

# CROSS-CULTURAL ADAPTATION OF THE QUALITY OF LIFE ASSESSMENT SCALE ON ALZHEIMER DISEASE

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**ABSTRACT - Objective:** To present the internal validation of the quality of life (QOL) evaluation scale for patients with Alzheimer's disease (AD) and their caregivers/family members, proposed by Logsdon et al. **Method:** The scale was adapted through translation, back translation and equivalence evaluation. The Portuguese version was administered to a sample of 40 patients with mild to moderate AD according to NINCDS ADRDA and DSM-III-R criteria, and also to their respective caregivers/family members. **Results:** The reliability of the instrument was excellent, both in the intra and the inter-examiner test-retest. The correlation coefficients for the intra-examiner assessment were 0.87/0.95/0.95 ( $p < 0.001$ ) for the patient, family and caregiver versions, respectively. The correlation coefficients for the inter-examiner assessment were 0.76/0.96/0.93 ( $p < 0.001$ ) for the patients, family and caregiver versions, respectively. The reliability was excellent for both the patient and the relatives' versions in relation to the patient's QOL ( $\alpha = 0.81$  and 0.85, respectively), and also in relation to the caregiver's QOL ( $\alpha = 0.84$ ). **Conclusion:** The adapted version of the instrument proved to be straightforward and brief, presenting excellent stability and reliability. The Portuguese version can be obtained by contacting the first author.

**KEY WORDS:** quality of life, Alzheimer disease, caregiver and cross-cultural adaptation.

## Adaptação transcultural da escala de avaliação de qualidade de vida na doença de Alzheimer

**RESUMO - Objetivo:** Apresentar os dados de validação interna da escala de qualidade de vida (QV) para pacientes com doença de Alzheimer (DA) e seus respectivos cuidadores/familiares, proposta por Logsdon e col. **Método:** A escala foi adaptada seguindo metodologia que envolveu a tradução, retrotradução e avaliações de equivalência. A versão em português foi ministrada a 40 pacientes com DA provável, segundo os critérios do NINCDS ADRDA, e de intensidade leve a moderada, segundo os critérios do DSM-III-R e a seus respectivos cuidadores/familiares. **Resultados:** A estabilidade do instrumento foi excelente no teste-reteste intra e inter-examinador. Os índices de correlação encontrados na avaliação intra-examinador foram 0,87/0,95/0,95 ( $p < 0,001$ ) para as versões do paciente, do familiar e do cuidador, respectivamente. Na avaliação inter-examinador os índices de correlação foram 0,76/0,96/0,93 ( $p < 0,001$ ). A confiabilidade foi excelente para as versões do paciente e do familiar em relação à QV do paciente ( $\alpha = 0,81$  e 0,85, respectivamente) e com relação a QV do cuidador ( $\alpha = 0,84$ ). **Conclusão:** O instrumento mostrou-se de fácil e rápida aplicação, apresentando excelente estabilidade e confiabilidade após sua adaptação. A versão em português pode ser obtida com a primeira autora.

**PALAVRAS-CHAVE:** qualidade de vida, doença de Alzheimer, cuidadores, adaptação transcultural.

Alzheimer's disease (AD) is a degenerative brain disease characterized by the progressive loss of memory and other cognitive functions which cause significant impairment in the patient's daily life activities and social and occupational performance as well in their quality of life<sup>1,2</sup>. Quality of life (QOL) is a concept that has received several definitions, depending both on the context in which it is used

and the examiner's guidance<sup>3-6</sup>. The assessment is used to evaluate the satisfaction level concerning the treatment as well as the attention received by the patient and the caregiver/family which is equivalent to a measure of the satisfaction assessment as a consumer<sup>6</sup>. Besides its increasing use as a measure of results, the QOL assessment has been also used in decisions on allocation of resources in the

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public health area<sup>7</sup>. The QOL concept is multi-factorial having several definitions in the literature<sup>8,9</sup>. In the dementia context, the QOL definition as proposed by Birren and Deutchman<sup>3</sup> is described as multidimensional, including issues such as social, environmental, health, emotional state and spiritual aspects (religiosity). Whitehouse and Rabins<sup>3</sup> add work, leisure activities or hobbies, cognitive skills, economic success, and psychological welfare to this definition, and finalize by stressing that QOL is determined by the individual's perception of the relative importance of each of these factors.

Logsdon et al.<sup>4</sup> developed a QOL assessment scale for patients with AD which comprises the patient's and his/her family's version of the patient's QOL, in addition to the caregiver's version of his/her own QOL. This instrument proved to be stable having high inter and intra-examiner reliability.

The purpose of this study is to present cross-cultural<sup>10-12</sup> adaptation data, and internal validation of the QOL assessment scale on AD, as proposed by Logsdon et al.<sup>4</sup>.

## METHOD

The scale was proposed by Logsdon to minimize the effect of cognitive loss resulting from the disease, and was designed using plain language and simple and straightforward answers<sup>4</sup>. The instrument consists of 13 items quantified on a four-score scale, with score 1 classified as poor, and score 4 as excellent where total score ranges from 13 to 52. Scores can be calculated for the patient's, and the caregiver's reports, and these reports can be combined into a total score incorporating the patient's and the caregiver's/relative's version<sup>4,5</sup>. As the assessment focuses on the patient, the total scoring weight is calculated by multiplying the patient report score by 2, adding the caregiver's/family's report score, and then dividing the result by 3. Complementary to this instrument is a version where the evaluation focus is on the QOL caregiver. The originally proposed instrument is in the English language. Details are in Novelli<sup>22</sup>. In brief, initially, the instrument as proposed by Logsdon et al.<sup>4</sup> underwent cross-cultural adaptation comprising the following phases: 1. Translation of the instrument, originally in English, into Portuguese by two independent translators. Then, comparison of the similarities was made between the two resulting translations and, following this, the initial version in Portuguese was produced. 2. Back-translation, whereby the initial Portuguese version was retranslated into English by two independent translators, thus revealing discrepancies in the English-to-Portuguese translation. 3. Assessment of the idiomatic, semantic, conceptual and cultural equivalences conducted by a body of judges who formed an

interdisciplinary assessment committee. The committee was made up of five judges as follows: three physicians (a neurologist, a psychiatrist and a rheumatologist), a psychologist and an occupational therapist. All the judges had experience in research activities on areas related to the study. 4. Production of the Portuguese version incorporating the adjustments proposed by the judges, which had resulted from issues on which there was disagreement. Items for which an agreement index 80% was not achieved, were considered items in disagreement. 5. Pre-test of the instrument to verify the instrument understanding by the target population. The scale was administered to 32 elderly people, as follows: 12 without cognitive impairment, 10 with mild dementia, and to their respective caregivers/family. 6. Production of the final version of the QOL-AD translated and adapted.

The first property that was verified was the test-retest reliability of the adapted instrument. The objective was to verify the instrument stability over time. This property was evaluated by means of test-retest intra and inter-examiner administration by 2 independent examiners (MMPCN and HHDR) with a two-week interval, where this was administered to a sample of 17 patients in the intra-examiner test-retest, and to 13 patients in the inter-examiner test-retest.

For the verification of the internal consistency of the adapted instrument, it was administered to a random sample of 40 patients with probable AD according to the NINCDS ADRDA13 criteria, with mild to moderate symptomatology, according to both the DSM-III-R14 criteria and MMSE scores<sup>15-18</sup>, and also according to their respective caregivers/ family at the Behavioral and Cognitive Neurology Outpatient Clinic of the Hospital das Clínicas of the University of São Paulo School of Medicine (HCFMUSP).

The patients responded to the evaluation in the form of an interview, whereas the caregivers responded in the form of a questionnaire. The study was approved by the Ethics in Research Committee of the HCFMUSP and all participants signed the informed consent term.

The data were input to Excel worksheets and analyzed by the SPSS program, version 10.0. The following tests were used in the statistical analysis: 1. Kendall's agreement coefficient, in the cross-cultural evaluation of the idiomatic, semantic, cultural and conceptual equivalence of the QOL-AD. 2. Pearson's correlation coefficient and Kappa's statistical test, in the test-retest analysis. 3. In the internal consistency of the adapted instrument, the coefficient used was the Cronbach's Alfa, correlating each of the items with the total score, and again with the item "life as a whole". 4. Descriptive analyses were made (means and standard deviation) of the socio-demographic variables and of the descriptive data from instrument application to the sample. 5. The significance level was set for values of  $p \leq 0.05$ . 6. The scale can be obtained from the first author.

## RESULTS

Initially the data on the cross-cultural adaptation of the instrument will be presented, and subsequently the results of the application of the sample evaluation.

In Table 1 we show the agreement of mean percentages among the judges in the semantic, idiomatic, conceptual and cultural evaluation of the original version, relative to the QOL-AD translated version.

We observed that, in the evaluation of conceptual equivalence, the value of K was 0.316, not thereby presenting a statistically significant agreement. We verified the changes proposed by the judges with regard to the adaptation of the statements for our cultural and conceptual patterns. where Some items were seen to present disagreement and, for which, the suggestions made by the judges were accepted. The modified items were:

Concerning the item "energy", we observed 40% disagreement and the suggestions of the judges linked the modification of the term to "willingness", so as to better represent our cultural and conceptual patterns.

The item "living situation" also obtained the same level of disagreement as that just described; the proposed modification was the alteration of the term to "dwelling."

The item "you as a whole" obtained an index of disagreement of 60% and the suggested modification was a change to "you in general".

Another item with a disagreement of 60% was the "ability to do chores" according to the judges, a conceptual difference exists between ability and capacity, and that the term that would be best suited to the focus of the evaluation is "capacity to do tasks."

The same reasoning was applied with the item "ability to do things for fun", which obtained an index of disagreement of 60%. The same suggested proposal as in the previous item was followed for this item, hence modifying it to "capacity to do leisure activities."

The last modified item was "life as a whole", with an index of disagreement of 40%, where the suggestion was modification to "life in general."

In Table 2 the coefficients of correlation of the evaluations are described, employing intra and inter-examiner for each version, including one for the patient and for the family, with respect to the patient's QOL, and one for the caregiver on their own QOL.

The test of Kappa assumes values from -1 to +1, where the negative values indicate agreement inferior to that expected by chance, whereas positive values, superior agreement to that expected

Table 1. Agreement of means percentages between judges concerning the semantic, idiomatic, conceptual and cultural equivalence between the original version and the translated version of Quality of Life - AD and the coefficient of Kendall.

Equivalence evaluations	Agreement of means	Coefficient of Kendall
Semantic and idiomatic equivalence	86.36%	K = 0.343**
Conceptual equivalence	86.00%	K=0.316
Cultural equivalence	78.46%	K=0.359*

p<0.05\* p<0.01\*\*

Table 2. Pearson's correlation coefficients and Kappa's test values for patient, family and caregiver evaluations.

Evaluations	Intra-examiner (n=17)	Inter-examiner (n=13)
Patient (1)	Pearson=0.87 Kappa=0.710*	Pearson=0.76 Kappa=0.743*
Caregivers (2)	Pearson=0.95 Kappa=1.000*	Pearson=0.96 Kappa=1.000*
Caregivers (3)	Pearson=0.95 Kappa=0.912*	Pearson=0.93 Kappa=0.658*

p<0.001\*; (1) Patient reports on own QOL; (2) Caregiver reports on patient QOL; (3) Caregiver reports on own QOL.

Table 3. Socio-demographic profile of patients and their respective caregivers.

Socio-demographic characteristics	Mild dementia (n=20)	Moderate dementia (n=20)
Age (patients)	73.20 ± 8.07	74.45 ± 5.95
Educational level (patients)	4.90 ± 3.94	5.95 ± 3.95
Gender (patients)	Fem - 75% Male - 25%	Fem - 70% Male - 30%
MMSE <sup>a</sup>	18.80 ± 3.20	12.90 ± 3.33
Age (caregivers)	61.60 ± 13.41	55.85 ± 16.65
Educational level (caregivers)	7.20 ± 3.69	11.50 ± 4.28
Gender (caregivers)	Fem - 80% Male - 20%	Fem - 70% Male - 30%
Relationship	Wife - 30% Daughter - 5% Sister - 15% Son - 5% Husband - 5% Granddaughter - 5% Niece - 5%	Daughter - 40% Son - 15% Sister - 10% Husband - 15% Wife - 20%

<sup>a</sup>MMSE, Mini-Mental State Examination.

by chance, at different levels, with 1 being perfect agreement<sup>18</sup>.

The patient's and their caregiver's socio-demographic characteristics are presented in Table 3. In regard to Table 3, the identified statistical significance in comparison to the MMSE was expected since the analyses used groups with different levels of severity (mild and moderate). The equivalence with sub groups was emphasized concerning the caregiver's scholarship degree. Unfortunately, the matching of the patient's groups and also its respective caregivers was not possible. Given that the scale is easy to answer, along with an adequate standardization of the questions and with an acceptable average scholarship for the group of mild patients, we believe that the occurrence of bias in interpretation is unlikely.

The mean scores in the evaluation of QOL, and the mean time of application for the mild and moderated AD cases, are presented in Table 4.

Despite the fact that the table presents a reduction in the mean score of QOL-AD in all versions, with increased severity of the disease, this difference is not statistically significant probably due to the great variability of the data.

Table 4. Mean and standard deviations of the scores distributed across the 3 versions of the QOL-AD, and the duration of application (in minutes) between the groups of mild and moderate dementia.

Application of QOL- AD	Mild dementia	Moderate dementia
Patient (1)	34.95 ± 5.10	35.90 ± 5.59
Caregivers (2)	30.65 ± 6.93	29.40 ± 5.78
Caregivers (3)	36.95 ± 5.17	33.85 ± 6.59
Time of application (1)	5.75 ± 1.80	5.55 ± 1.76
Time of application (2)	5.25 ± 2.75	4.35 ± 2.73
Time of application (3)	4.50 ± 1.67	4.90 ± 1.77

(1) Patient reports on own QOL; (2) Caregiver reports on patients QOL; (3) Caregiver reports on own QOL.

The mean time of application of the evaluation was six minutes for the patient version, five minutes for the version of the caregiver/family, and five minutes for the caregiver version.

The alpha results were satisfactory in all versions. In the patient's version we obtained an alpha=0.81, whilst for the relative's version in relation to the patient's QOL we obtained a coefficient of alpha = 0.85, and in the caregiver's version on his/her own QOL, the alpha obtained was 0.84

In Table 5 we present the correlation coefficients for each item in the patient's report and for the caregiver/family.

## DISCUSSION

The cross-cultural adaptation of an evaluation instrument goes beyond mere translation by taking into consideration cultural and linguistic aspects for the target population<sup>9-11</sup>. The methodology employed in the present study followed the proposals made by Guillemin et al.<sup>11</sup>, where the stages are characterized by the cross-cultural adaptation of QOL evaluations.

With the presented data, we verified that the QOL-AD scale is a promising measure for investigation of this variable in the disease. The instrument allows evaluation of QOL using the patient's and the caregiver/family's view, thereby making the assessment more comprehensive and corresponds to two out of three possible ways of evaluating the quality of life phenomenon. This study provides reliability and stability of information in the patient's versions, and caregiver/family's version, in the patient's QOL and the evaluation of the caregiver's QOL. The QOL-AD was shown to be brief and easy to administer in patients with mild to moderate

Table 5. Correlation coefficients between the items, and the internal consistency, of the QOL-AD.

Item	(1)		(2)		(3)	
	(Total)	(Life as Whole)	(Total)	(Life as Whole)	(Total)	(Life as Whole)
1. Physical health	0.77**	0.67**	0.39*	0.26	0.57**	0.37*
2. Energy	0.65**	0.33*	0.59**	0.29	0.68**	0.45**
3. Mood	0.51**	0.23	0.49**	0.47**	0.42**	0.45**
4. Living situation	0.52**	0.45**	0.77**	0.50**	0.59**	0.51**
5. Memory	0.50**	0.46**	0.70**	0.60**	0.57**	0.40*
6. Family	0.42**	0.30	0.76**	0.69**	0.69**	0.31
7. Marriage	0.48**	0.25	0.55**	0.22	0.45**	0.32*
8. Friends	0.24	0.36*	0.52**	0.26	0.50**	0.27
9. You as a whole	0.65**	0.46**	0.63**	0.48**	0.76**	0.66**
10. Ability to do chores	0.53**	0.12	0.58**	0.48**	0.54**	0.12
11. Ability to do things for fun	0.62**	0.41**	0.60**	0.37*	0.52**	0.40*
12. Money	0.51**	0.34*	0.54**	0.27	0.61**	0.48**
13. Life as a whole	0.73**	—	0.75**	—	0.80**	—
Alpha Coefficient	0.81		0.85		0.84	

\*P<0.05 \*\*P<0.01; (1) Patient reports on own QOL; (2) Caregiver reports on patient QOL; (3) Caregiver reports on own QOL. Spearman correlations are given for items; Pearson correlation is given for the total score.

AD. No patient or caregiver refused to complete the evaluation or demonstrated difficulties in understanding the instrument.

The stability and the reliability of the instrument were very good. The intra and inter-examiner correlation coefficients, after a two-week interval, were 0.87/0.95/0.95 ( $p<0.001$ ), and 0.76/0.96/0.93 ( $p<0.001$ ), respectively, for the patient, the family and the caregiver versions. Comparing the results of the adapted version with those of the original instrument, we found similar values for stability of the instrument, with an intra-class of the original instrument of 0.76 for the patient, and 0.92 for the caregiver/family.

The reliability of the evaluation after the cross-cultural adaptation was excellent for the patient's version, as well as for the caregiver/family's version, in relation to the patient's QOL ( $\alpha = 0.81$  and  $0.85$ , respectively) and to the caregiver's QOL ( $\alpha = 0.84$ ). Similarity was also identified in reliability on comparison of the results of the original and adapted versions of the instrument with the patient's versions and of the caregiver/family on the patient's QOL ( $\alpha$  of  $0.88$  and  $0.87$ , respectively).

The disagreement among the patient's reports and caregiver/family's reports found in this study has also been observed by others<sup>4,19,20</sup>, but the correlation in the total score was adequate. The disagreement among the reports could originate from the different methods of administration of the evaluation<sup>4</sup>.

We also identified that the instrument presents differences of score means in all versions, although not to a statistically significant degree, with increased dementia severity, a somewhat expected finding given the progressive nature of the disease. The importance of evaluating QOL in AD is based on the unquestionable impact of the disease on the patients' and their family and caregivers' daily lives. In addition, there is a need to evaluate to what extent the therapeutic interventions improve the QOL of the patient<sup>3,4</sup>, and also their impact on the caregiver<sup>21</sup>.

With regard to limitations of the study, we found difficulties related to the sample size, which make the generalization of the data and the matching of the patient groups difficult. Studies with a larger sample should be conducted in the future.

In conclusion, the Portuguese version of the scale proposed by Logsdon et al.<sup>4</sup> seems to be a promising measure for the investigation of QOL in AD in our country. The Portuguese version can be obtained by contacting the first author of the study. The adapted instrument was shown to be brief and easy to administer, while being stable and reliable with internal consistency of its items adequately representing the phenomenon that they intend to evaluate<sup>22</sup>. Future studies should investigate the reasons for the disagreement found between the patients' and the caregivers/family's report, and should determine the point at which the patient's cognitive impairment affects the reliability of the evaluation, and finally, which symptoms have a larger impact on the evaluation of QOL, so that future efforts can be focused on these areas.

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