



City Research Online

City, University of London Institutional Repository

Citation: van Ewijk, L., Versteegde, L., Raven-Takken, E. & Hilari, K. (2016). Measuring quality of life in Dutch people with aphasia: development and psychometric evaluation of the SAQOL-39NL. *Aphasiology*, doi: 10.1080/02687038.2016.1168919

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/14924/>

Link to published version: <https://doi.org/10.1080/02687038.2016.1168919>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Title: Measuring Quality of Life in Dutch People with Aphasia: Development and Psychometric Evaluation of the SAQOL-39NL.

Short Running Title: Development of the Dutch SAQOL-39

Authors: Lizet van Ewijk, PhD, Lotte Versteegde, MSc, Evelijn Raven, MSc, Katerina Hilari, PhD

Affiliations

Lizet van Ewijk, PhD. Corresponding author. HU Utrecht University of Applied Science, Department of Speech and Language Therapy. Heidelberglaan 7, 3584 CS, Utrecht, the Netherlands. +31 88481 5939 . lizet.vanewijk@hu.nl

Lotte Versteegde, MSc. HU Utrecht University of Applied Science, Department of Speech and Language Therapy. Heidelberglaan 7, 3584 CS, Utrecht, the Netherlands. Lotte.versteegde@hu.nl

Evelijn Raven, MSc. HU Utrecht University of Applied Science, Department of Speech and Language Therapy. Heidelberglaan 7, 3584 CS, Utrecht, the Netherlands. Merem Behandelcentra, Revalidatiecentrum de Trappenberg, the Netherlands. Evelijn.raven@hu.nl

Katerina Hilari, PhD. City University London, Division of Language and Communication Sciences. k.hilari@city.ac.uk

Number of words: 4570 (including tables)

Acknowledgements.

We are very grateful to all participating aphasia centres and the aphasic participants, and the bachelor SLT students at the HU University of Applied Sciences who were involved in the first stages of the development of this instrument.

ABSTRACT

Background: Cross-cultural adaptation of health related quality of life (HRQL) scales is useful as it allows comparisons of therapy outcomes across different countries to be drawn.

Aims: A) To adapt the English Stroke and Aphasia Quality of Life– 39 item generic stroke scale (SAQOL-39g) into Dutch B) To investigate the psychometric properties (acceptability, internal consistency, test-retest reliability and construct validity) of the Dutch version (SAQOL-39NL).

Methods & procedures: A) Established guidelines for cross-cultural adaptation of self-report measures were followed. B) Individuals with chronic aphasia were recruited from six centres in The Netherlands. Participants completed the SAQOL-39NL and a visual analogue scale on HRQL in an interview format with an aphasia specialist speech and language therapist.

Outcomes & results: A) the cross cultural adaptation resulted in a consensus version of the SAQOL-39NL, which participants (n=13) felt was informative and of value in assessing the impact of stroke on their lives. B) The SAQOL-39NL was acceptable (no missing data; no floor or ceiling effects) to people with chronic aphasia (n=47). Internal consistency (Chronbach's alpha = 0.89 for scale; 0.84-0.91 for domains), and test-retest reliability were excellent (ICC=0.90 for scale, 0.70-0.93 for domains). Internal validity (moderate intercorrelations between domains), and convergent validity ($r = 0.45$) were good.

Conclusions & implications: The SAQOL-39NL is a psychometrically sound measure of HRQL for Dutch speaking people with aphasia. As is common with new measures, its psychometric properties need to be evaluated further; and its appropriateness as a

clinical outcome measure needs to be determined. Yet, the SAQOL-39NL is a promising new measure for use in clinical practice, audit and research.

Keywords: quality of life, SAQOL-39, outcome measures

INTRODUCTION

Each year around 45,000 people in the Netherlands suffer a stroke (Vaartjes, Reitsma, & de Bruin, et al., 2008). Truelsen et al. (2006) show that in Western Europe the proportion of the population aged 65+, in which most stroke events occur, will increase from 20% in 2000 to 35% in 2050, indicating that the number of strokes is likely to increase dramatically over the next few decades. Furthermore, as stroke mortality rates decline (Ingall, 2004) there is an increase in the number of individuals surviving stroke with residual impairments and disability.

A stroke has a profound effect on the physical, emotional and social abilities of the affected individual. Traditionally rehabilitation care focused on the physical and functional impact of stroke on daily life. More recently the impact of stroke on health related quality of life (HRQL) has become an important outcome in rehabilitation care (Teasell et al., 2014).

One of the most devastating effects of stroke is the development of aphasia, a language disorder that affects approximately 30% of stroke survivors (Engelter et al., 2006). Aphasia severely affects the individuals' ability to communicate; their participation in social activities; and their social support (Cruice, Worrall, & Hickson, 2005; Hilari & Northcott, 2006; Hilari, 2011). Between 62-70% of people with

aphasia (PWA) develop clinical depression (Kauhanen et al., 2000). Those with aphasia are also prone to losing their friends and to social isolation and exclusion (Parr, 2007; Northcott & Hilari, 2011). Despite these detrimental effects, most stroke-specific quality of life scales have not been developed and tested with people with stroke and aphasia and/or cognitive decline (Hilari, 2011). When aphasic individuals are included in stroke outcome studies, it is evident that their HRQL is severely affected. In a cohort study exploring long term outcomes of people with stroke, it was found that the individuals with aphasia participated in less activities and reported worse quality of life than those without aphasia, even when physical abilities, well-being and social support were comparable (Hilari, 2011).

As yet, there is no reliable, valid instrument to measure HRQL in Dutch people with stroke and aphasia. Post-stroke aphasia is often still an exclusion criterion in large cohort studies investigating long-term outcome in stroke (e.g. Liu et al., 2014; Visser, et al., 2014). In the Restore4Stroke project (van Mierlo et al., 2014), a longitudinal study on quality of life in people with stroke and their partners, aphasia was not an exclusion criterion, but for PWA with affected verbal communication, HRQL was not self-reported. Instead, observational measures were used to gauge their quality of life. This is a problematic choice since quality of life is highly personal; and even partners of PWA have difficulties estimating the less observable domains of HRQL of their spouse, such as the psychosocial domain (Cruice et al., 2005).

The need for a reliable and valid Dutch HRQL instrument suitable for those with stroke with and without aphasia is evident. Raven, van Ewijk and Beelen (2014) carried out a review and critical appraisal of HRQL scales for individuals with

aphasia and concluded that the Stroke and Aphasia Quality of Life scale (SAQOL-39, Hilari, Byng, Lamping, & Smith, 2003) is the most reliable and valid instrument currently available (in English). The instrument demonstrates excellent accessibility, reliability, validity, and good responsiveness to change in PWA (Hilari et al., 2003) and people with stroke with or without aphasia (SAQOL-39g, Hilari et al., 2009). It has been adapted for several languages, including in Europe: Italian (Posteraro, et al., 2004), Greek (Kartsona & Hilari, 2007; Efstratiadou et al., 2012), Spanish (Lata-Caneda et al., 2009), Norwegian (Berg, Haaland-Johansen, & Hilari, 2010), and Flemish (Manders, Dammenkens, Leemans, & Michiels, 2010). Furthermore, the SAQOL-39 is currently used in large-scale evaluations of the effectiveness of aphasia therapy in Germany (Baumgaertner et al., 2013) and Australia (Godecke et al., 2014). Adapting this existing measure for Dutch will not only allow the measurement of HRQL outcomes in people with stroke and aphasia in The Netherlands, but will also allow comparisons of outcomes across different countries.

The current paper presents the process of cultural adaptation and evaluation of the psychometric properties of the Dutch SAQOL-39g.

METHODS

The process of translation and adaptation of the SAQOL-39g to the SAQOL-39NL will be described first (phase I), followed by the methods used to evaluate the psychometrics properties of the SAQOL-39NL (phase II).

Phase I: Translation and cross-cultural adaptation

The SAQOL-39g (Hilari et al., 2009) was used for translation. The guidelines for the process of cross-cultural adaptation of self-report measures described by Beaton, Bombardier, Guillemin, & Bosi Ferraz (2000) were used for the adaptation process, which consisted of six stages:

1. Translation: three translators translated the SAQOL-39g into Dutch: two speech and language therapy students (informed translators) and one law student (the uninformed translator).
2. Synthesis. The three translators resolved any discrepancies between the translations, until they reached agreement about the Dutch wording of each item.
3. Backward translation: two naive Dutch-English bilingual speakers translated the measure back to English. One of these speakers was familiar with aphasia and medical terminology; the other did not have any health care related expertise. Both were blind to the original questionnaire.
4. Expert committee review. The translators, the authors and two independent speech and language therapists discussed any discrepancies between the original SAQOL-39g and the backward translated version. The pre-test Dutch SAQOL-39 (SAQOL-39NL) was derived.
5. Pre-test. The SAQOL-30NL was field tested in a group of 13 PWA. Three speech and language therapy students, as well as an independent senior speech and language therapist were involved. The distribution of responses was examined for missing items. In addition, both participants and testers were asked to comment on acceptability and clarity of the measure.

6. Synthesis. Results from stage 5 were used to develop the consensus version of the SAQOL-39NL.

The format of the SAQOL-39NL is the same as the original. The consensus version of the SAQOL-39NL can be found in appendix 1. For ease of comparison, the items IDs match those of the English version.

Phase II: Evaluating the psychometric properties of the SAQOL-39NL

Design and participants

A repeated-measures multi-centre study was carried out in which people with chronic aphasia due to stroke were recruited from six aphasia centres (Almere/Bussum, Drachten, Leeuwarden, Terneuzen, Tilburg and Utrecht). People were excluded if they: had acquired aphasia <1 year ago; had a known history of mental health problems; had other severe or potentially terminal comorbidity; suffered from primary progressive aphasia; or did not speak Dutch pre-morbidly. All participants provided written consent. The research proposal was vetted and approved by the Utrecht University of Applied Sciences Medical Ethical Committee.

Measures

The SAQOL-39NL comprises 39 questions that tap the participant's subjective evaluation of functioning in three domains: physical, psychosocial and communication. Each question is scored on a 5-point scale with one of two response formats [1= 'kon het helemaal niet' (could not do this at all), 5 = 'helemaal geen moeite' (no difficulties) and 1= 'zeker ja' (Definitely yes), 5= 'zeker nee' (Definitely

no)]. The domain scores and overall score are calculated by averaging across items. The convergent validity of the SAQOL-39NL was tested against a single visual analogue scale (VAS) assessing health-related quality of life after stroke. Although using a VAS for measuring HQRL has its limitations (Hilari, 2013), no other existing HRQL measure in Dutch is suitable for PWA. Aphasia was based on SLT diagnosis. To obtain an indication of the severity of aphasia, the SLT at each centre was asked to rate the participant's language skills on a scale from 0-10 (0= no verbal language, 10 = no language disorder).

Procedure

Each participant was interviewed in a quiet room by their speech and language therapist. Interviews lasted between 30-45 minutes and were completed in one session. Participants were offered a break if needed.

Psychometric evaluation and data analysis

In line with Hilari et al. (2009) standard psychometric methods were used to evaluate acceptability, internal consistency, test-retest reliability and construct validity. For acceptability the following criteria were used: missing data <10%; skewness $> \pm 1$ for no more than 25% of items. With regards to the distributions of scores for individual items, floor and ceiling effects <80% (i.e., high endorsement rates at the bottom and top ends of the response scale). For internal consistency: Cronbach's alpha (α) > 0.70 ; item-total correlations ≥ 0.30 (Nunally & Bernstein, 1994); test-retest reliability ICC ≥ 0.75 (Streiner & Norman, 2008). For internal validity we expected moderate correlations between domains and overall score and between domains; and for

convergent construct validity a moderate / strong correlation between SAOL-39NL and VAS.

RESULTS

Phase I: Cross-cultural adaptation and translation

Translation

The first three stages of adaptation comprised: forward translation by three translators, synthesis of these translations, and a backward translation by two bilingual translators. The original version and back-translations were compared. There were no conceptual differences to the original in 35/39 items. Mostly, slight differences were detected, which did not lead to conceptual or semantic differences between the original and back-translations (e.g. '*doing daily work around the house*' became '*carrying out daily household chores around the house*' in one of the back translations). The uninformed translator's back-translation contained some items that were translated inaccurately, leading to semantic differences to the original (e.g. '*feel that your language problems interfered with your family life*' became '*felt that your speech problems were disturbing your family life*'). The most accurate and conceptually true to the original items were taken forward from the two back translations to create the pre-test version, which was used in the pre-test.

Pre-test

Participants

Thirteen participants were recruited at a local aphasia centre. Participants' ages ranged from 39-79 with an average (SD) of 62 (14.5). Average (SD) time post onset

was 7.8 years (4.9) ranging from 7-21years. Participant characteristics are presented in table 1.

Table 1. Phase I participant characteristics (n=13)

Characteristic	Number (percentage)
Gender	
Male	7 (54)
Female	6 (46)
Age	
<i>Mean (SD)</i>	62 (14.5)
<i>Range</i>	39-79
30-60	8 (62)
61-90	5 (38)
Marital status	
Single	2 (15)
Partner / Married	11 (85)
Number of children	
None	3 (23)
1 or more	10 (67)
Time post onset	
<i>Mean (SD)</i>	7.8 (4.9)
<i>Range</i>	4-18
1-5 yrs	7 (54)
6-10 yrs	4 (31)
11-15 yrs	0 (0)
16-20 yrs	2 (15)
Type of Aphasia	
Mixed	2 (15)
Transcortical sensory	1 (8)

Characteristic	Number (percentage)
Anomic	2 (15)
Global	1 (8)
Broca	2 (15)
Wernicke	1 (8)
Unknown	4 (31)
Additional medical information	
Visual difficulties	3 (23)
Epilepsy	3 (23)
Cognitive difficulties	1 (8)
Hearing aid	1 (8)
Average score SAQOL-39	
3.20-3.40	1 (8)
3.41-3.60	3 (23)
3.61-3.80	1 (8)
3.81-4.00	4 (30)
4.01-4.20	1 (8)
4.21-4.41	3 (23)

Both the speech and language therapists and PWA, felt the measure assessed information that had not previously been systematically documented. All participants reported they thought the measure was of great value in assessing the impact of stroke on their life. Based on the feedback of both the speech and language therapists and the PWA, the following changes were made:

Simplifications:

Instructions: “how much difficulty did you have” [*“hoeveel moeite heeft u gehad”*] was changed into “how much difficulty have you had” [*“hoeveel moeite had u”*]

M7: For “using a wheelchair”, “*Gebruik maken van een rolstoel*” was changed into “*een rolstoel gebruiken*”.

L3: For “Speaking clearly enough to use the telephone”, “*Duidelijk genoeg spreken om de telefoon te gebruiken*” was changed into “*Duidelijk genoeg spreken om te telefoneren*”.

MD6: For “Feel withdrawn from other people”, “*Het gevoel gehad dat u zich terugtrok van andere mensen*” was changed into “*Zich teruggetrokken van andere mensen*”.

Clarifications:

L5: For “Getting other people to understand you”, “*Andere mensen u laten begrijpen*” was changed into “*communiceren zodat anderen u begrijpen*”.

L6: For “Getting other people to understand you even when you repeated yourself”, “*Andere mensen u laten begrijpen, zelfs nadat u uzelf heeft herhaald*” was changed into “*communiceren zodat anderen begrijpen, zelfs nadat u uzelf heeft herhaald*”.

These changes were made to create the consensus version of SAQOL-39NL (appendix 1), the psychometric properties of which were investigated in Phase II.

Phase II: Psychometric properties of the SAQOL-39NL

Participants

Fifty aphasic subjects were recruited (a different cohort to the participants in phase I).

Three participants were excluded as they had acquired aphasia within the last 12 months. Participants' age ranged from 35 to 81 with an average (SD) age of 57(11).

Average (SD) time post onset was 5 years (4) and ranged from 1 year to 20 years post

onset. The level of impairment in production or comprehension was not formally assessed. Instead, a rough indication of communicative effectiveness was provided by the local SLT on a scale from 1-10. Participants had an average (SD) score of 5.8 (2) ranging from 2-9. All participants were able to understand the purpose and procedure of the instrument. Test-retest reliability data were obtained for 35 participants and the test-retest interval was 9+/-5 days. For five patients the re-test interval was between 21-41days due to holidays. Participant characteristics are described in table 2.

Table 2. Phase II participant characteristics (N=47)

Characteristic	Number (percentage)
Gender	
Male	23 (51)
Female	24 (49)
Age	
<i>Mean (SD)</i>	<i>57 (11)</i>
<i>Range</i>	<i>34-81</i>
30-60	24 (51)
61-90	20 (43)
Unknown	3 (6)
Aetiology	
Ischaemic (i)CVA	24 (51)
Haemorrhagic (h)CVA	9 (19)
iCVA and hCVA	3 (6)
Unknown	11 (23)
Marital status	
Single	8 (17)
Has partner / is married	26 (55)
Divorced	3 (6)

Characteristic	Number (percentage)
Unknown	10 (21)
Living arrangement	
Sheltered accommodation	1 (2)
Living alone	11 (23)
Living with family	25 (51)
Unknown	9 (19)
TPO	
<i>Mean (SD)</i>	5 (4)
<i>Range</i>	1-20
1-5 yrs	31 (66)
6-10 yrs	7 (15)
11-15 yrs	3 (6)
16-20 yrs	2 (4)
Unknown	4 (9)
Communication score*	
<i>Mean (SD)</i>	5.8 (2)
<i>Range</i>	2-9
<5.5	17 (36)
5.6-7.5	15 (32)
7.6-10	9 (19)
Unknown	6 (13)

*The Dutch grading system typically uses a 10 point scale, in which 1 equals very poor and 10 excellent.

The psychometric properties of the SAQOL-39NL are detailed in table 3; and compared to the original SAQOL-39g reported by Hilari et al. (2009).

Table 3. Psychometric properties of the SAQOL-39NL and comparison with SAQOL-39g

Property	Results	
	SAQOL-39NL (n=47)	SAQOL-39g (n=83) ¹
Acceptability		
Missing data (>10%)	0	0
Skewness ($z > \pm 1$)	11 items (28%)	4 items (10.26%)
Scale score range	1-5	1-5
Sample score range	2.33-4.54	1.72-4.46 (1.00-5.00)
Average (SD)	3.65 (0.58)	3.26 (0.70)
Floor effects	0	0
Ceiling effects	0	0
Internal consistency		
Cronbach's alpha		
Overall score	0.89	0.93
Domain scores	Physical = 0.91	Physical = 0.94
	Communication = 0.84	Communication = 0.85
	Psychosocial = 0.84	Psychosocial = 0.85
Item-Total correlations		
Overall	0.08-0.68 (8 items below 0.3)	0.23-0.69
Domain	Physical = 0.38-0.80	Physical = 0.48-0.81
	Communication = 0.48-0.71	Communication = 0.40-0.74
	Psychosocial = 0.19-0.61 (1 item below 0.3)	Psychosocial = 0.26-0.61
Test-retest reliability (ICC)		
	(n=35)	(n=17)
Overall score	0.90	0.98

¹ Adapted from Hilari et al. (2009)

Property	Results	
	SAQOL-39NL (n=47)	SAQOL-39g (n=83) ¹
Domain scores	Physical = 0.93	Physical = 0.98
	Communication = 0.70	Communication = 0.94
	Psychosocial = 0.89	Psychosocial = 0.97
Validity		
Intercorrelations between overall score & domains (r)	Physical = 0.73	Physical = 0.89
	Communication = 0.58	Communication = 0.56
	Psychosocial = 0.73	Psychosocial = 0.81
Intercorrelation between domains (r)	Physical/communication = 0.23	Physical/comm = 0.36
	Physical/psychosocial = 0.12	Physical/psychosocial = 0.50
	(non-significant)	Comm/psychosocial = 0.27
	Comm/psychosocial = 0.36	
Correlation SAQOL-39NL and VAS (r)	0.45 (p<.005)	-

Acceptability

The percentage of missing data was low; none of the items failed the criterion for missing data <10%. There were no floor or ceiling effects in the overall and domain SAQOL-39g scores, or in the individual items. The skewness criterion was marginally failed by 11 items showing negative skewness (SC4, SC5, M1, M8, M9, W2, UE2, UE4, UE5, MD3, FR7), just over 25%.

Internal consistency

Cronbach's alpha for the SAQOL-39NL was 0.89 for the overall score, 0.91 for the physical domain, 0.84 for the communication domain and 0.84 for the psychosocial domain. All fell within the 0.70 – 0.95 range typically considered indicating good internal consistency (Nunnally & Bernstein, 1994)

Test-retest reliability

Test-retest data were obtained for 35 subjects. Overall test-retest reliability was excellent (ICC= 0.90), with ICC=0.93 for the physical domain, ICC=0.89 for the psychosocial domain and ICC=0.70 for the communication domain.

Internal validity

Intercorrelations between domains were low-moderate (0.12-0.36). Intercorrelations between overall and domain scores were good and varied from 0.58-0.73.

Construct validity

The overall score on the SAQOL-39NL correlated with the VAS score for quality of life for each participant. A moderate correlation was found (Pearson's $r = 0.45$, $p < .005$)

DISCUSSION

To resolve a current lack of well-constructed HRQL measurements suitable for people with stroke and aphasia in the Netherlands, the SAQOL-39g was translated into Dutch and its psychometric properties were investigated. Overall the results showed that the SAQOL-39NL was an acceptable, valid and reliable scale for measuring HRQL in

chronic aphasia. Furthermore, the results were similar to those found for the original SAQOL-39g.

In terms of acceptability, none of the items failed the criterion for missing data; the overall percentage of missing data was very low (0.1%). Just over a quarter of the items showed a negative skewness, reflecting a higher quality of life. This proportion is higher than that found for the SAQOL-39g. One possible explanation for this might be the difference in participants. The SAQOL-39NL was administered to a group of participants with chronic aphasia (> 1 year post-stroke), all of whom were involved in activities in aphasia centres. These centres provide a setting for people with chronic aphasia to improve communication and participation in society, usually (long) after the process of rehabilitation has come to an end. It is therefore possible that there is a bias in the HRQL scores obtained for this group of people. The participants in the study by Hilari et al (2009) were up to 6 months post-stroke; and thus possibly at a different stage in their adjustment to life post-stroke.

The internal consistency and test-retest reliability of the measure was excellent and its internal validity was good. The convergent validity of the SAQOL-39NL was tested against a visual analogue scale (VAS) for HRQOL. A significant moderate correlation was found, indicating that the two scales measured similar constructs. The use of a single measurement to assess validity has its obvious limitations. The use of a validated HRQL scale as external validator would provide more reliable information; yet there is no gold standard health related quality of life measure in Dutch that is suitable for PWA.

Further research needs to evaluate the SAQOL-39NL against a range of related measures, tapping on its different domains such as the Barthel Index (Mahoney, Wood, & Barthel, 1958) of activities of daily living, and the General Health Questionnaire (Goldberg, 1972) for psychological distress. Such comparisons would strengthen the evidence on the construct validity of the measure. Moreover, further research could evaluate the psychometric properties of the SAQOL-39NL in a generic group of stroke survivors including those that do not have communication difficulties. This would increase the relevance and usability of the scale in stroke services outcome measurement. In addition, the current study did not investigate the measure's responsiveness to change. In order for clinicians to use the instrument to evaluate effectiveness of therapy, this will need to be investigated.

An important strength of the SAQOL-39NL is that it is a patient reported measure tapping on the impact of stroke and aphasia on people's lives. Yet, outcome measures should not only capture meaningful or functionally relevant changes, but should also facilitate comparisons to other clinical trials and clinical populations; and inform meta-analyses and other synthesis approaches (Brady et al., 2014). Cross-cultural adaptation of key outcome measures can facilitate these comparisons. The SAQOL-39NL adds to the evidence base of the SAQOL-39g, which has been adapted for use in many countries across the world and can thus allow international comparisons of stroke and aphasia outcomes. Such comparisons can highlight the most efficacious treatments and service provision models and thus lead the way to improvements in stroke and aphasia care provision.

In summary, the SAQOL-39NL is a psychometrically sound measure of HRQL for Dutch speaking PWA. As is common with new measures, its psychometric properties need to be evaluated further in independent samples; and its appropriateness as a clinical outcome measure needs to be determined. Yet, the SAQOL-39NL is a promising new measure for use in clinical practice, clinical audit and outcomes research.

REFERENCES

Baumgaertner, A., Grewe, T., Ziegler, W., Floel, A., Springer, L., Martus, P., and Breitenstein, C (2013). FCET2EC (From controlled experimental trial to= 2 everyday communication): How effective is intensive integrative therapy for stroke-induced chronic aphasia under routine clinical conditions? A study protocol for a randomized controlled trial. *Trials*, 14, 308.

Beaton, D., Bombardier, C., Guillemin, F., and Bosi Ferraz, M. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *SPINE*, 25, 3186-3191.

Berg, K., Haaland-Johansen, L. & Hilari, K. (2010). Slag og afasi - et mål for livskvalitet (SALK-39). Nordreisa: Statped Nord & Bredtvet kompetansesenter

Brady, M. C., Ali, M., Fyndanis, C., Kambanaros, M., Grohmann, K. K., Laska, A. C., ... & Varlokosta, S. (2014). Time for a step change? Improving the efficiency, relevance, reliability, validity and transparency of aphasia rehabilitation research through core outcome measures, a common data set and improved reporting criteria. *Aphasiology*, 28(11), 1385-1392.

Cruice, M., Worrall, L., & Hickson, L. (2005). Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners.

Aphasiology, 19(2), 111-129.

Efstratiadou E.A., Chelas E.N., Ignatiou M., Christaki V., Papathanasiou I., & Hilari K. (2012) Quality of life after stroke: evaluation of the Greek SAQOL-39g. *Folia Phoniatrica Logopaedica*, 64(4), 179-186

Engelter, S., Gostynksi, M., Papa, S., Frei, M., Born, C., Ajdacic-Gross, V., et al. (2006). Epidemiology of aphasia attributable to first ischemic stroke: Incidence, severity, fluency, etiology, and thrombolysis. *Stroke*, 37(6), 1379- 1384.

Goldberg, D.P. (1972). *The detection of psychiatric illness by questionnaire*. London: Oxford University Press.

Godecke ,E., Ciccone, N.A., Granger, A.S., Rai, T., West, D., Cream, A., et al. (2014) A comparison of aphasia therapy outcomes before and after a Very Early Rehabilitation programme following stroke. *International Journal of Language and Communication Disorders*, 49, 149-161.

Hilari, K. (2011). The impact of stroke: are people with aphasia different to those without? *Disability and Rehabilitation*, 33(3), 211-218.

Hilari, K., Byng, S., Lamping, D., and Smith, S. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): evaluation of acceptability, reliability and validity. *Stroke*, 34(8), 1944-1950.

Hilari K., Lamping D. L., Smith S. C., Northcott S., Lamb A. and Marshall J. (2009) Psychometric properties of the Stroke and Aphasia Quality of Life scale (SAQOL-39) in a generic stroke population. *Clinical Rehabilitation*, 23(6), 544-557

Hilari, K., and Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17-36.

Ingall, T. (2004). Stroke-Incidence, Mortality, Morbidity and Risk. *Journal of Insurance Medicin*, 36, 143-152.

Kartsona, A., and Hilari, K. (2007). Quality of life in aphasia: Greek adaptation of the Stroke and Aphasia Quality of Life Scale 39 items (SAQOL-39). *Europa Medicophysica*, 43, 27-35.

Kauhanen, M., Korpelainen, J., Hiltunen, P., Määttä, R., Mononen, H., Brusin, E., et al. (2000). Aphasia, Depression, and Non-Verbal Cognitive Impairment in Ischaemic Stroke. *Cerebrovascular Disease*, 10, 455-461.

Lata-Caneda, M., Piñeiro-Temprano, M., García-Fraga, I., García-Amesto, I., Barrueco-Egido, J., and Meijide-Failde, R. (2009). Spanish adaptation of the Stroke and Aphasia Quality of Life Scale 39 (SAQOL-39). *European Journal of Physical and Rehabilitation Medicin.*, 45, 379-384.

Liu N., Cadilhac, D.A., Andrew, N.E., Zeng, L., Li, Z., Li, J., Li, Y., Yu, X., Mi, B., Li, Z., Xu H., Chen, Y., Wang, J., Yao, W., Li, K., Yan, F., and Wang, J. (2014)

Randomized Controlled Trial of Early Rehabilitation After Intracerebral Hemorrhage
Stroke Difference in Outcomes Within 6 Months of Stroke. *Stroke* 45(12), 3502-3507.

Mahoney, F.I., Wood, O.H., Barthel, D.W. (1958) Rehabilitation of chronically ill
patients: the influence of complications on the final goal. *Southern Medical Journal*
51, 605–609.

Manders, E., Dammekens, E., Leemans, I., and Michiels, K. (2010). Evaluation of
quality of life in people with aphasia using a Dutch version of the SAQOL-39.
Disability and Rehabilitation, 32(3), 173-182.

Northcott, S., and Hilari, K. (2011) Why do people lose their friends after a stroke.
International Journal of Language and Communication Disorders, 46(5), 524-534.

Nunnally, J.C., and Bernstein IH. (1994) *Psychometric Theory*. 3rd ed. New York,
NY: McGraw-Hill.

Parr, S. (2007). Living with severe aphasia: tracking social exclusion. *Aphasiology*,
21(1), 98-123.

Posteraro, L., Formis, A., Bidini, C., Grassi, E., Curti, M., Bigli, M., et al. (2004).
Aphasia quality of life: reliability of the Italian version of the SAQOL-39. *Europa*
Mediophysica, 40(4), 257-262.

Raven-Takken, E., van Ewijk, L., and Beelen, A. (2014). Het meten van kwaliteit van
leven bij mensen met een afasie: een critically appraised topic. *Nederlands Tijdschrift*
voor Revalidatiegeneeskunde, 4, 152-156.

Streiner, D.L., and Norman, G.R. (2008). *Health measurement scales, a practical guide to their development and use*. New York: Oxford University Press. 29-33.

Teasell, R., Rice, D., Richardson, M., Campbell, N., Madady, M., Hussein, N., et al. (2014). The next revolution in stroke care. *Expert Review of Neurotherapeutics*, 14(11), 1307-1314.

Truelsen, T., Piechowski-Jozwiak, B., Bonita, R., Mathers, C., Bougouslavsky, J., and Boysen, G. (2006). Stroke incidence and prevalence in Europe: a review of the available data. *European Journal of Neurology*, 13, 581-598.

Vaartjes, I., Reitsma, J., and de Bruin, A. (2008). Nationwide incidence of first stroke and TIA in the Netherlands. *European Journal of Neurology*, 15(12), 1315-23.

van Mierlo, M., van Heugten, C., Post, M., Lindeman, E., de Kort, P., and Visser-Meily, J. (2014). A longitudinal cohort study on quality of life in stroke patients and their partners: Restore4Stroke Cohort. *International Journal of Stroke*, 9(1), 148-154.

Visser, M.M., Heijenbrok-Kal, M.H., van 't Spijker, A., Ribbers, G.M., and Busschbach, J.J.V. (2014) The effectiveness of problem solving therapy for stroke patients: study protocol for a pragmatic randomized controlled trial. *BMC Neurology*, 27, 13-76.

Supplement: SAQOL-39NL Scoresheet

SAQOL-39NL scoreblad

GEDURENDE DE AFGELOPEN WEEK (Herhaal zoals in SAQOL-39NL)

item ID	Hoeveel moeite had u met: (Herhaal voor elk item indien nodig)	Kon het helemaal niet	Veel moeite	Moeite	Een beetje moeite	Helemaal geen moeite	Domeinscores		
							Fysiek	Comm	Psycho- sociaal
SC1.	bereiden van voedsel?	1	2	3	4	5			
SC4.	aankleden?	1	2	3	4	5			
SC5.	een bad of douche nemen?	1	2	3	4	5			
M1.	lopen? (wanneer lopen niet mogelijk is, omcirkel bij M1, M2 en M3 1 en ga naar item M4)	1	2	3	4	5			
M4.	uw balans houden tijdens het voorover buigen of reiken?	1	2	3	4	5			
M6.	traplopen?	1	2	3	4	5			
M7.	lopen zonder te stoppen om te rusten of een rolstoel gebruiken zonder te stoppen om te rusten?	1	2	3	4	5			
M8.	staan?	1	2	3	4	5			
M9.	opstaan uit een stoel?	1	2	3	4	5			
W1.	het doen van dagelijks werk rondom het huis?	1	2	3	4	5			
W2.	afronden van taken die u gestart bent?	1	2	3	4	5			
UE1.	schrijven of typen, <i>d.w.z. gebruik maken van uw hand om te schrijven of typen?</i>	1	2	3	4	5			
UE2.	sokken aantrekken?	1	2	3	4	5			
UE4.	knopen dicht doen?	1	2	3	4	5			
UE5.	ritsen?	1	2	3	4	5			
UE6.	een pot openen?	1	2	3	4	5			
L2.	spreken?	1	2	3	4	5			

L3.	telefoneren?	1	2	3	4	5			
L5.	communiceren zodat anderen u begrijpen?	1	2	3	4	5			
L6.	communiceren zodat anderen u begrijpen, zelfs nadat u uzelf heeft herhaald?	1	2	3	4	5			
L7.	het vinden van het woord dat u wilde zeggen?	1	2	3	4	5			

GEDURENDE DE AFGELOPEN WEEK

Item ID	Heeft u: (Herhaal voor elk item indien nodig)	Zeker ja	Meestal ja	Niet zeker	Meestal nee	Zeker nee	Fysiek	Comm	Psycho-sociaal
T4.	dingen moeten opschrijven om ze te onthouden? (of iemand gevraagd om dingen voor u op te schrijven om te onthouden?)	1	2	3	4	5			
T5.	moeite gehad met beslissingen nemen?	1	2	3	4	5			
P1.	zich prikkelbaar gevoeld?	1	2	3	4	5			
P3.	het gevoel dat uw persoonlijkheid is veranderd?	1	2	3	4	5			
MD2.	zich ontmoedigd gevoeld over uw toekomst?	1	2	3	4	5			
MD3.	geen interesse in andere mensen of activiteiten gehad?	1	2	3	4	5			
MD6.	zich teruggetrokken van andere mensen?	1	2	3	4	5			
MD7.	weinig vertrouwen gehad in uzelf?	1	2	3	4	5			
E2.	zich de meeste tijd moe gevoeld?	1	2	3	4	5			
E3.	vaak moeten stoppen en rusten gedurende de dag?	1	2	3	4	5			
E4.	zich te moe gevoeld om te doen wat u wilde doen?	1	2	3	4	5			
FR7.	het gevoel gehad dat u tot last was voor uw familie?	1	2	3	4	5			
FR9.	het gevoel dat uw taalproblemen uw gezinsleven verstoren?	1	2	3	4	5			
SR1.	minder vaak dan u zou willen iets buitenshuis gedaan?	1	2	3	4	5			
SR4.	uw hobby's en vrije tijdsbesteding minder vaak gedaan dan u zou willen?	1	2	3	4	5			
SR5.	uw vrienden minder vaak gezien dan u zou willen?	1	2	3	4	5			
SR7.	het gevoel dat uw lichamelijke conditie uw sociale leven verstoort?	1	2	3	4	5			
SR8.	het gevoel dat uw taalproblemen uw sociale leven verstoren?	1	2	3	4	5			

	SAQOL-39NL Gemiddelde score	Tel alle items bij elkaar op en deel door 39			
	Fysieke score	$(SC \text{ items} + M \text{ items} + W \text{ items} + UE \text{ items}) / 16$			
	Communicatie score	$(L \text{ items} + FR9 + SR8) / 7$			
	Psychosociale score	$(T \text{ items} + P \text{ items} + MD \text{ items} + E \text{ items} + FR7 + SR1 + SR4 + SR5 + SR7) / 16$			

1. Omcirkel het door de correspondent gekozen cijfer voor ieder item.
2. Om domeinscores te berekenen: verander de items in de codenamen en bereken per kolom de domeinscores.