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Citation: Hilari, K., Owen, S. & Farrelly, S. J. (2007). Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. *Journal of Neurology, Neurosurgery and Psychiatry*, 78(10), pp. 1072-1075. doi: 10.1136/jnnp.2006.111476

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J. Neurol. Neurosurg. Psychiatry 2007;78;1072-1075; originally published online 26 Jan 2007;
doi:10.1136/jnnp.2006.111476

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Received 18 November 2006
Revised 11 January 2007
Accepted 11 January 2007
Published Online First
26 January 2007

Background and purpose: Health related quality of life outcomes are increasingly used to measure the effectiveness of stroke interventions. People with severe aphasia after stroke may be unable to self-report on such measures, necessitating the use of proxy respondents. We explored the level of agreement between people with aphasia (PWA) and their proxies on the Stroke and Aphasia Quality of Life Scale (SAQOL-39) and whether this agreement is influenced by demographic variables and proxy levels of depression and carer strain.

Methods: People with chronic aphasia (≥ 6 months post stroke) were recruited through the UK national charity for PWA. They were interviewed on the SAQOL-39 and their nominated proxies were interviewed on the SAQOL-39, the General Health Questionnaire and the Caregiver Strain Index. Proxy respondents had to be ≥ 18 years of age, see the person with aphasia at least twice a week and have no known severe mental health problems or cognitive decline.

Results: 50 of 55 eligible pairs (91%) took part in the study. Proxies rated PWA as more severely affected than PWA rated themselves. The SDs of the difference scores were large and the difference was significant for three of the four SAQOL-39 domains and the overall mean ($p \leq 0.01$). However, the bias as indicated by effect sizes was small to moderate (0.2–0.5). The strength of the agreement was excellent for the overall SAQOL-39 and the physical domain (intra-class correlation coefficient ICC 0.8), good for the psychosocial and communication domains (0.7) and fair for the energy domain (0.5). Demographic variables and proxy's mood and carer strain did not affect the level of agreement.

Conclusions: For group comparisons, proxy respondents who are in frequent contact with people with chronic aphasia can reliably report on their health related quality of life, using the SAQOL-39. Although there are significant differences between PWA and proxy responses, the magnitude of this difference is small to moderate.

Patient reported health related quality of life (HRQL) measures are increasingly used to evaluate stroke interventions. A considerable proportion of people with stroke may not be able to self-report on such measures because of cognitive or communication problems. In such cases, a person who knows the patient well may be asked to provide a proxy evaluation of the client's HRQL. Using proxy raters can prevent exclusion of those patients who are most severely affected by stroke and thus avoid systematic bias in study results.^{1 2}

A number of studies have looked at proxy and self-report agreement after stroke, using generic HRQL measures, such as the Sickness Impact Profile (SIP)¹ and the EQ-5D.^{3 4} A recent small study (30 pairs) looked at agreement between people with aphasia (PWA) and their proxies on the Short Form-36 and the Dartmouth COOP Charts.⁵ These studies concur with the general proxy literature in that (a) agreement is better for more concrete, observable domains (eg, physical) than for less observable domains (eg, psychosocial) and (b) proxies tend to score the patients as more severely affected than the patients score themselves.²

Stroke specific HRQL scales that have been developed through consultation with stroke survivors are more likely to capture the effects of stroke on HRQL that are most relevant and important for the patients. Two studies have looked at proxy and self-report agreement with stroke specific measures. Duncan and colleagues⁶ used the Stroke Impact Scale (SIS) and Williams and colleagues⁷ the Stroke Specific Quality of Life Scale (SS-QOL). They report findings consistent with the above.

In the former study, people who could not follow a three step command were excluded, and a further 13 pairs were not included in the analyses because the person with stroke was too aphasic or cognitively impaired. In the latter study, only people with mild aphasia were included (score ≤ 1 on the language item of the National Institute of Health Stroke Scale).

PWA represent the subgroup of stroke survivors that most need a proxy respondent. There is a pressing need for more information on the levels of agreement between PWA and their proxies on HRQL. We specifically aimed to do this using a scale specific to the population under study, the Stroke and Aphasia Quality of Life Scale-39 item (SAQOL-39).⁸ A secondary aim was to explore factors affecting the level of agreement. The stroke literature suggests that agreement is better in the longer term after the stroke⁴ and when the carer's perception of strain is low.^{7 9} Evidence on the effect of patient and proxy mood is conflicting, with Williams and colleagues⁷ reporting better agreement for depressed patients and Knapp and Hewison⁹ finding no effect for patient or proxy mood. The influence of these variables on the level of agreement on HRQL between PWA and their proxies needs further exploration.

Abbreviations: CSI, Caregiver Strain Index; FAST, Frenchay Aphasia Screening Test; GHQ, General Health Questionnaire; HRQL, health related quality of life; ICC, intra-class correlation coefficient; PWA, people with aphasia; SAQOL-39, Stroke and Aphasia Quality of Life Scale-39; SIP, Sickness Impact Profile; SIS, Stroke Impact Scale; SS-QOL, Stroke Specific Quality of Life Scale

SUBJECTS AND METHODS

Design and participants

We carried out a cross sectional survey targeting people with chronic aphasia. They were recruited through Speakability, the UK national charity for PWA. All Speakability groups in and within 1 h driving distance from London ($n = 13$) were invited to take part in the study and 12 agreed to participate. PWA had to meet the following eligibility criteria: (1) aphasia resulting from a stroke; (2) be at least 6 months post stroke and medically stable; (3) be able to nominate a significant other to act as a proxy respondent; and (4) score $\geq 7/15$ on the receptive subtests of the Frenchay Aphasia Screening Test (FAST),¹⁰ which is the cut-off score for self-completion of the SAQOL-39. Proxy respondents had to: (a) be ≥ 18 years of age, (b) see the person with aphasia at least twice a week and (c) have no known severe mental health problems or cognitive decline.

Procedure and measures

All participants were given written information on the project, which was also discussed with them and written consent was obtained. PWA had face to face interviews, and their proxies telephone interviews. This different mode of administration could potentially influence the results. However, preliminary data on the mode reliability of phone and live administration of the SAQOL-39 show it to be a stable measure, with an intra-class correlation coefficient (ICC) of 0.92 for the total mean score and ICCs of 0.72–0.96 for the subdomains (Hilari and Caute, in preparation: Mode reliability of the SAQOL-39).

Aphasia was screened using the receptive domains of the FAST. These comprise two sets of five oral and one set of five written commands of increasing complexity (from one to five information carrying words). Scores range from 0 to 15 with higher scores indicative of milder aphasia. PWA then completed the SAQOL-39 in an interview format with a speech and language therapist with expertise in aphasia. The SAQOL-39 has been adapted for use with PWA from the SS-QOL.¹¹ It consists of 39 items which cover four domains: physical, psychosocial, communication and energy. Domain and overall mean scores range from 1 to 5, with higher scores indicative of better HRQL. Proxy participants completed the following measures by telephone interview: the proxy SAQOL-39 which asks the respondent to answer the questions as they think their partner with aphasia would answer; the General Health Questionnaire-12 item (GHQ-12)¹²; and the Caregiver Strain Index (CSI).¹³ Scores on the GHQ-12 range from 0 to 12 and scores ≥ 3 indicate high emotional distress. Scores on the CSI range from 0 to 13 and a greater level of strain is identified by a score of 7 or more.

Data analysis

Descriptive statistics were used to examine participants' characteristics, PWA's HRQL and proxies' levels of distress and carer strain. Proxy and self-report agreement was explored by calculating ICCs. ICCs < 0.40 were seen as indicating poor agreement; 0.40–0.75 fair to good agreement; and 0.76–1.00, excellent agreement.¹⁴ Mean responses of the PWA and their proxies were compared for each domain and the overall SAQOL-39 using the paired samples Student's *t* tests. Effect sizes were calculated by dividing the mean difference score (proxy minus self-report score) by the SD of the difference score.¹⁵ An effect size of 0.2 was considered a small bias, 0.5 a moderate bias and 0.8 a large bias.¹⁶

RESULTS

Participants

A total of 50 of 55 eligible pairs (91%) took part in the study. One proxy respondent did not speak English and four declined

to take part. Respondents' characteristics are detailed in tables 1 and 2. PWA had a mean age of 63.4 (SD 11.5) years, the majority were male (56%), married/had a partner (74%) and 52% were involved in some type of work. They presented with varying degrees of receptive aphasia with 32% scoring 7–9/15 on the FAST, 38% 10–12 and 30% 13–15. Their proxies were mostly female (66%), somewhat younger (mean age 56.2 (SD 15.3) years) and 92% were related to the PWA. Proxy scores on the GHQ-12 were mean 2.6 (SD 2.9) with a median of 2.0; and on the CSI, 6.1 (3.4) with a median of 6.0; 58% were classified as having good emotional well being (GHQ-12 scores 0–2) and 52% as having low carer strain (CSI scores 0–6).

PWA's HRQL, as scored by themselves and their proxies on the SAQOL-39, is included in table 3. Proxies scored the participants with aphasia as more affected (means 2.8–3.7) than PWA scored themselves (means 3.1–4.0).

Proxy and self-report agreement

Table 3 details the mean SAQOL-39 scores of the PWA and proxies, the difference in mean scores (proxy–PWA) and the agreement statistics (ICCs, *t* tests and effect sizes). Although the proxy–PWA difference scores were small ($(-0.2) - (-0.4)$), their SDs were large (0.6–1.2) and the difference between them was significant for the overall SAQOL-39 ($t = 4.0$, $p \leq 0.001$) and three of its domains (communication $t = 3.4$, $p \leq 0.001$; physical $t = 2.9$, $p \leq 0.01$; and psychosocial $t = 3.0$, $p \leq 0.01$). Despite being statistically significant, these differences between the two groups were small to medium, as suggested by the effect sizes (0.2–0.5). Agreement based on the ICCs was excellent for the overall scale and the physical domain (0.8), good for the psychosocial and communication domains (0.7) and moderate for the energy domain (0.5).

PWA characteristics (age, sex, time post onset and number of comorbid conditions) and proxy characteristics (age, sex, relationship with PWA) did not affect the level of agreement on the SAQOL-39. Severity of receptive aphasia was not significantly correlated with the level of agreement for the overall SAQOL-39 mean and the physical and psychosocial

Table 1 Respondents' characteristics: participants with aphasia ($n = 50$)

Variable	n (%)
Sex	
Female	22 (44)
Male	28 (56)
Age (y)	
Mean (SD)	63.4 (11.5)
Range	32–80
Time post stroke (y)	
Mean (SD)	7.1 (6.1)
Range	1–37
Ethnic group	
Asian	4 (8)
Black	5 (10)
White	41 (82)
Marital status	
Married/has partner	37 (74)
Single	5 (10)
Divorced or widowed	8 (16)
Employment status	
Retired before stroke	17 (34)
Inactive because of stroke	7 (14)
Full time work	18 (36)
Part time or voluntary work	7 (14)
Student	1 (2)
FAST	
Mean (SD)	10.9 (2.3)
Range	7–15

FAST, Frenchay Aphasia Screening Test.

Table 2 Respondents' characteristics: proxies (n = 50)

Variable	n (%)
Sex	
Female	33 (66)
Male	17 (34)
Age (y)	
Mean (SD)	56.2 (15.3)
Range	19–78
Relationship to person with aphasia	
Spouse/partner	37 (74)
Child	6 (12)
Other family	3 (6)
Friend	4 (8)
GHQ-12	
Mean (SD)	2.6 (2.9)
Range	0–12
CSI	
Mean (SD)	6.1 (3.4)
Range	0–13

CSI, Caregiver Strain Index; GHQ, General Health Questionnaire.

domains, but approached significance for the communication domain ($r = 0.3$, $p = 0.057$) and was significantly correlated with agreement for the energy domain ($r = 0.3$, $p = 0.03$).

Various methods were used to explore the potential effect of proxies' carer strain and emotional distress on agreement. Independent sample *t* tests were used to compare agreement on the SAQOL-39 (proxy–PWA difference) of those with high (GHQ-12 score ≥ 3) versus those with low emotional distress and of those with high (CSI score ≥ 7) versus those with low carer strain. We also compared those with both high emotional distress and carer strain ($n = 11$) versus all others ($n = 39$). The results were not significant. As the mean and median scores for both the GHQ-12 and the CSI were close to the cut-off scores, we also used correlation and one way ANOVAs to look at the impact of distress and carer strain on agreement. Again, the results were not significant. We carried out these analyses with both the actual difference scores and the absolute difference scores.

DISCUSSION

This study looked at agreement between people with chronic aphasia and their proxies on the SAQOL-39. Our participants with aphasia were similar to stroke survivors in the UK. Stroke is more common in men and in older people,¹⁷ and in our sample 56% were male and 48% were more than 65 years old. However, our participants attended aphasia support groups and were likely to be better educated about aphasia. Our sample also represents the higher functioning PWA as 52% of them were involved in some type of work as opposed to the 6% reported in a previous study of PWA in Southeast London.¹⁸

Proxy scores were significantly different from the PWA scores on three of the four SAQOL-39 domains and the overall mean. The SDS of the difference scores were large, suggesting that

proxy scores may not necessarily be a good indicator of the self-report scores at the individual level.

At the group level, however, although the proxy respondents systematically rated the PWA as more severely affected than the PWA rated themselves, the magnitude of this bias, as expressed by effect sizes, was small to moderate (0.2–0.5). The magnitude of this bias is comparable but a little worse than those reported in stroke studies, using the SIP (0.01–0.44),¹ the EQ-5D (0.02–0.46)⁴ and the SIS (0.1–0.4).⁶ This would be expected as our sample was comprised exclusively of PWA. Compared with another study which only looked at PWA, the bias occurring on the SAQOL-39 is smaller than that observed with the Short Form-36 (4/8 scores ≥ 0.6 and up to 1.24) and the Dartmouth COOP Charts (4/9 scores ≥ 0.25 and up to 0.84).⁵ These findings suggest that, at a group level, only a modest amount of bias would be introduced when using proxy respondents to report on the HRQL of PWA, using the SAQOL-39. This may be preferable to the alternative of excluding PWA from studies.

Agreement on the ICCs was excellent for the overall SAQOL-39 mean score and the physical domain (0.8) and moderate for the energy domain (0.5). These findings are in line with the level of agreement on objective and subjective domains reported in the literature.² The ICCs for the psychosocial and communication domains of the SAQOL-39 (0.7), however, compare favourably with those reported in other studies. In their review of studies of proxy–patient agreement on the HRQL in people with chronic diseases, Sneeuw and colleagues² found that for studies with $n \geq 50$, median correlations for psychosocial domains were 0.48–0.50. In stroke studies, reported correlations were: for the psychosocial domain of the SIP 0.61,¹ for emotional functioning on the EuroQol 0.30,³ for social–cognitive domains on the Functional Independence Measure 0.61,¹⁹ for anxiety and depression on the EQ-5D 0.43,⁴ for all SS-QOL scores 0.30–0.59⁷ and for the memory, emotion, communication and social participation domains of the SIS 0.50–0.56.⁶

For practical reasons, the PWA in this study had face to face interviews and their proxies had telephone interviews. This is a limitation of the study, as the different mode of administration can introduce some bias. However, as stated in "Procedure and measures" above, preliminary evidence on the mode reliability of the SAQOL-39 suggest that it is a stable measure.

A larger sample size would have allowed us to explore in a more detailed way the potential relationship between participants' characteristics and agreement. However, our findings are in line with larger stroke studies, where the level of agreement was not associated with patient and proxy characteristics^{6–7} or proxy's mood.^{7–9} It was also not associated with carer strain, which contradicts the findings of other studies.^{7–20} This may be because of the overall good levels of agreement in our study, which may be related to the fact that all PWA were 1 year or more after stroke. Agreement tends to be better in the long term⁴ as patients are more stable²¹ and the pairs have had longer exposure to the symptoms.²²

Table 3 Comparison of respondents' scores on the SAQOL-39 (pairs, n = 50)

SAQOL-39	PWA (mean (SD))	Proxies (mean (SD))	Proxy–PWA difference (mean (SD))	ICC	t	Effect size
Scale	3.6 (0.6)	3.3 (0.7)	–0.3 (0.6)	0.8	4.0**	0.5
Physical	4.0 (0.8)	3.7 (0.9)	–0.3 (0.7)	0.8	2.9*	0.4
Psychosocial	3.5 (0.8)	3.1 (0.8)	–0.3 (0.8)	0.7	3.0*	0.4
Communication	3.2 (0.9)	2.8 (1.0)	–0.4 (0.8)	0.7	3.4**	0.5
Energy	3.1 (1.1)	2.9 (1.0)	–0.2 (1.2)	0.5	1.3	0.2

ICC, intra-class correlation coefficient; PWA, people with aphasia; SAQOL-39, Stroke and Aphasia Quality of Life Scale-39.

* $p \leq 0.01$; ** $p \leq 0.001$.

There is evidence in the literature that proxy and self-report agreement is better for less disabled patients.¹⁶⁻⁹ In their review, Sneeuw and colleagues² suggest that the relationship is U-shaped (ie, agreement is better for very good or very poor health status and worse for moderately impaired health status). We could not explore this in a meaningful way in our sample as all PWA had to be able to self-report on the SAQOL-39 and therefore had moderate–mild receptive aphasia. However, there was some indication in our findings that severity of receptive aphasia may influence agreement levels on the SAQOL-39 (significant for energy, approached significance for communication domain).

In conclusion, our findings suggest that, using the SAQOL-39, proxy respondents can provide reliable information on the HRQL of PWA, at the chronic stage post stroke. This by no means suggests that proxies should be used instead of PWA, when PWA can self-report. HRQL is a highly subjective concept and self-report is more valid than any proxy report. However, using proxies may be a viable way of obtaining information on the HRQL of PWA, so severely affected, that they are unable to self-report. In our study, although the proxies tended to report significantly more problems than the PWA reported themselves, the magnitude of this bias was at worst moderate. Further research is needed with larger samples of people with varying degrees of aphasia severity, in order to explore more indepth the factors influencing proxy–PWA agreement.

ACKNOWLEDGEMENTS

We are grateful to Speakability, the national charity for PWA in the UK, and in particular to Roz Rosenblatt for her assistance in the recruitment stage of this project.

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Competing interests: None.

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