Spanish adaptation of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39)

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Abstract

Aim. The stroke and aphasia quality of life scale-39 is an interviewer administered questionnaire that has been developed and validated in the United Kingdom to be applied to patients with chronic aphasia as a

consequence of a stroke. The objective of this article was to translate the Stroke and Aphasia Quality of

Life-39 Scale (SAQOL-39) into Spanish language, and evaluate its acceptability and reliability.

Methods. The cross-cultural adaptation of the SAQOL- 39 into Spanish was carried out by following the

translation and back-translation method. Twenty three patients with long-term aphasia due to stroke were

tested. The patients were interviewed twice in a period from 2 to 12 days. The acceptability of the Spanish

SAQOL- 39 was evaluated by examining the floor/ceiling effects and the missing data. The reliability was

assessed by Cronbach's alpha (internal consistence) and intraclass correlation coefficients (test-retest

reliability) for the overall scale and its subdomains.

Results. There were no difficulties to translate the original version into Spanish. There was good

acceptability demonstrated by minimal missing data and floor/ceiling effects. Test-retest reliability for the

overall score, and the subscales scores was 0.949 (0.854-0.944). Internal consistency analysis by

Cronbach's α was 0.950 (0.851-0.900).

Conclusion. This small scale study provided preliminary evidence for the acceptability and reliability of

the Spanish version of the SAQOL-39. Further testing in larger samples is needed to evaluate the validity

of the scale, its sensitivity to change and to confirm its reliability.

**Keywords**: Aphasia; Quality of life; Stroke.

The present pilot study has been presented as a Poster and published in the Proceedings of 6th

Mediterranean Congress of Physical and Rehabilitation Medicine with the title "Stroke and Aphasia

Quality of Life-39: Spanish translation and cross-cultural adaptation". Europa Medicophysica

2006;42:133-4.

In 1948, the World Health Organisation defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Bearing in mind that health includes multiple dimensions, the concept quality of life appears linked with health; it appears as the patient perception about, either the effects of a given disease, or the application of a certain treatment on different aspects of life, especially regarding its consequences on the physical, emotional and social welfare. <sup>2</sup>

Despite the wide development of generic and disease- specific instruments for health-status assessment, their use in examining the impact of stroke and stroke interventions has been limited. In 2002 it was reported that less than 2% of stroke trials included a patient viewpoint-measurement of the health state.<sup>3</sup> The questionnaires about quality of life enable the assessment from the viewpoint of the stroke patient; they also contribute to the rehabilitation planning, the quality control of medical practice and to the clinical and therapeutic research.<sup>4</sup> Post-stroke depression is higher in patients suffering from aphasia;<sup>5</sup> physical suffering and increased mortality are also higher.<sup>6,7</sup> However, people with aphasia, together with those who suffered cognitive alterations, were excluded from most of the studies about quality of life after stroke <sup>7-9</sup> due to the absence of adequate tools.<sup>10</sup> This fact marks such studies with an important bias.

Hilari *et al.*1<sup>1,12</sup> provided good evidence for the acceptability, reliability and validity of the SAQOL- 39, which is the adaptation of the stroke specific health-related quality of life scale (SSQOL) <sup>13</sup> for its use on people affected by aphasia.

The present work shows the Spanish translation and the subsequent cross-cultural adaptation of the Stroke and Aphasia Quality of Life Scale-39 (SAQOL- 39), together with the study of its reliability for being used on Spanish people with aphasia (Appendix I).

#### Materials and methods

### SAQOL-39

The SAQOL-39 is an interviewer-administered selfreport measure. It can be used with patients with any severity of expressive aphasia and with moderate or mild receptive impairment. The questionnaire has 39 questions involving 4 domains: physical (17 items),

psychosocial (11 items), communication (7 items) and energy (4 items). The timeframe of the questions is the past week <sup>11</sup>. Answers are framed into a 5 points Likert Scale following two different formats: 1="couldn't do it at all" to 5="no trouble at all" and 1="definitely yes" to 5="definitely no". During the administration, the interviewers can use different strategies for improving the comprehension of the person with aphasia.

#### **Translation**

The translation and the adaptation of the original scale to Spanish was carried out by following the translation and back-translation method in order to guarantee the conceptual equivalence of the terms used.<sup>14-16</sup>

In this translation and adaptation process the following steps were carried out:

- 1. two independent Spanish translations of the SAQOL were performed by two doctors and a professional Spanish translator. The two versions were then compared and a consensus version derived;
- 2. back-translation to English performed by an English linguist who did not know the original document;
- 3. comparison of the original document with the back-translation in order to assess the conceptual and the semantic equivalence carried out by experts;
- 4. test of the application of the scale in clinical setting.

The format of the Spanish adaptation of the SAQOL- 39 is the same as the original one, with permission of the developer.

#### Acceptability and reliability testing

Acceptability was assessed in terms of missing responses and floor/ceiling effects. The criteria for acceptability were missing data <10% and floor/ceiling effects <20%. Internal consistency is the precision of a scale, based on the homogeneity of the scale's items at one point in time. Cronbach's  $\alpha$  coefficient provides an estimation of the reliability. For group comparisons a commonly accepted minimal standard for reliability coefficients is 0.70. Reproducibility is defined as the stability of an instrument over time (test-retest). The minimal standard for reproducibility coefficients (intraclass correlation coefficients) is considered to be 0.70 for group comparisons. In

# Study population

The participants were recruited from the records of stroke patients with aphasia who had been discharged from the Rehabilitation Service of the Juan Canalejo Hospital. The inclusion criteria were: aphasia resulting from stroke of at least 1-year duration, oral comprehension superior or equal to 50th percentile on the Boston Diagnostic Aphasia Examination, and age comprised between 20 and 80 years. The exclusion criteria were: prestroke history of cognitive decline or psychiatric disorders and severe concomitant disease.

Thirty five patients were selected to take part in the study. Seven of them declined to participate and five were excluded because of further illnesses. Each participant was provided with written information of the study; written patient consent was eventually obtained. For the reliability study, patients were interviewed twice, in a period comprised between 2 and 12 days, at the Rehabilitation Office, by doctors of the Rehabilitation Service.

#### Measures

Information about demographic and clinical characteristics was collected from the clinical records. Those patients who had been diagnosed of poststroke depression by a psychiatrist were recorded. The diagnosis of aphasia had been reached using the Boston Diagnostic Aphasia test. During the application of the SAQOL-39 the severity of aphasia was assessed by means of the Severity Rating Scale from Goodglass and Kaplan <sup>18</sup> and the physical disability was measured by the Barthel index.<sup>19</sup>

#### Statistical análisis

Data analysis was performed by means of the SPSS 15.0 for Windows. The Cronbach's  $\alpha$  and the Intraclass Correlation Coefficient (ICC) were used respectively for the analysis of internal consistency of the scale and for the assessment of the reliability rate. Acceptability was assessed by calculating the percentage of missing date and the floor/ceiling effects for all domains.

#### **Results**

#### Translation and cross-cultural adaptation

First a translation from English into Spanish was carried out and after the back-translation conceptual and semantic concordances were confirmed by the experts. Only slight differences were detected between the back-translated and the original document: last week instead of past week, which had been translated as *la semana pasada*; mood for feelings, interpreted as *sentimientos*; shy with instead of withdraw from, for *retraído con (otra gente)*. Both, original and back-translation, were comparable and no changes were made in the Spanish document.

Twenty three patients with chronic aphasia caused by a stroke gave their consent and accepted to answer the questionnaire. The interviews lasted between 10 and 40 minutes (21.47±7.23). The 69.6 % of patients were males, with a mean age of 57 years (42-74). The clinical and demographic characteristics of the patients are shown in Table I.

#### **ACCEPTABILITY**

Table II describes the scores of the scale. Missing data were non relevant (0-4.3%) and floor/ceiling effects were below 20% for all domains, except for energy domain. The global score did not have floor/ceiling effects.

#### RELIABILITY

The internal consistency of the scale was good (Cronbach's  $\alpha$  score, 0.950 for the SAQOL-39 Scale, and 0.851-0.900 for the subscales). The test-retest reliability was proved by means of the ICC for the 23 patients; its values were 0.949 for the SAQOL-39 scale and range between 0.854 and 0.944 for the subscales (Table III).

# RESULTS OF THE SAQOL-39

The mean score for the full scale was 3.75 (range: 2.06-4.94); for the physical domain the result was 4.05 (2.40-5); for the communication domain 3.29 (1.57-5); for the psychosocial domain 3.67 (1.63-5); and for the energy domain 3.98 (1-5); (Table II).

#### **Discussion**

The application of a quality of life scale to patients affected by aphasia presents two main disadvantages: on one hand, oral comprehension difficulties during the interviews or writing comprehension problems in selfapplied questionnaires; on the other hand, the fatigue caused by long questionnaires, as it happens in most of the generic quality of life scales.<sup>20</sup> Studies of health related quality of life in aphasia have often used generic scales.<sup>20,21</sup> Few studies of health related quality of life in aphasia have used validated specific tools.<sup>22,23</sup> Hilari *et al.* adapted the specific SAQOL for its application on patients affected by aphasia and proved its adequate acceptability and reliability.12 SAQOL-39 has been translated into several languages as Italian,<sup>24</sup> Greek,<sup>25</sup> and Slovene <sup>26</sup> and their reliability has been proved for their clinical application in some cases.<sup>27</sup>

The guidelines suggested by several authors were used for the translation into Spanish.  $^{14,15}$  No difficulties were found during translation and, as when using the original version the survey had a high acceptability level. The test-retest reliability was good and the internal consistency resulted adequate, with ICC and Cronbach's  $\alpha$  values higher than the recommended values (0.70).  $^{16}$ 

The patients interviewed in this study presented demographic and clinical characteristics similar to the ones of the patients interviewed by Hilari in the original validation of the tool. In this study the aphasia tests used for diagnosis and severity assessment were different from those used by Hilari *et al*. The Boston Diagnostic Aphasia Examination was used, because it is not only internationally considered but it has also been adapted and tested for a Spanish-speaking aphasic population.<sup>18</sup>

The reliability of the Spanish adaptation of the scale was high: ICC values 0.94 for the SAQOL-39 scale and between 0.85 and 0.94 for the subscales. This result is similar to those of the original scale, with ICC values 0.98 for the total scale and between 0.89 and 0.98 for the subscales; <sup>12</sup> it is also similar to the Italian version with ICC values between

0.89 and 0.96.<sup>24</sup> The internal consistency was similar for the three validated tools: Cronbach's  $\alpha$  index values 0.93 (0.74-0.94) for the original version;<sup>12</sup> 0.91 (0.76-0.98) for the Italian version <sup>24</sup> and 0.95 (0.85-0.90) for the Spanish version.

Examining the results of this study, quality of life seems slightly superior than in previous studies. These results might be possibly related to the small size of the sample and the lower severity-mean severity score of aphasia, *i.e.* 3.34, *vs* 3.21 in the study carried out by Posterato.<sup>27</sup>

A wider clinical analysis is being currently made with the aim of finding out the repercussions that aphasia has throughout quality of life and its determining factors.

#### Conclusions

This preliminary study shows good acceptability and reliability of the Spanish adaptation of SAQOL-39 in a small sample of Spanish population with chronic aphasia caused by stroke. The SAQOL-39 should be used in larger samples in order to evaluate its validity, and to confirm the reliability of the scale for its clinical application.

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# APPENDIX I. SAQOL-39: Scoring Sheet. Spanish Version

Durante la semana pasada

| Дитате ta semana pasaaa   |   |   |  |   |  |
|---|---|---|--|---|--|
| ¿Cuánta dificultad tuvo (Repetir antes de cada ítem o cuando sea necesario) | No pude<br>hacerlo  | Mucha<br>dificultad   | Alguna<br>dificultad   | Poca<br>dificultad  | Ninguna<br>dificultad  |
| para preparar la comida?  | 1   | 2   | 3  | 4   | 5  |
| para vestirse?  | 1   | 2   | 3  | 4   | 5  |
| para bañarse o ducharse?  | 1   | 2   | 3  | 4   | 5  |
| para caminar?   | 1   | 2   | 3  | 4   | 5  |
| (Si no puede caminar, señale 1 y pase a la pregunta M7)                     |   |   |  |   |  |
| para mantener el equilibrio al inclinarse o al alcanzar algo?               | 1   | 2   | 3  | 4   | 5  |
| para subir escaleras?   | 1   | 2   | 3  | 4   | 5  |
| para caminar sin pararse a descansar o para moverse con silla de ruedas sin | 1   | 2   | 3  | 4   | 5  |
| pararse a descansar?  |   |   |  |   |  |
| para estar de pie?  | 1   | 2   | 3  | 4   | 5  |
| para levantarse de una silla ?  | 1   | 2   | 3  | 4   | 5  |
| para hacer las tareas de la casa?   | 1   | 2   | 3  | 4   | 5  |
| para terminar las tareas que empezó?  | 1   | 2   | 3  | 4   | 5  |
| para escribir a mano o a máquina?   | 1   | 2   | 3  | 4   | 5  |
| para ponerse los calcetines?  | 1   | 2   | 3  | 4   | 5  |
|   | ¿Cuánta dificultad tuvo (Repetir antes de cada ítem o cuando sea necesario)  para preparar la comida?  para vestirse?  para bañarse o ducharse?  para caminar?  (Si no puede caminar, señale 1 y pase a la pregunta M7)  para mantener el equilibrio al inclinarse o al alcanzar algo?  para subir escaleras?  para caminar sin pararse a descansar o para moverse con silla de ruedas sin pararse a descansar?  para estar de pie?  para levantarse de una silla ?  para hacer las tareas de la casa?  para terminar las tareas que empezó?  para escribir a mano o a máquina? | Cuánta dificultad tuvo (Repetir antes de cada ítem o cuando sea necesario)  para preparar la comida?  para vestirse?  para bañarse o ducharse?  para caminar?  (Si no puede caminar, señale 1 y pase a la pregunta M7)  para mantener el equilibrio al inclinarse o al alcanzar algo?  para caminar sin pararse a descansar o para moverse con silla de ruedas sin  pararse a descansar?  para estar de pie?  para levantarse de una silla ?  para terminar las tareas que empezó?  para escribir a mano o a máquina?  No pude hacerlo  No pude hacerlo | Cuánta dificultad tuvo (Repetir antes de cada ítem o cuando sea necesario)  para preparar la comida?  para vestirse?  para bañarse o ducharse?  para caminar?  (Si no puede caminar, señale 1 y pase a la pregunta M7)  para mantener el equilibrio al inclinarse o al alcanzar algo?  para caminar sin pararse a descansar o para moverse con silla de ruedas sin  para estar de pie?  para estar de pie?  para levantarse de una silla ?  para terminar las tareas que empezó?  para escribir a mano o a máquina?  No pude  Mucha  dificultad  Mucha  dificultad | Alguna dificultad tuvo (Repetir antes de cada ítem o cuando sea necesario)  para preparar la comida?  para vestirse?  para bañarse o ducharse?  para caminar?  (Si no puede caminar, señale 1 y pase a la pregunta M7)  para mantener el equilibrio al inclinarse o al alcanzar algo?  para caminar sin pararse a descansar o para moverse con silla de ruedas sin  para estar de pie?  para elevantarse de una silla ?  para la caminar las tareas de la casa?  para terminar las tareas que empezó?  para escribir a mano o a máquina?  No pude  Mucha Alguna  Mucha Alguna  Mucha Alguna  Mucha Alguna  Para sillente la casar algo.  1 2 3  3 3  3 3  3 4  3 4  4 2 3  4 2 3  4 2 3  4 2 3  4 2 3  4 3 4  4 2 3  4 3 4  4 4 2 3  4 5 4 3  4 5 4 3  4 5 4 3  4 5 5 5 6 5 6  4 6 7 5 7 6 7 6  4 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 | No pude hacerlo  Mucha dificultad luvo (Repetir antes de cada ítem o cuando sea necesario)  para preparar la comida?  para vestirse?  1 2 3 4  para vestirse?  1 2 3 4  para bañarse o ducharse?  1 2 3 4  (Si no puede caminar, señale 1 y pase a la pregunta M7)  para mantener el equilibrio al inclinarse o al alcanzar algo?  para caminar sin pararse a descansar o para moverse con silla de ruedas sin  para estar de pie?  para estar de pie?  para levantarse de una silla ?  para levantarse de una silla ?  para terminar las tareas que empezó?  1 2 3 4  4 2 3 4  4 3 4  4 4 3 4 4 5 5 6 7 6 7 6 7 6 7 6 7 6 7 6 7 6 7 6 7 |

| UE4. | para abrocharse los botones?  | 1 | 2 | 3 | 4 | 5 |
|------|---|---|---|---|---|---|
| UE5. | para subir la cremallera?   | 1 | 2 | 3 | 4 | 5 |
| UE6. | para abrir un tarro?  | 1 | 2 | 3 | 4 | 5 |
| L2.  | para hablar?  | 1 | 2 | 3 | 4 | 5 |
| L3   | en hablar claramente por teléfono?  | 1 | 2 | 3 | 4 | 5 |
| L5.  | en conseguir que otras personas le entendieran?                                     | 1 | 2 | 3 | 4 | 5 |
| L6.  | en encontrar la palabra que quería decir?   | 1 | 2 | 3 | 4 | 5 |
| L7.  | en conseguir que otras personas le entendieran incluso repitiéndolo?                | 1 | 2 | 3 | 4 | 5 |
| T4.  | ¿Tuvo que escribir las cosas para recordarlas (o pedir a alguien que las escribiera | 1 | 2 | 3 | 4 | 5 |
|      | para que usted las recordase)?  |   |   |   |   |   |
| T5.  | ¿Le resultó difícil tomar decisiones?   | 1 | 2 | 3 | 4 | 5 |
| P1.  | ¿Estuvo irritable?  | 1 | 2 | 3 | 4 | 5 |
| P3.  | ¿Le pareció que le había cambiado el carácter?                                      | 1 | 2 | 3 | 4 | 5 |
| MD2. | ¿Se sintió desanimado por su futuro?  | 1 | 2 | 3 | 4 | 5 |
| MD3. | ¿Perdió el interés por las personas o actividades?                                  | 1 | 2 | 3 | 4 | 5 |
| MD6. | ¿Se sintió retraído con otra gente?   | 1 | 2 | 3 | 4 | 5 |
| MD7. | ¿Tuvo poca confianza en sí mismo?   | 1 | 2 | 3 | 4 | 5 |
| E2.  | ¿Se sintió cansado la mayor parte del tiempo?                                       | 1 | 2 | 3 | 4 | 5 |
| E3.  | ¿Tuvo que pararse a menudo a descansar durante el día?                              | 1 | 2 | 3 | 4 | 5 |
| E4.  | ¿Se sintió demasiado cansado para hacer lo que quería?                              | 1 | 2 | 3 | 4 | 5 |
| FR7. | ¿Sintió que era una carga para su familia?  | 1 | 2 | 3 | 4 | 5 |
| FR9. | ¿Sintió que sus problemas para hablar afectaban a su vida familiar?                 | 1 | 2 | 3 | 4 | 5 |
| SR1. | ¿Salió de casa con menos frecuencia de lo que le gustaría?                          | 1 | 2 | 3 | 4 | 5 |
|      |   |   |   |   |   |   |

| SR4. | ¿Practicó sus aficiones y diversiones con menos frecuencia de lo que le hubiera | 1 | 2 | 3 | 4 | 5 |
|------|---|---|---|---|---|---|
|      | gustado?  |   |   |   |   |   |
| SR5. | ¿Vió a sus amigos con menos frecuencia de lo que le hubiera gustado?            | 1 | 2 | 3 | 4 | 5 |
| SR7. | ¿Sintió que su estado físico afectaba a su vida social?                         | 1 | 2 | 3 | 4 | 5 |
| SR8. | ¿Sintió que sus problemas al hablar afectaban a su vida familiar?               | 1 | 2 | 3 | 4 | 5 |
|      |   |   |   |   |   |   |

SAQOL-39 Puntuación media: sumar todas las respuestas y dividir entre 39

Puntuación de la escala Física (SC+M+W+UE+SR7)/17

Puntuación de la escala Comunicación (L+FR9+SR8)/7

Puntuación de la escala Psicosocial (T5+P+MD+FR7+SR1+SR4+SR5)/11

Puntuación de la escala Vitalidad (T4+E)/4

**TABLE I**. Demographic and clinical characteristics.

| Variable   | N. (%)       |
|--|--------------|
| Sex  |              |
| Female   | 7 (30.4%)    |
| Male   | 16 (69.6%)   |
| Age  | 10 (07.070)  |
| Mean (SD)  | 57±10.64     |
| Range  | 42-74        |
| Stroke type  | 72 /7        |
| Ischemic   | 19 (82.6%)   |
| Hemorrhagic  | 4 (17.4%)    |
| Time since stroke (months)                           | (17.770)     |
| Mean (SD)  | 43.97±46.56  |
| Range  | 11.41-216.92 |
| Employment status                                    | 11111 210172 |
| Active   | 3 (13%)      |
| Unemployment   | 2 (8.7%)     |
| Retired  | 16 (69%)     |
| Homemaker  | 2 (8.7%)     |
| Aphasia type (Boston Diagnostic Aphasia examination) | ` ,          |
| Broca  | 9 (39.1%)    |
| Wernicke   | 1 (4.3%)     |
| Transcortical motor aphasia                          | 5 (21.7%)    |
| Transcortical sensory aphasia                        | 3 (13%)      |
| Anomic aphasia                                       | 1 (4.3%)     |
| Global aphasia                                       | 4 (17.4%)    |
| Severity rating scale (0-5)                          |              |
| Mean (SD)  | 3.34±1.02    |
| Range  | 2-5          |
| Barthel Index  |              |
| Range  | 85-100       |
| Depression   |              |
| Yes  | 5 (21.7%)    |
| No   | 18 (78.3%)   |
| Social situation                                     |              |
| Family support                                       | 19 (82.6%)   |

| Living alone      | 3 (13%)  |
|-------------------|----------|
| Institutionalized | 1 (4.3%) |

**TABLE II**. Mean scores of SAQOL-39 and its domains.

|               | Mean (SD)   | Range     | Floor/ceiling<br>effect (%) |  |
|---------------|-------------|-----------|-----------------------------|--|
| Physical      | 4.05 (0.73) | 2.40-5    | 0/43                        |  |
| Communication | 3.29 (0.99) | 1.57-5    | 0/4.3                       |  |
| Psychosocial  | 3.67 (1.06) | 1.63-5    | 0/4.3                       |  |
| Energy        | 3.98 (0.86) | 1-5       | 4.3/39.1                    |  |
| SAQOL-39      | 3.75 (0.86) | 2.06-4.94 | 0/0                         |  |
|               |             |           |                             |  |

**TABLE III**. Internal consistency and test-retest reliability.

| SAQOL-39      | Cronbach's α | ICC   |
|---------------|--------------|-------|
|               |              |       |
| Total score   | 0.950        | 0.949 |
| Physical      | 0.890        | 0.944 |
| Communication | 0.864        | 0.894 |
| Psychosocial  | 0.900        | 0.933 |
| Energy        | 0.851        | 0.854 |
|               |              |       |

ICC: intraclass correlation coefficient.