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Research Article

The Validity and Reliability of The Turkish Version of The Quality of Life Scale For Patients With Alzheimer's Disease (QOL-AD)

Burcu AKPINAR¹, Özlem KÜÇÜKGÜÇLÜ²

¹DEÜ Hemşirelik Fakültesi, İç Hastalıkları Hemşireliği, İzmir, Türkiye ²DEU Hemşirelik Fakültesi, İç Hastalıkları Hemşireliği, İzmir, Türkiye

Summary

Objective: QOL is a multidimensional concept set as indicator to assess the effect of interventions applied to the Alzheimer patients. The objective of this study is to assess the validity and reliability of the Quality of Life in Alzheimer's Disease (QOL-AD) scale for the Turkish society.

Methods: This research is a methodological study. The sample was composed of 72 individuals diagnosed with Alzheimer's disease and their caregivers. Research data were collected in the dementia outpatient clinic of a university hospital and İzmir branch of the Alzheimer's Association. QOL-AD gives information about the QOL of the patient. The scale is composed of 13 items, each of which is assessed over a 4-point scale (1 point is bad, 4 point is excellent). The minimum score obtained from the scale is 13, maximum score is 52.

Results: Translation and back translation were performed to evaluate the language validity of the scale. Besides, it was determined that the expert opinions regarding the content validity were compatible (Kendall's $W=.223$, $p=.095$). Internal consistency reliability coefficient (cronbach alpha) of QOL-AD scale for the patients was found as 0.84 while intraclass correlation coefficient was found as 0.79. However, internal consistency reliability coefficient (cronbach alpha) of caregivers' reports on patients' quality of life (C-PQOL) was 0.77 while intraclass correlation coefficient was 0.72.

Conclusion: The results indicate reliability and validity of the Turkish version of the QOL-AD in the Turkish society.

Key words: Alzheimer's disease, quality of life, validity, reliability

Alzheimer Hastalığı olan Bireylerin Yaşam Kalitesi Ölçeği'nin Türkçe Versiyonunun Geçerlik ve Güvenirliği

Özet

Amaç: Yaşam kalitesi, Alzheimer hastası bireylere yapılan girişimlerin etkisini değerlendirmek için kriter alınan çok boyutlu bir kavramdır. Bu araştırmanın amacı Alzheimer Hastalığında Yaşam Kalitesi Envanteri'nin (AH-YKÖ) Türk toplumu için geçerlik ve güvenirliğini test etmektir.

Yöntem: Bu araştırma metodolojik bir çalışmadır. Örneklem Alzheimer hastalığı tanısı olan 72 birey ve onların bakım verenleri dahil edilmiştir. Araştırma verileri bir üniversite hastanesinin demans polikliniğinde ve Alzheimer derneği İzmir şubesinde toplanmıştır. AH-YKÖ, hastanın o anki sahip olduğu yaşam kalitesi hakkında bilgi vermektedir. Envanter, 13 maddeden oluşmakta, her bir madde 4 puanlık skala üzerinden (1 puan kötü ve 4 puan mükemmel) değerlendirilmektedir. Toplam puan aralığı 13-52'dir.

Bulgular: Envanterin dil geçerliliğinde çeviri - geri çeviri yapılmıştır, içerik geçerliliğinde ise alınan uzman görüşlerinin uyumlu olduğu saptanmıştır (KW = .223, p = .095). AH-YKÖ

formunun hastalar için olan iç tutarlılık güvenilirlik katsayısı (cronbach alpha) 0.84 grup içi korelasyon katsayısı (intraclass Correlation Coefficients-ICC) 0,79 bulunmuştur. AH-YKÖ formunun bakım verenler için olan iç tutarlılık güvenilirlik katsayısı (cronbach alpha) 0.77 grup içi korelasyon katsayısı (intraclass Correlation Coefficients-ICC) 0.72 bulunmuştur.

Sonuç: AH-YKÖ formunun Alzheimer hastalarının yaşam kalitesinin değerlendirilmesinde geçerli ve güvenilir bir araç olarak kullanılabileceği bulunmuştur.

Anahtar Kelimeler: Alzheimer Hastalığı, Yaşam Kalitesi, Geçerlilik, Güvenilirlik

INTRODUCTION

Dementia can affect the quality of life of a patient from many aspects including cognitive, physical, emotional and social functions⁽²¹⁾. In spite of this, quality of life is one of the important concepts which have not been properly addressed in the literature of dementia^(10,15,16). This is because of the fact that it is difficult and complex to make a quality of life definition in the dementia syndrome characterized by cognitive impairment^(3,16). Factors making the identification of the quality of life difficult in people with dementia are loss of insight and cognitive impairment. Another factor is the lack of a golden standard for measuring the quality of life in the people with dementia⁽²⁴⁾. In the literature, subjective, objective and observational methods are used to measure the quality of life of the people with dementia^(9,15,17,28). Each method has its own advantages and disadvantages. Matsui et al. (2006) report that subjective scales to which only patients who have cognitive impairments give answers are not reliable and inadequate. Thus, it is stated that observational scales are more appropriate for people with advanced dementia^(17,15). However, these scales are also widely criticized on the grounds that they are answered by the caregivers and health professionals who decide on behalf of patients, they can not reflect the reality and they are against the nature of subjectivity^(22,28). Appropriateness of these scale is also disputable on the grounds that different perceptions between caregivers and patients, patients should participate in decisions that may affect their own cares and caregivers can be influenced by their

own mental healths and problems while they are answering the questions about the quality of life of the patients^(8,13,16,23). Therefore, it is expressed in the literature that scales assessing the quality of life of people with Alzheimer's should focus on the opinions of both patients and caregivers^(13,15,17). Quality of Life in Alzheimer's Disease Scale developed by Logsdon et al. (1999) to measure the quality of life of people with dementia is one of the valid and acceptable scales and it is answered by both patients (self-report) and caregivers (proxy) independently. Thus, it provides the opportunity to learn opinions of both patients and caregivers about the quality of life of the patient⁽¹⁰⁾. It is also reported that this scale is simpler and easier than the other scales developed to measure the quality of life in people with Alzheimer's and has better internal validity and reliability than the others^(12,13). It is stated in the literature that QOL-AD is used in the studies of National Institute of Aging Co-operative⁽²⁴⁾, its validity and reliability were evaluated in several societies^(5,9,12,13,14,15,18,25,29,30) and it is used in intercultural comparison studies⁽²⁴⁾. Results of these studies have all shown high reliability and validity of the scale. However, in our country, there is not any study assessing the validity and reliability of this scale. Thus, this research was carried out to examine the validity and reliability of QOL-AD scale for the Turkish society.

MATERIAL AND METHODS

Sample and Setting

Data of this methodological research were collected in dementia outpatient clinic of a

University Hospital and in Izmir branch of Alzheimer's association between January 2011 and February 2012. Research sample was composed of 83 patients who were diagnosed with Alzheimer's disease according to the DSM-IV criteria and their caregivers. Sample size was determined by considering the principle that the sample size should be at least five times bigger than the total item number in validity and reliability studies^(1,4). Sample size was calculated as at least five times bigger than the scale items. Individuals who were diagnosed with Alzheimer's disease in accordance with DSM-IV criteria, have a MMT score of 10 and over and voluntarily accepted to participate in the study were included in the sample. As to the exclusion

criteria, patients with behavioral problems inhibiting the interview (screaming, roaming around, aggressiveness etc.) or with communication problems (visual or hearing impairment etc.) were excluded from the sample⁽¹⁵⁾. Caregivers included in the research are individuals responsible for the primary care of the patient and they provide care to patients at least 24 hours a week. Written informed consent was obtained from all people with dementia and their caregivers.

Sociodemographic Characteristic

Distribution of sociodemographic characteristic of patients and caregivers in the sample is showed in the Table 1.

Table 1. Examination of Sociodemographic Properties of Patients and Caregivers

	n	%	X ± SD
People with Alzheimer's			
<i>Age</i>	83		76.84 ± 7.51
<i>Sex</i>			
<i>Female</i>	48	57.8	
<i>Male</i>	35	42.2	
<i>MMT</i>	83		19.38 ± 4.89
Caregivers			
<i>Age</i>	83		54.64 ± 12.13
<i>Sex</i>			
<i>Female</i>	65	78.3	
<i>Male</i>	18	21.7	
<i>Degree of relationship</i>			
<i>Spouse</i>	23	27.7	
<i>Daughter</i>	39	47.0	
<i>Son</i>	12	14.5	
<i>Caretaker</i>	3	3.6	
<i>Daughter-in-law</i>	3	3.6	
<i>Sister</i>	3	3.6	

Instruments

In the research, Data Collection Form for Patients and Caregivers and Quality of Life in Alzheimer's Disease (QOL-AD) Scale were used.

Data Collection Form for Patients and Caregivers; is composed of eight questions containing information regarding sociodemographic properties, disease and degree of relationship.

Quality of Life in Alzheimer's Disease Scale (QOL-AD); The original scale was developed by Logsdon, Gibbons, McCurry and Teri in 1999 in America. It consists of 13 items concerning physical health, energy, mood, living situation, memory, family, marriage, friends, you as a whole, ability to do chores, ability to do things for fun, money, and life as a whole⁽¹²⁾. It is answered by both patients and caregivers independently. While caregivers complete the scale independently, the scale is answered for the patients through interviews. Questions of the scale are simple, clear and understandable to enable the people with Alzheimer's who have cognitive failure understand them easily⁽¹²⁾. It takes 5 minutes in total with caregivers to answer this scale concerning the quality of life of patients. On the other hand, it takes 10-15 minutes with patients⁽¹²⁾.

QOL-AD is a likert-type scale and scored from 1 (poor) to 4 (excellent). Scores are calculated separately for self reports and proxy reports. These two reports can be combined into a total score incorporating the patient's and the caregiver's versions. To calculate the total score, score obtained through the answers of patients is multiplied by two, added to the score of caregivers and then, divided into three. Score range of the scale is 13-52. A higher score of the scale indicates a better quality of life.

Validity and reliability of the scale were evaluated in different cultures and societies. Matsui et al. (2006) studied on

the validity and reliability of the scale for the Japanese society and reported that the scale was valid and reliable for the Japanese society (cronbach alpha for patients : 0.84; cronbach alpha for caregivers: 0.82; test retest reliability for patients ICC: 0.84, for caregivers: 0.91). It was also stated that the scale was valid for the French society (Cronbach alpha for patients: 0.83; Cronbach alpha for caregivers: 0.79)³⁰. Novelli, Nitrini and Caramelli (2010) reported that the scale was reliable and valid for the Brazilian society (Cronbach alpha for patients: 0.80; Cronbach alpha for caregivers: 0.83). In the study conducted by Thorgrimsen et al. (2003) in London, it was revealed that the scale was a valid and reliable instrument (Cronbach alpha: 0.82). It was concluded in the study conducted by Fuh and Wang (2006) in Taiwan that the scale was valid and reliable for the society (Cronbach alpha for the patients: 0.83; Cronbach alpha for the caregivers: 0.79). It was also reported that the scale was a valid and reliable instrument for the Spanish society⁽⁶⁾. It was stated in the scale guideline that the scale was translated into Portuguese, Danish, German, Italian, Swedish and Greek and cultural reliability was evaluated.

Data Collection

Data were collected by the researchers from patients and caregivers who accepted to participate in activities held in dementia outpatient clinics of a University Hospital and in İzmir branch of Alzheimer's association between January 2011 and February 2012. In case that patients or caregivers expressed that they did not understand the question or they were hesitant about how to respond the question, the researcher made explanations in line with the guideline. Accordingly, single, widow or divorced individuals were asked about "their relationships with the people that they found closest" instead of spouse. In case that participants stated that they did

not have any friends in response to the item about “ friendship relationships”, they were asked how they were feeling due to this situation. Scale application took about 10 minutes with the patients and around 5 minutes with the caregivers.

Analysis of the Data

Sociodemographic and clinical characteristics of patients and caregivers were evaluated in terms of average,

number and percentage. Translation- back translation was carried out for language validity while expert opinions about the content validity were analyzed with Kendall good fit coefficient. In the reliability analyses, cronbach alpha internal consistency reliability coefficient, intraclass correlation coefficient and item analysis were used (Table 2). Significance level was examined as .05 in all analyses.

Table 2. Statistical Methods Used in the Examination of Psycholinguistic and Psychometric Properties of QOL-AD

	<p>Language Validity</p> <ul style="list-style-type: none"> ✓ Translation from English into Turkish ✓ Back translation from Turkish into English
Validity	<p>Content Validity</p> <ul style="list-style-type: none"> ✓ Expert opinions and Kendall w test were used. <p>Descriptive Statistics</p> <ul style="list-style-type: none"> ✓ Standard error
Reliability	<p>Internal Consistency Reliability Coefficient</p> <ul style="list-style-type: none"> ✓ Calculation of the cronbach alpha reliability coefficient ✓ Intraclass Coreelation Coefficient=ICC <p>Item Analysis</p> <ul style="list-style-type: none"> ✓ Item total score

Research Ethics

Permissions were received from the university hospital where the research was carried out and İzmir branch of Alzheimer's association. Ethics committee approval was taken from "Non-Invasive Clinical Researches Assessment Commission of Dokuz Eylül University". Furthermore, written permissions were obtained from Rebecca Logsdon who is scale's author and the individuals accepting to participate in the study.

Research Limitations

Reliability and validity of QOL-AD scale were assessed for patients with a MMT score of 10 and over. However, there is need for a instrument to assess the quality of life of patients with MMT scores less than 10. Original scale used in this study could not be tested through another valid and reliable measurement tool in terms of sensitivity or distinctiveness.

Language Validity

To test the language validity, the scale was firstly translated into Turkish by four academicians, one instructor and one foreign language specialist who had a good command of both cultures and languages and who were Turkish native speakers. Afterwards, researchers examined all translated documents and prepared the Turkish version with the best translations representing all the items. This text, then, was re-translated into English by another foreign language expert. After necessary arrangements were made in line with the expert opinions, Turkish version of QOL-AD was prepared and the language validity as the basis of scale applications was provided.

Content Validity

Based on the principle that items of the original form and the Turkish version should be equivalent, the Turkish version and the original form were submitted to the assessment of seven experts who specialised in this field and had a good command of English. Items of the scale were examined by the experts in terms of understandability, fitness for purpose, compatability with the culture and scored between 1 and 4 (1=not suitable, 2=It should be made suitable, 3=Suitable but requires small modifications, 4=significantly suitable). Compliance level of the expert opinions was analyzed by non-parametric Kendall W analysis. Content validity of QOL-AD was assessed through Kendall W analysis of assessment scores of experts to all items and it was determined that there was not a significant difference between scores given by the experts for each item (Kendall W= .223; p= .095) and there was compliance between experts. Thus, no item was excluded from the scale. After language and content validity tests, a pre-application was carried out on eight patients meeting the criteria of the sample and the scale reached on its final version. Pre-application data were not used in the research.

Reliability Analyses

Descriptive Characteristics

When results of the Standard Error which is one of the descriptive statistics were examined, it was observed that the error rate was 0.61 and 0.56 and it was smaller than the half of the mean (Table 3).

Table 3. Examination of Descriptive Characteristics of QOL-AD Scale

QOL-AD	Item number	Mean	Standard Deviation (SD)	Standard Error (SE)	Minimum-Maximum
Patients' reports on their own QOL	13	35.11	5.55	0.61	22.00 - 51.00
caregivers' reports on patients' QOL	13	32.06	5.11	0.56	20.00 - 45.00

Internal Consistency Reliability Coefficient

Cronbach alpha internal consistency reliability coefficient of patients' reports on their own QOL was found as .84 while it was .77 in the caregivers' reports on patients' QOL (Table 4). Intraclass correlation coefficient (ICC) of the patients' reports on their own QOL was 0.77 (95% GA 0.68-0.85) while it was 0.71 (95 % GA 0.58-0.80) in the s caregivers' reports on patients' QOL. Test-retest was evaluated for 32 patients and 36 caregivers. The scale displayed a good test retest reliability with an intraclass correlation

coefficient more than 0.70 (ICC) (0.74 for patients and 0.73 for caregivers).

Item Analyses

Item-item total score correlation coefficients of QOL-AD scale vary between 0.33 (4th item) in minimum and 0.69 (2nd item) at maximum for patients. As to the caregivers, they vary between 0.32 (4th item) in minimum and 0.64 (2th item) at maximum. It was detected that the correlation coefficients of the scale were above .20 which is generally accepted as lower limit by researchers (Table 6).

Table 4. Examination of Internal Consistency Reliability Coefficients of QOL-AD (n= 72)

QOL-AD	Original Scale Cronbach Alpha (α)	Applied QOL-AD form Cronbach Alpha (α)
Patients' reports on their own QOL	0.88	0.84
caregivers' reports on patients' QOL	0.87	0.77

Table 5. Examination of Mean, Standard Deviation and Intraclass Correlation Coefficients of QOL-ADS by the Sections Concerning Patients and Caregivers

Items	Patients		Caregivers		Intraclass correlation coefficients	P
	Mean	SS	Mean	SS		
1. Physical Health	2.6	0.8	2.5	0.6	0.40	0.01
2. Energy	2.5	0.9	2.5	0.8	0.40	0.01
3. Mood	2.0	0.9	2.0	0.7	0.38	0.02
4. Living Situation	3.1	0.5	3.1	0.6	0.57	0.00**
5. Memory	2.2	0.8	1.9	0.7	0.28	0.06
6. Family	3.2	0.6	2.9	0.7	0.48	0.01*
7. Marriage	3.2	0.6	2.8	0.7	0.43	0.01*
8. Friends	3.2	0.5	2.9	0.7	0.51	0.01*
9. You as a whole	2.8	0.6	2.5	0.6	0.05	0.40
10. Ability to do chores	2.6	0.9	2.2	0.9	0.48	0.00**
11. Ability to do things for fun	2.7	0.9	2.2	0.8	0.51	0.00**
12. Money	2.8	0.7	2.7	0.5	0.38	0.02
13. Life as a whole	3.0	0.7	2.6	0.6	0.46	0.00**
Total scale	35.8	5.5	32.9	4.8		

* p < 0.001; ** p < 0.0001

Table 6. Examination of Item-Item Total Score Correlation Coefficients of QOL-AD for patients and caregivers (n= 72)

QOL-AD items	Item-Item Total		Item-Item Total	
	Score Correlation Patients (r)	for P	Score Correlation Caregivers (r)	for P
1. Physical Health	.54	.000*	.56	.000*
2. Energy	.69	.000*	.64	.000*
3. Mood	.54	.000*	.44	.000*
4. Living Situation	.33	.003	.32	.003
5. Memory	.43	.000*	.47	.000*
6. Family	.56	.000*	.53	.000*
7. Marriage	.57	.000*	.49	.000*
8. Friends	.68	.000*	.46	.000*
9. you as a whole	.66	.000*	.46	.000*
10. Ability to do chores	.50	.000*	.59	.000*
11. Ability to do things for fun	.59	.000*	.50	.000*
12. Money	.48	.000*	.41	.000*
13. Life as a whole	.61	.000*	.63	.000*

* p < 0.0001

DISCUSSION

Assessment of the Validity

Language Validity

During the translation process performed within the scope of language validity, translation of a scale into another language changes its nature due to “conceptualisation” and “expression differences”. Thus, scale items need to be examined in detail, necessary modifications should be made to render the scale meaningful in the target language and it should be standardized according to the

norms of individuals using the target language in order to minimize the differences between the original scale and its translated version⁽²⁾. In this research, the Turkish version similar to the original QOL-AD scale was prepared and the language validity criterion as the first step of scale adaptation studies was fulfilled.

Content Validity

Content validity examines to what extent a tool measures the basic elements of the structure to be measured⁽²⁾. In other words, it examines whether the items or questions

of the instrument are compatible with the measurement purpose or they can represent the topic to be measured^(4,31). An assessment of the individual developing or adapting the scale can be misleading⁽²⁷⁾. Thus, cooperation and consultation with the specialists of the field are necessary^(27,31). In this study, it was detected that expert opinions concerning the content validity of QOL-AD were consistent, in other words, experts reached consensus on the items ($W=.223$; $p=.095$).

This result indicates that the scale is understandable, applicable, compatible with the measurement purpose and it represents the topic to be measured. QOL-AD scale took its final version after necessary modifications were made at the end of expert opinions and pre-application data. In this way, language and content validity criteria were provided. Afterwards, psychometric examinations were performed.

Assessment of the Reliability

Descriptive Characteristics

When results of the Standard Error which is one of the descriptive statistics were examined, it was observed that the error rate was 0.56 and 0.61 and it was smaller than the half of the mean (Table 3). A lower value of the standard error in this research is an indicator of the reliability of the measurement tool⁽³²⁾. Standard deviation indicates the position of data according to the mean value within the frequency distribution⁽²⁰⁾. Under normal conditions, standard deviations should be lower than the mean value.

Internal Consistency Reliability Coefficient

Internal consistency reliability coefficient is a criterium frequently applied in the scale development and adaptation studies⁽¹¹⁾. Internal consistency reliability coefficient value must be between zero and one⁽¹⁹⁾. According to the assessment criterium, if it is $.00 \leq \alpha < .40$, the scale is not reliable; if it is $.40 \leq \alpha < .60$, the scale

has a low reliability; if it is $.60 \leq \alpha < .80$, it is considerably reliable; and if it is $0.80 \leq \alpha < 1.00$, the scale is highly reliable (4,19,27). Generally accepted internal consistency coefficient value is $.70$ ⁽²⁷⁾. While cronbach alpha internal consistency reliability coefficient of QOL-AD scale is 0.84 for the patients and 0.77 for the caregivers, this coefficient is $.88$ for the patients and $.87$ for the caregivers in the original scale. Accordingly, it was determined that these coefficients were similar in both forms and the scale was highly reliable (Table 4). Depending on the basic principle on which the internal consistency reliability coefficient is based, it is obvious that the scale is composed of independent units to fulfill a specific purpose and these units have known and equal weights. In general, it can be accepted that the scale measures the same point consistently.

Item Analyses

Another method analyzing the internal consistency of a scale is the item analyses. In the item analysis, relationships between item, scale and the sub-scale are put forward⁽⁴⁾. While there were not sub-scales of the scale examined in this research, item total score correlation of the scale was calculated with "pearson product-moment correlation coefficient"^(7,27). Pearson correlation coefficient values are classified as very low if it is $.00 \leq \alpha \leq .25$; as low if it is $.26 \leq \alpha \leq .49$; as medium if it is $.50 \leq \alpha \leq .69$; as high if it is $.70 \leq \alpha \leq .89$ and significantly high if it is $.90 \leq \alpha \leq 1.00$ ⁽¹⁾. Even though lower limit value of the item-total score correlation coefficient varies from one source to another, a value lower than $.30$ means a serious problem with these items⁽²⁶⁾. Exclusion of an item should be determined by considering the changes observed in the alpha coefficient and the mean value obtained when the item displaying low correlation is deleted⁽⁴⁾. Item-total score correlation coefficients of this research varied between $.33$ and $.69$. According to the results of the analysis,

correlation coefficient of the 4th item was .33 and that of the 2nd item was .69 (Table 6) but the cronbach alpha mean values did not change when these items were excluded. Furthermore, the correlation coefficients were above 30. The fact that many researchers typically accept the lower limit as .20 in practice was another reason of not excluding these items⁽⁷⁾. Thus, it was decided not to exclude the items. These results could not be compared to the original scale as item-total score correlation coefficients of the original scale were not given⁽¹²⁾.

Applicability of Research Results

This study revealed that QOL-AD scale was a reliable and valid instrument to assess the quality of life of people with Alzheimer's. QOL-AD scale can be used in the clinic and care centers especially to assess the impacts of treatment and nursing care on the quality of life of the patient. Simplicity and practicality of the scale offer advantages in terms of its applicability. Periodical assessment of the QOL in the centers where people with Alzheimer's receive long term care and treatment, in particular, will contribute to the improvement of treatment and nursing care to be offered to them.

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Correspondence to:

Özlem Küçükgülü

E-mail: ozlem.kuguclu@deu.edu.tr

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