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Stroke and aphasia quality-of-life scale-39: Reliability and validity of the Turkish version

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Abstract

Purpose: The aim of this study was to adapt the stroke and aphasia quality-of-life scale-39 (SAQoL-39) to the Turkish language and carry out a reliability and validity study of the instrument in a group of patients with aphasia.

Method: The study was a descriptive study and contained three phases: adaptation of the SAQoL-39 to the Turkish language, administration of the scale to 30 aphasia patients and reliability and validity studies of the scale. Internal consistency was assessed with Cronbach's alpha and test-re-test reliability was explored ($n = 14$). The adaptation process was completed based on inter-rater agreement on the translated items and within the scope of final editing by the authors of the study.

Result: The SAQoL-39 in Turkish exhibited high test-re-test reliability (ICC = 0.97) as well as acceptability with minimal missing data (0–1.4). This instrument exhibited high internal consistency (Cronbach's $\alpha = 0.70$ –0.97), domain-total correlations ($r = 0.76$ –0.85) and inter-domain correlations ($r = 0.40$ –0.68).

Conclusion: The analysis shows that the Turkish version of SAQoL-39 is a scale that is highly acceptable, valid and reliable and can be easily used in evaluating the quality-of-life of Turkish people with aphasia.

Keywords: Aphasia; quality-of-life; stroke and quality-of-life scale-39; validity and reliability

Introduction

Chronic diseases have begun to increase as the mean life span has been increasing all around the world. According to the data provided by World Health Organisation (WHO), 15 million people have a stroke every year around the world (Mackay & Mensah, 2004). Stroke, depending on its severity and type, can cause destructive effects in life of the individual (Kim, Warren, Madill, & Hadley, 1999) by seriously affecting their physical, cognitive and speech functions (Jaracz, Jaracz, Kozubski, & Rybakowski, 2002).

In recent years, it has become a very important issue to measure the quality-of-life of aphasic patients in stroke clinics. Such measures are designed to evaluate the adaptive abilities to the acquired disorders after stroke (Posteraro, Formis, Grassi, Bigli, Nati, ProiettiBocchini, et al., 2006) because many individuals with aphasia are prone to depression and diminished participation in social relations, leading to changes in quality-of-life (Davidson, Howe, Worrall, Hickson, & Togher, 2008).

The Stroke Specific Quality-of-Life Scale (SSQoL), which was developed by Williams, Weinberger, Harris, Clark, and Biller (1999) has an important place in the literature. However, the development of the first quality-of-life scale specific to people with aphasia was developed by Hilari, Byng, Lamping, and Smith (2003). The development of the "Stroke and Aphasia Quality of Life Scale-39 (SAQoL-39)" was based on the idea that stroke-specific quality-of-life scales were not appropriate for the people with aphasia because of the linguistically complicated items. The SAQoL-39 has been adapted to several different languages by the researchers in the field, including Italian (Posteraro, Formis, Bidini, Grassi, Curti, Bigli, et al., 2004), Greek (Kartsona & Hilari, 2007), Spanish (Lata-Caneda, Pineiro-Temprano, Garcia-Fraga, Garcia-Armesto, Barrueco- Egado, & Mejjide-Failde, 2009), Dutch (Manders, Dammekens, Leemans, & Michiels, 2010), Kannada (Kiran & Krishnan, 2012), Portuguese (Rodrigues & Leal, 2013) and Hindi (Mitra & Krishnan, 2015).

As far as we know from the literature, there still is no instrument to evaluate the quality-of-life for people with aphasia in Turkey. Absence of valid and reliable information related to the quality-of-life of the individuals who are seriously affected from the stroke and experience isolation and depression may affect the rehabilitation process of these individuals and the quality of the services given to them.

The primary goal of this study was to adapt the SAQoL-39 scale developed by Hilari et al. (2003) to the Turkish language and to carry out a validity and reliability study of the instrument. The secondary goal of this study was to observe the patients with aphasia living in Turkey in a clinical setting and to determine their quality-of-life within the scope of affected sub-domains in the scale.

Method

Design

The overall study consisted of three phases, each lasting ~8 weeks. First, there was an adaptation phase in which the original scale was linguistically adapted to the Turkish language. Next, there was an implementation phase of the adapted form of the SAQoL-39-Turkish version, in which 30 aphasia patients took part. The last phase of the study was the validity and reliability measurement of the instrument.

Participants

The participants in the current study were determined by criteria-dependent sampling selection with the following criteria: (a) participants' native language should be Turkish, (b) they should be older than 18 years old, (c) their loss of language ability due to stroke should be for a period of time longer than 4 months, (d) they should have no cognitive or mental disorders before stroke, (e) they should have a minimum score of 33/66 on the auditory comprehension sub-test of the Aphasia Language Evaluation Test in Turkish-ADD (Maviş & Toğram, 2009) and (f) they should be literate before the stroke. Participation in the study was voluntary. Before the initiation of the study, the study protocol was explained to the participants in details and they gave their written informed consent. Participants were recruited from a neurology department, in a governmental hospital in Turkey.

Nine of the 30 participants with aphasia were aged between 23–44 years, 14 were between 45–59 years and seven were between 60–74 years ($x = 50.8$ years ± 10.5 ; 18 women, 12 men). All of the participants with aphasia had left hemisphere damage as a result of cerebrovascular events. Thirteen participants had 5 years of education, three participants had 8 years of education, nine participants completed 11 years of education and,

lastly, five participants held a bachelor degree (years of education = 8.7 years ± 3.4).

The participants were also grouped according to time post-onset of stroke. Five were in the group of 3–6 months, six were in the group of 6–12 months and 19 were in the group of 13 months or more (post-onset time $x = 7.4 \pm 8.2$). The participants with aphasia were divided into three groups in terms of the type of aphasia: 12 had fluent, 16 had non-fluent and two participants had global aphasia.

Data collection tool

Stroke and Aphasia Quality-of-Life-39 scale (SAQoL-39). The SAQoL-39 is comprised of 39 items across four sub-domains and the implementation phase is based on personal interviews with the patients. The responses given to each item are distributed on a five-point Likert scale: "1: Couldn't do it at all", "2: A lot of trouble", "3: Some trouble", "4: A little trouble" and "5: No trouble at all". For the 18 items within the scope of psycho-social and energy sub-domains, emotional reactions and possible problems experienced by the patients are questioned and responses are rated as follows: "1: Absolutely yes", "2: Mostly yes", "3: Not sure", "4: Mostly no" and "5: Absolutely no". The total score of the scale is the sum of the scores taken from each of the sub-domains. As a result of applying the SAQoL-39 scale, four different scores are obtained: physical score, communication score, psycho-social score and energy score. While higher scores represent high quality-of-life, low scores represent low quality-of-life.

Adaptation of the SAQoL-39 scale to the Turkish language. The original English version of the SAQoL-39 Scale was obtained from Dr Hilari and necessary permission was obtained for the adaptation of the English version to the Turkish version. The form, including 39 scale items, was translated from English into Turkish by a speech-language pathologist (SLP) and two intern SLPs. The reason why the translation process was not made by a professional translator was the occurrence of technical terminology associated specifically with the field of speech-language pathology in the scale. Because speech-language pathology has been a developing field in Turkey, it is thought that professional translators who are not familiar with the terminology cannot be as successful as SLPs already working in the field. However, SLP inclusion criteria were determined as follows: native Turkish speaker holding a bachelor of science degree from a university in which language of instruction is in English and having at least 6 months experience in assessment and treatment of acquired language and speech disorders. Translation of each item was completed independently by each SLP. The

resulting three translations were examined by seven academic members specialised in language and speech therapy. Each member examined the three translations for each scale item and ranked them from 1 (best) to 3 (worst).

In the final phase of the translation process, the Turkish version of the scale was analysed linguistically by the authors of the study and the length of the sentences was shortened to facilitate understanding and responding by the patients with aphasia. While the final Turkish version of the scale probed identical content to the original scale, some verbal explanations were planned for some items because some words are not commonly used in Turkish as in English. For example; because the word “hobby” was not a common word for Turkish people and the thought that people with aphasia may have difficulty with this item “Did you perform your hobbies less than you desired during the past week?”, an example (familiar game for Turkish people) was used for this item like “Did you play less backgammon last week, Mr/Mrs. . .?”. Lastly, the final form of the scale was completed for its use in subsequent phases of this study.

Administration of the scale. Before the administration, the participants of the study and his/her relatives were informed about the aim and the importance of the study. During the administration, two documents were used. The first document was the manual containing general guidelines to be read by the participants, example items and the items belonging to sub-domains. The second document was the rating sheet to be used by the researcher. The rating sheet included the items of the scale, written guidelines under every item and the responses of the item.

In the beginning of each sub-domain, the content of the items and types of responses are explained using example items. All items of the scale and their response formats were presented to the individuals with aphasia visually to ease their perception. The individuals with aphasia were expected to visually follow the items while being read by the researcher through the printed manuals in front of them. After the items and responses were read by the researcher, the participants were asked to show their responses (for example; No trouble at all) on the paper with their fingers. The participants who are capable of expressing themselves verbally were not asked to show the items; instead, responses were obtained verbally.

When the participants could not understand the content of an item or when they seemed to be unsure about their responses, the content of the item was explained by the researcher with examples and responses to the item were re-represented. During the administration of the scale, it was determined as a criterion that the verbal explanations for the unclear items wouldn't exceed 30%. During the administration, the expression “during the past week” was repeated by the researcher for all of the

items. The shortest administration took 10 minutes, while the longest took 30 minutes.

Validity and reliability study of the SAQoL-39 Turkish version

Validity. Validity analysis of the SAQoL-39 Turkish version was examined in three categories: content validity, structural validity and criterion validity. During content validity analysis, two different stages—adaptation of the scale to Turkish language and expert opinion—were performed in order to determine the degree of the scale and every item in the scale to measure the desired feature. Inter-Professional Correlation Coefficient was calculated. During structural validity analysis the difference between scale scores of the end groups, correlation between scale score and sub-domain scores and correlation between sub-domains and internal consistency coefficient were examined. In order to test structural validity of the adapted scale, explanatory factor analysis technique and varimax axis rotation technique were used. During criterion validity analysis, the correlation between scores of participants taken from the auditory comprehension sub-test of the ADD (Maviş & Toğram, 2009) and the communication sub-domain of the SAQoL-39 Turkish version were examined.

Reliability. During reliability analysis of the SAQoL-39 scale, the Cronbach Alpha coefficient and item analysis were used dependently on the original version of the scale in order to measure internal consistency and homogeneity of the items of the scale.

For item analysis, item-total score correlation method was used. It was expected that total correlation of the items would generally be higher than +0.30 (Hilari et al., 2003). In order to measure the stability of measurement data obtained with the method of test-re-test, the same scale was applied to the participants a second time under the same conditions at 2–4 weeks after the first administration of the scale. The test-re-test method was applied to 14 participants and Pearson correlation coefficient was used for analysis of compliance between the first and the second scale scores.

Data analysis

All statistical analysis was performed using SPSS v.20.0. Also, the p -value <0.05 was considered significant in this study.

Result

Acceptability analysis

The SAQoL-39 Turkish version has high acceptability; there was minimal missing data between 0–1.4,

the scale showed no minimum/maximum ceiling effect and there were only two distorted items (see Table I).

Validity analysis. Content validity. The content validity of the scale was examined in two different stages: (a) adaptation process of the scale and (b) expert opinion.

- (a) *Adaptation process of the SAQoL-39 scale to the Turkish language:* The process was done as mentioned in the section of “Adaptation of the SAQoL-39 Scale to the Turkish Language”. In this process, also, different adaptations of the SAQoL-39 scale into other languages in the literature (Kartsona & Hilari, 2007; Kiran & Krishnan, 2012; Lata-Caneda et al., 2009; Posteraro et al., 2004) were examined and the adaptation process was completed.
- (b) *Expert opinion:* During content validity analysis of the SAQoL-39 Turkish version, ratings of seven academics specialised in the field of language and speech therapy were obtained for the Turkish translations of the SAQoL-39 scale items by three SLPs. Inter-Professional Kappa Compliance Coefficient was calculated as 0.98 and this means that items of the scale represent the qualities to be measured sufficiently.

Structural validity. In order to measure the structural validity of the scale, five different analyses were used: (a) examination of the difference between scale scores of the extreme groups; (b) examination of correlations between scale score and sub-domain scores; (c) examination of correlation between sub-domains; (d) factor analysis; and (e) internal consistency coefficient (Cronbach Alpha coefficient).

- (a) *Examination of the difference between scale scores of the extreme groups:* In the study of structural validity of the scale, first the difference between “total scores” of the extreme groups was examined. For this study, scores of the participants were ranked from high to low and, then, statistically significant differences were determined in terms of total scores between the participants in the bottom slice of 27% ($n=10$) and top slice of 27% ($n=10$). Based on the analysis, it was seen that there was a statistically significant difference between the participants in the bottom slice of 27% and top slice of 27% in terms of test scores [$t(18) = -11.85, p < 0.001$]. This significant difference is evidence for structural validity of the test.
- (b) *Examination of correlations between scale scores and domain scores:* The second analysis of structural validity was performed to examine the correlations

between total scale score and sub-domain scores. In this analysis, the correlation of sub-domain scores and the total score of the scale was examined based on Pearson correlation coefficients. According to the results of analysis, a considerable positive correlation was detected between “physical” ($r=0.85, p < 0.01$), “communication” ($r=0.76, p < 0.01$), “psycho-social” ($r=0.80, p < 0.01$) and “energy” ($r=0.80, p < 0.01$) sub-domains and the total score of the scale taken by the participants. High positive correlation of sub-domains with the total score of the scale is evidence for high structural validity of the SAQoL-39 Turkish version.

- (c) *Examination of correlation between sub-domains:* The third analysis in structural validity was performed to measure the correlation between sub-domains. According to the results of analysis, positive correlation was detected between communication and physical sub-domains ($r=0.51, p < 0.01$); psycho-social and communication sub-domains ($r=0.68, p < 0.01$); energy and physical sub-domains ($r=0.62, p < 0.01$); energy and psycho-social sub-domains ($r=0.68, p < 0.01$); psycho-social and physical sub-domains ($r=0.40, p < 0.05$) and energy and communication sub-domains ($r=0.44, p < 0.05$). The correlation between sub-domains is within the range of $r=0.40 - 0.68$ values and this means that there is a significant relationship between sub-domains of the SAQoL-39 Turkish version and this is evidence for structural validity of the scale.
- (d) *Factor analysis:* The fourth analysis for structural validity study was factor analysis. The scores taken from sub-domains were examined through principal component factor analysis and the sub-domain with a factor load higher than 0.40 and loading components were determined. Eigenvalues and variance percentages of the resulting factors are given in Table II. According to the results of analysis; the principal component factor analysis with varimax rotation revealed four factors corresponding to 47.4% of the total variance and having an eigenvalue higher than 2.0. Factor 1 stands for 16.7% of total variance, Factor 2 for 13.1%, Factor 3 for 10.4% and Factor 4 for 6.9%. Concerning the factors for the SAQoL-39 Turkish version, every factor making up the variables was selected using the values over the factor load of 0.40. Factor 1 is composed of physical sub-domain (0.48–0.86), Factor 2 of communication sub-domain (0.40–0.86), Factor 3 of psycho-social sub-domain (0.46–0.89) and finally Factor 4 of energy sub-domain (0.52–0.87).
- (e) *Internal consistency coefficient:* Another form of evidence for structural validity of the SAQoL-39 Turkish version is that the internal consistency coefficient

Table I. Acceptability analysis of the Stroke and Aphasia Quality-of-Life scale-39 Turkish version.

Scale acceptability	
Missing data (%)	0–1.4
Range of scale scores	1–5
Range of sub-scale scores	2.17–4.03
Mean (SD)	3.30 (0.46)
Minimum/maximum effect (%)	0/0
Distortion ($> \pm 1$), affected items	3 (7.7)

Table II. Eigenvalues and variance percentages of the factors of the Stroke and Aphasia Quality-of-Life scale-39.

Factor	Eigenvalue	Variance percentage	Accumulated percentage of variance
1	6.543	16.7	16.7
2	5.140	13.1	29.9
3	4.092	10.4	40.4
4	2.714	6.9	47.4

(Cronbach Alpha) given under reliability analysis in this study is high (0.94).

Criterion validity. During statistical analysis, the correlation between communication sub-domain scores of the participants and the scores taken from auditory comprehension sub-test of Aphasia Language Evaluation Test in Turkish-ADD (Maviş & Toğram, 2009) was examined through Pearson correlation coefficient in order to measure simultaneous criterion validity of the scale. It was revealed that there was a positive, significant relationship at the level of 0.05 between communication score taken from the scale and auditory comprehension score taken from ADD ($r = 0.44$).

Reliability analysis. The SAQoL-39 Turkish version was examined within two reliability categories: internal consistency and stability.

Internal consistency.

- (a) *Mean of item-total score correlation coefficients:* Mean of item-total score correlation coefficient of the scale was found for every sub-domain. Correlation coefficients of the items of physical sub-domain with the total score of the scale vary between 0.48–0.84 ($M = 0.70$); correlation coefficients of the items of communication sub-domain with the total score of the scale vary between 0.58–0.74 ($M = 0.64$); correlation coefficients of the items of psycho-social sub-domain with the total score of the scale vary between 0.34–0.85 ($M = 0.63$); and correlation coefficients of the items of energy sub-domain with the total score of the scale vary between 0.55–0.85 ($M = 0.72$). Accordingly, it shows that internal consistencies of physical, communication, psycho-social and energy domains are high.
- (b) *Cronbach alpha coefficient:* Cronbach alpha coefficients obtained as a result of analysis made to determine internal consistency in reliability analysis according to the SAQoL-39 Turkish version are given in Table III. According to the results, it shows that the internal consistency of the SAQoL-39 Turkish version was high.

Test-re-test reliability of the scale. The 14 aphasia patients took part in a test-re-test reliability study. The re-test was applied 2–4 weeks after the first implementation of the test. In the test-re-test reliability study, Pearson correlation coefficient was

Table III. Cronbach alpha coefficients of the sub-scales of Stroke and Aphasia Quality-of-Life scale-39 Turkish version and the total scale.

Domains	Cronbach alpha coefficient
Physical	0.94
Communication	0.97
Psycho-social	0.86
Energy	0.70
Total scale	0.94

calculated in order to find the consistency between the first and the second implementation. It was seen that the consistency between the first and the second scale scores was significant ($r = 0.97$, $p < 0.001$) and the SAQoL-39 Turkish version was found to be considerably reliable in terms of test-re-test reliability.

Discussion

The SAQoL-39 scale items were translated from English into Turkish by a SLP and by two intern SLPs. After that, the Turkish version of the scale was analysed linguistically. Some items (e.g. M7: During the past week, how much trouble did you have in walking without stopping to rest or using a wheelchair without stopping to rest?, L7: During the past week how much trouble did you have in getting other people to understand you even when you repeated yourself?) had long length of utterance and they were semantically and syntactically complex, so repetitions were needed for the patients with aphasia. Furthermore, some verbal explanations were prepared for the items; for instance, researchers needed to give an explanation for not only the SR4 item (Did you perform your hobbies less than you desired during the past week?) but also for the W1 item (During the past week, how much trouble did you have in doing daily work around the house?).

As a result of structural validity analyses, it was revealed that validity of structure was high. It was observed that the correlations of scale domains with the scale score ($r = 0.76$ – 0.85) had a positive high correlation similar to the original scale ($r = 0.38$ – 0.58). According to the results of correlation analyses between domains, while correlation values of the domains in the original scale were within the range of 0.10–0.47, they ranged from 0.40–0.68 values in this study.

These results show a significant relationship between domains of the Stroke and Aphasia Quality of Life-39 scale and structural validity of the scale is as high as in the original scale. Additionally, as a result of factor analyses, four factors were revealed: physical, communication, psycho-social and energy. The results are in parallel to the study of Hilari et al. (2003). The same four factors were revealed also in the study of Hilari et al. (2003). These are physical, psycho-social domains, communication and energy domains which are affected mostly in the individuals with aphasia after stroke. A significant relationship between communication score of the scale and auditory comprehension sub-test score of ADD (Maviş & Toğram, 2009) shows that the validity of criteria of the SAQoL-39 scale is also high in addition to validity of content and structure.

According to reliability analysis in the study, it was revealed that the internal consistency and test-re-test reliability of the SAQoL-39 Turkish version

were high with Cronbach Alpha coefficient ranging from 0.70–0.94 for the domains and at 0.94 for the entire scale. The results of internal consistency and test–re-test reliability show parallelism to the results of the original scale (Hilari et al., 2003) and other adaptation studies of the scale (Kartsona & Hilari, 2007; Kiran & Krishnan, 2012; Lata-Caneda et al., 2009; Posteraro et al., 2004). Cronbach alpha coefficients of the domains of the original scale are within the range of 0.74–0.94; values for the Spanish adaptation were within 0.85–0.90 and for the Italian adaptation were within 0.76–0.97. Cronbach alpha coefficient of the entire original scale was 0.93; similar to the Spanish adaptation at 0.95, the Kannada adaptation at 0.90 and the Italian adaptation at 0.91.

The public awareness of aphasia and knowledge level about aphasia are taken into consideration in studies that examined the quality-of-life of people with aphasia. There is very little research about awareness and knowledge about aphasia, perspectives, attitudes and views of Turkish people toward aphasia and individuals with aphasia. The awareness and knowledge about aphasia in Turkish people is low. The results from two surveys designed to assess public awareness of aphasia in Turkey have shown that many people have inadequate knowledge about the disorder, its causes and its treatment (Maviş, 2007; Toğram, 2012). Maviş (2007) reported that 65.8% of the respondents had never heard of aphasia, while Toğram (2012) reported that 32.6% of participants had heard of aphasia. Public knowledge and awareness may affect quality of delivered services, quality-of-life and acceptance of individuals with aphasia. Additionally, information about cultural attitudes to aphasia and stroke and family involvement are also important to improve quality-of-life for people with aphasia. Considering the studies on caregiver views related to people with aphasia in Turkish literature, families of people with aphasia stated that need to knowledge and counseling related to aphasia, having limited communication settings, difficulty on living with a person with aphasia and necessity for psychological support (Özmen, 2014). Also, Maviş, Doğramacı, and Diken (2005) reported that primary caregivers had negative perspectives regarding the situation of individuals with aphasia.

In the light of the results, it is seen that the SAQoL-39 Turkish version is highly acceptable in terms of its data. In addition, its validity and reliability are highly similar with the original version of the scale.

Limitations and future directions

The most important limitation of the study was the relatively small sample size. For this reason, these findings cannot be generalised to the broader community based on this study alone. Another limitation

was the recruitment of participants from the investigator's own community and networks. This may have limited the sample in terms of socio-economic or cultural background; aspects that are well known to influence quality-of-life. In future studies, it will be important to study the effect of aphasia type on quality-of-life, as well as the relation between patient report and proxy report to see the agreements between patients and their spouses.

Conclusion

Patients with aphasia living in Turkey, like patients in other countries, are prone to social isolation and depression after a sudden stroke. They have trouble in communication due to their acquired language disorders and this negatively affects the quality of their life. It is well known that stroke is a health threatening condition, which is approximately equal in men and women (NIDCD, 2008). Although there is not much scientific data about the effects of aphasia on stroke survivors in Turkey, clinical observations are clear that they are socially and emotionally affected. Not only do they lose their jobs, but also they lose their authority in their family life. So, assessment of the quality-of-life for people with aphasia is considerably important to facilitate the adaptation of individuals to their new life after stroke and to determine the clinical interventions for them through a patient centered approach.

Concerning all data obtained in this study, it is clear that the SAQoL-39 Turkish version is a valid and reliable instrument in order to determine the health-related quality-of-life of the aphasia patients living in Turkey.

Declaration of interest

The author reports no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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