WORKING MEMORY CAPACITY AND SUBJECTIVE COMMUNICATION DIFFICULTIES IN HIGH-LEVEL APHASIA

Robert Benjamin Cavanaugh

A thesis submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Science in the Department of Allied Health Sciences in the Division of Speech and Hearing Sciences.

Chapel Hill
2015

Approved by:

Katarina L. Haley

Adam Jacks

Prudence Plummer

Antoine L. Bailliard

ABSTRACT

Robert Benjamin Cavanaugh: Working Memory Capacity and Subjective Communication Difficulties in High-Level Aphasia
(Under the direction of Katarina L. Haley)

This study sets out to assess working memory capacity in people with high-level aphasia, who score above the threshold for disordered on standardized assessments but continue to report everyday communication challenges. Additionally, we collected subjective reports of everyday communication difficulties experienced by people with high-level aphasia. These reports were analyzed qualitatively to determine patterns across participants and identify potential sources of assessment and intervention. Five people with high-level aphasia and five neurologically healthy controls completed short-term and working memory tasks and participated in a semi-structured interview. Results indicate that short-term and working memory are impaired for at least some people with high-level aphasia and that digit span tasks have potential as sensitive measures for working memory impairment in high-level aphasia. Furthermore, people with high-level aphasia report salient communication difficulties, reduced social participation, difficulties returning to work, and a keen awareness of their persisting impairments. Implications for assessment and intervention are discussed with relation to both reduced working memory capacity and subjective communication difficulties reported by people with high-level aphasia.

ACKNOWLEDGEMENTS

I cannot express enough gratitude to the people who contributed to this study. Many thanks to the extraordinarily helpful and accessible members on my committee, Dr. Katarina Haley, Dr. Adam Jacks, Dr. Prudence Plummer, and Dr. Antoine Bailliard. Thank you, to the participants who kindly donated their time and effort. To Amanda Cardo, whose constant reassurance and technical expertise I could not have gone without. Lastly, I would like to thank my parents, Jim and Deb Cavanaugh, sister Katie, and the many other family members who have supported me over the years and encouraged me to never stop learning.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

A-FROM	Living with Aphasia; Framework for Outcome Measurement
ALA	Assessment for Living with Aphasia
BDS	Backward Digit Span
FDS	Forward Digit Span
LPAA	Life Participation Approach to Aphasia
LS	Listening Span
MOCA	Montreal Cognitive Assessment
QVSFS	Questionnaire for Verifying Stroke Free Status
SAQOL-39	Stroke and Aphasia Quality of Life Scale
SLUMS	St. Louis University Mental Status Exam
TONI-4	Test of Non-Verbal Intelligence 4
WAB-R	Western Aphasia Battery – Revised
WS	Word Span

CHAPTER 1: BACKGROUND AND RATIONALE

Introduction

Despite scoring above the criterion for 'normal' on standardized assessments, many individuals with aphasia report being troubled by communication difficulties (Armstrong, Fox, & Wilkinson, 2013). Experienced speech-language pathologists recognize these subjective complaints and appreciate that they are not captured by most aphasia batteries. However, few studies have sought to characterize the difficulties they report. Clinically feasible procedures for identifying underlying impairments or objectively validating the complaints are also sparse (Frankel, Penn, & Ormund-Brown, 2010). The vast majority of aphasia research focuses on more severe and easily identified aphasia presentations. In contrast, evidence-based evaluative resources for high-level aphasia are limited (Cruice, Worral, & Flickson, 2006; Marshall, 1993; Jaecks, Hielscher-Fastabend, & Stenneken, 2012).

Even if identified, very mild cases of aphasia are also likely to present treatment challenges to clinicians who have less experience with this patient population and a limited evidence body from which to derive treatment methods (Armstrong, Fox, & Wilkinson, 2013). Sensitive assessment tools are necessary to improve the identification of persisting language difficulties after brain injury and to provide direction for researching treatment outcome measures for high-level aphasia (Kemper, McDowd, Pohl, Herman, & Jackson, 2006; Frankel, Penn, & Ormund-Brown 2010).

Defining High-level Aphasia

McNeil and Pratt (2001) described a need for explicit definitions of aphasia within the aphasia literature. One definition by Rosenbek, LaPointe, and Wertz (1989, p. 53) offers a strong general definition of aphasia and a starting point for a defining high-level aphasia. They write:

> *Aphasia is an impairment, due to acquired and recent damage of the central nervous system, of the ability to comprehend and formulate language. It is a multi-modality disorder represented by a variety of impairments in auditory comprehension, reading, oral-expressive language, and writing. The disrupted language may be influenced by physiological inefficiency or impaired cognition, but it cannot be explained by dementia, sensory loss or motor dysfunction.*

If we understand aphasia to follow this definition, then differences in aphasia severity should reflect impairments in the various components of language. Therefore, many standardized aphasia batteries address each language component separately to provide an aphasia diagnosis and severity rating. One such examination, the Western Aphasia Battery – Revised (WAB-R), assesses the components mentioned by Rosenbek and colleagues (1989) and provides an overall score between 0 and 100, the "aphasia quotient" (AQ; Kertesz, 2007). A person's aphasia quotient is then tied to aphasia severity with lower scores indicating greater severity of aphasia. Mild aphasia is generally classified with an aphasia quotient between 76 and 93.8, the cutoff for scoring as not aphasic.

Many individuals who score above the WAB-R's cutoff for aphasia may still retain a clinical diagnosis of aphasia, or at least report communication difficulties that negatively impact their quality of life. Thesis individuals are sometimes referred to as "not aphasic by WAB (NABW)" or as having "residual" or "high-level aphasia" In this paper, we have employed the term "high-

level aphasia" to describe the disorder experienced by these individuals due to the term's use in prior studies and its distinction from "mild" aphasia.

To identify measures sensitive to the complaints of people with high-level aphasia, it is reasonable to start with the complaints of people experiencing this condition. Understanding the person's subjective experiences can identify the challenges necessary to capture their impairment in formal testing. We are not aware of qualitative or survey studies that have been conducted with this population. Cruice, Worral, and Hickson (2006) studied quality of life perspectives for a relatively diverse group of people with aphasia and family members. The study included one person with a high-level aphasia. The woman described by Cruice et al. (2006) had a WAB-R aphasia quotient above the cut-off, at 95.2, yet reported reduce communicative life participation, psychological changes, and reduced quality of life. Clearly, she was still affected by language impairments and was given a clinical diagnosis of aphasia through clinical judgment. A prominent complaint was that communication difficulty increased with fatigue. The daughter also reported that her mother's perception differed from her own. While the daughter viewed her mother as high-level compared to other people with aphasia, her mother viewed her aphasia as a significant disability.

Published personal accounts are another source for preliminary hypotheses regarding high-level aphasia. Dr. Scott Moss, a stroke survivor with a very mild aphasia, wrote of his experience with subtle communication deficits in his book "Recovery with Aphasia" (1972). His experience has been cited in the literature (Wertz, 1978; Jaeks, 2012). Despite his functional recovery, Dr. Moss described difficulty conceptualizing language, reduced ability to participate in social environments due to difficulty keeping up with conversations, and anxiety speaking in demanding and unpredictable settings as particularly affecting his communication. He also

reported difficulty mentally holding on to information to organize and express his thoughts (Moss, 1972). While aphasia is a largely heterogeneous impairment, these accounts provide a starting point for evaluating high-level aphasia.

Many of Dr. Moss' complaints may not be specific to individuals with aphasia, but more general to those who have suffered a brain injury. It is well known that stroke survivors can suffer from cognitive impairments, especially in memory, orientation, and attention without the presence of aphasia (Tatemichi, Desmond, Stern, Paik, Sano, & Bagiella, 1994). Differentiating aphasia from other consequences of brain injury, and stating an explicit definition of high-level aphasia is necessary to maintain consistency between studies (McNeil & Pratt, 2001). Furthermore, separating signs of aphasia from non-disordered language is difficult, and especially exacerbated by normal variations and disfluencies in non-disordered language

Jaecks, Hielscher-Fastabend, and Stenneken (2012) described the challenge of defining very mild aphasias when assessing people with residual aphasia using spontaneous speech analysis. Jaeks et al. defined residual aphasia as having "clear aphasic symptoms" in the acute phase after their stroke, being classified as having no aphasia or residual aphasia according to the Aachen Aphasia Test, and having deficits clinically diagnosed by 2-3 speech-language pathologists at the time of the study. The criteria for a clinical diagnosis used by the SLP's in Jaecks et al. (2012) was not specified.

Given the need for an explicit definition as discussed above, the following criteria form our definition of high-level aphasia. First, participants must have a history of aphasia in the acute phase after their brain injury. Secondly, participants must score above the cutoff for "aphasic" on the Western Aphasia Battery - revised (WAB-R; Kertesz, 2007). Unlike the study by Jaeks et al. (2012), participants were not required to have a current diagnosis of aphasia, since these

judgments are subject to clinician bias and our participants were not required to be participating currently in speech-language intervention.

To date, only a few studies have evaluated assessment tools for high-level aphasia and subsequent impairments. The aforementioned study by Jaeks and colleagues (2012) utilized a detailed linguistic analysis of spontaneous speech measuring information density, syntactic variability, linguistic errors, and cohesion to identify a number of variables sensitive to residual impairment. Participants with aphasia often used open class words and formulaic phrases and experienced phonemic instabilities, semantic paraphasias, and word finding difficulties. Armstrong, Fox, and Wilkinson (2013) compared the discourse semantics and lexical-grammatical content between a person with mild aphasia and her husband in conversation speech. The results indicated that the person with aphasia struggled to add complexity to her discourse, often failing to elaborate, be specific, and make her points with adequate clarity. These studies add to the view that many people who have recovered from aphasia per standardized assessments still have meaningful communication difficulties. They also show that discourse analysis can be useful for identifying communication impairments in people with mild and possibly high-level aphasia.

Unfortunately, the use of complex speech sample analysis is not feasible in many clinical settings due to time constraints, high productivity requirements, and inaccessible analytical tools. Main concept analysis, a simplified method of discourse analysis, shows promise as a sensitive tool for identifying high-level aphasia that fits within the confines of clinical practice. Richardson and Hudspeth (submitted) describe main concept analysis as a sentence level measure that gathers information at the broader, discourse level. The analysis is based on brief

discourse samples and appears to provide reliable diagnostic information regarding discourse abilities without placing a large burden on the clinician with tedious transcription and analysis.

Using the narratives of a large sample of non-clinical speakers, Richardson and Hudspeth (submitted) developed main concept lists for three discourse tasks: the broken window scene, the Cinderella story, and the peanut butter and jelly procedural task (MacWhinney, Fromm, Forbes, & Holland, 2011). These lists are used to gauge performance for people with aphasia by comparing their content with the discourse content of people without neurological history. Richardson, Saunders, Hudspeth, Jacks, Silverman, and Haley (2015) found a strong relationship between performance on discourse production tasks and social integration and quality of life in aphasia as measured by the Assessment for Living with Aphasia (Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen, & Dickey, 2010). In this study, main concept analysis will provide a measure of discourse abilities, possibly differentiating the participants with aphasia linguistically from control participants.

Assessment of High-level Aphasia via Working Memory

It is well documented that people with aphasia have reduced working memory capacities compared to people without brain injury (Wright & Shishler 2005) but few studies have assessed working memory capacity explicitly in people with high-level aphasia. Working memory assessments may be a practical means for identifying high-level aphasia.

Working memory is a construct explaining our ability to temporarily retain and manipulate information (Baddeley, 2003). Popularized by Baddeley's multi-component framework, working memory has a long history in the field of cognitive psychology and a growing research body in relation to aphasia. The original model of working memory created by Baddeley and Hitch

(1986) includes a central executive system that allocates attentional resources to two lower-level slave systems: the visuospatial sketch pad and the phonological loop. The visuospatial sketchpad acts as a short-term storage system for visual and spatial information. The rehearsal and maintenance of verbal information is accomplished by the phonological loop. Baddeley (2003) later added the episodic buffer component as a bridge between the visuospatial sketchpad and the phonological loop and as a link to long-term memory.

The phonological loop component of working memory is responsible for short-term storage of verbal information and is particularly relevant to the study of aphasia. The phonological loop is made up of two subcomponents: the phonological input store and the articulatory rehearsal process. The phonological store acts as the temporary storage holder while the articulatory process functions to maintain information in the phonological store (Baddeley, 2012). When the central executive allocates attentional resources for phonological storage and articulatory rehearsal, these components form the mechanism for the short-term storage of information for immediate recall.

Early studies linked the phonological loop function primarily with language comprehension (Baddeley, 2003), but we speculate that phonological loop impairments likely have negative affects on expressive language as well. It is possible that phonological loop impairment causes the central executive to allocate more attention for language comprehension, thereby constraining attentional resources for language production. Another possibly is that impaired articulatory rehearsal has negative effects on speech production, especially in extended discourse when more preparation and planning of expressive language is necessary. A recent study by Herman, Houde, Vinogradov, & Nagarajan (2013) has linked phonological loop impairments to

damage in Broca's area, the classical neurologically damaged area in aphasia, using magnetoencephalographic recordings.

A large variety of experimental designs and working memory tasks have shown that people with aphasia generally have reduced working memory capacities compared to individuals with no history of neurological injury (Lang & Quitz, 2012; Sung et al., 2009; Mayer& Murray 2012; Martin, Kohen, Kalinyak-Fliszar, Soveri, & Laine, 2011). Differences in working memory capacity between people with aphasia and healthy controls have been found using forward and backward digit span tasks, word span tasks, the n-back task, semantic and synonymy judgment tasks, and reading/listening span tasks (Martin et al., 2011; Mayer & Murray 2012; Wright & Shishler, 2005) As such, working memory capacity is increasingly accepted as a factor in language impairment in aphasia.

While the evidence for reduced working memory capacity in people with aphasia is strong, the extent of working memory's contribution to language impairment is controversial. For one, the relationship between working memory and aphasia, whether causal or parallel, is uncertain (Wright & Fergadoitis, 2012, Frankel et al., 2007). Reduced working memory capacity may contribute to receptive or expressive impairments in aphasia. On the other hand, language impairment and reduced working memory capacity may both be the result of a larger process affected by brain injury. Secondly, some authors attribute working memory deficits to the phonological loop and/or articulatory rehearsal mechanisms (Mayer & Murray, 2012) while others assert that poor working memory capacity is a result of an impaired central executive system and reduced capabilities of attention control (Hula & McNeil 2008). Martin et al. (2005) suggests that both phonological storage and executive function play a role in reduced verbal working memory capacity for people with aphasia.

The picture is further muddied by disagreements on the definition of working memory. Other frameworks, such as those by Hasher and Zacks, Daneman and Carpenter, and Waters and Caplan. employ slightly different mechanisms to describe how working memory functions (Wright & Shisler, 2005). Comparison across studies can be problematic when different models of working memory are used. Furthermore, there are disagreements on what tasks provide the best measures of working memory capacity (Mayer & Murray 2012).

Our current knowledge of working memory capacity of individuals with high-level aphasia is limited. One study of working memory capacity and aphasia included participants who have a clinical diagnosis of aphasia but scored above the criterion on standardized tests. Martin et al.'s (2005) study assessing the relationship between working memory load and the processing of sounds and meanings of words in aphasia included 4 subjects scoring above WAB's 93.8 cutoff. Given the performance by people with high WAB scores, they suggested that "verbal span tasks that vary semantic and phonological content can provide important diagnostic information in cases of mild aphasia" (Martin et al., 2005 p. 488).

Unlike on the simpler tasks that form the basis of standardized assessments such as the Western Aphasia Battery (Kertesz, 2007) or Boston Diagnostic Aphasia Examination (Goodglass & Kaplan, 1983), verbal working memory tasks likely force individuals to engage simultaneously in language and memory processing, rather than focusing on a single aspect (Kemper et al., 2006). The combined cognitive and linguistic demands may better resemble the demands of real-life communicative situations where people with high-level aphasia report difficulties. If working memory capacity is impaired in people with high-level aphasia, then working memory tasks may provide sensitive diagnostic information towards identifying high-level aphasia.

A practical benefit of working memory tasks is that, given their complex demands and design flexibility, they are appropriate for assessment across the lifespan (Mayer & Murray, 2012; Tariq, Tumosa, Chibnall, Perry, & Morley, 2006). They are a component of many well-known cognitive screenings such as the Montreal Cognitive Assessment (Nasreddine et al., 2005), and the St. Louis University Mental Status Exam (Tariq et al., 2006) because working memory capacity is often impaired in the setting of cognitive decline, stroke, traumatic brain injury, and other neurological damage.

Recently, working memory tasks have been used to identify mild cognitive impairment without aphasia due to traumatic brain injury (Johnson, Smith, & Kennedy, 2011). Johnson et al. found that a verbal working memory task was especially sensitive to mild deficits in TBI and suggested that the verbal working memory task used, the listening span, may be a productive clinical tool for assessing mild TBI. Kemper et al. (2006) utilized a dual-task paradigm with stroke survivors, assessing the costs on performance when two independent tasks, such as walking and talking, are performed simultaneously. Similar to working memory tasks, dual-task assessments are generally thought to be cognitively demanding due an increased load on the attention allocation function of the central executive. Participants performed within normal limits on standardized assessments, but poorly on the dual-task assessments, suggesting that stroke survivors are particularly affected when attentional resources are stretched.

The nature of aphasia has presented some unique challenges to those wishing to estimate working memory capacity. Evaluating a cognitive construct using verbal stimuli and responses when language is impaired is inherently complex (Mayer & Murray, 2012; Wright et al., 2007). Some studies have taken steps to reduce the linguistic load of working memory tasks so that language impairment is less likely to affect performance. Examples of task modifications include

using images as stimuli or requiring non-verbal or yes/no responses. Other researchers have controlled their study participants by excluding subjects with severe expressive or receptive impairments (Mayer & Murray, 2012). To our knowledge, however, no study has restricted examination of working memory performance to people with high-level aphasia. Nor has any study evaluated the effect of linguistic load on working memory capacity to determine if a higher linguistic load improves the sensitivity of working memory assessments towards high-level aphasia. In the proposed study, we have elected to use verbal working memory tasks that ask respondents to manipulate words, digits, and other linguistic material. This choice was motivated by our objective to evaluate these tasks as screening tools sensitive to high-level aphasia.

The backward digit span (BDS) is the first of two verbal working memory tasks used in the study. The BDS requires participants to recall increasing lengths of digit series in reverse order. The backward digit span has greater attentional demands compared to a simple, forward digit span, due to the need for articulatory rehearsal as well as mental manipulation of stored information (Baddeley, 2007). Individuals with moderate and mild aphasia generally perform poorly on backward digit span tasks (Laures-Gore, Marshall, & Verner, 2011; Ronnberg, Larsson, Fogelsjoo, Nilsson, Lindberg, & Angquist, 1996; Ween, Verfaellie, & Alexander, 1996). To our knowledge, no studies have used either the forward digit span or the backward digit span to assess individuals with high-level aphasia. The high demands on storage and manipulation of information suggest the backward digit span may be sensitive to impairment also in high-level aphasia. Brevity and simplicity make the backward digit span a practical option as an addition to a larger aphasia battery.

The second verbal working memory task is the 'Listening span' task (Tompkins et al. 1994). The task is a derivative of Meredyth Daneman and Patricia Carpenter's original reading span

task (Daneman & Carpenter, 1980), adapted by Tompkins et al. to assess working memory in people with aphasia and people with right hemisphere disorders. Participants listen to a series of sentences, and make a true/false decision immediately after each sentence. At the end of each series, participants are asked to recall the last word of each sentence. As the task progresses, additional sentences increase the number of words participants are asked to recall. Because of the concurrent semantic judgments and word recall, we hypothesized that the linguistic demand would be significantly higher compared to the backward digit span.

Tompkins et al. (1994) found that the group with left hemisphere brain injury performed significantly worse on the "Listening span" than normal controls. Sixteen of the nineteen participants considered in the left-hemisphere brain injury group had formal diagnoses of aphasia. The listening span has subsequently been used in a limited number of studies looking at aphasia or TBI, and with consistent differences in performance between control and brain-injured groups (Johnson et al., 2011; Friedman & Gvion, 2003; Caspari, Parkinson, LaPointe, & Katz, 1998). The number of recall errors between control and mild TBI groups did not appear to overlap as well, though only a figure of the result is provided (Johnson et al. 2011). While administration time for the listening span may be slightly longer than for the backward digit task, it is clinically feasible and could be a practical assessment tool.

To tease out one possible explanation for differences in performance between the aphasia and control groups, a forward digit task and simple word span task was administered to participants in our study. It is possible that poor performance could be a result of impaired articulatory rehearsal or phonological store alone. However, Tompkins et al. (1994) found relatively little difference between neurologically healthy individuals and people with aphasia on simple span

tasks. We did not anticipate differences between control subjects and people with high-level aphasia.

Differences in nonverbal reasoning are another possible confounding variable. Higher levels of education and higher scores on measures of intelligence have been associated with better performance on working memory tasks in healthy individuals (Conway, Kane, & Engle, 2003). While non-verbal reasoning is a notoriously difficult construct to measure and education may be a proxy for many other factors, we still feel it is important to assess performance on an non-verbal reasoning measure to help establish a thorough profile of each participant. For this reason, we administered the Test of Non-Verbal Intelligence (TONI-4) to all participants to add to the overall cognitive profile for each participant and between groups (Brown, Sherbenou, & Johnsen, 2010). The use of the TONI-4 has been supported over a similar measure of nonverbal reasoning for people with aphasia, the Ravens progressive colored matrices (RCPM) due to a significant relationship between the RCPM's and aphasia severity (Christy & Friedman, 2005).

Communication Difficulties Experienced by People with High-level Aphasia

The negative effects of aphasia, in general, on quality of life and life participation have been well documented (Davidson, Worrall, & Hickson, 2003; Kagan et al., 2008). For people with aphasia, communication impairments constrain participation in daily activities, limit communicative opportunities, and reduce the number of social interactions. People with aphasia may also have reported depression, anxiety, and lowered self-esteem than people without history of aphasia (Cruice, Worrall, Hickson, and Murison, 2010). Differences in quality of life in people with and without aphasia are affected by level of independence, social relationships, and the communication environment (Ross & Wertz, 2003).

Less is known about the daily difficulties and quality of life of people with high-level aphasia, especially outside of the impairment domain. Some people with high-level aphasia have described difficulties with word finding and comprehension. Self-reports of difficulties and performance in conversational settings in prior case studies suggest that quality of life is most impacted socially for people with mild aphasia, especially in conversational speech, conversation in groups, and during arguments (Fox, Armstrong & Boles, 2010; Martin et al., 2005; Armstrong, Fox, & Wilkinson, 2013).

Life participation treatment approaches for aphasia are increasingly popular and are appropriate for people with high-level aphasia given their broad scope with regards to communicative life participation and flexible approach towards social communication (LPAA Project Group, 2000; Kagan, & Simmons-Mackie, 2007; Duchan, Linda, Garcia, Lyon, & Simmons-Mackie, 2001) Characterizing the difficulties reported by individuals with high-level aphasia under a life participation model should provide a holistic insight into the types of difficulties experienced by this population. By understanding the challenges of people with high-level aphasia, we can identify more sensitive impairment level metrics.

One such framework recently developed is the *Living with Aphasia: Framework for Outcome Measurement* (A-FROM). The A-FROM is meant as an aphasia friendly framework for assessment and intervention, compatible with the World Health Organization's International Classification of Functioning, Disability, and Health (ICF; Kagan et al., 2008; World Health Organization, 2001). One desired outcome of the framework is to improve intervention planning to maximize rehabilitation outcomes for people with aphasia (Kagan 2011). The A-FROM is comprised of four domains: participation in life situations, communication and language environment, language and related impairments, and personal identity, attitudes, and feelings.

The four domains intersect and overlap to form "life with aphasia." and each domain provides a target for assessment and intervention to improve overall quality of life for people with aphasia (Kagan et al., 2008). For example, speech-language pathologists might identify environmental barriers to life participation and target those environmental factors in intervention.

One benefit of the life participation approach is that it is intended to provide information regarding the ultimate outcomes of aphasia therapy, such as return to work, life satisfaction, and community reintegration (Kagan et al., 2011; Hinckley, 2002). One outcome of high importance to many people with mild aphasia is being able to return to work. While many patients, speech-language pathologists, and employers may assume people with milder aphasias will be more succesful in the work environment than those with more severe aphasias, this assumption is not supported by the limited literature available. Hinckley (2002) found that only one of three prior studies detected a significant relationship between aphasia severity and return to work. Furthermore, rates for return to work for people with aphasia are lower than the general stroke survivor population and very few people with aphasia in vocational studies have returned the their prior level of employment (Eisenson, 1966; Hatfield & Zangwill, 1975; Carriero, Faglia, & Vignolo, 1987; Rolland, & Belin, 1983; Dawson, & Chipman, 1995). The most recent study examining return to work outcomes in aphasia found a higher return to work rate compared to previous studies, but still only two of fifteen respondents of working age returned to their prior level of work (Hinckley, 2002).

While the research on vocational outcomes for people with aphasia is limited, it is nearly non-existent for people with mild and high-level aphasia. The subject pools of aphasia-related vocational research have largely included people with moderate and severe aphasia (Hinckley 2002; Eisenson, 1966; Hatfield & Zangwill, 1975; Carriero et al., 1987; Rolland, & Belin, 1983;

Dawson, & Chipman, 1995). More severe and non-fluent aphasia types have dominated the subject pools of prior studies. Understanding the difficulties of people with high-level aphasia may also provide evidence to their vocational outcomes and the barriers that impact return to work negatively.

There is a clear need for more information on the difficulties of individuals with high-level aphasia. A few case reports and small studies have explored potential diagnostic and therapeutic methods for people with high-level aphasia (Jaecks et al., 2012; Frankel et al., 2007). For example, Murray, Keeton, and Karcher (2006) found that training attention improved specific attention skills; but that generalization to untrained abilities are "less likely." Armstrong et al. (2013) and Fox et al. (2009) have explored conversational intervention for people with very mild aphasia with generally positive results.

To our knowledge, no studies have gathered a thorough and detailed description of the daily difficulties experienced by this population. Thus, one purpose of the present study was to expand our understanding of the lives of people with high-level aphasia and the difficulties they experience on a daily basis. This information will hopefully provide validation for other people with high-level aphasia, improve clinical services, and provide a substantial building block for future research.

Research Questions:

1. Do verbal working memory tasks differentiate between people with high-level aphasia and people with no history of neurological damage?
2. How do people with high-level aphasia characterize their difficulties with spoken language comprehension and production?

CHAPTER 2: METHOD

Participant Recruitment

Individuals with aphasia were recruited from the UNC Department of Allied Health Sciences Stroke Registry, medical facilities within the Raleigh-Durham-Chapel Hill, NC region, and through information distributed to participants in other research studies at UNC-Chapel Hill. Recruitment materials called for participation by people who had a stroke and aphasia, had "gotten much better," but "still have some trouble communicating." All participants with aphasia were medically stable and at least 6 months after injury with a history of only one acute brain injury. Inclusion criteria for aphasia severity was limited to scores of 93.8, and above on the Western Aphasia Battery-Revised (Kertesz, 2007). Past medical history in relation to aphasia was documented if available. Comorbid diagnosis of apraxia of speech or dysarthria was allowed, provided that the AOS or dysarthria were characterized as mild.

Initially, spouses and similar-aged siblings of individuals with aphasia were asked to participate as control participants in the survey. Additional participants for the control groups were recruited from the UNC Department of Allied Health Sciences Stroke Registry, which includes individuals who want to participate in research but have no past history of CVA, and through dissemination to participants in other UNC laboratories who had expressed an interest to be contacted for other studies. Participants were also recruited from the greater Chapel Hill, NC community.

Participants

Five individuals with past diagnosis of aphasia as a result of cerebrovascular accident (N=4) or focal traumatic brain injury (N=1) were enrolled in the study. There were also five individuals with no history of neurological disease, matched for age and education, in a control group. A review of medical records determined time post onset and verified aphasia diagnosis. All participants were fluent English speakers.

Two potential participants with aphasia were excluded from the study. One was excluded due to a high level of fatigue that hindered her ability to complete the experimental protocol. Another did not meet the criteria set forth for high-level aphasia - due to a lack of aphasia in the acute phase after stroke. Because two individuals with aphasia were excluded, one additional control participant was excluded to create even groups. The excluded control participant matched the least in age and education for any participant with aphasia. No participant, in either group, had a medical history of dementia, or any other neurological condition. All participants passed a hearing screening and reported functional vision.

See Table 2 for the age and education of both participant groups. Both groups are notable for high levels of education with seven post-graduate degrees overall and all participants completing at least some college. Two participants in each group had a Ph.D. Two participants in the control group and one in the aphasia group had master's degrees. The high-level aphasia group ranged between 48 and 64 years of age with an average of 51.8 years while the control participant group ranged between 53 and 68 years of age with an average of 55.6 years.

All five participants with high-level aphasia scored above the WAB-R cutoff of 93.8 (range 94.7-99.2) Medical records of all five participants verified initial diagnosis of aphasia in the acute phase after stroke. (See tables 1 and 2 for participant demographic information)

A1 was a 48 year-old male twenty-five months post-onset of left internal carotid artery dissection leading to a left MCA infarct. He initially presented with expressive language difficulties and also presents with mild dysarthria and right hemiparesis.

A2 was a 58 year-old male twenty-nine months post-onset left distal MCA, likely atherothrombotic. A2 initially presented with trouble expressing himself on the day of admission and with word finding difficulties and some replacement errors during further assessment. Like A1, he had a diagnosis of mild dysarthria and right hemiparesis.

A3 was a 58 year-old male, 115 months post-onset of left internal carotid artery dissection leading to a left MCA infarct. He presented with word finding difficulties in the acute phase after stroke and, like A1 and A2, carried a diagnosis of mild dysarthria and right hemiparesis.

A4 was a 64 year-old male twenty-five months post-onset of left MCA CVA that was likely embolic. He initially presented with some word searching as well as difficulties with word association and getting his words out. A history of homonymous hemianopsia was noted in his acute stage after stroke, but later resolved. He had no diagnosis of hemiparesis or dysarthria.

A5 was a 31 year-old female twenty-one months post-onset of traumatic brain injury characterized by a depressed skull fracture in the L temporoparietal region, subarachnoid hemorrhage, and craniectomy. She initially presented with no speech, then aphasia for two weeks, and predominantly apraxia of speech thereafter. A5 had no diagnosis of hemiparesis or dysarthria.

Clinical Testing

Testing took place at the University of North Carolina at Chapel Hill School of Medicine or at the individuals' place of residence. Testing was completed by two Master of Science students

in the Speech-Language Pathology program and was initially supervised by the associate professor and faculty mentor. Testing took approximately 70-100 minutes in total for both groups. The WAB-R fluency component, interview for communication difficulties, and discourse production analysis were recorded via Nexus-7 tablet for scoring analysis after the session. Audio files were stored, under password, at the Center for Aphasia and Related Disorders Lab at The University of North Carolina at Chapel Hill. Informed consent was acquired prior to participation along with a HIPAA authorization for release of medical records for participants in the mild aphasia group. All control participants passed the Questionnaire for Verifying Stroke Free Status (QVSFS; Meschia, Brott, Chukwudelunzu, Hardy, Brown, Meissner, Hall, Atkinson, & O'Brien, 2000) to rule out past history of CVA.

Language and Cognitive Testing

Tables 3 and 4 provide data for clinical testing for participants with high-level aphasia and control participants. All participants were first given the AQ portion of the WAB-R (Kertesz, 2007) to rule out more severe aphasia. The WAB-R fluency subtest was recorded to ensure accurate scoring of the fluency section. All participants with aphasia scored above the 93.8 cutoff on the WAB. History of aphasia was verified by medical record to ensure that they met the inclusion criteria for the study.

The Test of Non-verbal intelligence (TONI-4) was administered as a measure of non-verbal reasoning. The TONI-4 has been demonstrated as an effective measure for both brain-injured and neurologically intact individuals (Brown et al., 2010). Table 4 provides results on TONI-4 raw scores. Overlap on scores was noted between groups on the TONI-4. The aphasia group had a mean of 33.4 and range between 27 and 43 while the control group averaged 43.4 with a range

between 34 and 50. A possible relationship was noted between the TONI-4 and performance on the working memory assessments discussed below. Table 10 presents TONI-4 raw scores, forward and backward digit spans, and listening span error scores.

All participants completed the Stroke and Aphasia Quality of Life Scale (SAQOL-39), a stroke-specific healthcare related quality of life questionnaire that asks about physical, psychosocial, communication and energy domains (Hilari, Byng, Lamping, & Smith, 2003). The SAQOL-39 was chosen for its wide range of questions, and especially questions regarding physical difficulties that may adversely impact quality of life (Hilari, Lamping, Smith, Northcott, Lamb, & Marshall, 2009). The questionnaire was presented to each participant who was asked to rate experienced daily activities and feelings within the past week on a 5 point Likert scale. Control participants rated most items as "no trouble at all," while participants with high-level aphasia rated more items as having some difficulty, especially in the physical domain for participants with hemiparesis. (See Tables 3 and 4 for full clinical data)

All participants also completed a discourse production task involving main concept analysis (Richardson and Hudspeth, Submitted). Participants were presented with a laminated sheet of paper with four consecutive images of the "broken window" scene from the AphasiaBank (MacWhinney et al., 2011). Participants were asked to look at the images and "tell a story with a beginning, middle, and an end." Reponses were audio-recorded and later transcribed by a research assistant or the experimenter. Both the experimenter and a research assistant were trained on samples from a prior study for improving accuracy of coding. Responses were coded for inclusion of predetermined main concepts and accuracy of the responses. Main concepts were coded as Accurate Complete (AC), Accurate incomplete (AI), Inaccurate Complete (IC), and Absent (AB) following the guidelines provided by Richardson and Hudspeth (Submitted).

Agreement was calculated at 93%, as the percentage of matching codes for the entire participant pool. Items coded differently were discussed until a consensus was reached. (See Table 5 for Main Concept Analysis data)

A clear difference was not evident between groups on the main concept analysis. Possible scores on the task ranged from 0 to 24. Participants with high-level aphasia scored from 8 to 21 with an average of 13.2 while the control participants ranged from 9 to 21 with an average score of 14.4. High variability characterized the results for the main concept analysis and may have been more stable if we had used additional measures of discourse production via main concept analysis. The main concept analysis task was also the final task of the study, immediately following the short-term and working memory tasks; fatigue may have been a factor affecting performance on the main concept analysis task.

Short-Term Memory and Verbal Working Memory Tasks

Two tasks of short-term memory were administered to all participants in the following order: the forward digit span and then the simple word span (see Appendix B). The forward digit span and word span were administered to estimate the storage capacity of single digits and words in order to rule out impairment due to short-term memory impairment. Both tasks represent simple, short-term memory tasks for their working memory counterparts in this study.

For both spans, participants were instructed to immediately recall a series of digits or words. For the digit span, participants were instructed to repeat the digits in the same order as presented. For the word span, the order of response was not specified. For the word span, 1-2 syllable words were selected on the task for their similarity to target items from the working memory listening span task, simple words with high frequency and generally high imagability. After a list

of words was generated with similarity to each of the working memory targets, each word was assigned a number. A random number generator was then used to select the words for each trial.

Stimuli were presented at a comfortable loudness level via headphones. Prior to administration, the experimenter played a series of similarly calibrated words asking the participant to repeat the word and confirm a comfortable loudness level. The tests were administered from pre-recorded audio samples. The intensity of audio samples was equalized using a custom Praat script (Jacks, 2010; Boersma & Weenink 2013). Both digits and words were presented at one-second intervals with a maximum of 10 seconds provided for a response, before the next trial began. There were two trials for each digit span length and three trials for each word span length. For each trial, participants repeated the stimuli presented through the headphones. Digit and word spans were determined as the highest number of digits or words the participant was able to accurately recall in any one trial at that level, as per instructions on the Weschler Intelligence Test (Wechsler, 2008). The maximum forward digit span attainable was 9 digits and the maximum word span attainable was 5 words.

After the short-term memory tasks, two verbal working memory tasks were administered: the backward digit span and the listening span. (See Appendix B) The backward digit span was administered in the form of pre-recorded audio samples presented via headphones with the same constraints as the short-term memory tasks. Participants were asked to repeat a series of digits back to the examiner in reverse order. Two trials were administered for each level, starting with two digits and stopping when a participant failed to complete both trials correctly accurately. The participant's span was determined with the same method as the forward digit task, as the highest number of digits the participant was able to accurately recall in either trial. The highest backward digit span possible was 8 digits.

Stimuli for the listening span task were replicated from Tomkins et al. (1994). During the listening span task, participants listened to a series of previously recorded sentences, calibrated using the same custom Praat script (Jacks, 2010). They were asked to immediately make a judgment after each sentence on whether or not the sentence made sense. After all sentences in a series were presented, participants were then asked to repeat the last word of each sentence without regard to order. Difficulty increases with the number of sentences presented in a single series. Each level of the listening span task increased by one sentence, and included three series. Participants completed all levels of the task regardless of performance. Similar to Tompkins et al., (1994), participants were given a three second interval between sentences to allow for the true/false decision and a five second interval between each series. Participants were scored on accuracy of the true/false decision and accuracy of sentence-final word recall. Since errors on the true/false decision were rare, they are not reported in this study. Scores could range from 0 to 42 recall errors on the listening span task.

Interview about Communication Difficulties

All participants completed a semi-structured interview about possible communicative challenges experienced by participants in a variety of situations. Participants were given 20 cards with descriptions of daily situations (See Appendix B for full list) and asked to sort the cards into several categories along the question "How difficult is communicating when…" The categories were difficult, somewhat difficult, not difficult, and Not applicable/I don't do that anymore. Participants were prompted to consider a holistic view of communication that includes finding the right words, speaking clearly, understanding others, the amount of effort required for communication, and any anxiety that communication causes.

The scenarios presented on the cards were created from the research team's clinical experiences with people with mild aphasia, accounts of mild aphasia in the research literature, and personal accounts of mild aphasia (Fox, Armstrong, & Boles, 2009; Armstrong, Fox, & Wilkinson 2013; Martin et al., 2005; Jaeks et al., 2012; Moss, 1978). Some activities of daily living (e.g. "When you go shopping") were also chosen to provide a wide range of choices and situations not reported in previous case studies or personal accounts as difficult for people with high-level aphasia.

After the participants sorted each card, the experimenter started with the cards sorted into the "difficult" category (removing the others from view) and placed the cards side by side in front of the participant. If the participant did not place any cards in the difficult pile, the experimenter started with "somewhat difficult."

The participant was then asked to consider importance of each communicative situation, as a method of choosing the order of the discussion. As each card was chosen, the participant was asked "How is communicating difficult when…" Many times, the participant anticipated the question with each additional card and the prompt was no longer necessary. The experimenter discussed up to 10 cards placed in the "difficult," "somewhat difficult," and "not difficult" categories. During discussion of cards placed in the "not difficult" category, participants were encouraged to discuss communication in regards to the importance of that situation since communication in that situation was considered "not difficult". For cards placed in the "not applicable/I don't do that anymore" category, participants were asked if language impairment was related to that card placement.

The experimenter asked follow-up questions about the answers to elicit expanded and more specific responses, but refrained from using leading questions such as "Do you have difficulty

finding the right word" in order to reduce the influence of the experimenter's questions on participant responses. Follow-up questions took the form of open-ended questions such as "Can you be more specific" or "what do you mean by that?" Responses were recorded on a paper form and audio recorded for transcription. Due to technical difficulties, the mild aphasia interview with A1 was only transcribed by hand by the experimenter and an observer. We were thus not able to later check the accuracy of these transcriptions.

Participants were also asked if they currently worked or volunteered and if they wanted to work or volunteer more. If participants answered yes to the latter question, participants were asked to describe what they thought of as the largest barrier to their ability to work or volunteer more. Lastly, participants were asked to rate the questions "How much is aphasia a factor in your life" using a 10 centimeter visual analog scale with "100%" at the top and "0%" at the bottom. Responses for the visual analog scale rating were measured by hand and are reported in Table 3. Participant responses ranged from 1.2cm 8.1cm with an average of 4.5cm and indicate that aphasia is a major factor in the lives of some participants. It is important to note that one participant, A2, perceived this question as "how much do you let aphasia affect your life." His response may not be analogous to the responses of the other participants.

The interview was audio-recorded via encrypted Nexus 7 tablet and the examiner or a research assistant later transcribed interviews. Qualitative analysis was completed using open and focused coding for general patterns and determination of interview themes (Saldaña, 2012).

CHAPTER 3: RESULTS

Verbal Working Memory

Table 9 and Figures 1 and 2 report scores for the short-term memory and working memory tasks. Task performance was fairly homogenous within groups for the digit span tasks while the listening span task was characterized by significant variability within groups.

Exploratory comparisons for verbal working memory were made between groups for the backward digit span and the listening span. Given the small sample size in each group, it should be noted that the results do not support any conclusions about population difference and only offers preliminary data that may spur future research. Also, given that traumatic brain injury and cerebrovascular accident etiologies may differ in their presentation, it may be or may not be informative to include the participant with history of traumatic brain injury. The following results and discussion are written under the assumption that the inclusion of this participant does not change the limited suggestions we can draw from the exploratory data.

Within the limited sample size, there appeared to be a difference in the performance on both digit tasks between groups. We had predicted differences for digits backward and not digits forward. Contrary to our predictions, there was no overlap between the groups for the forward digit span, indicating that performance was likely different between groups. As shown in Figure 1, the control group forward spans ranged between 7 and 8 while the high-level aphasia group spans ranged between 4 and 6. There were expected group differences in the backward digit task:

the backward digit spans ranged between 2 and 5 for the high-level aphasia group and between 5 and 7 for the control group, with one individual in each group scoring a 5.

The word span task had an intentionally low ceiling as it was only intended to rule out short-term memory impairments as a variable for word recall on the listening span task. Most participants scored at ceiling on the word span task with others just below ceiling. Thus we found no differences in the word span between the high-level aphasia and control groups.

The recall errors on the listening span were characterized by high variability within groups and overlap with multiple subjects between groups. Scores for participants with high-level aphasia ranged between 6 and 24 errors with a mean of 16.4 errors on the listening span. Control participants scored between 2 and 14 errors with a mean of 7.4 errors. One participant, A2, chose to not attempt the five sentence level of the listening span task. Therefore, his listening span error score was adjusted by giving him 3 correct responses on each trial on the five sentence level, as 3 sentences was the highest level he was able to complete accurately.

Interview about Communication Difficulties

Qualitative analysis was completed for interviews with participants with high-level aphasia only and included responses to questions related to return to work and comments on the aphasia visual-analog rating scale. The experimenter or a research assistant transcribed interview recordings and each transcript was read and coded multiple times using open and then focused coding with respect to the research question. *In vivo* coding, using a word or short phrase directly from the participant's response, and descriptive coding, summarizing the participants response, were used. Initial open coding was broad, using both *in vivo* and descriptive coding, while focused coding was used to condense number of codes to a manageable size for analysis. A

codebook was created for all codes. Codes then were condensed multiple times with regards for common patterns across transcripts. A final 23 codes were selected and sorted into the domains of the A-FROM framework to organize the reported difficulties under a framework focused on life participation (Kagan et al., 2008; See Appendix C. for the condensed codebook) Reliability and Validity of the coding data was enhanced by review by a second author and discussion of analysis with colleagues. After sorting into categories, codes were analyzed for patterns and themes were created to provide generalizations from the interviews.

Themes were then categorized within the A-FROM framework (Kagan et al., 2008)(See Table 8 for a complete list of themes). The A-FROM was chosen as a structure for coding analysis to view the data in a life-participation approach, and so that discussion of codes and themes would focus on understanding barriers and facilitators of communicative life participation.

Themes within the Life Participation domain include "Participants experience reduced social participation" and "Participants struggle to reenter the workforce and/or engage in other meaningful activities." Personal Identity and Attitude related themes include "Participants feel self-conscious about their impairments" and "Participants feel more emotional." The Language and Community Environment themes are "Attitudes of environment affect communication positive or negatively." Themes within the Language and Speech Impairment domain include "Language use takes preparation," Language use requires focused attention," and "Participants experience salient difficulties with language use." One additional theme, "Participants experience typing difficulties" did not fit into any A-FROM domain, but was mentioned by all five individuals. It was not placed into an A-FROM domain because the reported reason was

related to fine motor control rather than aphasia. In the following, we discuss content within each of these themes.

Life Participation

A majority of participants reported some degree of reduced participation in group or social situations where demands for communicative effectiveness may be higher. A3 described his experience in group situations as such:

If I try to speak to a lot of people at once, then I say I get held up on myself so I don't do this. And I definitely, I don't go much to parties for the very same reason.

Participant A4 reported similar difficulties with social situations:

We went to Thanksgiving in [state] and I met some people that I had never met before. And for me that's a very uncomfortable situation. I'm trying to think of something clever and witty to say and I'm just kind of standing there like…duh.

Characteristics of communication in group situations may also exacerbate the difficulty experienced by people with high-level aphasia, as stated by A2:

I find myself, especially with my Yankee friends who all talk fast, less able to keep up and therefore, well not necessarily shy away, but I tend to only answer certain questions.

Overall, a pattern of reduced participation in group and social situations was evident throughout many interviews.

One element to the reduced social participation reported by participants is a sense of change compared to before the stroke. Participants reported a desire to participate in social situations but were hesitant or unwilling to do so. A3 said, *"I used to love to argue and debate. I used to love to."* And even though he acknowledged significant recovery had occurred, there was still a feeling of loss: "*Now I talk more than I used to, but not as much as before*."

Several participants reported a difficulty reentering the workforce, or finding meaningful activities that they felt they could be successful in. This desire to return to work or get involved in volunteering was particularly evident with A4:

...So I have debated can I go back [to work]? Where am I compared to where I was before I had the stroke? So that's kind of like…I don't know I really don't know. And I've had a lot of boredom so I'd kind of like to do something.

I'd really like to go back to work and do something kind of meaningful even if I couldn't go back to work if I could just do some volunteer work. At one time I was going [to go back to work]…but the jobs they were going to have me doing seemed so mundane. Like taking books and sorting. Pretty mundane stuff. I think I'd have to have a certain amount of interest level." I could go stock shelves at [local store]. I don't really want to stock shelves at [local store].

This participant was not alone in struggling to find a meaningful job or volunteer position that fit his interests and ability level. A3 expressed a desire to return to discussion groups about his academic topic of interest, but reported an inability to participate due to his aphasia:

The reason I haven't been able to is because the only groups like that around here are groups that do that professionally. And so I am not able to get in there and do it. Because not professional. So that's the problem, that's a small problem, but yeah, annoying.

Additionally, this participant was not interested in the topics or activities at the local aphasia group and felt stuck between his prior professional settings and the aphasia group.

A third participant reported success returning to work with a slightly reduced work load, but stopped after some time because he felt that his time was better spent in therapy, which he was receiving from multiple disciplines and with his family. On the other hand, the two participants reported success returning to work. One reported going from a 60+ hour work week to 20-50 hours per week depending on the amount of work and also planning one or two days off during

the work week. The other has returned to a fulltime job in her field of choice and is currently looking at advancing her career through additional school.

Personal Identity and Attitude

Participants' self-consciousness and self-awareness of their speech and language was one of the most often mentioned aspects of their current communication. A2 provided a detailed description of his feelings about his own self-awareness, and linked this self-awareness to reduced communicative participation:

People try to tell me that they really and truly can't hear my aphasia. I can hear it immensely just in my verbiage and the more I have to talk the more I know that eventually everybody is going to know that I have a problem….and so I do become self-conscious, self-aware of my words. And become a little more leery of having to talk very long off the cuff.

All other participants echoed his description of his self-awareness. A5 reported a concern with how her colleagues perceived her speech, but did not believe that she participated less because of this concern:

I think…talking with work colleagues is somewhat difficult because I feel that pressure to be perfect in what I'm saying so it's a little bit different.

A1 summed up the overall impact of his self-awareness on his personal identity, and reported a dislike of being identified as a stroke survivor:

I want to speak-what's the word-not be someone who's had a stroke. I want to talk like I did before. That's the key thing.

Two participants (A1 and A4) reported increased emotion to stimuli that did not previously invoke emotional responses. Though not reported by all participants, it's worth noting that reported very similar changes in their emotional responses as described by A1: "*Emotional issues get to me. I get so emotional with people like I never did before."*

Language and Community Environment

Highly related to the self-consciousness and self-awareness expressed by all participants how participant's communication affected their interactions with the environment. Two participants reported that a lack of knowledge of aphasia adversely impacted communication exchanges. In several instances, A3 reported difficulty with unfamiliar communication partners who did not have a prior knowledge of aphasia: *"A lot of people still think that anything that has to do with the brain being damaged must affect intellect."* He later stated,

When I go places where I don't know anything its hard to make contact with people. And it's hard to get people to accept my language as just being a physical thing, not a mental thing. So its hard for me to talk with them because they wont accept my…my reasoning. I'll say I know what I'm talking about here, they'll say yeah sure. Sot that's not really good….I'm having trouble saying it like I want to, I'm having trouble having people accept it, accept my spoken language

A2 reported similar experiences with unfamiliar partners with no knowledge of aphasia, but also acknowledged, "*if somebody knows what is truly aphasia, they give you all the leeway that you ever need…"* A2 was also the only participant to report successful self-advocacy for his aphasia and the difficulties his aphasia presents.

I try not to excuse away my abilities or inabilities. And if I run into a point when I am having trouble, that that point I say, pardon me my aphasia is kicking in a little bit so I will have difficulties with certain words and if you give me a second or two ill answer your question.

He also stated that he used to give presentations to large groups in his academic field, and continues to do so to some extent. When asked, A2 said that he sometimes discusses his aphasia with the audience before starting his presentation.

Language Impairment

Participants reported a variety of difficulties that were categorized into the impairment domain, but three broad themes emerged from the interviews. First, language use requires preparation. Four of the participants reported some degree of increased preparation for communication, whether for conversational speech or for other communicative purposes, such as work meetings or larger presentations. A1 reported that conversations and presentations both required more effort and concentration:

I have to think about what I'm going to say and the words I'm going to use…I have to slow down and I have to write down what I'm going to say. Can't just say it. I have to do dry runs all the time when before I never had to do it.

A2 reported preparing more for his presentations that before his stroke, but that he was much more concerned about communication he could not prepare for beforehand:

So I go to the [conference] and I presented my research. And what I had prepared was very easy. But what I didn't prepare for was other people's questions. And so I ran into small difficulties.

A5 also reported increased preparation for meetings to make sure that she communicates her message clearly and that *"I don't get stuck being unclear."*

Similar to needing preparation, participants also reported that language use requires focused attention. Several participants reported an inability to multi-task since their stroke as well. Two

participants, (A1 and A4)explicitly addressed their difficulty doing several things at once, one stating:

I used to be pretty good at multitasking and keep several things going on at the same time. Now, if I don't concentrate on what I'm doing, I'm going to forget and then slip off to the side and then an hour later I'm like oh yeah I'm supposed to be doing this.

A5 also reported increased attention needs for successful communication:

If I'm going to convey something clearly, I need to be fairly focused on it. Not to say that I can't multi-task but more so than before. For example, if I were watching TV and I'm on the computer and [my partner] asks me a question, I really have to listen to him in order to answer it. So that's a definite change.

Beyond needing more time and focus for successful communication, participants reported a variety of salient difficulties with language use. A3 described difficulties picking the words that express his thoughts most accurately as well as being unsatisfied with the dysfluencies in his speech: *"my words and not fluent, the language is not nice…It comes out in parts and pieces."* A3 also expressed a struggle to express themselves clearly and effectively when arguing or debating: *"Well I can get a message across no problem, but I can't argue a point. I can't try to make, I find it hard to stick to a point and make an argument."* A4 stated similar challenges:

I feel like at once time I could make a pretty good point. I feel like I get jammed up now I don't feel like I'm expressing the point clearly to where I put myself in a position that I'm winning, I feel like I'm not doing well.

Other Patterns

One last pattern that was apparent with all participants, though for a variety of reasons, was a difficult with typing and/or electronic communication. Three participants, A1, A2, and A3, reported difficulty typing due to hemiparesis. A4, despite not having any hemiparesis, reported he is now "hunting and pecking" for the keys whereas he was typing much quicker before his

stroke. A5 reported that she sometimes found herself misspelling words, “my brain thinks faster than I can clearly type,” more frequently than before the injury.

Vocational Outcomes & Aphasia Visual-Analog Rating

At the end of each interview, we asked each participant about their experiences with returning to work – whether they had returned to work and if they were working as much as they wanted. If they said that they were working less than desired, we also asked them to discuss their largest obstacle to returning.

Only the youngest participant had returned to work full time. Two participants had made some attempt to reenter the workplace since their stroke, but neither was able to find a satisfactory position. Both reported that their aphasia was their main concern and limitation with finding a satisfactory position. Another participant initially returned to work with slightly reduced hours, but has recently left to focus on therapy and spending time with his family. He reported a desire to go back to work now, but that he has other priorities at this time, including therapy and his family. The fifth participant reported successfully going back to the same job, but with fewer hours than before and more days off for spending time on activities he enjoys.

Ratings for the question “How much is aphasia a factor in your life” varied highly between participants, ranging from 1.2 to 8.1 on a 10cm visual analog scale. “0” represented 0%: “not a factor” and 10 represented 100% a factor in your life. Ratings on the scale clearly did not relate to WAB severity, TONI-4 raw score, SAQOL rating scores, Discourse Production Scores, or the number of scenarios sorted as difficult or somewhat difficult. (See table 3 for individual ratings on the visual-analog scale). For example, participants A2 and A3, who rated the visual analog question at 1.2cm and 8.1cm respectively scored similarly on the WAB (95.2 and 96.1) and

discourse production score (10 and 12). A1 and A4 rated the visual analog question similarly at 6.3cm and 5.0cm respectively, but had noticeably different scores on the SAQOL-39 (4.77 and 3.8) and discourse production task (8 and 15).

Interview: Sorting Differences between Groups

Qualitative analysis of the interview with control group participants is beyond the scope of this study. However, subtle sorting differences were evident on casual inspection relative to the high-level aphasia group. The high level aphasia group was more likely to sort items considered communicatively challenging as more difficult (e.g. when you argue or debate, when you give a speech or presentation, or when you talk with several people at once). In contrast, the control group was more likely to sort items that pertained to socially difficult communication situations (e.g. when you talk about important or emotional issues, when you talk one-on-one with family). In general, the high-level aphasia focused on items that were challenging as a result of their aphasia while control participants focused on communicative situations that were difficult for reasons unrelated to information transfer.

Several control participants needed more encouraging and a reframing of the prompt before beginning sorting the cards because they felt that all scenarios were "not difficult." Two control participants noted that few, if any of the scenarios posed any difficulty, and were then asked to consider the scenarios relative to each other to obtain some rank of communication situations and prompt a further discussion of communication challenges. (See Tables 6 and 7 for sorting selections for participants with high-level aphasia and control participants.)

CHAPTER 4: DISCUSSION

Though we had only anticipated differences on the working memory tasks, people with high-level aphasia scored lower on both digit span tasks than the control participants. Notably, the largest difference occurred on the forward digit span. Our interpretation of the listening span task is limited by high variation in scores for all participants, and the task does not appear to be diagnostically sensitive to high-level aphasia. However, the listening span task did reveal that some participants with high-level aphasia have impaired auditory-verbal working memory.

Qualitative analysis of the semi-structured interview indicated that participants with aphasia experience salient language difficulties and these difficulties have an adverse affect on several aspects of life participation. In the following, we discuss clinical implication of working memory assessments towards identifying high-level aphasia, The implications for results of the qualitative study are also discussed with regard to intervention and ultimate outcomes such as returning to work.

Short-term and Working Memory Performance

To determine if verbal working memory tasks can differentiate people with high-level aphasia and people without a neurological history, we assessed working memory capacity to in people with high-level aphasia and in the control group. Though the small sample size in the study limits the scope of our conclusions, some preliminary hypotheses can be made. First, there was no overlap between the groups in the forward digit task and minimal overlap in the backward digit task. We had predicted some difference on the backward digit task, but we were

surprised by the apparent difference in performance on the forward digit task. It is possible that phonological storage or articulatory rehearsal is sensitive to impairment in people with high-level aphasia, or that poor performance is a function of reduced attentional capabilities. Previous studies have predicted differences in people with mild aphasia on short-term memory span tasks (Martin et al., 2012) and these differences appear to extend to at least some people with high-level aphasia. The presence of such impairments may also be unrelated to aphasia and represent cognitive impairments that have been reported as a result of brain injury without aphasia (Tatemichi et al., 1994).

The ceiling we imposed on the word span inhibited our ability to inspect between group differences. It is possible that between group differences may exist on the word span task and affect performance on the listening span, especially since previous studies have identified differences in short-term memory for people with more severe aphasia compared to healthy controls (Martin et al., 2012). In this study, differences in the forward digit spans between groups suggest that differences exist on the word span between healthy controls and people with high-level aphasia.

We had anticipated the listening span would be particularly sensitive to high-level aphasia due to the increased linguistic load required by the task and previous findings in Tompkins et al. (1994) and Johnson et al. (2011). Preliminary results indicate that the listening span task does not appear to be a functionally useful diagnostic measure due to the high variability in performance for both participants with high-level aphasia and control participants, but may still provide useful information on auditory-verbal working memory for people with high-level aphasia. For at least some participants, short-term verbal recall was not the only factor impacting poor performance on the listening span task. It does appear that the sentence word-final recall and true/false

component in the listening task made an additional contribution to the reduced scores for people with minimal aphasia, suggesting that reduced working memory capacity likely has a central executive and attentional component in addition to impairments in the phonological loop.

Errors on the listening span task for people with aphasia ranged from six to twenty-four (out of forty-two) while errors for control participants ranged from two to fourteen. Several control participants demonstrated difficulty with the listening span while some participants with high-level aphasia were quite successful. Further testing with greater sample sizes may still detect group differences in the mean error rates between people with high-level aphasia and healthy controls, but we suspect the task would still not be diagnostically sensitive.

Several factors may account for the variability on the listening span task. Differences in strategy use were noted within both groups. Some participants appeared to orally rehearse the sentence-final words in order as the trial progressed and give their response in the order of sentence presentation. Other participants organized their responses in reverse order or did not organize responses by order at all. Participants who were able to quickly determine an effective strategy likely had an advantage over those who were not able to find effective strategies. Interpretation of scores is also impacted by a lack of baseline data to determine prior level of function. Scores for prior level of function may be necessary to assess the sensitivity of the task for the population, given the high variability in task performance.

Due to the small sample size, we cannot draw any conclusions about short-term and working memory tasks concerning their diagnostic validity for aphasia. However, it is clear that several individuals, especially participants A1 and A2 exhibited significant impairments in short-term and working memory as measured by the tasks used in the study. It may be useful for clinicians to consider the possibility of short-term and working memory impairments during assessment of

high-level aphasia and understand the effect of such impairments on the effectiveness of intervention. Previous studies have shown that people with mild aphasia perform poorly on working memory tasks and future research should expand their scope to include people who have seemingly recovered from aphasia as well (Martin et al., 2012).

Subjective Communication Difficulties

Overall, people with high-level aphasia reported salient difficulties with expressive and receptive language and that these difficulties have negative consequences on life participation. Many of the reported difficulties echoed those reported by previous studies and other published accounts (Fox, et al., 2009; Cruice et al., 2006, Moss, 1972). In this study, participants with high-level aphasia reported several meaningful language impairments: word-finding difficulties, reduced communicative clarity, and reduced fluency. They also reported that, compared to before their injury, successful communication required additional preparation beforehand, more time while speaking, and additional attention during conversation.

All of these elements impact participants' conversational communication and may be particularly evident in situations which were reported as difficult, such as group conversations and arguments. A number of studies (Martin et al., 2012; Fox et al., 2009; Armstrong et al., 2013; Jaeks et al., 2012) support this notion that language impairment in high-level aphasia leads to salient communication difficulties. Furthermore, the reports of participants in this study add to the growing body of evidence the language impairments of people with high-level aphasia have a tendency to manifest themselves in conversational speech on a daily basis, even if performance on standardized tasks is essentially unaffected.

A holistic look at the themes gathered through qualitative analysis reveals that relatively mild language impairments in people with high-level aphasia can have far-reaching effects on communicative life participation. As predicted by the A-FROM framework, we see a clear connection between language impairments, personal identities and attitudes, communication environments, and reduced life participation. Participants reported salient difficulties with language on a daily basis and persisting communicative needs, at times requiring more focus or time for communication. These difficulties, dysfluences, and/or increased communicative needs may not be readily apparent to the unfamiliar communication partner, but are often painfully obvious to the person with aphasia. The participants' keen self-awareness of impairments appears to impact interactions with familiar and unfamiliar communication partners and may contribute to reduced communicative life participation.

It is unclear whether the self-consciousness of people with high-level aphasia's is helpful in their recovery, communication competency, or life participation. A strong awareness of communication breakdowns can be beneficial in repairing those breakdowns to improve information transfer. However, awareness of anomia, dysfluencies, and reduced clarity may also be an obstacle for people with high-level aphasia if their awareness induces anxiety, nervousness, or dislike of social communication and reduces overall participation.

It is likely that participation in speech-language therapy targeted expressive communication awareness. Though the extent of past therapy participation was not formerly addressed in the study, all participants reported some history of speech-language therapy. It is possible that some of this treatment included coaching to self-monitor language production for imperfections. As a result, treatment may have magnified their self-awareness. Whereas many individuals without aphasia produce dysfluencies, experience anomia, and sometimes lack clarity in everyday

conversation, life participation is generally not affected negatively. However, since these salient communication difficulties appear to influence life participation for people with high-level aphasia, treatment that incorporates strategies for accepting imperfections in communication may be beneficial.

For people with high-level aphasia, past communication experiences and a strong awareness of their communication also appears to have impacted interactions with familiar and unfamiliar communication partners in a variety of settings. All participants reported concern for how they are perceived by communication partners and several expressed a desire to, if possible, hide any sign of impairment from unfamiliar communication partners. Self-consciousness of other's opinions is an understandable anxiety for many people without aphasia. However, participants also reported negative interactions, often characterized by unfamiliar communication partners' perceptions of reduced communicative competence and overall intelligence. Participants who may have experienced negative interactions while communicating may be more aware and self-conscious of their salient language difficulties. Their awareness and self-consciousness may influence them to participate less.

One distinction between the participants with high-level aphasia and people with more severe aphasia is the possibility of hiding the presence of aphasia to communication partners. For people with high-level aphasia, word finding difficulties and paraphasias are less common and grammatical structure is relatively intact. Consequently, the gap between "normal" and impaired communication is much smaller than it is for people with more severe aphasia. The desire and potential to be perceived as someone without aphasia may increase their awareness of difficulties and impact interactions with others negatively.

Disclosure of aphasia appears to improve communication for some people with high-level aphasia, but not all. One participant reported positive outcomes of disclosing his aphasia to communication partners, if those communication partners had an adequate understanding of aphasia. In contrast, another participant reported that most people will still not accept the validity of his communication, despite receiving an explanation of aphasia. Differences in communication partners may explain the contrasting reports of listener reactions to self-advocacy. These participants may also make different assumptions about listener reactions that affect perceptions of communication interactions. The relationship between perceptions of listener reactions and social participation in people with high-level aphasia is one area that warrants future exploration.

Returning to work is one ultimate outcome that posed a significant challenge for several participants with high-level aphasia in this study. Three of the four participants with history of stroke reported at least some difficulty returning to the level of work and the work setting they desired. Those three participants all indicated that aphasia played a significant role in their current decisions not to work. All three felt challenged in their previous work environments and expressed a desire to do something similarly challenging, if they did return to work. Past reports on factors affecting return to work for people with aphasia include aphasia severity, workplace flexibility, social support, motivation, and motor impairment (Hinckley, 2002; Eisenson, 1966; Hatfield & Zangwill, 1975; Carriero et al., 1987; Rolland, & Belin, 1983; Dawson, & Chipman, 1995). The ability to find any job versus the ability to find a desirable job appears was another important distinction for the participants in this study. The availability of desirable work opportunities is likely highly linked to workplace flexibility, social support, and motivation. Given the importance people with high-level aphasia place on the desirability of employment,

further study should focus on the relationship between these factors and their interrelated effect on vocational outcomes.

Work place accommodations likely play a large factor for return to work as well. For example, the participant who was able to return successfully to his previous job was able to adapt his work environment to suit the changes he experienced after his stroke. Similarly, Hinckley et al (2002) reported positive influences of flexible workplace environments towards return to work outcomes. A better understanding of the capacity of people with high-level aphasia to return to their prior level of work and methods of obtaining workplace adaptations may improve return to work rates for people with high-level aphasia.

Prior treatment studies have revealed some value in addressing spoken language production, cognition, and personal strategy use in individuals with mild and high-level aphasia (Fox et al., 2009; Murray et al., 2006; Frankel et al., 2007). For example, Fox et al., (2009 p. 954) used conversational therapy to address goals for a person with mild aphasia to improve the content and clarity of her conversational speech. They also encouraged the person with aphasia to acknowledge communication difficulties with metalinguistic statements, such as "give me a minute" as a strategy to obtain more time for putting her thoughts together. Value may also be added by addressing personal and environmental factors, such as the impact of self-awareness and the influence communication partners have on communication. Improving confidence, acceptance of communication dysfluencies, and the competence of communication partners may contribute to improved life participation.

One source for potential therapeutic methods comes from the stuttering literature. In intervention for stuttering, people who stutter are often counseled to understand that communication partners may have a poor understanding of stuttering, that they should inform

communication partners on the need for additional time, and that the person who stutters has the ability to promote awareness of stuttering and its ramifications (Montgomery, Bernstein Ratner, & Tetnowski, 2006). Furthermore, comprehensive approaches to stuttering intervention may include promoting increased understanding and acceptance of stuttering and "reframing assumptions about listener reactions" (Blomgren, 2010; Montgomery et al., 2006 p.189). Given the self-awareness of people with high-level aphasia and the effect their communication has on others, they may benefit from a better understanding of listener reactions, improved communication partner competence, and a general acceptance of dysfluency. Broadly speaking, these approaches may be helpful in lessening personal and environmental factors that adversely impact communicative life participation for people with high-level aphasia with or without improvements in language performance. If the goal for the person with high-level aphasia is to improve life participation in social settings and enhance their ability to return to work or get more involved in meaningful activities, intervention should account for the influence of all factors affecting life participation.

While it is not possible to draw any conclusions, we can speculate about the relationship between reported communication difficulties and working memory capacity of people with high-level aphasia. Most models of working memory operate on the idea that attentional capacity is finite. We saw that many participants with high-level aphasia may dedicate attentional resources towards feelings of self-consciousness and, at times, towards avoiding disclosure of any communication difficulties. People with high-level aphasia may experience fear or anxiety about being perceived by their communication partners as having a disability; this fear and anxiety consumes attentional resources. By dedicating some attention to these non-communicative functions, participants may take away from the resources available for communication.

Limitations

Due to the narrow window of time available for this study and difficulty identifying people with high-level aphasia, we were unable to enroll a sufficient number of participants to truly answer our research question on working memory capacity. The small sample size prohibited any strong conclusions about the sensitivity and stability of the short-term and working memory tasks. Future study on people with high-level aphasia should be conducted with a more sufficient sample size to enable statistical analysis.

In reflecting on the qualitative interview process, a number of factors may have influenced the study. The same experimenter conducted the interview with every participant. With each interview, we developed more detailed questions about the nature of daily challenges for people with high-level aphasia. Because we were curious about trends in people with mild aphasia, these more detailed questions may have been more present in interviews with participants conducted later in the study. In future studies we would seek to vary the administrator to reduce experimenter bias and would set out with more concrete rules for how the administrator interacts with participants during the interview to reduce the possibility that questions from the experimenter might influence participant responses.

Our category choice of "difficult," "somewhat difficult," and "not difficult" was likely not ideal for people with high-level aphasia. Many times, a participant placed a situation into the "not difficult" category because they did not ascribe any level of difficulty to the scenario even if was more challenging than before. Instead, we might ask participants to simply rank scenarios from easy to difficult and then discuss the most difficult scenarios.

Last, our use of the A-FROM framework for analysis of coding was motivated by our desire to view reported communication difficulties through a life participation approach. After analysis

and discussion, we felt that use of the A-FROM for analysis may have unnecessarily restricted our interpretation of the interview codes. Future analysis without regard to a specific framework may have improved our conclusions. Despite these potential biases in within the interview and subsequent analysis, we believe that the information gleaned represents valid everyday communicative challenges for the participants.

Conclusion

Both short-term memory and working memory capacity were significantly reduced in at least some people with high-level aphasia. Further study should focus on confirming the presence of short-term and working memory impairments in people with high-level aphasia and assessing the relationship between reduced short-term and working memory capacities and persisting communication impairments. People with high-level aphasia also report meaningful difficulties in all aspects of communicative life participation beyond the impairment domain, despite their high scores on standardized assessments. Reduced social engagement, difficulty returning to work, and keen self-consciousness of impairments are common themes for this population. Practicing clinicians should be aware of the substantial impact of subtle language impairments when designing intervention for people with high-level aphasia and consider how these subtle impairments, personal factors, and the communication environment affect communicative life participation. Further research should be geared toward methods of identifying and eliminating barriers to overall life participation and return to work outcomes that are specific to people with high-level aphasia.

APPENDIX A: TABLES AND FIGURES OF EXPERIMENTAL DATA

Table 1. Demographic Information for Participants with Minimal Aphasia

Subject	Age	Education	Months Post-Onset	Etiology	Location	Initial Aphasia description	WAB AQ	Other Comorbidities
A1	48	Bachelor's	25	L internal carotid artery dissection leading to left MCA infarct	L caudate nucleus, portions of left putamen and globus pallidus and overlying cortex	Expressive Language Difficulties	94.7	Right hemiparesis and mild dysarthria
A2	58	Ph.D.	29	Left distal MCA, likely atherothrombotic	left medial temporal lobe infarct extending into the left posterior limb of the internal capsule	Trouble expressing himself on day of admission. Word finding difficulties and some replacement errors.	95.2	Right hemiparesis, facial droop and mild dysarthria
A3	58	Ph.D.	115	Left internal carotid artery dissection leading to infarct	Left basal ganglia and periventricular white matter secondary to left internal cerebral artery dissection	Word finding difficulties	96.1	Right hemiparesis and dysarthria
A4	64	Some College	25	Left MCA likely embolic	Left parietal and lateral occipital lobes extending into the posterior aspect of the left temporal lobe	A bit of word searching, difficulties with word association and getting his words out	98.9	Right Homonymous hemianopsia
A5	31	Master's	21	Depressed skull fracture L temporoparietal region, subarachnoid hemorrhage, craniectomy	CT: left parietal skull fracture with underlying hemorrhage and edema	Mute initially, then aphasia for two weeks, then predominantly AOS	99.2	Mild Apraxia of Speech

Table 2. Demographic Information for Control Participants and Matched PWA

Subject	Age	Education	Matched Control Subject	Age	Education
A1	48	Bachelor's	C11	53	Master's
A2	58	Ph.D	C4	68	Ph.D
A3	58	Ph.D	C2	68	Ph.D
A4	64	Some College	C6	58	Technical Degree
A5	31	Master's	C12	31	Master's

Tables 3. and 4. Clinical Data for Participants with High-level Aphasia (above) and Control Participants (below)

Subject	WAB AQ	TONI-4 (RAW)	SAQOL Total	SAQOL Physical	SAQOL Communication	SAQOL Psychosocial	SAQOL Energy	Main Concept Analysis	"How much is aphasia a factor in your life?" Rating (0-10)
A1	94.7	29	4.77	4.76	4.71	4.9	4.5	8	6.3
A2	95.2	30	4.7	4.5	4.8	4.9	4.7	10	1.2
A3	96.1	38	4.2	4.41	4.28	4	5	12	8.1
A4	98.9	27	3.8	4.7	4.3	2.5	2.5	15	5.0
A5	99.2	43	4.6	4.9	4.7	4.4	4	21	2.1

Subject	WAB AQ	TONI-4 (RAW)	SAQOL Total	SAQOL Physical	SAQOL Communication	SAQOL Psychosocial	SAQOL Energy	Main Concept Analysis
C11	99.6	43	5	5	5	5	4.75	12
C4	100	50	4.87	5	5	4.5	4.5	18
C2	100	42	4.87	4.82	4.71	4.91	5	9
C6	99.2	34	4.71	5	4.85	4.45	4	21
C12	100	48	5	5	5	5	5	12

Table 5. Main Concept Analysis Codes and Scores for Broken Window Scene

Aphasia Group	A1	A2	A3	A4	A5
The boy was outside	AB	AB	AB	AB	AC
He was playing soccer	AC	AC	AC	AC	AC
The ball breaks the neighbors window	IC	AC	AC	AC	AC
The man is sitting in a chair	AB	AI	AB	AB	AC
The dad was startled	AC	AB	AB	AB	AC
The ball broke a lamp	AB	AC	AB	AC	AB
The man picked up the ball	AB	AC	AC	AC	AC
The man looked out the window	AB	AI	AC	AC	AC
Main Concept Score	8	10	12	15	21
Control Group	C11	C2	C8	C6	C12
The boy was outside	AB	AB	AB	AC	AC
He was playing soccer	AC	AC	AC	AC	AC
The ball breaks the neighbors window	AC	AC	AC	AC	AC
The man is sitting in a chair	AC	AB	AC	AC	AB
The dad was startled	AB	AC	AB	AC	AB
The ball broke a lamp	AB	AB	AC	AB	AB
The man picked up the ball	AB	AB	AC	AC	AC
The man looked out the window	AC	AC	AC	AC	AB
Main Concept Score	12	9	18	21	12

Table 6. Interview Card Sorting Selections for Participants with High-Level Aphasia

	Difficult (13%)	Somewhat difficult (33%)	Not difficult (50%)	N/A
1. When you do several things at once	A4,A3	A1, A5	A2	
2. When you argue or debate	A4, A3	A1, A5, A2		
3. When you write letters, emails, or notes	A4	A3, A5	A1,A2	
4. When you read letters, emails, or notes		A4	A1, A3, A5, A2	
5. When you feel sick or tired		A4, A2	A1, A5	A3
6. When you talk with people you don't know	A4	A2	A1, A3, A5	
7. When you attend social gatherings or parties		A4, A3, A5	A1, A2	
8. When you talk with several people at once	A4	A1, A3, A5, A2		
9. When you are in a new or unfamiliar situation	A4, A3	A5	A1, A2	
10. When you talk with children		A4	A1, A3, A5, A2	
11. When you go out to restaurants		A4	A1, A3, A5, A2	
12. When you attend religious services			A4, A1, A5, A2	A3
13. When you exercise	A4	A5	A1, A3,A2	
14. When you talk one on one with family		A4, A5	A1, A3, A2	
15. When you ask for help or directions	A4	A3, A1	A5, A2	
16. when you talk with former or current work colleagues		A4, A5	A1, A3, A2	
17. When you go shopping		A4	A1, A3, A5, A2	
18. When you talk with healthcare staff (doctors, nurses, and therapists)			A4, A1, A5, A2	A3
19. When you give a speech or presentation	A4	A1, A5, A2		A3
20. When you talk about important or emotional issues	A4	A3	A1, A5, A2	

Table 7. Interview Card Sorting Selections for Control Participants

	Difficult (9%)	Somewhat difficult (31%)	Not difficult (61%)	N/A
1. When you do several things at once	C4, C2	C6, C8	C11	
2. When you argue or debate	C2	C4, C8	C6, C11	
3. When you write letters, emails, or notes		C6, C8	C4, C11, C2	
4. When you read letters, emails, or notes		C6	C4, C11, C2, C8	
5. When you feel sick or tired		C8	C4, C6, C11, C2	
6. When you talk with people you don't know	C4	C8	C6, C11,C2	
7. When you attend social gatherings or parties			C4, C6, C11, C2, C8	
8. When you talk with several people at once		C4, C8	C6, C11,C2	
9. When you are in a new or unfamiliar situation	C4, C2	C6	C11, C8	
10. When you talk with children	C4	C11	C6, C2,C8	
11. When you go out to restaurants		C11	C4,C6, C2,C8	
12. When you attend religious services		C11	C4,C6,C2,C8	
13. When you exercise			C4,C6, C11,C2, C8	
14. When you talk one on one with family	C4	C11, C2, C8	C6	
15. When you ask for help or directions		C11	C4,C6,C2, C8	
16. when you talk with former or current work colleagues		C11, C8	C4,C6,C2	
17. When you go shopping		C11	C4,C6,C2, C8	
18. When you talk with healthcare staff (doctors, nurses, and therapists)		C6, C11,C8	C4, C2	
19. When you give a speech or presentation		C4, C6, C8	C11, C2	
20. When you talk about important or emotional issues	C4	C6, C2	C11, C8	

Table 8. Themes Derived from Qualitative Analysis Categorized by A-FROM

Life Participation	▪ Participants experience reduced social participation ▪ Participants struggle to reenter the workforce and/or engage in other meaningful activities
Personal Identity and Attitudes	▪ Participants feel more emotional ▪ Participants feel self-conscious about their impairments
Environment	▪ Self-advocacy as a solution to environmental concerns ▪ Attitudes of environment affect communication positively or negatively
Language & Speech Impairment	▪ Participants experience salient difficulties with language use ▪ Language use takes preparation ▪ Language use requires focused attention
Other	▪ Participants experience typing difficulties

Table 9. Performance on Short Term Memory and Working Memory Tasks for Participants with High-Level Aphasia (above) and Control Participants (Below)

Subject	Forward Digit Span	Backward Digit Span	Word Span	Listening Span (Errors)
A1	5	2	4	24
A2	4	3	4	20*
A3	5	5	5	21
A4	6	4	5	11
A5	5	3	5	6
C11	7	5	5	3
C4	8	6	5	2
C2	7	7	5	11
C6	7	6	5	14
C12	8	6	5	7

*Adjusted for incomplete listening span task

Table 10. TONI-4 Raw Scores and Performance on Short-Term and Working Memory Tasks, SAQOL-39 Scores, and Main Concept Analysis Scores

Subject	TONI-4	Forward Digit Span	Backward Digit Span	Word Span	Listening Span (Errors)	SAQOL Total	SAQOL Physical	SAQOL Communi-cation	SAQOL Psychosocial	SAQOL Energy	Main Concept Analysis
A1	29	5	2	4	24	4.77	4.76	4.71	4.9	4.5	8
A2	30	4	3	4	20	4.7	4.5	4.8	4.9	4.7	10
A3	38	5	5	5	21	4.2	4.41	4.28	4	5	12
A4	27	6	4	5	11	3.8	4.7	4.3	2.5	2.5	15
A5	43	5	3	5	6	4.6	4.9	4.7	4.4	4	21
C11	43	7	5	5	3	5	5	5	5	4.75	12
C4	50	8	6	5	2	4.87	5	5	4.5	4.5	18
C2	42	7	7	5	11	4.87	4.82	4.71	4.91	5	9
C6	34	7	6	5	14	4.71	5	4.85	4.45	4	21
C12	48	8	6	5	7	5	5	5	5	5	12

Figure 1. Forward Digit Span (DF), Backward Digit Span (DB), Word Span (WS) and Listening Span (LS) Recall Errors: comparisons between groups (Note that "Listening Span" scores are calculated as the number of recall errors)

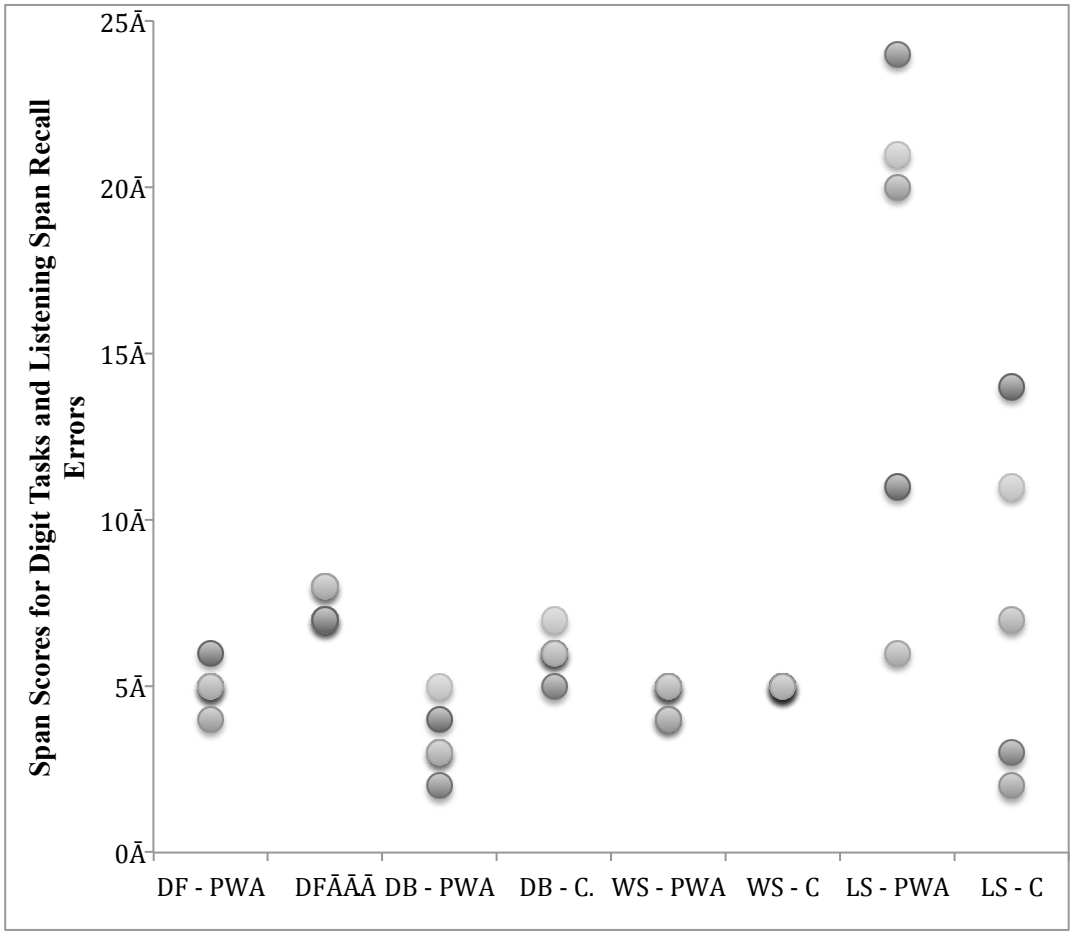


Figure 2. Forward Digit Span (DF), Word Span, Backward Digit Span (DB), and Listening Span Recall Errors (LS): scores by participant

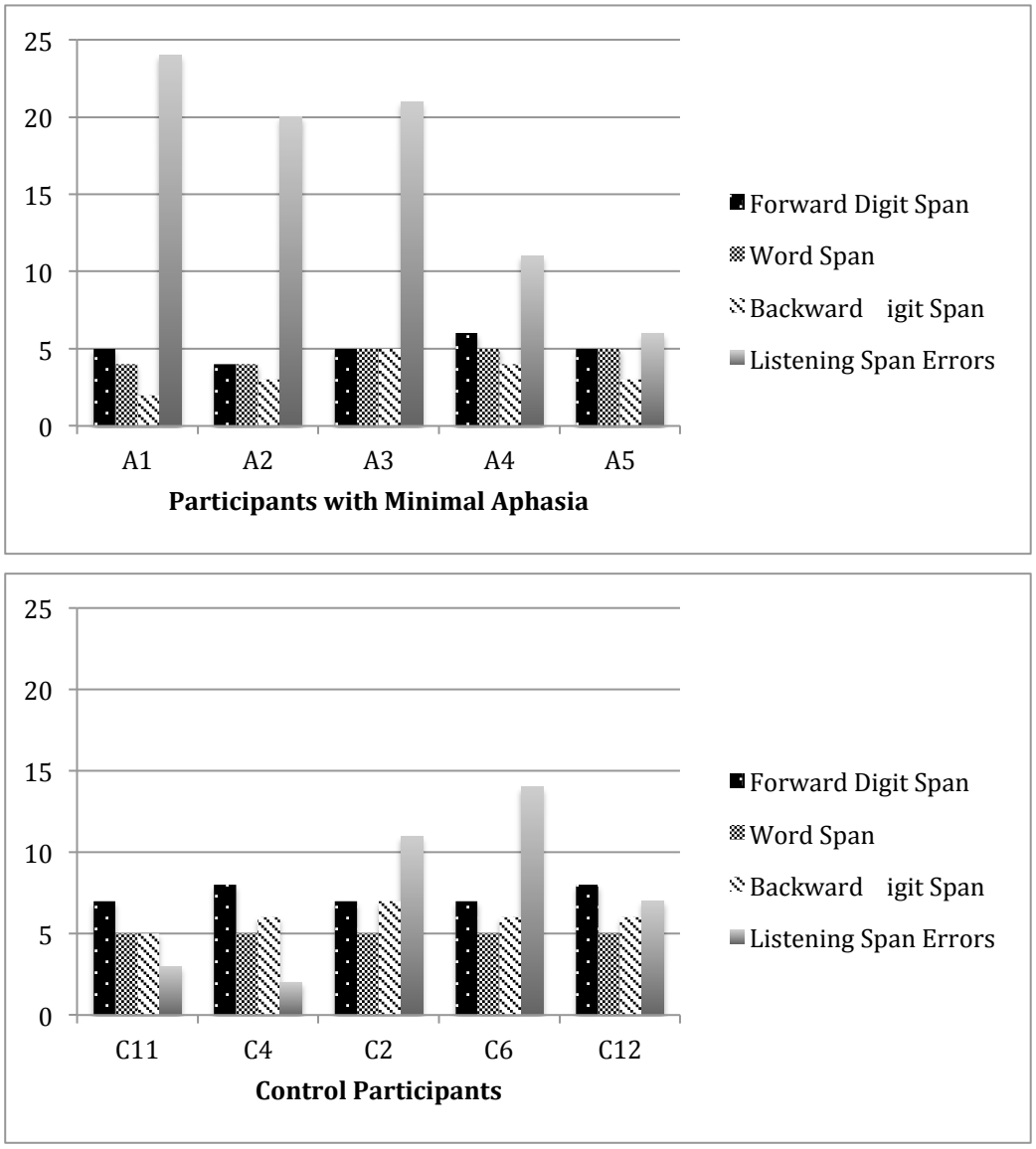
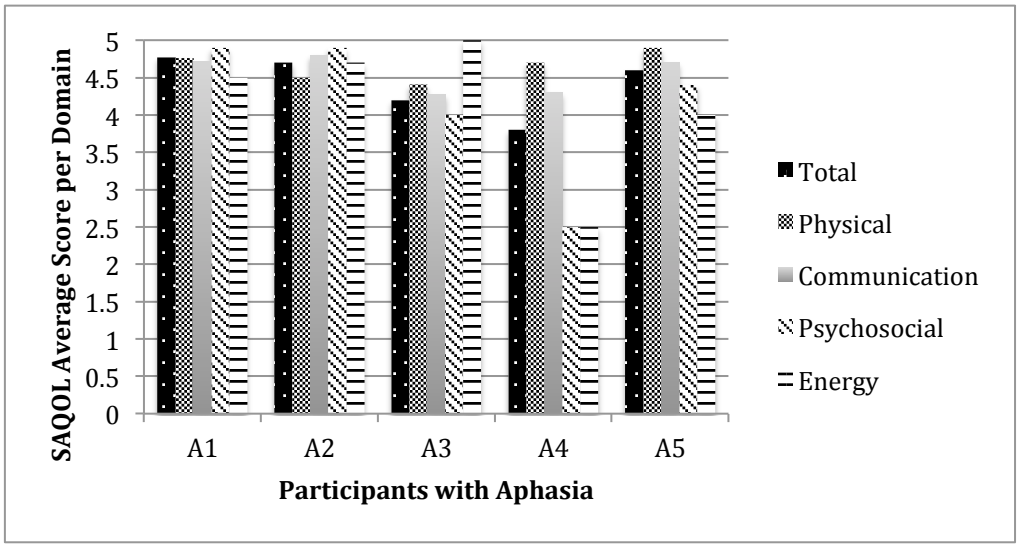
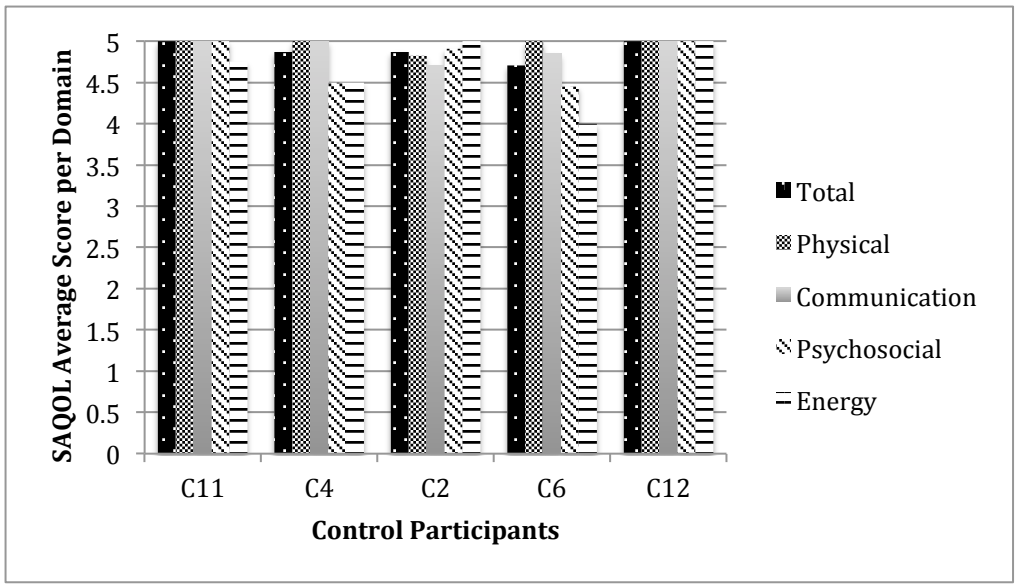


Figure 3. SAQOL Domain Scores for Participants with High Level Aphasia and Control Participants





APPENDIX B. TESTING RESOURCES

Forward Digit Span Task Stimuli

Item	Trial	Test_____ ___
1	1 2	1-7 6-3
2	1 2	5-8-2 6-9-4
3	1 2	6-4-3-9 7-2-8-6
4	1 2	4-2-7-8-1 7-5-8-3-6
5	1 2	5-9-1-4-8-2 3-7-5-8-2-7
6	1 2	6-1-9-8-5-7-3 4-1-7-9-3-8-6
7	1 2	5-8-1-9-2-6-4-7 3-8-2-9-4-6-7-1

Word Span Task Stimuli

3_1	Tigers	Leaves	Bush		
3_2	Scratch	Suits	Sinks		
3_3	Weed	Water	Years		
4_1	Sour	Trucks	Read	Red	
4_2	Jump	Churches	Run	Back	
4_3	Clock	Day	Couch	Toes	
5_1	Sports	Lips	Wet	Yellow	Cloud
5_2	Run	Car	Person	Toast	Ride
5_3	Milk	Vermont	Write	Black	Sing

Backward Digit Span Stimuli

Item	Trial	Test_____ ___
1	1 2	4-9 6-2
2	1 2	9-8-3 6-8-2
3	1 2	5-8-4-7 3-4-8-2
4	1 2	1-7-6-2-8 4-7-5-0-2
5	1 2	3-9-6-4-7-1 2-5-4-8-7-3
6	1 2	8-5-1-9-2-6-4 3-8-2-9-4-6-7

List of Interview Scenarios:

1. When you do several things at once
2. When you argue or debate
3. When you write letters, emails, or notes
4. When you read letters, emails, or notes
5. When you feel sick or tired
6. When you talk with people you don't know
7. When you attend social gatherings or parties
8. When you talk with several people at once
9. When you are in a new or unfamiliar situation
10. When you talk with children
11. When you go out to restaurants
12. When you attend religious services
13. When you exercise
14. When you talk one on one with family
15. When you ask for help or directions
16. When you talk with former or current work colleagues
17. When you go shopping
18. When you talk with healthcare staff (doctors, nurses, and therapists)
19. When you give a speech or presentation
20. When you talk about important or emotional issues

APPENDIX C: CONDENSED CODEBOOK FOR QUALITATIVE ANALYSIS

Life Participation	Community and Language Environment
"Used to do"	Ignorance of aphasia/condition affects communication/perception of PWA
Speak less because of aphasia	Language and Related Impairments
Difficulty reentering professional world	Need to write things down
Difficulty finding appropriate & stimulating activities	Need to prepare more for communication
Desire to do something meaningful	Need to do one thing at a time
Participate less in group/social situations	Slower to respond
Personal Identity, Attitudes and Feelings	Anomia/getting stuck/jammed up
Dislike of identity as stroke survivor	Difficulty explaining complex ideas/arguing/debating
More emotional/easily bothered by emotional stimuli	Increased effort for communication
Bothered/frustrated by expressive language	Work more tiring
Critical, aware, and/or self-conscious of expressive	More mistakes if not focusing on speech
Low Self-Esteem or confidence	Difficulty typing
Concern re: other people think about me	Memory Problems

REFERENCES

Armstrong, E., Fox, S., & Wilkinson, R. (2013). Mild aphasia: Is this the place for an argument? *American Journal of Speech-Language Pathology / American Speech-Language-Hearing Association, 22*(2), S268-78.

Baddeley, A. (2003). Working memory and language: An overview. *Journal of Communication Disorders, 36*(3), 189-208.

Baddeley, A. (2007). *Working memory, thought, and action* Oxford University Press.

Baddeley, A. (2012). Working memory: Theories, models, and controversies. *Annual Review of Psychology, 63*, 1-29.

Blomgren, M. (2010). Stuttering treatment for adults: An update. *Seminar in Speech-Lang, 31*, 272-282.

Boersma, P., & Weenink, D. (2013). *Praat, a system for doing phonetics by computer* (Version 5.3.51 ed.). http://www.praat.org/:

Brown, L., Sherbenou, R. J., & Johnsen, S. K. (2010). *TONI-4, test of nonverbal intelligence* Pro-Ed.

Carriero, M., Faglia, L., & Vignolo, L. (1987).
Resumption of gainful employment in aphasics: Preliminary findings *Cortex,* (26), 667±672.

Caspari, I., Parkinson, S. R., LaPointe, L. L., & Katz, R. C. (1998). Working memory and aphasia. *Brain and Cognition, 37*(2), 205-223.

Christy, E., & Friedman, R. (2005). Using non-verbal tests to measure cognitive ability in patients with aphasia: A comparison of the RCPM and the TONI. *Brain and Language, 95*(1), 195-196.

Clark-Cotton, M., Williams, R., Goral, M., & Obler, L. (2007). Language and communication in aging. *In-Chief: James E.Birren (Ed.), Encyclopedia of Gerontology, 2*, 1-8.

Conway, A. R., Kane, M. J., & Engle, R. W. (2003). Working memory capacity and its relation to general intelligence. *Trends in Cognitive Sciences, 7*(12), 547-552.

Cruice, M., Hill, R., Worrall, L., & Hickson, L. (2010). Conceptualising quality of life for older people with aphasia. *Aphasiology, 24*(3), 327-347.

Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation, 13*(1), 14-24.

Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology, 17*(4), 333-353.

Daneman, M., & Carpenter, P. A. (1980). Individual differences in working memory and reading. *Journal of Verbal Learning and Verbal Behavior, 19*(4), 450-466.

Davidson, B., Worrall, L., & Hickson, L. (2003). Identifying the communication activities of older people with aphasia: Evidence from naturalistic observation. *Aphasiology, 17*(3), 243-264.

Dawson, D. R., & Chipman, M. (1995). The disablement experienced by traumatically brain-injured adults living in the community. *Brain Injury, 9*(4), 339-353.

Duchan, R., Linda, J., Garcia, A. K., Lyon, J. G., & Simmons-Mackie, N. (2001). Life participation approach to aphasia: A statement of values for the future. *Language Intervention Strategies in Aphasia and Related Neurogenic Communication Disorders, 235*

Eisenson, J. (1966). Vocational implications resulting from intellectual and behavioral changes associated with aphasia in adults. *Rehabilitation Literature,* (27), 231-234.

Fox, S., Armstrong, E., & Boles, L. (2009). Conversational treatment in mild aphasia: A case study. *Aphasiology, 23*(7-8), 951-964.

Frankel, T., Penn, C., & Ormond‐Brown, D. (2007). Executive dysfunction as an explanatory basis for conversation symptoms of aphasia: A pilot study. *Aphasiology, 21*(6-8), 814-828.

Friedmann, N., & Gvion, A. (2003). Sentence comprehension and working memory limitation in aphasia: A dissociation between semantic-syntactic and phonological reactivation. *Brain and Language, 86*(1), 23-39.

Goodglass, H., & Kaplan, E. (1983). *Boston diagnostic aphasia examination booklet* Lea & Febiger.

Haley, K., Jacks, A., Richardson, J., & Silverman, M. (2015). Writing and using life-participation goals with people affected by aphasia. *Poster Presented at the Aphasia Access Conferences in Boston, MA. ,*

Hatfield, F. M., & Zangwill, O. L. (1975). Occupational resettlement in aphasia. *Scandinavian Journal of Rehabilitation Medicine, 7*(2), 57-60.

Herman, A. B., Houde, J. F., Vinogradov, S., & Nagarajan, S. S. (2013). Parsing the phonological loop: Activation timing in the dorsal speech stream determines accuracy in speech reproduction. *The Journal of Neuroscience : The Official Journal of the Society for Neuroscience, 33*(13), 5439-5453.

Hilari, K., Byng, S., Lamping, D. L., & Smith, S. C. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): Evaluation of acceptability, reliability, and validity. *Stroke; a Journal of Cerebral Circulation, 34*(8), 1944-1950.

Hilari, K., Lamping, D. L., Smith, S. C., Northcott, S., Lamb, A., & Marshall, J. (2009). Psychometric properties of the stroke and aphasia quality of life scale (SAQOL-39) in a generic stroke population. *Clinical Rehabilitation, 23*(6), 544-557.

Hula, W. D., & McNeil, M. R. (2008). Models of attention and dual-task performance as explanatory constructs in aphasia. *Seminars in Speech and Language, 29*(3), 169-87; quiz C 3-4.

Jacks, A. (2010). Praat: Scripts for clinical acoustics (sound equalization script) [computer program]. chapel hill, NC: The university of North Carolina at Chapel Hill.

Jaecks, P., Hielscher-Fastabend, M., & Stenneken, P. (2012). Diagnosing residual aphasia using spontaneous speech analysis. *Aphasiology, 26*(7), 953-970.

Johnson, S., Smith, K., & Kennedy, M. R. T. (2011). *Which auditory working memory measure is sensitive after brain injury?*. Poster presented at the ASHA Convention, San Diego, CA:

Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., & Dickey, L. (2010). Assessment for living with aphasia. *Toronto, ON: Aphasia Institute,*

Kagan, A., & Simmons-Mackie, N. (2007). Beginning with the end: Outcome‐Driven assessment and intervention with life participation in mind. *Topics in Language Disorders, 27*(4), 309-317.

Kagan, A., Simmons‐Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., . . . Sharp, S. (2008). Counting what counts: A framework for capturing real‐life outcomes of aphasia intervention. *Aphasiology, 22*(3), 258-280.

Kemper, S., McDowd, J., Pohl, P., Herman, R., & Jackson, S. (2006). Revealing language deficits following stroke: The cost of doing two things at once. *Neuropsychology, Development, and Cognition. Section B, Aging, Neuropsychology and Cognition, 13*(1), 115-139.

Kertesz, A. (2007). *The western aphasia battery – revised*. New York: Grune & Stratton.

Lang, C. J., & Quitz, A. (2012). Verbal and nonverbal memory impairment in aphasia. *Journal of Neurology, 259*(8), 1655-1661.

Laures-Gore, J., Marshall, R. S., & Verner, E. (2011). Performance of individuals with left-hemisphere stroke and aphasia and individuals with right brain damage on forward and backward digit span tasks. *Aphasiology, 25*(1), 43-56.

LPAA project group (2000). life participation approach to aphasia: A statement of values for the future. ASHA leader, 5(3). 4-6. <http://www.asha.org.libproxy.lib.unc.edu/publications/ashalinks.htm>.

MacWhinney, B., Fromm, D., Forbes, M., & Holland, A. (2011). AphasiaBank: Methods for studying discourse. *Aphasiology, 25*(11), 1286-1307.

Marshall, R. C. (1993). Problem-focused group treatment for clients with mild aphasia. *American Journal of Speech-Language Pathology, 2*(2), 31-37.

Martin, N., Kohen, F., Kalinyak-Fliszar, M., Soveri, A., & Laine, M. (2012). Effects of working memory load on processing of sounds and meanings of words in aphasia. *Aphasiology, 26*(3-4), 462-493.

Mayer, J. F., & Murray, L. L. (2012). Measuring working memory deficits in aphasia. *Journal of Communication Disorders, 45*(5), 325-339.

McDowell, S., Whyte, J., & D'Esposito, M. (1997). Working memory impairments in traumatic brain injury: Evidence from a dual-task paradigm. *Neuropsychologia, 35*(10), 1341-1353.

Meschia, J. F., Brott, T. G., Chukwudelunzu, F. E., Hardy, J., Brown, R. D.,Jr, Meissner, I., . . . O'Brien, P. C. (2000). Verifying the stroke-free phenotype by structured telephone interview. *Stroke; a Journal of Cerebral Circulation, 31*(5), 1076-1080.

Montgomery, C. S., Bernstein Ratner, N., & Tetnowski, J. (2006). The treatment of stuttering: From the hub to the spoke. *Current Issues in Stuttering Research and Practice,* , 159-204.

Moss, C. S. (1972). Recovery with aphasia: The aftermath of my stroke.

Murray, L. L., Keeton, R. J., & Karcher, L. (2006). Treating attention in mild aphasia: Evaluation of attention process training-II. *Journal of Communication Disorders, 39*(1), 37-61.

Murray, L. (2004). Cognitive treatments for aphasia: Should we and can we help attention and working memory problems? *Journal of Medical Speech-Language Pathology, 12*(3), XXV-XL.

Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., . . . Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society, 53*(4), 695-699.

Richardson, J., Saunders, W., Hudspeth, S., Jacks, A., Silverman, M., & Haley, K. (2015). The relationship between discourse performance and life participation in persons with aphasia. *Aphasia Access Leadership Summit,* Boston, MA.

Richardson, J. D., & Hudspeth, S. G. (2015). Main concepts for three different discourse tasks in a large non-clinical sample (submitted for publication). *Aphasiology,*

Rolland, J., & Belin, C. (Eds.). (1983). *The person with aphasia and the workforce.* In D. Lafond, Y. Joanette, J. Ponzio, R. DeGiovani, & M. T. Sarno (Eds.), Living with aphasia: Psychosocial issues (pp. 223±242). San Diego: Singular Publishing.

Rönnberg, J., Larsson, C., Fogelsjoo, A., Nilsson, L., Lindberg, M., & Angquist, K. (1996). Memory dysfunction in mild aphasics. *Scandinavian Journal of Psychology, 37*(1), 46-61.

Rosenbek, J. C., LaPointe, L. L., & Wertz, R. T. (1989). *Aphasia: A clinical approach* Pro Ed.

Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology, 17*(4), 355-364.

Saldaña, J. (2012). *The coding manual for qualitative researchers* Sage.

Sung, J. E., McNeil, M. R., Pratt, S. R., Dickey, M. W., Hula, W. D., Szuminsky, N. J., & Doyle, P. J. (2009). Verbal working memory and its relationship to sentence‐level reading and listening comprehension in persons with aphasia. *Aphasiology, 23*(7-8), 1040-1052.

Tariq, S. H., Tumosa, N., Chibnall, J. T., Perry III, M. H., & Morley, J. E. (2006). Comparison of the Saint Louis university mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder—a pilot study. *The American Journal of Geriatric Psychiatry, 14*(11), 900-910.

Tatemichi, T. K., Desmond, D. W., Stern, Y., Paik, M., Sano, M., & Bagiella, E. (1994). Cognitive impairment after stroke: Frequency, patterns, and relationship to functional abilities. *Journal of Neurology, Neurosurgery, and Psychiatry, 57*(2), 202-207.

Tompkins, C. A., Bloise, C. G., Timko, M. L., & Baumgaertner, A. (1994). Working memory and inference revision in brain-damaged and normally aging adults. *Journal of Speech and Hearing Research, 37*(4), 896-912.

Wechsler, D. (2008). Wechsler adult intelligence scale–Fourth edition (WAIS–IV). *San Antonio, TX: NCS Pearson,*

Ween, J. E., Verfaellie, M., & Alexander, M. P. (1996). Verbal memory function in mild aphasia. *Neurology, 47*(3), 795-801.

Wertz, R. T. (1978). *Treating mildly aphasic patients: A round table discussion*. Veterans Administration Hospital, Martinez, CA:

World Health Organization (WHO). (2001). *International classification for functioning, disability, and health.* (). Geneva, Switzerland: World Health Organization.

Wright, H. H., & Shisler, R. J. (2005). Working memory in AphasiaTheory, measures, and clinical implications. *American Journal of Speech-Language Pathology, 14*(2), 107-118.

Wright, H. H., Downey, R. A., Gravier, M., Love, T., & Shapiro, L. P. (2007). Processing distinct linguistic information types in working memory in aphasia. *Aphasiology, 21*(6-8), 802-813.

Wright, H. H., & Fergadiotis, G. (2012). Conceptualizing and measuring working memory and its relationship to aphasia. *Aphasiology, 26*(3-4), 258-278.

Yorkston, K. M., Bourgeois, M. S., & Baylor, C. R. (2010). Communication and aging. *Physical Medicine and Rehabilitation Clinics of North America, 21*(2), 309-319.