

The Care of Children with Special Health Care Needs in the Training of Health Professionals

Assistência à criança com necessidades especiais de saúde na formação de profissionais da saúde

Atención a niños con necesidades sanitarias especiales en la formación de profesionales sanitarios

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Abstract

Objective: To identify how care for children with special health care needs and their families was addressed during training, from the perspective of future health professionals, and whether they feel prepared to provide such care.

Methods: A descriptive, cross-sectional, quantitative study with the participation of 141 graduating students from health courses at a federal university in São Paulo, using an online questionnaire.

Results: The topic was addressed theoretically (53.4%), practically (2.9%), and both theoretically and practically (43.7%) during undergraduate education. Students from speech therapy (75%) and occupational therapy (72.4%) courses partially agreed that they are prepared to assist this population.

Conclusion: Most health courses address content related to the care of children with special health care needs and their families; however, in general, graduating students do not feel adequately prepared to care for this population.

Keywords

Pediatric nursing; Child; Chronic disease; Education Higher; Disabled persons

Resumo

Objetivo: Identificar como a assistência às crianças com necessidades especiais e suas famílias foi contemplada na formação, sob a ótica dos futuros profissionais da área da saúde e se estes se sentem aptos para prestar este cuidado.

Métodos: Estudo descritivo, transversal, quantitativo, com participação de 141 formandos dos cursos da saúde de uma universidade federal de ensino superior de São Paulo, por meio de questionário *on-line*.

Resultados: A temática foi abordada na teoria (53,4%), na prática (2,9%) e de forma teórico-prática (43,7%) durante a graduação. Os participantes dos cursos de fonoaudiologia (75%) e terapia ocupacional (72,4%) concordam parcialmente que estão aptos a atender essa clientela.

Conclusão: A maioria dos cursos da saúde contemplam o conteúdo sobre a assistência às crianças com necessidades especiais de saúde e suas famílias, no entanto, de modo geral, os formandos não se sentem aptos para atender esta população.

Descritores

Enfermagem pediátrica, Criança; Doença crônica; Educação Superior; Pessoas com necessidades especiais

Resumen

Objetivo: Identificar cómo se abordó la atención a niños con necesidades especiales de salud y sus familias durante la formación, desde la perspectiva de los futuros profesionales de la salud, y si se sienten capacitados para brindar dicha atención.

Métodos: Estudio descriptivo, transversal y cuantitativo con la participación de 141 estudiantes del último año de cursos del área de la salud de una universidad federal de São Paulo, mediante un cuestionario en línea.

Resultados: El tema fue abordado teóricamente (53,4%), en la práctica (2,9%) y de forma teórico-práctica (43,7%) durante la graduación. Los estudiantes de los cursos de fonoaudiología (75%) y terapia ocupacional (72,4%) estuvieron parcialmente de acuerdo en que están capacitados para atender a esta población.

Conclusión: La mayoría de los cursos del área de la salud incluyen contenidos sobre la atención a niños con necesidades especiales de salud y sus familias; sin embargo, en general, los estudiantes no se sienten preparados para atender a esta población.

Descriptorios

Enfermería pediátrica; Niño; Enfermedad crónica; Educación Superior; Personas con discapacidad

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Introduction

In Brazil, there are government policies and programs aimed at the demands of children, in order to guarantee a healthy and safe childhood. The Policy for Comprehensive Child Health Care focuses on comprehensive care, covering the child's growth and development process, beyond their illnesses.⁽¹⁾

Since 1990, the Statute of the Child and Adolescent and legislation based on the principles of the Unified Health System have guaranteed universal and equal access to actions and services for the promotion, protection and recovery of children's health.^(2,3)

In Brazil, the reduction in infant mortality rates is related to the population's better living conditions and access to health services with technological advances that have enabled children to survive longer. However, there has been an increase in the occurrence of chronic conditions among children, characterizing an epidemiological transition of childhood with a reduction in the infant mortality rate and an increase in the number of children with chronic conditions.⁽⁴⁾

This chronicity can be due to perinatal and/or acquired causes. In general, it occurs due to perinatal causes and is related to the birth of premature newborns (NBs) who survive, due to the advent of Neonatal Intensive Care Units and qualified technological and human resources.⁽⁵⁾ However, many of these NBs develop some chronic condition, which can generate the need for some kind of monitoring with demands and care during childhood, which can be temporary or permanent.^(6,7)

In Brazil, children with these characteristics are called Children with Special Health Needs (CSHCN), who have many clinical health diagnoses, such as prematurity, congenital malformations and other diseases acquired during their development, with constant need for multi-professional care and different health services.⁽⁸⁾

The literature points to a screening tool developed in the United States, which was translated and adapted for Brazil by Arrué, with six points for identifying CSHCN: continuous use of medication, a higher use of medical, mental health or psycho-educational services in comparison to other children in general, presence of functional limitations, need for rehabilitation therapy and the treatment or counseling for emotional, developmental or behavioral problems.⁽⁹⁾

CSHCN cannot be defined solely by their condition, they need support, welcoming and, above all, attendance which is considered very important for their development, as mentioned in the manual of the Brazilian Society of Pediatrics. Often, the needs of these children are neglected in relation to the different sectors of society, experiencing inequalities in their daily lives and with fewer opportunities to have access to quality healthcare and to develop in an inclusive environment.⁽¹⁰⁾

The National Health Policy for People with Disabilities was implemented with the aim of including this public in health and education services. In order to be implemented, it is essential to train health and education professionals in caring for CSHCN.⁽¹¹⁾ To this end, the training of these professionals needs to be reviewed and based on legislation, in order to meet this demand for assistance, since they will be the main agents of care and guardians of the rights acquired by these children.

The National Policy for Comprehensive Child Health Care sets out among its strategies that this group of children should be given priority in care through the use of the Singular Therapeutic Plan, the Home Care Service and de-hospitalization programs for the continuity of care for CSHCN within the scope of primary care and the establishment of the Health Care Network.⁽¹⁾

In addition, Ordinance No. 1.793 (1994) determines the need to include content on the ethical-political-educational aspects of normalization and integration of people with special needs in the training of health professionals, dialogue and referral to education services.⁽¹²⁾

Despite the relevance of the issue and the provisions of the legislation on the need to prepare professionals during their training to provide care for CSHCN, including the implementation of the attributes of Primary Health Care (PHC) related to access, reception, longitudinality and coordination of care for these children in health services), there is a gap in the training of health professionals on care for CSHCN, which is still neglected both in academia and in care.⁽¹³⁾

Based on these considerations, the question arises: are health graduates being prepared to care for CSHCN and their families?

With this in mind, the aim of this study was to identify, from the perspective of future health profes-

sionals, whether the training they have received enables them to provide care for children with special health needs CSHCN and their families.

Methods

This is a descriptive, cross-sectional, quantitative study carried out with 141 students from health courses at a federal university in São Paulo, with the sample defined by convenience. Students duly enrolled in the final year of the 13 undergraduate health courses at this institution (Nursing, Medicine, Physiotherapy, Speech Therapy, Nutrition, Psychology, Pharmacy, Biomedicine, Physical Education, Occupational Therapy and Health Technology, Radiology, Ophthalmology) were included.

The data collection period took place between 2020 and 2021. Data was collected electronically (via the web) in order to contact the largest number of students.

Contact was made with the student representatives of each health course by email, requesting that the survey be publicized to students in their final year of undergraduate studies, with the link to the online form, containing the Letter of Invitation and the Free and Informed Consent Form (FICF).

The Redcap database was used to enter the information acquired on the form, which contained:

- Part A - Characterization of the health students (gender, age and undergraduate degree);
- Part B - Identification of the theoretical and practical knowledge acquired during the undergraduate course on caring for CSHCN and their families, using a Likert scale (totally agree, partially agree, neither agree nor disagree, partially disagree and totally disagree) to measure their acquisition, for the frequency experienced in assisting CSHCN and their families (often, sometimes, rarely and never) and for satisfaction with the content acquired during the training, which helped in the planning and execution of assistance to children with disabilities and their families (totally satisfactory, satisfactory, neutral, not very satisfactory and unsatisfactory); content considered relevant to the subject (types of special needs, inclusion and accessibility, growth and development, legis-

lation, philosophy of patient- and family-centered care, difference between disability and special needs, communication and rehabilitation) and aptitude in caring for CSHCN and their families.

The data was tabulated in a Microsoft® Excel spreadsheet and analyzed using Epi Info 7 software. Categorical variables will be presented according to absolute and relative frequencies, and numerical variables according to descriptive statistics.

The study was approved by the Research Ethics Committee of the Federal University of São Paulo (CEP no. 4.009.752, Certificate of Submission for Ethical Appraisal: 31089020.4.0000.5505).

Results

A total of 141 final year health students took part in the study. Table 1 shows the sociodemographic data.

Table 1. Characteristics of final year health students

Categories	n(%)
Sex	
Male	27(19,1)
Female	114(80,9)
Age	
20-25 years	105(74,5)
26-30 years	25(17,7)
31-40 years	8(5,7)
> 40 years	3(2,1)
Courses	
Medicine	9(6,4)
Nursing	38(27)
Physical Therapy	20(14,2)
Nutrition	7(5)
Psychology	10(7,1)
Occupational Therapy	11(7,8)
Speech Therapy	16(11,3)
Health Technology	3(2,1)
Ophthalmic Technology	7(5)
Radiologic Technology	3(2,1)
Physical Education	5(3,5)
Pharmacy	7(5)
Biomedicine	5(3,5)

Table 1 shows a predominance of female students (80.9%), mostly aged between 20 and 25, reflecting the young profile of health graduates, predominantly from the Nursing, Physiotherapy and Speech Therapy courses. Table 2 shows the knowledge acquired by the students about caring for CSHCN and their families.

Table 2. Content acquired on assisting CSHCN and their families in theory and/or practice

Courses	Theory n(%)	Practice n(%)	Theory and practice n(%)	None n(%)	Total n(%)
Medicine	3(33,3)	1(11,1)	1(11,1)	4(44,4)	9(100,0)
Nursing	17(44,7)	0(0,0)	7(18,4)	14(36,8)	38(100,0)
Physical Therapy	9(45,0)	0(0,0)	10(50)	1(5,0)	20(100,0)
Nutrition	2(28,6)	0(0,0)	0(0,0)	5(71,4)	7(100,0)
Psychology	6(60,0)	0(0,0)	0(0,0)	4(40,0)	10(100,0)
Occupational Therapy	0(0,0)	0(0,0)	11(100,0)	0(0,0)	11(100,0)
Speech Therapy	5(31,3)	1(6,3)	10(62,5)	0(0,0)	16(100,0)
Health Technology	2(66,7)	0(0,0)	0(0,0)	1(33,3)	3(100,0)
Ophthalmic Technology	3(42,9)	1(14,3)	3(42,9)	0(0,0)	7(100,0)
Radiologic Technology	1(33,3)	0(0,0)	0(0,0)	2(66,7)	3(100,0)
Physical Education	2(40,0)	0(0,0)	3(60,0)	0(0,0)	5(100,0)
Pharmacy	3(42,9)	0(0,0)	0(0,0)	4(57,1)	7(100,0)
Biomedicine	2(40,0)	0(0,0)	0(0,0)	3(60,0)	5(100,0)

Table 2 shows that there is no definite pattern in how this content was taught among the health courses, the majority describing that assistance to CSHCN and their families was presented through theory. Occupational Therapy is an example of a course where 100% of respondents said they had been taught the subject in a theoretical-practical way during their degree, while Physiotherapy respondents were divided between a theoretical and a theoretical-practical way. It is noteworthy that some students report that they were not introduced to the subject during their training, except for students from the Speech Therapy, Occupational Therapy, Physical Education and Ophthalmic Technician courses. In relation to the theoretical part, the participants were asked about the content they considered most relevant for the care of CSHCN and their families, with emphasis on: types of special needs 118 (83,6%), inclusion and accessibility 132 (93,6%) and growth and development 129 (91,5%), while the least relevant were: legislation, philosophy of patient- and family-centered care and the difference between disability and special needs, respectively, 103 (73,0%).

Linked to the practical part, the frequency of experience in assisting CSHCN and their families was investigated, according to 61 (43,2%) of the respondents rarely and 21 (14,9%) never experienced this care, the students who often had experience with these children and their families were those from the Radiology Technician 2 (66,7%) and Speech Therapy 8 (50%) courses. When asked whether it was compulsory to have content on assisting CSHCN and their families, 138 (97,8%) students totally agreed that the

subject should be covered during their undergraduate studies. Regarding student satisfaction with the content acquired during their training, they pointed out that it helped them in planning and implementing assistance for CSHCN and their families, with 38 (27%) considering it satisfactory and 82 (58,1%) not very satisfactory. The courses in which the majority of students considered themselves satisfied with the acquisition of knowledge about CSHCN and their families were: Physiotherapy 11 (55%), Speech Therapy 10 (62,5%) and Radiology Technology 2 (66,7%) and the courses in which the majority of students considered themselves unsatisfied: Nutrition 5 (71,4%), Medicine 6 (66,7%) and Health Technology 2 (66,7%). After surveying the aforementioned aspects, students on health courses were asked about their ability to care for CSHCN and their families, which is shown in Table 3.

Table 3 shows that the students who most partially agree with their ability to care for CSHCN and their families are from the Speech Therapy, Occupational Therapy and Physical Education courses. The majority who partially disagree are from the Nutrition, Pharmacy and Health Technician courses.

Discussion

It is possible to observe that, despite the majority of students declaring that they had access to content on CSHCN and their families during their undergraduate studies, there is a lack of uniform planning among health courses in terms of teaching strategies. The theoretical and practical development of health care for

Table 3. Ability to care for CSHCN and their families.

Courses	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Medicine	1(11,1)	3(33,3)	2(22,2)	3(33,3)	0(0,0)	9(100,0)
Nursing	0(0,0)	9(23,7)	6(15,8)	19(50,0)	4(10,5)	38(100,0)
Physical Therapy	1(5)	8(40,0)	3(15,0)	7(35,0)	1(5,0)	20(100,0)
Nutrition	0(0,0)	1(14,3)	0(0,0)	5(71,4)	1(14,3)	7(100,0)
Psychology	0(0,0)	1(10,0)	1(10,0)	5(50,0)	3(30,0)	10(100,0)
Occupational Therapy	1(9,1)	8(72,7)	1(9,1)	1(9,1)	0(0,0)	11(100,0)
Speech Therapy	2(12,5)	12(75,0)	1(6,3)	1(6,3)	0(0,0)	16(100,0)
Health Technology	0(0,0)	0(0,0)	0(0,0)	2(66,7)	1(33,3)	3(100,0)
Ophthalmic Technology	0(0,0)	4(57,1)	0(0,0)	3(42,9)	0(0,0)	7(100,0)
Radiologic Technology	0(0,0)	1(33,3)	1(33,3)	1(33,3)	0(0,0)	3(100,0)
Physical Education	0(0,0)	3(60,0)	0(0,0)	2(40,0)	0(0,0)	5(100,0)
Pharmacy	0(0,0)	0(0,0)	0(0,0)	5(71,4)	2(28,6)	7(100,0)
Biomedicine	0(0,0)	0(0,0)	1(20,0)	3(60,0)	1(20,0)	5(100,0)

CSHCN and their families is essential in order to deal with the specific nature of care for this public.⁽¹⁴⁾

Despite advances in legislation and scientific evidence on the inclusion and care of CSHCN, this study found that there are still future health professionals who did not receive content on the care of this clientele in their training, as well as students who do not feel prepared to care for them, corroborating the results of Favaro's study.⁽¹⁵⁾ This fact may be associated with little satisfaction with the acquisition of this knowledge during training and less practical experience.

This highlights the importance of raising awareness during the training of these professionals about the care of this vulnerable population, based on theoretical and practical reflections, as well as the importance of seeking to improve skills for this care, in the specialties of pediatrics and/or special education.

The inclusion of the content of care for CSHCN and their families in the curricula of health courses brings future professionals closer to the reality of children, thus bringing to light the real meaning of humanized care, seeking theoretical-practical correlation, with opportunities to carry out interprofessional educational and care practices that corroborate the acquisition of competencies in the care of CSHCN and their families. With this, we hope to reverse the result presented in the study with primary care nurses, who reported a lack of humanization in the care of CSHCN and their families.⁽¹⁵⁾

One relevant aspect is that although it is essential to share theoretical and practical content on caring for CSHCN and their families, this does not guarantee that

the humanistic approach will be taken. It is important that future professionals who work with this clientele seek to improve their quality of life and the process of health and illness, by establishing a bond of trust with the child and their family, in order to carry out joint care planning with the multi-professional team. In practice, interconnected care with all the health specialties is essential for the treatment of these children to be effective to the fullest, addressing all their needs and those of their family cycle, which surrounds and guides the care.^(16,17)

This study showed that the majority of knowledge about caring for CSHCN and their families is centered on professions working in the rehabilitation field, such as speech therapy and physiotherapy. This area of health works in speech and hearing assessment and therapy in the area of oral and written communication, voice and hearing, as well as improving speech and voice patterns.⁽¹⁸⁾ In addition, Federal Decree 5.626/05 makes it compulsory for undergraduate courses to include the subject of Libras.⁽¹⁹⁾ Physiotherapy performs methods and techniques with the aim of restoring, developing and conserving the patient's physical capacity, and occupational therapy analyzes the patient's mental capacity through therapeutic and recreational methods.⁽²⁰⁾

A study⁽²¹⁾ that investigated the training of health professionals and care for people with disabilities identified the absence of curricular components that guarantee comprehensive and universal training for this population. This corroborates the results of this study, which showed that students were interested in deep-

ening their knowledge of topics such as inclusion and types of disability, which suggests that this content could be explored more in university environments.

These considerations make it clear that these future professionals need to be prepared to feel competent in caring for these children and their families, in order to draw up an ideal care plan for each case, with a view to improving the lives of these children, which should start as soon as they are discharged from hospital, with continuity in PHC, in conjunction with the Health Care Network, with home care in mind, with an emphasis on home visits and health education.⁽²²⁻²⁵⁾

To this end, different ways of teaching are expected in order to prepare and support future professionals.⁽²⁶⁾ This excellence in care planning, when not achieved by health course graduates, can lead to dissatisfaction, insecurity, fear and frustration with the profession, due to the lack of adequate training during their education.⁽¹⁵⁾

Health professionals play a very important role in the process of empowering the families and caregivers of these children, since they work directly in this care network, have the ability to bring out the potential rather than the limitations of the CSHCN, and consequently can provide a better quality of life for the whole cycle that encompasses this child.⁽⁴⁾

Conclusion

The conclusion is that, although health courses do cover the subject of care for CSHCN and their families to some extent, students do not feel adequately prepared for this type of care. It is necessary to strengthen theoretical and practical training and effectively include the subject in undergraduate curricula, in order to guarantee comprehensive and humanized care for this public. The study's limitations include the limited representation of some health courses.

Contributions

Miramontes EC, Guareschi AP, and Neves ET contributed to the study design, data analysis and interpretation, writing of the article, critical revision of the intellectual content, and approval of the final version to be published.

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