

## RESEARCH ARTICLE (ORIGINAL) 8

# Translation, cultural adaptation and validation of the Portuguese version of the Children with Special Health Care Needs Screener

*Tradução, adaptação cultural e validação da versão portuguesa do Children with Special Health Care Needs Screener*

*Traducción, adaptación cultural y validación de la versión portuguesa del Children with Special Health Care Needs Screener*

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**Abstract**

**Background:** Children with special health care needs (CSHCN) have a range of health care needs that can influence their integration and their academic life. Early identification of CSHCN is essential for family and school health teams to plan better health care and promote school inclusion.

**Objective:** To translate, culturally adapt, and validate the Children with Special Health Care Needs Screener (CSHCN Screener) for the Portuguese population.

**Methodology:** Methodological study including translation and semantic and cultural adaptation. A total of 390 parents of children from the northern region of Portugal participated in the study.

**Results:** The Portuguese version consists of 14 items. The panel of experts and the parents of CSHCN considered the instrument to be acceptable, understandable, and with content validity. The CSHCN Screener took about one minute to complete or self-complete.

**Conclusion:** The Portuguese version of the CSHCN Screener proves to be a valid and reliable tool for identifying CSHCN.

**Keywords:** child health; child; chronic disease; validation study; screening

**Resumo**

**Enquadramento:** Crianças com Necessidades de Saúde Especiais (NSE) apresentam diversas necessidades de saúde que podem influenciar a sua integração e o seu percurso escolar. A identificação precoce das NSE é fundamental para que as equipas de saúde familiar e escolar planeiem melhores cuidados de saúde e potenciem a inclusão escolar.

**Objetivo:** Traduzir, adaptar culturalmente e validar para a população portuguesa o instrumento *Children with Special Health Care Needs Screener* (CSHCN Screener).

**Metodologia:** Estudo metodológico que inclui a tradução e adaptação semântica e cultural. Participaram 390 pais de crianças da região norte de Portugal.

**Resultados:** A versão portuguesa é composta por 14 itens. O painel de peritos e os pais de crianças com NSE consideraram o instrumento aceitável, compreensível e com validade no conteúdo. O CSHCN Screener levou cerca de um minuto a ser preenchido ou autopreenchido.

**Conclusão:** A versão portuguesa do CSHCN Screener demonstra ser um instrumento válido e fiável na identificação de crianças com NSE.

**Palavras-chave:** saúde da criança; criança; doença crónica; estudo de validação; rastreamento

**Resumen**

**Marco contextual:** Los niños con Necesidades Sanitarias Especiales (NSE) tienen diversas necesidades sanitarias que pueden influir en su integración y en su trayectoria escolar. La identificación precoz de las NSE es esencial para que los equipos de salud familiar y escolar planifiquen una mejor atención sanitaria e impulsen la inclusión escolar.

**Objetivo:** Traducir, adaptar culturalmente y validar para la población portuguesa el instrumento *Children with Special Health Care Needs Screener* (CSHCN Screener).

**Metodología:** Estudio metodológico que incluye la traducción y la adaptación semántica y cultural. Participaron 390 padres de niños de la región norte de Portugal.

**Resultados:** La versión portuguesa consta de 14 ítems. El panel de expertos y los padres de niños con NSE consideraron que el instrumento era aceptable, comprensible y válido en cuanto al contenido. El CSHCN Screener tardó aproximadamente un minuto en completarse o autocompletarse.

**Conclusión:** La versión portuguesa del CSHCN Screener demuestra ser un instrumento válido y fiable para identificar a los niños con NSE.

**Palabras clave:** salud infantil; niño; enfermedad crónica; estudio de validación; tamizaje



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## Introduction

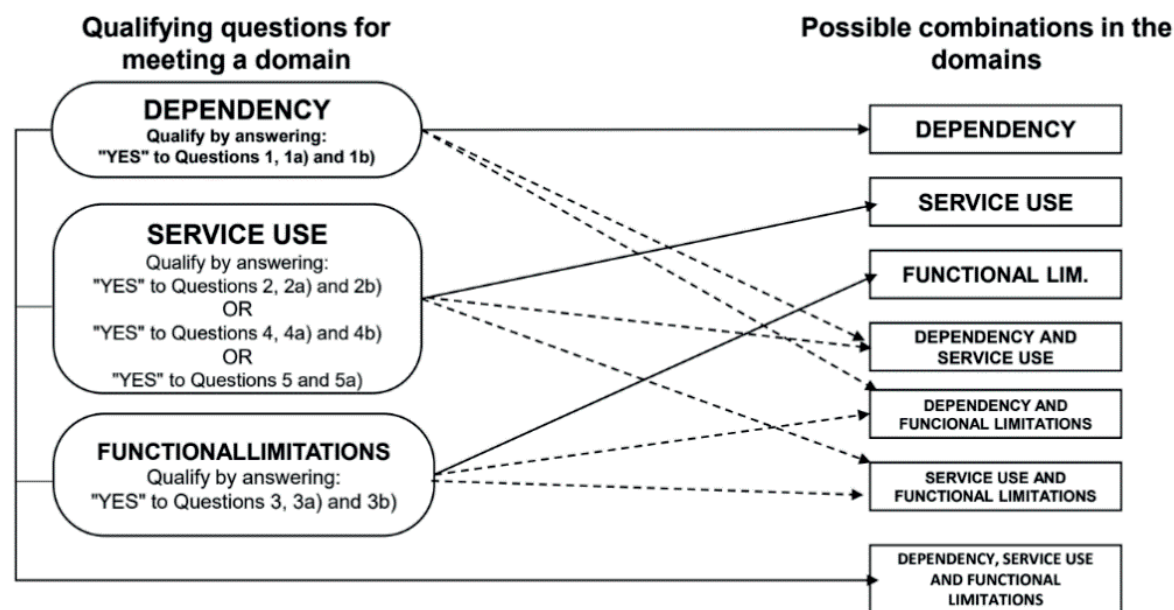
Education and health, that is, the family health team in partnership with the school health team of the local health units and the multidisciplinary support team for inclusive education of the School Cluster, as well as with the family, should identify children with special needs and refer them to the support services, ensuring continuous monitoring and coordination between all those involved in the learning process (Direção-Geral da Saúde [DGS] 2015). Portugal has adopted international guidelines in the field of school inclusion, namely in the School Health (2006 and 2015) and the Child and Youth Health (2013) programs, which include the role of family health and school health teams in assessing the health conditions of children and young people that may affect their well-being through early detection and monitoring (DGS, 2006; DGS, 2013; DGS, 2015). Decree-Law 54/2018 defines special health care needs (SHCN) as “the needs resulting from physical and mental health problems that have an impact on functioning, produce severe limitations in any organ or body system, involving irregularities in school attendance and that may compromise the learning process” (Decreto-Lei n.º 54/2018 de 6 de julho, p. 2920). In Portugal, the number of children with SHCN (CSHCN) remains undetermined (Pombal et al., 2017). However, there are countries such as the United States of America (USA), where national identification of CSHCN is facilitated. In the USA, a survey using the Children with Special Health Care Needs  *Screener* (CSHCN  *Screener*) found that approximately one in five children have a SHCN (Health Resources & Services Administration Maternal and Child Health Bureau, 2022). These data show that there is a need for a data collection tool in Portugal that allows rapid screening of CSHCN. This study aims to translate, culturally adapt, and validate the CSHCN  *Screener* for the Portuguese population, based on the original English version. The research hypothesis to be validated was: CSHCN can be screened using the CSHCN  *Screener*.

## Background

There are no validated instruments in the literature for the Portuguese population to identify the incidence and prevalence of CSHCN. However, in the USA, there is an instrument in English, developed in 2002, based on the Maternal and Child Health Bureau’s definition of CSHCN and on the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) (Bethell et al., 2002). It has been used in national surveys in the USA since 2001 and is available in several languages, including English, Spanish, Chinese, Japanese, Korean, and Russian due to the immigrant population in the United States. It has also been used in English-speaking countries such as the United Kingdom and Australia. It has been translated and culturally adapted for the German, Swiss, Brazilian, and Egyptian populations (Arrué et al., 2016; Mohler-Kuo & Dey, 2012; Scheidt-Nave et al., 2007; Wahdan & El-Nimr, 2018). The CSHCN  *Screener* uses criteria for identifying children with chronic conditions or SHCN. For a child/young person to qualify as having a chronic condition or SHCN, they must meet the following criteria: (1) the child/young person is currently experiencing a specific consequence; (2) the consequence is due to a health condition or situation; and (3) the expected duration of that condition or situation is 12 months or longer. The CSHCN  *Screener* consists of 14 questions, five of which are screening questions that ask whether the child/young person has experienced one of five different health consequences. Only children/young people with “yes” answers to all three parts of at least one screener question or to two parts in the last question will qualify as having a SHCN (The Child and Adolescent Health Measurement Initiative, 2002). The CSHCN  *Screener* also has 3 domains: (1) Dependency on prescription medications; (2) Service use above that considered usual or routine; and (3) Functional limitations. The domains are not mutually exclusive categories, since a child identified by the CSHCN  *Screener* can qualify on one or more domains (Figure 1).

**Figure 1**

*Domains of the CSHCN Screener – Adapted from The Child and Adolescent Health Measurement Initiative (2002)*



*Note.* Question 1 - Does your child currently need or use medicine prescribed by a doctor (other than vitamins)? Question 2 - Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age? Question 3 - Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do? Question 4 - Does your child need or receive special therapy, such as physical, occupational, or speech therapy? Question 5 - Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives treatment or counseling? Questions 1a, 2a, 3a, 4a - Is this because of any medical, behavioral, or other health condition? Questions 1b; 2b; 3b; 4b - Is this a condition that has lasted or is expected to last for at least 12 months? Question 5a - Has this problem lasted or is it expected to last for at least 12 months?

## Methodology

Methodological study involving translation and cultural and semantic adaptation into Portuguese, following the methodological procedures for cross-cultural adaptation proposed by Beaton et al. (2007).

**Step 1: Translation** - After receiving a positive opinion from the authors of the CSHCN *Screener*, two independent translators, fluent in English and native speakers of Portuguese, started the translation and linguistic adaptation of the instrument from English to Portuguese in Portugal. One of the translators had a background in the humanities area and was not familiar with the concept under study. The second translator had a Ph.D. in nursing and experience in higher nursing education and school health research. Neither translator had prior access to the original questionnaire.

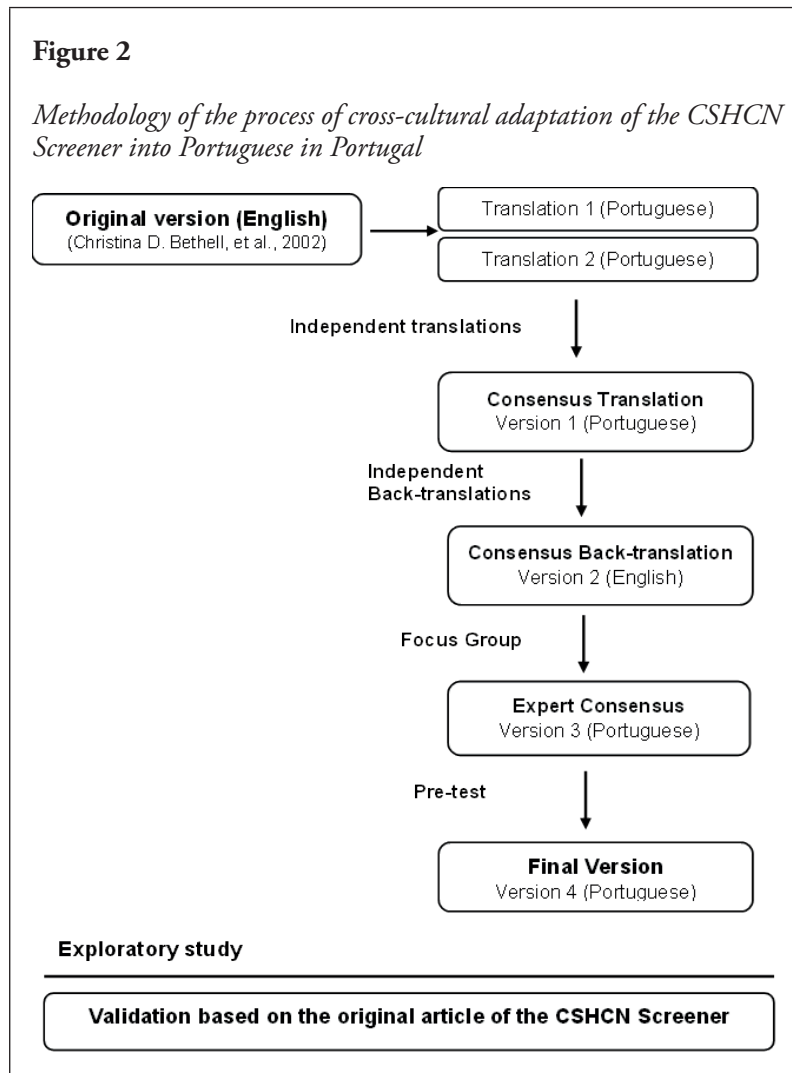
**Steps 2 and 3: Synthesis and back-translation** - After receiving the two translations (T1 and T2), a third person with a Ph.D. in nursing was asked to synthesize them. A meeting was held with the two translators to resolve the discrepancies found, resulting in a final document that was sent for back-translation (Version 1). A consensus meeting was then held with the two translators to correct small differences in meaning and/or content

between the original instrument and the version translated into Portuguese (Vilelas, 2020). **Step 4: Expert Group Review** - This step consisted of the content validation phase of the translated version of the CSHCN *Screener* by a group of experts, using the focus group method as a qualitative data collection technique. The purpose of this step was to identify or further explore opinions on a given topic among experts in the field and to consolidate the translated version through equivalence analysis in four areas: semantic, idiomatic, cultural, and conceptual (Guillemin et al., 1993). The expert group consisted of six researchers selected through purposive sampling based on the following cumulative criteria: being professionals in the field of nursing or health; with at least a master's degree; specialists in nursing; bilingual; professionals with experience in the development, validation, and cultural adaptation of instruments; and with experience in clinical practice in school health (Guillemin et al., 1993). Prior to the focus group, the members of the expert panel received a document consisting of two parts: (1) a form to characterize the expert; (2) the original and translated versions of the CSHCN *Screener* to familiarize themselves with the instrument and its translations. The focus group took place via Zoom at the end of July 2022. The lead researcher chaired the meeting and took note of the

experts' suggestions and contributions, making minor semantic and conceptual adjustments so that the items were easy to understand and applicable to the Portuguese population.

Step 5: Pre-test - The CSHCN  *Screener* was pre-tested on 40 parents of children being followed by the school health team of a community care unit of the Northern Regional Health Administration. This pre-test aimed to check if the instrument was understandable, how easy it was for

parents to answer, and how much time it would take to complete. Interviews and self-completion were also used. The instrument was administered to the same children by two different interviewers and the same results were obtained. The CSHCN  *Screener* was found to be easy to understand and administer, taking around 1 minute to complete in both the interview and the self-completion formats. These were the steps planned for cross-cultural adaptation (Figure 2).



Data were collected in a community care unit of the Northern Regional Health Administration, after a meeting with the team to explain the data collection methods. The literature suggests that the sample for validation studies should include 5 to 10 participants per item (Ribeiro, 2010). The CSHCN  *Screener* would require a minimum of at least 140 participants.

Participants were recruited in two ways: (1) children and young people receiving individual health care at the community care unit; and (2) children and young people attending an elementary school in the School Cluster. The inclusion criteria were: (1) children aged between 3 and 17 years; (2) who were enrolled in school; (3) and whose parents agreed to complete the questionnaire. They were recruited by telephone in the first case and by the school co-

ordinator in the second case, explaining the aim of the study and the voluntary nature of participation. Subsequently, a member of the school health team from the community care unit called them again to administer the CSHCN  *Screener*. Data were recorded in an Excel database shared on SharePoint, where they were protected and could only be accessed by the data collectors. Data were analyzed using IBM SPSS Statistics, version 28.0. Since this instrument has dichotomous nominal variables, its content validity was analyzed by a group of experts. Criterion validity was also assessed by comparing the results of other validation studies in other countries and correlation tests with the gender and age group variables, as recommended by the authors of the instrument. Reliability was assessed using the interobserver method by checking the agreement between

interviewers on the same topics.

With regard to statistical analysis, quantitative variables were described as mean or median (depending on whether their distribution was normal or not) and standard deviation, while qualitative variables were described by absolute frequency (*n*) and relative frequency (%). The chi-squared test was used to compare the identification rates (frequencies) of the groups of the CSHCN *Screeners* questions with the characteristics of the sample (gender and age group of the child). The significance level for the statistical tests was 0.05.

Positive identification on the CSHCN *Screeners* was determined for each child based on responses to the instrument and the scoring algorithm described earlier.

At all stages of the research process, the ethical procedures were followed, namely a favorable opinion from the Northern Regional Health Administration and authorization from the authors of the CSHCN *Screeners*, the Executive Director of a Cluster of Health Care Centers in the Northern region, the coordinator of the community care unit,

and the director of the School Cluster. Written informed consent was always obtained prior to data collection, and the confidentiality and anonymity of the data collected was always guaranteed.

## Results

The instrument was administered to 390 parents of children/young people. Most of the children/young people were female (55.13%) and attended primary school (46.92%). The mean age was 9.35 years (standard deviation = 3.67; minimum = 3; maximum = 17).

The questionnaire was completed quickly and there were no suggestions or changes needed to any of the items, indicating that the participants accepted and understood the items. The response time was similar to that measured in the pretest, with the questionnaire being completed in approximately 1 minute. Table 1 shows the CSHCN *Screeners* items in English and Portuguese.

**Table 1**

*Items of the Children with Special Health Care Needs Screeners*

Item	English	Portuguese
1	Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?	A sua criança necessita ou toma atualmente medicamentos prescritos por um médico (além de vitaminas)?
1a	Is this because of any medical, behavioral, or other health condition?	O motivo está relacionado com um problema médico, comportamental ou outra condição de saúde?
1b	Is this a condition that has lasted or is expected to last for at least 12 months?	Trata-se de uma condição que dura ou que se prevê que dure, pelo menos 12 meses?
2	Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?	A sua criança necessita ou usa mais cuidados de saúde, serviços de saúde mental ou serviços educacionais do que é habitual para a maioria das crianças da mesma idade?
2a	Is this because of any medical, behavioral, or other health condition?	O motivo está relacionado com um problema médico, comportamental ou outra condição de saúde?
2b	Is this a condition that has lasted or is expected to last for at least 12 months?	Trata-se de uma condição que dura ou que se prevê que dure, pelo menos 12 meses?
3	Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?	A sua criança tem alguma limitação ou é incapaz de fazer alguma atividade que a maioria das crianças da mesma idade consegue fazer?
3a	Is this because of any medical, behavioral, or other health condition?	O motivo está relacionado com um problema médico, comportamental ou outra condição de saúde?
3b	Is this a condition that has lasted or is expected to last for at least 12 months?	Trata-se de uma condição que dura ou que se prevê que dure, pelo menos 12 meses?
4	Does your child need or receive special therapy, such as physical, occupational, or speech therapy?	A sua criança necessita de fazer ou faz terapia, como fisioterapia, terapia ocupacional ou terapia da fala?
4a	Is this because of any medical, behavioral, or other health condition?	O motivo está relacionado com um problema médico, comportamental ou outra condição de saúde?
4b	Is this a condition that has lasted or is expected to last for at least 12 months?	Trata-se de uma condição que dura ou que se prevê que dure, pelo menos 12 meses?
5	Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives treatment or counseling?	A sua criança apresenta algum problema emocional, de desenvolvimento ou comportamental, para o qual necessita ou faz algum tratamento ou aconselhamento?
5a	Has this problem lasted or is it expected to last for at least 12 months?	Trata-se de um problema que se prolonga desde há, ou é expectável durar, pelo menos 12 meses?

Table 2 shows the positive identification on the CSHCN *Screenener* for each of the groups of five screening questions. The group of screening questions with the most positive scores was group 4 (47.05%). The group of questions with the least positive scores was group 3 (13.59%). With the exception of question 5, in some cases the main screening

question was positive but the subsequent questions in the group were negative, resulting in negative scores in the groups of screening questions: 2.1% ( $n = 8$ ) for question 1; 2.3% ( $n = 9$ ) for question 2; 0.3% ( $n = 1$ ) for question 3; and 2.1% ( $n = 8$ ) for question 4.

**Table 2**

*Distribution of identification rates by group of screening questions, according to gender (n and %)*

		Gender				Total <i>n</i>
		Female		Male		
		<i>n</i>	%	<i>n</i>	%	
Group of screening questions 1	Negative	157	73.0%	123	70.3%	280
	Positive	58	27.0%	52	29.7%	110
Total		215	100.0%	175	100.0%	390
Group of screening questions 2	Negative	110	51.2%	97	55.4%	207
	Positive	105	48.8%	78	44.6%	183
Total		215	100.0%	175	100.0%	390
Group of screening questions 3	Negative	187	87.0%	150	85.7%	337
	Positive	28	13.0%	25	14.3%	53
Total		215	100.0%	175	100.0%	390
Group of screening questions 4	Negative	103	47.9%	100	57.1%	203
	Positive	112	52.1%	75	42.9%	187
Total		215	100.0%	175	100.0%	390
Group of screening questions 5	Negative	150	69.8%	124	70.9%	274
	Positive	65	30.2%	51	29.1%	116
Total		215	100.0%	175	100.0%	390

*Note.* *n* = Absolute frequency; % = Relative frequency.

Positive identification of children/young people on the CSHCN *Screenener* occurs when at least 1 of the groups of screening questions is positive. In this sample, identification was positive in 66.92% of the participants ( $n = 261$ ).

With regard to the domains, Table 3 describes the rates of positive identification. The domain with the highest rates of positive identification was Domain 2 - Service use (68.72%).

**Table 3**

*Positive identification on the domains of the Children with Special Health Care Needs Screener*

	<i>n</i>	%
Domain 1 - Dependency		
Positive	110	28.21
Negative	280	71.79
Domain 2 - Service use		
Positive	268	68.72
Negative	122	31.28
Domain 3 - Functional Limitations		
Positive	53	13.59
Negative	337	86.41

*Note.* *n* = Absolute frequency; % = Relative frequency.

The distribution of rates of identification across the groups 4 and 5, respectively, of screening questions by age group is shown in Tables

**Table 4**

*Distribution of rates of identification across the groups of screening questions, by age group (Age groups 3 to 10 and 11 to 17; *n* and %)*

		Age group				Total <i>n</i>
		3 - 10 years		11 - 17 years		
		<i>n</i>	%	<i>n</i>	%	
Group of screening questions 1	Negative	191	75.5%	89	65.0%	280
	Positive	62	24.5%	48	35.0%	110
Total		253	100.0%	137	100.0%	390
Group of screening questions 2	Negative	147	58.1%	60	43.8%	207
	Positive	106	41.9%	77	56.2%	183
Total		253	100.0%	137	100.0%	390
Group of screening questions 3	Negative	224	88.5%	113	82.5%	337
	Positive	29	11.5%	24	17.5%	53
Total		253	100.0%	137	100.0%	390
Group of screening questions 4	Negative	151	59.7%	52	38.0%	203
	Positive	102	40.3%	85	62.0%	187
Total		253	100.0%	137	100.0%	390
Group of screening questions 5	Negative	194	76.7%	79	57.7%	273
	Positive	59	23.3%	58	42.3%	117
Total		253	100.0%	137	100.0%	390

*Note.* *n* = Absolute frequency; % = Relative frequency.

The statistical significance of the variation in the rates of identification by age and gender was assessed using the chi-squared test (Table 5). Statistically significant results are shown in bold, assuming a significance level of 0.05.

**Table 5**

*Statistical significance of the variation in the rates of identification across groups of screening questions of the Children with Special Health Care Needs Screener, by age (age groups 3 to 10 and 11 to 17) and gender*

	<i>Value</i>	<i>df</i>	<i>p</i>
Group of screening questions 1			
Gender	0.357	1	0.550
Age group	4.867	1	<b>0.027</b>
Group of screening questions 2			
Gender	0.705	1	0.401
Age group	7.304	1	<b>0.007</b>
Group of screening questions 3			
Gender	0.131	1	0.717
Age group	2.776	1	0.096
Group of screening questions 4			
Gender	3.297	1	0.069
Age group	16.811	1	<b>0.000</b>
Group of screening questions 5			
Gender	0.070	1	0.792
Age group	15.829	1	<b>0.000</b>

*Note.* *df* = Degrees of freedom; *p* = Probability of significance.

## Discussion

To the best of our knowledge, this study is the first to translate, adapt and validate the CSHCN *Screener* in Portugal. A rigorous methodology was used in the translation, adaptation and validation processes, following international guidelines and the methodology proposed by the authors of this instrument. Based on the analysis of the expert panel, this tool proved to measure what it was intended to measure (content validity). It was shown to have results similar to those of validation methods used in other countries (Arrué et al., 2016; Mohler-Kuo & Dey, 2012; Scheidt-Nave et al., 2007; Wahdan & El-Nimr, 2018). It was also found to be reliable based on the interobserver measurement performed.

These results show that the CSHCN *Screener* requires little administration time, both when administered by an interviewer and when self-administered.

A statistically significant variation in terms of age was found in children/young people positively identified on the CSHCN *Screener* in 4 of the 5 groups of screening questions (positively associated with the 11-17 age group in groups 2, 4 and 5 and with the 3-10 age group in group 1), which had already been identified in the original validation study (Bethell et al., 2002). Contrary to what was found in the same study, no statistically significant variation in gender was found among the children/young people positively identified on the CSHCN *Screener*. In any case, these results would be expected and explained by the composition of the sample, which was drawn

from two different sources and therefore had different characteristics in terms of age and the socioeconomic and health status of each of the groups (Bethell et al., 2002). The number of children positively identified on the CSHCN *Screener* in this study is consistent with other studies, particularly the association with older children and those who regularly use health services (Bethell et al., 2002; Newacheck et al., 1998), thus validating the previously formulated hypothesis. However, these results should be interpreted with caution as this is only a validation study and not an epidemiological study. Further comprehensive studies should be conducted in different settings to draw better conclusions on the prevalence of children/young people with SHCN. This study has some limitations, namely the fact that it was carried out in only one location in the country and that it was not possible to validate concurrent validity, given the lack of instruments assessing the same construct validated for the Portuguese population.

## Conclusion

The Portuguese version of the CSHCN *Screener* is a valid and reliable instrument for screening children/young people with SHCN. This instrument can be used in both clinical and research settings.

This is the first instrument available in Portugal to identify children/young people with SHCN. This can be a valuable contribution to the Portuguese national health



service, given that it can improve the early identification of children/young people with SHCN, enhance referrals between health professionals, and optimize the integration of care between family health teams, school health teams at community care units, hospital services, and schools. Its use could have an impact on the social phenomena of school absenteeism and situations of bullying and school segregation. It is considered to be a valuable tool to guide nursing practice in theory, clinical practice, and research, enabling family and school health nurses, in collaboration with the family and the school, to identify the conditions, needs and health measures to be implemented in order to enhance pedagogical practices focused on the full development of CSHCN, and also contribute to an environment suitable for learning.

Future studies should be conducted on the incidence and prevalence of CSHCN at local, regional, and national levels.

### Author contributions

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