

Translation and validation of a questionnaire on the impact of strabismus on the quality of life of patients

Tradução e validação de um questionário sobre impacto na qualidade de vida em pacientes com estrabismo

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ABSTRACT

Objective: To translate and validate the Adult Strabismus Quality of Life Questionnaire into Brazilian Portuguese.

Methods: A cross-sectional study for linguistic and cross-cultural validation of the Adult Strabismus Quality of Life Questionnaire in order to assess the quality of life in patients with strabismus. We have followed previous published guidelines on translation process to ensure the equivalence between the original and translated versions. The final version was applied in a pilot study to evaluate concordance and its reliability and reproducibility as a tool to be used in future studies.

Results: The translation and counter translation processes of the Adult Strabismus Quality of Life Questionnaire were conducted according to preestablished protocols. The analysis of the results obtained in the test-retest application of the questionnaire in a sample of 30 participants revealed a correlation coefficient of 0.67, which was deemed satisfactory for the validation process of this tool.

Conclusion: The Adult Strabismus Quality of Life Questionnaire was translated and validated according to preestablished protocols. The referred questionnaire has been used in studies worldwide, so this process will enable its application to better understand the impact of strabismus in patients' quality of life in the Brazilian population.

RESUMO

Objetivo: Traduzir e validar o questionário *Adult Strabismus Quality of Life Questionnaire (AS-20)* para o português brasileiro.

Métodos: Estudo transversal para validação linguística e transcultural do questionário *Adult Strabismus Quality of Life Questionnaire (AS-20)* para avaliação da qualidade de vida em pacientes com estrabismo. Foram seguidas as diretrizes já publicadas sobre o processo de tradução, para garantir a equivalência entre as versões original e traduzida. A versão final foi aplicada em um estudo-piloto para avaliar a concordância e sua confiabilidade e reprodutibilidade, como ferramenta a ser utilizada em estudos futuros.

Resultados: Os processos de tradução e contratradução do questionário *Adult Strabismus Quality of Life Questionnaire (AS-20)* foram realizados de acordo com protocolos preestabelecidos. A análise dos resultados obtidos na aplicação teste-reteste do questionário em uma amostra de 30 participantes revelou coeficiente de correlação de 0,67, que foi considerado satisfatório para o processo de validação desse instrumento.

Conclusão: O questionário *Adult Strabismus Quality of Life Questionnaire (AS-20)* foi traduzido e validado de acordo com protocolos preestabelecidos. O referido questionário vem sendo utilizado em estudos ao redor do mundo e, portanto, esse processo possibilitará sua aplicação para melhor compreensão do impacto do estrabismo na qualidade de vida dos pacientes da população brasileira.

INTRODUCTION

Strabismus affects people of all ages, but it is most common in children. There is a negative impact on health-related quality of life because of the change in appearance.⁽¹⁾ A growing number of studies have reported that patients with strabismus have a higher proclivity for mental illness and a negative impact on their self-image, relationships with others, and work.⁽²⁾

A cross-sectional study conducted in 11 cities in the center-west of São Paulo, Brazil, found that the prevalence of strabismus was approximately 1.4%, correlating with global data.⁽³⁾

The surgical treatment of strabismus aims to align the visual axes to achieve image fusion and binocularity restoration. In addition, it also intends to correct abnormal head position, expand the visual field, eliminate diplopia (double vision), improve eye motility, and promote psychomotor development.⁽⁴⁾ Although often overlooked, the benefits of improved self-esteem and psychological health should be considered in surgical decision-making.⁽⁵⁾

When compared to other interventions, strabismus surgery is effective, long-lasting, and has few risks. It is cost-effective, especially in children, because of their long life expectancy. In adults with long-term strabismus, the incidence of permanent postoperative diplopia is only 1%.^(6,7)

The quantitative assessment of the quality of life of patients with strabismus is an important contribution to the clinical examination because it allows for a better understanding of the condition and an accurate assessment of treatment effectiveness.⁽⁸⁾

Currently, no strabismus-specific questionnaire is available in Brazilian Portuguese. The *Adult Strabismus Quality of Life Questionnaire (AS-20)*^(2,9) is a standardized English questionnaire used to assess health-related quality of life and functional vision in adults with strabismus. The AS-20 questionnaire was developed based on patient interviews in which expressed feelings and phrases were collected. Subsequently, each statement by the patient was converted into a question, generating a 181-item questionnaire. Each question was refined, and items that could differ based on socioeconomic, cultural, or educational status were removed, yielding the AS-20 questionnaire, which consisted of 20 questions divided into a psychosocial scale and a functional scale.^(8,10)

With its validation in Portuguese, another valuable resource for assessing the impact of strabismus on an individual's daily life will be available, thereby making it possible to measure the results of the treatment in clinical practice and research, corroborating the definition of

clinical treatments, and identifying patients in need of psychosocial support, occupational therapy, and rehabilitation.^(8,11)

The aim of this study was to translate and validate the Portuguese version of this questionnaire. The AS-20 questionnaire is self-administered, and each of the 20 questions about feelings and difficulties in patients with strabismus is designed to be answered on a five-point Likert-type scale (never corresponds to 100; rarely, to 75; sometimes, to 50; often, to 25; and always, to zero). The median total score can range from zero (worst quality of life) to 100 (best quality of life).

METHODS

The present study was approved by the *Universidade Estadual de Campinas (Unicamp)* Research Ethics Committee (number CAAE: 18913819.8.0000.5404, protocol number 3.571.455) and was performed in accordance with the Declaration of Helsinki.

The original English version of the AS-20 questionnaire was translated into Portuguese using a three-phase process first proposed by Beaton et al. and Gjersing et al., as described in figure 1.^(12,13)

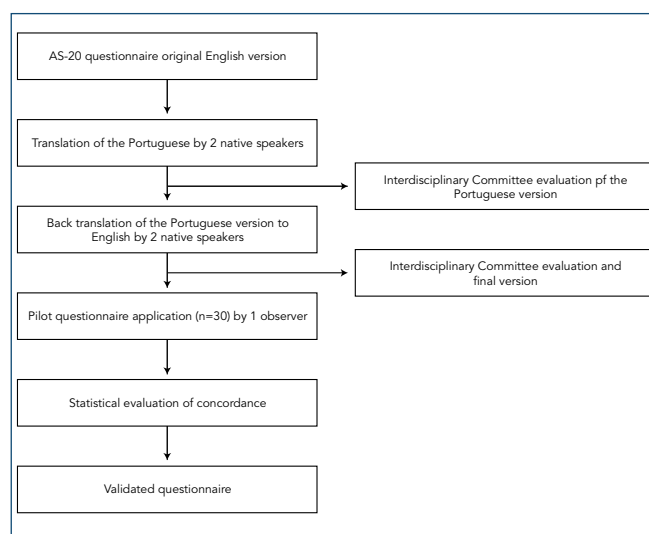


Figure 1. The study design according to the guideline proposed for the translation and validation processes.

The following is the original English version of the AS-20 questionnaire:

Psychosocial subscale
1. I worry about what people will think of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
2. I feel that people are thinking about my eyes even when they do not say anything.
() Never, () Rarely, () Sometimes, () Often, () Always

Continue...

Continuation.

3. I feel uncomfortable when people look at me because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
4. I wonder what people are thinking when they look at me because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
5. People do not give me opportunities because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
6. I am self-conscious of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
7. People avoid looking at me because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
8. I feel inferior to others because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
9. People react differently to me because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
10. I find it difficult to initiate contact with people I do not know because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
Functional subscale
11. I cover or close one eye to see things better.
() Never, () Rarely, () Sometimes, () Often, () Always
12. I avoid reading because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
13. I stop doing things because my eyes make it difficult to concentrate.
() Never, () Rarely, () Sometimes, () Often, () Always
14. I have difficulty with depth perception.
() Never, () Rarely, () Sometimes, () Often, () Always
15. My eyes feel strained.
() Never, () Rarely, () Sometimes, () Often, () Always
16. I have difficulty reading because of my eye condition.
() Never, () Rarely, () Sometimes, () Often, () Always
17. I am stressed because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
18. I am concerned about my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
19. I cannot enjoy my hobbies because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always
20. I need to take frequent breaks while reading because of my eyes.
() Never, () Rarely, () Sometimes, () Often, () Always

Source: Fossum P, Le Meur G, Couret C, Pechereau A, Hode F, Albert F, et al. [Validation of the French version of the health-related quality of life questionnaire for adult strabismus (AS-20)]. J Fr Ophtalmol. 2017;40(9):738-43.

The following is the original Portuguese version of the AS-20 questionnaire:

AS-20 Portuguese Version
1. Eu me preocupo com o que as pessoas vão pensar sobre a condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
2. Eu sinto que as pessoas estão observando os meus olhos mesmo quando elas não dizem nada.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
3. Eu me sinto desconfortável quando as pessoas estão olhando para mim por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
4. Eu me pergunto o que as pessoas estão pensando quando estão olhando para mim por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
5. Eu sinto que as pessoas não me dão oportunidades por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
6. Eu tenho consciência do desvio dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
7. As pessoas evitam olhar para mim por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
8. Eu me sinto inferior aos outros por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
9. As pessoas reagem de maneira diferente comigo por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre

Continue...

Continuation.

10. Acho difícil iniciar contato com pessoas que não conheço por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
11. Eu cubro ou fecho um olho para ver melhor.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
12. Eu evito ler por causa dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
13. Paro de fazer coisas porque a condição dos meus olhos dificulta a concentração.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
14. Eu tenho problemas com a visão de profundidade.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
15. Sinto meus olhos cansados.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
16. Eu tenho problemas de leitura por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
17. Eu me sinto estressado por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
18. Eu me preocupo com a condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
19. Eu não consigo aproveitar as coisas que gosto de fazer por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre
20. Eu preciso fazer pausas frequentes quando leio por causa da condição dos meus olhos.
() Nunca, () Raramente, () Às vezes, () Frequentemente, () Sempre

Source: Fossum P, Le Meur G, Couret C, Pechereau A, Hode F, Albert F, et al. [Validation of the French version of the health-related quality of life questionnaire for adult strabismus (AS-20)]. J Fr Ophtalmol. 2017;40(9):738-43.

First, two independent translators and native Portuguese speakers translated and cross-culturally adapted the English version into Portuguese, followed by an evaluation of the translated version by a panel of two ophthalmologists (one general ophthalmologist and one strabismus specialist), two residents, and a medical student.

The Portuguese version was then translated into English by two independent native speakers, and the same interdisciplinary panel evaluated and compared it to the original English version. Based on the suggestions of the interdisciplinary committee, the translation was revised by the researchers to establish the final version.

The final version of the questionnaire was administered to a group of 30 volunteers over the age of 18 years old to verify the agreement of the answers and the validation process. Participants signed an Informed Consent Form. To assess the reproducibility of the questionnaire, a second test was conducted with the same volunteers (Table 1).

The AS-20 questionnaire is self-administered, and each of the 20 questions about feelings and difficulties in the individual with strabismus is designed to be answered on a 5-point Likert-type scale (never corresponded to 100; rarely, to 75; sometimes, to 50; often, to 25, and always, to 0). The median total score can range from zero (worst quality of life) to 100 (best quality of life). Figure 1 displays the study design according to the guidelines proposed for the translation and validation processes.

Table 1. Qualitative, descriptive analysis of test and retest answers for each of the 20 questions administered to the 30 participants

Questions (q)	0 Always	25 Often	50 Sometimes	75 Rarely	100 Never
q1_test	0	0	0	3 (10)	27 (90)
q1_retest	0	0	2 (6.67)	0	28 (93.33)
q2_test	0	0	0	1 (3.33)	29 (96.67)
q2_retest	0	0	1 (3.33)	1 (3.33)	28 (93.33)
q3_test	0	0	0	1 (3.33)	29 (96.67)
q3_retest	0	0	1 (3.33)	0	29 (96.67)
q4_test	0	0	0	0	30 (100)
q4_retest	0	0	0	0	30 (100)
q5_test	0	0	0	0	30 (100)
q5_retest	0	0	0	1 (3.33)	29 (96.67)
q6_test	0	0	0	0	30 (100)
q6_retest	0	0	0	3 (10)	27 (90)
q7_test	0	0	1 (3.33)	0	29 (96.67)
q7_retest	0	0	0	0	30 (100)
q8_test	0	0	0	0	30 (100)
q8_retest	0	0	0	0	30 (100)
q9_test	0	0	0	0	30 (100)
q9_retest	0	0	0	0	30 (100)
q10_test	0	0	0	0	30 (100)
q10_retest	0	0	0	0	30 (100)
q11_test	0	0	0	0	30 (100)
q11_retest	0	0	0	0	30 (100)
q12_test	0	0	0	0	30 (100)
q12_retest	0	0	0	0	30 (100)
q13_test	0	0	0	0	30 (100)
q13_retest	0	0	0	0	30 (100)
q14_test	0	0	1 (3.33)	0	29 (96.67)
q14_retest	0	0	0	1 (3.33)	29 (96.67)
q15_test	0	0	0	0	30 (100)
q15_retest	0	0	0	1 (3.33)	29 (96.67)
q16_test	0	0	1 (3.33)	0	29 (96.67)
q16_retest	0	0	0	1 (3.33)	29 (96.67)
q17_test	0	0	0	0	30 (100)
q17_retest	0	0	0	0	30 (100)
q18_test	0	0	0	1 (3.33)	29 (96.67)
q18_retest	0	0	1 (3.33)	1 (3.33)	28 (93.33)
q19_test	0	0	0	0	30 (100)
q19_retest	0	0	0	0	30 (100)
q20_test	0	0	0	1 (3.33)	29 (96.67)
q20_retest	0	0	1 (3.33)	1 (3.33)	28 (93.33)

Results expressed as n (%).

Statistical methodology

To describe the answers of the questionnaire in relation to the Likert scale categories, frequency tables with absolute values (n) and percentages (%) were created. To describe the answers according to the value corresponding to each category as well as to describe the total results according to the dimension and general result, descriptive analyses of mean, standard deviation, median, 1st quartile, 3rd quartile, minimum, maximum, and sample size were conducted. (Tables 2,3,4)

The intraclass correlation coefficient was used to assess the agreement between test and retest results. For the questions in which the test results had no variance in their answers, it was not possible to calculate any measure of agreement (Table 5).

For statistical analysis, the following computer programs were used: The Statistical Analysis System (SAS) for Windows, version 9.4 (SAS Institute Inc., 2002-2008, Cary, NC, USA and R Core Team, 2020) and R: A language and environment for statistical computing. (R Foundation for Statistical Computing, Vienna, Austria. URL: <https://www.r-project.org>). For the interpretation of the intraclass correlation coefficient, the following values were used according to Koo et al.⁽¹⁴⁾: <0.5, poor correlation; 0.5 to 0.75, moderate; 0.75 to 0.90, good; and >0.9, excellent.

RESULTS

The Portuguese version of the AS-20 questionnaire was administered twice to a group of 30 volunteers over the age of 18 years old. Because the questionnaire consisted of simple and direct questions, reproducibility was good and there were no difficulties during the translation and adaptation phases. Similarly, no disagreements arose during the other stages of the process. Correlation coefficient values were consistently satisfactory and statistically significant for all 20 items.

Table 2. Values of the quantitative descriptive analysis of the scores pertaining to questions one to ten (psychic scale)

(n=30)	Average	Standard deviation	Median	First quartile	Third quartile	Minimum	Maximum
Test	99.42	1.42	100.00	100.00	100.00	95.00	100.00
Retest	98.92	2.34	100.00	100.00	100.00	90.00	100.00

Table 3. Values of the quantitative descriptive analysis of the scores pertaining to questions 11 to 20 (functional scale)

(n=30)	Average	Standard deviation	Median	First quartile	Third quartile	Minimum	Maximum
Test	99.50	1.66	100.00	100.00	100.00	92.50	100.00
Retest	99.25	1.87	100.00	100.00	100.00	92.50	100.00

Table 4. Values of the quantitative descriptive analysis of the scores pertaining to questions 1 to 20 (psychic scale and functional scale)

(n = 30)	Average	Standard deviation	Median	First quartile	Third quartile	Minimum	Maximum
Test	99.46	1.02	100.00	98.75	100.00	96.25	100.00

Table 5. Results of the intraclass correlation coefficient between test and retest answers for the psychic scale (answers 1 to 10), functional scale (answers 11 to 20), and both scales (answers 1 to 20)

Test/retest	ICC	95%CI95
Psychic scale	0.67	0.41-0.83
Functional scale	0.77	0.56-0.87
All	0.67	0.40-0.83

ICC: intraclass correlation coefficient; 95%CI: 95% of confidence interval.

Table 1 shows the qualitative descriptive analysis of the test and retest answers for each of the 20 questions administered to the 30 participants. For each question, the absolute values of the number (n) and the percentage of participants who responded (%) are presented along with their assigned scores for each category of the Likert scale.

According to Koo et al., in the interpretation of the intraclass correlation coefficient for the psychic scale (questions one to ten), the agreement index between the test and retest was 0.67, revealing a moderate level of agreement. For the functional scale (answers ranging from 11 to 20), the agreement index between the test and retest was 0.77, indicating a good level of agreement. In the total answers (psychic and functional scales together, answers ranging from 1 to 20), the agreement index between test and retest was 0.67, revealing a moderate level of agreement.⁽¹⁴⁾

DISCUSSION

Strabismus surgery is often classified as an aesthetic procedure in patients who do not have binocular vision potential or have diplopia; however, this term is considered incorrect because it is not just a beautifying procedure but rather an instrument to restore normalcy as a result of pathology.⁽¹⁵⁾

Strabismus is one of the most debilitating ophthalmological conditions.⁽¹⁶⁾ The impact on the quality of life of patients with strabismus is similar to that of macular degeneration and mild stroke but greater than that of diabetic retinopathy. However, unlike these conditions, strabismus can be surgically corrected, thereby substantially improving the quality of life of these patients.⁽¹⁷⁾

Questionnaires are useful tools in health-related research, and they are increasingly being used to analyze the quality of life related to a specific disease, quantify symptoms, assess the natural course of the disease, and determine the effects of treatment strategies.⁽¹⁾

The use of standardized and validated research instruments allows for comparisons of results from different studies at the national and international

levels, but the use of validated questionnaires does not guarantee their legitimacy for use in different

languages and cultures. Therefore, language translation, along with cross-cultural adaptation of validated questionnaires, becomes necessary to achieve the equivalence of these questionnaires to be used in different languages, countries, and cultures.^(11,18,19)

Quality of life questionnaires can quantify the psychosocial consequences of strabismus in an individual's life. The assessment of quality of life is an important aspect to consider in the management of patients with strabismus in order to define surgical procedures and indications because it allows for a better understanding of this condition and access to effective treatment. Adults with strabismus appear to have a lower quality of life, but questionnaires are not used to define procedures in clinical practice.⁽²⁰⁾ The use of questionnaires allows for the evaluation of treatment outcomes in clinical practice and clinical trials.⁽²⁰⁾

Although there have been few studies evaluating the AS-20 questionnaire in children, it can be used to assess the quality of life in children with strabismus through parental perception. When compared to the VFQ-25, the AS-20 questionnaire was more sensitive in detecting functional and psychosocial changes.⁽¹¹⁾

The translation and validation of the AS-20 questionnaire in this study will provide a new tool for assessing the impact of strabismus surgery on different age groups and disease subtypes as well as help in the standardization of a resource for clinical research in the field.

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