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Health profile and care demands of children with special health needs

Perfil de saúde e demandas de cuidado de crianças com necessidades de saúde especiais

Perfil de salud y demandas de cuidados de niños con necesidades especiales de salud

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Abstract

Objective: To identify the profile and clinical care demands of children with special health needs cared for by Primary Health Care teams in a city in the countryside of Ceará. **Methods:** A cross-sectional study with a quantitative approach, carried out in a Family Health Unit in the city of Tauá, Ceará, from May to December 2023. To identify children with special health needs (CSHCN), the Triagem de Crianças com Necessidades Especiais de Saúde instrument was applied to family members at home. **Results:** The majority of children were male (71.4%), preschoolers and schoolchildren (85.8%), students (82.1%), accompanied by their mother (82.1%), with family income greater than or equal to a minimum wage (60.7%) and living in urban areas (92.9%). The most significant demands were medication demands (85.7%) and development demands (85.7%), being perceived by family members/guardians or professionals in the age group of 1 to 3 years (39.3%). Of the 28 children, 89.3% have a diagnosis. It was observed that 60.7% have autism spectrum disorder (ASD), with six having a diagnosis of associated attention deficit hyperactivity disorder (ADHD). **Conclusion:** It was evident that health care is still mostly medical-centered on care for CSHCN treated in Primary Health Care.

Descriptors: Primary Health Care; Child Health; Nursing Care.

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Whats is already known on this?
The identification of children with special health needs allows for a better assessment of the care provided and reorientation of actions, contributing to creating comprehensive, universal and equitable policies.

What this study adds?
The research highlights the profile and care demands of children with special health needs cared for by Primary Health Care teams, bringing contributions to the field of care, teaching and research.

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Resumo

Objetivo: *Identificar o perfil e as demandas de cuidados clínicos de crianças com necessidades de saúde especiais atendidas por equipes da Atenção Primária à Saúde em uma cidade no interior do Ceará.* ***Métodos:*** *Estudo transversal, com abordagem quantitativa, realizado em uma Unidade de Saúde da Família do município de Tauá, Ceará, no período de maio a dezembro de 2023. Para a identificação das crianças com necessidades de saúde especiais (CRIANES), aplicou-se o instrumento Triagem de Crianças com Necessidades Especiais de Saúde junto aos familiares em domicílio.* ***Resultados:*** *A maioria das crianças era do sexo masculino (71,4%), pré-escolares e escolares (85,8%), estudantes (82,1%), acompanhados pela mãe (82,1%), com renda familiar maior ou igual a um salário mínimo (60,7%) e morando em área urbana (92,9%). As demandas mais significativas foram as demandas medicamentosas (85,7%) e de desenvolvimento (85,7%), sendo percebidas pelos familiares/responsáveis ou profissionais na faixa etária de 1 a 3 anos (39,3%). Das 28 crianças, 89,3% possuem diagnóstico. Observou-se que 60,7% possuem transtorno do espectro autista (TEA), com seis possuindo o diagnóstico de transtorno de déficit de atenção e hiperatividade (TDAH) associado.* ***Conclusão:*** *Evidenciou-se que a atenção à saúde ainda é majoritariamente médico-centrada no cuidado às CRIANES atendidas na Atenção Primária à Saúde.*

Descritores: *Atenção Primária à Saúde; Saúde da Criança; Cuidado de Enfermagem.*

Resumén

Objetivo: *Identificar el perfil y las demandas clínicas de atención de niños con necesidades especiales de salud atendidos por equipos de Atención Primaria a la Salud en una ciudad del interior de Ceará.* ***Métodos:*** *Estudio transversal, con abordaje cuantitativo, realizado en una Unidad de Salud de la Familia de la ciudad de Tauá, Ceará, de mayo a diciembre de 2023. Para identificar niños con necesidades especiales de salud (NCNES), Se aplicó el instrumento Triagem de Crianças com Necessidades Especiais de Saúde a los familiares en el domicilio.* ***Resultados:*** *La mayoría de los niños eran varones (71,4%), preescolares y escolares (85,8%), estudiantes (82,1%), acompañados de su madre (82,1%), con ingresos familiares mayores o iguales al salario mínimo (60,7%) y residentes en zona urbana (92,9%). Las demandas más significativas fueron las de medicación (85,7%) y las de desarrollo (85,7%), siendo percibidas por familiares/tutores o profesionales en el grupo de edad de 1 a 3 años (39,3%). De los 28 niños, el 89,3% tiene diagnóstico. Se observó que el 60,7% presenta trastorno del espectro autista (TEA), con seis teniendo diagnóstico de trastorno por déficit de atención con hiperactividad (TDAH) asociado.* ***Conclusión:*** *Se evidenció que la atención en salud sigue estando mayoritariamente médicamente centrada en la atención de los NCNES atendidos en la Atención Primaria de Salud.*

Descriptores: *Atención Primaria de Salud; Salud Infantil; Atención de Enfermería.*

INTRODUCTION

Technological advances in the 1990s changed child care practices, contributing to an increase in the survival rate of children with highly complex diseases and providing growth in the group of children living with chronic conditions. These children have been classified using different terms, such as technology-dependent children (TDC), chronically ill children (CIC), children with disabilities and children with special health needs (CSHCN). The term CSHCN is more comprehensive and inclusive.(1,2)

CSHCN require continuous health care of a complex nature, often with a plurality of diagnoses, dependence on health services and different professional categories.(2) They are classified into five groups, according to their clinical care needs, such as developmental, technological, medication, modified usual and mixed care demands.(3)

In the first group, there are children who require psychomotor and social recovery with support from professionals, such as physiotherapists, occupational therapists and speech therapists. Technological demands include those that use some technology resulting from procedural care, such as tracheostomy, gastrostomy, colostomy and indwelling bladder catheter, including home care.(4,5)

The third group includes those who are dependent on medication, that is, who use one or more drugs periodically or continuously at home. Demands of changed habits are any other care that differs from the care offered to a healthy child, including the performance of common tasks, such as hygiene, feeding, changing clothes, mobility and special care, such as using diapers for children over 3 years of age, use of devices to aid mobility, such as wheelchairs, orthoses and prosthetics.(4)

Mixed care demands include those that present demands from more than one group, with the need to diversify consultations with pediatrician, neuropediatrician, physiotherapist, speech therapist, among others, with follow-up by a multidisciplinary rehabilitation team.(6) This continuous care at home is one of the greatest challenges for caregivers. In view of this, the need for family members/caregivers to be trained to provide this care is highlighted. It is necessary to carry out health education by professionals from the multidisciplinary team to promote caregivers' knowledge of how to care for a CSHCN.(1-4)

Faced with these care needs, Primary Health Care (PHC) is characterized by a set of actions with the objective of developing comprehensive care that impacts people's autonomy and their health situation, and must be operationalized in defined territories, considering the specific characteristics of their population, through the exercise of care and management practices, in the form of teamwork.(7,8) It is the gateway to health services, playing a role in coordinating care so that interaction occurs between all elements of the Health Care Network (RAS),⁽⁷⁾ since children with chronic conditions need to be assisted in all levels of health care.⁽⁹,¹⁰⁾

It is essential that care for CSHCN begins in PHC, allowing for better therapeutic results, reducing hospital admissions and the demand for emergency services, through coordinated and resolute care. In view of this, there is a need to identify CSHCN and their health demands, as this will allow for a better assessment of the assistance provided to these children and reorientation of actions, contributing to creating comprehensive, universal and equitable policies that provide necessary social support for family members, enabling the improvement of care provided and resolution.(11) Care for CSHCN is complex and, therefore, involves different professional categories, such as nursing.

Therefore, assistance provided to CSHCN requires knowledge and skills on the part of health professionals so that children receive appropriate treatment and care.(12) In the municipality of Tauá, Ceará, data on CSHCN relate only to children with disabilities, with 149 children aged 0 to 12 years old according to the city's Health Department.(13) According to estimates, 150 to 304 would be CSHCN, considering the prevalence of CSHCN in Brazil.(14)

Although there are several studies on CSHCN in different care contexts, there is still a significant gap in knowledge about the specific profile and these demands. Much of the research focuses on general aspects or specific groups of diseases, neglecting the scope and complexity of conditions that require specialized care.(1,2,3,5,6) Therefore, it is imperative to carry out studies on the profile of CSHCN and their care demands, promoting more effective, inclusive and equitable support for these children and their families, as well as the formulation of public policies and support programs that truly meet the diverse needs of these children, constraining the development of effective intervention strategies.

Therefore, the following research question was chosen: what is the profile and clinical care demands of CSHCN living in the city of Tauá, Ceará? The study aimed to identify the profile and clinical care demands of CSHCN treated by PHC teams in a city in the countryside of Ceará.

METHODS

The present study is characterized as a cross-sectional study with a quantitative approach, prepared based on STRengthening the Reporting of OBservational studies in Epidemiology (STROBE).(15) Study design was chosen due to the need to recognize CSHCN in the municipality of Tauá, Ceará, which currently does not have data on this estimate, thus applying a screening instrument to survey this quantity.

The locus of the study was the assigned area of a Family Health Unit (FHU), which has two Family Health Strategies (FHS) and a multidisciplinary team, composed of a psychologist, nutritionist, physiotherapist and social worker. According to the city's Health Department(13), the two areas have 7,046 registered people, 2,294 families and around 1,207 children, with data extracted from the Electronic Citizen Record (PEC).

To identify the number of children aged 0 to 12 years and screen CSHCN, 13 community health workers (CHW) working in the FHU territory were contacted, who had undergone prior training carried out by the researcher, lasting an average of one hour, to explain the research objectives and what CSHCN are and their demands.

To compose the sample of this study with family members, family members/caregivers over 18 years of age from CSHCN aged 0 to 12 years and who accompany CSHCN who have had at least two consultations in health care services prior to the day of data collection in the last six months.(16) Child and Adolescent Statute (ECA) criteria were adopted, ensured by Law 8,069/90, which classifies a person aged up to 12 years of age as a child and a person in the age group from 12 to 18 as an adolescent.(17)

Family members/caregivers who do not know children's clinical conditions to respond to the data collection instruments, who do not have the ability to understand, express and understand the documents presented and are unaware of or do not accompany CSHCN in the services/points of care in which they are inserted were excluded from the sample. When consenting to participate in the research, family members/caregivers of CSHCN signed the Informed Consent Form (ICF).

The instrument for identifying CSHCN was the *Triagem de Crianças com Necessidades Especiais de Saúde* (CRIANES), translated and culturally validated for Brazil in 2012, from its original version created in the United States, the Children with Special Health Care Needs Screener (NS-CSHCN). It has five items with "yes" or "no" answers, making it possible to identify children who already have chronic, physical, developmental, behavioral or emotional conditions and who need health services, in addition to those required by children in general. Additional information was collected on identification, sociodemographic data (sex, age, family income and years of study) and clinical conditions of CSHCN through electronic/printed medical records and/or exams/reports held by family members.(18)

The CSHCN Screener® allows to define the prevalence and profile of CSHCN and identify the health needs domains, making it possible to assess the conditions of access to the service network, expand coverage and resolve the demands presented by this population group so that policies and programs can be appropriately adapted to guarantee access to the necessary health services and care.(19) It is noteworthy that this instrument was used in other English-speaking countries to determine the prevalence of CSHCN, such as Australia and the United Kingdom, translated and culturally adapted in other countries such as Switzerland, Brazil and Egypt.(20)

The research was carried out from May to December 2023, comprising the phase of data collection, organization, analysis and discussion for subsequent consolidation and presentation of results. Variables were analyzed descriptively, in which absolute numbers and percentages were calculated to express the importance of each variable in relation to the whole. The research was approved by Opinion 6,039,743 of the Public Health School of Ceará Research Ethics Committee (ESP/REC).

RESULTS

Subsequently, data relating to the identification of the 28 CSHCN aged 0 to 11 will be presented. To represent the compilation of data resulting from the research, tables were created on the sociodemographic and clinical profile in association with special health needs demands, including diagnoses, medications, health and education services used.

Table 1. Relationship of the socioeconomic characterization of children with special health needs aged 0 to 11 years with special health needs demands. Tauá, Ceará, Brazil, 2024

VARIABLES	MULTIPLE DEMAND		SINGLE DEMAND		TOTAL	
	N	%	N	%	N	%
Sex						
Male	18	90	2	10	20	71.4
Female	4	50	4	50	8	28.6
Age						
Infant	0	0	1	100	1	3.5
Toddler	1	33.4	2	66.6	3	10.7
Preschooler	11	91.6	1	8.4	12	42.9
Schoolchildren	10	83.3	2	16.7	12	42.9
Study						
Yes	20	86.9	3	13.1	23	82.1
No	2	40	3	60	5	17.9
Family income¹						
<1 minimum wage	7	63.6	4	36.4	11	39.3
≥ minimum wage	15	88.2	2	11.8	17	60.7
Region						
Urban	22	84.6	4	15.4	26	92.9
Rural	0	0	2	100	2	7.1
Caregiver/guardian						
Mother	20	87.0	3	13.0	23	82.1
Father and mother	1	50	1	50	2	7.2
Others	1	33.4	2	66.6	3	10.7

Source: prepared by the authors.

From the 28 CSHCN identified, it was observed that 22 had multiple health demands; 71.4% are male; 85.8% are preschoolers and schoolchildren aged 4 to 11; 82.1% study in regular public or private schools; 60.7% have a monthly family income equal to or greater than the minimum wage, and, in 12 families, it was certainly influenced by the Continuous Payment Benefit (BPC); 92.9% families lived in the urban perimeter; in 82.1% of families, the mother was the main family member/responsible for the care provided to CSHCN; other family members such as grandmother and sister (10.7%) were also reported during the research.

Table 2. Clinical characterization of children with special health needs according to special health needs demands. Tauá, Ceará, Brazil, 2024

VARIABLES	MULTIPLE DEMAND		SINGLE DEMAND		TOTAL	
	N	%	N	%	N	%
Age at which the need was perceived						
<1 year	3	42.8	4	57.2	7	25.0
1 to 3 years	10	90.9	1	9.1	11	39.3
3 to 6 years	9	90	1	10	10	35.7
Development demand						
Yes	22	91.6	2	8.4	24	85.7
No	0	0	4	100	4	14.3
Technological demand						
Yes	1	100	0	0	1	3.6
No	21	77.7	6	22.3	27	96.4
Medication demand						
Yes	21	87.5	3	12.5	24	85.7
No	1	25	3	75	4	14.3
Modified habit demand						
Yes	19	95	1	5	20	71.4
No	3	37.5	5	62.5	8	28.6
Mixed care demand						
Yes	22	100	0	0	22	78.6
No	0	0	6	100	6	21.4

Source: prepared by the authors.

Table 2 deals with the clinical profile of CSHCN, using the screening instrument. Development, technological, medication, modified usual care and mixed care demands were considered, and the age at which special health needs were perceived by family members/guardians or professionals, with the majority being in the age group of 1 to 3 years (39.3%), with a prevalence of developmental and medication demands at 85.7% of CSHCN identified.

Table 3. Clinical characterization of children with special health needs. Tauá, Ceará, Brazil, 2024

VARIABLES	MULTIPLE DEMAND	SINGLE DEMAND	TOTAL	
	N	N	N	%
Diagnosis				
Yes	22	3	25	89.3
No	0	3	3	10.7
Medications in use				
Up to two	18	3	21	75.0
Two or more	3	0	3	10.7
Does not use	1	3	4	14.3
Health service				
Public network	21	6	27	96.4
Private network	1	0	1	3.6
Education services				
Regular education	20	3	23	82.1
Does not study	2	3	5	17.9

Source: prepared by the authors.

In Table 3, it was observed that, of the 28 children, 89.3% have a diagnosis; 17 (60.7%) have autism spectrum disorder (ASD), with six having an associated diagnosis of attention deficit hyperactivity disorder (ADHD), totaling nine (32.1%) children with ADHD. Regarding medications, 75% use up to two medications; 96.4% carry out monitoring in public health services, such as the Psychosocial Care Center (CAPS – *Centro de Atenção Psicossocial*), polyclinic, Basic Health Unit, hospitals; and 20 attend regular education, where two CSHCN also have links with the Association of Exceptional Parents and Friends (APAE - *Associação de Pais e Amigos Excepcionais*).

Table 4. Number of children with special health needs followed up by professional category and professionals providing assistance. Tauá, Ceará, Brazil, 2024

VARIABLES	NUMBER OF CSHCN	%
Professional categories		
Nurse	3	10.7
Doctor	23	82.1
Physiotherapist	2	7.1
Occupational therapist	18	64.3
Speech therapist	5	17.9
Dental surgeon	1	3.6
Nutritionist	5	17.9
Psychologist	15	53.6
Psychopedagogue	2	7.1
Number of professionals		
Up to two professionals	10	35.7
Up to four professionals	13	46.4
Up to six professionals	3	10.7
More than six professionals	2	7.2

Source: prepared by the authors.

Table 4 deals with the number of CSHCN monitored by each professional category and the number of professionals who provide assistance to these children. It was observed that, of the 28 CSHCN, 82.1% are followed up by doctors and 46.4% are followed up by up to four professionals.

DISCUSSION

Sociodemographic characterization showed a predominance of male CSHCN, in line with international studies.(21,22) Considering that the most frequent medical diagnoses were ASD and ADHD, the predominance of males in ASD is justified, as they are four times more likely to present the diagnosis in relation to females, requiring sensitivity from professionals for early diagnosis and correct monitoring.(11-22)

In relation to age, the majority of preschoolers and schoolchildren were identified. Comparing this data to the most identified health conditions, in this case, ASD and ADHD, it is observed that there is a direct relationship between the two, as neurodevelopmental disorders have been presented as an important public health issue in recent years and triggered discussions and changes within the scope of health systems in different countries. In the case of ASD, it is recommended that the diagnosis be made early - preferably from the first year of life -, whereas, in ADHD, the diagnosis is recommended between the ages of 5 and 7. This process can be initiated in PHC when identifying children with developmental delays in childcare consultations, for instance.(23,24)

The predominance of the maternal figure was identified as the main informant and companion of CSHCN in their needs. Families, especially mothers, who are most often considered the primary caregiver, assume an enormous responsibility in carrying out technical care and control symptoms of children's condition outside the health institution, potentially losing days of work or having to give up their job, suffering financial difficulties and being overwhelmed both emotionally and physically while dealing with the care of that child, often resulting in needs greater social support supports.(25)

The importance of including education services in the research is highlighted, as, like the home, which is the natural space for children, school must also be included as an essential element of their overall physical, mental and social development.(25)

Economic classification indicated a predominance of families that lived on at least one minimum wage, often coming from BPC. In comparison to a study carried out in Alexandria, Egypt, the challenges experienced by families went beyond children's clinical aspects and were related to social vulnerabilities, such as low income and low level of education of caregivers, where of the 405 families interviewed (60.1%) indicated that their income is insufficient to meet the needs.(21)

Regarding the area of residence, this study showed a huge difference between those who lived in urban and rural areas, which implies a considerable portion of CSHCN living in urban areas, which can provide these families with timely access to specialized services that are mostly concentrated in the urban area of the municipality.

In relation to the demands presented by CSHCN, there was a predominance of children between 4 and 11 years old with multiple demands, with developmental and medication demands being more frequent, indicating that they are definitive CSHCN, i.e., those who have continuous needs for care. This data is also related to the most frequent medical diagnoses, such as ASD and ADHD, as these are issues that impact children's development and, in many cases, require continuous use of medication to control some characteristics of the disorders.(24-26)

In relation to the professional category that provides care for CSHCN, there was more emphasis on the medical category, followed by occupational therapy and, finally, psychology. It can be deduced that doctors follow up children from the period when the disorder is suspected until the diagnosis is made and medication is prescribed. Meanwhile, occupational therapy acts directly on teaching focused on daily living skills and/or issues related to sensory processing disorder (through the sensory integration method), and psychology can act both in the phase of suspicion of diagnosis, helping to close it and teaching social skills, especially with the use of ABA therapy which, although not exclusive, is often conducted by psychologists.(24-26)

There is an appreciation for the role of pediatricians and the understanding that access to services occurs only through medical consultations, indicating a biological conception by family caregivers. In order to overcome this current scenario of children's health, especially CSHCN, the importance of the nurse's role in the process of development and implementation of PHC attributes in its entirety is evident.(27)

It is important that nurses, especially those working in PHC, develop actions that can be carried out through health education groups with families who have CSHCN and carry out home visits to promote effective access to PHC and, consequently, strengthen the role of the nursing care team that overcomes the disease-centered model.(23,27)

A study carried out in Chile with caregivers and nurses of CSHCN identified that there are different barriers and problems for implementing care for these children, such as inequality in public care policies, invisibility of CSHCN in the PHC context and lack of psychosocial and economic support for families.(28)

It is important to highlight the importance of PHC attributes being discussed in the training of future professionals as well as during continuing education to promote access to and follow-up of CSHCN. In PHC, priority must be given to health promotion and disease prevention, especially in children who already have special health demands. Within the scope of care, it is believed that the breadth and feasibility of access and follow-up in PHC can reduce morbidity and mortality and improve the quality of life of these children and their families.(27)

Carrying out collection only in one FHU can be pointed out as a possible limitation of this study, raising the need to cover all FHUs for a more reliable profile of CSHCN in the municipality and which can also be carried out in other health services in different regions of the country. However, the present study contributes to advancing knowledge about the number of CSHCN in a territory without any previous study carried out to date about the profile of care demands and health and education services and professionals usually required by children and their families.

CONCLUSION

The majority of children are male and live in the urban area of the municipality, living on a family income greater than or equal to the minimum wage to maintain the family's general needs, and are students, often accompanied by their mother. Medication and developmental demands were the most significant, being perceived by family members/guardians or professionals aged 1 to 3 years, which reinforces the importance of a multidisciplinary team in monitoring these children.

The most prevalent diagnoses were ASD and ADHD, which reaffirms the need to reorient actions in health and education services based on more resolute and specific public policies that meet the demands of children and families.

The results of this study may contribute to the analysis of assistance provided to CSHCN in relation to the role of health professionals in supporting CSHCN and their families, expanding the perspective of professionals and managers towards the organization of the service network at their levels of care, contributing to more equitable and resolute care through access to PHC.

CONTRIBUITIONS

Contributed to the conception or design of the study/research: Lins MPC. Contributed to data collection: Lins MPC, Oliveira AKL, Leopoldo AF, Dimas DR. Contributed to the analysis and/or interpretation of data: Lins MPC, Oliveira AKL, Leopoldo AF, Dimas DR. Contributed to article writing or critical review: Lins MPC, Gonçalves JL, Depianti JRB, Oliveira JD. Final approval of the version to be published: Oliveira JD.

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