

1 **Gavel Club for people with aphasia: Communication confidence and quality of**
2 **communication life**

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1 **Abstract**

2 *Background:* Many factors that contribute to successful living with aphasia intersect with the
3 benefits one can get from attending an aphasia group. Affiliated with Toastmasters
4 International, Gavel Clubs (GCs) for people with aphasia (PWA) provide a range of
5 communication activities that promote public speaking and leadership skills. The constructs
6 of communication confidence and quality of communication life (QCL) were introduced over
7 a decade ago but have not been widely investigated.

8 *Aims:* This study aims to investigate the association between weekly participation in GC
9 public speaking activities for PWA and the constructs of QCL and communication
10 confidence. In addition, the study aims to explore the association between the severity of
11 aphasia, QCL and communication confidence.

12 *Method:* Eight members of a GC for PWA, who attended 31-33 weekly GC meetings per year
13 between 2012 and 2016, participated in assessments of their QCL (using the ASHA Quality of
14 Communication Life (ASHA QCL)), communication confidence (using the Communication
15 Confidence Rating Scale for Aphasia (CCRSA)) and aphasia severity (using the Western
16 Aphasia Battery-Revised (WAB-R)). A link was sought between severity of aphasia and the
17 constructs of QCL and communication confidence.

18 *Results:* QCL improved significantly over four years of participation in the GC ($Z=2.103$,
19 $n=8$, $p=.035$, $r=.74$). Communication confidence also improved significantly ($Z=1.973$,
20 $p=.049$, $r=.70$). No associations were found between the two scales nor between the scales
21 and severity of aphasia.

22 *Conclusions:* Weekly participation in GC group activities was associated with improved
23 QCL, as measured by the ASHA QCL, and improved communication confidence as measured
24 by the CCRSA. Decision making (measured by the CCRSA) and Roles and Responsibilities
25 domain (in the ASHA QCL) also improved. More research is needed to verify these findings
26 using a study design that includes a control group, to identify the links between the various
27 psychosocial aspects at play in the life of PWA and to conceptualise how the gains achieved
28 with GC participation can be applied more broadly to successful living with aphasia.

29

1 **Keywords**

2 aphasia; group; Gavel Club; communication confidence; quality of communication life;

3 aphasia severity

4

5

1 **Introduction**

2 When faced with the sudden effects of a stroke and progressing through the various
3 stages of care and rehabilitation (acute care, inpatient and community rehabilitation services)
4 and on to post-rehabilitation life, people with aphasia (PWA) are at high risk of psychosocial
5 sequelae. These include depression, isolation and reduced quality of life (QoL) (Code &
6 Herrmann, 2003; Cruice, Worrall, Hickson, & Murison, 2003; Hilari & Northcott, 2006;
7 Worrall et al., 2016; Worrall, Hudson, Khan, Ryan, & Simmons-Mackie, 2017). Simmons-
8 Mackie et al. (2014) state that direct actions aimed at improving the quality of life of PWA
9 are required to make a difference in psychosocial health following a stroke

10 ***Community-based aphasia groups***

11 The length of stay in a stroke ward (considered the best acute service for improving
12 outcomes of people with stroke (Child et al., 2011), or in a rehabilitation service, has
13 significantly reduced over the years (Fearon & Langhorne, 2012). This, coupled with the
14 rights of people living with the effects of a stroke to enjoy equity in life opportunities, has
15 propelled clinicians to pursue ‘real-life’ outcomes and life re-engagement goals when
16 working with PWA. These are clearly emphasised by the Life Participation Approach to
17 Aphasia (LPAA) (Duchan et al., 2001). The Aphasia Institute in Toronto, the Aphasia Center
18 of California and the now closed UK Connect are examples of community-based services that
19 foster these important aims.

20 Clinical guidelines (Stroke Foundation of New Zealand, 2010), clinical pathways such
21 as the Australian Aphasia Rehabilitation Pathway (AARP) (Power et al., 2015) and best
22 practice guidelines, including C.A.P.E. (Elman, 2016) which promotes connections with
23 other PWA, use of augmentative and alternative communication options, partner training and
24 education, now exist to provide clinicians with a framework on which community-based
25 aphasia groups can evolve to deliver evidenced based services for PWA (Elman, 2016).
26 Aphasia centres and community-based groups for PWA, described as “interactive
27 communities” (Elman 2016, p154), offer activities which have been shown to play a distinct
28 and central role in psychosocial adjustment for PWA (Holland, 2007). These have been found
29 to provide positive experiences of competence, inclusion, support and development of
30 identity (Lanyon, Rose & Worrall, 2013).

31 Van Der Gaag et al. (2005) noted the paucity of studies examining the effect of such

1 community-based aphasia services for people with chronic aphasia. They reported significant
2 improvement in QoL and communication after six months' participation in group activities
3 along with improvements in participants' sense of autonomy and self-confidence. Elman and
4 Bernstein-Ellis (1999) reported gains after participation in a communication group including
5 improved confidence and enjoyment in making friends.

6 Affiliated with Toastmasters International, Gavel Clubs (GCs) for PWA offer novel
7 group activities that promote public speaking and leadership skills (Toastmasters
8 International, 2016a, 2016b). Public speaking is generally described as one of the most
9 daunting tasks to engage in (Botella et al., 2010). GC participants (known as 'members')
10 attend Club meetings to engage in this challenging task, typically delivering a 1-2 minute
11 impromptu speech each week and a 4-6 minute prepared speech approximately five times a
12 year. Using a format and structure developed by Toastmasters (Toastmasters New Zealand,
13 2016), GCs offer attainable speaking challenges set within a predictable framework with
14 which members become well versed. The Club is a positive and supportive environment
15 where confidence with public speaking can grow.

16 ***Successful living with aphasia***

17 Over the last ten years, research has identified factors associated with living
18 successfully with aphasia. Most of these studies have been qualitative in nature, involving
19 interviews with PWA, with speech language therapists (SLTs), and with family members
20 and/or friends (Brown, Worrall, Davidson, & Howe, 2010; 2011a; 2011b; 2012; 2013; Cruice
21 et al., 2006; Grohn, Worrall, Simmons-Mackie, & Hudson, 2014; Grohn, Worrall, Simmons-
22 Mackie, & Brown, 2012; Holland, 2006). Themes from these studies such as maintaining
23 meaningful social relationships, making new friends with aphasia, taking responsibility for
24 continued communication improvement, confidence in communication skills,
25 acknowledgement that successful living with aphasia is a journey over time, acceptance of
26 the changes that have happened and coming to terms with one's new identity, have been
27 found to be associated with successful living with aphasia. Many of these themes overlap
28 with the benefits that Elman and Bernstein-Ellis (1999) have identified as being associated
29 with attending an aphasia group.

30 ***Quality of life (QoL)***

31 Health related QoL studies examine the impact that a health condition has on a

1 person's ability to live a fulfilling life. This is achieved by examining perceptions and
2 feelings of satisfaction across a range of domains (Bullinger, Anderson, Cella, & Aaronson,
3 1993). QoL is usually measured through self-report scales. PWA have been poorly
4 represented or excluded from QoL studies because their communication difficulties make it
5 difficult to complete language based self-report scales. When included, their QoL has often
6 been reported via a proxy which is a less desirable method of measuring QoL due to the
7 highly personal nature of QoL (Hilari, Byng, Lamping, & Smith, 2003). Hilari, Byng,
8 Lamping and Smith (2003) and Cruice et al. (2003) have shown an association between QoL
9 and severity of aphasia, with poorer quality of life results obtained for people with more
10 severe aphasia. Other factors are also associated with better QoL for PWA. Cruice, Hill,
11 Worrall and Hickson (2010), Eadie et al. (2006), and Worrall et al. (2011) have identified that
12 participation in life roles and engagement in activities are strongly correlated with QoL.

13 ***Quality of communication life (QCL)***

14 In 2004 Paul et al. developed a self-report tool called the ASHA Quality of
15 Communication Life Scale (ASHA QCL). Using simplified language, large print and a visual
16 analogue scale, this tool measures specific domains that can be affected by aphasia. Paul et al.
17 conducted a factor analysis which supported the hypothesised domain structure (Eadie et al.,
18 2006). Eadie et al. (2006) noted that internal reliability and validity had not been reported for
19 the ASHA QCL. To understand the relationship between QoL and QCL, Bose, McHugh,
20 Schollenberger, and Buchanan (2009) compared these two constructs using the SAQOL-39
21 (Hilari et al., 2003) to measure QoL and the ASHA QCL to measure QCL. The results
22 showed that the concepts are not interchangeable and the authors concluded that QoL and
23 QCL capture two different but equally important aspects of life with aphasia.

24 ***Communication confidence***

25 Communication confidence is defined as "a feeling about one's power to participate
26 in a communication situation, one's sense about one's own skills and/or ability to express
27 oneself and to understand the communications of others" (Babbitt, Heinemann, Semik, and
28 Cherney (2011; p. 727). Babbitt and Cherney (2010) designed the CCRSA (Communication
29 Confidence Rating Scale for Aphasia) to measure confidence with communication. Babbitt et
30 al. (2011) administered the CCRSA to 47 PWA and found very good person and item
31 reliability. A distinction between *mastery* level of a communication act and *confidence* level

1 (which may or may not include mastery) of the same act is suggested when administering the
2 scale. When giving instructions, the examiner explains: We don't want to know how *well* you
3 can do the task but how *confident* you feel doing the task. For example, a person might not
4 sing very well, but she may feel very confident about her singing (Babbitt & Cherney, 2010).

5 According to Babbitt and Cherney (2010), communication confidence is illustrated by
6 a circular/wheel-shaped model where increased participation in life activities, increased
7 autonomy and self-determination and increased communication confidence all interact. In
8 2011, Cherney et al. compared the CCRSA and the ASHA QCL. The authors concluded that
9 QCL and communication confidence might be two different constructs and cautioned that "it
10 is unknown how communication deficits may be exacerbated by decreased confidence in
11 communicating" (p. 728). They called for more research in this field.

12 ***Aims of the study and hypothesis***

13 Anecdotal evidence such as an increase in confidence reported by PWA when
14 stepping into leadership roles to facilitate groups for PWA has been described by Penman and
15 Pound (2007). A review of qualitative studies on consumer views of communication groups
16 conducted by Attard, Lanyon, Togher and Rose (2015) identified, amongst others, a theme of
17 increased confidence and self-acceptance associated with participation in aphasia groups.
18 However, in their systematic review, Lanyon, Rose and Worrall (2013) were not able to
19 identify clear psychosocial benefits from attending community-based and outpatient aphasia
20 groups.

21 Despite growing interest internationally in GCs for PWA (Hallowell, 2016), to our
22 knowledge, there has not been any study on the effects that GC activities have on
23 communication skills or the wellbeing of members. This has led us to query the impact of
24 regular GC attendance, targeting the development of public speaking and leadership skills. In
25 the current study, which uses a Phase I design, as described by Robey (2004), two aspects of
26 psychosocial wellbeing, namely quality of life with respect to communication (Paul et al,
27 2004) and communication confidence (Babbitt & Cherney, 2010), were investigated in a
28 small group of community-based GC members who present with a range of types and
29 severities of chronic aphasia, across different times post-onset. Like Cherney et al. (2011), we
30 compared the CCRSA and the ASHA QCL, to determine the relationship between these two
31 relatively similar tools in a GC context. Because QoL is reportedly poorer for people with

1 more severe aphasia (Worrall et al., 2017, Hilari et al., 2003 and Cruice et al., 2003), we
2 scrutinised the results of the single participant with severe aphasia to determine potential
3 therapeutic effects of GC participation for others with severe aphasia. We hypothesised that
4 any person with aphasia, regardless of their aphasia severity, will benefit from participation
5 in GC activities.

6

7 **Method**

8 *Participants*

9 The current GC was formed in September 2012, the start time of the study, with an
10 SLT instigator and a small number of foundation members. Potential foundation members
11 were already attending a choir for people with neurological conditions and/or a coffee group
12 run by a national aphasia association. They were given written and verbal information (in an
13 accessible manner) about the purpose of a GC for PWA. The invitation to join was open to
14 anyone with aphasia, regardless of severity, who had an interest in improving their overall
15 communication skills under the leadership of an SLT and a Toastmasters Mentor, following
16 the Toastmasters International approach. Twelve PWA initially indicated their interest, but,
17 when more information was provided about the weekly commitment required, this reduced to
18 10 foundation members. At the study start (in September 2012), two of these 10 potential
19 participants withdrew due to health issues and/or being too busy, leaving a total of eight
20 research participants.

21 Participants were aged 44-71 years (M 61.88, SD 9.8) at study start; three were female
22 and five male. Time of aphasia duration ranged from 2-18 years. Seven participants had
23 English as their first language and one had been speaking English as a second language for
24 over 20 years. All participants were assessed at study start point and study end point (in 2016)
25 with the Western Aphasia Battery-Revised (WAB-R) (Kertesz, 2006). Calculating the WAB-
26 R aphasia quotient (AQ), six participants had mild (AQ above 76), one had moderate (AQ 51-
27 75), and one had severe (AQ 26-50) aphasia. The average WAB-R AQ at the start of the study
28 was 82.57 (SD 23.7). Despite the research being open to people with all levels of severity,
29 only one person with severe aphasia elected to participate. Perhaps the perceived challenges
30 associated with public speaking were a deterrent for people with severe communication
31 difficulties. The characteristics of the participants are summarised in Table 1.

1 (Table 1 about here)

2 ***Gavel Club (GC) structure and timing***

3 Table 2 outlines the structure of a typical GC meeting. The GC speaking activities
4 include a 1-2 minute impromptu speech (known within Toastmasters International as a ‘Table
5 Topic’), presented weekly by each member and based on topics selected by members
6 (Toastmasters International, 2016c), along with a 4-6 minute prepared speech presented on a
7 voluntary basis during the year. Typically, each member presents approximately five prepared
8 speeches per year. For the prepared speeches, members prepare a speech on a topic of their
9 choice in the week preceding the speech presentation. Members often received input from
10 their spouse or family members when preparing their speech. If this was not available,
11 members were welcome to seek support from the meeting facilitators (either the SLT, an SLT
12 student or a volunteer) in the preparation of their speech. Any effects of this tailored support
13 was not examined in this study.

14 (Table 2 about here)

15 A requirement of this GC was for the SLT or SLT student meeting facilitators to
16 present an annual workshop on total communication strategies to members. Members were
17 aware that total communication strategies rendered their speeches easier to deliver and to
18 understand. GC members were encouraged to use written notes and visual supports such as
19 pictures, slide show (e.g., PowerPoint), drawing, props, use of gestures, and keywords written
20 on the board prior to or during speech presentation. Some members brought an electronic
21 tablet to show pictures during their speeches. None of the research participants used a
22 specifically prescribed augmentative communication device at the meetings (or in their life
23 outside the meetings). Maps and numbers charts were available during meetings and were
24 used at times by members. Ultimately, members decided for themselves whether they wished
25 to use pictorial or prop support. At times and during any part of the meetings, the audience
26 (i.e. GC members, SLT, volunteers or SLT students) asked questions of the speakers.
27 Questions were mainly used to provide support to members with more severe expressive
28 language difficulties.

29 All impromptu and prepared speeches were evaluated by a fellow member who
30 provided specific feedback using Toastmasters International evaluation guidelines. A picture
31 board was used to help members structure their evaluation around four Toastmasters-

1 prescribed aspects. These include speech (e.g., voice volume), body language,
2 structure/language (e.g., use of honorifics, conclusion) and effectiveness (e.g., level of
3 persuasiveness). Annual training was provided by SLTs on how best to evaluate speeches.

4 In addition to the speeches and speech evaluations, members were encouraged to
5 volunteer for different leadership roles that provided the formal structure of the GC meetings.
6 Examples of these roles include Chairperson and ‘Wordster’ (Wordster presents a word, joke
7 or quote. If presenting a word, the Wordster challenges GC members to use it in their
8 speaking activities). The role of the Table Topic Master is to prepare (before the meeting) and
9 present (during the meeting), the questions or statements used for impromptu speeches. A
10 Toastmaster introduces the speakers, titles of the prepared speeches and the prepared speech
11 evaluators. A General Evaluator provides an overall review of the whole meeting.
12 A celebration day concluded each GC year. On celebration day, all club members joined in
13 one single event to each present a prepared speech to a wider audience including family
14 members, friends, community organisations, academic staff, students and community SLTs.

15 For ease of replication, the GC format has been comprehensively described in the
16 Aphasia Gavel Club Handbook and Resource Book created by the SLT instigator and
17 colleagues (Read, Moore, & Gillard, 2014a, 2014b).

18 *Pilot phase*

19 A pilot phase (September-November 2012; start date coinciding with the study start
20 date) saw the gradual introduction of speaking activities and meeting roles. At the end of the
21 pilot phase (November 2012), members reported enjoying the challenges of the public
22 speaking activities, felt that their communication skills had improved and reported improved
23 confidence with communication. As per members’ wishes, the group established itself with
24 regular meetings thereafter, officially joining Toastmasters International with the election of
25 an Executive Committee in 2013. A few months prior to starting the study/pilot phase, the
26 SLT instigator committed to attending Toastmasters International meetings at a local club.
27 This involvement ensured the GC meeting format remained close to the Toastmasters’
28 approach, but with adaptations made for aphasia accessibility. One to three Toastmasters
29 mentors, with full credentials and involved in local clubs also attended the pilot phase
30 meetings and subsequently joined meetings whenever possible, at least a few times per year.
31 These mentors provided ongoing guidance to the SLT instigator and the GC members. The

1 GC years and assessments of members that came after the pilot phase followed the format
2 outlined in Table 3.

3 The data reported in the current study were collected from the time the GC pilot was
4 established in September 2012 until the end of the study in May/June 2016. Participants
5 completed the ASHA QCL at the beginning and at the end of the GC pilot phase respectively
6 in September and November 2012, again 3 months later at the 2013 GC start time and again at
7 study end time, in May /June 2016, after four months of participation in weekly GC meeting
8 in that year. The CCRSA was administered to all participants starting from the 2013 start time
9 (the year that followed the completion of the pilot phase), at a frequency of three times per
10 year until the study end time (Table 3). A decision was made to add the CCRSA to the
11 measuring instruments at the 2013 start time as a potential ceiling effect was detected in the
12 ASHA QCL scores after completion of the pilot phase in 2012.

13 ***Current study***

14 Participants met weekly over four years, with three-four month blocks of weekly
15 meetings (divided into two annual semesters), for a total of 31-33 meetings per year. In 2013
16 (year 2 of GC), for a period of one semester, meetings were scheduled on a fortnightly basis,
17 but after one semester this changed to weekly meetings at the request of members who
18 reported forgetting their skills over a period of two weeks and wanting weekly sessions
19 instead. Southern hemisphere mid-winter (June-July) and summer breaks (November-
20 December-January) are timetabled into the GC calendar.

21 Member attendance was high with 1-3 missed meetings per semester for most
22 members. Meetings were co-facilitated by a Toastmasters mentor and one or two SLTs,
23 including the SLT instigator. Four to six volunteers were present at each meeting to assist
24 with various aspects, from room and refreshment set up, to supporting members during their
25 speeches. In the last three years of the study, two SLT students also provided support during
26 meetings. Students and volunteers received two one-hour training sessions from one of the
27 facilitating SLTs about the nature of aphasia and were taught strategies to support
28 communication with PWA. Videos, role playing and hands-on practice with volunteering
29 members were used as training tools. Written material was also provided. Further education
30 about communication took place in a debriefing session after most meetings.

31

1 *Measures*

2 Two rating scales were selected for this study, the ASHA QCL (Paul et al., 2004) and
3 the CCRSA (Babbitt & Cherney, 2010). The ASHA QCL comprises 18 questions with a five-
4 point rating scale. The lowest mark on the scale corresponds to a score of 1 and the highest
5 mark to a score of 5. The first 17 ASHA QCL items relate to three domains:
6 Socialisation/Activities; Confidence/Self-Concept; and Roles and Responsibilities. One item
7 in the ASHA QCL (Q14 “I am confident I can communicate”) asks about communication
8 confidence. The scores for the first 17 items in the ASHA QCL are summed up and divided to
9 obtain the individual final overall mean results used in the research. The 18th and last item of
10 the test “In general, my quality of life is good” is described as a general wellbeing question;
11 this item is not part of a domain and is not used to calculate the overall mean score for an
12 individual.

13 Babbitt and Cherney (2010) modified items from the ASHA QCL to create the
14 CCRSA, a tool that measures communication confidence. ASHA QCL questions were
15 reformulated to include the concept of confidence through insertion of the term “confident” in
16 several questions (e.g., CCRSA “How confident are you about your ability to talk with
17 people?” is adapted from the ASHA QCL “I can talk to people”). The CCRSA was selected
18 because GC members and family anecdotally reported improved confidence following the GC
19 pilot phase.

20 The CCRSA comprises 10 questions and uses a 10-point rating scale for each item
21 with the lowest mark corresponding to a score of 0 and the highest mark to a score of 100,
22 increasing in equal increments of 10. The selected score for each answered question is then
23 matched to a corresponding value of 1 to 4 as per the scale instructions (e.g., if the PWA rates
24 a question at 60, they obtains a score of 3 as questions rated as 60, 70 or 80 all correspond to a
25 value of 3). The corresponding values for the 10 questions are then added to obtain the final
26 score, with the lowest final score being 10 and the highest being 40.

27 *Procedure*

28 Participants completed the ASHA QCL four times, at the study start time (coinciding
29 with the September 2012 pilot start), at the November 2012 end time (end of pilot phase), 3
30 months later at the 2013 start time and at the study end in May/June 2016. The CCRSA was
31 administered to all participants beginning from the 2013 GC start time, three times per year

1 until the study end in 2016 (Table 3). Participants did not see their earlier results; new forms
2 were distributed each time measures were taken.

3 (Table 3 about here)

4 ***Statistical analysis***

5 Nonparametric analyses were performed due to the small sample size and the ordinal
6 nature of the rating scale data. Paired data were compared using Wilcoxon signed-rank tests,
7 with effect sizes estimated using r (Z divided by square root of n). Values of $r > 0.5$ indicate a
8 large effect size. A Friedman analysis of variance was used to evaluate CCRSA scores
9 collected on multiple occasions. Spearman correlations were used to measure associations
10 between ASHA QCL, CCRSA and WAB-R AQ scores. As Bonferroni corrections have not
11 been applied for multiple comparisons, reported significant findings ($p < .05$) should be
12 regarded as statistical trends warranting further investigation.

13

14 **Results**

15 ***ASHA Quality of Communication Life (QCL)***

16 The ASHA QCL was used four times during the course of the study (Table 4). Median
17 ASHA QCL ratings for the four test occasions are listed in Table 5. Question 5 (Q5) “I meet
18 the communication needs of my job or school” was not applicable for four out the eight
19 participants and Q16 “I have household responsibilities” was answered as ‘not applicable’ by
20 two out of eight participants (on one occasion only), but all other questions were responded
21 to. With Q5 excluded, Cronbach’s alpha coefficient for the 16 items included in the ASHA
22 QCL overall score (not including Q18) indicated good internal reliability ($\alpha = .757$ to $.839$).
23 Ratings were high (rating of 5) for all participants for some items such as Q8 “I follow news,
24 sports, and stories on TV/movies”.

25 Related-samples Wilcoxon signed-rank tests were used to compare 2012 study start
26 and 2012 end time ratings (examining the effect of the two months’ attendance of GC during
27 the pilot phase); 2012 end time (at the end of the pilot phase) and 2013 start time ratings
28 (examining the effect of a 3-month break in GC); and 2012 study start time and 2016 study
29 end time ratings (examining changes over the entire four-year period). Significant differences
30 in scores are indicated in Table 5 and summarised in Table 6. Overall and Domain scores

1 showed a difference pre- versus post-two months of GC in 2012 for: overall ASHA QCL,
2 $Z=2.201$, $n=8$, $p=.028$, $r=.78$, and Domain 3 (Roles and Responsibilities), $Z=2.539$, $n=8$,
3 $p=.011$ $r=.90$.

4 The comparison of 2012 end time (end of pilot phase) versus 2013 start time scores
5 showed a significant drop in scores after a summer break of about three months for the overall
6 scores, $Z=2.032$, $n=7$, $p=.042$, $r=.77$, but not for Domain 3 (Roles and Responsibilities)
7 scores. The comparison of 2012 study start time and 2016 study end time scores showed a
8 significant improvement across the four years of GC participation for overall ASHA QCL
9 scores, $Z=2.103$, $n=8$, $p=.035$, $r=.74$, and Domain 3, $Z=2.023$, $n=8$, $p=.043$ $r=.78$. None of the
10 comparisons showed significant differences for ASHA QCL Domains 1
11 (Socialisation/Activities) and 2 (Confidence/Self-concept), the general wellbeing question
12 (Q18), or the single confidence question (Q14). Note that the differences in ASHA QCL
13 scores across time would not be interpreted as statistically significant if Bonferroni
14 corrections for multiple comparisons are applied, and hence these findings should be
15 interpreted as statistical trends only.

16 (Table 4 about here)

17 (Table 5 about here)

18 (Table 6 about here)

19 ***Communication Confidence Rating Scale (CCRSA)***

20 The CCRSA was administered on 11 occasions at approximately 6-monthly intervals
21 from the start of 2013 until the end of the study in 2016 (Table 7). Responses to individual
22 CCRSA items ranged from not confident (e.g. Q5: speaking on the phone) to very confident
23 (e.g. Q3: following news and sports on TV). Friedman's nonparametric repeated measure
24 analysis of variance for the six participants completing the CCRSA on all occasions showed a
25 significant improvement in overall CCRSA scores across test occasions ($\chi^2=21.90$, $df=10$,
26 $n=6$, $p=.016$).

27 When 2013 (start of year 2 of GC, $n=7$) and 2016 (middle of year 4 of GC, at the end
28 of the study) CCRSA scores were compared using Wilcoxon signed rank tests, Q9 “How
29 confident do you feel that you can make your own decisions”, $Z=2.070$, $p=.038$, $r=.73$, and
30 overall CCRSA scores, $Z=1.973$, $p=.049$, $r=.70$, showed significant improvements. Pairwise

1 comparisons between all 11 CCRSA time points were not undertaken due to the probability of
2 Type 1 error associated with performing multiple comparisons.

3 (Table 7 about here)

4 (Table 8 about here)

5 ***Correlation analysis: aphasia severity, ASHA QCL and CCRSA***

6 The average WAB-R AQ at the start of the study was 82.57 (*SD* 23.7) but decreased to
7 80.58 (*SD* 24.1) at the 2016 end of study time. A Wilcoxon signed-rank test confirmed that
8 this reduction in AQ scores four years later was significant, $Z=2.383$, $n=8$, $p=.017$, $r=.84$.

9 *ASHA QCL versus CCRSA*: ASHA QCL scores at 2012 end time (post-GC pilot) and
10 at the start of GC in 2013 were highly correlated with scores on the CCRSA administered at
11 2013 GC start time ($R_s=.880$, $n=8$, $p=.004$ and $R_s=.927$, $n=7$, $p=.003$, respectively). This
12 correlation between ASHA QCL and CCRSA scores was anticipated as the CCRSA items
13 were adapted from the ASHA QCL. When the questionnaires were re-administered at study
14 end time in 2016, there was a weaker correlation between ASHA QCL and CCRSA scores
15 ($R_s=.693$, $n=8$, $p=.057$). The ASHA QCL confidence ratings (Table 5) indicate that
16 participants were more variable in 2012 and 2013 but by 2016 they rated themselves
17 consistently near the top of the scale for Q14. Domain 2 scores were high on average and
18 stable over time. Thus, the lack of correlation between WAB-R AQ scores and ASHA QCL
19 may be in part due to the limited spread in ASHA QCL ratings by the end of the study.

20 *WAB-R AQ versus ASHA QCL & CCRSA*: Nonparametric Spearman correlations
21 showed no association between 2012 study start time aphasia severity indicated by WAB-R
22 AQ scores and communication confidence measured in 2012 (start and end), 2013 (start) or
23 2016 (end of study) using the ASHA QCL Q14 “I am confident I can communicate” ($p>.05$).
24 There were also no correlations between aphasia severity and Domain 2: Confidence/Self-
25 Concept or CCRSA overall scores measured at the start of 2013 and in 2016 at the end of the
26 study. Figure 1 shows the lack of association between WAB-R AQ scores and 2013 and 2016
27 CCRSA ratings.

28 (Figure 1 about here)

1 **Discussion**

2 This study investigated changes in quality of life with respect to communication (Paul
3 et al, 2004) and changes in communication confidence (Babbitt & Cherney, 2010) in a small
4 group of participants with chronic aphasia who regularly engaged in GC activities aiming at
5 developing public speaking and leadership skills. The results obtained suggest an association
6 between weekly participation in GC activities, improved QCL as measured by the ASHA
7 QCL and improved communication confidence as measured by the CCRSA. Given the small
8 number of participants in this study, and the inclusion of only one participant with severe
9 aphasia, it is not clear how generalisable these results are and hence further study is needed to
10 verify these findings.

11 ***Improvement in overall QCL***

12 PWA participating in GC group activities showed improvements in overall ASHA
13 QCL scores and in Domain 3 results (Roles and Responsibilities). These results suggest that
14 GC activities may have a positive impact on QCL, and hence warrant further investigation
15 using a Phase II design (Robey, 2004) with a larger sample size to improve statistical power.
16 Cronbach's alpha coefficient calculated in the current study shows good internal reliability for
17 the ASHA QCL. The inclusion of participants with greater aphasia severity may reduce the
18 ceiling effect observed here for ASHA QCL scores.

19 To our knowledge, no studies have identified the elements that influence QCL for
20 PWA. There are a number of possible mechanisms whereby GC attendance could have had a
21 positive effect. With respect to the ASHA QCL, several questions probe the extent of
22 communicative interactions (e.g. Q1: "I like to talk to people, Q7: "People include me in
23 conversations", Q11: "People understand me when I talk"). In themselves, positive
24 communicative experiences gained through GC attendance could result in improved scores on
25 ASHA QCL. In turn, these experiences may open the way for further engagement in activities
26 and socialisation opportunities outside GC, which may positively influence scores. It would
27 be advantageous for future research to closely explore the extent to which participants are
28 socialising more or have added new activities to their lives since attending GC, to scrutinise
29 whether links between these and participation in a GC group can be established.

30 An overall high score was obtained on the first administration of the ASHA QCL at

1 the start of the study in 2012 (mean 3.93, SD .84, out of a maximum score of 5). At the
2 second administration (2012 end time), the overall ASHA QCL mean score had increased (to
3 4.45 out of 5) and the standard deviation had reduced (SD .27). A decision was made to
4 replace the ASHA QCL scale with the CCRSA at the end of the pilot phase (2012 end time)
5 because of this potential ceiling effect. At the time of joining the GC in 2012, all the research
6 participants were between two and 18 years post-stroke. It could be hypothesised that
7 participants were already enjoying a high level of QCL given that successful living with
8 aphasia is described as a journey over time (Brown et al., 2012; Holland, 2007). Moreover,
9 participants keenly joined the Club. This could denote the presence of a pre-existing positive
10 approach to life. As noted earlier, another reason for high ASHA QCL scores could be that
11 the majority of participants had mild aphasia.

12 ***Improvement in ASHA QCL Domain 3 “Roles and Responsibility”***

13 An improvement was observed for Domain 3, “Roles and Responsibilities” over the
14 period of the pilot study in 2012, and across the years of GC participation. GC members are
15 encouraged to step into leadership roles such as Chairperson, Wordster, Toastmaster and
16 Table Topic Master during the meetings. Engagement in these roles may have positively
17 impacted on the ASHA QCL “Roles and Responsibility” Domain scores and on life roles of
18 PWA, outside of meetings. Since 2013, an executive committee has been elected every year
19 by members. The roles of President, Vice President and Secretary are held by members. These
20 provide further responsibility and leadership opportunities for members who are encouraged
21 to make decisions about the running and development of the GC. Given the profound effect
22 on life roles of having a stroke (Le Dorze & Brassard, 1995; Lynch et al., 2008), participation
23 in GC leadership activities may help to address this issue.

24 ***Improvements in communication confidence***

25 An significant increase in communication confidence was recorded between the first
26 administration of the CCRSA in 2013 and the last one in 2016, and an analysis of variance
27 showed an improvement across the multiple occasions when the scale was administered.
28 Reasons for this increase may be similar to the reasons for improvement in ASHA QCL as
29 the assessments have similar questions. The single question: “How confident do you feel
30 making your own decisions” (Q9) showed an improvement in this time period. Decision

1 making, if looked at through Babbitt and Cheney's (2010) interactive communication
2 confidence model, may boost autonomy, self-determination and life participation and be in
3 itself an indicator of improvement in confidence. Encouraging PWA to make their own
4 decisions might be a way of improving confidence and sense of empowerment as Funnell and
5 Anderson (2003), have linked decision making and empowerment. They indicate that "people
6 are empowered when they have sufficient knowledge to make rational decisions" (p.454) and
7 further, that empowerment is achieved through one's right and responsibility to make one's
8 own decisions. We have yet to discover the exact mechanisms that influence communication
9 confidence in PWA.

10 Babbitt and Cherney (2010) suggest that communication confidence in the field of
11 aphasia, is experienced when one feels able to achieve a communication act despite having a
12 communication impairment. This is presented to the PWA in the administration instructions
13 of the CCRSA where focus is placed not on how *well* one completes a communication act but
14 on how *confident* one feels to perform that same act. This distinction supports the
15 establishment of an aphasia identity and an aphasia culture, whereby 'normal'
16 communication abilities are not required to convey a message and have a socially accepted
17 voice. The specific opportunities offered by a GC where communication confidence can grow
18 in a mutually supportive environment, modelled by other PWA who are progressing along the
19 "living better with aphasia" pathway, might spur positive changes in life engagement,
20 attitudes and moods. For example, members might share the tricks aphasia can play on them,
21 such as the production of a quirky semantic paraphasia. Being able to see the funny side of
22 things during GC activities can have a positive impact on confidence and may contribute to
23 the beneficial identity and attitude shifts that are associated with successful living with
24 aphasia.

25 As part of GC weekly speaking activities, questions are asked of members who are
26 encouraged to express opinions and ideas about a wide range of topics. Being given a forum
27 to express oneself to share views may be an empowering experience, especially if being
28 'silenced' by aphasia has been a predominant theme in one's life. When delivering their
29 prepared speeches, members stand at a podium in front of the group. It takes a degree of
30 courage (and a will to be heard) to express oneself in front of a group and this must be
31 especially true when one has aphasia. These elements, which are congruent with the A-
32 FROM framework developed by Kagan et al. (2008), interweave to create a canvas, against

1 which ways of facing life with aphasia can evolve, beyond the “coping with the disorder”
2 level (Holland, 2006, p. 44).

3 The end of year celebration day is another occasion where confidence can be built and
4 difference can be celebrated (Pound et al., 2000). Public speaking to a wider audience allows
5 members to showcase their improvements in communication and confidence, engage in
6 community education and by extension in self-advocacy action. Given the chronicity of
7 aphasia, the social learning gained through an approach that goes beyond fixing
8 communication difficulties and that aims to bring together people of different abilities is a real
9 strength of a GC.

10 Ultimately, the aim of a GC is to generalise gains to life outside the Club. All GC
11 members who took part in this study have also engaged in a number of other activities over
12 their GC years (e.g. media interviews and/or presentations at national or international SLT
13 conferences). In these activities, members talked about the reality of living with aphasia and
14 the effect that GC has had on their life.

15 ***Links between QCL and communication confidence***

16 As per Cherney et al. (2011), we were unable to demonstrate a link between QCL and
17 communication confidence, based on correlation analysis. The CCRSA scores were lower
18 than the ASHA QCL scores, presumably because scoring the *confidence* one feels *about* an
19 act is different to scoring the degree of *engagement in* the same act. As suggested by Babbitt
20 et al. (2011), the inclusion of the word “confidence” in the questions “might be the key to
21 allow for more self-analysis of communication skills” (p. 732). Given the high initial scores
22 obtained by participants on the ASHA QCL, the CCRSA scale provided more scope for
23 measuring improvements for our group of participants.

24 ***Severity of aphasia, QCL and communication confidence***

25 The results of this study suggest that members gained from participating in GC
26 activities, regardless of aphasia severity. No correlations were found between severity of
27 aphasia and the constructs of QCL or communication confidence. As six participants out of
28 eight had mild aphasia (two out of eight had either moderate or severe aphasia), these
29 numbers limit our ability to draw strong conclusions from our results. It is also possible that
30 selection bias may, at least partially, explain the lack of relationship between the three
31 measures. Perhaps people with a positive attitude to challenges, irrespective of their aphasia

1 severity, and those who were already experiencing a degree of QCL and communication
2 confidence, chose to join the GC, whereas others chose not to.

3 Consistent with Babbitt and Cherney (2010) we observed that, in the absence of
4 significant improvement in communication abilities, our research participants showed
5 improved QCL and CCRSA scores. A different tool, measuring non-verbal communication
6 skills (e.g., gestures, facial expressions, intonation) or one that is more sensitive to subtle
7 changes in syntax or morphology, might detect degrees of communication change.

8 ***Psychosocial health***

9 Participation in activities has been identified as having the most important influence
10 on QoL for PWA (Cruice et al., 2010). However, participating in activities alone, whether in
11 community-based programmes or other activities chosen by PWA, may not be enough to
12 produce a ripple effect on overall psychosocial health (Simmons-Mackie et al., 2014). To
13 further facilitate the transition towards successful living with aphasia, providing direct input at
14 the psychosocial level (Elman & Bernstein-Ellis, 1999), along with increased participation in
15 activities, is likely to produce best outcomes. The process of living successfully with aphasia
16 takes time and can be many years (Worrall et al., 2010). A number of psychosocial aspects
17 associated with successful living with aphasia have been reported. These include acceptance,
18 adjustment, taking responsibility for one self, re-engagement in life roles, self-esteem, mood,
19 positive attitude, hope, transforming identity, autonomy, self-determination, empowerment
20 and self-advocacy, self-expression, self-efficacy and confidence, communication confidence,
21 QoL and QCL (Brown, Worrall, Davidson, & Howe, 2010; 2011a; 2011b; 2012; 2013; Cruice
22 et al., 2006; Grohn, Worrall, Simmons-Mackie, & Hudson, 2014; Grohn, Worrall, Simmons-
23 Mackie, & Brown, 2012; Holland, 2006). It may be that GC participants' confidence in their
24 communication abilities and in their ability to make decisions increased their QCL thereby
25 supporting positive identity changes, self-empowerment and successful living with aphasia.

26 Collaboration between the fields of speech and language therapy and psychology
27 might help expose relationships between the various stroke-triggered psychosocial responses
28 and clarify how these relate to our current models. Research outcomes in this area might
29 identify elements that are critical to communication and psychosocial improvements (Elman,
30 2016) and help expand the knowledge required for clinicians to provide insightful input to
31 PWA that assists adjustment and/or shortens the road to living well with aphasia. It might also

1 help us to better understand how group activities such as GC can benefit PWA.

2 ***Limitations and future research***

3 The size of this research sample is small which limits statistical power and the strength
4 of our conclusions regarding the benefits of GC. Communication confidence and QCL are
5 dynamic processes in the same way as QoL is dynamic (Cruice et al., 2003), and they are
6 open to influences external to GC participation that might have affected the results obtained in
7 this study. There was no control group of PWA receiving usual care for the same time period
8 as GC. As interest in GCs for PWA continues to grow, there may be opportunities in the
9 future for multi-centred studies examining the effects of a GC for a larger number of
10 participants including those with more severe aphasia. Possible self-selection bias is another
11 limitation which is difficult to fully address, even in a larger (Phase II) study design.

12 Regardless of the recorded improvement in communication confidence and QC, the
13 results of this research, which sought to detect the presence of a therapeutic effect (Robey,
14 2004), have not established a causal link between GC attendance and improvements in these
15 two aspects. A prospective randomised controlled study design is needed to verify that the
16 improvements relate to GC participation,

17 **Conclusion**

18 Over recent years, there has been a focus on the psychosocial experience of living with
19 aphasia. The current study suggests an association between improvements in communication
20 confidence, QCL, decision making and engagement in Roles and Responsibilities and
21 participation in GC activities for PWA. Developing strong personal skills such as public
22 speaking and leadership within the supportive GC environment might be a conduit to self-
23 empowerment and more successfully living with aphasia. The recommended next step is to
24 replicate this study with a larger number of participant members and in a variety of settings
25 (e.g., rehabilitation clinics or informal spaces such as libraries and community centres), using
26 a more robust study design, to determine the efficacy and effectiveness of a GC for PWA.

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20 in 2013 and 3.5 years later in 2016. Dotted and solid linear trend lines are for the data from
21 2013 and 2016, respectively. Correlations were not significant.

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1 Table 1

2 *Participant characteristics at commencement of pilot phase (September 2012)*

Participant	Age	Sex	Handedness	Type and side of stroke	Aphasia duration*	Aphasia Type	Aphasia Quotient**	
							Study start	Study end
							2012	2016
1	71	M	Right	left ischaemic	1;11	Broca	37	35.6
2	70	M	Right	left haemorrhagic	2;05	Anomic	97	96.2
3	67	M	Left	left haemorrhagic	18;05	Wernicke	54.1	50.8
4	53	F	Right	left carotid artery dissection	5;01	Anomic	98.2	98.4
5	71	F	Right	left ischaemic	7;06	Anomic	98	96.8
6	60	M	Right	left ischaemic	5;04	Anomic	97	95.7
7	59	F	Right	left ischaemic	2;07	Anomic	93.6	90.3
8	44	M	Right	left haemorrhagic	12;05	Anomic	85.7	80.9
<i>Mean</i>	61.9				6;11		82.57	80.6
<i>SD</i>	9.8				5;09		23.7	24.1

3 *Notes.* * Aphasia duration is reported as years;months

4 ** Aphasia quotient calculated using the Western Aphasia Battery-Revised (WAB-R)
 5 (Kertesz, 2006).

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1 Table 2

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3 *Timing of a typical GC meeting*

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Time	Roles and tasks
10:00	President's Welcome: call to order, welcome and apologies
10:05	Chairperson's Welcome: introduces theme, reviews agenda and conversation rules (e.g., one person speaking at a time) Birthdays/anniversaries/special events or happenings
10:10	Wordster: presents joke, word or quote of the day
10:15	Table Topic Master: introduces Table Topics and Evaluations
10:50	Refreshment Break
11:05	Toastmaster: introduces Prepared Speeches and Evaluations
11:35	Time Keeper's Report
11:40	Wordster's Report
11:45	General Evaluation
11:55	General Business and Agenda for Next Meeting
12:00	Close of Meeting

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1 Table 3.

2 *Assessment time line*

	2012		2013			2014			2015			2016	
	Start	End	Start	Mid	End	Start	Mid	End	Start	Mid	End	Start	End
ASHA-QCL	•	•	•										•
CCRSA			•	•	•	•	•	•	•	•	•	•	•

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1 Table 4.

2 *ASHA Quality of Communication Life (ASHA QCL) individual participant data*

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Year	Time	P1	P2	P3	P4	P5	P6	P7	P8
2012	Start	4.56	4.24	3.41	3.75	3.38	4.12	3.56	4.41
	End	4.44	4.41	4.47	4.50	3.69	4.65	4.31	4.65
2013	Start	3.82	--	3.88	4.44	3.76	4.53	3.63	4.53
2016	End	4.00	4.44	4.00	4.13	3.75	4.44	4.50	4.65

4 *Note.* Maximum score= 5. P = Individual participants. -- = missing data (one absent member)

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1 Table 5

2 *ASHA Quality of Communication Life (ASHA QCL) average group ratings for the overall*
3 *questionnaire (Questions 1-17), the three sub-domains, Q14 and the general wellbeing*
4 *question (Q18)*

	Study start 2012 (n=8)	End 2012 (n=8)	Start 2013 (n=7)	Study end 2016 (n=8)
Overall (Q 1-17)	3.93 (.84) ^{1,3,4}	4.45 (.27) ¹	3.88 (.76) ³	4.38 (.71) ⁴
Domain 1 ‘Socialization/ Activities’	4.08 (.77)	4.38 (.33)	4.00 (.57)	4.54 (.65)
Domain 2 ‘Confidence/ Self-concept’	4.17 (1.25)	4.42 (.46)	3.83 (1.33)	4.33 (.75)
Domain 3 ‘Roles & Responsibilities’	3.88 (.88) ^{2, 5}	4.63 (.63) ²	4.50 (.75)	4.50 (.85) ⁵
Q14 ‘I am confident that I can communicate’	3.50 (1.75)	4.00 (1.00)	4.00 (1.00)	4.50 (1.00)
Q18 ‘In general, my quality of life is good’	5.00 (1.00)	5.00 (.00)	4.00 (1.00)	5.00 (.75)

5 *Notes.* Maximum score = 5. Medians and interquartile ranges (in parentheses) are shown.
6 Higher numbers indicate better outcomes. Superscript numbers (1 to 5) indicate significant
7 differences between pairs of scores ($p < .05$, Bonferroni corrections not applied). Start 2013:
8 $n=7$ (one absent member).

1 Table 6

2 *Wilcoxon statistical results for the American Speech-language-hearing Association Quality of*
3 *Communication Life (ASHA QCL) comparisons over time which showed significant*
4 *differences ($p < .05$) for Overall and Domain 3 ratings*

Comparison (Time 1 vs. Time 2)	ASHA QCL	Time 1 Mdn (IQR)	Time 2 Mdn (IQR)	Wilcoxon results
Start-2012 vs. end- 2012 (start vs. end of pilot phase, $n=8$)	Overall	3.93 (.84)	4.45 (.27)	$Z=2.201, p=.028, r=.78$
	Domain 3	3.88 (.88)	4.63 (.63)	$Z=2.539, p=.011, r=.90$
End-2012 vs. start- 2013 (before vs. after summer break, $n=7$)	Overall	4.47 (.33)	3.88 (.76)	$Z=2.032, p=.042, r=.77$
Start-2012 vs. end- 2016 (study start vs. end, $n=8$)	Overall	3.93 (.84)	4.38 (.71)	$Z=2.103, p=.035, r=.74$
	Domain 3	3.88 (.88)	4.50 (.85)	$Z=2.023, p=.043, r=.78$

5 *Note:* Maximum score= 5. Large effect sizes ($r > .5$) were obtained. Mdn=median,
6 IQR=interquartile range.

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1 Table 7

2 *Communication Confidence Rating Scale for Aphasia (CCRSA) individual participant data*

3

Year	Time	P1	P2	P3	P4	P5	P6	P7	P8
2013	Start	29	--	31	35	25	36	25	34
	Mid	30	32	30	35	--	35	21	35
	End	31	34	31	36	29	38	27	35
2014	Start	30	34	33	35	32	35	25	37
	Mid	32	--	28	37	30	36	28	37
	End	26	37	35	37	30	38	23	36
2015	Start	29	37	32	35	29	37	32	39
	Mid	29	--	38	36	32	37	22	34
	End	33	38	37	38	31	40	29	37
2016	Start	28	--	36	38	29	40	35	37
	End	28	38	36	34	31	37	33	37

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5 *Note.* Maximum score = 40. P = Individual participants. -- = missing data (absent members).

1 Table 8

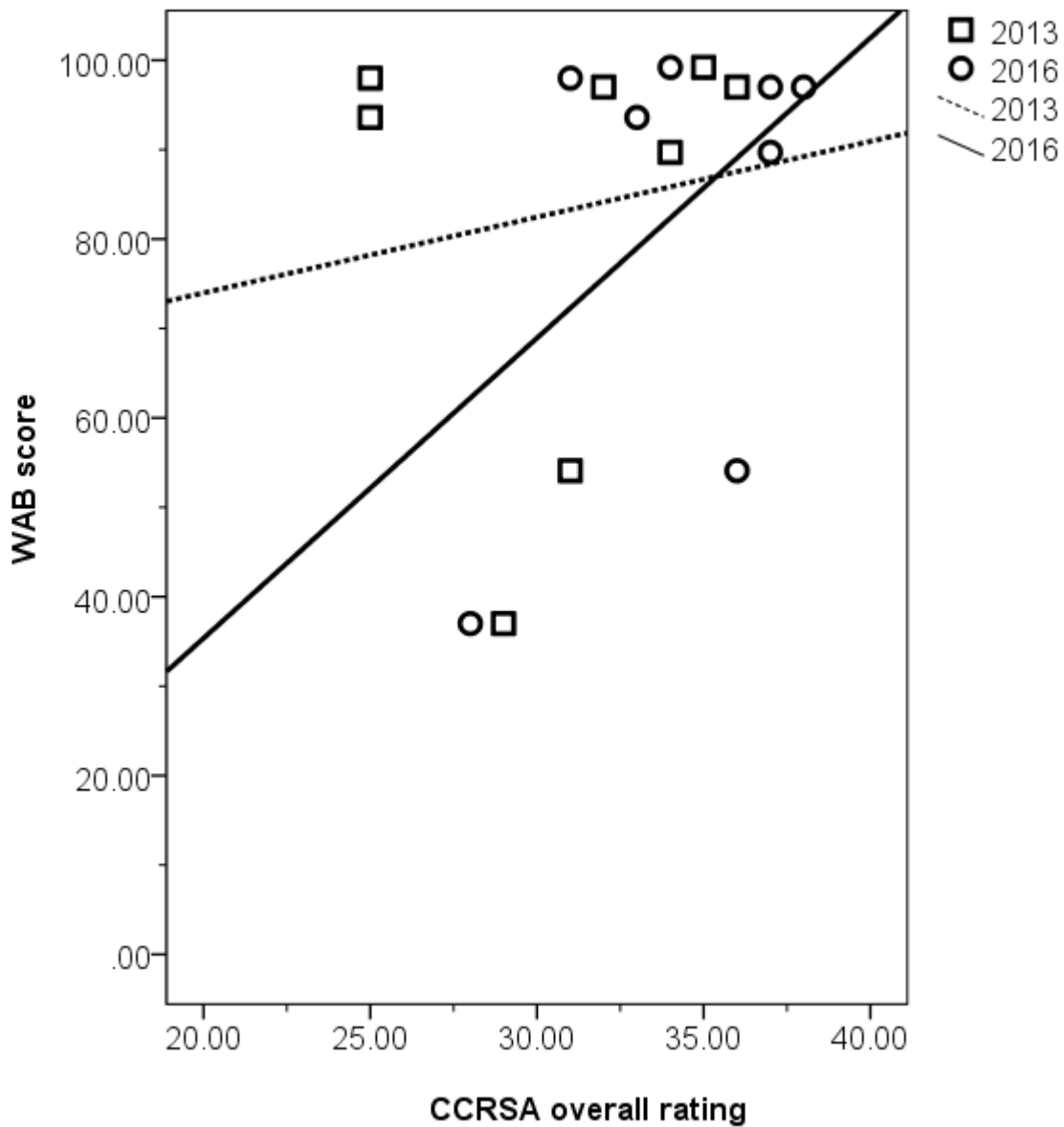
2 *Communication Confidence Rating Scale for Aphasia (CCRSA) results [median (interquartile*
 3 *range)] for overall CCRSA ratings (average of Questions 1 to 10) and for each time point for*
 4 *Question 9*

5

Year	Measure	Overall CCRSA ratings			Question 9 (...own decisions)	
		Study start	Mid	End	Start	Study end
2013	Mdn	31.50	31.00	32.00	3.00	
	(IQR)	(8.75)	(10.00)	(5.00)	(1.50)	
	<i>n</i>	8	7	7	8	
2014	Mdn	32.50	33.50	32.00		
	(IQR)	(6.25)	(4.50)	(9.00)		
	<i>n</i>	8	8	7		
2015	Mdn	33.50	34.00	37.00		
	(IQR)	(7.25)	(8.00)	(6.5)		
	<i>n</i>	8	7	8		
2016	Mdn	36.00	35.00			4.00
	(IQR)	(9.00)	(5.50)			(0.00)
	<i>n</i>	7	8			8

6 *Note.* Maximum score = 40

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2 **Figure 1.** Scatter plot showing association between Western Aphasia Battery (WAB-R)
 3 scores and Communication Confidence Rating Scale for Aphasia (CCRSA) ratings obtained
 4 at the start of 2013 and 3.5 years later in May/June 2016 (end of the study). Dotted and solid
 5 linear trend lines are for the data from 2013 and 2016, respectively. Correlations were not
 6 significant.

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