Stroke and aphasia quality of life scale in Kannada-evaluation of reliability, validity and internal consistency

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Abstract

Background: Quality of life (QoL) dwells in a person's overall well-being. Recently, QoL measures have become critical and relevant in stroke survivors. Instruments measuring QoL of individuals with aphasia are apparently rare in the Indian context. The present study aimed to develop a Kannada instrument to measure the QoL of people with aphasia. Study objectives were to validate Stroke and aphasia quality of life-39 (SAQOL-39) into Kannada, to measure test–retest reliability and internal consistency. **Materials and Methods:** The original English instrument was modified considering socio-cultural differences among native English and Kannada speakers. Cross-linguistic adaptation of SAQOL-39 into Kannada was carried out through forward–backward translation scheme. The scale was administered on 32 people from Karnataka (a state in India) having aphasia. For a direct understanding of the subject's QoL, scores were categorized into QoL severity levels. Item reliability of the Kannada version was examined by measuring Cronbach's alpha. Test-retest reliability with minimum missing data and excellent test–retest reliability (ICC = 0.8). Value of Cronbach's α observed for four items modified in the original version was 0.9 each and the mean α of all Kannada items was 0.9, demonstrating high internal consistency. **Conclusions:** The present study offers a valid, reliable tool to measure QoL in Kannada-speaking individuals with aphasia. This tool is useful in a cross-center, cross-national comparison of QoL data from people with aphasia. This instrument also permits direct translation into other Indian languages as the items are culturally validated to the Indian population. This study promotes future research using the Kannada SAQOL-39.

Key Words

Aphasia, Kannada, quality of life, stroke and aphasia quality of life-39, stroke

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Introduction

Quality of life

QoL refers to an individual's perception of position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.^[1] Recently, QoL has become a critical measure in healthcare services. This is because any disorder can impact a person's ability to lead a fulfilling life.^[2] In healthcare, the term 'health-related quality of life' (HRQoL) is often used. This approach narrows consideration to those aspects of QoL that

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are deemed to be positively or negatively affected by medical or healthcare intervention.^[3]

In people with brain-damage, communication disorders have also been found to be significantly associated with poor QoL because of the importance of communication for social contacts and integration.^[4-6] Measures of HRQoL are particularly relevant in stroke survivors where the key aims of rehabilitation are to facilitate adaptation to disability, promote social and community integration, and maximize well-being/QoL.^[7] Still, generic HRQoL measures or even stroke-specific HRQoL measures are, to a large extent, not accessible to researchers and clinicians dealing with people having aphasia.^[8]

To address these issues, the stroke-specific quality of life scale^[9] was modified in the UK for the purpose of using it with individuals having aphasia.^[10] The resulting instrument – the stroke and aphasia quality of life-39 (SAQoL-39) – is proven to be a valid and reliable measure for the assessment of HRQoL in people with aphasia.^[8] This scale has been adapted and

standardized to various non-English-speaking populations such as Spanish and Italian to name a few.

However, the scales developed in other countries to measure QoL cannot be directly used in another, owing to the difference in the culture and standards of living in different countries.^[11]

Standardized instruments to measure the QoL in individuals with aphasia are apparently rare in the Indian context. A few instruments developed in the country are not accessible to the professionals working with people having aphasia. In addition, such instruments seldom permit the cross-cultural and cross-national comparison of the data. These limitations pose the need to develop an instrument that permits the comparison of QoL in people with aphasia across cultures and nations. The present study aimed to develop an instrument in Kannada (the language spoken in Karnataka state in India) to measure the QoL in people with aphasia. The specific objectives of the study were to validate the SAQoL-39 (Hilari *et al.*, 2003) by culturally and linguistically adapting it into Kannada and to evaluate the instrument's acceptability, reliability, and internal consistency.

Materials and Methods

The original (English) version of SAQoL-39 and the permission to adapt it to Indian languages were obtained from the authors.

The items in the original version were examined thoroughly for suitability in terms of socio-cultural standards by five experienced speech-language pathologists (SLPs). These SLPs were requested to examine the items and suggest modifications, wherever necessary. The SLPs agreed upon the use of all items without modification except four. These items were: Self-Care SC1: Preparing food?; Upper extremities function UE2: Putting on socks?; (Thinking) T4: Have to write things down to remember them, (or ask somebody else to write things down for you to remember)?; (Personality) P1: Feel irritable? Additionally, the SLPs were required to provide alternate items measuring the same parameter intended to be measured by the original question and also which are suitable to the socio-cultural background of the population under study.

Subsequent to the modification of these four items, a forward–backward translation scheme was used to develop the Kannada version of SAQoL-39. For this purpose, seven bi-literate (Kannada and English) individuals from different regions of Karnataka were chosen. They were randomly categorized under the following two groups:

- Group I : Consisting of four translators, assigned for the purpose of forward translation
- Group II: Consisting of three translators, assigned for the purpose of backward translation

The socio-culturally modified English version of the questionnaire was given to Group I to (forward) translate into Kannada. This group was instructed not to change the meaning of the items during the translation process. As the translators were from different regions of Karnataka, usage of different names to represent a particular item in the questionnaire owing

to the regional variations in Kannada was noted. Care was taken to incorporate the most popular and widely used word in the final draft version of the Kannada questionnaire. This version was then given to Group II for backward translation to English with the same instructions given to Group I. The Kannada version of the instrument was tested by administering it on a group of 32 participants with aphasia recruited from different hospitals and rehabilitation centers across Karnataka. Test–retest reliability data were collected within a period of 15 days from 13 participants of the study.

Psychometric evaluation

Test–retest reliability

Test–retest reliability was examined by re-administering the scale on 13 participants with aphasia of the total 32 participants, within a period of 15 days. The intraclass correlation coefficient (ICC) was calculated for the overall SAQOL-39 mean score using SPSS Ver. 16 for windows. The Kannada version of SAQOL-39 showed excellent test–retest reliability (ICC = 0.8).

Internal consistency

It was noted that there was no difference between the back-translated Kannada version of the instrument and the modified version of the original English questionnaire. In this way, the Kannada version of the instrument was validated and was prepared in the form of 'SAQOL-39-Presenter's booklet in Kannada' (Appendix 'A').

Furthermore, to ascertain that the instrument is valid with the modified items in Kannada, Cronbach's alpha^[12] – a measure of internal consistency – was calculated for the Kannada version of the scale using the Statistical analysis software (SAS; Version 9.2). The value of Cronbach's α observed for the four modified items was 0.9 [Table 1] and the mean Cronbach's α of all the items in the Kannada SAQOL-39 was also 0.9, indicating an excellent internal consistency as well as high item reliability of the instrument.

Acceptability of the scale

The acceptability of the Kannada SAQOL-39 was demonstrated by minimal missing data.

The quality of life measure

From the data obtained after the administration of the Kannada version of SAQOL-39 on a group of 32 people with aphasia, the overall QoL score as well as the scores on each sub-domain were calculated. Overall and sub-domain scores range from 1 to 5. In general, the higher the score, the better is the QoL and vice-versa.

In our adopted instrument, for an easy and direct understanding of the subjects' level of QoL, score on the 5-point rating scale was operationally categorized as follows: Score of 1 or 2 : Severely affected OoL

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Score of 3	:	Moderately affected QoL
Score of 4	:	Mildly affected QoL
Score of 5	:	Normal QoL

Discussion

The instruments developed for one particular population may not be suitable for another socio-culturally distinct

Table 1: Cronbach's coefficient alpha with deleted variable (appendix A)

Item number as per the	Deleted variable	Raw varia	bles	Standardized variables	
Kannada SAQOL-39		Correlation with total	Alpha	Correlation with total	Alpha
1	SC1	0.81	0.96	0.79	0.97
2	SC4	0.84	0.96	0.83	0.97
3	SC5	0.85	0.96	0.84	0.97
4	M 1	0.87	0.96	0.86	0.97
5	M4	0.85	0.96	0.84	0.97
6	M6	0.87	0.96	0.87	0.97
7	M7	0.85	0.96	0.85	0.97
8	M8	0.87	0.96	0.87	0.97
9	M9	0.81	0.96	0.79	0.97
10	W 1	0.85	0.96	0.84	0.97
11	W2	0.87	0.96	0.87	0.97
12	UE1	0.66	0.96	0.66	0.97
13	UE2	0.83	0.96	0.83	0.98
14	UE4	0.23	0.97	0.23	0.98
15	UE5	0.88	0.96	0.87	0.97
16	UE6	0.88	0.96	0.87	0.98
17	L2	0.72	0.96	0.73	0.98
18	L3	0.69	0.96	0.70	0.98
19	L5	0.73	0.96	0.75	0.98
20	L6	0.70	0.96	0.72	0.98
21	L7	0.76	0.96	0.77	0.98
22	T4	0.56	0.96	0.56	0.98
23	T5	0.73	0.96	0.74	0.98
24	P1	0.20	0.97	0.22	0.98
25	P3	0.44	0.96	0.46	0.98
26	MD2	0.66	0.96	0.68	0.98
27	MD3	0.41	0.97	0.42	0.98
28	MD6	0.62	0.97	0.63	0.98
29	MD7	0.55	0.97	0.56	0.98
30	E2	0.72	0.96	0.71	0.98
31	E3	0.81	0.96	0.8	0.98
32	E4	0.82	0.96	0.82	0.98
33	FR7	0.72	0.96	0.75	0.98
34	FR9	0.47	0.97	0.5	0.98
35	SR1	0.85	0.96	0.86	0.98
36	SR4	0.8	0.96	0.82	0.98
37	SR5	0.86	0.96	0.88	0.98
38	SR7	0.81	0.96	0.84	0.98
39	SR8	0.67	0.96	0.7	0.98

SAQOL-39=Stroke and aphasia quality of life, SC=Self care, M=Mobility, W=Work, UE=Upper extremities function, L=Language function, T=Thinking, P=Personality, MD=Mood, E=Energy and fatigue, FR=Family life, SR=Social life

population.^[12] With this viewpoint, the original English version of SAQOL-39 was presented to a group of five experienced SLPs to read and opine on the suitability of the items in the Indian context. Among the 39 items, four items were found to be inappropriate due to socio-cultural differences that exist between the target population (Kannada-speaking Indians) and the English-speaking population focused by the original version. Subsequently, two of the four items were minimally modified and the remaining two were replaced with new ones (Appendix A). However, when making such amendments, adequate care was taken to incorporate changes for the four items without altering the parameter the original question was intended to measure such as 'self-care,' 'upper extremities function,' 'thinking,' and 'personality.' The four items were as follows:

SC1: Preparing food? – In the Indian context, mostly females are involved in preparing food unlike males, on a routine basis. Hence, such a question put forth to the male subject may become inappropriate. Therefore, the question was modified by adding the phrase "having food?" and the question finally included in the culturally adapted instrument was preparing food/having food?

UE2: Putting on socks? Culture differs across countries and such differences are generally noted in the dressing pattern as well. In India, 'socks' may not be widely used by the people (especially in the lower and middle socio-economic sections, which constitute the major portion of the Indian population).^[13] In this context, incorporating this question may prove to be inappropriate. Hence, that question from the original version was replaced with a new one, "using toilet without others' assistance?."

T4: Have to write things down to remember them, (or ask somebody else to write things down for you to remember)?

This question although culturally suitable to the Indian population necessitated minimal modification to make it easily comprehendible. This question, therefore, was modified as "have to write things down (on calendar, diary, chit) to remember them, (or ask somebody else to write things down for you to remember)?"

P1: Feel irritable?

This question, although appropriate to the Indian context, was still replaced with a new question, which meant the same but made it easy to understand. Later, the group of forward translators (i.e., English to Kannada) went through the original version of the questionnaire and stated that the modified question was easy for them to understand, at least during the translation process to Kannada as the phrase "feel irritable?" has no exact phrase in Kannada unlike for the modified question "usually get angrier than before?."

The alternate items provided by the experienced SLPs were considered and the four items were changed subsequent to the arrival at a consensus.

The forward–backward translation scheme used by Lata-Caneda *et al.* $(2009)^{[14]}$ in the development of the Spanish version of SAQOL-39 was used in the present study. This ensured validity and ascertained that the translated version was unaltered in terms of the contents of the questionnaire. However, the four items of the original questionnaire were replaced with the culturally suitable items. Hence, the internal consistency of the Kannada version of SAQOL-39 was assessed by calculating Cronbach's α . The value of α observed for the four novel items that were modified in the original version and incorporated

in the Kannada version was 0.9. Even the mean α value of all the items in the Kannada SAQOL-39 was 0.9, thus ensuring that the overall consistency of the instrument remained high. Furthermore, the alpha value obtained in the present study was comparable to that of the original study (0.93: Hilari *et al.*, 2003)^[8] as well as an adapted and standardized version of the same to Spanish^[14] (0.95: Lata-Caneda *et al.*, 2009).

The instrument was administered on a group of 32 Kannada-speaking people with aphasia. In addition, it was re-administered on a subgroup of 13 subjects to assess the test–retest reliability; the comparison of scores between the two administrations revealed a high correlation (ICC = 0.8). Therefore, the current instrument was found to be a reliable tool to assess the QoL in Kannada-speaking people with aphasia.

Conclusion

The current research resulted in the adaptation of a well-known instrument (SAQOL-39) to measure the QoL in the English-speaking population to the Kannada-speaking individuals with stroke and aphasia. The newly adapted instrument exhibited good acceptability, test–retest reliability, and internal consistency, and thus proved to be a valid and reliable tool to measure the QoL of Kannada-speaking individuals with stroke and aphasia.

Strengths of the study

The 'Kannada SAQOL-39' potentially yields a score showing the extent to which a person's QoL is affected subsequent to stroke and/or aphasia, on a scale of severity ranging from 'normal QoL' to 'severely affected QoL,' which is the unique aspect of this instrument, not found in either the original English instrument or any other tools assessing QoL in individuals with stroke and/ or aphasia. As the current study offers a new, culturally valid instrument, it will also foster a number of studies in the future. The adaptation of this instrument to other Indian languages is under way at our center.

Limitations of the study

The instrument was tested on a small group of people with aphasia. This, in turn, calls for the administration of Kannada SAQOL-39 on a larger population to determine the effect of various demographic variables on the QoL in people with stroke and aphasia. Psychometric properties tested were mainly restricted to intra-rater reliability by measuring 'test–retest reliability' and content validity through the measure of internal consistency.

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