

Semantic validation of the Portuguese version of the Adult attention-deficit disorder/hyperactivity disorder (ADHD) Quality of Life Questionnaire (AAQoL)

Validação semântica da versão em língua portuguesa do Questionário de Qualidade de Vida em Adultos (AAQoL) que apresentam transtorno de déficit de atenção/hiperatividade (TDAH)

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Abstract

Background: Attention-deficit disorder/hyperactivity disorder (ADHD) in adults is associated to worse measures of quality of life, both in clinical and epidemiological samples and their evaluation is important when understanding the burden of the disorder in different areas of patients' lives. There is not any instrument in the Portuguese language to assess quality of life in adults with ADHD. **Objectives:** To develop a Portuguese version of the Adult ADHD Quality of Life Questionnaire (AAQoL) to be used in Brazil. **Methods:** Five consecutive steps including translation, back-translation, evaluation of semantic equivalence, debriefing with patients and controls and definition of a final version. **Results:** After all steps, the final version was chosen considering many aspects, including similarity to the original version, friendly understanding and level of semantic equivalence of the 29 terms. **Discussion:** The Portuguese version of the AAQoL will provide measures of quality of life similarly to the original version.

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Keywords: Translating, attention-deficit hyperactivity disorder, quality of life, validation studies.

Resumo

Introdução: O transtorno de déficit de atenção/hiperatividade (TDAH) em adultos está associado às piores medições de qualidade de vida, tanto em amostras clínicas como em epidemiológicas, e sua avaliação é importante para entender a extensão do transtorno nas diferentes áreas da vida dos pacientes. Não há nenhuma ferramenta em português para avaliar a qualidade de vida em adultos que apresentam TDAH. **Objetivos:** Desenvolver uma versão em língua portuguesa do *Adult ADHD Quality of Life Questionnaire* (AAQoL) para ser utilizado no Brasil. **Métodos:** Cinco etapas consecutivas que incluem tradução, versão para a língua de origem, avaliação da equivalência semântica, discussão com os pacientes e controles e definição da versão final. **Resultados:** Após todas as etapas, a versão final foi escolhida levando em conta vários aspectos, inclusive semelhança com a versão original, facilidade de compreensão e nível de equivalência semântica de 29 termos. **Conclusão:** A versão em língua portuguesa do AAQoL fornecerá medições de qualidade de vida similar à versão original.

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Palavras-chave: Tradução, transtorno de déficit de atenção/hiperatividade, qualidade de vida, estudos de validação.

Introduction

Although there are controversies about the number of symptoms required for diagnosis of the adult form of ADHD, since DSM-IV cutoff was established based on samples of 6 to 16 year-old subjects, the majority of clinical trials use these criteria. In two studies with non-clinical samples^{1,2}, validity of ADHD diagnosis in adults has demonstrated that subjects with greater number of symptoms had worse indicators of global functioning and impairment. Given the single evidence of significant academic impairment of ADHD, among many others, one should expect a myriad of worse outcome measures for children with the disorder³. Several cumulative evidences in recent years revealed high rates of ADHD-associated functioning impairment which potentially have a negative influence in quality of life (QoL). Despite those findings, until recently there were no instruments developed to capture quality of life indicators in adult patients with ADHD. Studies using widely-used scales, such as SF-36, have indicated that only certain subscales were related to remission of ADHD symptoms, suggesting that more specific instruments for these patients are needed^{4,5}.

The Adult ADHD Quality of Life Questionnaire (AAQoL)⁶ was developed based on systematization of data on the impact of the disorder in everyday activities reported by patients, by experts and also information collected from scientific literature. In its current version, AAQoL is a Likert-type scale consisting of 29 items distributed in the following four subscales: *Productivity* (11 items), *Psychological Health* (6 items), *Life Perspectives* (7 items), and *Relationships* (5 items). In the original study of scale validation, construct validity of AAQoL was confirmed for the whole set of its items, as well as for four dimensions (subscales) of the instrument. Internal consistency of the scale has been shown to be adequate, with a Cronbach's alpha of 0.93⁶. In the validation study of the original scale, ADHD patients had shown a greater number of divorces, higher unemployment rates and lower mean income compared to the matched control group, which are aspects that illustrate a more accentuated impairment in *Productivity* and *Relationships* subscales⁶.

Quality of life scales are particularly important for efficiency assessment of drug or non-drug therapies, as efficacy studies, by far the most common ones, give information about *symptomatic remission* with the therapy employed, but do not indicate changes occurred in

the impact of disruption on different areas of patient's life. Therefore, the purpose of this study is to perform a semantic validation in Portuguese of the ADHD Adult Quality of Life Questionnaire (AAQoL) instrument in a sample of adult patients with ADHD.

Methods

After authorization of the original instrument's authors, semantic validation was based on general guidelines of a method proposed by Herdman *et al.*⁷ and previously used with an adult ADHD sample in our country⁸ with five consecutive stages: a) translation of the original instrument; b) back-translation; c) formal appreciation of equivalence between translation and back-translation; d) debriefing with a convenience sample, and e) final review by field experts, involving authors of this study, original scale's author, and two invited psychiatrists, who are experienced in treating adults with ADHD. This study was approved by IPUB – UFRJ Research Ethics Committee.

The first stage is consisted of two translations of the original document from English into Portuguese, separately made, one of which performed by a translator, and the other performed by a fluently English and Portuguese-speaking psychiatrist with experience in treating adult patients with ADHD. The same number of items, the same title and the same five or six options of frequency responses were maintained. Block division was also maintained, according to the original. The second stage is consisted of two back-translations into English of such separately made translations in the previous stage by professionals with the same profile of the first stage. The third stage is consisted of the formal appreciation of semantic equivalence by authors of this study. For this, *general meaning* (concepts to which original terms refer) and *referential meaning* (correspondence between terms in English and in Portuguese) of wording of each item of scale were evaluated^{7,9}. Particularly regarding conceptual equivalence, it was tried to evaluate the correspondence between the North-American and Brazilian cultures for different daily life contexts addressed in the scale. A summary version was prepared and used in the forth stage, which was a debriefing with a convenience sample. In this phase, 10 healthy control subjects as well as 10 ADHD patients, as diagnosed according to DSM-IV system criteria, were interviewed using Module K-SADS-PL Diagnostic Interview (adapted version 6.0). Patients were also interviewed in order to control for any current psychiatric diagnosis other than ADHD. Patients were considered to be those having previous diagnosis before 12 years of age – as proposed by some authors¹⁰ – and current diagnosis, i.e., at least six inattention symptoms in Module A and/or six hyperactivity-impulsivity symptoms in Module B. Our group has previously demonstrated Impairment in at least two areas was investigated by a direct questioning by examiners who decided on the presence of impairment according to their expertise and clinical judgment. Remaining criteria of DSM system were also employed. Patients were enrolled consecutively in Attention Deficit Study Group (GEDA) of UFRJ's Institute of Psychiatry. Controls were equally enrolled in GEDA; these were defined as subjects with less than four current symptoms of both dimensions (inattention and hyperactivity-impulsivity) matched for age, sex and education without any current psychiatric diagnosis. The fifth stage is consisted of a final review by field experts and by the original scale's author.

Results

The final version in Portuguese is shown in table 1. Both back-translations revealed good measures of equivalence for referential and general meaning compared to the original instrument; agreement between pairs (translations-back-translations) varied somewhat in the majority of 29 items. Questions presenting lower agreement were discussed and redefined in stage 3. Among them, item "Lack of satisfactory time" was the one with lower agreement between

translation and back-translation, and was discussed with the original document's author. The concept of "quality time", in the original document, has revealed to be of difficult correspondence and it was chosen to use the term "satisfactory time" that has a broader sense than only sufficient amount of time. In the forth stage, this item has revealed to be of good understanding by patients.

In the forth stage, item "using your energy well" was poorly understood by a small number of patients, to whom direct questioning by the interviewer (after self-completion) has revealed certain confusion regarding intended sense. Some subjects checked that items "Feel you irritate people" and "Feel that people are frustrated with you" were potentially correlated, but both were included in the original instrument. The same was valid to items "Feel overloaded" and "Felt upset because you were tired".

Discussion

Several studies showing significant impairment associated to ADHD symptoms in adults, such as listed on DSM-IV, stressed out the necessity of investigating the impact of such impairment on quality of life indexes of patients with this disorder. The use of more generic quality of life scales – such as SF-36 – in studies with ADHD subjects have shown that only some indexes were correlated to symptoms of this disorder, stressing out the necessity of more specific instruments^{4,5}.

AAQoL was selected because it is an easily and rapidly applied instrument, in addition to having been developed to investigate the impact of ADHD symptoms on quality of life of patients with this disease. Thus, items that may be divided in four subscales, assessing productivity, psychological health, life perspectives, and relationships, which are areas commonly affected in ADHD patients and have closer relation to ADHD than areas assessed by SF-36 scale, such as physical health and pain, for example, were used.

AAQoL translation used detailed systematic for formal appreciation of semantic equivalence, similarly to several other similar studies in our field, due to the fact that terms and expressions may have different approaches, specificities, and connotations, inherent to every language and culture.

Debriefing in a limited number of subjects should always be considered as a main limitation of semantic validation studies, as in this study, considering the sociocultural heterogeneity in Brazil. For quality of life studies, other forms of equivalence rather than semantic – such as, for example, functional equivalence – have been emphasized by some authors⁷; this may be particularly important once quality of life is a concept widely subjected to variations in different cultures. However, a comparative analysis of the traditional methodology, similar to those used in the present study, with a laborious process for its obtaining, including focus group and multiple pretests (among other procedures), has not revealed significant differences in a study on quality of life instruments¹¹.

Conclusion

The AAQoL Portuguese version obtained in this study will provide measures of quality of life similarly to the original instrument, meeting the need for specific instruments to evaluate this aspect in ADHD adult subjects, and allowing an objective measurement of the degree of disease impact on different areas contributing to the quality of life of these subjects.

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Potential conflicts of interest

Paulo Mattos is a member of the advisory committee and speaker for Janssen-Cilag and Novartis laboratories.

Table 1. Versão final em português da *Adult ADHD Quality of Life Questionnaire* (AAQoL)

As perguntas a seguir referem-se ao impacto que o TDAH teve na sua vida nas ÚLTIMAS 2 SEMANAS. Para cada pergunta, circule sua resposta. Não existem respostas certas ou erradas

Nas ÚLTIMAS 2 SEMANAS, até que ponto foi difícil para você:	Nem um pouco	Não muito	Um pouco	Muito	Extremamente
Manter a casa (ou apartamento) limpa ou arrumada	1	2	3	4	5
Administrar suas finanças (como descontar cheques, controlar o saldo bancário, pagar as contas em dia)	1	2	3	4	5
Lembrar de coisas importantes	1	2	3	4	5
Conseguir fazer suas compras (comida, roupas ou coisas para a casa, por ex.)	1	2	3	4	5
Ficar atento enquanto interagia com outras pessoas	1	2	3	4	5

Nas ÚLTIMAS 2 SEMANAS, com que frequência você:	Nunca	Raramente	Algumas vezes	Frequentemente	Muito frequentemente
Sentiu-se sobrecarregado(a)	1	2	3	4	5
Sentiu-se ansioso(a)	1	2	3	4	5
Sentiu-se deprimido(a)	1	2	3	4	5
Sentiu que não foi capaz de atender às expectativas dos outros (em casa ou no trabalho)	1	2	3	4	5
Sentiu que irritou as pessoas	1	2	3	4	5
Sentiu que é preciso muito esforço para fazer e terminar as coisas	1	2	3	4	5
Sentiu que as pessoas ficam frustradas com você	1	2	3	4	5
Sentiu que teve uma reação exagerada em situações difíceis ou estressantes	1	2	3	4	5
Sentiu que usa bem sua energia (que ela dá resultados positivos)	1	2	3	4	5
Sentiu que consegue passar bons momentos com os outros	1	2	3	4	5
Sentiu que é capaz de administrar bem a sua vida	1	2	3	4	5
Sentiu-se tão produtivo(a) quanto gostaria de ser	1	2	3	4	5

Nas ÚLTIMAS 2 SEMANAS, até que ponto você se perturbou com:	Nem um pouco	Não muito	Um pouco	Muito	Extremamente
Conflitos nos seus relacionamentos	1	2	3	4	5
Falta de tempo satisfatório para estar com as outras pessoas	1	2	3	4	5

Nas ÚLTIMAS 2 SEMANAS, até que ponto você se sentiu incomodado(a):	Nem um pouco	Não muito	Um pouco	Muito	Extremamente
Pelo fato de estar exausto(a)	1	2	3	4	5
Pelas oscilações (altos e baixos) de suas emoções	1	2	3	4	5

Nas ÚLTIMAS 2 SEMANAS, até que ponto foi problemático para você:	Nem um pouco	Não muito	Um pouco	Muito	Extremamente
Terminar trabalhos ou tarefas (no trabalho ou em casa)	1	2	3	4	5
Começar tarefas que você não acha interessantes	1	2	3	4	5
Administrar muitos projetos ao mesmo tempo	1	2	3	4	5
Terminar as coisas no tempo certo	1	2	3	4	5
Saber onde estão coisas importantes (como chaves, carteira)	1	2	3	4	5

Nas ÚLTIMAS 2 SEMANAS, com que frequência você:	Nunca	Raramente	Algumas vezes	Frequentemente	Muito frequentemente	Não se aplica
Sentiu-se bem consigo mesmo(a)	1	2	3	4	5	----
Sentiu que as pessoas gostam de estar com você	1	2	3	4	5	----
Sentiu que o seu relacionamento íntimo está indo bem do ponto de vista emocional	1	2	3	4	5	<input type="checkbox"/>

References

- Kooij JJ, Buitelaar, Van Der Oord DJ, Furer JW, Rijnders CA, Hodiament PP. Internal and external validity of attention-deficit hyperactivity disorder in a population-based sample of adults. *Psychol Med.* 2005;35(6):817-27.
- Kessler RC, Adler L, Barkley R, Biederman J, Conners CK, Demler O, et al. The prevalence and correlates of adult ADHD in the United States: results from the National Comorbidity Survey Replication. *Am J Psychiatry.* 2006;163(4):716-23.
- Pastura G, Mattos P, Pruffer A. Desempenho escolar e transtorno do déficit de atenção. *Rev Psiq Clín.* 2005;32(6):324-9.
- Adler LA, Sutton VK, Moore RJ, Dietrich AP, Reimherr FW, Sangal B, et al. Quality of life assessment in adult patients with attention-deficit/hyperactivity disorder treated with atomoxetine. *J Clin Psychopharmacol.* 2006;26:648-52.
- Landgraf JM. Monitoring quality of life in adults with ADHD: reliability and validity of a new measure. *J Atten Disord.* 2007;11(3):351-62.
- Brod M, Johnston J, Able S, Swindle R. Validation of the adult attention-deficit/hyperactivity disorder quality-of-life scale (AAQoL): a disease-specific quality-of-life measure. *Qual Life Res.* 2006;15(1):117-29.
- Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. *Qual Life Res.* 1998;7(4):323-5.

8. Mattos P, Segenreich D, Saboya E, Louzã M, Dias G, Romano M. Trans-cultural adaptation of the Adult Self-Report Scale into Portuguese for evaluation of adult attention-deficit/hyperactivity disorder (ADHD). *Rev Psiq Clín.* 2006;33(4):188-94.
9. Reichenheim ME, Moraes CL, Hasselman MH. Semantic equivalence of the Portuguese version of the Abuse Assessment Screening tool used for the screening of violence against pregnant women. *Rev Saude Publica.* 2000;34(6):610-6.
10. Rohde LA, Biederman J, Zimmermann H, Schmitz M, Martins S, Tramontina S. Exploring ADHD age-of-onset criterion in Brazilian adolescents. *Eur Child Adolesc Psychiatry.* 2009;(3):212-8.
11. Perneger TV, Leplege A, Etter JF. Cross-cultural adaptation of a psychometric instrument: two methods compared. *J Clin Epidemiol.* 1999;52(11):1037-46.