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# Reliability and validity of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) for a Serbian population

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## Abstract

**Purpose:** Aphasia has a negative impact on a person’s quality of life (QOL). The Stroke Aphasia Quality of Life-39 scale (SAQOL-39) is a widely-used measure of health-related quality of life (HRQOL) developed for people with aphasia that has been translated into several languages. Its psychometric properties have been examined not only in English, but also in other languages. This study examined the reliability and validity of a translation and adaptation of the SAQOL-39 into Serbian in Serbian-speaking people with aphasia.

**Method:** Using forward and backward translation, the SAQOL-39 was translated and adapted from English into Serbian and its psychometric properties were examined in 90 Serbian-speaking people with a broad range of times post-onset of aphasia. Internal consistency, test–retest reliability and other analyses were conducted.

**Result:** Internal consistency and test–retest reliability of the Serbian version was high (Cronbach’s  $\alpha > 0.9$ ; ICC  $\geq 0.87$ ), which is similar to versions of the scale in other languages.

**Conclusion:** The Serbian translation and adaptation of the SAQOL-39 was shown to be a valid and reliable measure of QOL in people with aphasia with reliable psychometric properties and is suitable for the assessment of Serbian people with aphasia.

**Keywords:** *Quality of life; Aphasia; Stroke and Aphasia Quality of Life Scale-39; SAQOL-39; Serbian*

## Introduction

Aphasia is the universally used term used to describe the communication problems observed following a stroke or other forms of brain damage (predominantly to the left hemisphere). Not only is aphasia a cause of communication difficulties, which are often severe, but it can also cause life-changing psychosocial problems for a person with aphasia (PWA) and for the members of their family. These changes can affect every aspect of life for people with aphasia: Social and community engagement (Code, 2003; Hilari, Needle, & Harrison, 2012), sense of self (Brumfitt, 1993), and emotional life (Code & Herrmann, 2003).

Our subjective sense of well-being is derived from our current experience of life as a whole (Campbell,

1976). Our emotional life, both positive and negative, emerges from our interaction with society. Following a stroke, the PWA may experience a sudden reduction in their ability to function in the activities of everyday life, for example, participation limitations in leisure, occupational, social, and family activities. They may experience negative emotional reactions to the enormous changes in their lives. For many, this can lead to severe depression (Code & Herrmann, 2003; Hackett & Pickles, 2014) and anxiety. Up to 44% of people with chronic aphasia can experience anxiety (Morris, Eccles, Ryan, & Kneebone, 2017).

Aphasia may have more severe consequences on quality of life (QOL) for PWA than any other disease, disability, or condition. Lam and Wodchis (2010) conducted a large study of health-related quality of life (HRQOL) in 66,193 residents in hospital-based

long-term care in Ontario, Canada. They used the Health-Status Index (MDS-HSI), which is a universally used measure in North American long-term care facilities based on a range of clinical assessments. Multivariate linear regressions revealed the impact of 60 diseases and 15 conditions on HRQOL. Following regression analysis aphasia showed the largest negative relationship to MDS-HIS, followed by cancer and Alzheimer's disease. The implications are that aphasia may have the most severe consequences for those affected than any other disease, disability, or condition.

QOL is a complex construct entailing a person's perception of their life in the context of the culture and value systems in which they live, in relation to their goals and expectations, standards, and concerns (The WHOQOL Group, 1998). The language processing difficulties accompanying aphasia, which can be severe, make the assessment of QOL in people with aphasia problematic. Additionally, the lack of appropriate measures has hindered the reliability of assessment results. The Stroke Specific Quality of Life (SSQOL) scale was developed to measure the QOL of people following a stroke (The WHOQOL Group, 1998) and Hilari and colleagues (Hilari, Byng, Lamping, & Smith, 2003) developed the Stroke Aphasia Quality of Life scale (SAQOL-39) specifically for use with people with aphasia following a stroke.

The original SAQOL-39 includes 39 questions spread across four domains (physical, communication, psychosocial, energy) and has good psychometric properties for stroke survivors with or without aphasia (Hilari et al., 2003). The SAQOL-39 has quickly become the most widely used measure of QOL in English-speaking people with aphasia after stroke. The recent ROMA consensus statement (Wallace et al., 2019) recommends the SAQOL-39 be included as a core outcome measure in phases I–IV aphasia treatment studies for adults with stroke-aphasia. The psychometric properties of the SAQOL-39 have been examined not only in English (Hilari et al., 2003), but also in Mandarin Chinese (Guo et al., 2017), Dutch (van Ewijk, Versteegde, Raven-Takken, & Hilari, 2017), Hindi (Mitra & Krishnan, 2015); Turkish (Noyan-Erbaş & Toğram, 2016), Italian (Posteraro et al., 2004), Korean (Gimsujeong & Gimdeokyeong, 2012), and Chinese (Lin, Chen, Feng, Cai, & Deng, 2013) as well as other languages.

The current study examines the psychometric properties of a Serbian version of the SAQOL-39, which has not previously been developed for the examination of QOL in people with aphasia secondary to stroke with a broad range of aphasia onsets. We used the original SAQOL with 4 domains, which was at our disposal when the study began. Most of the published papers at that time concerned the original version of the scale.

## Method

### *Translation*

Translation of SAQOL-39 from English into Serbian followed the cross-cultural adaptation process suggested by Beaton, Bombardier, Guillemin, and Ferraz (2000). It involved two experienced professional translators. The first was a teacher of English and professional translator and the second was also a professional translator who also had experience working on the translation of many tests and manuscripts for aphasia in the last 20 years.

Both translators had university level education. First, the first translator completed an initial translation from English into Serbian. The translation was passed to the second translator who translated the Serbian back into English and had not seen the original source document. Item identities and the scoring method were left unchanged. Following this, the translators compared their versions and agreed on the final version. A committee made up of the three Serbian English-speaking authors of this paper reviewed the forward and backward translations. A consensus was reached to produce a final version after a period of pre-testing where some minor discrepancies were corrected (See [Supplementary Appendix](#) for the final Serbian version).

### *Participants*

A total of 90 Serbian-speaking people with aphasia aged between 30 and 73 years of age participated in the study. All participants were recruited from the Institute for Psychophysiological Disorders and Speech Pathology, in Belgrade, where they were all undergoing treatment for their speech and language problems. The study was performed in accordance with the ethical standards of the Declaration of Helsinki. The protocol was approved by the Institute's Human Research Ethics Committee. All participants gave informed voluntary consent to participate in the research and none declined to participate. To obtain a sufficient number of participants, the research spanned a period of 3 years (May 2014–May 2017).

Candidates were chosen randomly and we adopted the following inclusion criteria: Aphasia from a single left-hemisphere stroke; right-handed; Serbian language speaker with normal pre-stroke language functions; over 18 years of age; at least 8 years of primary education; normal literacy development and normal pre-stroke literacy function; adequate hearing, vision, and comprehension to enable participation.

Exclusion criteria were: History of dementia; history of other neurological or psychiatric illness or of developmental or other acquired speech or language disorder.

Participants were from 2 to 36 months post-onset. Pre-stroke occupation was determined with reference to the Classification of Occupations (Office of

Population Censuses and Surveys (OPCS), 1980) into the six socio-economic groups.

### Procedure

All participants were assessed by one of the first three authors, who are all qualified speech and language therapists and have experience in working with PWA. Aphasia was diagnosed with the Boston Diagnostic Aphasia Examination (BDAE; Goodglass & Kaplan, 1983), translated and adapted into Serbian (Vuković, 2011, 2015), and on the Serbian translation of the SAQOL-39. The translated SAQOL-39 was re-administered by the same researcher who had carried out the original assessment to 20 of the participants in a quiet room three weeks after the initial assessment to examine test-retest reliability. Most participants included had sufficient levels of comprehension to understand the assessor without much difficulty.

Participants with more severe aphasia were helped by having the questions read out to them by the assessor, repeating and explaining where necessary. On average, participants needed 60 minutes to complete the BDAE, and 20 minutes for SAQOL-39. The participants were assessed individually as they were available to us until we reached the number 90. All participants were able to complete the assessments in one session.

### Data analyses

We conducted analyses similar to other researchers to evaluate the psychometric properties of the Serbian version of SAQOL (e.g. Hilari et al., 2003; van Ewijk et al., 2017). To assess acceptability, we carried out an inspection of missing data, an analysis of floor and ceiling effects, and the skewness of the distribution of scores for each item. We used Cronbach's alpha to investigate internal consistency. For construct validity, we conducted bivariate correlations (Spearman's rho) between the four domains of the measure. We used intraclass correlations for test-retest reliability. The data analyses were carried out with the Statistical Package for the Social Sciences – SPSS<sup>TM</sup> for Windows, version 23.0, 2015. Based on findings from a systematic review of the psychometric properties of SAQOL-39 across languages (Ahmadi, Tohidast, Mansuri, Kamali, & Gopee, 2017), we predicted relatively stronger correlations in terms of internal consistency and test-retest reliability, but weaker correlations between domains. We interpreted correlations using descriptive terms based on Schober, Boer, and Schwarte (2018).

### Result

The sample comprised 42 female and 48 male participants whose aphasia duration was on average 10.8 months ( $SD = 7.3$ ; range 2–36 months). There were 44 fluent and 46 nonfluent participants. Severity and type of aphasia (fluent and nonfluent) were

determined with the BDAE (Goodglass & Kaplan, 1983). Severity was calculated from the total BDAE score and the Rating Scale of Speech Characteristics score. Accordingly, there were 11 people with mild aphasia, 32 people with mild-moderate aphasia, 40 people with moderate aphasia, and seven people with severe aphasia. We were not concerned to classify participants into the classical aphasia “types” (e.g. Broca's, Wernicke's, etc.), which most contemporary researchers and clinicians consider an outmoded and unreliable process.

Table I provides information about the age and education of participants. The mean age was 56.23 years (range 30–73). The mean years of education was 13.7 (range 11–17). Table II shows the socio-economic and marital status of the sample. The range of occupations sampled may be biased towards higher socio-economic groups. Eighty-five of the 90 participants had occupations ranging between Professional to Skilled Manual, with just five who were Partly skilled or Manual workers. Marital status appeared to be well balanced with 41 single and 38 married. There were 11 widowed participants.

In terms of acceptability, there were no missing data and no floor or ceiling effects. Inspection of the distribution of scores of each item showed that six of the 39 items (15%) were skewed ( $>1$ ). The items were: T5, P1, P3, SR4, SR5, and T4. Table III presents the SAQOL-39 descriptive statistics for people with aphasia. The results in Table IV relate to the

Table I. Age and education information of participants.

Variables	Descriptive statistics		
	Mean	SD	Range
age (years)	56.3	10.28	30–73
education (years)	13.7	2.1	11–17

Table II. Occupation and marital status information.

Variables	Number	Sample proportion
Occupation		
Professional	20	22.2%
Intermediate	24	26.7%
Skilled non-manual	21	23.3%
Skilled manual	20	22.2%
Partly skilled manual	2	2.2%
Unskilled manual	3	3.3%
Marital status		
Single	41	45.5%
Married	38	42.2%
Widowed	11	12.2%

Table III. Descriptive statistics of SAQOL ratings.

SAQOL domains	Descriptive statistics		
	Mean	SD	Range
Total	2.27	.69	1.18–4.43
Physical	2.65	.93	1.00–4.76
Communication	2.32	.67	1.00–4.00
Psychosocial	1.99	.80	1.00–4.45
Energy	1.84	.78	1.00–4.50

Table IV. Internal consistency between the four domains (spearman correlations).

	Physical	Communication	Psychosocial	Energy
Physical	–	0.596*	0.412*	0.386*
Communication		–	0.627*	0.518*
Psychosocial			–	0.728*
Energy				–

\* $p < 0.05$ .

Table V. Internal consistency and test–retest reliability.

Domain	Internal consistency	Test-retest reliability
Total	.961	.931
Physical	.977	.945
Communication	.905	.900
Psychosocial	.923	.936
Energy	.922	.873

construct validity analyses. All correlations were statistically significant at  $p \leq 0.0125$  level (two-tailed; Bonferroni corrected). Table IV also shows the descriptors which follows those reported in Schober et al. (2018). Overall, all correlations between domains were positive. In terms of descriptors, they ranged from “weak” (between physical and energy,  $\rho = 0.386$ ) to “moderate” (between physical and psychosocial,  $\rho = 0.412$ ; between communication and psychosocial,  $\rho = 0.627$ ) as well as “strong” (between psychosocial and energy,  $\rho = 0.728$ ). None of the correlations were “very strong”, i.e. 90 or greater (Schober et al., 2018).

Table V presents the results of the internal consistency (evaluated with Cronbach’s alpha) and test–retest reliability (evaluated with intraclass correlations, ICC) analyses. As all coefficients were 0.905 or higher, the internal consistency can be described as “very strong” (Schober et al., 2018). Similarly, according to Koo and Li (2016) descriptors of ICC, test-retest reliability for the total score (0.931) was “excellent”, i.e. 0.900 or above. The ICC of 0.945 and 0.936 for the physical and communication domains respectively are also “excellent”. The ICCs of the psychosocial domain (0.900) and energy (0.873) domains are “good” (Koo & Li, 2016).

## Conclusion

As outlined in the Introduction, QOL for people with aphasia has been shown to be particularly poor, even when compared to other significant health conditions (Lam & Wodchis, 2010). Assessing QOL is clinically important in enabling treatment to be based on reliable information about the QOL of those in rehabilitation. Valid and reliable measures are required to assess QOL in people with aphasia and the SAQOL-39 has been shown to be a valid and reliable measure

of QOL in people with aphasia in several language versions.

This study examined the adaptation of SAQOL-39 in 90 Serbian-speaking people with aphasia and some key psychometric properties. The findings suggest that the Serbian version of the measure is acceptable. The internal consistency and test–retest reliability of the Serbian version was high (Cronbach’s  $\alpha > 0.9$ ; ICC  $\geq 0.873$ ), similar to other versions of the scale (Guo et al., 2017; Hilari et al., 2003; van Ewijk et al., 2017). Correlation coefficients between subdomains in the Serbian SAQOL ranged from 0.386 to 0.728 (all statistically significant at 0.05). These coefficients are higher than those reported in other languages. For example, in the Dutch version, van Ewijk et al. (2017) reported correlations between subdomains from 0.12 to 0.36, which are indeed on the lower side of the correlation scale. Similarly, in the English version (Hilari et al., 2003), correlations between subdomains ranged from 0.10 to 0.47. The differences may reflect cultural perceptions of HRQOL that should be explored in future studies.

Overall, the Serbian translation of the SAQOL-39 shows reliable psychometric properties, similar to findings in other languages (Ahmadi, Tohidast, Mansuri, Kamali, & Gopee, 2017) and is suitable for assessment of Serbian people with aphasia. However, further studies are needed to elicit perspectives about QOL from people with aphasia, carers, and clinicians. The perceptions of QOL from the point of view of carers is important, as Hilari and colleagues highlighted in their research (Hilari et al., 2003; 2012).

The perceptions of the relatives and carers of people with aphasia can also be examined with the Serbian version of the SAQOL-39. Future research can use the Serbian version of the SAQOL-39 to explore the effectiveness of interventions for QOL in people with aphasia and relationships between QOL and a range of other factors.

## Declaration of interest

All authors have contributed to the research reported in this paper and have agreed on its content. The research was approved by the Ethics Committee of the Institute for Psychophysiological Disorders and Speech Pathology, Belgrade. The study was performed in accordance with the ethical standards laid down in the Declaration of Helsinki. All participants gave their consent to participate in the research. The authors declare no conflicts of interest and funding was neither sought or obtained for the research.

## Supplementary material

Supplemental data for this article can be accessed at <http://dx.doi.org/10.1080/17549507.2021.1971298>.

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