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To cite this article: Gregoire Python, Mélissa Henchoz, Elodie Séchaud, Leïla Simao, Sophie Arheix-Parras & Bertrand Glize (25 May 2025): Health-related quality of life in French-speaking persons with chronic aphasia: adaptation and validation of the SAQOL-39F, *Aphasiology*, DOI: [10.1080/02687038.2025.2508448](https://doi.org/10.1080/02687038.2025.2508448)

To link to this article: <https://doi.org/10.1080/02687038.2025.2508448>



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Published online: 25 May 2025.



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Health-related quality of life in French-speaking persons with chronic aphasia: adaptation and validation of the SAQOL-39F

Gregoire Python ^{a,b}, Mélissa Henchoz^a, Elodie Séchaud^a, Leïla Simao^a, Sophie Arheix-Parras ^c and Bertrand Glize ^c

^aFaculty of Psychology and Educational Sciences, University of Geneva, Geneva, Switzerland;

^bNeurorehabilitation Unit, Department of Clinical Neurosciences, CHUV, Lausanne, Switzerland; ^cPhysical and Rehabilitation Medicine Unit, CHU Bordeaux, University of Bordeaux, Bordeaux, France

ABSTRACT

Background: Quality of life measures related to health issues such as aphasia are essential to perform a comprehensive assessment of each individual situation and provide adequate care. The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) is a tool internationally recognized covering three domains: communication, physical and psychosocial. Currently, the SAQOL-39 is not validated in French.

Aims: Three experiments were conducted to: 1) adapt the SAQOL-39 in French, 2) validate the scale in persons with aphasia, 3) explore the responses given by neurotypical persons to this self-questionnaire.

Methods and procedures: In Experiment 1, guidelines were used for the cross-cultural adaptation of the SAQOL-39 in French. Preliminary testing of the scale was conducted in six persons with aphasia. In Experiment 2, twenty-two persons with chronic aphasia were recruited in Switzerland and in France. Participants completed the SAQOL-39F twice, as well as the Sickness Impact Profile 65 (SIP-65). Acceptability, reliability and validity were analyzed. In Experiment 3, twenty-two matched neurotypical controls completed the SAQOL-39F. We explored the specificity of the overall scale, of each domain and of each item.

Outcomes and results: The SAQOL-39 was successfully adapted in French following a forward-backward translation procedure. The validation in persons with aphasia revealed good acceptability, validity and reliability of the scale. The exploration in a matched group of neurotypical individuals showed a good specificity of the overall scale and of the three domains assessed by the SAQOL-39, whereas a few individual items were not particularly discriminant.

Conclusion: The present findings support the use of the SAQOL-39F in the assessment of French-speaking persons with aphasia.

ARTICLE HISTORY

Received 10 December 2024
Accepted 7 May 2025


KEYWORDS

chronic health condition;
quality of life; post-stroke
aphasia; self-questionnaire;
well-being

Introduction

Aphasia has a major impact on health-related quality of life (HRQoL) (Lam & Wodchis, 2010). In people with aphasia (PWA), HRQoL can be influenced either primarily by aphasia

CONTACT Gregoire Python  gregoire.python@unige.ch  Neuropsycholinguistics Lab, Geneva University, 40 Bd du Pont-d'Arve, Geneva 1205, Switzerland

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/02687038.2025.2508448>.

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and associated cognitive impairments, or secondarily by social isolation or/and low mood (Doogan et al., 2018). The onset of aphasia in one's life deeply modifies the way of communicating with others and participating in social interactions. Additionally, physical limitations also typically appear alongside aphasia, due to the vicinity of language and sensorimotor neural networks. It is therefore crucial to investigate all these domains by means of self-reported measures in PWA (Hilari et al., 2003, 2012).

The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) is a self-questionnaire specifically developed for PWA that shows good psychometric properties (Hilari et al., 2003). The SAQOL-39 is part of the core set of evidence-based measures highly recommended to assess aphasia treatment outcomes (Wallace et al., 2019). It consists of 39 questions that PWA rate on a 5-point Likert scale. In its generic version (SAQOL-39 g; Hilari et al., 2009), the questions are classified in three domains: physical (16 questions), communication (7 questions), psychosocial (16 questions). The scale has been translated/adapted in at least 17 languages¹ (Ahmadi et al., 2017). However, no version of the SAQOL-39 g currently exists in French.

To evaluate HRQoL in PWA with tools validated in French, it is currently possible to use a shortened version of the Sickness Impact Profile (SIP-136), the SIP-65 (Bénaïm et al., 2003). This shortened version for PWA includes 65 questions in physical, psychological and social domains. Even though the original questionnaire has been shortened, the questions of the SIP have not been specifically elaborated for PWA. In addition, the responses are binary in the SIP (Yes/No): such answer format does not allow the individuals to provide a nuanced answer and might lead to positive bias (Rivera-Garrido et al., 2022). As the SIP-65 can be considered the current gold-standard in French to assess HRQoL in aphasia, it will be compared to the French version of the SAQOL-39 g, named thereafter SAQOL-39F.

In previous studies conducted in other languages, PWA self-ratings at the SAQOL-39 g have been compared to self-ratings of brain-damaged persons without aphasia. Usually, a significant difference has been found between the two populations with lower scores for PWA (e.g., Guo et al., 2017; Hilari et al., 2009; Kristinsson & Halldorsdottir, 2021; Manders et al., 2010), especially in the communication domain (Sommer et al., 2024). Another type of comparison was also sometimes made between PWA self-ratings and caregivers' ratings at the SAQOL-39 g. In general, it was shown that caregivers' rated post-aphasia HRQoL lower than PWA themselves (e.g., Azizbeigi-Boukani et al., 2021; Hilari et al., 2007; Ignatiou et al., 2012). The few studies comparing self-ratings of PWA with self-ratings of matched neurotypical persons (NTP) showed that all domains of the SAQOL-39 were rated lower by PWA than NTP (e.g., Bueno-Guerra et al., 2024; Manders et al., 2010). However, a detailed comparison per item was sparsely conducted and could provide fine-grained data about the items/areas mostly discriminant within the scale, that should deserve particular interest for therapeutic inputs. Such a detailed exploratory analysis per item is proposed here.

The aims of the present study were:

- (1) to translate and culturally adapt the SAQOL-39 g into French (Experiment 1);
- (2) to validate the SAQOL-39F in a population of chronic French-speaking PWA (Experiment 2);
- (3) to explore the specificity of the SAQOL-39F by item (Experiment 3).

As the SAQOL-39 g has already been successfully translated/adapted in many languages, we expect to find similar psychometric properties in French than in other multilingual versions of the scale. Additionally, we expect NTP to report higher scores than PWA for most of the items.

Experiment 1: cross-cultural translation/adaptation and preliminary testing of the SAQOL-39F

The first experiment aimed at translating and culturally adapting the SAQOL-39 g into French, to make the SAQOL-39F available for French-speaking PWA. Permission to translate and adapt the SAQOL-39 g was obtained from the original author.

Methods

Participants

Five university students (three in speech and language therapy, one in engineering, one in law) and six speech and language therapists (SLTs) were involved in the cross-cultural translation and adaptation of the SAQOL-39 g into French. A preliminary version of the scale was tested on six PWA. The PWA were French-speaking and suffered a left hemispheric stroke (3 ischemic, 3 hemorrhagic) at least 12 months prior their enrolment (range 17–236, mean 113, SD 87). Their mean age was 63 (range 39–73, SD 12) and the mean years of education was 12 (range 9–16, SD 2). Aphasia severity was assessed by Goodglass et al. (1964) Aphasia Severity Rating Scale (ASRS) from 0 to 5, where 0 means “no usable speech or auditory comprehension” and 5 means “minimal discernable speech handicaps, patient may have subjective difficulties which are not apparent to listener”. Participants with ASRS scores from 2 to 4 were included, whereas PWA with lower/higher scores were excluded, as well as participants with severe cognitive impairments who would be unable to follow the entire protocol. PWA did not have any known history of psychiatric or neurological disease before their stroke. Participant data is summarized in Table 1. Participants were recruited in university hospitals in Switzerland (CHUV, Lausanne) and France (CHU, Bordeaux), as part of larger research protocols validated by local ethics committees. They all gave written informed consent in accordance with the Declaration of Helsinki.

Table 1. Characteristics of the PWA recruited for experiment 1.

| Participant | Gender | Age | Handedness | Education | Type of stroke | Lesion site in LH | TPO | Aphasia type | Aphasia severity |
|-------------|--------|-----|------------|-----------|----------------|-------------------|-----|--------------|------------------|
| Pa | F | 39 | R | 16 | Hemorrhagic | Temporal | 28 | Conduction | 4 |
| Pb | F | 63 | L | 12 | Ischemic | Perisylvian | 236 | Global | 2 |
| Pc | F | 70 | R | 13 | Hemorrhagic | Frontal | 97 | TC Motor | 3 |
| Pd | F | 61 | R | 11 | Hemorrhagic | Basal ganglia | 110 | Broca | 2 |
| Pe | F | 70 | A | 11 | Ischemic | Perisylvian | 191 | Conduction | 4 |
| Pf | M | 73 | R | 9 | Ischemic | Perisylvian | 17 | Broca | 3 |

F = Female; M = Male; R = Right; L = Left; A = Ambidextrous; LH = Left Hemisphere; TPO = Time Post stroke Onset.

Materials & procedure

The presentation form and the scoring form of the SAQOL-39 g (Hilari et al., 2009) were translated from English into French, following the guidelines of Beaton et al. (2000) in six stages:

- (I) Initial English-French Translation: two forward translations of the SAQOL-39 g into French were performed by four persons: translation A was done individually by three informed translators (a SLT and two students in speech and language therapy) and translation B was done by an uninformed translator (university student in law);
- (II) Synthesis: the three informed translators met to resolve translation issues between A and B versions, and to reach a consensus;
- (III) Back Translation French-English: the output of Stage II was translated backwards by two bilingual persons blind to the original questionnaire: translation A' was done by an informed translator (student in speech and language therapy) and translation B' was done by an uninformed translator (university student in engineering);
- (IV) Expert Committee Consensus: the informed translators and three independent SLTs compared the original SAQOL-39 g to versions A' and B', they discussed until they reached agreement about the French wording of the entire questionnaire (note that members of the committee came from Switzerland and from France, to optimize acceptability in both countries);
- (V) Pre-Test: the pre-SAQOL-39F was administered to six PWA by two SLTs for preliminary testing. The eight people involved were asked to comment on the clarity of the wording;
- (VI) Finalization: the final version of the SAQOL-39F was elaborated by the expert committee following the comments obtained in stage V.

The administration guide of the SAQOL-39 g was translated by one SLT and two students in speech and language therapy.

Results

The final scoring form, presentation form and administration guide of the SAQOL-39F can be found in the supplementary material.

During stage IV, the expert committee decided that it was too restrictive to begin all questions of the second part of the questionnaire with the same words as in the original version ("Did you ..."), because two different auxiliaries are used in French ("Avez-vous ... " or "Etes-vous ... "). For greater clarity, all questions of the second section were transcribed in full.

The comments of the six PWA and the two SLTs in stage V led to the following modifications:

- for the general instructions, « Durant la semaine écoulée, quelles difficultés avez-vous eues pour ... » was replaced by « Durant cette dernière semaine, à quel point c'était difficile de ... »

- item M4: « Garder l'équilibre en vous penchant ou en vous étirant » was simplified and replaced by « Garder l'équilibre »
- item M7: « Marcher sans faire de pause ou utiliser une chaise roulante sans faire de pause » was replaced by « Marcher (ou utiliser une chaise roulante) sans avoir besoin de faire une pause »
- item M8: « Vous tenir debout » was clarified and replaced by « Vous tenir debout (sans marcher) »
- item W1: « Effectuer les tâches domestiques quotidiennes » was simplified and replaced by « Effectuer les tâches domestiques »
- item W2: « Terminer les tâches que vous aviez commencées » was clarified and replaced by « Terminer les choses que vous aviez commencées à la maison »
- item UE1: « Ecrire à la main ou taper sur un clavier, c'est-à-dire, utiliser votre main pour l'écriture manuscrite ou dactylographiée » was rephrased and replaced by « Utiliser votre main pour tenir un crayon/stylo ou taper sur un clavier »
- item L3: « Parler suffisamment bien pour utiliser le téléphone » was simplified and replaced by « Parler au téléphone »
- item L7: « Vous faire comprendre par les autres, même en répétant plusieurs fois » was replaced by « Vous faire comprendre par les autres, même après avoir répété plusieurs fois ».

Interim discussion

The SAQOL-39g was translated and adapted into French, to provide clinicians and researchers working with PWA a tool recognized internationally to assess HRQoL. The inclusion of PWA within the adaptation process led to substantial rewording. The final version of the SAQOL-39F seems suitable for use in Switzerland and in France, and hopefully in other French-speaking countries such as Belgium, Canada, *etc.* The benefits of the current adaptation will be further discussed in the general discussion.

Experiment 2: validation of the SAQOL-39F

The second experiment investigated the psychometric properties of the SAQOL-39F in a group of persons with chronic aphasia.

Methods

Participants

Twenty-two PWA, who did not participate in Experiment 1, were recruited for Experiment 2 (8 females, 14 males). They were French-speaking and suffered a left hemispheric stroke (19 ischemic, 3 hemorrhagic) at least 12 months prior their enrolment (range 17–191, mean 76, SD 53). Their mean age was 60 (range 33–82, SD 13) and the mean years of education was 14 (range 9–18, SD 2). Aphasia severity was assessed by Goodglass et al. (1964) ASRS from 0 to 5, where 0 means “no usable speech or auditory comprehension” and 5 means “minimal discernable speech handicaps, patient may have subjective difficulties which are not apparent to listener”. Participants with ASRS scores from 1 to 5 were

Table 2. Characteristics of the PWA recruited for experiment 2.

| Participant | Gender | Age | Handedness | Education | Type of stroke | Lesion site in LH | TPO | Aphasia type | Aphasia severity |
|-------------|--------|-----|------------|-----------|----------------|-------------------|-----|--------------|------------------|
| P1 | F | 58 | R | 12 | Ischemic | Perisylvian | 65 | Broca | 5 |
| P2 | F | 58 | R | 14 | Ischemic | Perisylvian | 128 | Broca | 5 |
| P3 | M | 73 | R | 13 | Ischemic | Perisylvian | 93 | Wernicke | 4 |
| P4 | F | 57 | R | 11 | Ischemic | Perisylvian | 117 | Broca | 2 |
| P5 | M | 55 | L | 16 | Ischemic | Perisylvian | 138 | Broca | 4 |
| P6 | M | 62 | R | 16 | Ischemic | Perisylvian | 79 | TC Sensory | 2 |
| P7 | F | 68 | R | 15 | Hemorrhagic | Temporo-parietal | 151 | Wernicke | 2 |
| P8 | F | 70 | A | 18 | Ischemic | Perisylvian | 48 | Wernicke | 3 |
| P9 | M | 69 | R | 13 | Ischemic | Perisylvian | 52 | Conduction | 4 |
| P10 | M | 33 | R | 17 | Ischemic | Perisylvian | 23 | Broca | 2 |
| P11 | M | 63 | R | 13 | Ischemic | Perisylvian | 157 | Broca | 3 |
| P12 | M | 55 | R | 12 | Ischemic | Insular | 17 | Anomic | 5 |
| P13 | M | 74 | R | 12 | Ischemic | Perisylvian | 191 | Conduction | 4 |
| P14 | M | 48 | R | 12 | Ischemic | Fronto-insular | 30 | TC Motor | 5 |
| P15 | M | 73 | R | 17 | Ischemic | Perisylvian | 28 | Wernicke | 4 |
| P16 | M | 55 | R | 12 | Ischemic | Perisylvian | 17 | Global | 1 |
| P17 | M | 62 | R | 10 | Ischemic | Perisylvian | 22 | Broca | 4 |
| P18 | M | 66 | R | 12 | Ischemic | Perisylvian | 119 | Global | 1 |
| P19 | F | 38 | R | 14 | Hemorrhagic | Perisylvian | 53 | Broca | 3 |
| P20 | F | 82 | R | 15 | Ischemic | Perisylvian | 72 | Conduction | 4 |
| P21 | F | 38 | R | 17 | Ischemic | Parietal | 60 | Anomic | 5 |
| P22 | M | 72 | R | 12 | Ischemic | Perisylvian | 19 | Wernicke | 2 |

F = Female; M = Male; R = Right; L = Left; A = Ambidextrous; LH = Left Hemisphere; TPO = Time Post stroke Onset.

included. We excluded PWA with very severe aphasia scoring 0 at the ASRS or/and with severe cognitive impairments who would be unable to follow the entire protocol. Persons with global aphasia had sufficient comprehension skills to understand the purpose of the experiment and the questions using the presentation form and reformulations when necessary. PWA did not have any known history of psychiatric or neurological disease before their stroke. Participant data is summarized in [Table 2](#). Participants were recruited in university hospitals in Switzerland (CHUV, Lausanne) and France (CHU, Bordeaux), as part of larger research protocols validated by local ethics committees. They all gave written informed consent in accordance with the Declaration of Helsinki.

Materials and procedure

The final version of the SAQOL-39F was used (see Experiment 1). The 39 questions of this self-questionnaire covered three domains: physical (16 items), communication (7 items), psychosocial (16 items). The assessed individuals had to answer using a Likert scale from 1 to 5. A higher score indicated a higher health-related quality of life (5=no difficulty). PWA were tested at home by three university students finishing their Master studies in speech and language therapy. Test-retest reliability was assessed in all participants, with an interval of 15 ± 7 days.

Data analyses

To test the acceptability of the SAQOL-39F, the same criteria as the original tool were used (Hilari et al., 2003): completeness of data (<10% missing responses) and distribution of

data (floor/ceiling effects with < 80% of responses at the bottom/top ends of the response scale; skewness of data with < 25% of items showing an asymmetry coefficient of $z > \pm 1$). The reliability of the SAQOL-39F was assessed for the overall score and for each domain by internal consistency measures (Cronbach's alpha/coefficients) and test-retest measures (Intraclass Correlation Coefficients, ICC). The validity of the SAQOL-39F was assessed in terms of construct validity with regard to internal relationships (Pearson's correlations between the overall score and each domain, as well as between domains) and in terms of criterion validity (Pearson's correlation between the scores obtained at the SAQOL-39F and at the SIP-65). Note that in the SAQOL-39F higher scores indicate better HRQoL, whereas in the SIP-65 higher scores reflect reduced HRQoL, so that a negative correlation was expected. Until now, the SIP-65 was the most cited tool validated in French to assess quality of life in PWA. Finally, to explore if the severity of aphasia was related to HRQoL, we computed Pearson's correlations between ASRS scores and SAQOL-39 scores for the overall scale and for each domain.

Results

The overall SAQOL-39F score reached 3.76 on average in the PWA group (range 2.23–4.94), with a standard deviation of 0.74. Regarding acceptability, there was no missing data, so that 0 items reached the criterion for missing data set at > 10%. Negative skewness of $z > -1$ was found for 28% of the items, i.e., 11 questions (SC1, SC4, SC5, M1, M8, W2, UE2, UE4, UE5, P3, MD3). No floor/ceiling effects were found in the overall and domains scores, or in the individual items. The psychometric properties of the SAQOL-39F can be found in Table 3. In terms of internal consistency, Cronbach's coefficients were excellent for the overall score (0.95), for communication (0.94) and for the physical domain (0.92). The alpha was good for the psychosocial domain (0.89). Test-retest reliability was good: according to the classification of Koo and Li (2016), Intraclass Correlation Coefficients (ICC) were good for the overall score (0.82) and for each domain (Physical: 0.76, Communication: 0.83, Psychosocial: 0.82). Concerning the construct validity targeting internal relationships, Pearson's correlations showed that the overall score

Table 3. Psychometric properties of the SAQOL-39F.

| Reliability measures | | | | Validity measures | | | |
|--------------------------|------|-------------------------------|------|---|--------|------------------------|--------|
| Internal consistency (a) | | Test-retest reliability (ICC) | | Construct validity – Internal relationships (r) | | Criterion validity (r) | |
| Overall | 0.95 | Overall | 0.82 | Overall-Physical | 0.85 | SAQOL-39F vs SIP-65 | -0.83 |
| | | | | | p<.001 | | p<.001 |
| Physical | 0.92 | Physical | 0.76 | Overall-Communication | 0.83 | | |
| | | | | | p<.001 | | |
| Communication | 0.94 | Communication | 0.83 | Overall-Psychosocial | 0.85 | | |
| | | | | | p<.001 | | |
| Psychosocial | 0.89 | Psychosocial | 0.82 | Physical-Communication | 0.69 | | |
| | | | | | p<.001 | | |
| | | | | Physical-Psychosocial | 0.52 | | |
| | | | | | p=.01 | | |
| | | | | Communication-Psychosocial | 0.53 | | |
| | | | | | p=.01 | | |

was significantly related to each domain score, and that all domain scores significantly correlated with each other. For the criterion validity, the mean scores at the SAQOL-39F significantly correlated with the mean scores at the SIP-65, suggesting an adequate convergence between the two tools. Concerning the impact of aphasia severity on HRQoL, ASRS scores significantly correlated with SAQOL-39F overall scores ($r = .43$, $p = .04$), the communication domain ($r = .56$, $p < .01$) and the physical domain ($r = .46$, $p = .03$), but not with the psychosocial domain ($r = .18$, $p = .43$).

Interim discussion

The psychometric evaluation of the SAQOL-39F in a sample of chronic PWA showed that it was an acceptable, valid and reliable scale in French. Overall, the results were similar to those found for the original SAQOL-39 g and other translated/adapted versions. Note however as a limitation that we did not fully evaluate reliability, validity and responsiveness of the SAQOL-39F according to the nine measurement properties of the CONsensus-based Standards for the selection of health Measurement INSTRUMENTS.² For instance, it could be useful in future research to test the inter-rater reliability or the responsiveness of the SAQOL39-F (i.e., its ability to detect changes in HRQoL over time). For the criterion validity, it seems that scores at the SAQOL-39F converge with scores at the SIP-65, the current gold-standard in French to assess HRQoL in PWA. Even if the SIP-65 could introduce response bias due to its binary response format, there was nevertheless a significant negative correlation between the two scales, suggesting that the scores at the SAQOL-39F might consistently reflect the current gold-standard measures. Finally, aphasia severity seems related to HRQoL ratings in the present sample, especially in terms of communication abilities and physical associated deficits. The benefits and the limitations of the current validation will be further discussed in the general discussion.

Experiment 3: comparison of persons with aphasia (PWA) and NeuroTypical persons (NTP)

The third experiment compared the SAQOL-39F ratings of PWA from Experiment 2 with ratings of NTP. The aim was not to obtain normative data, but to explore the specificity of the scale and more especially which items were the most (or the less) discriminant.

Methods

Participants

Twenty-two NTP, with similar age ($t(21) = 1.29$, $p = .21$) and education ($t(21) = -.55$, $p = .58$) as the PWA of Experiment 2, were recruited for Experiment 3 (13 females, 9 males). They were French-speaking and did not have any known history of psychiatric or neurological disorders. Their mean age was 57 (range 35–78, SD 9) and the mean years of education was 13 (range 9–17, SD 2). Participant data is summarized in Table 4. Participants were recruited by three university students finishing their Master studies in speech and language therapy, as part of larger research protocols validated by local ethics committees. They all gave written informed consent in accordance with the Declaration of Helsinki.

Table 4. Characteristics of NTP recruited for experiment 3.

| Participant | Gender | Handedness | Age | Education |
|-------------|--------|------------|-----|-----------|
| N1 | M | L | 57 | 13 |
| N2 | F | R | 54 | 15 |
| N3 | F | R | 55 | 12 |
| N4 | M | R | 52 | 12 |
| N5 | M | R | 56 | 15 |
| N6 | F | R | 54 | 15 |
| N7 | F | R | 54 | 13 |
| N8 | F | R | 76 | 12 |
| N9 | M | R | 70 | 13 |
| N10 | F | R | 58 | 11 |
| N11 | F | R | 35 | 13 |
| N12 | F | L | 54 | 12 |
| N13 | F | R | 58 | 12 |
| N14 | M | R | 58 | 12 |
| N15 | F | R | 78 | 9 |
| N16 | M | L | 47 | 17 |
| N17 | F | R | 60 | 15 |
| N18 | M | L | 57 | 17 |
| N19 | M | R | 57 | 17 |
| N20 | F | R | 54 | 15 |
| N21 | M | R | 48 | 12 |
| N22 | F | R | 55 | 12 |

F = Female; M = Male; R = Right; L = Left.

Materials and procedure

The final version of the SAQOL-39F was used (see Experiments 1 and 2). As the NTP did not present with aphasia/language disorders, the terminology “vos difficultés de langage” (in English “your language problems”) from items FR9 and SR8 was adapted into “votre langage” (in English “your language”). NTP were tested at home by three university students finishing their Master studies in speech and language therapy.

Data analyses

To estimate the extent to which responses differed between the PWA group and the NTP group, one-sided paired t-tests were used between groups to compare: the overall scores, the scores of each domain and the scores of each item of the scale.

Results

The mean scores and standard deviations for each group and the comparison between the two groups can be found in [Table 5](#). PWA scores were significantly lower than NTP scores, both for the overall scale and for each domain. At the item level, all means were descriptively lower for PWA as compared to NTP. For the physical domain, 75% of items (12/16) were scored significantly lower by PWA than by NTP. For the communication domain, 100% of items (7/7) were scored significantly lower by PWA than by NTP. For the psychosocial domain, 50% of items (8/16) were scored significantly lower by PWA than by NTP.

Standard deviations were numerically larger in the PWA group as compared to the NTP group. The 22 NTP usually showed some variance in scoring, except for 2 items where

Table 5. Mean scores and standard deviations per group for the total scale, for each domain and for each item, and statistical comparison.

| | PWA group (n=22) | | NTP group (n=22) | | p |
|---------------|------------------|------|------------------|------|-------|
| | Mean | SD | Mean | SD | |
| Overall | 3.76 | 0.74 | 4.63 | 0.39 | <.001 |
| Communication | 3.14 | 1.17 | 4.86 | 0.23 | <.001 |
| Physical | 4.22 | 0.72 | 4.84 | 0.22 | <.001 |
| Psychosocial | 3.57 | 0.89 | 4.31 | 0.75 | .002 |
| Item1 SC1 | 4.50 | 0.67 | 4.77 | 0.43 | .06 |
| Item2 SC4 | 4.95 | 0.21 | 4.91 | 0.43 | .33 |
| Item3 SC5 | 4.91 | 0.29 | 5.00 | 0.00 | .08 |
| Item4 M1 | 4.41 | 0.85 | 4.73 | 0.63 | .08 |
| Item5 M4 | 4.05 | 1.05 | 4.68 | 0.57 | .008 |
| Item6 M6 | 3.91 | 1.23 | 4.77 | 0.53 | .002 |
| Item7 M7 | 4.23 | 0.97 | 4.91 | 0.43 | .002 |
| Item8 M8 | 4.27 | 1.12 | 4.86 | 0.35 | .01 |
| Item9 M9 | 4.27 | 0.94 | 4.82 | 0.50 | .01 |
| Item10 W1 | 4.14 | 1.04 | 4.86 | 0.35 | .002 |
| Item11 W2 | 4.09 | 1.27 | 4.64 | 0.73 | .04 |
| Item12 UE1 | 3.36 | 1.53 | 4.91 | 0.29 | <.001 |
| Item13 UE2 | 4.23 | 1.19 | 4.77 | 0.53 | .03 |
| Item14 UE4 | 4.18 | 1.05 | 4.95 | 0.21 | .001 |
| Item15 UE5 | 4.09 | 1.19 | 4.95 | 0.21 | .001 |
| Item16 UE6 | 3.91 | 1.23 | 4.91 | 0.29 | <.001 |
| Item17 L2 | 3.14 | 1.28 | 4.95 | 0.21 | <.001 |
| Item18 L3 | 3.00 | 1.35 | 5.00 | 0.00 | <.001 |
| Item19 L5 | 3.32 | 1.29 | 4.95 | 0.21 | <.001 |
| Item20 L6 | 2.91 | 1.23 | 4.45 | 0.67 | <.001 |
| Item21 L7 | 3.59 | 1.18 | 4.86 | 0.47 | <.001 |
| Item22 T4 | 2.55 | 1.68 | 3.36 | 1.53 | .05 |
| Item23 T5 | 3.68 | 1.29 | 4.45 | 0.86 | .01 |
| Item24 P1 | 3.27 | 1.52 | 3.73 | 1.28 | .14 |
| Item25 P3 | 3.86 | 1.46 | 4.82 | 0.66 | .004 |
| Item26 MD2 | 3.36 | 1.40 | 4.32 | 0.95 | .006 |
| Item27 MD3 | 4.14 | 1.32 | 4.55 | 0.80 | .11 |
| Item28 MD6 | 3.68 | 1.43 | 4.82 | 0.66 | .001 |
| Item29 MD7 | 3.68 | 1.32 | 4.41 | 1.10 | .03 |
| Item30 E2 | 3.14 | 1.61 | 3.73 | 1.35 | .10 |
| Item31 E3 | 3.45 | 1.44 | 4.09 | 1.11 | .05 |
| Item32 E4 | 3.82 | 1.44 | 4.36 | 0.95 | .07 |
| Item33 FR7 | 3.91 | 1.48 | 4.86 | 0.64 | .004 |
| Item34 FR9 | 3.18 | 1.71 | 4.86 | 0.47 | <.001 |
| Item35 SR1 | 3.32 | 1.49 | 4.55 | 1.10 | .002 |
| Item36 SR4 | 3.82 | 1.44 | 4.09 | 1.27 | .25 |
| Item37 SR5 | 3.95 | 1.21 | 4.23 | 1.31 | .24 |
| Item38 SR7 | 3.45 | 1.57 | 4.64 | 0.58 | .001 |
| Item39 SR8 | 2.82 | 1.56 | 4.95 | 0.21 | <.001 |

a ceiling effect was observed. All 22 NTP indicated that they had no trouble at all (i.e., they all scored 5/5) for the items:

- SC5: trouble to take a bath/shower;
- L3: trouble to speak clearly enough to use the phone.

In the NTP group, most of items reached mean scores above 4/5, except 3 items:

- T4: did you have to write things down to remember them (or ask somebody else to write things down for you to remember)? (mean 3.36/5);

- P1: did you feel irritable? (mean 3.73/5);
- E2: did you feel tired most of the time? (mean 3.73/5).

For these 3 items, the mean scores of NTP remained descriptively higher as compared to PWA, but the difference between the groups did not reach significance.

Interim discussion

The administration of the SAQOL-39F in a sample of NTP confirmed that it was a relevant and sensitive tool to evaluate HRQoL in PWA, as the mean scores of each domain were significantly lower in PWA than in age- and education-matched NTP. Note however as a limitation that inter-rater reliability and test-retest reliability were not examined in Experiment 3. At the item level, it was interesting to note that all items of the communication domain were highly discriminant, whereas some items from the physical domain and from the psychosocial domain did not robustly differentiate the two groups. For instance, the items “do your hobbies less often than you would like” (SR4) or “see friends less often than you would like” (SR5) were rated in a similar way by both groups, even if the underlying reasons might (or not) differ between the groups. This suggests that either neurotypical adults might suffer from physical or psychosocial limitations in the absence of neurological disorders, or that the present sample of PWA did not present with severe physical or psychosocial deficits at the chronic stage. The benefits of the current exploration will be further discussed in the general discussion.

General discussion

The present experiments aimed at adapting the SAQOL-39 g into French, validating the tool in a sample of chronic French-speaking persons with aphasia and exploring the specificity of the scale by comparing item scores with a sample of neurotypical individuals. The SAQOL-39F was successfully adapted and made available in French, validated in a sample of chronic PWA with good psychometric properties in terms of validity and reliability, and most items showed discriminant value. In terms of direct clinical implications, the validated SAQOL-39F can be used from now on to measure aphasia treatment outcomes in French-speaking PWA, as part of an evidence-based core outcome set (Wallace et al., 2019). In everyday clinical practice with French-speaking individuals, within-subject comparisons can now be made with an internationally recognized tool over the course of speech and language therapy to estimate the evolution of HRQoL in each PWA. The current results will be put in perspective with data from other languages without claiming to be exhaustive (see Table 6 for some SAQOL-39 data in other languages)¹. Actually, a transcultural meta-analysis including all language versions of the SAQOL-39 could be very informative to better understand the variables affecting health-related quality of life in aphasia over the world.

Descriptively, the present sample of PWA tested with the SAQOL-39F reported higher overall scores than PWA tested with the original SAQOL-39 (Hilari et al., 2003), the Persian version (Azizbeigi-Boukani et al., 2021), the Portuguese version (Rodrigues & Leal, 2013) or the Serbian version for instance (Vukovic et al., 2022). The scores of French-speaking PWA were more similar to scores of PWA tested in

Table 6. SAQOL-39 validation sample size, time post-stroke and overall score in some other languages.

| Authors and publication year | Language | PWA sample size (n) | Time post-stroke (mean±SD, range) | Overall score (mean±SD) |
|---------------------------------------|------------|---------------------|---|-------------------------|
| Hilari et al. (2003) | English | 83 | 42±37.1 months, 13–250 | 3.26±0.70 |
| Posteraro et al. (2004) | Italian | 12 | ~1 to 4 years, na | 4.14±0.67 |
| Kartsona and Hilari (2007) | Greek | 10 | 4.4±na years, 1–8 | 3.54±0.75 |
| Lata-Caneda et al. (2009) | Spanish | 23 | 44±46.6 months, 11–217 | 3.75±0.86 |
| Manders et al. (2010) | Dutch | 43 | 4±3 months, 0.5–16 | 3.65±0.58 |
| Rodrigues and Leal (2013) | Portuguese | 33 | 32±29.9 months, 11–120 | 3.17±0.75 |
| Kamiya et al. (2015) | Japanese | 54 | 2.1±na years, 0.6–5.8 | See Fig. 1, p. 2563 |
| Qiu et al. (2019) | Chinese | 84 | 38 PWA <6 months 21 PWA 6–12 months 19 PWA >12 months | 3.51±0.6 |
| Kristinsson and Halldorsdottir (2021) | Icelandic | 10 | 121±66 months, na | 3.73±0.66 |
| Azizbeigi-Boukani et al. (2021) | Persian | 30 | 10 PWA <6 months 20 PWA ≥6 months | 3.19±0.79 |
| Vukovic et al. (2022) | Serbian | 90 | 11±7 months, 2–36 | 2.27±0.69 |
| Širca Ule and Vidmar (2024) | Slovenian | 73 | 58±na months, 5–278 | 3.55±0.70 |
| Sommer et al. (2024) | Danish | 22 | 29.6±55.7 months, 1–266 | 3.50±0.70 |
| Current report | French | 22 | 76±53 months, 17–191 | 3.76±0.74 |

na = information not available

Spanish (Lata-Caneda et al., 2009), Icelandic (Kristinsson & Halldorsdottir, 2021), Dutch (Manders et al., 2010), Slovenian (Širca Ule & Vidmar, 2024), Danish (Sommer et al., 2024), Greek (Kartsona & Hilari, 2007), Chinese (Qiu et al., 2019) or Japanese (according to Figure 1 in Kamiya et al., 2015). On top of inherent interindividual differences, several factors could explain the variation of scores across versions.

First, the chronicity of aphasia might play a role. As in the original study, French-speaking participants were recruited at least 12 months post-stroke here. Descriptively, PWA from the present sample were on average at a more chronic stage of recovery than in the original study. Some SAQOL-39 versions like Icelandic, Spanish, Portuguese, Japanese, Slovenian also included rather chronic PWA and from a large range of times post-stroke. In contrast, other versions included PWA in the first 6 months post-stroke, for instance Persian and Chinese. Interestingly, the Serbian version which reported the lowest overall scores included participants from 2 months post-stroke onwards. Longitudinally, it has been shown that a SAQOL-39 test-retest interval of 8 months led to significantly higher scoring for communication and psychosocial domains in PWA that were first tested 7 ± 4 months post-stroke (Manders et al., 2010). In a sample of post-stroke individuals (comprising a minority of PWA), an increase in SAQOL-39 scores has been reported between the acute stage and 3 months post-stroke, with changes beginning to plateau between 3 and 6 months (Hilari et al., 2009). Therefore, it is likely that HRQoL evolves positively over time, at least for some PWA.

Second, the severity of aphasia or/and the presence of comorbidities could negatively impact HRQoL. In the present sample, there was a significant relationship between ASRS scores and SAQOL-39F ratings for the overall scale, as well as for the communication domain and for the physical domain. This result is consistent with existing literature, especially for the communication domain (e.g., Dvorak et al., 2021; Hilari et al., 2012; Williamson et al., 2011). Therefore, the variation of SAQOL-39 scores across studies and PWA samples could reflect a varying level of aphasia severity. The presence of comorbidities (such as other cognitive deficits, mood disorders, sensorimotor impairments, etc.) was not assessed here and could also have a direct or indirect impact on HRQoL (Doogan et al., 2018).

Third, the sample size might also partially explain the variation of scores across language versions. Determining the sample size for the psychometric validation of scales seems to lack clear recommendations (Anthoine et al., 2014). Whereas the initial development of the SAQOL-39 in English involved 83 PWA, validations in other languages were undertaken in various sample sizes (from 10 PWA in Greek or in Icelandic, 12 PWA in Italian, 23 in Spanish to 84 PWA in Chinese, 90 in Serbian for instance). Therefore, the current sample size of 22 PWA seems to fit well into the range of other SAQOL-39 versions. Although numerous translations and validations have already shown good psychometric properties (Ahmadi et al., 2017), a sample size of 22 PWA remains only a first step towards the validation of the SAQOL-39 in French. Generalizing the results from the present study still deserves caution due to the small sample size and its heterogeneity, and further testing on a larger sample is recommended. Another limitation of the present study is the lack of caregivers' ratings. To further assess the relevance of the SAQOL-39F and capture the impact of aphasia not only on PWA themselves but also on their relatives' perceptions, future studies could compare ratings of PWA with ratings of caregivers, as it has been done in some other languages.

Fourth, cultural and socioeconomic factors specific to each individual, country or living area might also influence health-related ratings. The well-being of the overall population in a given place seems related to the human development index (Koochi et al., 2017). It is therefore possible that the availability and performance of healthcare systems impacted the scores of SAQOL-39 across countries. To delineate specifically the role of health in quality of life measures, future studies could compare different types of quality of life in PWA: overall quality of life (with generic scales not focusing on health), quality of communication life, etc. The present exploratory investigation in a small sample of neurotypical individuals suggested that even in a population without stroke, psychosocial aspects might be rated as unsatisfactory. Social participation and activities might be important factors affecting quality of life, with or without aphasia. Interestingly, the psychosocial domain was the only domain not correlating with aphasia severity in the present sample of PWA. Although quality of life could be estimated by generic questionnaires focusing on pre-determined domains, the concept of "quality of life" is highly subjective and multidimensional (O'Boyle, 1994). It has been defined as "*individual's perceptions of their position in life in the context of the culture and value systems where they lived and in relation to their goals, expectations, standards and concerns*" (WHOQOL Group, 1996, p. 354). As long as each person can have his or her own goals, expectations, standards and concerns in life, quality of life determinants will vary accordingly. Therefore, to capture individual quality of life closer to reality, an individual rating scale allowing the choice of the most important domains in life might be an interesting option to consider (O'Boyle, 1994). Moreover, to understand if quality of life scores are directly impacted by aphasia, it would be crucial to investigate the pre-morbid/pre-aphasia state in future self-reported questionnaires. To this aim, an alternative would be to develop a scale where PWA could explicitly report the level of *change* before vs after the onset of aphasia.

Notes

1. For an up-to-date list of available languages, see <https://cityaccess.org/tests/saqol-39g/>
2. <https://www.cosmin.nl>

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Gregoire Python  <http://orcid.org/0000-0002-9239-6035>

Sophie Arheix-Parras  <http://orcid.org/0000-0002-6146-7275>

Bertrand Glize  <http://orcid.org/0000-0001-9618-2088>

Data availability statement

The individual dataset can be obtained by contacting the authors.

Supplemental online material

The final scoring form, presentation form and administration guide of the SAQOL-39F are included as supplementary material.

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