activities of daily living, the greater the chance of having a technological device to help breathe and eat. Neurological diseases are acquired as sequelae of infections, prematurity, trauma or due to congenital malformations, corresponding to the main diagnoses of CRIANES in health services.²¹

As for the demands for care, technological ones related to the management of tracheostomy, gastrostomy and semi-implantable catheter stand out; eating, respiratory and body hygiene habits modified due to the use of the devices. Both determine complex care that requires knowledge and practices that are not common in family caregivers’ lives.^{18, 22-25}

If, on the one hand, access to the specialized and highly complex care network of the Unified Health System ensured continuous and complex health care; on the other, it determined challenges for the hospital-home transition in articulation with the primary care network and the follow-up in specialized care. In this sense, a discharge when coordinated by the three care networks (primary, specialized and high complexity) has contributed to overcome the challenges of this transition after discharge from the hospital.^{18,22-23} Children with special health needs, who live in contexts of social vulnerability, may require benefits from the federal government’s cash transfer program to protect their growth and development and guarantee their fundamental rights.

CONCLUSIONS

Caring for children with special health needs requires reformulation of the routine of life of the family caregiver who is hospitalized every time the child is readmitted. The areas of needs also determine demands for hospital care in the management of medicines for continuous use, adaptations in care during feeding, bathing and grooming the child, in the management of tracheostomies and gastrostomy. All nursing care with a set of fundamental

knowledge that needs to be shared with the family caregiver who accompanies the child so that they can take care of the child after hospital discharge. It is about learning to provide complex, continuous and long-term care.

Sometimes children with special health needs remained in the high complexity hospital for more than a year, even after the acute condition had stabilized. De-hospitalizing this group represents a challenge for the discharge coordination process in conjunction with health care networks (basic, specialized and urgent and emergency) to meet clinically complex care demands.

It is necessary to expand studies on the prevalence of children with special health needs hospitalized, in addition to the application of the Screener to increase the visibility of these children in high complexity treatments. It is necessary to institute de-hospitalization policies to support the hospital-home transition of these children. The formulation of more health actions and public policies can contribute to the care of a child with complex demands in the Unified Health System. It is necessary to outline a nursing care agenda shared with families of children with special health needs in the hospital-home-community transition in partnership with the family health strategy nursing team.

The study presents geographical limitations and is restricted to a hospital in a city with a hospital of high complexity reference for the Unified Health System. Therefore, it is necessary to conduct further investigations with children and youth in different health care settings.²¹

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