

CHARACTERIZATION OF CHILDREN AND ADOLESCENTS WITH SPECIAL HEALTHCARE NEEDS IN SCHOOL GROUPS, PORTUGAL

CARACTERIZAÇÃO DAS CRIANÇAS E ADOLESCENTES COM NECESSIDADES DE SAÚDE ESPECIAIS DE AGRUPAMENTOS DE ESCOLAS, PORTUGAL

CARACTERIZACIÓN DE NIÑOS Y ADOLESCENTES CON NECESIDADES ESPECIALES DE SALUD EN GRUPOS DE ESCUELAS, PORTUGAL

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Objective: to characterize children and adolescents with Special Healthcare Needs from two school groups, focusing on sociodemographic characteristics, types of Special Healthcare Needs, and support received. **Method:** a cross-sectional, descriptive study involving 101 children and adolescents with Special Healthcare Needs. Data were collected through a form and analyzed using the *Statistical Package for the Social Sciences*. **Results:** 61.4% were male, aged between 10-15 years (58.4%), attending the 2nd cycle (60.3%), with specific learning disorders (45.5%). They utilized therapy (48.5%), medication (30.7%), and adaptive equipment (18.8%). **Conclusion:** children and adolescents with Special Healthcare Needs exhibit vulnerabilities and require various forms of support. The Community and Public Health Nursing Specialist plays a key role in managing partnerships and networking between schools and healthcare systems, contributing to meeting the special healthcare needs of these children and adolescents.

Descriptors: Child Health. Adolescent Health. Nursing. Community Health Nursing. Health Promotion.

Objetivo: caracterizar as crianças e os adolescentes com Necessidades de Saúde Especiais de dois Agrupamentos de escolas, relativamente às características sociodemográficas, tipos de Necessidades de Saúde Especiais e de apoios. *Método:* estudo transversal, descritivo, com 101 crianças e adolescentes com Necessidades de Saúde Especiais. Os dados foram coletados em um formulário e tratados no *Statistical Package for the Social Sciences*. *Resultados:* 61,4% eram do sexo masculino, com idade entre 10-15 anos (58,4%), frequentavam o 2º ciclo (60,3%), tinham perturbações específicas da aprendizagem (45,5%), recorriam à terapia (48,5%), medicação (30,7%) e a equipamentos adaptativos (18,8%). *Conclusão:* as crianças e os adolescentes com Necessidades de Saúde Especiais apresentam vulnerabilidades e necessitam de diversos apoios. O Enfermeiro Especialista em Enfermagem Comunitária e de Saúde Pública assume

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a gestão de parcerias e trabalho em rede entre as escolas e os sistemas de saúde, contribuindo para a satisfação das necessidades de saúde especiais das crianças e dos adolescentes.

Descritores: Saúde da Criança. Saúde do Adolescente. Enfermagem. Enfermagem em Saúde Comunitária. Promoção da Saúde.

Objetivo: caracterizar a niños y adolescentes con Necesidades Especiales de Salud de dos grupos de escuelas, en cuanto a características sociodemográficas, tipos de Necesidades Especiales de Salud y apoyo. Método: estudio descriptivo transversal, con 101 niños y adolescentes con Necesidades Especiales de Salud. Los datos fueron recolectados en un formulario y procesados en el Statistical Package for the Social Sciences. Resultados: el 61,4% eran hombres, con edades entre 10-15 años (58,4%), cursaban el 2do ciclo (60,3%), tenían trastornos específicos del aprendizaje (45,5%), utilizaban terapia (48,5%), medicación (30,7%) y dispositivos de adaptación (18,8%). Conclusión: los niños y adolescentes con Necesidades Especiales de Salud son vulnerables y requieren apoyo variado. El Enfermero Especialista en Enfermería de Salud Comunitaria y Pública asume la gestión de alianzas y trabajo en red entre escuelas y sistemas de salud, además de contribuir en la satisfacción de las necesidades especiales de salud de niños y adolescentes

Descritores: Salud Infantil. Salud del Adolescente. Enfermería. Enfermería en Salud Comunitaria. Promoción de la Salud.

Introduction

According to the National School Health Program of the Directorate-General for Health of Portugal, Special Healthcare Needs are defined as “[...] those arising from health problems that impact functionality and require intervention in the school environment, such as irregular attendance or the need for special conditions in school attendance, and a negative impact on the learning process or individual development”^(1,43).

In recent decades, there has been a steady decline in infant mortality rates⁽²⁾. However, the number of children with chronic and/or disabling conditions has increased⁽³⁾. This may be attributed to improved healthcare, leading to higher survival rates, particularly among premature newborns, those with congenital anomalies, or certain chronic conditions⁽⁴⁾. Regardless of the diagnosis, children and adolescents with complex health conditions require temporary or permanent care, often associated with motor, functional, behavioral, emotional, and developmental limitations⁽⁵⁾. This group of children and adolescents shares the need for increased mobilization of hospital and community resources, including medical technology/devices and pharmacological resources, to ensure quality of life⁽²⁾.

In Brazil, children with certain chronic conditions are referred to as Children with Special

Healthcare Needs (*Crianças com Necessidades de Saúde Especiais* - CRIANES), a term first introduced by the Maternal and Child Health Bureau in the United States in 1998 through the expression Children with Special Health Care Needs (CSHCN)⁽⁶⁾. This concept encompasses not only chronic diseases but also the child's life needs and healthcare service utilization⁽⁷⁾.

Mental disorders have a significant impact on the 5-14 and 15-19 age groups, and according to the World Health Organization (WHO), it is estimated that around 20% of children and adolescents will experience at least one mental disorder before reaching 18 years of age. Functional or structural body changes, such as chronic illness, disability, and developmental disorders, affect school performance. Emotional and behavioral disorders, such as sadness, fatigue, and aggression, also influence academic performance⁽¹⁾.

In the United States, one in five children (20%) has Special Healthcare Needs⁽⁸⁾. In Brazil, this group represents about a quarter of the child population⁽⁹⁾. According to the latest census conducted by the Brazilian Institute of Geography and Statistics (IBGE) in 2010, 21.7% of children and adolescents under 14 years old had at least one type of disability⁽⁹⁾. In Portugal, however, there is underreporting regarding the systematic identification of children and adolescents with

Special Healthcare Needs, which compromises healthcare planning in schools⁽¹⁰⁾. Additionally, there is no validated tool in Portugal to quickly identify and screen these children and adolescents, estimate prevalence, infer the magnitude of the problem, or understand the profile of the school population with Special Healthcare Needs⁽¹¹⁾.

In both Brazil and Portugal, inclusive practices have progressed in various areas to ensure access to the same services regardless of personal and social circumstances, particularly education⁽¹²⁾. An example of this is the creation of the National School Health Program (*Programa Nacional de Saúde Escolar* - PNSE) by the Directorate-General for Health of Portugal and the School Health Program (*Programa Saúde na Escola* - PSE) by Brazil's Ministries of Health and Education in 2007, aimed at providing the school community with participation in programs and projects that integrate health and education⁽¹³⁾.

In Portugal, School Health is one of the areas of operation for Community Care Units, which are functional units composed of a multidisciplinary team coordinated by a nurse. These units provide care in the community, including homes, schools, and businesses⁽¹⁴⁾. It is important to intervene in these younger age groups to prevent the use of potentially inappropriate medications, which is high in the general population, particularly among the elderly, predisposing them to more comorbidities and increased healthcare costs⁽¹⁵⁾.

According to Portuguese Regulation No. 743/2019, School Health should be managed by Nurses with specific competencies, particularly Community and Public Health Nursing Specialists⁽¹⁶⁾. These nurses plan their interventions according to the National School Health Program to meet the needs of school-aged children and adolescents, promoting health, preventing disease within the educational community, and reducing the impact of health problems on academic performance⁽¹⁾.

Thus, the Community and Public Health Nursing Specialist plays a crucial role in schools, working in collaboration with educational institutions to develop Individual Health Plans for each child and adolescent with Special Healthcare Needs. These

plans assess the impact of their health conditions on functionality and identify health measures to improve academic performance, which is essential for personalized care⁽¹⁾.

The school is an integral part of a child's and adolescent's life, as they spend most of their time there. Therefore, its role should not be underestimated, especially for those with Special Healthcare Needs. Given that limitations and vulnerabilities of this group may pose challenges, schools must offer appropriate responses to facilitate their participation in school life, ensuring their inclusion. Additionally, children and adolescents with Special Healthcare Needs face multiple barriers to academic success, such as higher absenteeism, grade repetition, and calls to parents due to problems occurring at school, which can decrease their motivation and academic performance. Another barrier is bullying, which can affect their behavior and interactions with others⁽¹⁷⁾.

Therefore, it is essential to conduct research in this area to contribute to better health outcomes, inclusive education, greater equity, participation, and accountability for the well-being and quality of life of children and adolescents with Special Healthcare Needs.

This study aimed to characterize children and adolescents with Special Healthcare Needs from two school groups in terms of sociodemographic characteristics, types of Special Healthcare Needs, and support received.

Method

This was a cross-sectional descriptive study with a quantitative approach, conducted with children and adolescents with Special Healthcare Needs from two school groups in the Porto district, northern Portugal, covering preschool, primary, and basic education⁽¹⁸⁾.

Inclusion criteria were: having at least one Special Healthcare Need; attending one of the two school groups during the 2022/2023 academic year. Exclusion criteria were: children and adolescents outside the 3-15 age range; and those from the two school groups with Special

Healthcare Needs whose specific type could not be identified due to missing information in the MIM@F and SCLínico Health Information Systems.

A non-probabilistic convenience sample was used, resulting in 101 children and adolescents.

Data were collected using a form filled out by the researchers. It consisted of three parts: the first included sociodemographic and school characteristics (gender, age, schooling level, and grade repetition); the second referred to types of support used (healthcare services, therapies, medication, and adaptive/corrective equipment); the third concerned types of Special Healthcare Needs (specific learning disorders, communication/language disorders, vision impairment, emotional disorders, hyperactivity and attention deficit disorder, asthma, diabetes, autism spectrum disorders, bone/joint/muscle conditions, hearing impairment, epilepsy, Down syndrome, others).

Data collection was carried out by researchers through consultation of documentation in the SCLínico and MIM@F Health Information Systems, focusing only on variables relevant

to the study. Data were collected in December 2022 and January 2023.

For statistical analysis, a database was created using Statistical Package for the Social Sciences (SPSS) version 24.0. Descriptive statistics were used.

Ethical principles involving human research were respected as outlined in the Declaration of Helsinki and Vancouver guidelines, including privacy, anonymity, confidentiality, and conflict of interest. The study was approved by the Ethics Committee for Health of the Northern Regional Health Administration (Approval No. 93/2022, dated 08.04.2022).

Results

Of the total sample of children and adolescents with Special Healthcare Needs (n=101), most were male (61.4%), aged between 10-15 years (58.4%), attending the 2nd cycle (60.3%), and had never repeated a grade (92.1%) (Table 1). The mean age was 10.00 ± 2.65 years, with a mode of 12 years; the minimum age was 3 years, and the maximum was 15 years.

Table 1 – Sociodemographic and school characteristics of children and adolescents. Porto, Portugal – 2023. (N= 101)

Variables	Frequency	
	n	%
Gender		
Female	39	38.6
Male	62	61.4
Age group		
3-5 years old	6	6
6-9 years old	36	35.6
10-15 years old	59	58.4
Schooling		
Preschoolers	7	6.9
1st Cycle	33	32.8
2nd Cycle	61	60.3
Grade repetition		
No	93	92.1

Source: the authors.

Regarding types of support used, most children and adolescents with Special Healthcare Needs accessed the National Health Service (51.5%), 48.5% received some type of therapy, predominantly speech therapy (71.4%), 30.7%

used medication—mainly central nervous system stimulants like methylphenidate for treating hyperactivity and attention deficit disorder or bronchodilators for asthma treatment. Of the 31 children and adolescents using

medication, 12 used methylphenidate and 9 used bronchodilators. Additionally, 18.8% used adaptive/corrective equipment such as glasses or wheelchairs (Table 2).

Table 2 – Types of support used by children and adolescents. Porto, Portugal – 2023. (N= 101)

Variables	Frequency	
	n	%
Healthcare service		
Public	52	51.5
Private	12	11.9
Both	37	36.6
Therapy		
Yes	49	48.5
Types of therapy		
Speech therapy	35	71.4
Occupational therapy	11	22.4
Physiotherapy	2	4.1
Psychological support	23	46.9
Other	-	-
Medication		
Yes	31	30.7
Methylphenidate	12	38.7
Bronchodilators	9	29.0
Other(1)	10	32.3
Adaptive/corrective equipment		
Yes	19	18.8
Types of Adaptive/Corrective Equipment		
Glasses	18	94.7
Hearing aid	-	-
Wheelchair	1	5.3

Source: the authors.

Notes: Conventional sign used:

- Numerical value equal to zero not resulting from rounding.

(1) "Other" refers to all medication that is not methylphenidate and bronchodilators.

Regarding the most prevalent types of Special Healthcare Needs, it was found that 46 (45.5%) had specific learning disorders, 28 (27.7%) had communication/language disorders, 16 (15.8%) had vision impairment, 14 (13.9%) had emotional disorders, 11 (10.9%) had hyperactivity and attention deficit disorder, and 10 (9.9%) had asthma (Table 3).

Other children and adolescents (28.7%) had Special Healthcare Needs such as food allergies, obesity/overweight, medication allergies, celiac disease, Steinert's myotonic dystrophy, Cornelia de Lange syndrome, Bell's palsy, Noonan syndrome, and Charge syndrome (Table 3).

Table 3 – Types of Special Healthcare Needs among children and adolescents. Porto, Portugal – 2023. (N = 101)

(continued)

Variables	Frequency	
	n	%
Specific learning disorders	46	45.5
Communication/language disorders	28	27.7
Vision impairment	16	15.8

Table 3 – Types of Special Healthcare Needs among children and adolescents. Porto, Portugal – 2023.
(N = 101) (conclusion)

Variables	Frequency	
	n	%
Emotional disorders	14	13.9
Hyperactivity/Attention Deficit	11	10.9
Asthma	10	9.9
Diabetes	5	5
Autism spectrum disorders	5	5
Bone/joint/muscle conditions	5	5
Hearing impairment	4	4
Epilepsy	2	2
Down syndrome	2	2
Other(1)	29	28.7

Source: the authors.

Note: (1) "Other" refers to Special Healthcare Needs not listed in the table.

Discussion

The results showed that most children and adolescents with Special Healthcare Needs were male (61.4%), aged between 10-15 years (58.4%), and attended the 2nd cycle (60.3%).

In the literature, data on Portuguese school-aged children and adolescents with Special Healthcare Needs are scarce, making national comparisons difficult. However, we highlight the report *The Health of Portuguese Adolescents in a Pandemic Context*, which used a sample of 5,809 children and adolescents from the 6th grade (29.5%), 8th grade (33.5%), and 10th grade (37%), with an average age of 14.09 years from 40 school groups across mainland Portugal. The study aimed to analyze adolescents' lifestyles and behaviors in various life contexts⁽¹⁹⁾.

The report found that 18.8% of young people had long-term illnesses—an increase compared to the previous year (15.1%). Among these students, 543 (49.8%) had some type of allergy (respiratory or medication-related), 384 (35.2%) required glasses for better vision, 299 (27.4%) had asthma, 117 (10.7%) had mental health issues, and other conditions such as heart disease (3.8%), language difficulties (3.1%), obesity (2.8%), hearing difficulties (2.6%), diabetes (2%), kidney disease (2%), epilepsy (1.6%), motor difficulties (0.8%), arthritis (0.7%), and cerebral palsy (0.6%) were also reported⁽¹⁹⁾.

The findings of this report⁽¹⁹⁾ are not in accordance with the results presented here, since the most prevalent problems identified were specific learning and communication/language disorders (45.5% and 27.7% respectively) among children with Special Healthcare Needs. However, given the results presented in this report and in this study, it was found that vision disorders, emotional disorders, asthma, diabetes, bone, joint or muscular alterations, hearing disorders, and epilepsy were common Special Healthcare Needs (Table 3).

The results of this study, presented in Table 3, showed that specific learning and communication/language disorders were the most prevalent Special Healthcare Needs, which is in agreement with data collected by the General Directorate of Education and Science Statistics⁽²⁰⁾, as it reports that in Portugal, in the 2017/2018 academic year, approximately 87,039 children and adolescents with learning difficulties were identified, from preschool to secondary education, representing a 7% increase compared to the 81,672 children and adolescents with learning difficulties in the 2016/2017 academic year. According to this same document from the General Directorate of Education and Science Statistics, the majority of preschool children showed *severe difficulty* in the areas: *Acquiring and applying knowledge* (55%), *Language acquisition* (52%), and *Communication* (48%). Regarding students enrolled in primary or

secondary education with learning difficulties, they showed predominantly *severe difficulty* in the areas of *School learning* (52%), *General learning* (47%), and *Language* (31%)⁽²⁰⁾.

In the United States between 2021 and 2022, more than seven million students were referred to special education services; of these students, 32% had specific learning disorders, 19% had communication/language disorders, 15% had other health problems such as asthma or diabetes, and 12% had autism spectrum disorders⁽²¹⁾.

Another study conducted between 2015-2017 across three municipalities in southern and southeastern Brazil aimed to estimate the prevalence and profile of children with Special Healthcare Needs. It found that among a sample of 6,853 children, 25.3% had Special Healthcare Needs - most requiring healthcare services or medication for chronic conditions like respiratory issues or asthma⁽²²⁾.

Our study also found that among children and adolescents with Special Healthcare Needs, 48.5% received some type of therapy—predominantly speech therapy (71.4%). In Portugal's literature, no prevalence studies on Developmental Language Disorder were identified; however, according to data from the 2011 Census, there are between 80 to 110 children per thousand with this disorder in Portugal⁽²³⁾.

It was found that 30.7% used medication and 18.8% used adaptive/corrective equipment. According to the report **The Health of Portuguese Adolescents in the Context of Pandemic**, of the 1,090 students identified with prolonged illnesses, health problems, or diagnosed disabilities, 26% were diagnosed at birth, 50% during childhood, and 24% less than 2 years ago. Furthermore, 594 (54.5%) needed to take medication, 317 (29.1%) reported that it affected their participation in leisure activities, 297 (27.2%) reported that it affected school attendance and participation, 199 (18.3%) reported that it affected participation in family activities, and 136 (12.5%) needed to use special equipment such as glucose meters, crutches, wheelchairs, hearing aids, adapted computers, among others⁽¹⁹⁾.

In the school context, teachers play a crucial role in identifying children and adolescents with Special Healthcare Needs. They are responsible for collaborating with the School Health Team to refer, monitor, and implement individualized care plans, ensuring the management of these children's problems and needs, including access to the resources available to the community.

However, there is still insufficient knowledge about the scope of this issue. In many school groups in Portugal, family doctors fail to identify these children and adolescents in Health Information Systems, and communication between the School Health Team and healthcare organizations is lacking⁽²⁴⁾.

A study conducted in three municipalities in southern and southeastern Brazil between 2015 and 2017 also found that 53% of children and adolescents with Special Healthcare Needs did not have a formally registered diagnosis⁽²²⁾.

Among healthcare professionals, nurses are recognized as key health educators⁽²⁵⁾. Specifically, Community and Public Health Nursing Specialists and Pediatric Nursing Specialists, as part of the School Health Team, can plan and implement interventions. They are vital in their proximity to the community, particularly the school community, identifying problems, setting priorities, establishing and evaluating intervention projects, and acting as pivotal figures in coordination and interdisciplinary collaboration^(1,26).

Each school must acknowledge the diversity of its students and find ways to address this diversity by adapting teaching processes to individual characteristics and conditions. Schools must also mobilize the necessary resources to ensure access to learning. Likewise, healthcare organizations should collaborate with educational institutions to achieve shared goals that promote the development and learning of children and adolescents with Special Healthcare Needs⁽²⁴⁾.

This study was limited by the use of a non-probabilistic convenience sample and secondary data.

Nevertheless, the research achieved its objectives and is expected to contribute to the development of community intervention projects aimed at improving the inclusion and quality of life of children and adolescents with Special Healthcare Needs in the school setting.

Conclusion

In the sociodemographic and school profile of children and adolescents with Special Healthcare Needs, males aged 10-15 years attending the 2nd cycle of education are predominant.

The most prevalent type of Special Healthcare Need was specific learning disorders, and these children and adolescents exhibited increased vulnerabilities, requiring various forms of support, such as therapy, medication, and adaptive/corrective equipment. However, not all were properly identified in Health Information Systems.

Addressing Special Healthcare Needs is a step toward accepting diversity, promoting respect, and recognizing the personal value and merit of these children and adolescents. Nevertheless, this group remains particularly vulnerable in the school environment, as their needs may hinder learning.

Given this, the Community and Public Health Nursing Specialist and the Pediatric Nursing Specialist play a crucial role. Their skills enable them to intervene in health planning, contribute to the empowerment of groups and communities, coordinate community health programs, and achieve the objectives of the National Health Plan. These competencies are essential for promoting health, preventing disease, and reducing the impact of health problems on school performance. In this regard, these professionals have taken on the management and coordination of partnerships and networking between schools and healthcare systems, contributing to an improved quality of life for these children and adolescents.

The study results were presented to the multidisciplinary team of the Community Health Unit responsible for the School Groups. Thus, this research has already made significant contributions, particularly in developing School

Health projects aimed at improving the quality of life for children and adolescents with Special Healthcare Needs.

However, it is crucial to encourage further research on this topic, expanding the geographical scope to consolidate data on the prevalence and incidence of children and adolescents with Special Healthcare Needs in Portuguese schools. The goal is to quantify and characterize this vulnerable population, contributing to better inclusion and learning in the school context. Additionally, it is essential to ensure the continuous training of professionals working in schools, particularly Specialist Nurses, as they are responsible for implementing the National School Health Program.

Collaborations:

1 – conception and planning of the project: Juliana da Conceição Leal Soares, Maria João Filomena dos Santos Pinto Monteiro e Ana Cristina Lima Mimoso Caramelo;

2 – analysis and interpretation of data: Juliana da Conceição Leal Soares, Maria João Filomena dos Santos Pinto Monteiro e Ana Cristina Lima Mimoso Caramelo;

3 – writing and/or critical review: Juliana da Conceição Leal Soares, Maria João Filomena dos Santos Pinto Monteiro e Ana Cristina Lima Mimoso Caramelo;

4 – approval of the final version: Juliana da Conceição Leal Soares, Maria João Filomena dos Santos Pinto Monteiro e Ana Cristina Lima Mimoso Caramelo.

Conflicts of interests

There are no conflicts of interest.

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