

AUTISM QUESTIONNAIRE INTO BRAZILIAN PORTUGUESE STIGMA AND KNOWLEDGE QUESTIONNAIRE: PRELIMINARY STUDY

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Abstract: Introduction: Autism stigma and knowledge the original Questionnaire (ASK-Q) consists of 49 statements that measure 4 subscales, which involve specific knowledge about: diagnosis and symptomatology, etiology, treatment and stigma of autism spectrum disorder (ASD). This instrument has proved to be useful as a form of scientific investigation to analyze the knowledge and stigma of ASD in broad populations. The current study aims to translate into Portuguese, culturally adapt and validate the ASK-Q questionnaire. **Methodology:** The study was divided into four stages: 1) Translation, comparison of the two versions translated into Brazilian Portuguese and back -translation into English; 2) Semantic equivalence analysis; 3) Pre -test of the preliminary questionnaire, in order to verify the agreement of the judges' answers; 4) Pilot study to demonstrate practical applicability of the translated questionnaire, as well as to assess the knowledge and stigma of the selected sample about ASD. **Results:** The consolidated version in Portuguese was evaluated by the Content Validation Index (CVI), which obtained a result above 0.80 in all items and a p-value greater than 0.05, being considered adequate, without the need for adjustments. The pilot study demonstrated adequate knowledge of kindergarten teachers about ASD. **Conclusions:** It is concluded that the Portuguese version of the ASK-Q, translated and culturally adapted, presented satisfactory validity for assessing the knowledge and stigma of education professionals, as well as easy application in early childhood education institutions. The validation of the questionnaire into Portuguese strengthens the scientific and clinical fields of research on ASD in Brazil.

Keywords: Autistic Spectrum Disorder, Knowledge, Early Childhood Teachers.

INTRODUCTION

Autism Spectrum Disorder (ASD) is considered a neuropsychiatric syndrome defined by the presence of communication and social interaction disorders, as well as by the presence of repetitive, stereotyped and restrictive behavioral patterns. (GOMES et al., 2015). It is a multifactorial condition related to genetic and environmental factors, considered permanent, but early intervention generates better cognitive development and quality of life. (BRAZILIAN SOCIETY OF PEDIATRICS, 2019).

Autism has gained greater visibility in recent years, due to the significant increase in the number of cases. It is estimated that it affects 1 in 88 live births in the world. In the US, 1 in 54 children is diagnosed, which corresponds to about 2% of the total number of children in the country (MCCARTY; FRYE, 2020). In Brazil, in 2010, it was estimated that about 500 thousand people were living with autism. (GOMES et al., 2015). Studies suggest that relationship and social interaction disorders were one of the first symptoms reported by parents. Within this category, alterations such as absence of social smile, lack of shared attention, little eye contact and few communicative gestures were considered (MANOHAR; KANDASAMY; CHANDRASEKARAN; RAJKUMAR, 2019).

Difficulties in speech and language development represent the second group of most present and noticeable alterations in children who were diagnosed within the spectrum. Signs such as speech not acquired before 3 years of age, regression or stagnation in speech, echolalia and difficulty in understanding the other's speech were important signs reported by parents and caregivers. (MANOHAR; KANDASAMY; CHANDRASEKARAN; RAJKUMAR, 2019).

In order to assist in the early identification of children with the spectrum, the Ministry of Health (2014) published the Guidelines for Attention to the Rehabilitation of People with ASD, in which they listed the development indicators and warning signs in the following age groups: from zero to 6 months, from 6 to 12 months, from 12 to 18 months, from 18 to 24 months, from 24 to 36 months. Just as the Brazilian Society of Pediatrics (SBP) published the Autism Spectrum Disorder Guidance Manual, highlighting the most common early signs.

Despite scientific and public policy efforts on early screening for ASD, several epidemiological studies suggest that the average age at diagnosis remains between 4-5 years (ZWAIGENBAUM et al., 2015). According to the Law and Guidelines and Bases of the Union (2005), early childhood education aims to accompany the integral development in its physical, psychological, intellectual and social aspects, complementing the action of the family and the community. At this stage, the assessment of the child is carried out by the educators by monitoring and recording their development in the institution.

From this perspective, it is important for these education professionals to be encouraged to know the initial developmental milestones (social and emotional) of the child in the age group from 0 to 3 years, as well as to be instructed about the early signs of the disorder. autistic spectrum. Early referral for a medical evaluation and follow-up based on the observed information will contribute to the early diagnosis of autism, changing the prognosis and mitigating the symptoms.

The absence of validated instruments, in Brazil, that assess the knowledge of education professionals on the proposed theme, justifies such research, since the application of Autism stigma and knowledge Questionnaire in

educational institutions that serve children from zero to five years old will provide an overview of future interventions for the adequate preparation of these professionals. Therefore, the objective of this study was to translate, validate and culturally adapt Autism stigma and knowledge Questionnaire (ASK-Q) for Brazilian Portuguese.

METHODOLOGY

Methodological study of translation, adaptation and validation of the ASK-Q questionnaire for use in Brazilian Portuguese. The questionnaire consists of 49 questions divided into four dimensions: diagnosis and symptomatology (D/S), etiology (ET), treatment (TR) and stigma (ES) of autism spectrum disorder. The work was carried out in four stages: 1) translation, comparison of the two versions translated into Portuguese and back -translation into English; 2) semantic equivalence analysis; 3) pre-test to verify the agreement between the participants' answers; and 4) pilot study.

1) Translation, comparison of the two versions translated into Brazilian Portuguese and back -translation into English

The initial translation was performed by 2 independent Brazilian translators, with mastery of the English language and health terminology. Then, the comparison step was performed by a third translator, who compared the versions obtained in Portuguese, analyzing the presence of ambiguities and discrepancies in words, phrases and meanings, and at the end, a preliminary questionnaire translated into Portuguese was obtained. At the end of this stage, the preliminary questionnaire was back -translated into its original language. The translators responsible for this stage had English as their official language and followed

the same characteristics as the translators of the initial translation.

2) Semantic equivalence analysis

A multidisciplinary committee made up of health professionals familiar with the content of the instrument and all four translators involved in the process compared the questionnaires back -translated into English with the original questionnaire. Thus, a consolidated version in Portuguese was obtained, which was submitted to content validation (CVI) in the next step.

3) Pre-test of the preliminary questionnaire

For this stage, 21 professionals from early childhood education were selected, from an institution that provides pedagogical support and care for children from 0 to 5 years old, including both teachers and classroom assistants and other workers who are part of the child's usual routine. in the nursery or nursery. According to Sousa and Rojjanasrirat (2010), the sample for carrying out the pre - test, aiming at the translation, adaptation and validation of the instrument must be composed of 10 to 40 subjects. The sampling technique selected for the study was non-probabilistic for convenience.

The questionnaire translated into Portuguese was tested in the desired language, regarding understanding, clarity of questions and answers and difficulties encountered.

Each participant classified the questionnaire questions according to the Likert scale composed of the following scores: 1 for I did not understand; 2 to understand little; 3 to understand more or less; 4 to understand; and 5 for fully understood. At the end of the questionnaire, there was a space for suggestions and observations. Items not understood by more than 20% of the participants were re-evaluated. The evaluators

of this stage were not included in the pilot study.

To consider validation, the Content Validation Index (CVI) was used in three ways, as described by Galindo-Neto (2019): First, the agreement of the judges was obtained about each item, called I-CVI (Item - Level Content Validity Index); In the second stage, the proportion of items that obtained agreement from each judge was calculated, called S-CVI (Scale-level Content Validity Index); And the third stage consists of the average of the S-CVI, called S-CVI/AVE (Scale-level Content Validity Index, Average Calculation Method). The binomial test, with a significance level of 5%, was used to verify whether the proportion of agreement was statistically equal to or greater than 0.80. Statistical analyzes were performed in R, version 4.2.1 (THE R CORE TEAM, 2022).

Finally, for the analysis of reliability and internal consistency of the instrument, Cronbach's alpha coefficient was used.

4) Pilot study

Held in a kindergarten institution located in Aracaju (SE). The final version of the questionnaire translated into Brazilian Portuguese was applied in order to assess the knowledge and stigma of 24 selected education professionals, as well as to demonstrate its practical applicability. The instrument was answered virtually via Google Forms. Statistical analyzes were performed using R software, version 4.2.1 (THE R CORE TEAM, 2021). Descriptive analysis was used to characterize the studied sample, the categorical variables were described through their absolute and relative frequencies.

The 49-item instrument is divided into four subscales: diagnosis, etiology, treatment and stigma. For each item of the questionnaire, the participants had to choose between two answers: "agree" or "disagree", and at the end

the descriptive measures of the total number of correct answers (average, standard deviation, minimum and maximum) were calculated.

The average of correct answers was classified as 1) adequate or 2) inadequate, depending on the score obtained, as seen below: 1) diagnosis (0–10 inadequate; 11–18 adequate), etiology (0–10 inadequate; 11–16 adequate), treatment (0–9 inappropriate; 10–14 adequate), and stigma (0–2 endorse stigma; 3–7 do not endorse stigma (Harrison, Bradshaw, et al., 2017). Statistical analyzes were performed on R, version 4.2.1 (THE R CORE TEAM, 2022).

The study was authorized by the authors of the original ASK-Q. The project was submitted by the Research Ethics Committee, under CAAE: 63434722.6.0000.0217 and all participants signed the informed consent form.

RESULTS

The process of translation, validation and cross-cultural adaptation of the ASK-Q was completed properly and all steps described in the proposed method were strictly followed.

The stages of translation, back -translation and analysis of semantic equivalence resulted in the consolidated version of the ASK-Q for Brazilian Portuguese. The version produced was analyzed by the multidisciplinary committee and translators for the occurrence of ambiguities, discrepancies in words, phrases and divergence of meanings.

The consolidated version in Portuguese was applied in the pre-test in a sample of 21 early childhood education professionals. Of these, all (100%) were female, 8 (38.1%) were aged between 26 and 36 years and 9 (42.8%) had undergraduate and graduate degrees in education.

For each item of the questionnaire, the CVI was applied. The test verified that the calculated value was greater than 0.80 and that the p-value

was greater than 0.05 (significance level 5%), in all 49 items, a result that demonstrates the correct judgment by the judges, not adjustments are required. (TABLE 2)

The evaluation of internal consistency showed a Cronbach's alpha coefficient equal to 0.873, evidencing high reliability and consistency of the instrument.

In the pilot study, the final version translated into Portuguese was applied to 24 early childhood education professionals from another institution that offers pedagogical support for children aged 0 to 5 years located in Aracaju, Sergipe.

The objective of the pilot study was to assess the knowledge and stigma of the selected sample about ASD, as well as test the instrument in order to review and improve the necessary points.

Among the participants, 23 (95.8%) were women and 1 man (4.2%), most of them aged between 37-49 years (41.7%); 11 had completed higher education (45.8%); 9 had between 10 and 20 years of experience in their professional area (37.5%). Regarding the performance of training courses on autism: 3 never took it (12.5%); 7 perform it, but rarely (29.2%) and 9 perform it annually (37.5%).

All subjects (100%) reported having contact with children with ASD in their work environment, however, 25% (6) said they were not safe when dealing with or assisting children with the disorder. Among the main difficulties reported by professionals in the process of teaching students with autism, the lack of training and technical knowledge (66%) and the unpredictability of the child's behavior (34%) were highlighted.

Among the four dimensions of the questionnaire, the diagnosis subscale had the highest percentage of errors, while the etiology subscale represented the one with the highest number of correct answers, as shown in Table 3.

Item	no	BR	I-CVI**	p-value***
Item 1	21	100.0	1.0	0.0184
Item 2	21	100.0	1.00	0.0184
Item 3	21	100.0	1.00	0.0184
Item 4	19	90.5	0.90	0.3574
Item 5	21	100.0	1.00	0.0184
Item 6	21	100.0	1.00	0.0184
Item 7	21	100.0	1.00	0.0184
Item 8	21	100.0	1.00	0.0184
Item 9	21	100.0	1.00	0.0184
Item 10	21	100.0	1.00	0.0184
Item 11	21	100.0	1.00	0.0184
Item 12	21	100.0	1.00	0.0184
Item 13	21	100.0	1.00	0.0184
Item 14	21	100.0	1.00	0.0184
Item 15	21	100.0	1.00	0.0184
Item 16	21	100.0	1.00	0.0184
Item 17	21	100.0	1.00	0.0184
Item 18	21	100.0	1.00	0.0184
Item 19	21	100.0	1.00	0.0184
Item 20	21	100.0	1.00	0.0184
Item 21	21	100.0	1.00	0.0184
Item 22	21	100.0	1.00	0.0184
Item 23	21	100.0	1.00	0.0184
Item 24	21	100.0	1.00	0.0184
Item 25	21	100.0	1.00	0.0184
Item 26	21	100.0	1.00	0.0184
Item 27	21	100.0	1.00	0.0184
Item 28	21	100.0	1.00	0.0184
Item 29	21	100.0	1.00	0.0184
Item 30	21	100.0	1.00	0.0184
Item 31	21	100.0	1.00	0.0184
Item 32	21	100.0	1.00	0.0184

Item 33	21	100.0	1.00	0.0184
Item 34	21	100.0	1.00	0.0184
Item 35	21	100.0	1.00	0.0184
Item 36	21	100.0	1.00	0.0184
Item 37	21	100.0	1.00	0.0184
Item 38	21	100.0	1.00	0.0184
Item 39	21	100.0	1.00	0.0184
Item 40	21	100.0	1.00	0.0184
Item 41	21	100.0	1.00	0.0184
Item 42	21	100.0	1.00	0.0184
Item 43	21	100.0	1.00	0.0184
Item 44	21	100.0	1.00	0.0184
Item 45	21	100.0	1.00	0.0184
Item 46	21	100.0	1.00	0.0184
Item 47	20	95.2	0.95	0.1153
Item 48	21	100.0	1.00	0.0184
Item 49	21	100.0	1.00	0.0184

*Percentage of agreement; **Item- Level Content Validity Index; ***Binomial test l

Table 2: Distribution of the results of the agreement analysis of the 21 judges in the pre -test stage. Aracaju, 2022.

Subscale	Average	Standard deviation	Minimum	Maximum
Diagnosis	15.4	1.2	13.0	18.0
Treatment	12.4	1.0	10.0	14.0
Etiology	14.3	1.6	9.0	16.0
Stigma	6.4	0.7	5.0	7.0

Table 3: Distribution of means in terms of total hits by subscale. Aracaju, 2022.

DISCUSSION

In the field of health, there is an increasing number of scales and questionnaires with the aim of evaluating phenomena and assisting in conducts and measures in clinical practice. Most of these studies are carried out in languages other than Brazilian Portuguese and require rigorous stages of translation and validation to be used in the Brazilian reality. However, such a process does not only involve literal translation of the text and requires methodological rigor that adapts to the linguistic, cultural and area of knowledge that will be used. (DALLA, et al., 2017; ALEXANDRE; COLUCI, 2022).

In view of this, it can be inferred that the absence, in the present study, of divergent terms in the translation stage can be justified by the careful choice of translators, as well as their detailed assessments and approach to the proposed theme.

Regarding the assessment of semantic equivalence of the ASK-Q items, the instrument proved to be viable, with high reliability and internal consistency and easy reproducibility. Content validation was considered adequate, given that all scores (CVC) found, both the global and individual scores for each question, were statistically equal to 0.80, with a calculated p-value greater than 0.05. The present study is a pioneer in the translation and validation of this instrument into Portuguese.

The application of the ASK-Q in the pilot study phase revealed that the research subjects had adequate knowledge about autism spectrum disorder, taking into account the score established by the original authors. However, when the result of each subscale was evaluated separately, items related to “diagnostic” knowledge showed a low percentage of correct answers when compared to the others. This dimension encompasses statements related to the symptoms of ASD

and its early signs.

The Law of Directives and Bases of National Education (LDBEN) states that early childhood education is the first stage of basic education and pedagogical assistance must be offered in day care centers for children from zero to three years old and in preschools for children aged four. to five years. (BRAZIL, 1996). It is noteworthy that this context represents the phase in which the first signs of ASD may appear.

In recent years, some research has been carried out with the aim of evaluating the real needs, demands and challenges of early childhood education professionals in school inclusion and identification of children with signs of autism. (FIORINI; MANZINI, 2016; MATOS; MENDES, 2015). Schmidt et al. (2016) point out as a real need, the development of skills and competences in educators of educational services.

In order to collaborate with future research, it is expected that the translation of the ASK-Q into Portuguese will help in the investigation and identification of deficits in the knowledge of educators in the areas related to diagnosis/symptoms, etiology, stigma and treatment of ASD. With this, the progress of children in the school environment, as well as educational practices and teaching quality, would be positively affected, favoring the improvement of training and instrumentalization programs, didactic resources and school structure.

Some limitations must be highlighted in relation to this research and application of the questionnaire. The study consisted of participants from a particular private children’s education institution in Aracaju (SE), chosen for the convenience of the researchers. Furthermore, it involved a small sample size. It is important to emphasize the need to carry out new studies, using representative samples.

CONCLUSIONS

It is concluded that the Portuguese version of the ASK -Q, translated, validated and culturally adapted to Brazilian Portuguese, presented reliability, internal consistency and satisfactory reproducibility, being, therefore, considered valid for assessing the knowledge and stigma of Spectrum Disorder Autistic in the Brazilian population, especially in early childhood education professionals. The process followed was carried out rigorously, according to the adopted reference, reaching the proposed objectives.

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