Prevalence of children with special healthcare needs: An epidemiological survey in Brazil

Andrea Moreira Arrué, PhD [a,*], Yara Hahr Marques Hökerberg, PhD [b], Leonardo Bigolin Jantsch, PhD [c], Silvana Granado Nogueira da Gama, PhD [d], Raquel de Vasconcellos Carvalhaes de Oliveira, PhD [e], Aline Cristiane Cavicchioli Okido, PhD [f], Ivone Evangelista Cabral, PhD [g], Regina Aparecida Garcia de Lima, PhD [h], Eliane Tatsch Neves, PhD [c]

[a] Sergio Arouca National School of Public Health, Fiocruz and Federal Institute of Paraná, Paraná, Brazil
[b] Sergio Arouca National School of Public Health, Fiocruz and Evandro Chagas National Institute of Infectious Diseases, Fiocruz, Rio de Janeiro, Brazil
[c] Federal University of Santa Maria, Rio Grande do Sul, Brazil
[d] Sergio Arouca National School of Public Health, Fiocruz, Rio de Janeiro, Brazil
[e] Evandro Chagas National Institute of Infectious Diseases, Fiocruz, Rio de Janeiro, Brazil
[f] Federal University of São Carlos, São Paulo, Brazil
[g] Anna Nery School of Nursing, Federal University of Rio de Janeiro and State University of Rio de Janeiro, Rio de Janeiro, Brazil
[h] University of São Paulo at Ribeirão Preto College of Nursing, São Paulo, Brazil

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ABSTRACT

Purpose: We aimed to estimate the prevalence and delineate the profile of children with special healthcare needs (CSHCN) in the three municipalities of Brazil's southern and southeastern regions from 2015 to 2017.

Design and methods: This cross-sectional study included 6853 children aged 0–11 years. Participants were selected through complex sampling in 32 primary healthcare units. The Brazilian version of the Children with Special Healthcare Needs Screener© and a questionnaire were used to identify sociodemographic and family characteristics, health status, and health services utilization. Simple and multiple logistic regression models were used to evaluate the association between family and child characteristics and prevalence ($P < 0.05$).

Results: The prevalence of CSHCN was 25.3% (95% confidence interval: 21.0–30.0). Most participants required health services or were on long-term medication for a current chronic condition; approximately 53% of CSHCN had no formally recorded diagnoses. The most frequent health problems were respiratory conditions, asthma, and allergies. Approximately 60% of the CSHCN patients underwent follow-up examinations of the specialties pneumology, pediatrics, otorhinolaryngology, speech therapy, neurology, and psychology. Children of school age, of male sex, with premature birth, with a history of recurrent hospitalization, from non-nuclear families, and from underprivileged social classes were identified as risk factors for classification as CSHCN.

Practice implication: These results contribute to the unprecedented mapping of these children in healthcare networks in Brazil.

Conclusion: The high prevalence of CSHCN in medium and large municipalities in the southern and southeastern regions was associated with the child's previous health conditions and family structure.

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Introduction

Children with special health care needs (CSHCN) are broadly defined as children who have or are at increased risk of having physical, mental, emotional, or other types of conditions requiring a type or amount of health-related service beyond those generally required by healthy children (McPherson et al., 1998). The epidemiological changes in child and adolescent health in the United States gave rise to this comprehensive and inclusive definition as a response to the biomedical model's insufficiency to meet children's demands in only the health system. Tracking CSHCN became imperative to learn the specificities of their access to these services and understand how the quality of life could be improved with coordinated care in-network focusing on the family (Bethell et al., 2015).

In this context, the CSHCN Screener© (CS©) was developed to identify those who need special healthcare services beyond a formally established medical diagnosis. It allows the evaluation of each child's particular care demands by grouping health needs together according to three domains depending on the prescribed medications for a specific clinical condition, use of healthcare services above what is considered regular or routine, and presence of functional limitations (US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2020).

The prevalence of children and young adults with special health care needs (CYSHCN) (aged 0–17 years) in American and European countries ranges from 15% to 33% (US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau; Arim et al., 2015; O'Connor et al., 2017; Goldfeld et al., 2012); however, in Brazil, there are no official CSHCN estimates as yet (Neves et al., 2013). To fill this gap, the translation and cross-cultural CS© adaptation into Brazilian Portuguese was performed (Arrué et al., 2016) as it is a validated instrument (US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau). An understanding of the prevalence and characteristics is essential for understanding this population subgroup's epidemiology regarding planning additional and specific healthcare actions and the services supply (Bethell et al., 2015). This study aimed to estimate the prevalence and delineate the profile of CSHCN (aged 0–11 years) and their families.

Methods

This multicenter cross-sectional study was conducted in three Brazilian municipalities with a population of >100,000 inhabitants, Santa Maria (Rio Grande do Sul), Ribeirão Preto (São Paulo), and Rio de Janeiro (Rio de Janeiro State). The three cities are located in Brazil's South and Southeast regions, are regional reference hubs in child healthcare, and have similar development levels (Brazilian Institute of Geography and Statistics, 2017). The regions were selected as they were the most populated and urbanized in Brazil, with high economic and industrial indices. In addition, the selection criteria took into account the proximity to the proponent institutions and the field of activity of the researchers involved in the project.

Data collected was in the context of Primary Health Care under the Unified Health System in Brazil. This system is public and free for all Brazilian citizens. However, a private health system can be used by citizens who can afford it. Most Brazilians look for public units when they have a health problem.

Participants were recruited using the primary healthcare network of the three municipalities included in the study. All adults aged ≥18 years who visited the healthcare unit, lived with children (aged 0–11 years) and knew their current health conditions, birth information, and family characteristics were eligible (Child and adolescent health measurement initiative, 2021).

The sample size of 981 participants was calculated using the R 3.0.3 program based on the following parameters: number of children (aged 0–11 years) residing in the three cities, the prevalence ($P = 0.20$) based on American estimates (Child and adolescent health measurement initiative. The children with Special Health Care Needs (CSHCN) screener, 2021), significance level of 5% ($\alpha = 0.05$), a difference of $d = 0.025$, and the effect of the study design estimated for the complex sample of deff $= 2$. This was a representative sample of children aged 0–11 years in the three municipalities.

The selection strategy was conducted in three stages. First, a sample of children aged 0–11 years was recruited from each municipality. Subsequently, 35 healthcare units were selected based on the probability proportional to size: 18 units ($n = 574$ families) in Rio de Janeiro, 9 units ($n = 286$ families) in Ribeirão Preto, and 8 units ($n = 121$ families) in Santa Maria.

The first participant was randomly selected, and the selection interval (skip) was defined as the ratio between the population enrolled in the healthcare unit and the sample size $n = 981$ was used. All individual family members who responded YES to the question asking if they were relatives of a child (aged 0–11 years) were invited to participate in the study after explaining its objectives, risks, and benefits. If there was more than one child aged <12 years in the family, the children were sequenced according to chronological birth order. Thereafter, a draw was conducted to determine the child's eligibility. The selection process occurred as follows: if the family caregiver informed that there were four children under 12 years of age, a draw was made using cards numbered from 1 to 4, according to the child's birth order, one being the oldest and four the youngest. The children did not answer any questions, all questions about the instrument were answered by the family caregivers responsible for the child, so one of the inclusion criteria was that this family member knew the child's health history.

Data collection was performed through an epidemiological survey conducted by duly trained research teams between April 2015 and July 2017.

The outcome variable CSHCN was measured using the instrument CS©, comprising five dichotomous items (yes/no) distributed in three dimensions (Brazilian Institute of Geography and Statistics, 2017). The CSHCN variable was analyzed dichotomously (yes/no) and subdivided into eight groups according to the recommendations in the instrument dimensions: those who 1) do not need special attention to health, 2) only need medications, 3) only need health services (HS), 4) only have functional limitations, 5) use medications and require HS, 6) use medications and have functional limitations, 7) use HS and have functional limitations, and 8) are on long-term medication treatment, have some functional limitations, and require HS. The names of the medications were recorded and classified based on the Anatomical Therapeutic Chemical (ATC) system.

In addition to this instrument, the questionnaire included variables answered by the primary caregiver on the sociodemographic characteristics of the child (birth date, sex, color/race, relationship with whom they live, or school or daycare attended). Health condition (medical or health diagnosis) and types of units, services, and specialists attended were later grouped according to the family members' answers. Hospitalization, birth (prenatal care, delivery, prematurity, and birth weight), and family (child's position in the family, number of siblings, gap between siblings, and financial aid received from government or other sources) data were also collected.

The income level was classified according to the criteria established by the Brazilian Association of Research Companies (ABEP) (ABEP, and Brazilian Association of Research Companies, 2015), ranging from A to E, with the latter representing the lowest class. These criteria were used to divide the population into six socioeconomic strata.

Data analysis was performed using the survey package of R software (Davis et al., 2015). The estimates were considered to design effect and sample weights, as defined by the selection probabilities' inverse product at each sampling plan stage (municipality, health unit, and participant). Initially, the CSHCN prevalence was calculated for each subgroup, with its respective 95% confidence interval (CI), by combining the

three dimensions measured. Subsequently, the expanded and straightforward frequencies of the sociodemographic variables, health conditions (pregnancy, birth, delivery, and child hospitalization), and family characteristics were evaluated according to the CSHCN prevalence. Wald statistics for a complex sample were used to assess the differences in proportions (Davis et al., 2015). For age, the median and interquartile ranges were calculated.

Simple logistic regression models were used to evaluate each independent variable's association and CSHCN outcome using the odds ratio (OR). Variables with a P-value of <0.20, or those considered relevant in the literature, were included in the multiple logistic regression models. Five models were tested: the first evaluated the child's sociodemographic variables effect; the second tested the impact of the child's gestation and birth conditions, adjusted for the child's sociodemographic characteristics, the third model included the child's health conditions, the fourth included the family characteristics, and the last model included all variables associated with the CSHCN prevalence in the previous models. Finally, the independent variables with a P-value of <0.05, remained in the models. Adjusted ORs and their respective 95% CIs were calculated. The adjustment quality was evaluated using Akaike's information criterion; the lower the value, the better the model adjustment.

This study was approved by the ethics committees of the proposed institutions and study participants and was performed according to Brazilian research ethics regulations.

Results

After applying the expansion factor, the sample included 1001 participants, representing 6854 children. In the three cities, most respondents were mothers (66%), grandparents (20%), other relatives, such as an uncle, brother, or cousin (9.7%), and fathers (4.3%).

The primary caregivers of these children were mostly their mothers (78%) and grandparents (12%); however, some families had shared custody (2.1%), followed by the child's father only (3.7%), other relatives, and the school or even a hired person (3.8%). The caregivers were aged 14–82 years (M_d = 33 years), and 70% of caregivers were aged 20–39 years (Fig. 1).

The CSHCN prevalence rates in this epidemiological survey and the CS© items and domains (Brazilian version) are presented in Table 1.

The prevalence of CSHCN was 25.3% (95% CI: 21.0–30.0). Most patients required long-term medication treatment or healthcare services for current chronic conditions. According to the ATC system, 925 CSHCN used medication, mostly for respiratory (n = 690), digestive and metabolic (n = 114), central nervous system (n = 109), skin (n = 55), and other disorders (n = 51). Some children used multiple medications, and 30 respondents could not provide the medication's name or purpose. Children who used supplemental vitamins accounted for <1% of those using medication and were not classified as having CSHCN.
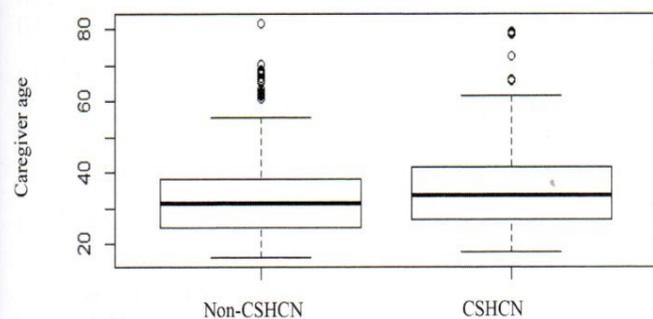
Table 1
Prevalence of children with special healthcare needs (aged 0–11 years) according to the items and domains of the CS©, 2015–2017, in Brazil.

Sample		2015–2017	
Children No. (no expansion)		6854 (1001)	
CSHCN No. (no expansion)		1736 (239)	
CSHCN prevalence (95% CI)		25.3% (21.0–30.0)	
CS© items/domains		CSHCN	
	N	%	(95% CI)
Items			
1. Chronic condition medication use (≥1 year)	925	13.50	(10.3–17.0)
2. Medical, school, or psychosocial follow-up	884	12.90	(9.3–18.0)
3. Functional limitation	300	4.38	(2.6–7.0)
4. Physiotherapy, occupational therapy, or speech therapy	336	4.90	(3.0–8.0)
5. Emotional, developmental, or behavioral problem	616	8.98	(6.1–13.0)
Domains			
Chronic condition medications use (≥1 year)	524	7.6	(5.0–11.0)
Health services (HS) use	682	10.0	(6.9–14.0)
Functional limitation	30	0.4	(0.07–3.0)
Medication and HS use	230	3.3	(2.0–6.0)
Medication use and functional limitation	58	1.0	(0.2–3.0)
HS and functional limitation use	99	1.4	(0.06–3.0)
Medication use, HS use, and functional limitation	113	1.6	(0.8–3.0)

CS© = Children with Special Healthcare Needs Screener©; CSHCN = Children with special health needs; CI = confidence interval.
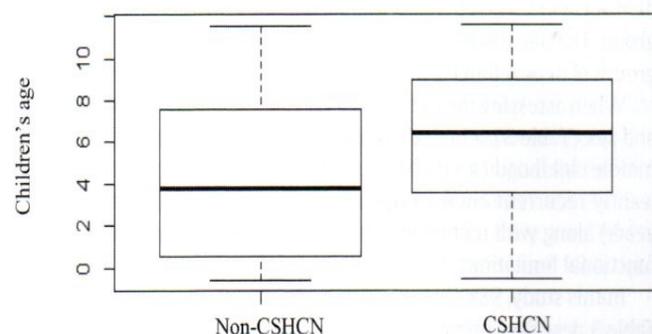

Fig. 2. Age distribution of children, stratified according to the children with special health needs (CSHCN) and non-CSHCN groups. 2015–2017, in Brazil.

Regarding health problems, 53% (n = 923) of CSHCN did not present with previously confirmed diagnoses. Of the 47% (N = 813) diagnosed as CSHCN, 81 had multiple health conditions, with 894 diagnoses in total. The most common were respiratory problems[1] (n = 250), asthma (n = 110), allergies (n = 84), infectious and contagious diseases (n = 40), behavioral or emotional disorders (n = 35), gastrointestinal problems (n = 29), epilepsy or seizure crisis (n = 12), attention deficit hyperactivity disorder (n = 5). The prevalence of respiratory problems[1] was relatively high when they were grouped. Most families could not identify the health condition's name and instead described it as a respiratory problem. Since asthma is a chronic disease with a confirmed diagnosis requiring specialized treatment, it was classified separately; the family members often indicated this condition in the questionnaire as a "type of allergy," under which respiratory, food, and dermatological allergies are all included. The researchers used open questions to assess the child's health condition and categorized it according to the family members' answers.

Most families (70%) used public health services for consultations or examinations only, while the remaining 30% of families used private or mixed services. 38% of CSHCN accessed primary healthcare (PHC);

Fig. 1. Age distribution of children's caregivers, stratified according to the children with special health needs (CSHCN) and non- CSHCN group. 2015–2017, in Brazil.

[1] Bronchitis, Bronchiolitis, Pneumonia, Sinusitis, Upper Airway Infections, and other Upper Respiratory Tract Diseases according to the International Classification of Diseases - ICD 10 (except asthma).

Table 2

Distribution of affirmative answers (N = 1736) of CSHCN (aged 0–11 years) according to the items of the instrument CS©–Brazilian version by sex and age. Brazil, 2015–2017, in Brazil.

CS© Brazilian version items	Sex			Age		
	Female	Male	p value*	0–5	6–11	p value*
	N = 853 (%)	N = 883 (%)		(N = 788)	(N = 948)	
In any of the items	49.1	50.9	0.36	45.4	54.6	0.02
1. Use of medication	44.0	55.0	0.02	56.0	44.0	0.83
2. Medical, educational, or psychosocial follow-up	47.0	52.0	0.46	36.0	64.0	0.004
3. Functional limitation	60.0	40.0	0.49	18.0	82.0	0.01
4. Physiotherapy, occupational therapy, or speech therapy	38.0	62.0	0.20	27.0	73.0	0.05
5. Emotional, developmental, or behavioral problem	49.0	50.0	0.71	18.0	82.0	<0.001

* Wald statistics; CS© = Children with Special Healthcare Needs Screener©; CSHCN = Children with special healthcare needs.

35% accessed emergency services, outpatient clinics, private clinics, or third-sector services (non-governmental organizations); 24% did not access service; and 3% could not inform which health service they accessed.

A specialist followed up only 60.3% (n = 1047) of CSHCN. The care providers who frequently examined this patient group were pulmonologists (n = 283), pediatricians (n = 267), otorhinolaryngologists (n = 136), speech therapists (n = 171), neurologists (n = 135), psychologists (n = 92), allergy and immunology specialists (n = 43), and cardiologists (n = 34).

Most of the children were girls (53.2%), white (68.4%), below 5 years old (57.8%), and attended part-time daycare or school (55.2%). The median age was 6 years in the CSHCN group and 4 years in the non-CSHCN group. The age distribution of children in the CSHCN and non-CSHCN groups is depicted in Fig. 2.

When assessing the instrument's distribution with respect to the age and sex (Table 2), a high CSHCN prevalence was found among boys in middle childhood (aged 6–11 years). The use of medication was significantly recurrent among boys, toddlers, and preschoolers (aged 0–5 years) along with mental health problems, the need for follow-up, and functional limitations.

In this study, 98% (95% CI,97–99) of mothers received prenatal care. Table 3 describes prenatal care, birth, and hospitalization data for both the groups.

CSHCN chances increased approximately twice among children whose family members reported one hospital admission and four times among those with more than two hospitalizations.

Table 4 shows the family and economic characteristics.

The primary caregivers were predominantly mothers (78%), and the probability of them leaving their jobs (OR = 2.77; 95% CI = 1.74–4.39) or missing work to care for CSHCN (OR = 2.03; 95% CI = 1.22–3.39) was higher.

Most families' profiles had a nuclear structure, belonged to class C, and were not registered in any government cash transfer program. There was no statistical significance of family risk, which established priorities in home care for families registered in the primary healthcare network.

The results of multiple logistic regression models used to assess the association between family and child characteristics and CSHCN prevalence are shown in Table 5. The best-fitting multiple logistic regression model included the age, sex, history of premature birth, history of previous hospitalization, and children not living with parents and belonging to low-income families (classes D or E of the ABEP criterion). However, the only significant variables were history of previous hospitalization and those not living with parents.

Discussion

This epidemiological survey is the first to estimate the prevalence of primary healthcare in CSHCN in a developing country using the CS©. The results showed that one in four children investigated either have or are at risk of developing special healthcare needs according to the CSHCN definition.

The CSHCN prevalence found in this study is consistent with that found in a PHC study, which used CS© to identify CSHCN to improve the care quality and resource allocation and reported a prevalence of 16.8% (n = 246) (Davis et al., 2015). Pediatricians providing primary care reported that approximately 28% of children belonged to this group (Okumura et al., 2018).

The number of children aged <5 years who used continuous drugs for chronic conditions was alarming. The most common medications were used for the treatment of respiratory, gastrointestinal, and central nervous system disorders. Usually, PHC units routinely perform the dispensation of drugs for acute cases under medical prescriptions and are frequently updated on stock drugs. CSHCN are frequently administered long-term drugs, and psychotropic agents are commonly used. Approximately one in three CSHCN require ongoing medication treatment (Huang et al., 2020).

Our study findings showed that over half of CSHCN had not received a clinical diagnosis, suggesting that CS© could be used to detect children in need of healthcare services for some chronic conditions without a defined medical diagnosis. Many of these children had never received a diagnosis or information from services indicating that they are CSHCN

Table 3

Characterization of the sample according to data on prenatal, delivery, birth, and child health conditions, 2015–2017, in Brazil.·

Variables	CSHCN (No)		CSHCN (Yes)			OR% (95%IC)
	N	%	N	%	p-value*	
Number of prenatal visits						
Up to 5 appointments	369	7.7	75	4.5	0.25	1
6 appointments or more	4389	92.3	1589	95.5		1.78 (0.63–5.02)
Delivery						
Cesarean section	2679	52.5	954	55.1	0.67	1
Normal	2424	57.5	779	44.9		0.90 (0.56–1.44)
Gestational age						
To term	4305	84.1	1325	76.5	0.25	1
Premature	612	12.0	333	19.2		1.77 (0.93–3.34)
Post-term	201	4.0	75	4.3		1.21 (0.46–3.17)
Birth weight						
<2500 g	269	5.3	157	9.4	0.39	1.80 (0.74–4.37)
2500 g to 3999 g	4293	85.3	1392	83.1		1
≥4.000 g	473	9.3	126	7.5		0.82 (0.35–1.87)
Problems at birth						
On	4424	86.6	1368	79.1	0.08	1
Yes	687	13.4	362	20.9		1.70 (0.97–2.96)
Previous hospitalization						
On	3849	75.2	876	50.5	<0.001	1
One	880	17.2	437	25.2		2.18 (1.10–4.32)
Two or more	389	7.6	422	24.3		4.78 (2.15–10.6)

* Wald statistics; CSHCN = Children with special health needs; OR = odds ratio.

Table 4
Family profile and economic characteristics of the Brazilian from 2015 to 2017.

Variables	CSHCN (No)		CSHCN (Yes)		p-value*	OR (%95%IC)
	N	%	N	%		
Type of family						
Nuclear	3547	69.8	1090	63.1		1
Extensive	1011	19.8	289	16.7		0.92 (0.54–1.56)
Monoparental	392	7.7	240	14.0		1.99 (1.00–3.95)
Compound	137	2.7	289	6.1	0.11	2.51 (0.75–8.39)
Inclusion in a government cash transfer program						
On	3938	77.0	1285	74.0		1
Yes	1177	23.0	451	26.0	0.57	1.17 (0.68–2.00)
Socioeconomic class†						
A and B	1306	25.5	511	29.5		1
C	3072	60.0	912	52.5		0.75 (0.47–1.20)
D and E	740	14.5	313	18.0	0.31	1.08 (0.63–1.84)

*Wald statistics; † ABEP criteria = Brazilian Association of Research Companies. Economic classification criteria in Brazil. 2015.
CSHCN = Children with special health needs; OR = odds ratio IC = Correlation Index.

(Ghandour et al., 2018). An Italian study (Cianci et al., 2020) reported that 70% of CSHCN who were hospitalized and accessed emergency care services for children had precise medical diagnoses, indicating that medical underdiagnoses as a Brazilian characteristic. However, the most frequently reported health problems were respiratory system disorders, allergies, and behavioral or emotional changes.

The study identified a high prevalence of CSHCN among boys with mental health problems in middle childhood (aged 6–11 years). This finding is consistent with that of a study that examined this population's characteristics and demonstrated a higher prevalence among boys with early onset mental health conditions (Parasuraman et al., 2020). Our study findings showed that approximately 9% of children required monitoring due to mental or physical health problems, 5% needed rehabilitation, and 4.4% had some functional limitations or disabilities. All of these demands require good coverage by health insurance. An American study aimed to explore comparative differentials in healthcare needs, healthcare utilization, and the health status of CSHCN showed that

this group is a highly social and health vulnerable population (Sarkar et al., 2017).

Our data showed that 70% of families used public services when the child needed consultations or examinations, a percentage similar to that reported in a national survey of household samples, in which 69.8% of the population sought public health services (Brazilian Institute of Geography and Statistics & IBGE, 2019). Although this service in Brazil is considered a system gateway, it needs to be (re)organized to allow an orderly access to the public health network (Harzheim et al., 2020).

Healthcare systems worldwide differ in terms of programs, policies, services, and access. In Brazil, the Unified Health System is organized as a system of decentralized networks, with PHC as the user's healthcare system entrance door, acting as the coordinator and articulator of the other care networks (specialized, medium, and high) (Harzheim et al., 2020). Access to specialized centers in a restricted manner is linked to resolutivity, goes beyond the geographical dimension, and involves economic, cultural, organizational, and service supply issues (Souza et al., 2020; Stopa et al., 2017). The more invisible the child is to PHC, the greater the risk of postponing diagnostic investigation, treatment, and follow-up, which increases the chronicity of any underlying condition.

The organization of healthcare services that best enables care provision to CSHCN and their families is a serious concern and priority worldwide (Coller et al., 2020). Family care recognition and support network integration in care are relatively abstract, but should be considered a priority in the advancement of this scientific area.

Our results showed that most caregivers were women (mothers) who had to quit their jobs to be full-time caretakers, suggesting that these children's health conditions caused changes to the families' dynamics. An international study with CYSHCN (Romley et al., 2017) revealed that their caregivers had high rates of financial problems, reduced working hours, needed to stop working, or avoided changing jobs because of health insurance. These effects were high even for caregivers whose children had worse conditions (Romley et al., 2017). In neonatal and obstetric care, prematurity was the only predictor of birth associated with CSHCN; these results were consistent with those of a North American study (Korhonen et al., 2018).

Male children of school age, born prematurely, with a history of hospitalization, who did not reside with their mother and father, and

Table 5
Estimated family risk odds ratios (AIC) and 95% confidence intervals of the sample in the logistic regression model, 2015–2017, in Brazil.

Variable	Category	Model 1	Model 2	Model 3	Model 4	Model 5
Age	6 to 11 years old	1.96 (1.15–3.35)	2.22 (1.33–3.73)	1.75 (1.02–3.00)	1.73 (0.98–3.06)	1.69 (0.99–2.90)
Sex	Male	1.24 (0.77–1.98)	1.14 (0.68–1.92)	1.19 (0.76–1.88)	1.19 (0.66–2.15)	1.26 (0.68–2.33)
Color	Non-white	1.07 (0.71–1.62)	–	–	–	–
Prenatal	<6 queries	–	0.43 (0.14–1.35)	–	–	–
Gestational age	Premature	–	1.68 (0.89–3.18)	–	–	1.35 (0.67–2.73)
Birth weight	Low weight	–	0.65 (0.23–1.89)	–	–	–
Intercurrences at birth	Yes	–	–	1.13 (0.59–2.17)	–	–
Hospitalization	One	–	–	2.07 (1.05–4.08)	–	2.93 (1.42–6.04)
	≥Two	–	–	4.16 (1.76–9.86)	–	4.44 (2.16–9.12)
Nuclear Family	On	–	–	–	1.79 (1.04–3.10)	1.82 (1.02–3.25)
Has siblings	On	–	–	–	1.14 (0.62–2.09)	–
Socioeconomic class	D or E	–	–	–	1.29 (0.69–2.40)	1.41 (0.72–2.77)
AIC		1124	1044	1084	814	772

AIC = Akaike's information criterion.

belonged to the less privileged social classes had an increased probability of being CSHCN according to the CS© criteria. The leading risk factors are at the individual, family, and community levels (Newacheck et al., 2008), and health conditions are correlated with access to healthcare services (Ghandour et al., 2018), mediated by the public and private supply of the population's service network and socioeconomic level (Barreto, 2017).

Limitations

This study had several strengths and limitations. To our knowledge, this is the first population-based study using a probabilistic representative sample to estimate the prevalence and describe the epidemiological profile of CSHCN in a developing country. This study recruited participants in the public healthcare system's primary care network of three large municipalities in the southern and southeastern regions of Brazil, the country's most developed areas, which favors a comparison between our findings and those obtained in developed countries. Regarding limitations, the children's relatives were recruited in PHC units, some of which were excluded due to urban violence, which may represent a potential selection bias. Although most informants were mothers and grandmothers, some respondents were not direct caregivers, indicating a potential measurement bias. However, this problem should have been minimized because the CS© addresses the child's current, mainly long-lasting, issues.

The data were collected during a period of political crisis, possibly affecting the federal government's financial assistance, altering the Brazilian social pyramid. Future longitudinal and prospective studies are needed to identify the predictive CSHCN factors and evaluate the potential risk factors of these children in order to improve care for this population.

Conclusion

The CSHCN prevalence in Brazil was 25.3%, that is, one in every four children had special healthcare needs associated with a previous health condition, family structure, socioeconomic status, or political context. These findings can help map these children in the healthcare network, preventive strategies, and actions directed at providing this vulnerable group's needs and broadening the debate on chronic conditions in childhood, prioritizing adolescence and adulthood transition strategies. The importance of an international consensus that allows the comparison of estimates in epidemiological research is also highlighted. Other aspects that deserve investigation include the predictive and prognostic factors of this population subgroup.

We recommended to develop this study in other regions of the country to expand estimates on the prevalence of CSHCN in Brazil. This could be contributed to develop a protocol for a systematic follow-up of these children, especially in the primary health care network.

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Author contributions

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.
Each author meets to all four Criteria:

1. Substantial contribution(s) to conception and design, acquisition of data, or analysis and interpretation of data; and
2. Drafting the article or revising it critically for important intellectual content; and
3. Final approval of the version to be published, and
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest

None.

CRediT authorship contribution statement

Andrea Moreira Arrué: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Yara Hahr Marques Hökerberg:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Leonardo Bigolin Jantsch:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Silvana Granado Nogueira da Gama:** Conceptualization, Data curation, Investigation, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing. **Raquel de Vasconcellos Carvalho de Oliveira:** Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Aline Cristiane Cavicchioli Okido:** Methodology, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing. **Ivone Evangelista Cabral:** Conceptualization, Data curation, Investigation, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing. **Regina Aparecida Garcia de Lima:** Methodology, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing. **Eliane Tatsch Neves:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2022.08.013.

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