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# **The impact of stroke: Are people with aphasia different to those without?**

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## **Abstract**

**Purpose:** Stroke rehabilitation programmes aim to improve functional outcomes and quality of life. This study explored long term outcomes in a cohort of people admitted to two acute stroke units with stroke. Comparisons were drawn between people with aphasia (PWA) and people without aphasia.

**Methods:** People admitted to hospital with a first stroke were assessed at 2-weeks, 3-months and 6-months post-stroke. Measures included: the Barthel Index for Activities of Daily Living (ADL), the Frenchay Aphasia Screening Test, the General Health Questionnaire-12 for emotional well-being and the Stroke and Aphasia Quality of Life Scale-39g. Extended ADL and social support were also measured at three and six months, with the Frenchay Activities Index and the Social Support Survey respectively.

**Results:** Of 126 eligible participants, 96(76%) took part and 87(69%) were able to self-report. Self-report data are reported here. Although outcomes improved significantly across time, at six months people continued to experience substantial functional limitations (16% aphasic; 32% dependent on basic ADL); participation limitations (79%  $\leq$  30 on the FAI); high psychological distress (45%) and compromised quality of life (54%  $\leq$  4 on the SAQOL-39g). Levels of social support remained relatively stable. Though at three months post-stroke PWA were significantly more likely to experience high psychological distress (93% versus 50% for those without), across time, there were no significant differences between PWA and those without on psychological distress and also ADL and social support. There were, however, significant differences on extended ADL ( $F(1,68) = 7.80, p < 0.01$ ) and quality of life ( $F(1, 69) = 6.30, p < 0.05$ ).

**Conclusion:** People with aphasia participated in less activities and reported worse quality of life after stroke than people without aphasia, even when their physical abilities, well-being and social support were comparable. Implications for clinical practice and future research are discussed.

## **INTRODUCTION**

Stroke is the most common cause of long-term disability in the western world. More than 50% of people who survive a stroke are left with physical disabilities and at least 15% with aphasia<sup>1</sup>. Understanding what aspects of people's lives are most affected and whether there are any differences between stroke sub-groups can guide clinicians' choice of assessments used to inform intervention.

A number of studies have explored the impact of stroke on people's lives, reporting diminishing social networks<sup>2</sup>; reduced participation in activities (e.g. getting around) and roles (e.g. work)<sup>3</sup>; reduced health-related quality of life (HRQL)<sup>4,5</sup>; and high levels of depression<sup>6</sup>. However, most stroke outcome studies either exclude people with aphasia or include only the milder cases. Proxy respondents are sometimes used for people with aphasia. This methodological heterogeneity makes it difficult to see whether people with aphasia are similarly affected by stroke as those without.

Research focusing specifically on people with aphasia has identified similar themes. There is a high prevalence of depression (62-70%)<sup>7</sup>; people with aphasia lose contact with their friends<sup>8</sup>; they perform less social activities than non-aphasic peers and derive less satisfaction from them<sup>9</sup>; and their health related quality of life is compromised<sup>10,11</sup>. Yet, we still do not know whether there are any significant differences in these areas between stroke survivors with aphasia and those without.

This study explored stroke outcomes from the sub-acute setting to six months post-stroke and directly compared people with aphasia to those without on activities of daily living (ADL), extended ADL, social support, psychological distress and health-related quality of life.

## **METHODS**

This is a sub-study of a larger study exploring quality of life<sup>12</sup> and psychological distress<sup>13</sup> post-stroke. The methods detailed in these previous reports will be summarised here. The study was approved by the relevant National Health Service (NHS) Local Research Ethics Committees.

## **Participants**

Participants were recruited from two acute stroke units based in teaching hospitals and were followed for six months. People with a first ever stroke, over 18 years of age were eligible to take part. People were excluded if they: did not live at home or had a known history of mental health problems or cognitive decline prior to the stroke; had other severe or potentially terminal co-morbidity; were too unwell to give informed consent; did not speak English pre-morbidly. Participants' aphasia was screened with the Frenchay Aphasia Screening Test (FAST)<sup>14</sup> to identify those able to self-report on the questionnaires used. People with any severity of expressive language difficulties and moderate or mild receptive language difficulties ( $\geq 7/15$  receptive FAST) were able to self-report. Proxy respondents were used for people with severe receptive aphasia and their results are not included here.

## **Procedure**

Participants were interviewed while still in hospital (baseline), three months and six months ( $\pm$  one week) post-stroke. They all completed a range of measures, in the same order, in an interview format. At baseline some participants required more than one visit to complete the battery of tests used. Presentation and administration of measures were modified to make them accessible to people with aphasia. Established methods were adopted<sup>15,16,17</sup>: large font (minimum 14), key words in bold, few items per page, and where appropriate pre-prepared pictures were used<sup>i</sup>.

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<sup>i</sup> Modified scales are available from the author on request.

Participants were interviewed by an aphasia-specialist Speech and Language Therapist trained in facilitating the communication of people with aphasia. Practice items were introduced to ensure participants understood the format of each questionnaire; and respondents pointed to their response option which was recorded by the interviewer.

## **Measures**

Stroke severity was determined using the National Institute for Health Stroke Scale (NIHSS)<sup>18</sup>. The NIHSS is a 15-item neurologic examination scale used to evaluate the effect of stroke on levels of consciousness, eye movement, visual-field loss, motor strength (face, arm, leg), ataxia, sensory loss, language, speech and neglect. Scores on the NIHSS range from 0-31; higher scores reflect more severe strokes. Stroke lesion was recorded using the Oxford stroke classification system of total anterior circulation, partial anterior circulation, posterior circulation and lacunar strokes. Aphasia was assessed with the FAST, as indicated above, and presence of aphasia was determined using its cut-off scores<sup>14</sup>. The FAST covers auditory comprehension, reading comprehension (receptive domains) and expressive language and writing (expressive domains). Scores on the FAST range from 0-30; higher scores indicate better language skills. Activities of daily living (ADL) were measured with the Barthel Index (BI)<sup>19</sup>. The BI comprises 10 items that cover basic ADL: feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility and stairs. Scores range from 0-100; higher scores indicate better functioning. Psychological distress was assessed using the General Health Questionnaire–12 item (GHQ-12)<sup>20</sup>. The GHQ is a measure of distress that has been extensively used as a screening tool for psychiatric disorders. Its focus is on psychological components of ill-health as it was designed to detect those forms of psychiatric disorder which may have relevance to people attending medical clinics. GHQ scores range from 0-12; higher scores are indicative of higher distress.

Scoring >3 on the GHQ-12 is indicative of high psychological distress for people with stroke<sup>6</sup>. Extended ADL were measured with the Frenchay Activities Index (FAI)<sup>21</sup>. The FAI consists of 15 items that cover domestic, social, leisure activities and work. Scores on the FAI range from 0-45, with higher scores indicating better functioning. At baseline while still in hospital, people reported on their activity levels before they had the stroke, as the timeframe for the FAI questions is the past 3-6 months. Perceived social support was measured with the Medical Outcomes Studies Social Support Survey (SSS)<sup>22</sup>. The SSS assesses the perceived availability of different types of support: tangible (practical support such as behavioural assistance or material aid), emotional (e.g., someone to confide in, someone with whom to share private thoughts and fears), informational (e.g., feeling there is someone whose advice you value, who can offer information or guidance), social companionship (the availability of other people to do fun things with you) and affectionate support (e.g., whether there is someone who will show you love and affection). It consists of 19 items. Scores on the SSS range from 1-5; higher scores indicate better perceived support. The timeframe for questions on social support is 'the past month' so at baseline people were asked to think about the month before their stroke. Health-related quality of life was measured with the Stroke and Aphasia Quality of Life scale – 39 item generic stroke version (SAQOL-39g)<sup>12</sup>. The SAQOL-39g consists of 39 items that cover people's subjective evaluation of their functioning in three domains: physical, psychosocial and communication (sample page in Appendix). Scores on the SAQOL-39g range from 1-5; higher scores indicate better quality of life.

### **Data analysis**

Descriptive statistics were used to summarise the data. T-tests, chi-squares and ANOVAS were used as appropriate to compare participants. Repeated measures ANOVAs were conducted to see whether there were any significant differences in

each of the outcome measures over time (baseline, three and six months post-stroke) between people with and people without aphasia.

## RESULTS

### Respondent characteristics

The sample in this study is the same as that reported in detail in Hilari et al., 2010<sup>13</sup>. Of 126 eligible people, 96 (76%) agreed to take part. Nine of the 96 participants had severe receptive aphasia requiring proxy respondents; their results are not reported here. Table one presents the characteristics of the remaining 87 (69%) participants and compares those with to those without aphasia at baseline. In the total sample, the majority were white (75%), male (60%) and married/had a partner (52%). A quarter of the sample came from different ethnic backgrounds: Asian (11%), Black (7%) and mixed-race (7%). They ranged in age from 18-91 (mean 69.7± 14.1) and 73% had two or more co-morbid conditions.

Thirty two participants had aphasia at baseline. Of those, 13% had severe expressive aphasia (expression scores on the FAST 0-3 out of 10), 50% moderate (4-7 out of 10) and 37% mild expressive aphasia (8-10). In terms of auditory comprehension, 3% had severe receptive aphasia (auditory comprehension scores on the FAST 0-3 out of 10), 58% moderate (4-7 out of 10) and 39% mild receptive aphasia (8-10). Comparing people with aphasia to those without at baseline, there were no significant differences between them on demographic variables, overall health and stroke type and classification. However, people with aphasia had suffered more severe strokes than those without aphasia [ $t(84)=-2.85, p<.01$ ].

[table 1 about here]

76 participants (87%) were followed-up at three months and 71 (82%) at six months post-stroke and their characteristics were similar to the original sample. At six



months, there were no significant differences between people with aphasia and those without on demographic, health variables, stroke type and stroke severity.

### **Stroke outcomes across time for the overall sample**

Table two details stroke outcomes across time from baseline to six months post-stroke. Early post-stroke, respondents were severely affected with 67% dependent on ADL (BI scores < 90) and 40% scoring  $\leq 60$ , which is predictive of long-term disability. They significantly improved with time [ $F(2,130)=52.6, p<.001$ ], but at six months 32% were still dependent on some ADL (7% <60). Psychological distress levels were high early post-stroke (66% scored > 3 on the GHQ-12) and although they significantly reduced with time [ $F(2,140)=7.1, p=.001$ ] they remained high at six months (45% scored >3). Differences on the GHQ-12 were only significant between baseline and six months. Feelings of perceived social support remained relatively stable post stroke. Extended ADL significantly increased between three and six months [ $t(70) = -2.03, p<.05$ ]. Yet, they remained low at six months with 50% scoring <20 out of 45 on the FAI and 79%  $\leq 30$ . Health-related quality of life was compromised at all time points, with 77% at baseline, 62% at three months and 54% at six months scoring  $\leq 4$  out of 5. Still, HRQL improved significantly from baseline to three and six months [ $F(2,140)=17.2, p<.001$ ].

[table 2 about here]

### **Comparisons between people with aphasia and people without aphasia**

Table three compares participants with aphasia to those without aphasia on stroke outcomes at six months post-stroke. People with aphasia performed significantly less extended activities of daily living [ $t(69)=3.26, p<.01$ ] and reported significantly lower quality of life [ $t(69)=2.02, p<.05$ ].

[table 3 about here]

Figures one to five compare participants who remained aphasic at six months to those without aphasia across time. There were no significant differences on basic activities of daily living (figure 1) and on perceived social support (figure 2).

[figures 1 and 2 about here]

Across time, aphasia was not a significant factor in differences on psychological distress, though the interaction of time and aphasia was significant [Wilks' Lambda=0.88,  $F(2,68)=4.45$ ,  $p<0.05$ ] (figure 3).

[figure 3 about here]

Given the use of cut-off scores for the GHQ-12, psychological distress can also be looked at as a categorical variable. Looking at those with high versus those with low psychological distress, at three months post stroke people with aphasia were more severely affected ( $\chi^2(1) = 8.61$ ,  $p<0.01$ ).

Lastly, at all time points after their stroke participants with aphasia performed significantly less extended activities of daily living [time: Wilks' Lambda=0.45,  $F(2,67) = 40.96$ ,  $p<0.001$ ; aphasia:  $F(1,68) = 7.80$ ,  $p<0.01$ ; interaction: Wilks' Lambda=0.86,  $F(2,67) = 5.53$ ,  $p<0.01$ ] (figure 4) and reported significantly worse health-related quality of life [time: Wilks' Lambda=0.88,  $F(2,68) = 4.87$ ,  $p<0.05$ ; aphasia:  $F(1,69) = 6.30$ ,  $p<0.05$ ; interaction: ns] (figure 5).

[figures 4 and 5 about here]

## **DISCUSSION**

We followed a cohort of stroke survivors from acute stroke to six months post-onset, exploring outcomes across time and drawing comparisons between those with aphasia and those without. Although outcomes improved significantly across time, at six months people continued to experience substantial functional limitations (16%

aphasic; 32% still dependent on some basic ADL); participation limitations (79% scored  $\leq 30$  on the FAI); high psychological distress (45%) and compromised quality of life (54%  $\leq 4$  on the SAQOL-39g). Levels of social support remained relatively stable over the first six months post-stroke. At three months post-stroke those with aphasia experienced significantly higher psychological distress than those without aphasia. However, this difference disappeared by six months. Across time, participants with aphasia performed significantly less extended activities of daily living and experienced significantly worse quality of life than those without aphasia. These findings are discussed in detail, before highlighting strengths and limitations of the current study and drawing the clinical implications of the findings.

### **Stroke outcomes across time for the overall sample**

Within the overall sample, 16% still had aphasia at six months post-stroke. This is in line with the prevalence of aphasia in the long-term reported in other studies (15%<sup>1</sup>; 19%<sup>23</sup>). In terms of ADL, the majority had achieved good levels of independence, yet some still required assistance in some areas. Specific ADL that people required help with were bathing and taking stairs. These findings are similar to those reported for people at one year<sup>24</sup> post-stroke.

Participants were more severely affected on extended ADL than on basic ADL. This finding, along with similar results of other follow-up studies<sup>23,25</sup> highlights the reduction in participation in social activities and community life that people with stroke face in the long-term. A recent study<sup>3</sup> using path analysis to explore factors affecting participation restriction in the long-term post-stroke found that the strongest predictors were functional disability ( $\beta=.51$ ), depression ( $\beta=.27$ ) and low self-esteem ( $\beta=.20$ ).

Psychological distress in this current sample was found to be high, with 45% potentially in the depressed range at six months post-stroke. This frequency is at the

higher end of those reported for hospital-based studies in the medium/long term post stroke: 34% (95% CI: 24% to 45%)<sup>6</sup>. This may be explained by the inclusion of people with aphasia in our study, who are commonly excluded from stroke studies of depression and for whom the frequency of depression is higher (62% one year post-stroke)<sup>7</sup>. Health-related quality of life was also compromised in this sample and low quality of life persisted at six months post-stroke. This is in line with findings of population studies that report poor HRQL in the long term (2-3 years) post-stroke<sup>4,5</sup>.

### **Comparisons between people with aphasia and people without aphasia**

Comparing people with aphasia to those without aphasia, we found that in the first few months after stroke, aphasia did not detrimentally affect how well supported people felt by those around them. A previous study exploring perceived social support in people with chronic aphasia reported similar findings, with participants reporting high levels of support and severity of aphasia having no significant correlation with perceived social support.<sup>8</sup> Other aspects of social support, such as friendships and feeling integrated and engaged in one's social circle and social activities seem to be more severely affected by aphasia.<sup>8,9,26,27</sup>

A complex picture emerged in terms of psychological distress. As reported in a previous study, of those with aphasia at three months, 13 of the 14 (93%) experienced high distress (GHQ-12 score > 3), as opposed to 31 of the 62 (50%) without aphasia ( $\chi^2(1) = 8.61, p < .01$ )<sup>13</sup>. Yet by six months, this difference had disappeared. The psychological distress of those without aphasia remained relatively unchanged between three and six months, whereas it improved significantly for those with aphasia [interaction: Wilks' Lambda=0.88,  $F(2,68)=4.45, p < 0.05$ ]. This suggests that the mood of people with aphasia is affected differently by time post-stroke. A contributing factor to their improving well-being between three and six months may be the high levels of perceived social support. Evidence

suggests that perceived social support is particularly important when people experience acute stress as it can alleviate the stress response, whereas it is not so important when people do not experience stress<sup>28</sup>. It may be that at about three months post-stroke people with aphasia experience stress, beginning to realise the long-term nature of their aphasia, that those without aphasia do not experience. People with aphasia therefore benefit more from their perceived social support than those without aphasia and their distress gradually lessens. This pattern however is unlikely to continue in the longer term, as aphasia becomes chronic. In the longer term post stroke ( $\geq 1$  year) the prevalence of high emotional distress and depression is higher for people with aphasia<sup>7</sup> than other stroke survivors.<sup>6</sup>

Across time post-stroke people with aphasia performed significantly less extended ADL and experienced significantly lower HRQL. It is likely that these differences were due to aphasia, as at six months post-stroke the two groups were similar in other potentially contributing factors, i.e., demographic variables, overall health, stroke type, stroke severity, physical abilities, psychological distress and perceived social support.

It is not surprising that people with aphasia performed few extended ADL. As indicated above, aphasia studies show that people with aphasia perform less social activities than healthy older adults<sup>9</sup>, feel less engaged and integrated and are at risk of social isolation and exclusion<sup>26, 27</sup>. However, people with stroke excluding people with aphasia also experience participation restrictions<sup>3</sup>. Our findings enrich this picture by showing that people with aphasia perform significantly worse than a comparable group of people with stroke without aphasia. Looking at which extended ADL were particularly affected for people with aphasia, we found that it was not physical activities like doing housework or going for a walk, but rather social, leisure activities and work: shopping, hobbies, travelling for pleasure, work ( $p < .001$ ); i.e. activities that required communication.

The picture is similar for HRQL, where stroke studies often exclude people with aphasia<sup>4</sup> or use proxy respondents alongside self-report data<sup>5</sup>. Although proxy respondents may give relatively accurate responses when disease-specific quality of life scales, like the SAQOL-39, are used<sup>29</sup>, they generally overestimate patient disabilities<sup>30</sup>. This study contributes to the literature by drawing direct comparisons between people with stroke with aphasia and those without aphasia and showing that those with aphasia are more severely affected.

### **Strengths and limitations**

Strengths of this study include a longitudinal design with high follow-up rate; interview-based data collection which facilitated the inclusion of people with aphasia; and the consideration of a wide range of variables. Still, a limitation of the study is that factors, such as cognitive impairment, were not considered, as we tried to keep respondent burden low. Another unavoidable limitation is that the results of people with very severe receptive aphasia were not included, since proxy respondents were used for them.

### **Research and clinical implications**

Our findings have important research and clinical implications. Further studies with larger samples of people with aphasia in the longer term post-stroke (six months onwards) are needed to begin to unravel the complex relationships between aphasia, activity and HRQL and explore the potential impact of severity and type of aphasia. From a methodology perspective, this study design (interview based; adaptation of measures and administration) has demonstrated that people with any severity of expressive aphasia and moderate to mild receptive aphasia can be included in stroke studies, minimising selection bias. Speech and Language Therapists with their expertise in facilitating communication with people with aphasia, have an important role to play in such studies.

In terms of clinical practice, implications are twofold. Firstly, broader measures such as HRQL scales are essential in stroke assessment and outcome measurement. By taking into consideration respondents' subjective evaluation of their functioning and well-being, clinicians get a more holistic picture of how stroke, and where applicable aphasia, has affected their lives. This way they can make more informed decisions on what needs to be targeted in intervention. Single HRQL scales are also more feasible to use in clinical practice and cause far less respondent burden than a battery of scales, each tapping on one aspect of quality of life.

Lastly, these findings suggest that people with stroke, and particularly those with aphasia, need long-term service provision that takes into account their affected mood. Such service provision should aim to target participation and quality of life through community-based interventions, e.g., participation in personally relevant meaningful activities. Further research is needed to determine what interventions most contribute to a better quality of life after stroke and aphasia.

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**Table 1: Respondent characteristics at baseline**

<b>Characteristics</b>	<b>Total sample n=87</b>	<b>People without aphasia n=55</b>	<b>People with aphasia n=32</b>
	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
Gender			
Female	35 (40)	23 (42)	12 (38)
Male	52 (60)	32 (58)	20 (62)
Age			
Mean [SD]	69.7 [14.1]	69.8 [15.1]	69.5 [12.5]
Co-morbid conditions			
Mean [SD]	2.4 [1.4]	2.3 [1.4]	2.4 [1.3]
Ethnic group			
Asian	10 (11)	6 (11)	4 (12)
Black	6 (7)	4 (7)	2 (6)
White	65 (75)	42 (76)	23 (72)
Other/mixed	6 (7)	3 (6)	3 (10)
Marital status			
Married - Has partner	45 (52)	26 (47)	19 (59)
Single	20 (23)	13 (24)	7 (22)
Divorced - Widowed	22 (25)	16 (29)	6 (19)
Stroke type			
Ischaemic	75 (86)	45 (82)	30 (94)
Haemorrhagic	12 (14)	10 (18)	2 (6)
Stroke classification			
LACS	24 (27.5)	18 (33)	6 (19)
POCS	24 (27.5)	17 (31)	7 (22)
TACS	13 (15)	5 (9)	8 (25)
PACS	26 (30)	15 (27)	11 (34)
Stroke severity (NIHSS)			
Mean [SD]	6 [4.5]	5 [3.8]*	8 [5.2]*

LACS: Lacunar stroke; PACS: Partial anterior circulation stroke; POCS: posterior circulation stroke; TACS: Total anterior circulation stroke

\* : p<.01

**Table 2: Stroke outcomes across time for overall sample**

<b>Outcome – Measure (score range)</b>	<b>Baseline n=87</b>	<b>3 months n=76</b>	<b>6 months n=71</b>	<b>p</b>
	<b>Mean (SD)</b>			
Activities of Daily Living (ADL) – Barthel Index (0-100)	65.8 (31.6) (n=84)	89.6 (18) (n=75)	91.2 (15.5) (n=69)	p<.001
Extended ADL – Frenchay Activities Index (0-45)	27.9 (8.2)*	17.9 (11.8)	19.1 (11.9)	p<.001
Social support – Social support scale (1-5)	3.8 (1)* (n=86)	4 (.9) (n=73)	3.8 (1.1) (n=70)	ns
Psychological distress – General Health Questionnaire (0-12)	4.9 (3.6)	4.2 (3.8)	3.5 (3.6)	p=.001
Quality of Life (QOL) – Stroke & Aphasia QOL scale-39 (1-5)	3.5 (0.8)	3.8 (0.7)	3.9 (0.8)	p<.001

\* : Participants reporting for before the stroke

**Table 3: Stroke outcomes at 6 months post stroke: comparing participants with aphasia to those without.**

Outcome – Measure (score range)	Participants without aphasia n=60	Participants with aphasia n=11	p
Mean (SD)			
Activities of Daily Living (ADL) – Barthel Index (0-100)	92.8 (13.7) (n=58)	82.7 (21.6)	ns
Extended ADL – Frenchay Activities Index (0-45)	21 (11.5)	9 (8.9)	p<.01
Social support – Social support scale (1-5)	3.8 (1.1)	3.8 (0.8) (n=10)	ns
Psychological distress – General Health Questionnaire (0-12)	3.6 (3.6)	2.9 (3.6)	ns
Quality of Life (QOL) – Stroke & Aphasia QOL scale-39 (1-5)	4 (0.8)	3.4 (0.8)	p<.05

**Figure 1: Differences between participants with aphasia and those without on basic activities of daily living across time post stroke (n=71)**

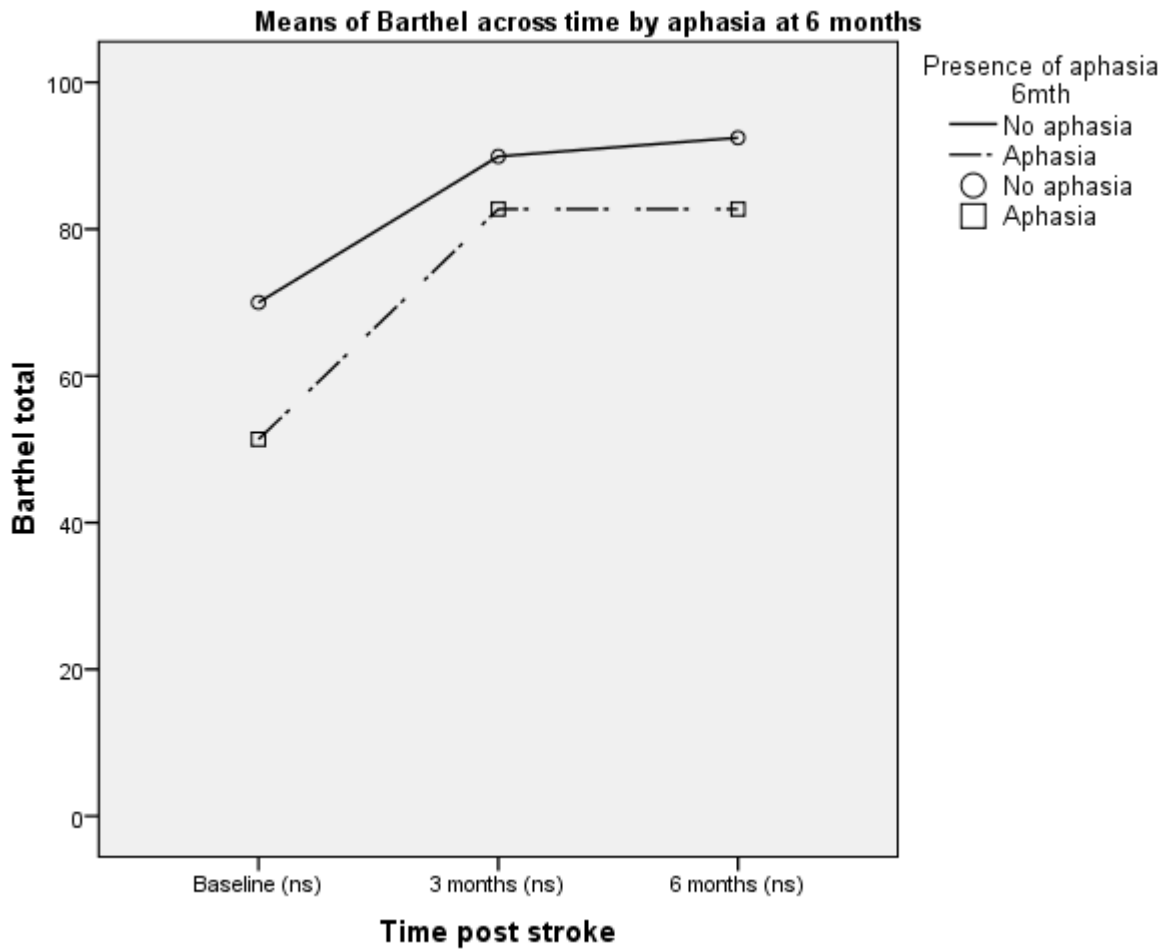


Figure 2: Differences between participants with aphasia and those without on social support across time post stroke (n=71)

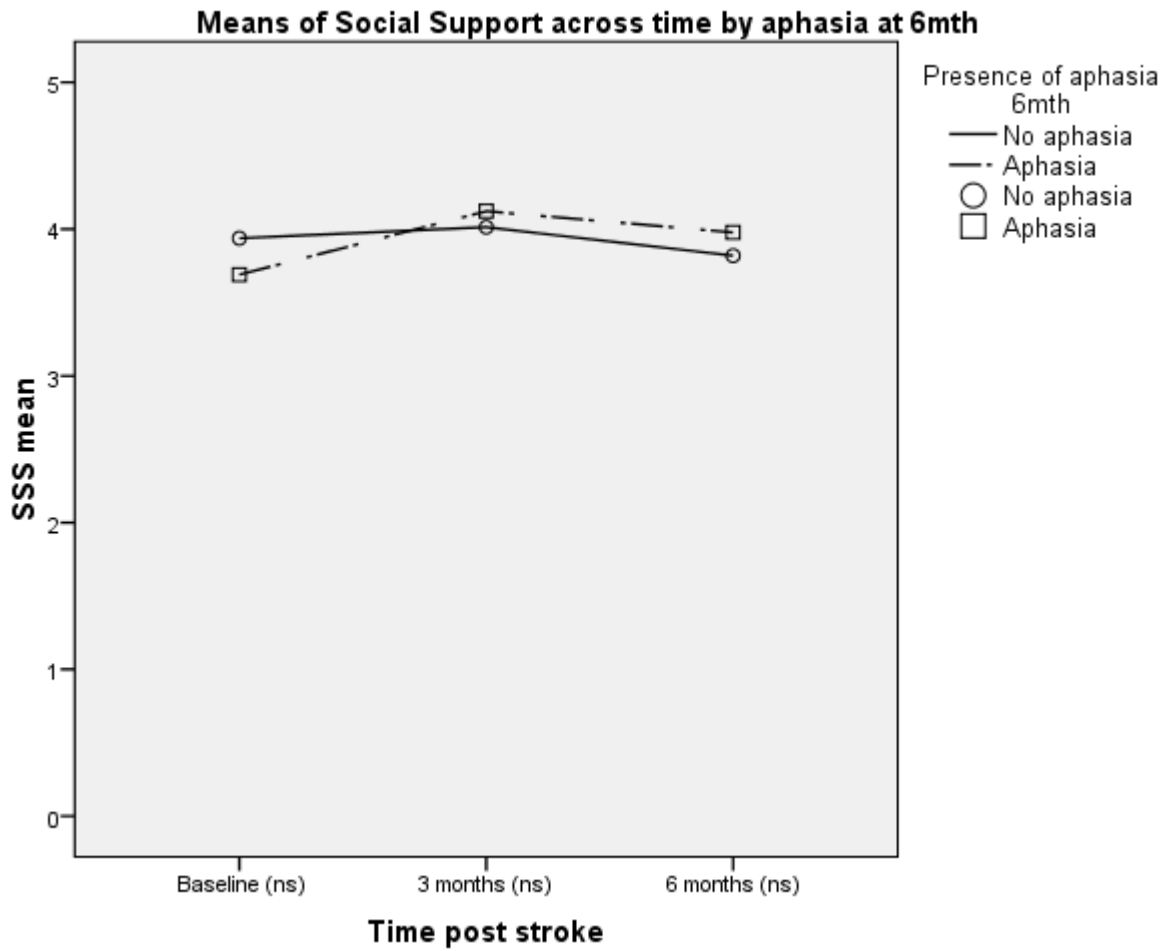
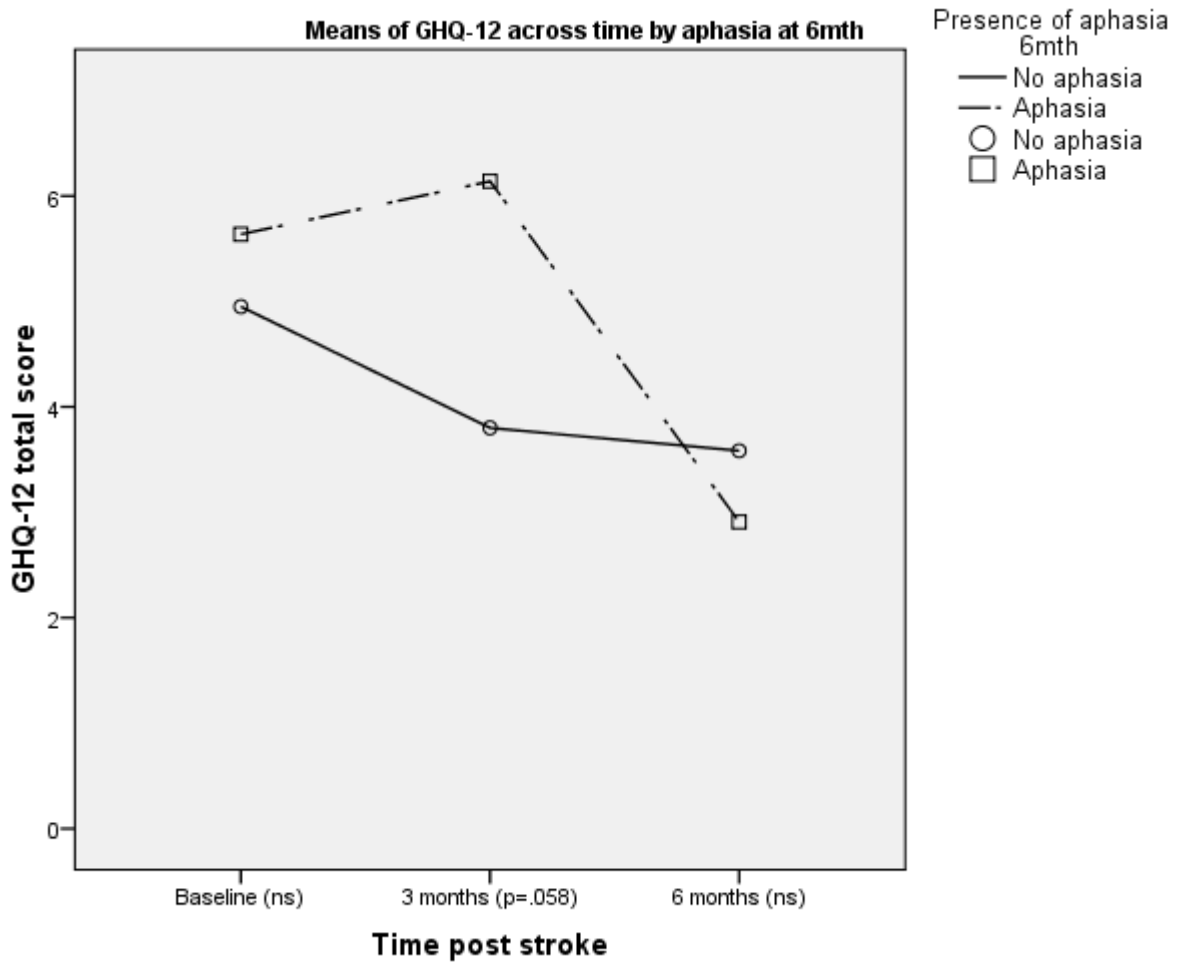


Figure 3: Differences between participants with aphasia and those without on psychological distress across time post stroke (n=71)



**Figure 4: Differences between participants with aphasia and those without on extended activities of daily living across time post stroke (n=71)**

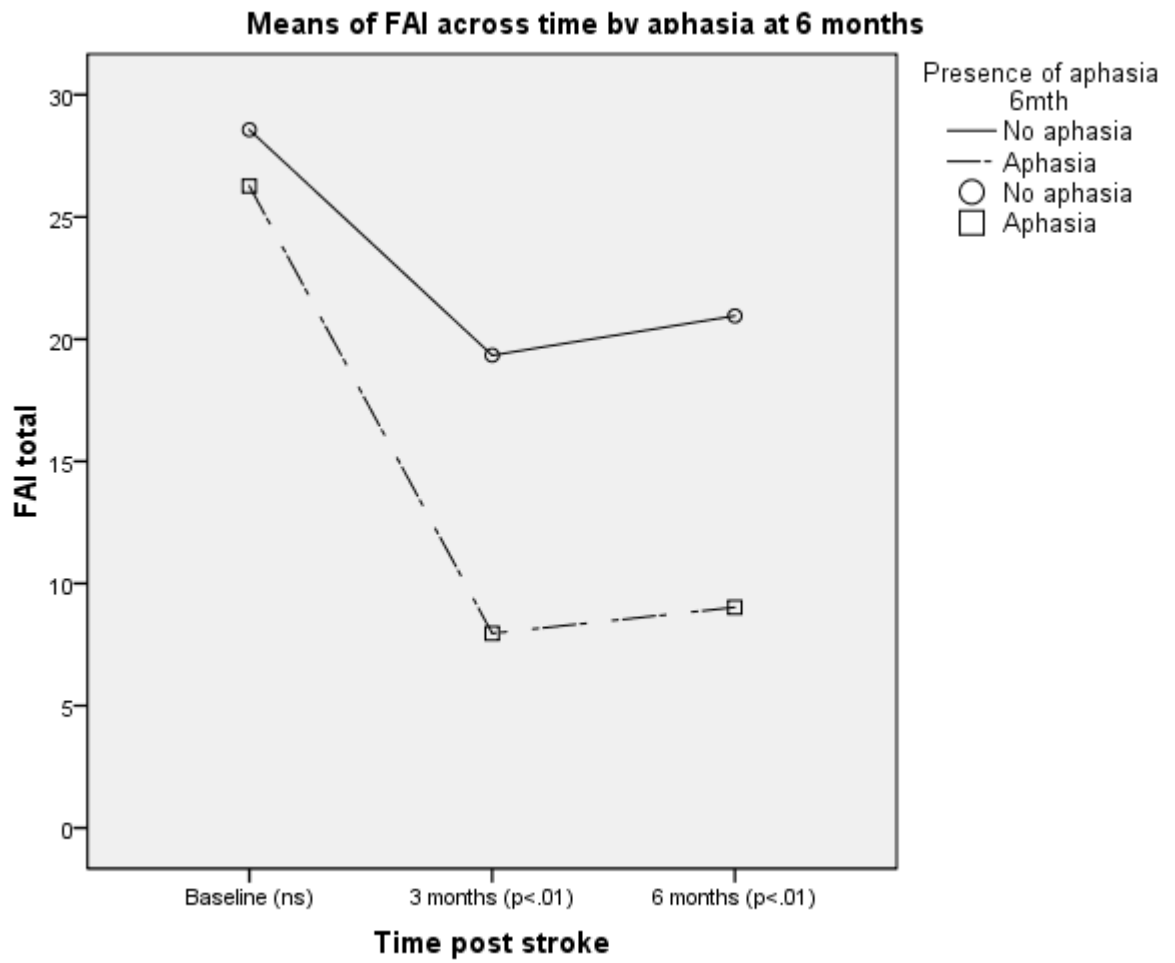
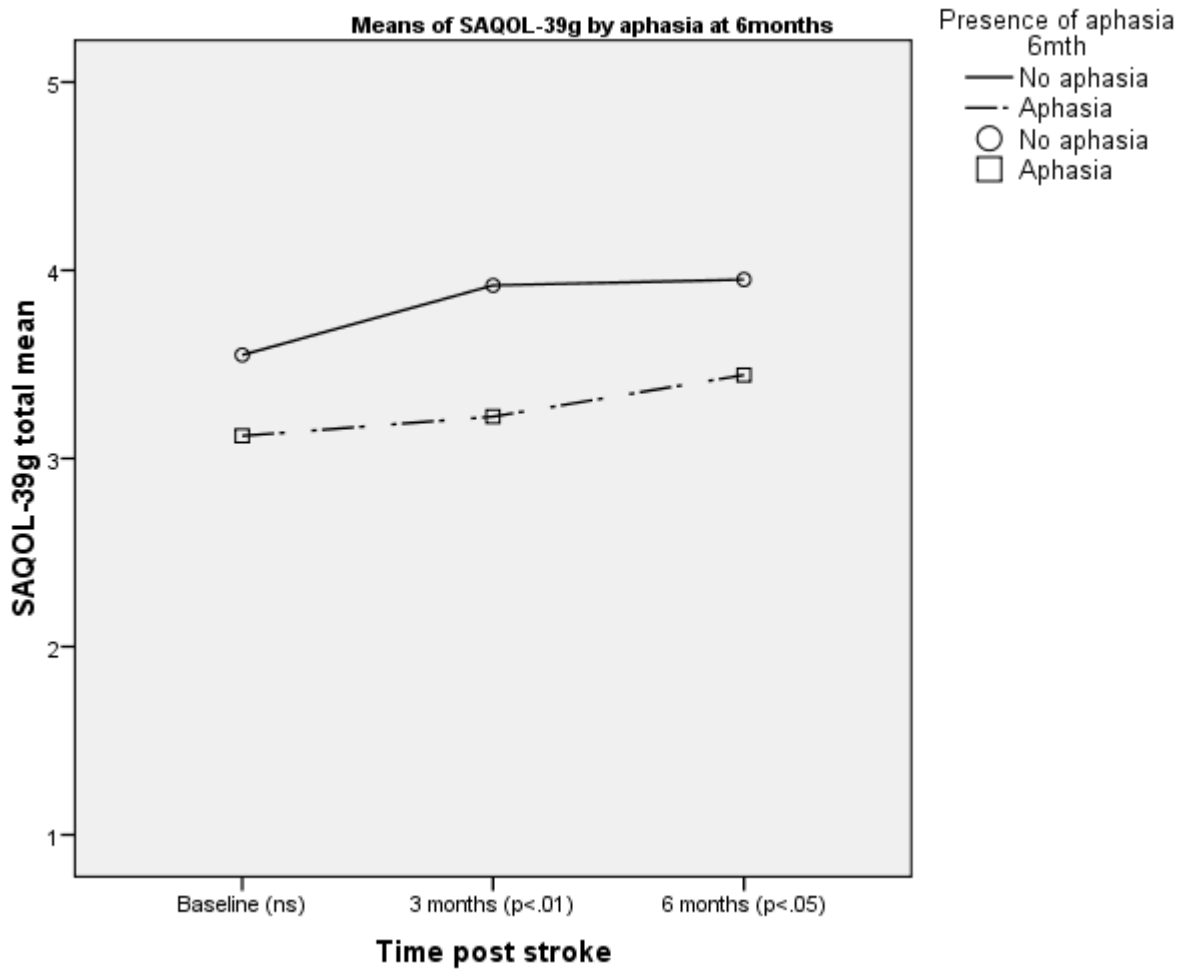




Figure 5: Differences between participants with aphasia and those without on quality of life across time post stroke (n=71)



## APPENDIX

Sample page of the SAQOL-39g comprising four questions from the psychosocial domain.

During the past week Did you					
Feel <b>discouraged</b> about your <b>future</b> ?					
Have <b>no interest</b> in other <b>people</b> or <b>activities</b> ?	x				✓
Feel <b>withdrawn</b> from other people?	<b>Definitely yes</b>	<b>Mostly yes</b>	<b>Not sure</b>	<b>Mostly no</b>	<b>Definitely no</b>
Have <b>little confidence</b> in yourself?					

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