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# Health-related quality of life in people with severe aphasia

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## **Abstract**

*Background:* Health-related quality of life (HRQL) measures are increasingly used to help us understand the impact of disease or disability on a person's life and to measure the effectiveness of interventions. A small number of studies have looked at perceived HRQL in people with mild or moderate aphasia. They report that reduced HRQL is associated with low psychological well-being and depression, reduced activity levels and high levels of communication disability. Still, very little is known about the quality of life of people with severe aphasia.

*Aims:* This study aimed to evaluate the HRQL of people with severe aphasia as rated by their proxy respondents. To increase our understanding of these proxy evaluations, the findings were compared to those of two other studies of HRQL in people with moderate or mild aphasia, using proxy and self-report respondents.

*Methods:* A questionnaire-based cross-sectional survey was carried out, where proxies of people with severe aphasia reported on their HRQL. The people with severe aphasia who took part in this study were part of a larger cohort of people with aphasia who were able to self-report on their HRQL. Aphasia was assessed with the ASHA-FACS and the FAST and HRQL with the SAQOL scale (proxy-reported). SAQOL-39 scores were derived from the SAQOL.

*Results:* People with severe aphasia's quality of life, as measured by their proxies (n=12), was low and more than one standard deviation below that of the standardisation sample of the SAQOL. The overall mean score for the SAQOL-39 and the means for its physical and communication domains were below the 20<sup>th</sup> centile. They were also significantly lower than those of the comparison studies of self-reports (n=83) and proxy ratings (n=50) of people with mild or moderate aphasia ( $p \leq 0.003$ ). In the comparison studies, there were no significant differences between the self-report and proxy ratings of people with mild or moderate aphasia.

*Conclusions:* This small study suggests that the HRQL of people with severe aphasia, as reported by their proxies, is severely compromised. Further research, using a wide range of methodologies, is needed in order to address the challenge of understanding better the quality of life of people with severe aphasia.

**What this paper adds**

Health related quality of life (HRQL) reflects the impact of a health state on a person's ability to lead a fulfilling life. Studies have shown that HRQL in people with aphasia is affected by their emotional well-being, the severity of their communication disability and their activity levels. However, little is known about the impact of *severe* aphasia on people's lives.

This study explored the HRQL of people with severe aphasia by asking their proxies to report for them. We compared our findings with HRQL data from people with mild or moderate aphasia. We found that HRQL in people with severe aphasia is greatly compromised and significantly worse than that of people with less severe aphasia. This study raises the challenges of assessing quality of life in people with severe communication impairments and draws clinical implications.

# Health-related quality of life in people with severe aphasia

## INTRODUCTION

Health related quality of life (HRQL) reflects the impact of a health state on a person's ability to lead a fulfilling life (Bullinger, Anderson, Cella & Aaronson, 1993). It incorporates the individual's perception of and satisfaction with his/her physical, mental/emotional, family and social functioning (Berzon, Hays & Shumaker, 1993). HRQL outcome measures are increasingly used to evaluate health care interventions and service provision. They allow us to better understand and measure the impact of disease on the patient's life as a whole (Patrick & Erickson, 1993) and to incorporate the patient's perspective in clinical decision making (Mayou & Bryant, 1993). This is in line with current international and UK national directives (U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, Center for Biologics Evaluation and Research, Center for Devices and Radiological Health, 2006; NHS Executive, 1999; Department of Health, 2007). These initiatives put emphasis on using patient reported outcomes in the evaluation of the effectiveness of interventions and on informing service delivery and organisation with clients and carers' views.

Recently, a special issue of *Aphasiology* (2003) focused on the quality of life of people with aphasia (PWA). Their quality of life was distinguished from that of people without stroke and aphasia mainly on three domains: level of independence, social relationships and access to aspects of their environment (Ross & Wertz, 2003). Within PWA, reduced HRQL was associated with low psychological well-being and depression, reduced activity levels and high levels of communication disability (Cruice, Worrall, Hickson & Murison, 2003; Hilari, Wiggins, Roy, Byng & Smith, 2003a). These studies called for intervention programmes that specifically target functional communication, emotional health and social participation. Therapy services that aim at enhancing social companionship and make information more accessible for people with aphasia may also positively impact on HRQL (Hilari & Northcott, 2006).

These reports increase our understanding of the impact of aphasia on people's lives. Still, these studies have excluded people with severe aphasia. Evaluating the HRQL of people with severe aphasia

is a major challenge. The extent of their language disability prevents people with severe aphasia from expressing their views on their HRQL. It is, therefore no surprise that no study to date, to the best of our knowledge, has specifically looked at the HRQL of people with severe aphasia.

From a qualitative perspective, methods like in-depth interviewing may pose insurmountable barriers, especially for people with severe receptive aphasia. Recently, Parr (2007) used ethnography to look at a related area: social inclusion in people with profoundly compromised language due to aphasia. Ethnographic methods, like participant and non-participant observation and analysis of artefacts such as diaries, can reflect the everyday experiences of people with aphasia and thus their social inclusion. Observation, however, is limited in informing us how a person feels about their quality of life. Similarly, people with severe aphasia are likely to find it difficult to fully reflect their feelings and well-being, their life satisfaction and quality of life in diaries.

Following a quantitative paradigm, researchers who want to evaluate the HRQL of people who are unable to report for themselves typically ask proxy respondents – significant others of the affected people - to report on their partners' HRQL. Evaluating one's HRQL is highly subjective and therefore using proxy respondents is not without problems. A question that arises is how accurate the proxy evaluations are. In their review of the literature on proxy and self-report agreement on HRQL, Sneeuw, Sprangers & Aaronson (2002) found that a) agreement is better for more concrete, observable domains (e.g., physical) than for less observable domains (e.g., psychosocial) and b) proxies tend to score patients as more severely affected than the patients score themselves. External factors may also influence agreement. In the area of post stroke quality of life, agreement is better in the long-term post stroke (Pickard, Johnson, Feeny, Shuaib, Carriere and Nasser, 2004) and when the carer's perception of strain is low (Williams, Bakas, Brizendine, Plue, Tu, Hendrie and Kroenke, 2006; Knapp and Hewison, 1999).

Cruice, Worrall, Hickson and Murison (2005) reviewed the relevant literature and looked at agreement between PWA and their proxies on two generic measures of quality of life (the Short Form -36 and the Dartmouth COOP Charts). Their findings concur with the general proxy literature as agreement was better for observable domains than for less observable domains and proxies scored PWA as more severely affected than the PWA scored themselves. Hilari, Owen and Farrelly (2007) also explored

agreement between PWA and their proxies on quality of life, but did so using a stroke and aphasia specific HRQL measure: the Stroke and Aphasia Quality of Life scale-39 item version (SAQOL-39, Hilari, Byng, Lamping, Smith & Wiggins, 2003b). Fifty pairs of people with mild or moderate aphasia and their proxies took part in this study. This study, in line with the findings above, reported some significant differences between PWA and their proxies. However, the effect sizes were small to moderate (0.2-0.5), suggesting that these differences were of questionable clinical significance. Agreement was very high on the overall SAQOL-39 mean and the physical, psychosocial and communication subdomains (ICC=0.7-0.8) and moderate for the energy subdomain (ICC=0.5). These findings suggest that by using a measure tailored to people with aphasia, it is possible for proxy respondents to provide good estimations of their partners with aphasia HRQL.

This report aims to:

- Evaluate the HRQL of people with severe aphasia, as reported by their proxies on the SAQOL scale.
- Understand better the meaning of these proxy evaluations by comparing them with:
  - Proxy HRQL data for people with moderate or mild aphasia (Hilari, Owen & Farrelly, 2007)
  - Self-report HRQL data for people with moderate or mild aphasia (Hilari et al., 2003a)

These studies have been chosen because they allow direct comparisons as they have used the same measure and similar methodologies.

## **METHODS**

### **Design and Participants**

The people with severe aphasia in this study were part of a larger cohort of PWA. The self-report data on HRQL of the people with less severe aphasia in that cohort has been previously reported (Hilari et al., 2003a). The methodology of the study has been described in detail in the previous report and will be summarised here. The study was a cross sectional survey, comprising a questionnaire-based interview of PWA. They were recruited as a clustered sample from two Speech and Language Therapy (SLT) Service

Providers (NHS Trusts) -one inner city and one semi-rural- and a not-for-profit organisation for people with aphasia. All recruiting sites were in Southeast England. The inclusion criteria were: aphasia due to a stroke, at least one year post onset, no known pre-stroke history of severe cognitive decline or mental health problems, and living at home prior to the stroke. Proxy participants were nominated by the person with aphasia and had to be in daily face to face contact with the person with aphasia for at least two years.

### **Procedure**

Review of SLT records was undertaken to identify eligible participants. Consent was obtained from eligible participants in writing at least 2 days after information giving, to ensure people had enough time to absorb the information and make their decision (Department of Health, 2001). Information on the project and consent forms were 'aphasia friendly' (e.g., short sentences, key words in bold, pictographic representations of main concepts) and participants' communication (understanding and expression) was facilitated by the main investigator, a SLT with extensive experience in communicating with people with aphasia. Participants were interviewed at home or in their SLT site by the main investigator. Participants' aphasia was screened with the Frenchay Aphasia Screening Test (FAST) (Enderby, Wood & Wade, 1987). If people scored less than 7/15 on the receptive domains of the FAST it was assumed, based on previous research (Hilari & Byng, 2001), that they could not reliably self-report on the SAQOL. They were classified as having severe aphasia and with their consent a proxy respondent was used. This data from the people with severe aphasia and their proxies is the main focus of this paper.

### **Measures**

Data were collected on PWA's demographic variables (age, sex, ethnic background, socioeconomic status, marital status, employment status), stroke type, communication disability and HRQL. Information on demographic and stroke related variables was collected from the participants' SLT notes. It was confirmed and supplemented through a short interview with the proxy respondents.

Communication disability was assessed with the American Speech and Hearing Association Functional Assessment of Communication Skills for Adults (ASHA-FACS) (Frattali, Thompson, Holland,

Wohl & Ferketic, 1995). The ASHA-FACS focuses on communicative activities that people with aphasia perform and whether they perform them independently or with assistance. Examples of items include requesting information of others, explaining how to do something, expressing feelings and writing messages. It is rated by the SLT of the person with aphasia based on observations of this person or observations by others who are familiar with the person. Its response format is a scale ranging from 1-7 and lower scores indicate increased communication disability.

HRQL was assessed with the SAQOL. The SAQOL is a 53 item questionnaire that asks about the effects of stroke and aphasia on people's lives. It has high internal consistency (Cronbach's alpha = 0.93), test-retest reliability (ICC = 0.98) and construct validity (convergent  $r=0.44-0.59$  and discriminant  $r=0.26-0.29$  validity) (Hilari et al., 2003b). Its response format is a 5-point scale ranging in some questions from 'couldn't do it at all' to 'no trouble at all' and in others from 'definitely yes' to 'definitely no'. The mean scale score ranges from 1-5 and high scores are indicative of higher HRQL.

The SAQOL was developed before its shorter version, the SAQOL-39, and it was the only available instrument when the data collection of this study took place. To allow comparisons with the results of related studies, SAQOL-39 scores were derived from the SAQOL. Apart from the overall mean score that ranges from 1-5, the SAQOL-39 also gives four subdomain scores: physical, psychosocial (including family and social issues), communication and energy. The SAQOL-39 has high internal consistency (Cronbach's alpha=0.74-0.94), test-retest reliability (ICC=0.89-0.98) and construct validity (convergent  $r=0.55-0.67$  and discriminant  $r=0.02-0.27$  validity) (Hilari et al., 2003b).

### **Data analysis**

Descriptive statistics were used to look at the participants' characteristics and the HRQL of people with severe aphasia as reported by their proxies. A *t*-test and an effect size were used to evaluate whether there was a significant difference between the SAQOL score and the extracted SAQOL-39 score. An effect size of 0.2 was considered a small bias, 0.5 a moderate bias and 0.8 a large bias (Cohen, 1988). One way ANOVA and effect sizes were used to compare these proxy SAQOL-39 scores of people with

severe aphasia with the self-report SAQOL-39 scores of people with moderate and mild aphasia of the sample in the broader study (Hilari et al., 2003a) and the proxy SAQOL-39 scores of people with moderate and mild aphasia from another study (Hilari et al., 2007).

## **RESULTS**

### **Participants**

Ninety-five PWA of 116 eligible participants (82%) took part in the broader study. Of the 95, 83 (87.4%) were able to self-report on their HRQL and their results have been previously described (Hilari et al., 2003a). The remaining 12 (12.6%) had such severe aphasia (FAST receptive score < 7/15) that they were unable to self-report. For those participants proxy respondents were used. Their results are reported here and compared with the broader study and another study on proxy and self-report agreement on the SAQOL-39 (Hilari et al., 2007).

Table one details the characteristics of the 12 people with severe aphasia and their proxies and compares them with the samples of the comparison studies. The proxy respondents in this study were close friends or relatives of the PWA, with the exception of one who was a key worker. They were similar to those in the Hilari et al. (2007) study: Eight of them were female (66.7% versus 66%). Four of them were related to the person with aphasia (83.3% vs 92%). The people with severe aphasia in this study were similar to the other groups in that the majority was older [mean (SD) = 63.7(10.1)], married/having a partner (n=9, 58.3%) and of white ethnic background (n= 10, 83.3%). People with severe aphasia in this study were different from the PWA in the other studies in gender (equal number of men and women versus more men in the other studies) and in their employment status. Three of them (25%) were inactive even before the stroke compared to 0% in the other groups. None of them were in work or education, compared to 6% in the rest of PWA drawn from the same population and 52% in the Hilari et al. (2007) study. Lastly, the PWA in the Hilari et al. (2007) study were longer post onset [7.1(6.1) years versus 3.8 (2.2) and 3.5 (3.09) years].

[Table 1 about here]

Participants' aphasia characteristics are detailed in table two and are graphically compared with the other studies in figure one. As would be expected, all aspects of communication as measured by the ASHA-FACS were lower in this group compared with the PWA in the overall sample from which they were drawn. The ASHA-FACS mean (SD) score for the severe aphasia group was 3.48 (0.90) as opposed to 5.78(0.89) for the overall sample. The differences were significant for the overall mean,  $t(92) = 8.29$ ,  $p < 0.001$ , and all the ASHA-FACS sub-domains ( $p < 0.001$ ). In the Hilari et al (2007) study, participants' aphasia was only assessed with the receptive domains of the FAST. The receptive FAST score (SD) of the people with severe aphasia in this study was 4.33 (1.07) out of a possible 15, and it was significantly lower than the equivalent score in the Hilari et al (2003a) study: 11.40 (2.8) [ $t(92) = -9.35$ ,  $p < 0.001$ ] and the Hilari et al (2007) study: 10.92 (2.28) [ $t(60) = -9.69$ ,  $p < 0.001$ ].

[Table 2 about here]

[Figure 1 about here]

The HRQL of participants with severe aphasia was rated by their proxies on the SAQOL, from which the SAQOL-39 scores were extracted. Table three details the quality of life of the participants with severe aphasia as rated by their proxies on the SAQOL and SAQOL-39. The mean (SD) scores were respectively 2.65 (0.68) and 2.48 (0.70). The difference between these two scores was not significant [ $t(11) = 0.620$ ,  $p = .542$ ] and the effect size was small  $d = 0.2$ .

[Table 3 about here]

The proxy SAQOL-39 scores of the participants with severe aphasia were then compared to those of the overall self-rated sample from which they were drawn (Hilari et al., 2003a) and the proxy scores in the Hilari et al (2007) study (see table four), using a one-way ANOVA. The differences between these three groups were significant for the overall quality of life score [ $F(2,142) = 7.65, p \leq 0.001$ ] and for the physical [ $F(2,142) = 7.01, p \leq 0.001$ ] and communication domains [ $F(2,142) = 5.98, p = 0.003$ ]. Post hoc comparisons with a Tukey HSD correction for multiple comparisons revealed that only the scores of people with severe aphasia were significantly different from the other two groups, i.e. there were no significant differences between the self-reporting people with mild or moderate aphasia and the proxy ratings for people with mild or moderate aphasia. As statistical significance does not equate clinical significance, we also compared the proxy mean scores of the participants with severe aphasia to the mean scores in the other two studies using effect sizes. Effect sizes were large ( $d= 0.92 - 1.22$ ) for the overall, physical and communication SAQOL-39 scores and small to moderate ( $d= 0.28 - 0.64$ ) for the energy and psychosocial domains.

[Table 4 about here]

## **DISCUSSION**

### **Main findings**

This study aimed to shed some light on the health-related quality of life of people with severe aphasia. In terms of their demographic characteristics (age, ethnic background, time post onset, marital status), our participants were similar to the overall population of people with aphasia, from which they were drawn (Hilari et al., 2003a). In terms of their aphasia and their communication disability, as assessed with the FAST and the ASHA-FACS, their profiles demonstrate that they had significantly more difficulty in communicating than the people in the rest of the sample. This finding, combined with the fact that none of them was involved in any type of work or further education activity, suggests that they had severe communication disability.

Close friends and relatives and one key-worker provided HRQL ratings for the people with severe aphasia. Their mean (SD) score on the SAQOL was 2.65 (0.68). This is more than one standard deviation below the mean of the people with mild or moderate aphasia of the standardisation sample of the SAQOL: mean(SD) = 3.39(0.62) (Hilari et al., 2003b). To allow a more detailed picture of the HRQL to emerge, we extracted SAQOL-39 overall and sub-domain scores from the SAQOL scores. The SAQOL-39 scores were not significantly different from the SAQOL scores. Moreover, any difference between them was not clinically meaningful, as indicated by the small effect size ( $d = 0.2$ ).

Our results showed that the mean SAQOL-39 scores for our group of people with severe aphasia were low, ranging from 1.88 to 2.68. They were significantly lower than the comparison studies for the overall mean and the means of the physical and communication sub-domains ( $p \leq 0.003$ ). We are confident for the significance of these results, as the effect sizes were large ( $d = 0.92 - 1.22$ ) and the achieved power ranged from 0.84 - 0.96 (G\*Power 3: Faul, Erdfelder, Lang & Buchner, 2007). This means there was a 84-96% chance that we detected a true difference, despite the small number of participants ( $n=12$ ) in the severe aphasia group.

Compared to the standardisation sample of the SAQOL-39, the HRQL scores for our group of people with severe aphasia were shown to be severely compromised. The means for the psychosocial and energy domains were below the 35<sup>th</sup> and 45<sup>th</sup> centile respectively. The overall mean score and the means for the physical and the communication domain were below the 20<sup>th</sup> centile (Hilari, 2003).

These results seem to suggest that the quality of life of people with severe aphasia is significantly worse than that of people with moderate or mild aphasia. However, we need to view this interpretation with caution. Firstly, we have not explored the physical disabilities of our participants. This is a limitation of the study as physical disabilities can impact on HRQL. Larger studies of people with severe aphasia, controlling for physical disability may be able to unravel the impact of severe aphasia as opposed to the impact of severe stroke. Still, previous research suggests that severity of communication disability in itself

impacts on HRQL over and above physical health and activity levels (Cruice et al., 2003; Hilari et al., 2003a).

Secondly, as we have no self-report data on people with severe aphasia, one may argue that the difference between our results and the self-report data on the SAQOL-39 is simply an artefact of who rates HRQL. In other words, the results may be worse for the people with severe aphasia because they don't rate their HRQL themselves, but their proxies do it for them. Indeed there is evidence in the proxy HRQL literature that proxies tend to score people as more severely affected than people score themselves (see Sneeuw et al., 2002, for a review). If this were the main reason behind the lower quality of life of people with severe aphasia, then one would expect that all proxy data on the HRQL of people with aphasia, not just those of people with severe aphasia, would be lower than self-report data. Yet, in our results the proxy and self-report data on HRQL of the people with mild or moderate aphasia were not significantly different.

Still, one might wonder whether proxy responding becomes less accurate as aphasia severity increases. Indeed the literature suggests that there is a relationship between level of agreement and severity of disability. In their review Sneeuw et al (2002) suggest that the relationship is U-shaped: i.e., agreement is better for very good or very poor health status and worse for moderately impaired health status. If this is true for people with aphasia, then one would expect that proxy respondents would be reasonably accurate for people with severe aphasia.

Moreover, the proxy data of people with severe aphasia were significantly different, for three of the five SAQOL-39 scores, from the proxy data of people with mild or moderate aphasia. Thus, comparing like to like, the quality of life of people with severe aphasia was shown to be more severely affected.

### **Clinical implications and future research**

People with severe aphasia are often excluded from stroke outcome studies because of their communication disabilities. In clinical practice, they are also often excluded from self-report evaluations of

HRQL and well being. The SAQOL-39 can provide a viable way of getting information on the HRQL of people with severe aphasia and this study has shed some light on how to interpret such findings.

Our results suggest that overall HRQL in people with severe aphasia and aspects of quality of life related to communication and physical functioning are severely affected. Is there a need for more resources to specifically address the needs of people with severe aphasia? At present in the UK, long-term community based rehabilitation is not the norm. Yet the cost of managing a patient with stroke rises from £1,943 for rapid recovery to £62,138 for those requiring long-term care (The Stroke Association, 2007). The National Clinical Guidelines for Stroke suggest that continuing decline after stroke can be reversed by further rehabilitation after transfer to community, which may also prevent further hospital readmission. They also advocate addressing participation, with 'leisure and social activity to encourage independence and reintegration to normal life' (Royal College of Physicians, 2004, p. 79). Clinicians need to make these guidelines applicable to people with severe aphasia in order to maximise their quality of life and begin to address the personal, social and financial impact of stroke.

Worrall and Holland (2003) called for creative study to obtain the opinions of people with severe aphasia on their HRQL. This is a challenge yet to be met and indeed it may not be feasible to meet in any single research exploration. An accumulation of research evidence from different paradigms, such as proxy data, ethnographic explorations and social indicators research can begin to unravel what the big picture is for people with severe aphasia. It will help us understand what life is like with severe aphasia, what the main issues are in relation to quality of life and what we can do about them.

## **Conclusion**

In summary, our findings with this small group of people with severe aphasia suggest that their HRQL is severely compromised. Overall HRQL and aspects of HRQL related to communication and physical health are significantly worse than those of people with less severe aphasia. Service providers and rehabilitation professionals may need to consider how to enhance communication, social activity and participation and maximise people's quality of life, in order to reduce the impact of severe aphasia.

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**TABLE 1. Participants' characteristics and comparison with related studies**

Variable	Severe aphasia n (%)	Hilari et al. (2003a) n (%)	Hilari et al. (2007) n (%)
<b>PARTICIPANTS WITH APHASIA</b>	<b>N=12</b>	<b>N=83</b>	<b>N=50</b>
Gender			
Female	6 (50)	31 (37.3)	22 (44)
Male	6 (50)	52 (62.7)	28 (56)
Age			
Mean [SD]	63.7 [10.1]	61.67 [15.47]	63.4 [11.5]
Range	44-77	21-92	32-80
Time post stroke			
Mean in years [SD]	3.8 [2.2]	3.5 [3.09]	7.1 [6.1]
Range	1-9	1-20	1-37
Ethnic group			
Asian	1 (8.3)	7 (8.4)	4 (8)
Black	1 (8.3)	11 (13.3)	5 (10)
White	10 (83.3)	65 (78.3)	41 (82)
Marital status			
Married/has partner	7 (58.3)	52 (62.6)	37 (74)
Single	2 (16.7)	14 (16.9)	5 (10)
Divorced or widowed	3 (25)	17 (20.5)	8 (16)
Employment status			
Retired before stroke	7 (58.3)	31 (37.3)	17 (34)
Inactive because of stroke	2 (16.7)	47 (56.6)	7 (14)
Full-time, part-time or voluntary work	0	3 (3.6)	25 (50)
Inactive before the stroke	3 (25)	0	0
Student	0	2 (2.4)	1 (2)
<b>PROXIES</b>	<b>N=12</b>	<b>N/A</b>	<b>N=50</b>
Gender			
Female	8 (66.7)		33 (66)
Male	4 (33.3)		17 (34)
Relationship to person with aphasia			
Spouse/partner	6 (50)		37 (74)
Child	4 (33.3)		6 (12)
Other family	0		3 (6)
Friend	1 (8.3)		4 (8)
Key worker	1 (8.3)		0

: Shading indicates the person who completed the health-related quality of life assessment.

**TABLE 2. Participants with severe aphasia scores on the ASHA-FACS and the FAST (n=12)**

	Mean (SD)	Range	Scale Range
ASHA-FACS			
Social communication	3.22 (0.91)	1.86–4.86	1-7
Communication of basic needs	5.20 (1.15)	3.14-6.57	1-7
Daily planning	2.91 (1.20)	1.40-5.60	1-7
Reading, writing and number concepts	2.58 (1.11)	1.00-4.70	1-7
ASHA-FACS mean	3.48 (0.90)	2.02-5.05	1-7
FAST			
Comprehension	3.33 (1.30)	1-5	0-10
Expression	1.17 (2.21)	0-6	0-10
Reading	1.00 (1.04)	0-3	0-5
Writing	0.42 (1.16)	0-4	0-5
FAST total	5.92 (3.60)	2-15	0-30

**Table 3: Mean scores on the SAQOL and the extracted SAQOL-39 of the proxies of people with severe aphasia (n-12)**

Instrument	Mean (SD)	Range
SAQOL	2.65(0.68)^	1.70-3.89
SAQOL-39		
Overall mean	2.48(0.70)^	1.54-3.72
Physical domain	2.57(1.10)	1.08-4.81
Psychosocial domain	2.68(0.78)	1.73-4.27
Communication domain	1.88(0.80)	1.14-3.86
Energy domain	2.61(1.22)	1.00-4.50

^: difference not significant [ $t(11) = 0,62, p = 0.542$ ]

**Table 4: Comparison of SAQOL-39 mean (SD) scores of people with severe aphasia with people with moderate and mild aphasia**

SAQOL-39	Current study n=12	Hilari et al (2003a) n=83	Hilari et al (2007) n=50
Rater	Proxy	PWA	Proxy
Overall mean	2.48(0.70)**	3.27(0.70)	3.31(0.66)
Physical domain	2.57(1.10)**	3.53(0.98)	3.71(0.88)
Psychosocial domain	2.68(0.78)	3.21(0.86)	3.13(0.84)
Communication domain	1.88(0.80)*	2.80(0.88)	2.85(0.95)
Energy domain	2.61(1.22)	3.12(1.09)	2.92(0.95)

\* : difference significant from other two groups,  $p < 0.05$  \*\* : difference significant from other two groups,  $p \leq 0.001$

**Figure 1: Comparison of aphasia profiles of people with severe aphasia with people with moderate and mild aphasia**

