



## Validation of Autism Stigma Knowledge – Questionnaire (ASK-Q) for Brazilian Portuguese

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### ABSTRACT

**Background:** Low levels of knowledge among health professionals about autism spectrum disorders (ASD) can impair the care provided to people with autism. In Brazil, there are still no validated instruments that assess the knowledge of pharmacy students and pharmacists regarding ASD.

**Objective:** This study aimed to carry out the cross-cultural adaptation of the Autism Stigma Knowledge Questionnaire (ASK-Q) into Brazilian Portuguese and to evaluate the evidence of content validity.

**Methods:** This study was conducted in two stages, as recommended in the literature. Stage 1 corresponded to cross-cultural adaptation carried out in six phases (translation of the ASK-Q, synthesis of the translations, evaluation by a committee of experts, evaluation by the target audience of pharmacy students and pharmacists, reverse translation, and evaluation by the author of the original instrument). Step 2 corresponds to the assessment of content validity evidence.

**Results:** The instrument presented semantic, idiomatic, conceptual, and cultural equivalences, and the author considered the adaptation adequate. Content validity had an adequate coefficient (0.89). The ASK-Q was cross-culturally adapted to the Brazilian context according to the main theoretical framework.

**Conclusions:** Future studies will be conducted to evaluate other evidence for the validity of the ASK-Q-Brasil. These studies will be fundamental in assessing knowledge about ASD.

### 1. Introduction

Autism spectrum disorder (ASD) consists of a group of neurodevelopmental disorders that, according to the American Psychiatric Association, is present in 1% of the world's population.<sup>1</sup> In the last 50 years, this prevalence has been increasing, mainly because of awareness, improvement of reported information, expansion of diagnostic criteria, and better diagnostic tools.<sup>2</sup> In Brazil, population studies that estimate the prevalence of ASD are incipient and the prevalence of autism in the Brazilian population, is unknown.

In this scenario, people with ASD suffer from stigmatization and discrimination,<sup>3</sup> which has had a significant impact on mental health,

exacerbated symptoms of depression, stress, and anxiety in parents<sup>4</sup> and caregivers.<sup>5</sup> This problem can be explained by the low level of knowledge of the population, which implies negative judgment, rejection of behaviors, and derogatory comments about people with ASD.<sup>6</sup>

Studies on the assessment of knowledge about ASD have shown that parents,<sup>7</sup> education professionals,<sup>8</sup> and health professionals<sup>9,10</sup> may have gaps in knowledge. McBain et al.,<sup>11</sup> reported that insufficient preparation by primary care providers and disparities in access to services hamper the diagnosis and treatment of this condition. Therefore, health professionals, including pharmacists, must have adequate knowledge to effectively treat individuals with ASD.<sup>10</sup>

Pharmacists' can assist in the management of pharmacotherapy,

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early identification, and establishing an appropriate communication process with patients and/or caregivers.<sup>12</sup> A study conducted in Thailand showed that pharmacists' performance promoted the resolution of problems related to the use of medicines by people with autism.<sup>13</sup> However, studies have shown that pharmacists<sup>10,14,15</sup> and pharmacy students<sup>14</sup> have low levels of knowledge about autism.

Measurement instruments were used to estimate knowledge of ASD. A systematic review conducted by Harrison et al.,<sup>16</sup> identified 44 knowledge assessment instruments for autism in the literature for parents, caregivers, and professionals. However, these instruments did not have defined sub-domains (e.g., etiology, diagnosis, treatment, stigma) or the necessary evidence of validity (reliability, factor analysis), which could compromise the assessment of knowledge. Thus, based on the findings of this review, Harrison et al.,<sup>17</sup> developed the Autism Stigma Knowledge – Questionnaire (ASK-Q), an instrument that assesses knowledge about ASD, with subdomains related to diagnosis, etiology, treatment, and stigma. The authors evaluated the properties of the ASK-Q, and adequate intercultural consistency was found in the context of another country (Mongolia); the application of test-retest (two-week period) revealed adequate internal consistency ( $\alpha = 0.721$ ), good reliability ( $ICC = 0.86$ ) and stability by detecting changes in knowledge levels before and after intervention.<sup>18</sup>

Thus, considering that there are no Brazilian studies that assess the knowledge of pharmacists and pharmacy students about ASD and since it is important that instruments applied in other countries have cross-cultural adaptation,<sup>17</sup> the objective of the present study is to carry out cross-cultural adaptation and evaluate the evidence of validity of the ASK-Q instrument in Brazilian Portuguese.

There are no Brazilian studies that assess the knowledge of pharmacists and pharmacy students about ASD, and only one cross-cultural adaptation and validation of the ASK-Q into Brazilian Portuguese was found.<sup>19</sup> However, the published study has some gaps in explaining the methods used, and the phases of the process are not described in detail, making understanding and reproducibility difficult. There are no references on the recommendations that the authors used in the translation and adaptation, and validation was not carried out with professionals qualified in the content or construct, as proposed by the Delphi technique, which guarantees validation through consensus between experts. Furthermore, the cross-cultural adaptation proposed by Silva et al.,<sup>19</sup> also does not describe evaluation by the author of the instrument himself. Therefore, we understand that this previous study does not meet the proposal of this work, with gaps that could compromise the quality of the translation, adaptation and validation of the instrument. Therefore, the objective of the present study is to carry out cross-cultural adaptation and evaluate the evidence of validity of the ASK-Q instrument in Brazilian Portuguese. This study followed the best practices, as recommended by the author of the instrument.

## 2. Methods

This was a cross-cultural adaptation and content-based validity evidence assessment study conducted from October 2020 to June 2021. The study was carried out in two stages) cross-cultural adaptation of the ASK-Q to the Brazilian Portuguese, and 2) assessment of content-based evidence of validity.

The present study was part of the research entitled "Evaluation of knowledge of Brazilian Pharmacy students and pharmacists about Autistic Spectrum Disorder" developed by researchers at the Federal University of Espírito Santo, Brazil. This study aimed to assess the level of knowledge of Brazilian pharmacists and pharmacy students and, subsequently, proposed strategies to improve the care provided to people with ASD by pharmacists, with a focus on training and continuing education of pharmacists.

### 2.1. Measuring instrument: ASK-Q

The ASK-Q instrument was developed by researchers at the University of Georgia, USA, based on a comprehensive review of the existing instruments in the literature. Evaluation of the instrument's psychometric properties showed excellent indices of internal consistency (Cronbach's  $\alpha$  of 0.88)<sup>17</sup> and reliability (interclass correlation coefficient of 0.86).<sup>18</sup> According to Harrison et al.,<sup>16</sup> the ASK-Q had the potential to identify regions and countries that demonstrate knowledge deficits.<sup>16</sup>

The instrument had 49 items and four subscales: diagnosis (18 items), etiology (16 items), treatment (14 items), and stigma (7 items). The possibilities of answers were dichotomous ('agree' and 'disagree'), and each correct answer was equivalent to one point. When summed up, the participants' knowledge about ASD is classified as adequate or inadequate.<sup>17</sup> For each subscale, the following cut-off score ranges reflected adequate knowledge: diagnosis (11–18 points), etiology (11–16 points), and treatment (10–14 points). For items that assessed knowledge and stigma, a correct answer indicates that they did not endorse stigma. Therefore, the stigma subscale scored in reverse, such that higher scores (3–7 points) demonstrated a failure to endorse stigma and lower scores (0–2 points) indicated endorsement of stigma.<sup>18</sup>

### 2.2. Step 1: Cross-Cultural Adaptation of the ASK-Q

The cross-cultural adaptation was carried out through six phases: translation, synthesis of translations, evaluation by a committee of experts, evaluation by target population, back-translation, and evaluation by the author of the instrument.<sup>20</sup>

1. Phase 01 (translation): The instrument was translated into the target language (Portuguese). Brazilian translators fluent in English were selected for this study. Participants performed the translation independently.
2. Phase 02 (synthesis of translations): The researchers synthesized the versions, compared the original version with the translated versions, and evaluated the semantic, linguistic, conceptual, and idiomatic discrepancies. At this stage, terms and definitions contained in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)<sup>1</sup> and regulated vocabularies such as Medical Subject Headings (MeSH), Health Science Descriptors (Decs), and Cambridge Dictionary were used.
3. Phase 03 (assessment by expert committee): Participants were selected to compose the expert committee based on the attributes of having experience in cross-cultural adaptation and evaluation of psychometric analyses, working in English language teaching, or being diagnosed with autism. Online meetings were held in the presence of the study researchers and analysis of the material produced (original instrument, translated versions, and synthesized version). The instrument layout and instructions were evaluated, items were judged, the scope and adequacy of the items' expressions, and whether the terms and expressions were adequate for the audience for which the instrument was intended.
4. Phase 04 (assessment by the target population): The version produced by the expert committee was evaluated using a sample of the target audience (pharmacists and pharmacy students), selected for convenience. Participants from five regions of Brazil were recruited for this study. Two meetings were held (one with pharmacists and one with pharmacy students), and through a qualitative assessment, the participants were asked about their understanding of the items. In addition, the time taken by each participant to complete the questionnaire was recorded.
5. Phase 05 (reverse translation): The synthesized and revised Portuguese version was translated into the source language (English) by a native English-language translator fluent in Portuguese.

6. Phase 06 (assessment by the author of the instrument): The author received the back-translated version of the instrument and detailed information on the procedures performed for evaluation and opinion via email.

2.3. Step 2: validity evidence based on the content of the translated and adapted instrument

The evaluation of evidence of validity based on the content was carried out by a committee of experts, who were identified through a search of the Lattes Platform using the term “Autistic Spectrum Disorder.” Plataforma Lattes is a curriculum platform for Brazilian researchers and academics, and is currently adopted by most universities, institutes, and research funding institutions.

After identifying the experts on the Lattes platform, they were ranked using the criteria proposed by Fehring (1987). The following criteria were established: being a master and/or doctor in the areas of psychiatry, neurology, pediatrics, psychology (1 point for a master; 2 points for a doctor), with dissertation and/or thesis on TEA (1 point for dissertation; 2 points for thesis), with experience in clinical practice at TEA (1 point per year of clinical practice), and/or scientific production (1 point per published scientific article) (see Complementary Materials). The participant was considered an expert in autism when he obtained a score

of at least five points and the invitation was sent by e-mail.

Content-based validity was assessed using the Delphi technique. This technique allowed the construction and validation of information through consensus among experts and consisted of a systematic method of judging information on a given topic through validations articulated in phases or cycles, without the evaluators meeting physically.<sup>21</sup>

The participating experts evaluated the instrument using a virtual form available in the Google Forms application. The form contained the original (in English) and adapted versions (in Portuguese) of the instrument. For each item, the experts assessed criteria related to language clarity, practical relevance, and theoretical relevance using a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree). The content validity coefficient (CVC) was calculated to determine the level of agreement among experts, with a cutoff point of at least 0.80 to determine satisfactory levels among experts.<sup>22</sup> Fig. 1 presents a flowchart of the steps used in this method.

2.4. Ethical considerations

This study was approved by the Ethics Committee in Research with Human Beings of the Federal University of Espírito Santo campus Alegre (CAAE 39222520.6.0000.8151). All participants signed an informed

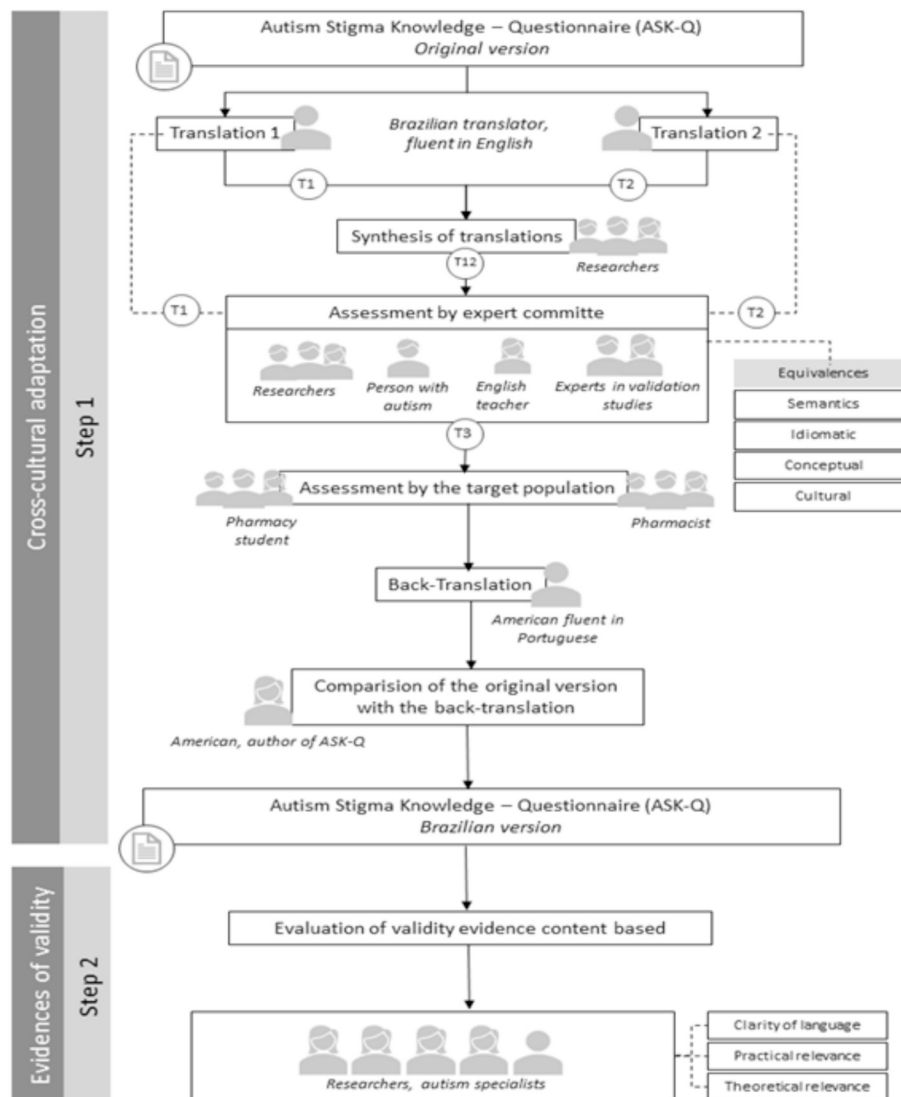


Fig. 1.. Flowchart of the Stages of Cross-Cultural Adaptation and Content Validation.

consent form, and a confidentiality and secrecy statement.

### 2.5. Community involvement

In this study, one of the researchers participating in the expert committee phase had autism. In addition, one researcher was a pharmacist and the uncle of a child with autism, and another researcher, also a pharmacist, dispensed medicines for fathers, mothers, caregivers, and people with autism. This research arises from the need to improve and humanize pharmaceutical care for people with autism in Brazilian pharmaceutical establishments.

## 3. Results

### 3.1. Step 1: Cross-cultural adaptation of the ASK-Q

The instrument was translated by two bilingual translators (one of whom was familiar with the construct, while the other was not), resulting in two versions: T1 and T2. Subsequently, three researchers compared the differences between the versions, analyzed them, made changes to exclude discrepancies, and synthesized a single version (T12). The expert committee then judged the instructions and layout as satisfactory, evaluated the items, and made relevant changes to adapt the instrument’s expressions and reach semantic, idiomatic, conceptual, and cultural equivalence. This phase resulted in the T3 version.

The translated, synthesized, and expert-evaluated version (T3) was evaluated by a sample of the target audience, which consisted of nine pharmacy students and 11 pharmacists, whose sociodemographic characteristics are described in Tables 1 and 2.

The mean time to answer the instrument was nine minutes and nine seconds for pharmacy students and nine minutes and 32 s for pharmacists. Participants judged that all items were understandable and that the instrument presented clarity, objectivity, adequate language, and ease of response. A translator performed a reverse translation of the synthesized and revised versions, originating from the back-translated version (the instrument’s language of origin, that is, English).

Then, the author of the instrument evaluated this version; however, she was concerned about the adaptation of item 40 due to the exclusion

**Table 1**  
Sociodemographic Characteristics of Pharmacy Students in the Evaluation Phase by the Target Population.

Variable	Pharmacy students (n = 9)	
	n	%
Gender		
Male	4	44.4
Female	5	55.6
Age		
18 to 19	2	22.2
20 to 21	2	22.2
22 to 23	4	44.4
24 or older	1	11.2
Brazilian region		
Midwest	1	11.2
Northeast	2	22.2
North	1	11.2
Southeast	3	33.2
South	2	22.2
University/Higher education institution		
Public	8	88.9
Private	1	11.1
Pharmacy student school year <sup>a</sup>		
1	2	22.2
2	0	0
3	1	11.1
4	5	55.6
5	1	11.1

<sup>a</sup> In Brazil, the degree in Pharmacy (bachelor degree) lasts 05 years.

**Table 2**  
Sociodemographic Characteristics of Pharmacists in the Evaluation Phase by the Target Population.

Variable	Pharmacists (n = 11)	
	N	%
Gender		
Male	2	18.1
Female	9	81.9
Age		
24 to 29	1	9.1
30 to 35	6	54.6
36 to 41	1	9.1
42 or older	3	27.2
Brazilian region		
Midwest	2	18.2
Northeast	2	18.2
North	1	9.1
Southeast	4	36.3
South	2	18.2
University/Higher education institution		
Public	6	54.6
Private	5	45.4
Year of graduation on Pharmacy <sup>a</sup>		
1990 to 2010	4	36.3
2011 to 2020	7	63.7
Occupation area		
Public community pharmacy	6	54.6
Public health service management	3	27.2
None	1	9.1
Others	1	9.1

of the term “medical test”. To avoid bias, the researchers requested an evaluation by an expert committee. The use of the expression “laboratory or imaging exams” was suggested, as expressions in Brazilian Portuguese have the same meaning as the original version of the item. Thus, item 40 had the following wording: “Currently, there are no laboratory or imaging exams to diagnose autism.” The researchers explained to the author that in Brazil, the term “medical test” refers to tests requested or performed by physicians, such as physical and/or anthropometric tests. Accepted by the author, thus approving the adaptation of the ASK-Q in Brazilian Portuguese.

### 3.2. Step 2: Validity evidence based on ASK-Q content

Of the 40 experts invited to assess content-based validity evidence, five participated in the study. Among them, four were psychologists and one was a doctor (neuropsychiatrist); most were women (n = 4), three specialists had a master’s degree, and two had a doctorate in progress. The scientific production of the experts totaled eight articles on the construct under evaluation. The time of clinical experience with autism ranged from five to 10 years, and the score according to the established criteria ranged from five to 10 points.

Round iterations of the Delphi technique are required. All items were considered validated owing to the agreement between experts determined by the CVC, which presented a result of 0.89. The indices for language clarity, theoretical relevance, and practical relevance are listed in Table 3. Furthermore, suggestions for writing the items were judged and accepted by the researchers, except for the suggestion to change the expression “person with autism” to “autistic person” The researchers concluded that the switch would not harm the Brazilian version of the ASK-Q.

Finally, the authors of the present study kept the original title (ASK-Q) plus the word “Brazil.”

## 4. Discussion

The ASK-Q differs in that it was developed for use in different cultures and settings, and to more accurately document disparities in autism knowledge around the world.<sup>17</sup> In 2020, the instrument was

**Table 3**  
Clarity indices, Practical and Theoretical Relevance.

Item	Content Validity Coefficient			CVC
	Clarity of language	Practical Relevance	Theoretical Relevance	
Item 1	1.00	1.00	1.00	1.00
Item 2	0.95	0.95	1.00	0.97
Item 3	0.85	0.90	1.00	0.92
Item 4	0.85	1.00	1.00	0.95
Item 5	0.95	0.95	0.95	0.95
Item 6	0.95	0.90	1.00	0.95
Item 7	1.00	1.00	1.00	1.00
Item 8	0.85	1.00	0.95	0.93
Item 9	1.00	1.00	1.00	1.00
Item 10	0.90	0.80	0.80	0.83
Item 11	0.85	0.90	0.90	0.88
Item 12	0.95	1.00	1.00	0.98
Item 13	1.00	1.00	1.00	1.00
Item 14	0.95	1.00	1.00	0.98
Item 15	0.80	0.90	0.90	0.87
Item 16	0.85	1.00	1.00	0.95
Item 17	0.85	0.90	1.00	0.92
Item 18	1.00	1.00	1.00	1.00
Item 19	1.00	1.00	1.00	1.00
Item 20	1.00	1.00	1.00	1.00
Item 21	0.95	1.00	1.00	0.98
Item 22	0.80	1.00	1.00	0.93
Item 23	1.00	1.00	1.00	1.00
Item 24	0.85	1.00	1.00	0.95
Item 25	0.85	1.00	1.00	0.95
Item 26	1.00	1.00	1.00	1.00
Item 27	1.00	1.00	0.75	0.92
Item 28	1.00	1.00	1.00	1.00
Item 29	1.00	1.00	1.00	1.00
Item 30	1.00	1.00	1.00	1.00
Item 31	1.00	1.00	1.00	1.00
Item 32	0.95	1.00	1.00	0.98
Item 33	1.00	1.00	1.00	1.00
Item 34	0.90	1.00	1.00	0.97
Item 35	1.00	1.00	1.00	1.00
Item 36	1.00	1.00	1.00	1.00
Item 37	1.00	1.00	1.00	1.00
Item 38	0.95	1.00	1.00	0.98
Item 39	1.00	1.00	1.00	1.00
Item 40	1.00	1.00	1.00	1.00

**Table 3 (continued)**

Item	Content Validity Coefficient			CVC
	Clarity of language	Practical Relevance	Theoretical Relevance	
Item 41	0.95	1.00	1.00	0.98
Item 42	1.00	1.00	1.00	1.00
Item 43	0.90	1.00	1.00	0.97
Item 44	1.00	0.95	0.95	0.97
Item 45	1.00	1.00	1.00	1.00
Item 46	0.95	1.00	1.00	0.98
Item 47	0.95	1.00	1.00	0.98
Item 48	1.00	1.00	1.00	1.00
Item 49	1.00	1.00	1.00	1.00

adapted to the Chinese language and used in a study that evaluated the knowledge of Chinese citizens compared with data from US citizens.<sup>23</sup> Furthermore, the ASK-Q assesses knowledge about ASD more broadly, with an emphasis on the subdomains of diagnosis, etiology, treatment, and stigma.<sup>17</sup> Thus, the ASK-Q proved to be a promising instrument to be cross-culturally adapted to the Brazilian context and obtain a broad understanding of the knowledge of Brazilian pharmacists and pharmacy students.

With the cross-cultural adaptation and assessment of evidence of the content validity of the ASK-Q, it will be possible to assess the knowledge of the Brazilian population about ASD, especially pharmacists and pharmacy students. Knowledge is essential for pharmacists to develop clinical skills in caring for people with ASD. These professionals need to be trained in order to provide appropriate care.<sup>11,24</sup> Thus, future studies will be able to identify the national panorama of knowledge about ASD among students and pharmacists, as well as plan interventions focused on the training of pharmacy students and continuing education of pharmacists. These strategies will enable improvements in the care of people with autism carried out by pharmacists.

In the present study, improvements were made in the stages of cross-cultural adaptation of the ASK-Q instrument, and the methodological choices ensured the necessary rigor. The literature recommends adopting a rigorous methodology to maintain linguistic, technical, and construct equivalence.<sup>25</sup> In the expert committee phase, the suggested and performed changes were based on the recommendations of Borsa et al.,<sup>20</sup> regarding the structure, layout, instrument instructions, scope, and adequacy of the item expressions. The results indicate that the committee contributed by improving the quality of the translations, as reformulations carried out in items ensured the adequacy of cultural expressions, making the instrument suitable for the target audience of this study.<sup>26</sup>

One person with autism participated in the expert committee. This strategy was important in the process of validation, given that the inclusion of people with autism contributed to the appropriate language used in the instrument,<sup>25</sup> in addition to attributing the character of inclusion of the autistic community in research on autism.

The evaluation phase by the target audience included representatives from different Brazilian federative units. This strategy contributed to the study's development regarding the adequacy of the research instrument for Brazil, a country with continental dimensions and distinct regional characteristics. In addition, in this phase, adequate understanding of the instrument and its items by the participants was observed, which corroborates the recommendations proposed by Borsa et al.<sup>20</sup>

There is no consensus in literature regarding the reverse translation

phase.<sup>27</sup> In this study, we decided to perform the test after evaluation by the target audience. Other studies performed reverse translation after the synthesis of the translated versions and before evaluation by an expert committee.<sup>28,29</sup> However, the researchers identified the need for the author of the instrument to judge the version closest to the final one.

In this research, there was careful reflection for the establishment of criteria for the selection of experts to carry out the evaluation of evidence of content validity, and the CVC was satisfactory, as recommended by Hernández-Nieto<sup>22</sup> and corroborated by studies that adapted cross-culturally measuring instruments for Brazilian Portuguese, with results above 0.80 (range = 0.85–1.0)<sup>30</sup> and 0.97.<sup>31</sup> Thus, expert selection criteria may be used in future studies to assess content-based validity evidence.

The present study has limitations with regard to the evaluation stage of the target audience since it only included pharmacy students and pharmacists. Thus, future studies can assess knowledge in other target populations such as health professionals and the general population. As for strengths, the present study was adapted to the Brazilian context through recommendations from recent literature<sup>32</sup> and conceptual equivalence was confirmed by the main author of the instrument. In addition, changes, substitutions, and/or exclusions of terms, words, and/or expressions conducted at different stages of the adaptation process show that the instrument is suitable for the Brazilian context. Thus, the novelty of adapting the ASK-Q to Brazilian Portuguese stands out.

## 5. Conclusions

The ASK-Q instrument was cross-cultural adapted to the Brazilian context through rigorous methodological processes and presented adequate evidence of content validity. From the ASK-Q-Brasil will make it possible to carry out scientific research in Brazil that highlights the national panorama of knowledge about autism and future improvements in services aimed at the population with autism.

## Authors' statement

This manuscript is not under consideration, and will not be submitted to publication, in another journal.

## Compliance with ethical standards

This study was approved by the Ethics Committee in Research with Human Beings of the Federal University of Espírito Santo campus Alegre (CAAE 39222520.6.0000.8151).

## Informed consent

All participants signed an informed consent form, and a confidentiality and secrecy statement.

## CRediT authorship contribution statement

**Paulo Vítor Schultz:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Conceptualization. **Bárbara Brambila-Manso:** Writing – review & editing, Data curation. **Larissa Couto-Rosa:** Writing – review & editing, Writing – original draft. **Kérlin Stancine Santos Rocha:** Validation, Supervision, Project administration, Methodology, Conceptualization. **Dyego Carlos Souza Anacleto de Araújo:** Validation, Supervision, Project administration, Methodology, Formal analysis, Conceptualization. **Lorena Rocha Ayres:** Validation, Supervision, Project administration, Methodology, Data curation, Conceptualization. **Genival Araujo dos Santos Júnior:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Formal analysis, Data curation, Conceptualization.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.rcsop.2024.100495>.

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