

QUALITY OF LIFE MEASURES FOR APHASIA:  
PATIENT AND CAREGIVER PERSPECTIVES

A Thesis by

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PATIENT AND CAREGIVER PERSPECTIVES

The following faculty members have examined the final copy of this thesis for form and content, and recommend that it be accepted in partial fulfillment of the requirement for the degree of Master of Arts, with a major in Communication Sciences and Disorders.

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## DEDICATION

To my parents, Chris and Linda Ryan, and my brother, James, all of whom have instilled in me the value of hard work and to appreciate the rewards from perseverance through life's challenges, and whose love and support are constant. Also, to Mark Koch who has been my strength and sanity through this journey.

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## ABSTRACT

The purpose of this study was to compare two quality of life measures designed for persons with aphasia. Five persons with chronic expressive aphasia and their nominated family member/caregiver participated in this study. A preliminary interview was conducted with each participant. The Stroke and Aphasia Quality of Life Scale (SAQOL-39) and Assessment for Living with Aphasia (ALA) were then administered. Assessments were administered to family members under two conditions: (1) how they would rate the PWA's quality of life and (2) how they thought the PWA would rate themselves. A brief post-assessment interview was then given to help establish the validity of the quality of life assessments given.

The reported outcomes on individual measures for each participant were compared against outcomes on the other (i.e., SAQOL-39 vs. ALA). Outcomes reported by the PWA were then compared to those reported by their family member. Responses from the preliminary interviews were analyzed to establish common themes, as well as to aid in establishing validity of the quality of life assessments used.

Results indicated substantial variances existed between assessment outcomes and PWAs vs. family members. The dual presentation (i.e., "as" PWA and "for" PWA) of each assessment allowed responses by caregivers to be closer to those of the PWA, suggesting that similar practice or at minimum a "priming" of the caregiver should occur prior to administration of any qualitative assessment for which they will serve as proxy to gain the most accurate picture. Outcomes also suggested that these assessments, in combination best captured the overall picture for each PWA's quality of life.

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## CHAPTER 1

### **Introduction**

The National Stroke Association (2015) reports that approximately 800,000 new or recurrent strokes occur each year in the United States. Stroke is the fifth leading cause of death, and the leading cause of disability for adults in the United States. It is estimated that two-thirds of stroke survivors will have some type of disability. And, approximately half of those survivors will have aphasia (Centers for Disease Control, 2013). Persons with aphasia (PWAs) are often among the most severely affected stroke survivors (Hilari et al., 2009). The National Aphasia Association (n.d.) estimated that there are at least 1 million people in the United States living with aphasia.

Aphasia is defined as an acquired language disorder resulting from neurological damage usually secondary to stroke. The impact of the injury to the portions of the brain responsible for language masks inherent aptitude and compromises conversational interactions (expressively and/or receptively), as well as in reading and writing (Brookshire, 2007; Kagan & Simmons-Mackie, 2013). The acquired language impairments can create limitations on communication – a detrimental outcome due to the importance of successful communication for experiencing the world and establishing relationships (Shadden, 2005). Such impairments are often incorrectly interpreted as negative reflections on cognitive abilities (Brookshire, 2007).

The abrupt onset of aphasia can create dramatic shifts in the dynamics of family and social life (Shadden, 2005). Prather (1970) suggests that communication should be considered as a result of a relationship, focusing on the “us” of communication partners. The identities that we create for ourselves directly result from communicative interactions with others, particularly those closest to us (Shadden & Agan, 2004; Shadden, 2005). Because personal identity is

constructed, adjusted, and maintained through such interactions, aphasia not only impacts the identity of PWAs, but that of their significant others as well (Wertsch, 1991; Shadden, 2005).

In 1948, the World Health Organization (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948). In 2001, the WHO developed the International Classification of Functioning, Disability and Health (ICF) model as an attempt draw attention to the different health-related factors concerning global functioning and quality of life (QoL) (Manders, Dammekens, Leemans & Michaels, 2010). The model defines health in terms of Health Conditions and Contextual Factors. Health Conditions include Body Structure and Function (e.g., anatomy and physiology), as well as Activities and Participation (e.g., involvement in and execution of a task or action during life situations). Contextual Factors refer to Personal and Environmental Factors, including the internal and external factors around which people construct and carryout their lives. (World Health Organization, 2001). This framework has catapulted an already transitioning protocol of aphasia intervention to that of a predominately socially-based approach (Brookshire, 2007; Simmons-Mackie, 2000, 2008).

A socially-based approach to aphasia intervention seeks to use successful functioning within all aspects of one’s life as the ideal outcome. Such an outcome should be measured through a quality of life scale; however, few exist that are designed to accommodate the communication deficits of persons with aphasia. As a result, PWAs are often excluded from studies which measure stroke intervention outcomes. Hilari, Byng, Lamping & Smith (2003) responded to this need by creating the Stroke and Aphasia Quality of Life Scale (SAQOL-39) to measure health-related QoL in persons with aphasia. Similarly, Kagan, et al. (2011) have created

the Assessment for Living with Aphasia (ALA), another valid and reliable measure of QoL for PWAs.

The current study sought to use these two QoL measures to assess the appropriateness of family members and/or caregivers as proxies for PWAs in reporting QoL. If deemed appropriate, such findings would allow greater access to a more severe population of PWAs. The assessments would provide clinicians with information on factors of QoL important to their patients, enabling the development of individualized clinical interventions toward the ultimate goal of “living successfully with aphasia.” To do this, we looked at the following factors, all relating to the use of quality of life assessments with persons with aphasia. The first was to determine if domain-specific and overall outcomes are similar between the Stroke and Aphasia Quality of Life Scale (SAQOL-39) and the Assessment for Living with Aphasia (ALA), two valid and reliable quality of life measures for aphasia. The second was to compare the outcomes of these measures between the person with aphasia and their primary caregiver who, in many life situations, may serve as their proxy. The need for this comparison was to determine the reliability of these measures when completed by persons other than the primary participant. The third objective was to determine how well these quality of life measures captured the traits each participant considered important when measuring such a concept in their own lives. The fourth and final objective was to determine whether those with high QoL outcomes can be considered to be “living successfully with aphasia.”

## CHAPTER 2

### Review of the Literature

#### Quality of Life

The understanding of what factors are important to each individual patient is imperative for developing intervention plans that best enable PWAs to successfully live a life with aphasia. The concept of quality of life is one that relates back to the WHO(1948) definition of health. It is a highly subjective measure of an individual's perception of their life in relation to their cultural beliefs, morals, personal expectations, and goals (World Health Organization, 1996). In recent years, the concept has become increasingly more important in healthcare. The ICF framework (WHO, 2001) has paved the way for the endorsement of social approaches to interventions across the health-care field within the last decade.

As a result, the concept of social communicative participation has become a focus of speech-language pathology intervention after the American Speech-Language-Hearing Association's (ASHA) adoption of the ICF model (ASHA, 2001; Gray, Baylor, Eadie, Kendall, & Yorkston, 2012). Treatment models now predominantly focus on language and communication within functional environments and activities (Shadden, 2005). One such model is the Life Participation Approach to Aphasia (LPAA). It encourages the consideration of the consequences of aphasia in all aspects of a person's life and social participation, focusing on the real-life goals of PWAs throughout the intervention process, thus enabling treatment to lead to an ideally enhanced QoL (LPAA Project Group, 2000; Purdy & Hindenlang, 2005; Shadden, 2005; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). Outcomes of participation-driven therapy are measured using QoL measures. Such measures have been developed for

general use (e.g., WHOQoL, WHO, 1996). However, many of these general QoL tools are not designed to adequately evaluate the communicative consequences of aphasia on a person's life.

Bose, McHugh, Schollenberger, and Buchanan (2009) sought to compare the QoL outcomes of persons with aphasia with those of matched healthy controls. Given the limitation of QoL measures suitable to accommodate the communication difficulties of PWAs, Bose and colleagues selected two QoL scales to encompass a more holistic picture of QoL: the Stroke and Aphasia Quality of Life Scale-39, (SAQOL; Hilari et al., 2003) and the American Speech Language Hearing Association's Quality of Communication Life Scale (QCL; Paul et al., 2004). Outcomes showed that QoL in those participants with aphasia was lower than that of the control group. The study also found that although all participants showed similar values in all domains of the assessments, differential performance outcomes revealed that communication was the most affected domain for persons with aphasia.

### **Stroke and Aphasia Quality of Life Scale**

One of the measures Bose and colleagues (2009) used, The Stroke and Aphasia Quality of Life Scale (SAQOL-39; Hilari et al., 2003) is a 39-item psychometric evaluation adapted for persons who have had a stroke resulting in chronic aphasia (i.e., that in which language impairments persist beyond the acute stages, or six-months post-onset as referred to by some doctors within the medical model) (Hinckley, Hasselkus & Granzfried, 2013; Kendall, Oelke, Brookshire & Nadeau, 2015) from the Stroke-Specific Quality of Life Scale (SS-QOL; Williams, Weinberger, Harris, Clark & Biller, 1999). The scale assesses QoL in four sub-domains: physical, communication, psychosocial, and energy. In the domain of physical functioning, 17 items related to the use of lower and upper extremities in performing daily activities (e.g., getting

dressed, climbing stairs) are assessed. The communication domain includes 7 items that assess each person's ability to communicate with others (e.g., speaking on phone, finding the correct words to say). The domain of psychosocial functioning uses 11 items to assess psychological, emotional, and social aspects of an individuals' life (e.g., changes in mood and personality, family life, and socialization). Finally, 4 items relate to the energy level of the respondents (e.g., need for rest, level of energy).

Hilari and colleagues (2003) initially designed the SAQOL as a 53-item scale; however, a lack of support in some hypothesized subdomains led them to reduce the number of items to the shorter SAQOL-39. A study of 83 participants with chronic aphasia suggested that the SAQOL-39 is a reliable and valid test of QoL in PWAs. Outcomes also exhibited differences between participants with varying levels of aphasia severity, suggesting the measure appropriate for use with persons of any severity of expressive aphasia and mild-to-moderate severity of receptive aphasia (Hilari & Byng, 2001; Hilari et al., 2003).

### **Assessment for Living with Aphasia**

The development of the SAQOL-39, along with further research into treatment approaches for aphasia, has driven the development of another QoL assessment designed specifically for PWAs, the Assessment for Living with Aphasia (ALA; Kagan et al., 2011). This tool a pictographic, self-report measure designed to evaluate the impact of aphasia on a person's life. The ALA was based on the Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008) domains of functional living with aphasia. These domains include: Participation in life situations; Personal identity, attitudes, and feelings; Communication and language environment; and Language and related impairments. Drawing from the ICF model and

expanding to include those factors relevant to the lives of persons with aphasia, the A-FROM was intended as a user-friendly framework for outcome measurement focusing on real-life outcomes. Kagan and colleagues designed the ALA as an assessment tool to capture meaningful outcomes across the A-FROM domains. The use of supported communication (e.g., pictographic visual aids) enhances the accessibility of the measure to those with varying severities of aphasia.

In determining the validity and reliability of the ALA, Simmons-Mackie, et al. (2014) administered the assessment, as well as three reference measures to assess construct validity: Communication-Associated Psychological Distress Scale of the Burden of Stroke Scale (BOSS CAPD; Doyle et al., 2004), the Visual Analogue Self-Esteem Scale (VASES; Brumfitt & Sheeran, 1999), and the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39; Hilari et al., 2003) to 101 participants with chronic aphasia. Significant correlations between the ALA and reference tests were reported to establish construct validity. Simmons-Mackie and colleagues also reported discrimination between the language impairment domain in all aphasia severity groups, and differentiated outcomes in participation and total scores between mild, moderate and severe levels aphasia.

### **Living Successfully with Aphasia**

The domains which have been targeted within assessments such as the SAQOL-39 and ALA are the result of the shift in intervention models to that of a socio-pragmatic approach. This progression resulted in QoL becoming a primary consideration for the effectiveness of aphasia treatment. Around the same time, questions began to arise on how best to classify the achievement of high quality of life while living with chronic aphasia. Holland (2006) first examined the idea of “living successfully with aphasia” as an alternative to the traditional

‘deficit’ model of aphasia treatment (Brown, Worrall, Davidson & Howe, 2012). Prominent features of the concept found in exploratory studies were social relationships, support, and independence (Boles, 2006; Cruice, Worrall, & Hickson, 2006; Holland 2006). Additionally, involvement in personally meaningful activities, renegotiating self-identity, setting future goals, time post-stroke, good physical and psychological health, and the influence of other personal characteristics were highlighted (Cruice et al., 2006; Hinckley, 2006; Holland, 2006).

Brown et al. (2012) furthered this line of research through a qualitative meta-analysis of reports from 25 individuals with aphasia (Brown, Worrall, Davidson & Howe, 2010b), 24 family members (Brown, Worrall, Davidson & Howe, 2011), and 25 speech-language pathologists (Brown, Worrall, Davidson & Howe, 2010a) to establish overarching themes in defining the concept of “living successfully with aphasia.” Those themes were: participation, meaningful relationships, support, communication, positivity, independence, and living successfully with aphasia as a journey over time (Brown et al., 2012).

Such findings take the development and analysis of treatment outcomes beyond the quantitative results of clinician-directed tasks. Instead, the focus becomes the potential positive qualitative and psychosocial aspects of the recovery process, allowing clinical interventions to enable individuals to experience success while living with aphasia. The intended result a positive personal narrative, which refers to an individual’s assumed, developing, and integrated story of the self (McAdams, 2008). It would then be reasonable to expect that high overall scores in and across the domains captured in QoL measures such as the SAQOL-39 and ALA should correlate with the achievement of “living successfully with aphasia.”



## Caregiver's Role in Intervention and Outcomes

Common themes seen throughout discussions of QoL and living successfully with aphasia are those of communication, meaningful social relationships, and support. The implications of aphasia on quality of life not only affects the PWAs, but their significant others as well. As a result, the family member or caregiver's understanding and perception of aphasia can greatly impact the recovery process of the PWA, in addition to their familial dynamic (Croteau & Le Dorze, 2001). Family members and caregivers are thus valued stakeholders and members of the rehabilitation team. They help to bridge the gap between clinical and real-life objectives and serves as facilitators and partners in their loved one's journey toward successfully living with aphasia (Brown et al., 2011; Lyon et al., 1997; Purdy & Hindenlang, 2005; Simmons-Mackie et al., 2010). Information provided by family members/caregivers can then be used to develop individualized intervention plans, which are greatly important, but often overlooked (Rohde, Townley-O'Neill, Trendell, Worrall & Cornwell, 2012).

Highly individualized treatment plans are imperative to helping PWAs toward living successfully with aphasia; however, the subjectivity of QoL between PWAs, speech-language pathologists, and family members/caregivers can pose challenges in developing such treatment plans (Croteau & Le Dorze, 2001; Kagan et al., 2008; Rohde et al., 2012). For those PWAs who present with significant difficulty expressing themselves, caregivers can provide health professionals with invaluable insight into the personal narratives of their loved ones. Thus, the use of these individuals as proxy respondents (i.e., a person who responds on behalf of the patient/participant) would allow a more severe population of PWAs to be reached for QoL studies. It would also be beneficial in the clinical setting to develop treatment protocols. However, concerns of whether caregivers would assess the patient as they think the PWA would

respond or if the proxy would provide their own perspective on the PWAs QoL exist, limiting the use of proxy respondents in many cases (Carod-Artal, Coral, Trizotto, & Moreira, 2009; Crouteau & Le Dorze, 2006). Hilari, Owen & Farrelly (2007) developed a proxy version of the SAQOL-39 and conducted a study to determine its reliability. The outcomes from 50 PWA-caregiver pairs indicated that proxies rated PWAs as more severely affected than the PWAs rated themselves. However, the discrepancies were determined as not significant enough to discount proxy respondents who are in frequent contact with a PWA with chronic aphasia as reliable reporters of health-related quality of life for that person.

### **Purpose of the Study**

Although the findings of Hilari et al.'s (2007) study show promising potential for the use of proxy respondents for QoL measures of PWAs, they are limited in that the study only utilized one QoL measure for aphasia. The recent development of the ALA has provided an opportunity for further research to be done in this area. As a result, this study was designed to answer the following questions:

- 1) Are comparable domain outcomes between the quality of life measures similar for each participant? Both the SAQOL-39 and the ALA target the main domains of communication and overall participation. The ALA interview questions give greater focus to the impact aphasia has on communication, where as the SAQOL-39 provides fewer questions targeting communication-only to allow greater emphasis on the physical implications of the disorder. For that reason, the term “comparable” was included in the research question to specify that only those areas targeting similar information (e.g., SAQOL-39: During the past week, how much trouble did you have speaking? and ALA:

How would you rate your talking?; SAQOL-39: During the past week, did you have little confidence in yourself? and ALA: Do you feel confident?). Both the SAQOL-39 (Hilari et al., 2003) and ALA (Kagan et al., 2011) were developed from an underlying ICF framework; and Kagan and colleagues utilized the SAQOL-39 and its related findings in development of the ALA. Therefore, it may be speculated that participants' scores on the comparable domains of the two assessments would yield similar results.

- 2) Are overall outcomes between the quality of life measures similar for each participant?

Given the rationale above, it may be predicted that the overall outcomes between the two QoL assessments may differ due to the difference in domains and weighting of target questions between assessments. However, it would be expected that these differences would not be significant enough to deem the assessments incomparable measures.

- 3) Is there consistency among outcomes (by domain and overall) of quality of life measures for aphasia from the person with aphasia and their caregiver? Based on the outcomes of Hilari, et al.'s (2007) study, it may be predicted that the differences between outcomes yielded by PWAs and their respective caregivers would not be significant enough to determine them unreliable as proxy respondents.

- 4) Do the assessments used capture the traits each participant considered important for measuring QoL in their own lives? Both the SAQOL-39 and ALA were developed from extensive research into factors of importance to QoL as defined by both professionally endorsed "umbrella" models (e.g., WHO's ICF model, AFROM) and those described by PWAs and other stakeholders during focus groups (Hilari et al., 2003; Kagan et al., 2008, 2011). Thus, participants may generate some alternative ideas; however, it may be hypothesized that their differences will not be significant enough to deem the assessments

individually or in combination as invalid.

- 5) Can those with high overall quality of life scores be considered in “successful management” of their aphasia? The elements of most importance for “living successfully with aphasia” as described by Brown et al. (2012) align with those domains depicted in both the SAQOL-39 (Hilari et al., 2003) and the ALA (Kagan et al., 2011). Therefore, it may be hypothesized that persons rating themselves with higher quality of life will consider themselves to be living “successfully” with aphasia.

## CHAPTER 3

### **Methodology**

#### **Participants**

Participants were recruited through the Wichita State University Speech-Language-Hearing Clinic. Participants with aphasia had to meet the following eligibility criteria: (1) expressive aphasia resulting from stroke; (2) be at least a minimum of six-months post-stroke; (3) be able to nominate a family member or caregiver to act as the proxy respondent; and (4) have no known premorbid neurological illness, psychiatric disorders and/or cognitive decline. The proxy respondents had to meet the following criteria: (1) be at least 18 years of age; (2) see the PWA at least 4 times per week on average; and (3) have no known neurological illness, psychiatric disorders, and/or cognitive decline. Eligible participants were invited to take part in the study, and written consent was obtained from those willing to take part.

The current study included five persons with chronic expressive aphasia and their nominated family member/caregiver. Two additional couples were excluded from the study as a result of inability to complete the necessary components. Demographic information for all participating couples is summarized in Table 1. Three male and three female participants with aphasia took part in the study. Average age of PWA participants was 58.6 years and the average time post-onset of aphasia was 3;11 (years;months). All PWA participants had expressive aphasia. Four of the five were of a moderate severity level as assessed by the Western Aphasia Battery and one was of a mild severity level. Each of the five PWA participants nominated one family member who was closest to them to participate in the study, all of whom live with the PWA who nominated them. All five family members were female including three wives, one daughter, and one mother.

Table 1

*Participant demographics*

<b>PWA Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Time Post Onset (years;months)</b>	<b>Type of Aphasia</b>	<b>Severity</b>	<b>Caregiver/ Family Member</b>
1	75	F	4;3	Expressive	Moderate	Daughter
2	49	F	3;4	Expressive	Moderate	Mother
3	57	M	10;2	Expressive	Moderate	Wife
4	57	M	0;9	Expressive	Moderate	Wife
5	55	M	0;11	Expressive	Mild	Wife
Average	58.6	--	3;11	Expressive	Moderate	--

**Procedure**

All participants had previously been administered the Western Aphasia Battery – Revised (WAB-R; Kertesz, 2006) during recent aphasia evaluations. These results were utilized as a credible evaluation of each PWA participant’s aphasia severity level. The WAB-R establishes a severity rating through assessment of spontaneous speech, auditory verbal comprehension, repetition, naming, reading, writing, apraxia, constructional, visuospatial and calculation tasks. These subtests are scored on a numerical scale which yields an overall severity score, the Aphasia Quotient.

A preliminary interview was conducted with each PWA and caregiver to gather unbiased insight into each participants’ understanding of the concepts targeted within the study. During Hilari et al.'s (2007) study, face-to-face interviews were administered with PWAs; however, their proxies received telephone interviews following determination that the alternative administration approach was stable. Despite this finding, we have elected to conduct interview and assessment administrations in a face-to-face manner to eliminate environmental distractions. Additionally, this administration approach allowed the interviewer to report and utilize any supplementary commentary or non-verbal gestures as qualitative data.

Each participant was then administered two counterbalanced assessments: the ALA and

SAQOL-39. A modified version of the SAQOL-39 was administered to PWAs to include a pictographic support (see Appendices J and K). Caregivers were administered the assessments under two counterbalanced conditions: (1) as their interpretation of the PWA's QoL, and (2) as they believe the PWA would respond. This dual administration was selected in hopes of reducing personal bias from the caregiver in their interpretation of the PWA's response. The pictographic supports for both the ALA and SAQOL-39 were presented to the caregiver under the response "as the PWA" condition. Assessment administration averaged between 15-30 minutes each for caregivers and 30-45 minutes each for PWA. Following administration of all assessments, a brief follow-up interview was conducted to establish thoroughness of questioning.

## **Interviews**

A preliminary ethnographic interview was conducted at the beginning of the session with both the PWA and caregiver. The interview was designed to emulate a friendly conversation in which the interviewer was able to follow the topical trajectories of the conversation that may have strayed from the questions when they felt it was appropriate (Westby, Burda, & Mehta, 2003). The following predetermined set of open-ended questions and planned prompts were included in each interview:

1. Tell me what it's like [for PWA and you] to live with aphasia.
2. What do you think of when you hear "Quality of Life"?
3. Tell me about your [PWA's] quality of life?
4. What would "living successfully with aphasia" look like for you?
  - a. What factors do you believe would help you [PWA] live successfully with aphasia?

- b. Would you say that you [PWA] is living successfully with aphasia?
5. What do you think about the concepts of “quality of life” and “living successfully with aphasia” together?

Interviews varied in length from 15-30 minutes, and were audio-tape-recorded and transcribed verbatim. Throughout interview with PWAs, supportive communication aids (e.g., pictographic aid, visual scales) were used for support as needed (see Appendices L and M). The visual scale in Appendix K was used as support for question 4b.

Following the conclusion of the final QoL measure, a brief post-assessment interview was held with each participant to target their thoughts on the two QoL measures administered, including whether or not the measures captured those traits the participant considered most important for determining quality of life in their own life. Participants were asked to share (if any) traits not addressed between the assessments. The purpose of this final question was to determine the validity of the results.

## **Scoring of Assessments**

### ***Western Aphasia Battery – Revised (WAB-R)***

Raw scores from spontaneous speech, comprehension, repetition, naming, reading and writing, praxis, and construction tasks were added and multiplied by two to obtain the Aphasia Quotient. The AQ is the summary value of the patient’s aphasic deficit. Classifications are as follows, regardless of type of aphasia or etiology: 0-25 is Very Severe, 26-50 is Severe, 51-75 is Moderate, and 76+ is Mild. An Aphasia Quotient (AQ) of 100 was considered normal. All scoring was completed prior to the start of this study.



### ***Stroke and Aphasia Quality of Life Scale (SAQOL-39)***

The SAQOL-39 includes questions in four domains: physical, psychosocial, communication, and energy. The measure can be used as either a self- or interview-administered assessment, and also includes a proxy version. Questions are asked in relation to how much difficulty the participant had with a specific activity during the previous week (see Appendix E). Responses are formatted as a 5-point scale (i.e., 1 = ‘Couldn’t do it at all’ and 5 = ‘No trouble at all’). The existing assessment was adapted to include a visual rating scale, which was provided to encourage a more accurate response from PWAs (see Appendix J and K). Scores from each question within subtest are totaled and divided by the number of questions administered to determine mean scores for each domain. Scores from all questions are totaled and divided by questions administered for a mean score indicative of quality of life. Higher scores reflect higher quality of life and percentile ranks for total and domain scores are provided.

The proxy version of this measure was administered under two counterbalanced conditions to the participating caregivers. The first asked the proxy to respond to the questions as they believe the person with aphasia would. The second asked the caregiver to respond with their personal interpretation of the PWA’s QoL (see Appendices B, C, G, & H). Scoring of these versions followed the same procedure as the original SAQOL-39.

### ***Assessment for Living with Aphasia (ALA)***

Questions in the ALA are asked within the areas of aphasia, participation, environment, personal, and “moving on with life” question to yield a quality of life profile and score (see Appendix A). Responses are formatted as a 9-point scale (i.e., 0-4 with 0.5 intervals with 0 = negative responses and 5 = positive responses). Scores from each question within subtest are

totaled and divided by the number of questions administered to determine mean scores for each domain. Scores from all scored questions are totaled and divided by questions administered for a mean score indicative of quality of life. Higher scores are indicative of higher QoL.

The measure also includes a series of frequency questions (e.g., How many days do you get out?) and clinical analysis questions (e.g., Do you get communication help at home?). Responses to these questions are not averaged into the total score, but are intended for use in further analysis of each examinee's results.

Although the ALA does not currently have a "proxy version," the existing version was adapted to be administered to caregivers as proxy for the purposes of the current study (see Appendices B & C). This version asked the proxy to respond to the questions as they believe the person with aphasia would. Scoring of this version followed the same procedure as the original ALA.

### **Data Analysis**

The ALA and SAQOL-39 were each developed to be scored on a 4-point and 5-point scale, respectively. To accommodate this difference, SAQOL-39 scores were converted to a reflect a 4-point scale as follows: Adjusted Maximum Score (AMS) = Total # Questions x 4 pts; Percentage of Possible Points Earned (%) = (Raw Score/Maximum Score) x 100; Average Item Score (AIS) = % Points earned x 4 pts; Adjusted Raw Score = AIS x # Questions. A percentage differential was determined to identify the relationship (higher, lower, or equivalent) between ALA and SAQOL scores for each participant, as well as the PWAs scores versus the caregiver's. Percentage scores were then analyzed to establish trends and outliers to create a meaningful 4-point rating scale. This scale served as a qualitative label of the percentage scores for each

domain and assessment, as well as an overall averaged score. The rating index was as follows: 0-30 (“P”-Poor), 31-55 (“F”-Fair), 56-85 (“G”-Good), 86-100 (“E”-Excellent).

*Research Question 1:* Are comparable domain outcomes between the quality of life measures similar for each participant?

A comparison of questions within each QOL was done to establish those domains with similar target questions (i.e., >50%). Intra-rater outcome ratings were then compared to allow for further discussion of domain outcome consistency.

*Research Question 2:* Are total assessment outcomes between the quality of life measures similar for each participant?

Outcome ratings from both assessments were compared to establish overall consistencies between QoL measures for each participant.

*Research Question 3:* Is there consistency among outcomes (by domain, assessment, and overall averages) of quality of life measures for aphasia from the person with aphasia and their nominated family member/caregiver?

Inter-rater outcome ratings were used to compare those those domains determined to be compatible, individual QoL assessment results, and an overall average of the two assessments.

The average assessment score was established by totaling the earned points of each measure and dividing it by the total possible points of each measure. The number was then multiplied by 100 to establish a percentage for overall possible points earned. The 4-point rating scale used for Research Questions 1 and 2 was then used to establish an “Overall QoL Rating”.

*Research Question 4:* Do the assessments used capture the traits each participant considered important for measuring QoL in their own lives?

Discussions during pre-and post-assessment interviews were analyzed using a thematic analysis (Smith & Osborn, 2003; Smith, Jarman & Osborn, 1999). Once, the researcher became familiarized with the text, general ideas within participants' statements were identified. These ideas were further analyzed to establish emerging themes (e.g., friends, family, significant others = companionship). Once themes were established, the number of occurrences within participants' responses was identified to determine the most frequently occurring themes within reported traits important to quality of life.

*Research Question 5:* Can those with high overall quality of life scores be considered to be "living successfully with aphasia"?

Participant responses gathered in from interviews (e.g., Would you say you are living successfully with aphasia?) were compared to how each participant rated themselves on the "Wall" question within the ALA (See Appendix E). This question targets the examinee's overall feeling towards their success in living the life they want to while living with aphasia. Higher scores (e.g., 3 or 4) on the "Wall" question correspond with living life with greater ease than lower scores.

## CHAPTER 4

### Results

**Research Question 1:** Are comparable domain outcomes between the quality of life measures similar for each participant?

Each PWA was administered each QoL assessment. Family members were administered each assessment under two conditions: responding “as” the PWA and responding “for” the PWA. An analysis of the questions asked in each assessment yielded the “Environment” and “Personal” domains of the ALA to be most comparable with the “Communication” and “Psychosocial” domains of the SAQOL-39, respectively. Questions in the ALA’s “Environment” and SAQOL-39’s “Communication” domains generally targeted effectiveness and comfort with verbal communication (i.e., speech). Those in the ALA’s “Personal” and SAQOL-39’s “Psychosocial” domains generally focused on potential changes in the PWA’s feelings toward themselves since their stroke. Participant outcomes from these domains is summarized in Tables 2 and 2a.

Table 2  
*Domain outcomes: ALA – Environment vs. SAQOL-39 - Communication*

PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
	ALA Environment			SAQOL-39 Communication			
1	12/16	75	G	24/28	85.8	+10.8	G/E
2	15/16	93.75	E	21.2/28	75.8	-17.95	G
3	9/16	56	G	21.2/28	75.8	+19.8	G
4	4/16	25	P	14.4/24*	62.8	+37.8	G
5	11/16	68.75	G	16.8/28	60	-8.75	G
FM as PWA	ALA Environment			SAQOL-39 Communication			
1a	9/16	56.25	G	20/28	71.4	+15.15	G
2a	16/16	100	E	13.6/28	48.4	-51.6	F
3a	10/16	63	G	17.2/28	61.4	-1.6	G
4a	11/16	68.8	G	8/24*	33.4	-35.4	F
5a	13/16	81.25	G	20.4/28	72.8	-8.45	G
FM for PWA	ALA Environment			SAQOL-39 Communication			
1a	14/16	87.5	E	23.2/28	82.8	-4.7	G
2a	13/16	81.25	G	15.2/28	45.8	-35.45	F
3a	12/16	75	G	19/28	54.2	-20.8	F
4a	11/16	68.8	G	8/24*	42.8	-26.0	F
5a	14	87.5	E	26/28	92.8	+5.3	E

The information depicted in Table 2 shows highly variable differences between each participant’s responses (e.g., -8.75 to +37.5 from PWAs) on the ALA’s Environment domain and

the Communication domain of the SAQOL-39. While limited trends were discovered within outcome data, participant assessment outcomes closely reflected those feelings, successes, and concerns revealed during the preliminary interviews. When comparing the ALA's Environment domain to the SAQOL's Communication domain, ten of the fifteen comparison revealed lower SAQOL-39 scores. However, most participants reported communication as their primary area of concern. Initially, it was hypothesized that more comparable outcomes would be found. Nevertheless, the ALA accounted for communicative support provided at home and in the community where the SAQOL-39 did not. During preliminary conversations, the frustration of communicating was clearly established, but there appeared to be a mixed response amongst PWAs and caregivers to the amount of communicative support provided in both the home and community. The majority of participants reported greater support at home versus in the community. As a result, ALA Environment scores were generally higher than those of the SAQOL-39, which only accounted for the initial difficulty without the compounding lack of support.

Table 2a  
*Domain outcomes: ALA – Personal vs. SAQOL-39 - Psychosocial*

PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1	29/44	66	G	40/44	91	+25	E
2	30/44	68.25	G	36.8/44	83.6	+15.35	G
3	44/44	100	E	38.8/44	88.2	-11.8	E
4	19/40*	43.3	F	11.2/40*	28	-15.3	P
5	38/44	86.25	E	28.8/44	65.4	-20.85	G
FM as PWA	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1a	28/44	63.75	G	40.8/44	92.8	+29.05	E
2a	30/44	68.25	G	24.8/44	56.4	-11.85	G
3a	30/44	68	G	30.4/44	69	+1.0	G
4a	25/40*	62.5	G	19.2/40*	48	-14.5	F
5a	35/44	79.5	G	36.8/44	83.6	+4.1	G
FM for PWA	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1a	30/44	68.25	G	40/44	91	+22.75	E
2a	21/44	47.75	F	28/44	63.6	+15.85	G
3a	36/44	82	G	26.4/44	60	-22.0	G
4a	34/40*	77.3	G	16/40*	40	-37.3	F
5a	40/44	91	E	38.4/44	87.2	-3.8	E

Similarly, Table 2a reveals highly variable outcomes between the Personal (ALA) and Psychosocial (SAQOL-39) domains. A less distinctive pattern was observed during analysis of outcomes between these domains. This may be attributed to the number of questions provided in each, as well as the wording of each question. The wording in the ALA appears more direct in targeting feelings such as depression and loneliness than that of the SAQOL-39. Each participant may have reacted differently to specific wording patterns which may have impacted the ratings they provided.

**Research Question 2:** Are total assessment outcomes between the quality of life measures similar for each participant?

Each participant's total measure outcome for both assessments was compared. Family member responses under each condition: responding "as" the PWA and responding "for" the PWA were considered separately. Table 3 summarizes the overall outcomes between quality of life measures for each participant. Adjusted raw scores reported for the SAQOL-39 were calculated as previously described.

Table 3

*Total assessment outcomes*

PWA	ALA			SAQOL-39			
	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1	95/148	64.25	G	127/156	81.6	+17.35	G
2	107/148	72.25	G	136/156	87	+14.75	E
3	123/148	83	G	119/152*	78	-5.0	G
4	39/140*	27.75	P	80.8/140*	57.7	+29.95	G
5	102/148	69	G	120/156	77	+8.0	G
FM as PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1a	92/148	61.75	G	129/156	82.6	+20.85	G
2a	94/148	63.5	G	108/156	69.5	+6.0	G
3a	72/148	49	F	108/152*	72	+23.0	G
4a	69/140*	49.25	F	92.8/140*	66.3	+17.05	G
5a	121/148	81.75	G	135/156	86.4	+4.65	E
FM for PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1a	114/148	77	G	131/156	84.2	+7.2	G
2a	82/148	55.5	G	114/156	72.8	+17.3	G
3a	84/148	57	G	98.8/152*	65.8	+8.8	G
4a	73/140*	52.25	F	88/140*	62.9	+10.65	G
5a	133/148	89.75	E	144/156	92.3	+2.55	E

\*One or both participants in the couple was unable or elected not to respond to one or more questions. Any questions unanswered by one participant in the couple was subsequently omitted on all forms for that couple.

Analysis of the percentage differentials between the SAQOL-39 and ALA for each participant shows no equivalencies. However, fourteen of the fifteen comparisons revealed higher SAQOL-39 percentage scores than ALA scores. The trend is also seen in the qualitative ratings (i.e., E, G) This is likely a result of each assessment giving greater emphasis on a different aspect of potential impairment as a result of a stroke. The SAQOL-39 was weighted more heavily to account for the physical and psychosocial implications of the accident. The ALA, on the other hand, lays greater emphasis on the communication and participation aspects. Two of the five PWA participants (i.e., Participants 2 and 3) reported physical implications secondary to their stroke. Participant 3 was the only participant to rate himself slightly higher on the ALA (i.e., +5.0 pts) than the SAQOL-39; however, he reported that the physical impairment does not greatly hinder his ability to participate in choice activities in day-to-day life. Both participants reported the use of compensatory techniques to accommodate these deficits (e.g., use



of cane, walker, or motorized chair; learning to write with non-dominant hand) which reduce impact.

**Research Question 3:** Is there consistency among outcomes (by domain, assessment, and overall averages) of quality of life measures for aphasia from the person with aphasia and their nominated family member/caregiver?

Areas of consistency among outcomes (domain and overall) for the quality of life measures between the PWA and their FM responding “as” the PWA were generally varied between couples. Each assessment domain, total assessment rating, and an overall averaged rating for both assessments were considered. Table 4a summarizes the outcomes on each assessment for both the PWA and their respective family member.

Table 4a

*Abbreviated domain, total assessment, and overall quality of life outcomes*

<i>Domain outcomes: ALA – Environment vs. SAQOL-39 - Communication</i>								
PWA	Assessment	Percentage	Rating	FM	Assessment	Percentage	Percentage Differential from PWA	Rating
1	ALA	75	G	1a	ALA	56.25	-18.75	G
	SAQOL-39	85.8	G/E		SAQOL-39	71.4	-14.4	G
2	ALA	93.75	E	2a	ALA	100	+6.25	E
	SAQOL-39	75.8	G		SAQOL-39	48.4	-27.4	F
3	ALA	56	G	3a	ALA	63	+7.0	G
	SAQOL-39	75.8	G		SAQOL-39	61.4	-14.4	G
4	ALA	25	P	4a	ALA	68.8	+43.8	G
	SAQOL-39	62.8	G		SAQOL-39	33.4	-29.4	F
5	ALA	68.75	G	5a	ALA	81.25	+12.5	G
	SAQOL-39	60	G		SAQOL-39	72.8	+12.8	G
<i>Domain outcomes: ALA – Personal vs. SAQOL-39 – Psychosocial</i>								
PWA	Assessment	Percentage	Rating	FM	Assessment	Percentage	Percentage Differential from PWA	Rating
1	ALA	66	G	1a	ALA	63.75	-2.25	G
	SAQOL-39	91	E		SAQOL-39	92.8	+1.8	E
2	ALA	68.25	G	2a	ALA	68.25	0	G
	SAQOL-39	83.6	G		SAQOL-39	56.4	-27.2	G
3	ALA	100	E	3a	ALA	68	-32.0	G
	SAQOL-39	88.2	E		SAQOL-39	69	-19.2	G
4	ALA	43.3	F	4a	ALA	62.5	+19.2	G
	SAQOL-39	28	P		SAQOL-39	48	+20.0	F
5	ALA	86.25	E	5a	ALA	79.5	-6.75	E
	SAQOL-39	65.4	G		SAQOL-39	83.6	+18.2	G
<i>Total assessment outcomes</i>								
PWA	Assessment	Percentage	Rating	FM	Assessment	Percentage	Percentage Differential from PWA	Rating
1	ALA	64.25	G	1a	ALA	61.75	-2.5	G
	SAQOL-39	81.6	G		SAQOL-39	82.6	+1.0	G
2	ALA	72.25	G	2a	ALA	63.5	-8.75	G
	SAQOL-39	87	E		SAQOL-39	69.5	-17.5	G
3	ALA	83	G	3a	ALA	49	-34.0	F
	SAQOL-39	78	G		SAQOL-39	72	-6.0	G
4	ALA	27.75	P	4a	ALA	49.25	+21.5	F
	SAQOL-39	59	G		SAQOL-39	66.3	+7.3	G
5	ALA	69	G	5a	ALA	81.75	+12.75	G
	SAQOL-39	77	G		SAQOL-39	86.4	+9.4	G
<i>Overall quality of life outcomes</i>								
PWA	Percentage	Rating	FM	Percentage	Percentage Differential from PWA	Rating		
1	73.1	G	1a	72.6	-0.5	G		
2	79.8	G	2a	66.4	-13.4	G		
3	80.5	G	3a	60.1	-20.4	G		
4	42.8	F	4a	57.8	+15.0	G		
5	73	G	5a	84.1	+11.1	G		

Outcomes between PWAs and caregivers again revealed highly variable outcomes. Only one instance of equivalency was noted; however, several instances of fairly close outcomes (e.g., +1.0, -2.25) were also noted. The further the percentage differentials were from zero indicated greater difference in participant outcomes. These differences tended to closely reflect verbal

reports by participants during the interview process. When analyzing the ALA's Environment domain and the Communication domain of the SAQOL-39, two large differentials (i.e., +43.8 and -37.4) were noted for the Couple 4's ratings on the ALA. This difference is likely due to the decreased time spent with one another since the spouse began working another job to maintain financial stability following Participant 3's stroke. Further analysis of the percentage scores for each couple revealed that in four of the five couples, the PWA rated themselves higher than their family member on the SAQOL-39 and lower than their family member on the ALA.

Analysis of percentage scores from the ALA's Personal domain and the Psychosocial domain of the SAQOL-39 revealed that in six of the ten comparisons, the PWA scored themselves equal to or higher than their family member. Four of the five PWAs rated themselves higher on the ALA than their family member, while three of the five PWAs rated themselves lower than their family member on the SAQOL-39. Participants 2 and 3 rated themselves higher than their family member on both assessments. Each of these participants were very sociable individuals prior to their strokes and the onset of aphasia. Interviews with Participants 2 and 3 revealed that while they wished they had more opportunities for socialization, employment, and independence (e.g., driving), they each held generally positive outlooks on their lives. Discussions with their family members divulged similar wishes for the PWAs; however, each family member's responses provided greater retrospective comparisons. This may likely be the reason for lower scores on the Personal and Psychosocial domains.

Total assessment outcomes between the ALA and the SAQOL-39 again revealed higher total scores (with the exception of Couple 3) on the SAQOL-39 versus that of the ALA. This again is indicative of the consideration the SAQOL-39 gives to the physical implications of stroke.

Overall averaged QoL outcomes revealed relatively close percentage scores (i.e., 20.4 percentage points or less) between all PWAs and their family members. In three of these four couples, percentage scores show that the PWA rated themselves equivalent to or better than their family member. In each of these cases, the PWA was three years' post-stroke or more. In the two pairings in which the PWA rated themselves lower, the stroke occurred within the last twelve months.

As with other comparative analyses within the study, limited equivalencies were extracted from these comparisons (i.e., 24 of 35 compared outcomes). It was found that family members responding "as" the person with aphasia reported scores generally closer to that of their PWA than when responding "for" (i.e., their personal outlook). Success in this area was likely due to the dual presentation of questions to the family members. Family members reported responding "as" the PWA was more challenging as it required them to "put themselves in the PWAs shoes". In many instances, the caregiver commented on how they thought their loved one would respond, but assessment scores did not reflect these insights as comparable between respondents. For example, Participant 5a shared that her husband would be "harder on himself" than she would be. Her responses while serving in the proxy "as-PWA" trial were lower than those under her opinion, but not as low as he ended up rating himself. Overall, family member/caregiver responses did not yield equivalent responses to those of their loved ones with aphasia. However, such differences were rarely so substantial that use of a family member/caregiver as a proxy respondent when assessing quality of life in person's with severe expressive and/or receptive language impairments.

The impact of the disabilities associated with each PWA's stroke greatly impacted their family members. While some reported a gradual "coming to terms" with the life change (or

figuring out a balance within their new roles), others are still in the stages of adjustment, or have never been able to get there. This impact on the family members' lives and/or their feelings toward the situation was reflected in their responses during each assessment. For example, limited time has past since Participant 4's stroke and while his wife shared that she was slowly on her way to coming to terms, she has had to change her lifestyle by picking up another job. As a result, she does not see her husband as often and thus found some questions difficult to answer.

**Research Question 4:** Do the assessments used capture the traits each participant considered important for measuring QoL in their own lives?

Analysis of participant preliminary interviews revealed three common themes of independence, effective communication, and companionship in traits most important for consideration when measuring aphasia quality of life.

#### *A desire for independence*

One of the most prominent themes in discussions of living with aphasia and those traits important to each participant when considering quality of life was personal independence. This was most often discussed in regards to the PWA. This theme captured activities such as walking, driving, freedom to partake in activities at the spur of the moment or a desired time. Employment was the most frequently mentioned activity. Independent living was discussed with those unmarried participants, including the ability to shop for food and personal items.

Both family members and PWAs discussed impact of the PWAs acquired dependence on the family member's life. All family members are working towards or have come to a point of acceptance; however, a potential regained independence for their loved one with aphasia would result in a similar outcome for them. One family member discussed the importance for them to

allow their loved one every opportunity for independence as it not only benefits the PWA, but affords the family member the opportunity for independence of their own (e.g., downtime, a meal out, or a long awaited trip to a family reunion).

### *Effective communication is important*

Another common theme among participants was the ability to communicate effectively. Many expressed frustrations with the difficulties they incur during conversational exchanges. One participant, still actively employed, describes a recent business trip as “stressful” and “more difficult” than it used to be. Where business deals easily flowed into small-talk prior to his stroke, he found himself needing to use the time previously spent with easy banter planning his next response. Such a change has left him questioning his new identity in a familiar environment.

Multiple family members expressed concern for a lack of patience and/or help available to their loved ones with aphasia in the community. Participant 2a explained that others are patient and provide as much assistance as they are able or know how to in familiar environments (e.g., the particular gym branch they attend and speech therapy). However, the response was drastically different if they were to go out to a new place or a gathering of unfamiliar/distant people. This lack of support coupled with an existing expressive language difficulty results both isolates her daughter in the new environment and decreases the desire to return to similar situations. Another participant noted similar experiences with interactions within his own family.

### *Companionship*

A third theme among participant responses was the importance of companionship. This came in multiple forms, including spouse/significant other, friends, and family. Many

participants reported not seeing friends as often as they would like to, and several reported dissatisfactions with the number of friends and relationships they currently had. Family members and persons with aphasia alike shared that many friends became increasingly distant or lost touch all together. Others have maintained a small group of friends, but may only get together once a month or once every few months.

All three areas were targeted within each assessment administered. And, together the assessments were able to target these areas through varied phrasing which periodically sparked additional commentary regarding the given topic by participants. The moments of additional insight enhanced the researcher's understanding of each participant's story. The multiple presentations of questions on these "most important" traits, as well as additional areas pertinent to evaluating aphasia quality resulted in participants reporting feeling all areas most important to them were addressed through one or both assessments.

**Research Question 5:** Can those with high overall quality of life scores be considered to be "living successfully with aphasia"?

Discussions during preliminary interviews revealed that all of the participants reported "living successfully with aphasia" as being the same or comparable to living with a good or excellent quality of life. When asked to describe what ideas or traits contribute to "successfully living with aphasia," participants offered traits such as independence; employment; freedom to choose what, when, and where to do things; friendship/companionship; a sense of belonging; and the ability to focus on life for the sake of living it, rather than focusing on getting past the aphasia first. These traits are similar to those mentioned by participants as "important for quality of life." Each participant was then asked how they felt they/their loved one was doing in terms of

these concepts. Table 5 shows each participants reported of quality of life during the preliminary interviews and the rating they assigned for themselves (or the PWA) on the “Wall” question.

Table 5  
*Participant report for “living successfully with aphasia” vs. “Wall” question*

PWA	Interview: <i>Would you say that you [PWA] is living successfully with aphasia?</i>	“Wall” Question		
		Raw Score	Percentage	Rating
1	Definitely Yes	4	100	E
2	Sometimes	2	50	F
3	Definitely Yes	4	100	E
4	Definitely No	1	25	P
5	Sometimes	2	50	F
<b>FM as PWA</b>				
1a	Mostly Yes	3	75	G
2a	Sometimes	2	50	F
3a	Mostly No	2	50	F
4a	Unsure	2	50	F
5a	Mostly Yes	3	75	G

Two PWA who reported excellent quality of life also rated themselves as a 4/4 on the “Wall” question of the ALA. Several other participants, including family members, rated the PWA with good quality of life, or a 3/4 on the “Wall” question. Participants rating themselves or loved one with a lower quality of life subsequently selected a lower rating on the “Wall” question. These patterns suggest that there was a positive relationship between higher quality of life outcomes and “living successfully with aphasia.”



## CHAPTER 5

### Discussion

This study sought to answer five questions regarding aphasia quality of life and the use of family members/caregivers as proxy respondents. First, we looked at domain outcomes between two quality of life measures for each participant. Second, we compared total assessment outcomes between quality of life measures for each participant. Next, we looked at domain, total assessment, and overall quality of life outcomes reported by the persons with aphasia and their family members. Then, we analyzed discussions with participants to discover common themes in traits important for overall quality of life. Finally, we looked into the relationship between higher quality of life outcomes and persons considering themselves to be “living successfully with aphasia.”

**Research Question 1:** Are comparable domain outcomes between the quality of life measures similar for each participant?

Both the SAQOL-39 (Hilari et al., 2003) and ALA (Kagan et al., 2011) were developed from an underlying ICF framework (WHO, 2001); and Kagan and colleagues utilized the SAQOL-39 and its related findings in development of the ALA. Further analysis of the questions from each assessment revealed the largest overlaps to be between the ALA’s Environment and Personal domains, and the SAQOL-39’s Communication and Psychosocial domains, respectively. And, a slight majority of paired outcomes were within the same rating bracket within both domain comparisons.

The Environment (ALA) versus Communication (SAQOL-39) comparison revealed the majority of participants rating themselves higher on the ALA domain than the SAQOL-39. The

additional consideration given by Kagan et al. (2011) to the environmental factors (e.g., available supported communication) resulted in a greater variance between domain outcomes. A common concern reported by participants and also cited in the literature (Purdy & Hindenlang, 2005; Simmons-Mackie et al., 2010) is the importance of supported communication and the implications of a lack of such support. The SAQOL-39 wording of questions regarding communication target “how much trouble” the PWA has had with different aspects of communication. The primary interpretation of this question by participants appeared to be “Do you have trouble with communicating and how much?” The ALA also targeted the deficit, but also sought to assess any contextual factors which may positively or negatively impact the implications of said deficit. The higher outcomes on the ALA suggest that this additional consideration improved one’s outlook within that domain of quality of life.

The Personal (ALA) versus Psychosocial (SAQOL-39) domains comparison did not reveal a clear suggestion as to why outcomes were not more similar. Consideration of the reported assessment outcomes and those comments interjected by participants during the assessments and interviews suggest that these differences occurred primarily due to presentation of the questions and each participant’s interpretations.

These differences suggest that while both assessments were developed using the same or similar frameworks, the design and structure of each assessment plays a significant role in the comparability of these two assessments.

**Research Question 2:** Are total assessment outcomes between the quality of life measures similar for each participant?

As initially predicted outcomes between differed as each assessment gave greater weight

to differing aspects of the implications of stroke and aphasia. The SAQOL-39 was weighted more heavily to account for the physical and psychosocial implications of the accident. The ALA lays greater emphasis on the communication and participation aspects. The sampling of persons with aphasia used in the current study included few that experienced significant physical implications from their stroke. As a result, a generally more positive outcome was seen on the SAQOL-39 versus the ALA. The differences that did occur, however, do support the importance of using both assessments to gain a more complete picture of each participant's quality of life as described in the ICF framework (WHO, 2001). Had the SAQOL-39 not been used, those physical implications which impacted important traits such as independence, would not have been considered as greatly or at all.

**Research Question 3:** Is there consistency among outcomes (by domain, assessment, and overall averages) of quality of life measures for aphasia from the person with aphasia and their nominated family member/caregiver?

Similar to Hilari et al.'s (2007) study, differences existed between responses by each PWA and caregiver. However, these differences were not substantial enough to discount the caregivers to serve as proxy respondents for their PWA. Comments made by caregivers during interviews and assessments supported claims within the literature that the implications of aphasia greatly impacted their life as well, and in combination with their own personal opinions (Brown et al., 2011; Croteau & Le Dorze, 2001; Kagan et al., 2008; Rohde et al., 2012), impacted the scores they reported on assessment measures. Within the current study, however, the dual presentation (i.e., "as" PWA and "for" PWA) of each assessment allowed responses by caregivers to be closer to those of the PWA. This finding indicates that the use of this dual

presentation or at minimum a “priming” of the caregiver should occur prior to administration of any qualitative assessment for which they will serve as proxy to gain the most accurate picture.

**Research Question 4:** Do the assessments used capture the traits each participant considered important for measuring QoL in their own lives?

Both the SAQOL-39 and ALA were developed from extensive research into factors of importance to QoL as defined by both professionally endorsed “umbrella” models (e.g., WHO’s ICF model, AFROM) and those described by PWAs and other stakeholders during focus groups (Hilari et al., 2003; Kagan et al., 2008, 2011). While many traits were targeted within both assessments, the use of two quality of life assessments provided a more comprehensive picture of each PWA’s quality of life by including those traits (e.g., supported communication on the ALA, specific physical tasks on the SAQOL-39) that were targeted only on one assessment.

Discussions during post-assessment interviews revealed that between the two assessments, participants felt all of the traits most important to them (e.g., independence, communication, and companionship) were best captured. However, while there are common themes among the traits most important for quality of life amongst people, it remains a highly subjective topic and the findings of this study support the need to use multiple tools (e.g., assessments, interviews) during such evaluations.

**Research Question 5:** Can those with high overall quality of life scores be considered to be “living successfully with aphasia”?

Brown et al. (2010a, 2010b, 2011, 2012) reported traits most important for PWAs to consider themselves living “successfully” included participation, meaningful relationships, support, communication, positivity, independence, and living successfully with aphasia as a

journey over time. Similar to their findings, participants of the current study reported independence, communication, and companionship as those traits most important for quality of life. Participants then went on to report that these same traits are important for “living successfully with aphasia.” This overlap suggests that the concepts of “quality of life” and “living successfully with aphasia” compliment each other when one considers a PWA reporting a higher quality of life to be living a more “successful” life with aphasia than one reporting a poorer quality of life. Individual traits and themes extracted from pre- and post-assessment interviews, as well as commentary throughout assessment administrations provided similar or more detailed information towards establishing where each PWA considered themselves on a QoL/ “successful living” continuum as the scores from both assessments. This indicates that while a formal assessment can be a useful tool in gathering information, it should not be used in isolation. Rather, a combination of assessment(s) and open discussion should be used to gather the richest information about an individual.

### **Clinical Implications**

Caregivers and/or family members of persons with aphasia play a much larger role in the rehabilitation process than is often thought of (Rohde, Townley-O’Neill, Trendell, Worrall & Cornwell, 2012). Discussions with these individuals during the current study revealed that differences of opinions and outlooks do occur within these couples. However, these caregivers/family members remain the people who know the PWA best. Many of these differences are a result of the changes in family dynamic (e.g., a spouse taking on an additional job, a child moving back in with parents, a parent moving back in with a child). While some of these situations can occur in any family, the element of dependence by the PWA requires their family members and/or caregivers to alter the manner in which they’ve functioned for much of

their adult life. The use of these individuals as proxy respondents could potentially allow a greater understanding of the implications of aphasia on one's quality of life and allow better treatment plans and frameworks to be established. However in doing so, the implications of aphasia on the family member/caregiver must be taken into account while considering the reported outcomes.

Overall, the findings from this study show the importance for QoL assessment in the rehabilitation process. While one or more aspects of one's impairment may be targeted through therapy, a step back by the rehabilitative team is necessary to evaluate progress for the whole person. Such a move is similar to that described by the World Health Organization in their ICF model (WHO, 2001). The current study attempted assessment of a broader range of impairment domains through the use of multiple QoL assessments. The differences in emphasis between the ALA and the SAQOL-39 allowed for the communicative, physical, and psychosocial implications of a stroke and aphasia to be assessed. Such an assessment would prove useful at varying intervals throughout a person's rehabilitative process and life.

### **Study Limitations**

Limitations of the present study include the small sample size. Although the study was sensitive to differences between a participant's responses, the small sample size limited its power to predict overall trends in PWA vs. Family Member QoL responses.

### **Future Research**

A primary focus of future research improvements could include a larger sample size of persons with aphasia and a family member or primary caregiver to further establish reliability of the caregiver as a proxy respondent on QoL measures. Additionally, for now it may be beneficial

to continue use of two or more quality of life measures to allow for a more comprehensive QoL assessment.

The ALA allowed greater insight into the communicative implications of a stroke and the resulting aphasia, and also incorporated helpful pictographic supports. The SAQOL-39 delved deeper into the physical implications, which can also greatly impact a person's perception of quality of life. Further analysis of each of these measures in combination with other established measures and/or quality of life related research to develop a comprehensive, yet functional measure may prove beneficial as quality of life outcomes become increasingly more important in the rehabilitation process.

The idea of generating a comprehensive and functional measure leads one to wonder how well quality of life outcomes can be implemented into the rehabilitation process. This may be particularly useful in settings such as long-term care units and university outpatient clinics, where patients are seen over an extended period of time (e.g., months or years). Assessing quality of life pre- and post-intervention (and possibly at intervals throughout treatment) may prove as a helpful tool in establishing the needs in a functional treatment plan for each patient and determining how successful the said plan has been.

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## TABLES

Table 1

*Participant demographics*

PWA Participant	Age	Gender	Time Post Onset (years;months)	Type of Aphasia	Severity	Caregiver/ Family Member
1	75	F	4;3	Expressive	Moderate	Daughter
2	49	F	3;4	Expressive	Moderate	Mother
3	57	M	10;2	Expressive	Moderate	Wife
4	57	M	0;9	Expressive	Moderate	Wife
5	55	M	0;11	Expressive	Mild	Wife
Average	58.6	--	3;11	Expressive	Moderate	--

Table 2

*Domain outcomes: ALA – Environment vs. SAQOL-39 - Communication*

PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
	<b>ALA Environment</b>			<b>SAQOL-39 Communication</b>			
1	12/16	75	G	24/28	85.8	+10.8	G/E
2	15/16	93.75	E	21.2/28	75.8	-17.95	G
3	9/16	56	G	21.2/28	75.8	+19.8	G
4	4/16	25	P	14.4/24*	62.8	+37.8	G
5	11/16	68.75	G	16.8/28	60	-8.75	G
FM as PWA	<b>ALA Environment</b>			<b>SAQOL-39 Communication</b>			
1a	9/16	56.25	G	20/28	71.4	+15.15	G
2a	16/16	100	E	13.6/28	48.4	-51.6	F
3a	10/16	63	G	17.2/28	61.4	-1.6	G
4a	11/16	68.8	G	8/24*	33.4	-35.4	F
5a	13/16	81.25	G	20.4/28	72.8	-8.45	G
FM for PWA	<b>ALA Environment</b>			<b>SAQOL-39 Communication</b>			
1a	14/16	87.5	E	23.2/28	82.8	-4.7	G
2a	13/16	81.25	G	15.2/28	45.8	-35.45	F
3a	12/16	75	G	19/28	54.2	-20.8	F
4a	11/16	68.8	G	8/24*	42.8	-26.0	F
5a	14	87.5	E	26/28	92.8	+5.3	E

Table 2a

*Domain outcomes: ALA – Personal vs. SAQOL-39 - Psychosocial*

PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1	29/44	66	G	40/44	91	+25	E
2	30/44	68.25	G	36.8/44	83.6	+15.35	G
3	44/44	100	E	38.8/44	88.2	-11.8	E
4	19/40*	43.3	F	11.2/40*	28	-15.3	P
5	38/44	86.25	E	28.8/44	65.4	-20.85	G
FM as PWA	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1a	28/44	63.75	G	40.8/44	92.8	+29.05	E
2a	30/44	68.25	G	24.8/44	56.4	-11.85	G
3a	30/44	68	G	30.4/44	69	+1.0	G
4a	25/40*	62.5	G	19.2/40*	48	-14.5	F
5a	35/44	79.5	G	36.8/44	83.6	+4.1	G
FM for PWA	<b>ALA Personal</b>			<b>SAQOL-39 Psychosocial</b>			
1a	30/44	68.25	G	40/44	91	+22.75	E
2a	21/44	47.75	F	28/44	63.6	+15.85	G
3a	36/44	82	G	26.4/44	60	-22.0	G
4a	34/40*	77.3	G	16/40*	40	-37.3	F
5a	40/44	91	E	38.4/44	87.2	-3.8	E

Table 3  
*Total assessment outcomes*

PWA	ALA			SAQOL-39			
	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1	95/148	64.25	G	127/156	81.6	+17.35	G
2	107/148	72.25	G	136/156	87	+14.75	E
3	123/148	83	G	119/152*	78	-5.0	G
4	39/140*	27.75	P	80.8/140*	57.7	+29.95	G
5	102/148	69	G	120/156	77	+8.0	G
FM as PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1a	92/148	61.75	G	129/156	82.6	+20.85	G
2a	94/148	63.5	G	108/156	69.5	+6.0	G
3a	72/148	49	F	108/152*	72	+23.0	G
4a	69/140*	49.25	F	92.8/140*	66.3	+17.05	G
5a	121/148	81.75	G	135/156	86.4	+4.65	E
FM for PWA	Raw Score	Percentage	Rating	Adjusted Raw Score	Percentage	Percentage Differential from ALA	Rating
1a	114/148	77	G	131/156	84.2	+7.2	G
2a	82/148	55.5	G	114/156	72.8	+17.3	G
3a	84/148	57	G	98.8/152*	65.8	+8.8	G
4a	73/140*	52.25	F	88/140*	62.9	+10.65	G
5a	133/148	89.75	E	144/156	92.3	+2.55	E

\*One or both participants in the couple was unable or elected not to respond to one or more questions. Any questions unanswered by one participant in the couple was subsequently omitted on all forms for that couple.



Table 4

*Outcomes: Domain, total assessment, and overall quality of life*

<i>Domain outcomes: ALA – Environment vs. SAQOL-39 - Communication</i>									
PWA	Assessment	Raw Score	Percentage	Rating	Family Member	Assessment	Raw Score	Percentage	Rating
1	ALA	12/16	75	G	1a	ALA	9/16	56.25	G
	SAQOL-39	24/28	85.8	G/E		SAQOL-39	20/28	71.4	G
2	ALA	15/16	93.75	E	2a	ALA	16/16	100	E
	SAQOL-39	21.2/28	75.8	G		SAQOL-39	13.6/18	48.4	F
3	ALA	9/16	56	G	3a	ALA	10/16	63	G
	SAQOL-39	21.2/28	75.8	G		SAQOL-39	17.2/18	61.4	G
4	ALA	4/16	25	P	4a	ALA	11/16	68.8	G
	SAQOL-39	14.4/24*	62.8	G		SAQOL-39	8/24*	33.4	F
5	ALA	11/16	68.75	G	5a	ALA	13/16	81.25	G
	SAQOL-39	16.8/28	60	G		SAQOL-39	20.4/28	72.8	G
<i>Domain outcomes: ALA – Personal vs. SAQOL-39 – Psychosocial</i>									
PWA	Assessment	Raw Score	Percentage	Rating	Family Member	Assessment	Raw Score	Percentage	Rating
1	ALA	29/44	66	G	1a	ALA	28/44	63.75	G
	SAQOL-39	40/44	91	E		SAQOL-39	40.8/44	92.8	E
2	ALA	30/44	68.25	G	2a	ALA	30/44	68.25	G
	SAQOL-39	36.8/44	83.6	G		SAQOL-39	24.8/44	56.4	G
3	ALA	44/44	100	E	3a	ALA	30/44	68	G
	SAQOL-39	36.8/44	88.2	E		SAQOL-39	30.4/44	69	G
4	ALA	19/40*	43.3	F	4a	ALA	25/40*	62.5	G
	SAQOL-39	11.2/40*	28	P		SAQOL-39	19.2/40*	48	F
5	ALA	38/44	86.25	E	5a	ALA	35/44	79.5	G
	SAQOL-39	28.8/44	65.4	G		SAQOL-39	36.4/44	83.6	G
<i>Total assessment outcomes</i>									
PWA	Assessment	Raw Score	Percentage	Rating	Family Member	Assessment	Raw Score	Percentage	Rating
1	ALA	95/148	64.25	G	1a	ALA	92/148	61.75	G
	SAQOL-39	127/156	81.6	G		SAQOL-39	129/156	82.6	G
2	ALA	107/148	72.25	G	2a	ALA	94/148	63.5	G
	SAQOL-39	136/156	87	E		SAQOL-39	108/156	69.5	G
3	ALA	123/148	83	G	3a	ALA	72/148	49	F
	SAQOL-39	119/152*	78	G		SAQOL-39	108/152*	72	G
4	ALA	39/140*	27.75	P	4a	ALA	69/40*	49.25	F
	SAQOL-39	80.8/140*	59	G		SAQOL-39	92.8/140*	66.3	G
5	ALA	102/148	69	G	5a	ALA	121/148	81.75	G
	SAQOL-39	120/156	77	G		SAQOL-39	135/156	86.4	G
<i>Overall quality of life outcomes</i>									
PWA	Adjusted Raw Score	Percentage	Rating	Family Member	Adjusted Raw Score	Percentage	Rating		
1	222.2/304	73.1	G	1a	220.8/304	72.6	G		
2	242.6/304	79.8	G	2a	202/304	66.4	G		
3	241.6/300*	80.5	G	3a	180.4/300*	60.1	G		
4	119.8/280*	42.8	F	4a	161.8/280*	57.8	G		
5	222/304	73	G	5a	255.8/304	84.1	G		

\*One or both participants in the couple was unable or elected not to respond to one or more questions. Any questions unanswered by one participant in the couple was subsequently omitted on all forms for that couple.

Table 5

Participant report for “living successfully with aphasia” vs. “Wall” question

PWA	Interview: <i>Would you say that you [PWA] is living successfully with aphasia?</i>	“Wall” Question		
		Raw Score	Percentage	Rating
1	Definitely Yes	4	100	E
2	Sometimes	2	50	F
3	Definitely Yes	4	100	E
4	Definitely No	1	25	P
5	Sometimes	2	50	F
<b>FM as PWA</b>				
1a	Mostly Yes	3	75	G
2a	Sometimes	2	50	F
3a	Mostly No	2	50	F
4a	Unsure	2	50	F
5a	Mostly Yes	3	75	G

Table 6

Participant #1 and #1a outcomes

PWA #1: 75 YO F - 4;3 TPS - MOD / FM #1A (DAUGHTER)																		
ALA PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	9	1.8	45	F	Physical	85	63	3.71	74.2	G	68	50.4	3	74.1	G		
Participation	64	41	2.56	64	G	Communication	35	30	4.29	85.8	G/E	28	24	3.4	85.7	G/E		
Environment	16	12	3	75	G	Psychosocial	55	50	4.55	91	E	44	40	3.6	90.9	E		
Personal	44	29	2.64	66	G	Energy	20	16	4	80	G	16	12.8	3.2	80	G		
Wall	4	4	4	100	E	Total	195	159	4.08	81.6	G	156	127	3.3	81.5	G	73.09	G
Total	148	95	2.57	64.3	G													
ALA as PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 as PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	5	1	25	P	Physical	85	68	4	80	G	68	54.4	3.2	80	G		
Participation	64	47	2.94	73.5	G	Communication	35	25	3.57	71.4	G	28	20	2.9	71.4	G		
Environment	16	9	2.25	56.3	G	Psychosocial	55	51	4.64	92.8	E	44	40.8	3.7	92.7	E		
Personal	44	28	2.55	63.8	G	Energy	20	17	4.25	85	G	16	13.6	3.4	85	G		
Wall	4	3	3	75	G	Total	195	161	4.13	82.6	G	156	129	3.3	82.6	G	72.63	G
Total	148	92	2.47	61.8	G													
ALA for PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 for PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	12	2.4	60	G	Physical	85	65	3.82	76.4	G	68	52	3.1	76.5	G		
Participation	64	54	3.38	84.5	G	Communication	35	29	4.14	82.8	G	28	23.2	3.3	82.9	G		
Environment	16	14	3.5	87.5	E	Psychosocial	55	50	4.55	91	E	44	40	3.6	90.9	E		
Personal	44	30	2.73	68.3	G	Energy	20	20	5	100	E	16	16	4	100	E		
Wall	4	4	4	100	E	Total	195	164	4.21	84.2	G	156	131	3.4	84.1	G	80.66	G
Total	148	114	3.08	77	G													

Table 7  
Participant #2 and #2a outcomes

PWA #2: 49 YO F - 3;4 TPS - MOD / FM #2A (MOTHER)																		
ALA PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	15	3	75	G	Physical	85	77	4.53	90.6	E	68	61.6	3.62	90.6	E		
Participation	64	45	2.81	70.3	G	Communication	35	26.5	3.79	75.8	G	28	21.2	3.03	75.7	G		
Environment	16	15	3.75	93.8	E	Psychosocial	55	46	4.18	83.6	G	44	36.8	3.35	83.6	G		
Personal	44	30	2.73	68.3	G	Energy	20	20	5	100	E	16	16	4	100	E		
Wall	4	2	2	50	F	Total	195	170	4.35	87	E	156	136	3.48	86.9	E	79.8	G
Total	148	107	2.89	72.3	G													
ALA as PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 as PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	6	1.2	30	P	Physical	85	67	3.94	78.8	G	68	53.6	3.15	78.8	G		
Participation	64	40	2.5	62.5	G	Communication	35	17	2.42	48.4	F	28	13.6	1.94	48.6	F		
Environment	16	16	4	100	E	Psychosocial	55	31	2.82	56.4	G	44	24.8	2.25	56.4	G		
Personal	44	30	2.73	68.3	G	Energy	20	20	5	100	E	16	16	4	100	E		
Wall	4	2	2	50	F	Total	195	135	3.46	69.2	G	156	108	2.77	69.2	G	66.45	G
Total	148	94	2.54	63.5	G													
ALA for PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 for PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	8	1.6	40	F	Physical	85	71	4.18	83.6	G	68	56.8	3.34	83.5	G		
Participation	64	38	2.38	59.5	G	Communication	35	16	2.29	45.8	F	28	12.8	1.83	45.7	F		
Environment	16	13	3.25	81.3	G	Psychosocial	55	35	3.18	63.6	G	44	28	2.55	63.6	G		
Personal	44	21	1.91	47.8	F	Energy	20	20	5	100	E	16	16	4	100	E		
Wall	4	2	2	50	F	Total	195	142	3.64	72.8	G	156	114	2.91	72.8	G	64.34	G
Total	148	82	2.22	55.5	F/G													

Table 8  
Participant #3 and #3a outcomes

PWA #3: 57 YO M - 10;2 TPS - MOD / FM #3A (WIFE)																		
ALA PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	14	2.8	70	G	Physical	80	56.25	3.52	70.4	G	64	45	2.81	70.3	G		
Participation	64	52	3.25	81.25	G	Communication	35	26.5	3.79	75.8	G	28	21	3.03	75.7	G		
Environment	16	9	2.25	56.25	G	Psychosocial	55	48.5	4.41	88.2	E	44	39	3.53	88.2	E		
Personal	44	44	4	100	E	Energy	20	17	4.25	85	G	16	14	3.4	85	G		
Wall	4	4	4	100	E	Total	190	148.3	3.9	78	G	152	119	3.12	78	G	80.53	G
Total	148	123	3.32	83	G													
ALA as PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 as PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	11	2.2	55	F	Physical	80	56	3.5	70	G	64	45	2.8	70	G		
Participation	64	19	1.19	29.75	P	Communication	35	21.5	3.07	61.4	G	28	17	2.46	61.4	G		
Environment	16	10	2.5	62.5	G	Psychosocial	55	38	3.45	69	G	44	30	2.76	69.1	G		
Personal	44	30	2.73	68.25	G	Energy	20	20	5	100	E	16	16	4	100	E		
Wall	4	2	2	50	F	Total	190	135.5	3.57	71.4	G	152	108	2.85	71.3	G	60.13	G
Total	148	72	1.95	48.75	G													
ALA for PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 for PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	12	2.4	60	G	Physical	80	54.5	3.4	68	G	64	44	2.73	68.1	G		
Participation	64	22	1.38	34.38	F	Communication	35	19	2.71	54.2	F	28	15	2.17	54.3	F		
Environment	16	12	3	75	G	Psychosocial	55	33	3	60	G	44	26	2.4	60	G		
Personal	44	36	3.27	81.75	G	Energy	20	17	4.25	85	G	16	14	3.4	85	G		
Wall	4	2	2	50	F	Total	190	123.5	3.25	65	G	152	99	2.6	65	G	60.93	G
Total	148	84	2.27	56.75	G													

Table 9  
Participant #4 and #4a outcomes

PWA #4: 57 YO M - 0;9 TPS - MOD / FM #4A (WIFE)																		
ALA PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	16	5	1.25	31.3	F	Physical	75	62	4.13	82.6	G	60	49.6	3.31	82.7	G		
Participation	64	10	0.63	15.6	P	Communication	30	18	3	60	G	24	14.4	2.4	60	G		
Environment	16	4	1	25	P	Psychosocial	50	14	1.4	28	P	40	11.2	1.12	28	P		
Personal	40	19	1.9	47.5	F	Energy	20	7	1.75	35	F	16	5.6	1.4	35	F		
Wall	4	1	1	25	P	Total	175	101	2.89	57.8	G	140	80.8	2.31	57.7	G	42.79	F
<b>Total</b>	<b>140</b>	<b>39</b>	<b>1.11</b>	<b>27.8</b>	<b>P</b>													
ALA as PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 as PWA	Max Score	Total	Raw Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	16	6	1.5	37.5	F	Physical	75	66	4.4	88	E	60	52.8	3.52	88	E		
Participation	64	25	1.56	39	F	Communication	30	10	1.67	33.4	F	24	8	1.33	33.3	F		
Environment	16	11	2.75	68.8	G	Psychosocial	50	24	2.4	48	F	40	19.2	1.92	48	F		
Personal	40	25	2.5	62.5	G	Energy	20	16	4	80	G	16	12.8	3.2	80	G		
Wall	4	2	2	50	F	Total	175	116	3.31	66.2	G	140	92.8	2.65	66.3	G	57.79	G
<b>Total</b>	<b>140</b>	<b>69</b>	<b>1.97</b>	<b>49.3</b>	<b>F</b>													
ALA for PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 for PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	16	3	0.75	18.8	P	Physical	75	64	4.27	85.4	G/E	60	51.2	3.41	85.3	G/E		
Participation	64	25	1.56	39	F	Communication	30	10	1.67	33.4	F	24	8	1.33	33.3	F		
Environment	16	11	2.75	68.8	G	Psychosocial	50	20	2	40	F	40	16	1.6	40	F		
Personal	40	32	3.2	80	G	Energy	20	16	4	80	G	16	12.8	3.2	80	G		
Wall	4	2	2	50	F	Total	175	110	3.14	62.8	G	140	88	2.51	62.9	G	57.5	G
<b>Total</b>	<b>140</b>	<b>73</b>	<b>2.09</b>	<b>52.3</b>	<b>F</b>													

Table 10  
Participant #5 and #5a outcomes

PWA #5: 55 YO M - 0;11 TPS - MILD / FM #5A (WIFE)																		
ALA PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	8	1.6	40	F	Physical	85	79	4.67	93.4	E	68	63.2	3.72	92.94	E		
Participation	64	43	2.69	67.3	G	Communication	35	21	3	60	G	28	16.8	2.4	60	G		
Environment	16	11	2.75	68.8	G	Psychosocial	55	36	3.27	65.4	G	44	28.8	2.62	65.45	G		
Personal	44	38	3.45	86.3	E	Energy	20	14	3.5	70	G	16	11.2	2.8	70	G		
Wall	4	2	2	50	F	Total	195	150	3.85	77	G	156	120	3.08	76.92	G	73	G
<b>Total</b>	<b>148</b>	<b>102</b>	<b>2.76</b>	<b>69</b>	<b>G</b>													
ALA as PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 as PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj RS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	12	2.4	60	G	Physical	85	80	4.71	94.2	E	68	64	3.76	94.12	E		
Participation	64	58	3.63	90.6	E	Communication	35	25.5	3.64	72.8	G	28	20.4	2.91	72.86	G		
Environment	16	13	3.25	81.3	G	Psychosocial	55	46	4.18	83.6	G	44	36.8	3.35	83.64	G		
Personal	44	35	3.18	79.5	G	Energy	20	17	4.25	85	G	16	13.6	3.4	85	G		
Wall	4	3	3	75	G	Total	195	169	4.32	86.4	E	156	135	3.46	86.41	E	84.1	G
<b>Total</b>	<b>148</b>	<b>121</b>	<b>3.27</b>	<b>81.8</b>	<b>G</b>													
ALA for PWA	Max Score	Raw Score	Avg Score	%	Rating	SAQOL-39 for PWA	Max Score	Raw Score	Avg Score	%	Rating	Adj MS	Adj TS	Adj AS	%	Rating	OAS 4 PT	Rating
Aphasia	20	16	3.2	80	G	Physical	85	82.5	4.85	97	E	68	66	3.88	97.06	E		
Participation	64	60	3.75	93.8	E	Communication	35	32.5	4.64	92.8	E	28	26	3.71	92.86	E		
Environment	16	14	3.5	87.5	E	Psychosocial	55	48	4.36	87.2	E	44	38.4	3.49	87.27	E		
Personal	44	40	3.64	91	E	Energy	20	17	4.25	85	G	16	13.6	3.4	85	G		
Wall	4	3	3	75	G	Total	195	180	4.62	92.4	E	156	144	3.69	92.31	E	91.1	E
<b>Total</b>	<b>148</b>	<b>133</b>	<b>3.59</b>	<b>89.8</b>	<b>E</b>													

## APPENDIXES

APPENDIX A  
ALA Questions for PWA

Question Number	A-FROM Domain	Question	Client Response	Score Type	Included in total
Q1	Participation	How much do you know about aphasia?	Point to scale	0-4 Rating	✓
Q2	Aphasia	How would you rate your talking?	Point to scale	0-4 Rating	✓
Q3	Aphasia	How would you rate your understanding?	Point to scale	0-4 Rating	✓
Q4	Aphasia	How would you rate your reading?	Point to scale	0-4 Rating	✓
Q5	Aphasia	How would you rate your writing?	Point to scale	0-4 Rating	✓
Q6	Aphasia	Overall how would you rate your communication?	Point to scale	0-4 Rating	✓
Q7	Participation	During a typical week, where do you go?	Point to pictographs &/or verbalize number of places	Numerical count of # of places	x
Q8	Participation	Do you get out to the places where you want to go?	Point to scale	0-4 Rating	✓
Q9	Participation	How many days do you get out in a week?	Point to pictographs &/or verbalize number of places	Numerical count of # of places	x
Q10	Participation	Are you satisfied with the number of days that you get out?	Point to scale	0-4 Rating	✓
Q11	Participation	Are you doing as much as you want at home or where you live?	Point to scale	0-4 Rating	✓
Q12	Participation	Are you doing as much as you want in the area or working or volunteering?	Point to scale	0-4 Rating	✓
Q13	Participation	Are you doing as much as you want with money and finances?	Point to scale	0-4 Rating	✓
Q14	Participation	Are you doing as much as you want about leisure and recreation?	Point to scale	0-4 Rating	✓
Q15	Participation	Are you doing as much as you want with learning new things, new activities, education?	Point to scale	0-4 Rating	✓
Q16	Participation	Are you getting around as much as you want?	Point to scale	0-4 Rating	✓
Q17	Participation	How are you doing with your roles and responsibilities?	Point to scale	0-4 Rating	✓
Q18	Participation	How is your relationship with [insert name of most important person]?	Point to scale	0-4 Rating	✓
Q19	Participation	How is having conversation with [insert name of most important person]?	Point to scale	0-4 Rating	✓
Q20	Participation	In a typical week, how many people do you talk to?	Point to pictographs &/or verbalize number of places	Numerical count of # of people	x
Q21	Participation	Are you happy with the number of relationships and friends that you have?	Point to scale	0-4 Rating	✓

APPENDIX A (continued)

Question Number	A-FROM Domain	Question	Client Response	Score Type	Included in total
Q22	Participation	Do you join in when conversation is about a simple topic?	Point to scale	0-4 Rating	✓
Q23	Participation	Do you join in when conversation is about a complex topic?	Point to scale	0-4 Rating	✓
Q24	Participation	Do you join in conversations at home?	Point to scale	0-4 Rating	✓
Q25	Participation	Do you join in conversations outside of your home – in the community?	Point to scale	0-4 Rating	✓
Q26	Environment	What do you do to help conversation?	Point to pictographs &/or verbalize number of places	Numerical count of # of communication strategies	x
Q27	Environment	What does [insert name of most important person] do to help you in conversation?	Point to pictographs &/or verbalize number of places	Numerical count of # of communication strategies	x
Q28	Environment	Do you get help to communicate at home?	Point to scale	0-4 Rating	x
Q29	Environment	Do you get help outside your home – in the community?	Point to scale	0-4 Rating	x
Q30	Environment	Do people feel comfortable talking to you at home?	Point to scale	0-4 Rating	✓
Q31	Environment	Do people feel comfortable talking to you outside your home – in the community?	Point to scale	0-4 Rating	✓
Q32	Environment	Do people at home know you are competent/intelligent?	Point to scale	0-4 Rating	✓
Q33	Environment	Do people outside your home – in the community know you are competent/intelligent?	Point to scale	0-4 Rating	✓
Q34	Personal	Are you in charge of your life?	Point to scale	0-4 Rating	✓
Q35	Personal	Do you feel confident?	Point to scale	0-4 Rating	✓
Q36	Personal	Do you feel respected?	Point to scale	0-4 Rating	✓
Q37	Personal	Do you feel accepted?	Point to scale	0-4 Rating	✓
Q38	Personal	Do you feel lonely?	Point to scale	0-4 Rating	✓
Q39	Personal	Do you feel depressed?	Point to scale	0-4 Rating	✓
Q40	Personal	Do you feel frustrated?	Point to scale	0-4 Rating	✓
Q41	Personal	Do you feel angry?	Point to scale	0-4 Rating	✓
Q42	Personal	Do you think good things about yourself?	Point to scale	0-4 Rating	✓
Q43	Personal	Do you have things you enjoy or look forward to?	Point to scale	0-4 Rating	✓
Q44	Personal	What will life be like in the future?	Point to scale	0-4 Rating	✓
Q45	The 'Wall'	Which one is you?	Point to scale	0-4 Rating	✓

## APPENDIX B

### ALA Instructions for Proxy as PWA

We would like to know how \_\_\_\_\_ is doing with activities or feelings that can sometimes be affected by stroke. Each question will ask about a specific activity or feeling. For each question, use the scale to select the rating that best describes how good or bad (much or little trouble) \_\_\_\_\_ has had with each feeling or activity.

PLEASE ANSWER EACH QUESTION FROM \_\_\_\_\_ PERSPECTIVE,  
i.e. AS YOU THINK \_\_\_\_\_ WOULD.

### ALA Instructions for Proxy for PWA

We would like to know how \_\_\_\_\_ is doing with activities or feelings that can sometimes be affected by stroke. Each question will ask about a specific activity or feeling. For each question, use the scale to select the rating that best describes how good or bad (much or little trouble) \_\_\_\_\_ has had with each feeling or activity.

PLEASE ANSWER EACH QUESTION FROM YOUR PERSPECTIVE,  
i.e. AS YOU THINK \_\_\_\_\_ EXPERIENCED



APPENDIX C  
ALA Questions for Proxy as PWA/for PWA

Question Number	A-FROM Domain	Question	Proxy Response	Score Type	Included in total
Q1	Participation	How much does [insert name] know about aphasia?	Point to scale/verbalize	0-4 Rating	√
Q2	Aphasia	How would [insert name] rate their talking?	Point to scale/verbalize	0-4 Rating	√
Q3	Aphasia	How would [insert name] rate their understanding?	Point to scale/verbalize	0-4 Rating	√
Q4	Aphasia	How would [insert name] rate their reading?	Point to scale/verbalize	0-4 Rating	√
Q5	Aphasia	How would [insert name] rate their writing?	Point to scale/verbalize	0-4 Rating	√
Q6	Aphasia	Overall how would [insert name] rate their communication?	Point to scale/verbalize	0-4 Rating	√
Q7	Participation	During a typical week, where does [insert name] go?	Point to pictographs &/or verbalize number of places	Numerical count of # of places	x
Q8	Participation	Does [insert name] get out to the places where they want to go?	Point to scale/verbalize	0-4 Rating	√
Q9	Participation	How many days does [insert name] get out in a week?	Point to pictographs &/or verbalize number of places	Numerical count of # of places	x
Q10	Participation	Is [insert name] satisfied with the number of days that they get out?	Point to scale/verbalize	0-4 Rating	√
Q11	Participation	Is [insert name] doing as much as they want at home or where they live?	Point to scale/verbalize	0-4 Rating	√
Q12	Participation	Is [insert name] doing as much as they want in the area or working or volunteering?	Point to scale/verbalize	0-4 Rating	√
Q13	Participation	Is [insert name] doing as much as they want with money and finances?	Point to scale/verbalize	0-4 Rating	√
Q14	Participation	Is [insert name] doing as much as they want about leisure and recreation?	Point to scale/verbalize	0-4 Rating	√
Q15	Participation	Is [insert name] doing as much as they want with learning new things, new activities, education?	Point to scale/verbalize	0-4 Rating	√
Q16	Participation	Is [insert name] getting around as much as they want?	Point to scale/verbalize	0-4 Rating	√
Q17	Participation	How is [insert name] doing with their roles and responsibilities?	Point to scale/verbalize	0-4 Rating	√
Q18	Participation	How would [insert name] rate their relationship with you [or insert name of most important person]?	Point to scale/verbalize	0-4 Rating	√
Q19	Participation	How would [insert name] rate having conversation with you [or insert name of most important person]?	Point to scale/verbalize	0-4 Rating	√

APPENDIX C (continued)

Question Number	A-FROM Domain	Question	Proxy Response	Score Type	Included in total
Q20	Participation	In a typical week, how many people does [insert name] talk to?	Point to pictographs &/or verbalize number of places	Numerical count of # of people	x
Q21	Participation	Is [insert name] happy with the number of relationships and friends that they have?	Point to scale/verbalize	0-4 Rating	√
Q22	Participation	Does [insert name] join in when conversation is about a simple topic?	Point to scale/verbalize	0-4 Rating	√
Q23	Participation	Does [insert name] join in when conversation is about a complex topic?	Point to scale/verbalize	0-4 Rating	√
Q24	Participation	Does [insert name] join in conversations at home?	Point to scale/verbalize	0-4 Rating	√
Q25	Participation	Does [insert name] join in conversations outside of their home – in the community?	Point to scale/verbalize	0-4 Rating	√
Q26	Environment	What does [insert name] do to help conversation?	Point to pictographs &/or verbalize number of places	Numerical count of # of communication strategies	x
Q27	Environment	What would [insert name] report you do to help them in conversation?	Point to pictographs &/or verbalize number of places	Numerical count of # of communication strategies	x
Q28	Environment	Does [insert name] get help to communicate at home?	Point to scale/verbalize	0-4 Rating	x
Q29	Environment	Do [insert name] get help outside their home – in the community?	Point to scale/verbalize	0-4 Rating	x
Q30	Environment	Do people feel comfortable talking to [insert name] at home?	Point to scale/verbalize	0-4 Rating	√
Q31	Environment	Do people feel comfortable talking to [insert name] outside their home – in the community?	Point to scale/verbalize	0-4 Rating	√
Q32	Environment	Do people at home know [insert name] are competent/intelligent?	Point to scale/verbalize	0-4 Rating	√
Q33	Environment	Do people outside your home – in the community know you are competent/intelligent?	Point to scale/verbalize	0-4 Rating	√
Q34	Personal	Is [insert name] in charge of their life?	Point to scale/verbalize	0-4 Rating	√
Q35	Personal	Does [insert name] feel confident?	Point to scale/verbalize	0-4 Rating	√
Q36	Personal	Does [insert name] feel respected?	Point to scale/verbalize	0-4 Rating	√
Q37	Personal	Does [insert name] feel accepted?	Point to scale/verbalize	0-4 Rating	√
Q38	Personal	Does [insert name] feel lonely?	Point to scale/verbalize	0-4 Rating	√
Q39	Personal	Does [insert name] feel depressed?	Point to scale/verbalize	0-4 Rating	√

APPENDIX C (continued)

<b>Question Number</b>	<b>A-FROM Domain</b>	<b>Question</b>	<b>Proxy Response</b>	<b>Score Type</b>	<b>Included in total</b>
Q40	Personal	Does [insert name] feel frustrated?	Point to scale/verbalize	0-4 Rating	✓
Q41	Personal	Does [insert name] feel angry?	Point to scale/verbalize	0-4 Rating	✓
Q42	Personal	Does [insert name] think good things about them self?	Point to scale/verbalize	0-4 Rating	✓
Q43	Personal	Does [insert name] have things they enjoy or look forward to?	Point to scale/verbalize	0-4 Rating	✓
Q44	Personal	What will life for [insert name] be like in the future?	Point to scale/verbalize	0-4 Rating	✓
Q45	The 'Wall'	Which one is [insert name]?	Point to scale/verbalize	0-4 Rating	✓

APPENDIX D  
ALA Scoring Form



Score Sheet for Assessment for Living with Aphasia (ALA)

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Administered By: \_\_\_\_\_

**INSTRUCTION TO CLINICIAN:**

Record the scores on the reverse side of this ALA score sheet by circling or checking the boxes to the corresponding questions. When calculating the total score for each section, exclude answers that are shaded in gray – these questions (Questions 7, 9, 20, 26 and 27) elicit frequency responses. Also exclude answers that are shaded in black – these questions (Questions 12, 28 and 29) can be scaled for clinical purposes, but should not be averaged into the totals. Once all the section totals have been calculated, transfer the scores to the summary table at the bottom of this page, and sum to obtain the total score and averages. Please refer to the Instructional Manual and accompanying DVD for additional instructions on scoring.

**ADDITIONAL NOTES:**

	MAXIMUM SCORE	TOTAL (sum of ratings)	AVERAGE SCORE
Aphasia Domain	20		= 5 =
Participation Domain	64		= 16 =
Environment Domain	16		= 4 =
Personal Domain	44		= 11 =
Wall Question	4		= 1 =
<b>TOTAL</b>	<b>148</b>		<b>= 37 =</b>

TO ORDER ADDITIONAL RESOURCES please contact:  
Aphasia Institute 73 Scarsdale Road, Toronto, ON M3B 2R2 Canada phone: 416-226-3636 fax: 416-226-3706 email: research@aphasia.ca  
www.aphasia.ca

APPENDIX D (continued)  
ALA Scoring Form

Name: \_\_\_\_\_

Aphasia Domain		Score	0	0.5	1	1.5	2	2.5	3	3.5	4
2	How do you rate your talking										
3	your understanding										
4	your reading										
5	your writing										
6	your aphasia										
			TOTAL (sum of ratings)								

**PLEASE NOTE**  
Question 1 is entered under the Participation Domain

Participation Domain		Score	0	0.5	1	1.5	2	2.5	3	3.5	4
1*	How much do you know about Aphasia										
7	During the week where do you go										
8	Do you get out to where you want to go										
9	How many days do you get out										
10	Are you satisfied with number of days										
11	Are you doing what you want at home										
12	at work & volunteering										
13	with finances & money										
14	with leisure & recreation										
15	with learning & education										
16	with getting around										
17	Roles and responsibilities										
18	How is your relationship with X										
19	Having a conversation with X										
20	How many people do you talk to										
21	Are you happy with relationships										
22	Do you join in simple conversations										
23	complex conversations										
24	Do you join in at home										
25	in the community										
			TOTAL (sum of ratings)								

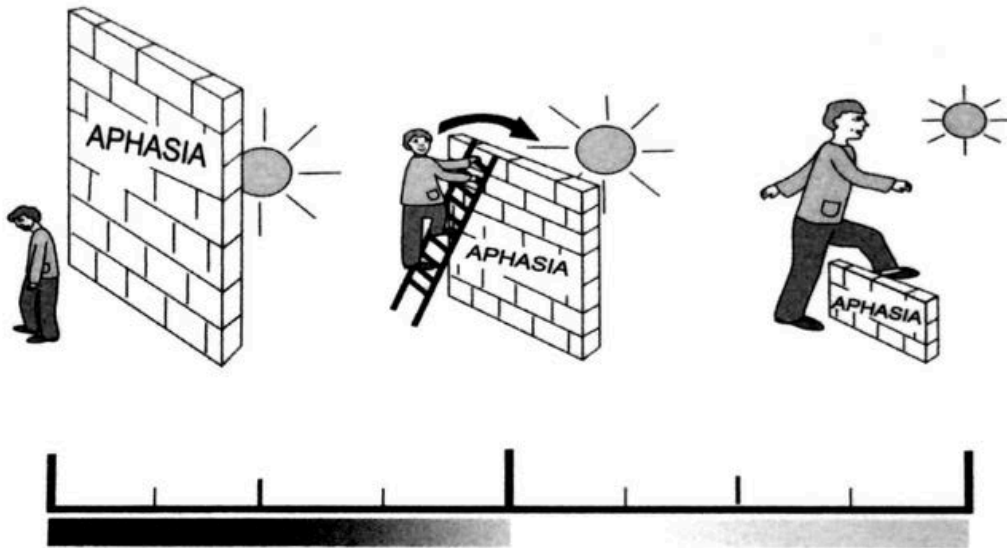
Environment Domain		Score	0	0.5	1	1.5	2	2.5	3	3.5	4
26	What do you do to help the conversation										
27	What does X do to help the conversation										
28	Do you get communication help at home										
29	Communication help in the community										
30	Comfortable talking at home										
31	Comfortable talking in the community										
32	Aphasia & competency at home										
33	Aphasia & competency in the community										
			TOTAL (sum of ratings)								

Personal Domain		Score	0	0.5	1	1.5	2	2.5	3	3.5	4
34	Are in charge of your life										
35	Do you feel confident										
36	Do you feel respected										
37	accepted										
38	lonely										
39	depressed										
40	frustrated										
41	angry										
42	Do you think good things about yourself										
43	Do you have things to look forward to										
44	How will life be in the future										
			TOTAL (sum of ratings)								

Wall Question		Score	0	0.5	1	1.5	2	2.5	3	3.5	4
45	Which one is you										
			TOTAL (sum of ratings)								

APPENDIX E  
ALA Wall Question

**Which one is you?**



APPENDIX F  
SAQOL-39 Questions for PWA

**DURING THE PAST WEEK**

Item ID	Domain	How much trouble did you have... <u>(Repeat before each item or as necessary)</u>	Client Response	Score Type
SC1.	Physical	preparing food?	Point to scale	0-5 Rating
SC4.	Physical	getting dressed?	Point to scale	0-5 Rating
SC5.	Physical	taking a bath or shower?	Point to scale	0-5 Rating
M1.	Physical	walking? <u>(If respondent can't walk, circle 1 and go to question M7)</u>	Point to scale	0-5 Rating
M4.	Physical	keeping your balance when bending over or reaching?	Point to scale	0-5 Rating
M6.	Physical	climbing stairs?	Point to scale	0-5 Rating
M7.	Physical	walking without stopping to rest or using a wheelchair without stopping to rest?	Point to scale	0-5 Rating
M8.	Physical	standing?	Point to scale	0-5 Rating
M9.	Physical	getting out of a chair?	Point to scale	0-5 Rating
W1.	Physical	doing daily work around the house?	Point to scale	0-5 Rating
W2.	Physical	finishing jobs that you started?	Point to scale	0-5 Rating
UE1.	Physical	writing or typing, <i>i.e. using your hand to write or type?</i>	Point to scale	0-5 Rating
UE2.	Physical	putting on socks?	Point to scale	0-5 Rating
UE4.	Physical	doing buttons?	Point to scale	0-5 Rating
UE5.	Physical	doing a zip?	Point to scale	0-5 Rating
UE6.	Physical	opening a jar?	Point to scale	0-5 Rating
L2.	Communication	speaking?	Point to scale	0-5 Rating
L3.	Communication	speaking clearly enough to use the phone?	Point to scale	0-5 Rating
L5.	Communication	getting other people to understand you?	Point to scale	0-5 Rating
L6.	Communication	finding the word you wanted to say?	Point to scale	0-5 Rating
L7.	Communication	getting other people to understand you even when you repeated yourself?	Point to scale	0-5 Rating

APPENDIX F (continued)

**DURING THE PAST WEEK:**

<b>Item ID</b>	<b>Domain</b>	<b>Did you... (Repeat before each item or as necessary)</b>	<b>Client Response</b>	<b>Score Type</b>
T4.	Energy	have to write things down to remember them, <i>(or ask somebody else to write things down for you to remember)</i> ?	Point to scale	0-5 Rating
T5.	Psychosocial	find it hard to make decisions?	Point to scale	0-5 Rating
P1.	Psychosocial	feel irritable?	Point to scale	0-5 Rating
P3.	Psychosocial	feel that your personality has changed?	Point to scale	0-5 Rating
MD2.	Psychosocial	feel discouraged about your future?	Point to scale	0-5 Rating
MD3.	Psychosocial	have no interest in other people or activities?	Point to scale	0-5 Rating
MD6.	Psychosocial	feel withdrawn from other people?	Point to scale	0-5 Rating
MD7.	Psychosocial	have little confidence in yourself?	Point to scale	0-5 Rating
E2.	Energy	feel tired most of the time?	Point to scale	0-5 Rating
E3.	Energy	have to stop and rest often during the day?	Point to scale	0-5 Rating
E4.	Energy	feel too tired to do what you wanted to do?	Point to scale	0-5 Rating
FR7.	Psychosocial	feel that you were a burden to your family?	Point to scale	0-5 Rating
FR9.	Communication	feel that your language problems interfered with your family life?	Point to scale	0-5 Rating
SR1.	Psychosocial	go out less often than you would like?	Point to scale	0-5 Rating
SR4.	Psychosocial	do your hobbies and recreation less often than you would like?	Point to scale	0-5 Rating
SR5.	Psychosocial	see your friends less often than you would like?	Point to scale	0-5 Rating
SR7.	Physical	feel that your physical condition interfered with your social life?	Point to scale	0-5 Rating
SR8.	Communication	feel that your language problems interfered with your social life?	Point to scale	0-5 Rating



APPENDIX G  
SAQOL-39 Instructions for Proxy as PWA

We would like to know how \_\_\_\_\_ is doing with activities or feelings that can sometimes be affected by stroke. Each question will ask about a specific activity or feeling. For each question, think about how that activity or that feeling has been in the past week. Provide the rating that best describes how much trouble \_\_\_\_\_ has had with each activity in the past week.

PLEASE ANSWER EACH QUESTION FROM \_\_\_\_\_ PERSPECTIVE,  
i.e. AS YOU THINK \_\_\_\_\_ WOULD.

SAQOL-39 Instructions for Proxy for PWA

We would like to know how \_\_\_\_\_ is doing with activities or feelings that can sometimes be affected by stroke. Each question will ask about a specific activity or feeling. For each question, think about how that activity or that feeling has been in the past week. Provide the rating that best describes how much trouble \_\_\_\_\_ has had with each activity in the past week.

PLEASE ANSWER EACH QUESTION FROM YOUR PERSPECTIVE,  
i.e. AS YOU THINK \_\_\_\_\_ EXPERIENCED

APPENDIX H  
SAQOL-39 Questions for Proxy as PWA/for PWA

**DURING THE PAST WEEK**

Item ID	Domain	How much trouble did s/he have... (Repeat before each item or as necessary)	Proxy Response	Score Type
SC1.	Physical	preparing food?	Point to scale/verbalize	0-5 Rating
SC4.	Physical	getting dressed?	Point to scale/verbalize	0-5 Rating
SC5.	Physical	taking a bath or shower?	Point to scale/verbalize	0-5 Rating
M1.	Physical	walking? (If s/he can't walk, circle 1 and go to question M7)	Point to scale/verbalize	0-5 Rating
M4.	Physical	keeping his/her balance when bending over or reaching?	Point to scale/verbalize	0-5 Rating
M6.	Physical	climbing stairs?	Point to scale/verbalize	0-5 Rating
M7.	Physical	walking without stopping to rest or using a wheelchair without stopping to rest?	Point to scale/verbalize	0-5 Rating
M8.	Physical	standing?	Point to scale/verbalize	0-5 Rating
M9.	Physical	getting out of a chair?	Point to scale/verbalize	0-5 Rating
W1.	Physical	doing daily work around the house?	Point to scale/verbalize	0-5 Rating
W2.	Physical	finishing jobs that s/he started?	Point to scale/verbalize	0-5 Rating
UE1.	Physical	writing or typing, <i>i.e. using his/her hand to write or type?</i>	Point to scale/verbalize	0-5 Rating
UE2.	Physical	putting on socks?	Point to scale/verbalize	0-5 Rating
UE4.	Physical	doing buttons?	Point to scale/verbalize	0-5 Rating
UE5.	Physical	doing a zip?	Point to scale/verbalize	0-5 Rating
UE6.	Physical	opening a jar?	Point to scale/verbalize	0-5 Rating
L2.	Communication	speaking?	Point to scale/verbalize	0-5 Rating
L3.	Communication	speaking clearly enough to use the phone?	Point to scale/verbalize	0-5 Rating
L5.	Communication	getting other people to understand him/her?	Point to scale/verbalize	0-5 Rating
L6.	Communication	finding the word s/he wanted to say?	Point to scale/verbalize	0-5 Rating
L7.	Communication	getting other people to understand him/her even when s/he repeated him/herself?	Point to scale/verbalize	0-5 Rating

APPENDIX H (continued)

**DURING THE PAST WEEK:**

Item ID	Domain	Did s/he... (Repeat before each item or as necessary)	Proxy Response	Score Type
T4.	Energy	have to write things down to remember them, (or if s/he cannot write: Have to ask somebody else to write things down for him/her to remember)?	Point to scale/verbalize	0-5 Rating
T5.	Psychosocial	find it hard to make decisions?	Point to scale/verbalize	0-5 Rating
P1.	Psychosocial	feel irritable?	Point to scale/verbalize	0-5 Rating
P3.	Psychosocial	feel that his/her personality has changed?	Point to scale/verbalize	0-5 Rating
MD2.	Psychosocial	feel discouraged about his/her future?	Point to scale/verbalize	0-5 Rating
MD3.	Psychosocial	have no interest in other people or activities?	Point to scale/verbalize	0-5 Rating
MD6.	Psychosocial	feel withdrawn from other people?	Point to scale/verbalize	0-5 Rating
MD7.	Psychosocial	have little confidence in his/herself?	Point to scale/verbalize	0-5 Rating
E2.	Energy	feel tired most of the time?	Point to scale/verbalize	0-5 Rating
E3.	Energy	have to stop and rest often during the day?	Point to scale/verbalize	0-5 Rating
E4.	Energy	feel too tired to do what you wanted to do?	Point to scale/verbalize	0-5 Rating
FR7.	Psychosocial	feel that s/he were a burden to his/her family?	Point to scale/verbalize	0-5 Rating
FR9.	Communication	feel that his/her language problems interfered with his/her family life?	Point to scale/verbalize	0-5 Rating
SR1.	Psychosocial	go out less often than s/he would like?	Point to scale/verbalize	0-5 Rating
SR4.	Psychosocial	do his/her hobbies and recreation less often than s/he would like?	Point to scale/verbalize	0-5 Rating
SR5.	Psychosocial	see his/her friends less often than s/he would like?	Point to scale/verbalize	0-5 Rating
SR7.	Physical	feel that his/her physical condition interfered with his/her social life?	Point to scale/verbalize	0-5 Rating
SR8.	Communication	feel that his/her language problems interfered with his/her social life?	Point to scale/verbalize	0-5 Rating

# APPENDIX I

## SAQOL-39 Scoring Form

Name: \_\_\_\_\_ d.o.b.: \_\_\_\_\_ A: \_\_\_\_\_ Date: \_\_\_\_\_

**SAQOL-39 Scoring Sheet**

**DURING THE PAST WEEK** (Repeat as in SAQOL-39)

Item ID	How much trouble did you have (Repeat before each item or as necessary)	Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all	Domain scores			
							Physical	Comm.	Psycho-social	Energy
SC1.	preparing food?	1	2	3	4	5				
SC4.	getting dressed?	1	2	3	4	5				
SC5.	taking a bath or shower?	1	2	3	4	5				
M1.	walking? (If respondent can't walk, circle 1 and go to question M7)	1	2	3	4	5				
M4.	keeping your balance when bending over or reaching?	1	2	3	4	5				
M6.	climbing stairs?	1	2	3	4	5				
M7.	walking without stopping to rest or using a wheelchair without stopping to rest?	1	2	3	4	5				
M8.	standing?	1	2	3	4	5				
M9.	getting out of a chair?	1	2	3	4	5				
W1.	doing daily work around the house?	1	2	3	4	5				
W2.	finishing jobs that you started?	1	2	3	4	5				
UE1.	writing or typing, i.e. using your hand to write or type?	1	2	3	4	5				
UE2.	putting on socks?	1	2	3	4	5				
UE4.	doing buttons?	1	2	3	4	5				
UE5.	doing a zip?	1	2	3	4	5				
UE6.	opening a jar?	1	2	3	4	5				
L2.	speaking?	1	2	3	4	5				
L3.	speaking clearly enough to use the phone?	1	2	3	4	5				
L5.	getting other people to understand you?	1	2	3	4	5				
L6.	finding the word you wanted to say?	1	2	3	4	5				
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5				

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**DURING THE PAST WEEK:**

Item ID	Did you (Repeat before each item or as necessary)	Definitely yes	Mostly yes	Not sure	Mostly no	Definitely no	Physical	Comm.	Psycho-social	Energy	
T4.	have to write things down to remember them, (or ask somebody else to write things down for you to remember)?	1	2	3	4	5					
T5.	find it hard to make decisions?	1	2	3	4	5					
P1.	feel irritable?	1	2	3	4	5					
P3.	feel that your personality has changed?	1	2	3	4	5					
MD2.	feel discouraged about your future?	1	2	3	4	5					
MD3.	have no interest in other people or activities?	1	2	3	4	5					
MD6.	feel withdrawn from other people?	1	2	3	4	5					
MD7.	have little confidence in yourself?	1	2	3	4	5					
E2.	feel tired most of the time?	1	2	3	4	5					
E3.	have to stop and rest often during the day?	1	2	3	4	5					
E4.	feel too tired to do what you wanted to do?	1	2	3	4	5					
FR7.	feel that you were a burden to your family?	1	2	3	4	5					
FR9.	feel that your language problems interfered with your family life?	1	2	3	4	5					
SR1.	go out less often than you would like?	1	2	3	4	5					
SR4.	do your hobbies and recreation less often than you would like?	1	2	3	4	5					
SR5.	see your friends less often than you would like?	1	2	3	4	5					
SR7.	feel that your physical condition interfered with your social life?	1	2	3	4	5					
SR8.	feel that your language problems interfered with your social life?	1	2	3	4	5					
SAQOL-39 Mean score		Add all items and divide by 39									
Physical score		(SC items+M items+W items+UE items+SR7)/17									
Communication score		(L items+FR9+SR8)/7									
Psychosocial score		(T5+P items+MD items+FR7+SR1+SR4+SR5)/11									
Energy score		(T4+E items)/4									

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APPENDIX J  
Visual Scale for SAQOL-39



**No trouble at all**

**5**

**A little trouble**

**4**

**Some trouble**

**3**

**A lot of trouble**

**2**

**Couldn't do it at  
all**

**1**



APPENDIX K  
Visual Scale for SAQOL-39 - Alternative

<b>Definitely No</b>	<b>5</b>
<b>Mostly No</b>	<b>4</b>
<b>Sometimes/ Not Sure</b>	<b>3</b>
<b>Mostly Yes</b>	<b>2</b>
<b>Definitely Yes</b>	<b>1</b>



APPENDIX L  
Interview Visual Scale



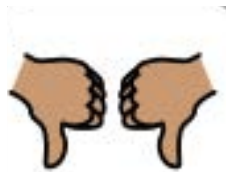
**5**

**4**

**3**

**2**

**1**



APPENDIX M  
Visual Aid for PWA QoL Interview Question

