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Development and validation of a short version of the Stroke-Specific Quality of Life Scale.

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ABSTRACT

Background and purpose

The Stroke-Specific Quality of Life scale (SS-QoL) is a well-validated measure of Health-related Quality of Life in patients with stroke, but, with 49 items, its length is a disadvantage. Our purpose was to develop and test a short version of the SS-QoL.

Methods

Secondary analyses of 3 different studies. We developed the short version using data from 141 patients with aneurysmal subarachnoid haemorrhage (SAH) and tested it on data from independent samples of 97 patients with SAH and 105 patients with ischemic stroke or intracerebral hemorrhage. We selected the item with the highest item-domain correlation from each of the SS-QoL domains to obtain a 12-item SS-QoL (SS-QoL-12) with a total score and physical and psychosocial sub-scores. Criterion validity of the SS-QoL-12 scores was tested in each sample with the original SS-QoL as reference.

Results

All three scores of the SS-QoL-12 showed good internal consistency (Cronbach's alpha 0.78-0.89). The SS-QoL-12 scores predicted 88-95% of the variance of the original SS-QoL. Mean differences between the SS-QoL-12 and the SS-QoL and their 95% confidence intervals were generally within 0.1 point on a 1-5 scale. The limits of agreement were generally within 0.4 point.

Conclusion

The SS-QoL-12 has good criterion validity for all subsets of stroke. Because it consists of only 12 questions, this short form will be easy to use in research and clinical settings.

INTRODUCTION

Persons who survive a stroke often experience a substantial decrease in their Health-Related Quality of Life (HRQoL).¹ The Stroke Specific Quality of Life scale (SS-QoL)^{2,3} is a well-known, standardized, disease-specific measure to assess HRQoL after stroke that has been validated in patients with different types of stroke.^{2,4-6} The SS-QoL consists of 49 items in 12 domains and takes about 15 minutes to complete. This length of the SS-QoL is a disadvantage, as patients with stroke often experience attention and concentration problems⁷ and the measurement of HRQoL is usually only one part of a larger measurement battery. A further drawback of the SS-QoL is that previous studies did not confirm its proposed structure of 12 domains.^{4,8} This number of domains is less practical for research into correlates of HRQoL, leaving a choice to use all 12 domain scores as dependent variables, or to use only the total SS-QoL score with a risk of concealing differences between HRQoL domains. In a previous study in patients with aneurysmal subarachnoid haemorrhage (SAH) we concluded that the 12 domains of the SS-QoL could be merged into 2 subtotal scores representing the dimensions of 'physical' and 'psychosocial' HRQoL.⁹ Both subtotal scores and the total score showed very high internal consistency (Cronbach's alpha 0.95 – 0.97). A 0.73 correlation between the physical and psychosocial subtotal scores however showed that one subtotal score explained only about half of the variance of the other.⁹ Using the two SS-QoL subtotal scores for physical and for psychosocial HRQoL might therefore be a good compromise between simplicity and a need to provide a profile of different aspects of health. The very high internal consistency of these physical and psychosocial subtotal scores suggested that these scores can be accurately reproduced with fewer items, and therefore that it could be possible to develop a short version of the SS-QoL that reveals one total score and two subtotal scores that are equivalent to those of the original 49-item version. Such a short

form would be more practical to use in a clinical setting and as an outcome measure in clinical studies.

The aims of this study were (1) to develop a short-form of the SS-QoL, and (2) to test this short version in independent samples of patients with ischemic stroke, intracerebral haemorrhage and SAH.

MATERIALS AND METHODS

Subjects

We used data from 3 previous studies. The largest available sample was used to develop the short SS-QoL. This sample consisted of all patients who had been treated by clipping or coiling after SAH between January 2003 and July 2005 in the University Medical Centre Utrecht (UMC Utrecht). SAH was diagnosed by computed tomography (CT) and aneurysms by computed tomographic angiography (CTA) or conventional angiography.^{9,10} Patients living in a nursing home and patients with severe co-morbidity or insufficient command of the Dutch language were excluded from the study. All eligible patients received a mailed questionnaire 2-4 years post-SAH.

One validation sample consisted of another group of patients with SAH, also treated at the UMCU, who had been discharged home and who had visited the SAH-outpatient clinic of the UMCU between September 2006 and September 2008. They completed a mailed questionnaire including the SS-QoL 1 year post-SAH (unpublished data).

The other validation sample consisted of patients with first-ever ischemic stroke or intracerebral haemorrhage (IS-ICH) admitted to the stroke units of three hospitals in The Netherlands.¹¹ Inclusion criteria were: age below 85 years, no co-morbidity that might affect outcome and testable within the first 21 days after stroke. Stroke was diagnosed based on the presence of both an acute focal deficit and an associated lesion on computed tomography

(CT) or magnetic resonance imaging (MRI) scans. Exclusion criteria were: (1) pre-existing drug abuse/depression/ADL dependence or cognitive impairment, (2) disturbed consciousness or inability to comprehend task instructions, (3) recurrent stroke, and (4) co-morbidity that might affect outcome. These patients completed the SS-QoL 6 to 11 months post-stroke. The Medical Ethics committee of the UMCU approved all study protocols and all patients gave written informed consent.

Instruments

The SS-QoL consists of 49 items encompassing 12 domains: self-care, mobility, upper extremity function, language, vision, work, thinking, family roles, social roles, personality, mood and energy. Each item is ranked on a 5-point scale, with higher scores indicating better function. Domain scores are the unweighted averages of the items scores and the total score is the unweighted average of the domain scores. All summary scores thereby also range from 1 up to 5.³ In an earlier study, we showed that the 12 domain scores can be merged in two subtotal scores, the first six domains in a physical subtotal score and the last six domains in a psychosocial subtotal score.⁹

Development of the short SS-QoL

To ensure that the short form represents the full scope of the original SS-QoL, one item was selected from each of the 12 domains of the SS-QoL. These domains showed high internal consistency in earlier studies, indicating conceptual homogeneity within each domain.^{2,4,9} The item with the highest item-total correlation, thereby being most representative for the domain score, was selected. These 12 items were grouped into physical and psychosocial dimensions according to the merging of the 12 domains of the SSQoL into a physical and a psychosocial dimension, as described above. The dimension scores and total score of the SS-QoL-12 are

the unweighted averages of the items scores and range from 1 up to 5. A score of, for example, 3.5 on the short version thereby should reflect the same level of HRQoL as a score of 3.5 on the original version.

Statistics

SS-QoL-12 subtotal and total scores were computed. Cronbach's alpha was used to assess internal consistency. Internal consistency requires a Cronbach alpha coefficient of at least 0.70.¹² Criterion validity was examined using the 49-item SS-QoL as reference. The percentages of variance of the SS-QoL scores that could be explained by the 12-item version scores were computed. Bland-Altman plots were used for visual inspection.¹³ Agreement between the 12-item and 49-item versions was examined at group level by computing the mean difference and its 95% confidence interval, and at individual level by computing the limits of agreement ($\pm 1.96 * SD_{\text{difference}}$).¹³ To substantiate these figures, they were expressed as effect sizes by dividing them by the standard deviation of the corresponding 49-item SS-QoL scores. The conventional interpretation of Effect Sizes is: 0.2 is small, 0.5 is medium and 0.8 is large.¹⁴

RESULTS

Population characteristics

The development sample consisted of 141 patients with SAH (response 81%). The SAH validation sample consisted of 97 patients (response 82%). The stroke validation sample consisted of 105 patients (response 71.7%). Respondent characteristics are displayed in table 1.

Table 1. Characteristics of patients

	Development sample (SAH; N=141)	Validation sample (SAH; N=99)	Validation sample (IS-ICH; N=105)
<i>Demographic data</i>			
Gender (% women)	66.7	82.0	47.6
Mean age in years (SD)	51.4 (12.3)	52.8	60.8 (14.3)
Educational level (% at least high school)	31.9	18	43.3
Living with partner (%)	64.9	62.6	
<i>Hospital data</i>			
Mean time after event in months (SD)	36.1 (7.9)	2.1 (1.0)	7.5 (1.3)
Infarction (%)	0	0	89.5
Location of aneurysm (%)			
ICA	23.4	23.4	
MCA	21.3	21.6	
AcomA/ACA	42.6	42.3	
Vertebrobasilar	12.8	11.7	
Complications after SAH (%)			
Re-bleeding	5.7	4.5	
Secondary ischemia	16.3	20.7	
Hydrocephalus	19.9	12.6	
Hydrocephalus and ischemia	3.5	2.7	
Lesion site			
Left supratentorial			42.5
Right supratentorial			43.7
Infratentorial			13.8
GOS at discharge (%)			
Dependent from others (III)	21.2	34.7	
Disability but independent (IV)	32.1	13.3	
Good outcome (V)	46.7	52	
Barthel Index 3 weeks post-stroke (% < 19)			59.6
Cognitive impairment 3 weeks post-stroke (%)*			41.8
SS-QoL scores (49-item) (mean; SD)			
Physical dimension	4.42 (0.60)	4.53 (0.51)	4.29 (0.66)
Psychosocial dimension	3.43 (0.96)	3.95 (0.92)	4.01 (0.84)
Total score	4.00 (0.68)	4.24 (0.65)	4.15 (0.65)

SAH: subarachnoid haemorrhage; IS-ICH: ischaemic stroke or intracerebral haemorrhage; ICA: internal carotid artery; MCA: middle cerebral artery; AComA: anterior communicating artery; ACA: anterior cerebral artery; Vertebrobasilar: arteries of the vertebrobasilar system. GOS: Glasgow Outcome Scale;

*Cognitive impairment: patients with disturbances in at least one cognitive domain (z-score < -1.65)¹¹

Development of the SS-QoL-12

In the development sample, the item-domain correlations of the selected items were very high (0.85-0.95) (table 2). In two domains, there were two items with equal highest item-domain correlations, and we arbitrarily chose one of these two items. The selected items are also displayed in table 2.

Table 2. Selection of 12-items out of the 49-item SS-QoL

Domain ⁽¹⁾	Cronbach's alpha 49-item SS-QoL	Item-total domain correlations 49-item SS-QoL	Item selected for SS-QoL-12	Response set ⁽²⁾	Explained variance of domain by chosen item
Self-care	.85	.77-.85	Did you need help taking a bath or shower?	1	73%
Mobility	.92	.81-.89	Did you have to stop and rest more than you would like when walking or using a wheelchair?	1	79%
Upper extremity	.86	.76-.88	Did you have trouble buttoning buttons? ⁽³⁾	1	78%
Language	.90	.80-.89	Did you have to repeat yourself so others could understand you?	1	80%
Vision	.80	.84-.87	Did you have trouble seeing the television well enough to enjoy a show?	1	75%
Work	.92	.91-.93	Did you have trouble doing daily work around the house?	1	87%
Thinking	.82	.82-.90	I had trouble remembering things.	2	81%
Family roles	.82	.78-.89	I felt I was a burden to my family. ⁽³⁾	2	80%
Social roles	.87	.72-.87	My physical condition interfered with my social life.	2	75%
Personality	.90	.81-.89	My personality has changed.	2	79%
Mood	.85	.71-.85	I was discouraged about my future	2	72%
Energy	.92	.90-.95	I was too tired to do what I wanted to do.	2	90%

- (1) Physical HRQoL: self-care, mobility, upper extremity function, language, vision, work
 Psychosocial HRQoL: thinking, family roles, social roles, personality, mood, energy

- (2) Response set 1: (1) couldn't do it at all; (2) a lot of trouble; (3) some trouble; (4) little trouble (5) no trouble at all
 Response set 2: (1) strongly agree; (2) moderately agree; (3) Neither agree nor disagree; (4) moderately disagree; (5) strongly disagree
- (3) Item arbitrarily chosen from 2 that had equal highest item-rest correlations

Criterion validity of the SS-QoL-12

In all three cohorts, the subtotal and total scores of the SS-QoL-12 showed good internal consistency and SS-QoL-12 scores explained high percentages of variance of the long version (table 3).

Table 3. Internal consistency and criterion validity of the SS-QoL-12 in three different samples

	Physical dimension	Psychosocial dimension	Total SS-QoL-12
Cronbach's Alpha			
Development sample	0.83	0.85	0.89
SAH validation sample	0.78	0.89	0.89
Stroke validation sample	0.80	0.77	0.85
Explained variance (%)			
Development sample	94	95	95
SAH validation sample	94	90	93
Stroke validation sample	91	88	91
Mean difference (95% CI) ⁽¹⁾			
Development sample	0.01 (-0.01 – 0.03)	-0.01 (-0.05 – 0.03)	0.07 (0.04 – 0.10)
SAH validation sample	0.02 (0.00 – 0.05)	0.13 (0.08 – 0.20)	0.08 (0.05 – 0.12)
Stroke validation sample	-0.01 (-0.05 – 0.03)	-0.05 (-0.10 – 0.01)	-0.03 (-0.07 – 0.01)
Limits of agreement			
Development sample	-0.31 – 0.32	-0.49 – 0.46	-0.30 – 0.43
SAH validation sample	-0.24 – 0.29	-0.56 – 0.83	-0.32 – 0.48
Stroke validation sample	-0.45 – 0.43	-0.67 – 0.57	-0.46 – 0.39

⁽¹⁾ Difference SS-QoL-49 and SS-QoL-12 (positive figure if mean score SS-QoL-49 < mean score SS-QoL-12)

The mean differences between scores on the short and long versions were negligible. The percentages of explained variance were very high in all samples, with the lowest percentage (91%) in the IS-ICH sample. A sensitivity analysis showed that an SS-QoL-12 version with

the two other items would have resulted in nearly identical Cronbach's alpha and explained variance figures (maximum 0.01 point or 1% lower). The limit of agreement were also widest in the IS-ICH sample (-0.46 – 0.39). The effect sizes of the individual differences between 12-item and 49 item total scores in the IS-ICH sample were however very small for most patients: between 0 and 0.2 for 53.4% of the sample, between 0.2 and 0.5 for 35.2% of the sample and between 0.5 and 0.8 for the remaining 11.4% of the stroke sample.

All 9 Bland-Altman plots showed a similar relationship between the mean of the 12-item and 49-item scores (X-axis) and the difference between these scores (Y-axis). The plot of the total scores in the stroke sample is displayed in figure 1.

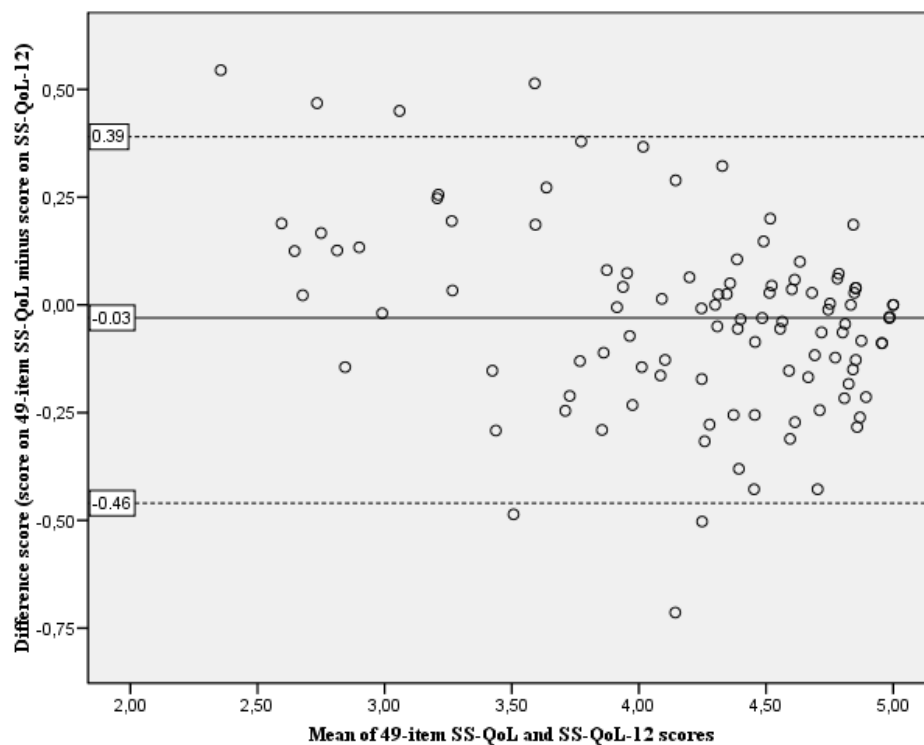


Figure 1: Bland-Altman plot of the differences between the SS-QoL and the SS-QoL-12 scores related to the mean of the SS-QoL and SS-QoL-12 scores in the IS-ICH sample.

Legend: Each circle represents an individual patient. The X-axis represents level of HRQoL, computed as the mean of the 12-item and 49-item scores and Y-axis represents the difference between scores on the 49-item and 12-item SS-QoL versions. The horizontal lines represent the mean difference and the limits of agreement

This plot shows that, in patients with low SSQoL scores, scores on the 12-item version were slightly lower than scores on the 49-item version. For the 10 stroke patients with the worst SS-QoL scores (SS-QoL 49 < 3.25), their mean SS-QoL-12 total score was only 0.16 (SD 0.21) points lower than their score on the original SS-QoL (Effect Size = 0.25).

DISCUSSION

We developed a short version of the SS-QoL, the SS-QoL-12, which appears a valid summary of the original 49-item SS-QoL for patients with ischemic stroke, intracerebral haemorrhage and SAH. This short form questionnaire differs from the long form by as little as 0.5 points on a 5 point scale. The major advantage of this short version is that it minimizes administration time with 37 questions or an estimated 10 minutes. This will make the shorter form easier to administer, and thereby a more practical tool in research and clinical practice

Our results appear robust as the figures from both validation samples were similar to each other and to the development sample. A few limitations however apply to this study. First, the SS-QoL-12 short form was developed in a SAH population. If we had used the sample of patients with ischemic or hemorrhagic stroke to develop the SS-QoL-12, some different items would have been selected. However, all item-domain correlations were high, as expected because this was the way the SS-QoL was developed, and differed only slightly between items and the results of the stroke validation sample were similar to those of the SAH validation sample. Second, we used existing SS-QoL data to validate the short version by selecting the SS-QoL-12 items from the database. In theory, actual answers on the SS-QoL-12

may deviate from answers retrieved for these items from the long SS-QoL, as a patient's answers on these questions might be shaped by the other questions as well. Our approach is however common,¹⁵ as it is less feasible to include short and long versions of the same measure in the same questionnaire, and even then bias by this kind of shaping cannot be excluded. Finally, since we used the Dutch SS-QoL, replication of this study using other language versions is recommended.

In conclusion, pending validation in prospective studies in other countries, we feel the SS-QoL-12 can replace the original SS-QoL in clinical and research settings if only total or subtotal scores are required. If the study goal is to report all 12 individual domain scores, the use of the original SS-QoL is recommended, as these domain scores would be based on only one item for each domain using the SS-QoL-12.

Ethics

The Medical Ethics committee of the UMCU approved all study protocols and all patients gave written informed consent.

Declaration of interest

None

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