Stroke and aphasia quality of Life Scale-39: investigating preliminary content validity of picture representations by people with mild to moderate aphasia

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STROKE AND APHASIA QUALITY OF LIFE SCALE-39: INVESTIGATING PRELIMINARY CONTENT VALIDITY OF PICTURE REPRESENTATIONS BY PEOPLE WITH MILD TO MODERATE APHASIA

A Thesis

Submitted to the Graduate Faculty of the Louisiana State University and Agricultural and Mechanical College in partial fulfillment of the requirements for the degree of Master of Arts

in

The Department of Communication Disorders

by

Lea J. Heise-Jensen
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TABLE OF CONTENTS

ACKNOWLEDGMENTS ........................................................................................................... ii

LIST OF TABLES ................................................................................................................... v

ABSTRACT ............................................................................................................................. vi

INTRODUCTION ...................................................................................................................... 1

LITERATURE REVIEW .......................................................................................................... 3
  Characteristics of Aphasia ................................................................................................. 3
  Aphasia and Quality of Life ............................................................................................... 5
  The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) ......................................... 7
  Photographs as Communicative Modifications for People with Severe Aphasia .............. 11
  Pairing High-Context Color Photographs With SAQOL-39 Items ................................... 17
  Aim of the Proposed Study ............................................................................................... 19

METHODS ............................................................................................................................ 21
  Design ............................................................................................................................... 21
  Participants ....................................................................................................................... 21
  Materials .......................................................................................................................... 22
  Procedures ......................................................................................................................... 25
  Reliability .......................................................................................................................... 27

RESULTS ............................................................................................................................... 28
  Data Analysis ..................................................................................................................... 28
  Descriptive Statistics ....................................................................................................... 28
  Item-by-Item Frequency Analysis ..................................................................................... 31
  Response Time Analysis .................................................................................................. 32
  Reliability Measures ......................................................................................................... 33

DISCUSSION .......................................................................................................................... 35
  Summary of Results ......................................................................................................... 35
  Study Limitations ............................................................................................................... 38
  Future Research ................................................................................................................ 39
  Conclusion ........................................................................................................................ 41

REFERENCES ......................................................................................................................... 42

APPENDIX A: ACRONYM DICTIONARY ................................................................................. 47

APPENDIX B: LOWEST RATED ITEMS ................................................................................. 48

APPENDIX C: IRB APPROVAL ............................................................................................. 51
LIST OF TABLES

1. Participant Demographic Information ................................................................. 22

2. *Boston Aphasia Severity Rating Scale* Descriptions ........................................... 23

3. Summary of Descriptive Statistical Analyses .......................................................... 29

4. Item-by-Item Summary of Mean Ratings ≥ 6 ......................................................... 31

5. Mean RTs by Aphasia Severity Level ..................................................................... 32

6. Summary of Mean RTs by Item ............................................................................ 33

7. Inter-Rater Reliability of Aphasia Severity Levels ............................................. 34
ABSTRACT

Speech-language pathologists must consider the clients’ quality of life (QoL) to provide effective and meaningful evidence-based treatment (ASHA, 2005). Quality of life assessment goes beyond language impairments and is often a key part of planning intervention. However, few QoL measures exist for people with aphasia (PWA). The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39; Hilari, 2003) is one of the few valid and reliable measures used to assess QoL in people with mild to moderate aphasia. However, the validity and reliability of the SAQOL-39 has not been established for individuals with severe aphasia who are unable to read and comprehend the written items (Hilari & Byng, 2001). Proxy reports for people with severe aphasia are not reliable and can contribute to misunderstanding of people with severe aphasia and their QoL (Hilari & Byng, 2009). High-context color photographs may access intact linguistic processes in PWA by bypassing their reading deficits (McKelvey, Hux, Dietz, & Beukelman, 2010). Therefore, visual aids may enhance accessibility of written assessments like the SAQOL-39 for people with severe aphasia. Preliminary content validity has been established for high-context color photographs paired with SAQOL-39 items by normal aging adults (Brouwer, 2013). The present study aimed to continue to establish the content validity of the photographs by investigating how 10 adults with mild to moderate aphasia, aged 30-89 years, rated similarities of photographic representations of SAQOL-39 items, rated on a 7-point Likert scale. The present results supported high content validity of photographic representations. The overall mean rating of items was 6.40 and 92% of the photographs were rated a 6 or 7 at least 60% of the time, indicating most people with mild to moderate aphasia rated photographs highly similar to the written questions they were paired with. This study’s results suggest the photographs may make the SAQOL-39 more accessible for people with severe aphasia to self-
report on their QoL. Further research is warranted to investigate accessibility of the photographs among the severe aphasia population.
INTRODUCTION

Speech-language pathologists must consider clients’ quality of life (QoL) to provide effective and meaningful evidence-based treatment (American Speech-Language-Hearing Association [ASHA], 2005). Quality of life assessment goes beyond language impairments and is an integral part of planning intervention for clients based on their personal experiences. However, current QoL measures are limited for use with people with aphasia (PWA). The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39; Hilari, 2003) is one of the few valid and reliable measures used to assess QoL in people with mild to moderate aphasia. However, the validity and reliability of the SAQOL-39 has not been established for individuals with severe aphasia who are unable to read and comprehend the written items (Hilari, Byng, Lamping, & Smith, 2003; Hilari et al., 2009). Often, proxy reports for people with severe aphasia are not reliable and can contribute to misunderstanding of people with severe aphasia and their QoL (Hilari & Byng, 2009).

Language deficits in PWA frequently result from strokes that damage cortical areas supplied by the middle cerebral artery (MCA). These damaged areas affect expressive language, sensory perception, and written and spoken language processes in PWA. However, visual processing of non-linguistic stimuli and general contextual information processing often remain intact (LaPointe, 2012). Research has suggested highly contextualized visual aids such as photographs may bypass linguistic deficits in PWA and make material more accessible to them (Dietz, Hux, McKelvey, Beukelman, & Weissling, 2009; Fox & Fried-Oken, 1996; McKelvey, Hux, Dietz, & Beukelman, 2010; Rose, Worrall, Hickson, & Hoffman; Wilkinson & Jagaroo, 2004). Preliminary content validity has been established for use of high-context color photographs paired with SAQOL-39 items by normal aging adults (Brouwer, 2013).
The current study aimed to extend Brouwer’s (2013) work by assessing the ratings of 10 adults with mild to moderate aphasia aged 30-89 years on how strongly they perceive high-context color photographs to represent SAQOL-39 items, rated on a 7-point Likert scale. It has been established that people with severe aphasia cannot independently comprehend written items on the SAQOL-39; therefore, we must first explore the perceived similarities as judged by people with mild to moderate aphasia (Hilari & Byng, 2009; Hilari, Owen, & Farrelly, 2007; Hilari et al., 2003, 2009). Evidence from Brouwer (2013) suggested strong content validity of photographic representations of written SAQOL-39 items among non-disordered older individuals. Establishing content validity among PWA is a necessary step before the photographic representations can be tested among people with severe aphasia.

Future studies will be necessary to establish the validity of using the photographs in conjunction with SAQOL-39 items for people with severe aphasia to self-report. If studies confirm that photographs are a valid augmentation to the SAQOL-39, it may be possible to measure the QoL of people with severe aphasia. This, in turn, will enable speech-language pathologists to gain a clearer understanding of what life is like for people with severe aphasia. Clinicians will be able to use self-reports to provide more individualized and functional intervention based on client preferences and communication needs.
LITERATURE REVIEW

This study is based on literature describing the limitations associated with PWA, QoL of PWA, limitations of the SAQOL-39 for use with people with severe aphasia, and use of visual communication modifications for people with severe aphasia.

Characteristics of Aphasia

Aphasia is an acquired language disorder that may affect expressive and receptive communication, social functioning, and QoL secondary to focal damage in the left hemisphere of the brain (Chapey, 2008; Papathanasiou, Coppens, & Potagas, 2013). It is multimodal in nature, meaning that any or all language modalities can be impaired. Affected areas include verbal expression, auditory comprehension, writing, and reading (Chapey, 2008). Recovery varies significantly among PWA and depends on many variables. While some PWA recover substantial language capabilities, many experience chronic and severe limitations that interfere with their daily lives (Beukelman & Mirenda, 1998; Chapey, 2008; Hilari, 2011; Hilari & Byng, 2009; Nadeau, Gonzalez Rothi, & Crosson, 2000; Papathanasiou et al., 2013; Parr, 2007).

Cerebrovascular attack (CVA; i.e., stroke) is the leading cause of aphasia although other possible etiologies include traumatic brain injury, brain tumor, or neurological diseases (Beukelman & Mirenda, 1998; Nadeau et al., 2000). Damage to the brain occurs during a stroke due to an interruption of blood flow to the affected area of the cerebral cortex or hemorrhagic bleeding into the brain. Without appropriate blood flow, brain cells in the affected area cannot access nutrients necessary for normal function such as glucose and oxygen (Chapey, 2008). Approximately 1 million people in the United States currently have aphasia and most cases are a result of stroke. It is estimated that approximately 80,000 people will acquire aphasia secondary to stroke each year in the United States (U.S. Department of Health, 2008).
Severity levels. As previously stated, recovery in PWA depends on many variables. However, it is believed that initial severity level is a reliable predictor of recovery (Chapey, 2008; Ross & Wertz, 1999). Some clinicians favor classification systems based on severity levels rather than the classical system based on neuroanatomical lesion location. For example, Beukelman and Mirenda (1998) suggested treatment could be more effective and practical for PWA when clinicians assessed the severity of specific communication impairments before considering specific neuropathology.

Mild aphasia. Individuals with mild aphasia may not display symptoms immediately recognizable by communication partners. People with mild aphasia might be capable of participating in normal conversations in a variety of settings, but may experience communication breakdowns when language is more complex or includes long phrases (Goodglass, Kaplan, & Barresi, 2001; Papathanasiou et al., 2013). Anomia, the inability to express a certain word or phrase the speaker intends to say, is common in many people with mild aphasia and can be a source of frustration between PWA and their communication partners (Nadeau et al., 2000).

Moderate aphasia. Moderate aphasia is often characterized by fragmented language expression and frequent communication breakdowns. People with moderate aphasia tend to display minimal difficulty during conversation about familiar topics, but display some loss of fluency in both expressive and receptive language. They may fail to appropriately convey messages more often, and display more verbal effort, than people with mild aphasia (Goodglass et al., 2001).

Severe aphasia. Individuals with severe aphasia typically demonstrate significant deficits in multiple or all communication modalities. Many people with severe aphasia retain little to no functional expressive language or spoken language comprehension (Goodglass et al., 2001).
People with severe aphasia typically have profound impairments in both expressive and receptive language and are often resistant to traditional speech and language intervention. It is especially important to recognize the deficits experienced by this population because global aphasia is the most common type of aphasia and causes severe language impairments in affected individuals (Garrett & Beukelman, 1995; Johannsen-Horbach, Cegla, Mager, & Scheppe, 1985). The limitations of people with severe aphasia highlight their need for treatment, while their resistance to traditional treatments highlights the need to develop more effective approaches to intervention.

Aphasia and Quality of Life

In addition to multimodal language impairments, PWA often report decreased satisfaction and participation in social activities, difficulty with daily self-care activities, and decreased overall QoL (Cruice, Hill, Worrall, & Hickson, 2010; Cruice, Worrall, & Hickson, 2006; Hilari, 2011; Hilari & Byng, 2001, 2009; Parr, 2007; Ross & Wertz, 2003). Quality of life is defined as “…individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relationship to their goals, expectations, standards, and concerns,” (The WHOQoL Group, 1998, p. 551). Clinicians often refer to this definition from the World Health Organization’s Quality of Life Assessment (WHOQoL) and International Classification of Functioning, Disability, and Health (ICF) frameworks when they describe domains related to QoL (ASHA, 2007; Threats, 2007, 2012; The WHOQoL Group, 1998).

Ross and Wertz (2003) assessed the impact aphasia has on 24 facets of QoL outlined by the World Health Organization. They administered 2 QoL assessments to a group of non-disordered adults and a group of people with chronic aphasia with the aim to explore which facets most clearly distinguish PWA from those without aphasia. Results showed people with
chronic aphasia were most affected by decreased QoL in level of independence, social relationships, and personal environment (Ross & Wertz, 2003). More recent studies supported these findings and suggested PWA experience higher rates of depression, participate in fewer activities, and initiate fewer communication interactions than people without aphasia (Cruice et al., 2006, 2010; Hilari, 2011). Evidence has suggested people with severe aphasia experience more QoL issues than people with mild to moderate aphasia, especially in terms of social exclusion, physical domains, and communication domains (Hilari & Byng, 2009; Parr, 2007). Parr (2007) completed an in-depth qualitative study that followed the daily lives of 20 people with severe aphasia secondary to stroke. Researchers observed social behaviors during three visits with participants in a variety of domestic and care settings. All participants experienced social exclusion in various ways, which Parr (2007) categorized as infrastructural (i.e., limited access to resources, inadequate income, limited services), interpersonal (i.e., limited group interaction and identification), and personal (i.e., isolation, low self-esteem, hopelessness). Results indicated severe aphasia affects many aspects of a person’s life and feelings of social exclusion can permeate general and emotional well being.

It is important for clinicians to understand clients’ personal views on their own QoL in order to provide the highest quality of care. ASHA states that clinicians must “…recognize the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with best current research evidence and their clinical expertise in making clinical decisions,” (ASHA, 2005). This guideline highlights the importance of including patient reports (i.e., QoL questionnaires) to supplement traditional objective assessments and guide interventions.
Research supports the notion that clients’ own perceptions of their impairments are beneficial to clinicians. Researchers have suggested the inclusion of patient-reported outcome measures can provide clinicians with insight into the impact that an impairment and its treatment has on patients’ lives. This can be valuable in identifying issues that typical quantitative assessments are not sensitive to, such as QoL (Coyne, Tubaro, Brubaker, & Bavendam, 2006; Pool, Hiralal, Ostelo, van der Veer, & de Vet, 2010). One specific advantage of using patient-reported outcome measures in clinical practice is the ability to measure changes in clients’ perceived emotional effects and daily functioning (Ross, 2006). This is especially relevant to clinicians working with PWA due to the previously discussed emotional impacts experienced by this population such as depression, social isolation, and decreased feelings of independence (Cruice et al., 2006, 2010; Hilari, 2011; Parr, 2007; Ross & Wertz, 2003). However, patient-reported outcome measures must be well developed with evidence of validity and reliability to ensure they are appropriate for evidence-based assessment. A well-developed patient-reported outcome measure should complement objective assessment data and provide a broader picture of the PWA’s impairments, activity limitations and social participation (Ross, 2006).

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

Few QOL assessments are specifically designed for PWA. Individuals with aphasia encounter difficulties in areas different from those found in other populations with acquired neurogenic disorders. Aphasia is a language disorder and may be concomitant with cognitive or physical deficits in stroke patients; therefore many traditional QoL measures are not appropriate for PWA. The SAQOL-39 was developed to address the absence of an assessment for PWA. It is a widely-used, reliable, and valid self-report scale that measures QoL in PWA via 39 questions
in 4 domains: physical, psychosocial, communication, and energy (Hilari, 2003; Hilari & Byng, 2001; Hilari et al., 2003, 2009).

While there are tools used to assess QoL in stroke survivors, many do not address the communication impairments experienced by PWA secondary to stroke. Prior to the development of the SAQOL-39, Hilari and Byng (2001) aimed to modify the Stroke Specific Quality of Life Scale (SS-QOL; Williams, Weinberger, Harris, Clark, & Biller, 1999) to provide an interview-based assessment to people with mild to moderate aphasia. Items were modified to be more “aphasia-friendly”, including larger font, simpler wording, and a scaled response format. Twelve participants with aphasia participated in a pilot study following these initial modifications. Hilari and Byng (2001) sought to obtain qualitative input from participants about how easy it was to use the response format. Participants did not conclusively agree that the response format was easy for them to use on all items. Based on further testing with PWA, the modified assessment was reduced from 53 to 39 items—the current SAQOL-39 (Hilari et al., 2003).

**Limitations of the SAQOL-39.** The SAQOL-39 has established validity and reliability for use as a self-report measure in people with mild to moderate aphasia (Hilari et al., 2003, 2007). However, other studies suggested it is not an appropriate measure for people with severe aphasia (Hilari & Byng, 2009). Hilari and Byng (2001) determined that PWA could reliably self-report on the SAQOL-39 if they demonstrated a score above 7 on the receptive domain of the Frenchay Aphasia Screening Test (FAST; Enderby, Wood, & Wade, 1987)—scores below 7 are indicative of severe aphasia. The SAQOL-39’s written format presents linguistic challenges to people with severe aphasia whose profound limitations affect their reading comprehension (Hilari & Byng, 2009).
Using proxy reports on behalf of people with severe aphasia. Because of the aforementioned linguistic deficits, caregivers or other individuals in close contact with PWA often provide reports when people with severe aphasia cannot reliably self-report on written items. However, proxy reports are often unreliable because proxies tend to rate deficits as worse than the individual would self-rate (Cruice, Worrall, Hickson, & Murison, 2005; Duncan et al., 2002; Engell, Hutter, Willmes, & Huber, 2002; Hilari & Byng, 2009; Rautakoski, Korpivaako-Huuhka, & Klippi, 2008). A negative bias from proxy reports inhibits clinicians from obtaining an accurate assessment of patients’ own QoL.

Cruice et al. (2005) highlighted discrepancies between self-reported QoL ratings and proxy ratings in PWA. This study included a sample of 30 PWA who were mostly fluent and demonstrated average spoken language comprehension, naming, and repetition skills. The research sample ranged from mild to moderate-severe aphasia, as categorized by the Western Aphasia Battery (WAB; Kertesz, 1982). Each participant elected a close friend or family member to serve as a proxy respondent. Elected respondents completed the same QoL measures on behalf of the PWA in an independent interview. Cruice et al. (2005) selected four measures of QoL that had not been developed specifically for PWA, including two health-related measures, one well-being measure, and one global QoL rating. Each participant was interviewed independently and responses were compared to determine the degree of agreement between PWA and their proxy respondents. Results indicated proxy respondents could not be considered wholly reliable substitutes for self-reports from PWA due to systemic differences in some areas of QoL. Proxy respondents rated global QoL significantly lower than PWA ($d = 0.52$) and overall, 60% of the proxy respondents rated global QoL of PWA lower than PWA self-reported. While there was high agreement on more objective measures such as physical limitations and
daily activities, proxy respondents demonstrated a negative bias toward rating aspects of their partner’s health-related QoL, global QoL, overall health, physical pain, vitality, mental health, and personal growth (Cruice et al., 2005). These findings are consistent with other literature highlighting the unreliability of proxy respondents in QoL measures.

In an earlier study, Duncan et al. (2002) compared QoL responses from a larger sample of 287 patient-proxy pairs. Each patient had suffered a stroke, but aphasia was not specifically addressed. Participants completed the Stroke Impact Scale (SIS; Duncan, Lai, Bode, & Perera, 2003), which includes eight domains addressing physical abilities, daily living activities, communication, emotion, memory and thinking, and social participation. Results supported a negative bias in proxy responses. Compared to their patient counterparts, proxy respondents rated stroke patients as more severely impacted in 7 of the 8 domains, 5 of which were considered statistically different. Differences were greatest in subjective domains such as emotions, cognition, and memory. Furthermore, differences in proxy-patient ratings were significantly greater as stroke severity increased. This is important to note because severely affected patients are more likely to use proxy respondents, yet proxy-patient agreement is less reliable for more severe populations (Duncan et al., 2002).

Studies are limited in measuring proxy responses and self-report differences on measures specifically developed for QoL in stroke patients with aphasia. However, following the development of the SAQOL-39, Hilari et al. (2007) analyzed the level of agreement between PWA and proxy respondents in physical, psychosocial, communication, and energy domains. The sample included 50 pairs of respondents and included only people with mild to moderate aphasia. Results were consistent with previous research in that proxy respondents tended to rate PWA as more severely impacted by aphasia than PWA rated themselves. Statistically significant
differences between proxy ratings and self-reported ratings were found in the physical, psychosocial, and communication domains. Despite statistically significance differences between the proxy and PWA groups, effect sizes were small to moderate (0.2 - 0.5), suggesting the magnitude of disagreement was small enough to justify the continued use of proxy respondents if no other possible alternative was available (Hilari et al., 2007).

Although Hilari and colleagues (2007) substantiated the use of proxy respondents for people with aphasia, we should explore whether we can modify the SAQOL-39 to allow people with severe aphasia to understand the questions and report for themselves. If we can find a way to increase the SAQOL-39’s accessibility for people with severe aphasia we could gain a more valid understanding of what effect severe aphasia has had on their QoL. Self-reports might enable clinicians to plan more meaningful, individualized, and effective treatment. One way to elicit input directly from people with severe aphasia might be to use pictures to augment written and spoken language on questionnaires and other assessment measures.

**Photographs as Communicative Modifications for People with Severe Aphasia**

**Visual processing.** Visual images are often used as modifications for individuals with communication disorders (Beukelman & Mirenda, 1998). Images may be especially useful for PWA due to impairments in multiple language domains. Many people with severe aphasia have difficulty processing linguistic symbols (i.e., written text); therefore some researchers posit augmentative and alternative (AAC) modifications that rely more on non-linguistic cognitive processes may facilitate more successful communicative interactions (Dietz at al., 2009; McKelvey et al., 2010; Wilkinson & Jagaroo, 2004). Cognitive skills such as visual perception, memory for personally relevant information, and general processing of contextual information
are non-linguistic in nature and are often preserved in PWA, regardless of severity (Chapey, 2008).

Because many people with severe aphasia have damage to cortical areas supplied by the middle cerebral artery (MCA), it is beneficial to consider the neurological underpinnings of the aforementioned cognitive processes. Clinicians who understand both damaged and intact processes are able to explore AAC modifications that rely on cognitive processes largely unaffected by neurological damage associated with severe aphasia. Cortical areas most affected by an MCA stroke include the following: inferior frontal gyrus, which is associated with expressive language; postcentral gyrus, which is associated with sensory perception; and the superior posterior temporal lobe, which is associated with written and spoken language processing (LaPointe, 2012). Visual processing of written language differs from processing of non-linguistic stimuli such as pictures. Written language is typically processed at the phonological level, and comprehension of both written and spoken language is associated with the left superior temporal lobe (LaPointe, 2012). Conversely, pictures are processed at the lexical-semantic level more so than at the phonological level, suggesting they are interpreted as meaning-related (Jerger, Martin, & Damian, 2002).

Jerger, Martin, and Damian (2002) studied the lexical-semantic relationship in children 5-7 years old with a simplified picture-word task. They found that children performed unreliably on the spontaneous generation of semantically related pairs of contextual category words. However, when they were provided with a picture, a semantically related word, and a semantically unrelated word, children were able to accurately identify the categorically related word. Although these results are based on a sample of young children, they may be useful to consider since adults with severe aphasia have impaired reading in addition to impairments in the
other language modalities—listening, speaking, writing and gesturing. Jerger, Martin, and Damian’s findings support the theory that semantically-related pictures influence linguistic processing, which in turn supports the view that linguistic processing is influenced by the interactivity between language comprehension and production (Jerger, Martin, & Damian, 2002).

Similarly, Wilkinson and Jagaroo (2004) argued that linguistic symbols within visual-graphic modes (i.e., letters, words, or pictures) are likely processed in the brain via two pathways: primary linguistic pathways and specific visual pathways. Both pathways must be accessed in order to provide a complete conceptual picture. People with aphasia are more likely to access the linguistic material along with the visual material by using visual aids to access the brain’s visual pathways (Wilkinson & Jagaroo, 2004). This holistic processing may benefit people with aphasia because their preserved visuospatial skills and recognition of people, events, and emotions serve as strengths in processing whole visual concepts that do not require phonological or auditory comprehension (Fox & Fried-Oken, 1996).

**Reading deficits in PWA.** Researchers take the aforementioned factors into consideration when addressing reading difficulties present in PWA. Visual aids can be especially useful since reading disorders such as acquired alexia also result from stroke. Alexia is the inability to read written words; many PWA acquire some degree of alexia and lose their premorbid reading abilities. Reading impairments are most commonly associated with damage to the left perisylvian cortical area; thus are common in PWA secondary to left MCA stroke (Beeson, Rising, Kim, & Rapcsak, 2010). Alexia often co-occurs with Broca’s aphasia and presents as a reading disorder that mirrors the person’s expressive language abilities. That is, people with Broca’s aphasia are more capable of communicating concrete, highly imageable words and topics than complex or abstract language. If reading is impaired in the same way, we
would expect PWA to have more difficulty comprehending complex or abstract written language (Bhatnagar, 2013).

The most common type of reading disorder acquired by people with severe aphasia is deep dyslexia. Deep dyslexia is a deficit in basic reading processing, including the ability to convert graphemes to phonemes and then to complete words (Beeson et al., 2010). It is often associated with severe Broca’s or mixed aphasia due to a large lesion in the left hemisphere. A person with aphasia who suffers from deep dyslexia may exhibit comprehension of key words such as nouns and verbs, but display multiple semantic and visual errors while reading function words and nonwords (Basso, 2003). Typical readers convert graphemes into phonemes before processing each phoneme in the semantic system. However, some hypothesize that individuals with deep dyslexia access the semantic system directly from each grapheme. This process suggests reading is accomplished by direct recognition of familiar words. This theory of familiarity is supported by evidence that shows people with deep dyslexia are more likely to successfully read concrete easily visualized nouns (Beeson et al., 2010).

**Use of visual stimuli to support written material.** A study conducted by Rose et al. (2011) found that using pictures to augment written information aided comprehension in PWA. Participants reported a perceived improvement, noting the graphics made their reading comprehension easier and quicker. Rose et al. (2011) aimed to explore the effects of aphasia-friendly modifications to printed education materials for people with aphasia. Forty PWA participated in a qualitative study using an interview format to provide input on their preferences of printed education material. Feedback was collected on why particular materials were chosen over others, what aspects were perceived to be helpful, and which aspects had a negative impact on the participants’ understanding of material. Results indicated the majority of participants
(87.2%; n = 34) preferred aphasia educational material that incorporated “aphasia-friendly” modifications. Participants reported shorter sentences (maximum 15 words), simple, universal language, personally relevant information, san serif font, bolded key points, and incorporated graphics were most helpful in aiding their comprehension. Participants stated that they were more likely to attempt to read materials that incorporated graphics and that these materials were easier to comprehend. However, some participants did not perceive the “aphasia-friendly” materials to be helpful. Three participants preferred the “aphasia-friendly” aphasia material the least, and 13 participants made at least one negative comment about the “aphasia-friendly” materials. The majority of negative comments pertained to the reduced amount of information provided to in shorter sentences (Rose et al., 2011). Together these data suggest PWA consider visual modifications to be effective for enhancing their comprehension of written materials.

While simple graphics may benefit some PWA, studies have suggested effective visual modifications for people with severe aphasia may need to bypass deficits in linguistic processing. This is achieved by incorporating highly contextualized, personally relevant color photographs in conjunction with written words or short phrases (McKelvey et al., 2010; Wilkinson & Jagaroo, 2004). Wilkinson and Jagaroo (2004) discussed the need for PWA to access intact cognitive processes for visual AAC to be effective. They emphasized that color can facilitate processing by improving recognition, recall, and speed of perception. Furthermore, pictures displaying a contextualized scene allow PWA to utilize residual visuospatial skills to interpret meaning based on the orientation and positions of objects in the photograph in relation to one another. Dietz et al. (2009) demonstrated the benefits of contextualized visuographic supports during reading comprehension tasks. Seven adults with severe aphasia as a result of a left CVA participated in the study, which involved reading 3 narratives with varying levels of visuographic support
(low-context photographs, high-context photographs, and no visuographic support). Researchers analyzed reading comprehension response accuracy, response time, and participants’ perceptions of visuographic usefulness. Results indicated statistically significant improvements in participants’ comprehension response accuracy in both the low- and high-context conditions compared to narratives with no visuographic support. Response times were faster when participants did not have any photographic support while they read. Dietz et al. (2009) hypothesized the faster response times may have been a result of participants’ decreased understanding of the written material, thus resulting in less time spent thinking about their responses. Lastly, participants rated the high-context photographs to be most helpful during the reading task, and the majority of participants stated that pictures would have helped them better comprehend the narrative that did not include photographic support. While there was not a significant difference in comprehension between the low-context and high-context conditions, these findings support the use of contextualized photographs to support reading comprehension in people with chronic, non-fluent aphasia.

McKelvey et al. (2010) provided further support for the use of contextualized photographs with written words. Their study also explored three conditions of different types of support, but differed from Dietz et al., (2009) in that personal relevance was explored. Participants included 8 adults with severe aphasia secondary to left CVA. Experimental tasks included three types of visual stimuli: personally relevant, contextualized photographs; non-personally relevant, contextualized photographs; and noncontextualized, iconic images. Visual stimuli were paired with three types of target words, including labels, actions, and socially relevant events. Personally relevant, contextualized photographs were selected from a collection provided by each participant, whereas non-personally relevant, contextualized photographs were
obtained from a generic, unrelated source on the Internet. Participants completed two tasks in which they were asked which visual stimulus they preferred to represent the paired word and a task that measured accuracy on which visual stimulus represented a given word. Researchers found participants showed a clear preference for personally relevant, contextualized photographs and that accuracy improved with personally relevant, contextualized stimuli as well (McKelvey et al., 2010). Their findings support the literature that emphasizes the benefits of providing people with severe aphasia with communicative supports that encourage intact cognitive abilities such as recognition. Visual recognition supports can enhance their ability to communicate with others (Beukelman, Fager, Ball, & Dietz, 2007; Dietz et al., 2009; McKelvey, Dietz, Hux, Weissling, & Beukelman, 2007; Wilkinson & Jagaroo, 2004).

**Pairing High-Context Color Photographs With SAQOL-39 Items**

The Louisiana State University Communication Outcomes Research Lab (LSU COR Lab) is the first known group to study the pairing of visual stimuli with SAQOL-39 items. Brouwer (2013) explored similarities between high-context color photographs with written SAQOL-39 items, as judged by adults without aphasia. Based on the literature supporting high-context, personally relevant color photographs as useful supplements to written material, Brouwer (2013) developed a set of photographs to represent SAQOL-39 items. A group of three undergraduate and graduate students reviewed 84 photographs during the first phase of the study and judged which photographs were most representative of each SAQOL-39 item. Two photographs were selected for each SAQOL-39 item as well as three practice items. Additional qualitative data were collected through written comments. Results indicated at least 2 out of 3 reviewers agreed that 95% of the questions were appropriately represented by at least one photograph. Based on qualitative feedback, new photographs were taken for the two items that
reviewers did not judge to be appropriately represented. A total of 42 photographs were selected for inclusion in the experimental task (3 practice items and 39 matched to SAQOL-39 items).

Following the expert review, 20 participants between the ages of 65 and 85 years rated the degree of similarity between each photograph and its paired written test item. All participants were native monolingual English speakers; had no history of neurological or language impairment; and demonstrated adequate vision, hearing, and cognition for purposes of the study. Using an electronically administered program via a laptop computer, participants were instructed to “decide how similar the photo is to the question” by rating each photograph on a 7-point Likert scale that set anchors as “1=very dissimilar” and “7=very similar” (p. 37).

Participants agreed that 95% of the photographs were highly similar to paired SAQOL-39 items. The mean rating for all 42 items was 6.06, with 39 photographs (93%) rated as ≥ 6 in at least 60% of responses. Of the 39 photographs paired with SAQOL-39 items, 37 (95%) were rated ≥ 6 in at least 60% of responses. Though results indicated high similarities among items overall, the study did not include measures of intra-rater reliability and failed to explore whether faster response times on items might indicate stronger perceived similarities than other items (Brouwer, 2013).

**Rationale for the proposed study.** It is necessary to ensure modifications are communicatively accessible to the disordered population before we can explore whether the modifications can successfully accommodate people with severe aphasia. Literature outlining the development of patient-reported outcome measures such as the SAQOL-39 stresses the importance of obtaining input directly from the target population during the measure’s development (Coyne et al., 2006). Patient input can be obtained through focus groups and interviews; these may shed light on qualitative limitations of assessment measures (Pool et al.,
2009). The process of obtaining qualitative patient input varies slightly when researchers seek to modify an existing measure in order to address a different population. Coyne et al. stated that patient input is not necessary during the initial stages of adapting a reliable and valid existing measure, but input should be obtained once the modifications have been established. The measure should then be reviewed by a sample of the new target population in order to ensure the modified version is relevant and accessible to the intended population.

In accordance with these guidelines, the first step in this research was to take photographs and explore whether people without aphasia perceived them as representative of SAQOL-39 items. Results from Brouwer (2013) suggested strong content validity of photographic representations of written SAQOL-39 items among neurotypical aging individuals. We must now establish content validity among the disordered population to judge whether paired items are perceived similarly to people with aphasia.

Though the photographic modifications’ target population is people with severe aphasia, the previously outlined limitations of people with severe aphasia suggest a need to first explore content validity among adults with mild to moderate aphasia because they are more likely to be able to understand the task and SAQOL-39 items. People with severe aphasia cannot accurately self-report on the existing written SAQOL-39 items, suggesting a lack of comprehension. By comparing photograph ratings by people with mild to moderate aphasia with ratings by people without aphasia, we can explore whether ratings are similar and able to be studied among people with severe aphasia.

**Aim of the Proposed Study**

The long-term goal of the present body of research is to develop a set of valid and reliable high-context color photographs representative of SAQOL-39 items that can be used as a
modification that will allow people with severe aphasia to self-report on their QoL. This study is a step toward that goal. The present study aimed to answer the following experimental question: How strongly do 10 adults with mild to moderate aphasia judge high-context color photographs to represent SAQOL-39 items, as rated on a 7-point Likert scale?
METHODS

Design

This was a prospective within-group exploratory study. The study was a partial replication of a previous study (Brouwer, 2013) in which 20 healthy older adults ages 65-85 years demonstrated the content validity of photographs used to represent SAQOL-39 questions. Dependent variables included the ratings and response time in milliseconds (ms) for each item. Response times were trimmed if they fell outside 3 standard deviations from the mean.

Participants

The study recruited a convenience sample of 10 adults aged 30-89 years with mild to moderate aphasia. Participants were recruited through flyers displayed at places where individuals with aphasia may frequent such as the LSU Speech Language and Hearing Clinic (LSU- SLHC), stroke support groups, senior citizen centers, outpatient centers, and rehabilitation centers. I also utilized word-of-mouth advertisement with colleagues and supervisors to assist with participant recruitment.

All participants met the following inclusion criterion: (1) between the ages of 30-89 years; (2) native monolingual English speakers; (3) no history of other neurological or language disorders; (4) one or more left hemisphere cerebrovascular accident(s) (CVA); (5) mild to moderate aphasia based on Boston Aphasia Severity Rating Scale (Goodglass et al., 2001); (6) aided or unaided hearing sufficient to complete the study; (7) minimum of aided or unaided 20/100 visual acuity as measured by the Rosenbaum Pocket Vision Screener (Rosenbaum, 1982); (8) no debilitating hemianopsia measured by National Institute of Health Stroke Scale (NIHSS; National Institute of Health, National Institute of Neurological Disorders and Stroke, 2003); (9) reading comprehension sufficient to complete the study measured by the “Sentence-Picture”
subtest of the Reading Comprehension Battery for Aphasia (RCBA; LaPointe & Horner, 1998); (10) adequate upper extremity motor function to use either left or right hand to input keyboard response.

I used a telephone screening to determine potential participants’ eligibility for study participation. The telephone screening included the following: age, native language, medical history, and language difficulties. Eligible participants were scheduled for an appointment at a location of their choosing (e.g. home, community center, LSU campus). Participant demographic details are displayed in Table 1.

Table 1. Participant Demographic Information

<table>
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<tr>
<th>ID #</th>
<th>Age (years)</th>
<th>Sex</th>
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<th>Months Post-Stroke</th>
<th>Boston Aphasia Severity Rating</th>
<th>RCBA Sentence Comprehension Score</th>
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</table>

*M age = 60.90 years (SD = 15.40 years); M months post-stroke = 25 (SD = 14.01)*

Materials

Screening measures. I administered and scored all screening measures according to standardized procedures outlined in each assessment manual. Only valid and reliable screening measures were selected for the study. Details about each screener’s purpose follow.

Aphasia Severity: The Boston Aphasia Severity Rating Scale (Goodglass & Kaplan 2001) is a valid and reliable tool used to determine aphasia severity on a scale of 0-5 and is part of the more extensive Boston Diagnostic Aphasia Examination (BDAE; Goodglass et al., 2001).
Aphasia severity was rated based on conversational and narrative speech obtained through free conversation and a picture description task. Participants with a severity rating of 2-5 (mild to moderate aphasia) were eligible for participation in this study. Severity rating indicators are listed in Table 2.

Table 2. *Boston Aphasia Severity Rating Scale* Descriptions

<table>
<thead>
<tr>
<th>Severity Rating</th>
<th>Aphasia Severity Level</th>
<th>Communication Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Severe</td>
<td>No usable speech or auditory comprehension</td>
</tr>
<tr>
<td>1</td>
<td>Moderate-to-severe</td>
<td>All communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener; exchange is limited and listener carries the burden of communication</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
<td>Conversation about familiar subjects is possible with help from listener; frequent failures to convey the idea, but the speaker shares the burden of communication</td>
</tr>
<tr>
<td>4 &amp; 3</td>
<td>Mild-to-moderate</td>
<td>Speaker can discuss almost all everyday topics with little or no assistance; some topics may be difficult due to reduction in speech and/or comprehension; some obvious loss of fluency in speech or comprehension, but expression is not significantly limited</td>
</tr>
<tr>
<td>5</td>
<td>Mild</td>
<td>Minimal discernible speech handicap; speaker may have subjective difficulties that are not obvious to the listener</td>
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</table>

Hearing: Participants with unaided or aided hearing based on responses during conversation were eligible for study participation. Formal hearing screening was not needed in this study because the bulk of the study was done on the computer.

Visual Acuity: The *Rosenbaum Pocket Vision Screener* (Rosenbaum, 1982) has demonstrated validity and reliability for people of all ages. Participants who accurately
completed the vision screener unaided or aided by reading the line with the smallest letters from 14 inches away were eligible for study participation.

Visual Field: The National Institute of Health Stroke Scale (NIHSS; NIH, 2003) is the “gold standard” for rating stroke severity by researchers who study stroke (Meyer, Hemmen, Jackson, & Lynden, 2002). Item 3 on the NIHSS assesses the presence of hemianopia, a visual field disturbance that may result from stroke. It was important to rule out hemianopia to ensure participants were able to see the entire computer screen, left to right, and the 7-item rating scale. To test for hemianopia the interviewer used finger movement in the various visual quadrants. If people have hemianopia, but look to the correct side with cueing, the item is considered “normal.” Participants who achieved a “normal” rating on Item 3 were eligible for the study.

Reading Comprehension: The Reading Comprehension Battery for Aphasia-2 (RCBA; LaPointe & Horner, 1998) is a valid and reliable criterion-referenced measure that assesses functional reading, reading prerequisite skills, and lexical decision-making in PWA. The “Sentence-Picture” subtest of the RCBA assesses reading comprehension by presenting a written sentence with three black and white line-drawn pictures. The participant is required to read the sentence and decide which picture best depicts the stimulus sentence (e.g., “He asked him for directions.”). Participants who accurately responded to at least 8 out of 10 items on the “Sentence-Picture” subtest were eligible for study participation.

Experimental Stimuli. The digital high-context color photographs used in the Brouwer (2013) study to represent the SAQOL-39 items were used in this study as well. Each photograph featured one or more adults in a home setting to depict the SAQOL-39 items. The SAQOL-39 questions were copied verbatim onto each computer screen. SAQOL-39 questions were written to assess the respondent’s personal difficulty with daily activities (Hilari & Byng, 2001).
**Apparatus.** The rating task was administered to each participant through a computer program that I developed using E-Prime 2.0 software (E-Prime, 2005). The program was displayed to the participant to complete on a Dell Latitude D820 laptop computer.

**Procedures**

Prior to data collection, I explained the study to participants, answered their questions, and obtained informed consent from them using an LSU IRB-approved consent form (Appendix C). I then administered the screening tools to determine ability to complete the study. Should a person fail any of the screening tools he/she would be excused from further participation. I proceeded to experimental data collection once the participant successfully passed the screening.

All procedures to ensure participant confidentiality were used, including assigning each participant a case number. Deidentified participant information was entered in the computer prior to conducting the experiment. The program displayed each photograph and written item pairing and was presented in a random order to control for order effects.

Each participant was seated at a comfortable distance from the laptop computer. I showed each participant the starting screen displaying the task’s instructions and verbally explained the 7-point Likert scale (1-“picture is NOT the same,” 4-“picture is SORT OF the same,” 7-“picture IS the same”) after the participant read the instructions.

Directions were displayed in black font against a white screen and were adapted from Brouwer (2013) to state:

Look at the picture.

Read the question below the picture.

How well do you think this picture matches the question?

Press a number 1-7 on the keyboard to respond.
Three guided practice questions were administered to ensure the participants’ understanding of the task’s instructions and establish familiarity with the computer program. Practice questions were introduced with the following screen prompt and were also displayed in large black font: “You will start with some practice ratings. Press SPACEBAR to continue.” During the first practice item, I modeled a response while reading the instructions and question aloud. During the second practice item, I guided the participant through the item as an interview format and I pressed the keyboard response. Finally, the participant completed the third practice item independently.

Every picture/question screen was displayed in the same way. The photograph was displayed at the top of the computer screen, the SAQOL-39 written item was under the photograph, and the 7-point rating scale was at the bottom of the screen. When the participant entered his/her response on the keyboard the next pairing automatically appeared on a new screen. After each participant completed the third practice item, the screen automatically displayed the following prompt in large black font: “Great job! You finished the practice.”

At this point, I answered any questions they may have had about the task. I reiterated that they were asked to rate the similarity of the photographs and questions as quickly as possible rather than responding with their personal responses to each question. When participants informed me they were ready to proceed to the rating task, I pressed “Shift + M” to display the following screen prompting each participant to continue the task:
Now you will rate more pictures.

Remember to rate how well each picture matches the question below it.

Choose your rating with the numbers on the keyboard.

1 = picture is NOT the same

4 = picture is SORT OF the same

7 = picture IS the same

Press SPACEBAR to continue.

The computer program then began to administer the rating task for the 39 pairs from the SAQOL-39 items. A total of 42 items were administered in a random order, including 39 SAQOL-39 items and three repeated pairs for intra-rater reliability. Each item was displayed exactly as the practice items. The software program recorded the participants’ response rating and RT.

**Reliability**

I established inter-rater reliability on the *Boston Aphasia Severity Rating Scale* using two additional raters with graduate-level clinical aphasia experience. These two raters listened to recorded samples of conversation and narrative speech (The Cookie Theft Picture; Goodglass & Kaplan, 2001) in a quiet lab setting and offered their own severity ratings for comparison. To determine intra-rater reliability, three duplicate stimuli pairs were presented during the experiment and compared by the investigator during data analysis.
RESULTS

This study aimed to answer the following experimental question: How strongly do 10 adults with mild to moderate aphasia judge high-context color photographs to represent SAQOL-39 items, as rated on a 7-point Likert scale?

Data Analysis

I calculated participants’ mean ratings, intra-rater reliability, standard error of the mean ratings (SEM), median rating, mode rating, mean response time, response time SEM, and $z$ score for each rated item. Inter-rater reliability was calculated for rater agreement of participants’ aphasia severity ratings on the Boston Aphasia Severity Rating Scale. Upon inspection of the raw data, I discovered one participant (Participant #3) who responded unreliably and was a clear outlier compared to the remaining 9 participants. This participant’s responses were removed from the final statistical analysis and will be discussed individually in the discussion. Time constraints did not permit further recruitment to replace this participant.

Descriptive Statistics

The mean rating, SEM, median, mode, mean response time (in milliseconds), response time SEM, and $z$ score were calculated for each photograph-question pairing. There were a total of 46 items, including three practice items, 39 SAQOL-39 items, and three duplicate items from the SAQOL-39. The mean rating for each item was also rounded to the nearest whole number to correlate more closely to the 7-point Likert scale used in the rating task. Mean ratings were rounded up if the number following the decimal was $\geq .50$ and rounded down if the decimal was $< .50$. A summary of descriptive statistics is displayed in Table 3.
Table 3. Summary of Descriptive Statistical Analyses

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<th>Item #</th>
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<th>SEM Rating</th>
<th>Practice A Median Rating</th>
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<td>7.00</td>
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<td>6</td>
</tr>
<tr>
<td>33</td>
<td>6.67</td>
<td>1.09</td>
<td>6.00</td>
<td>7.00</td>
<td>25288.67</td>
<td>6</td>
</tr>
<tr>
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<td>6.67</td>
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<td>7.00</td>
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<tr>
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<td>7.00</td>
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<tr>
<td>Total</td>
<td>6.40</td>
<td>0.91</td>
<td>6.77</td>
<td>6.90</td>
<td>23711.44</td>
<td>6.43</td>
</tr>
</tbody>
</table>
**Item rating mean.** Each item was rated on a scale from 1-7 (i.e., 1 = picture is not the same, 4 = picture is sort of the same, 7 = picture is the same). Mean ratings ranged from a minimum of 5.13 to a maximum of 7. The overall mean rating was 6.40, indicating that most participants rated photographs highly similar to the questions they were paired with. When mean ratings were rounded, all but two items had a mean rating ≥ 6, supporting the indication that most photographs were representative of written questions.

**Standard error of the mean.** The standard error of the mean (SEM) for each item ranged from 0 to 1.96. The overall SEM for all items was 0.91, indicating that most ratings were distributed tightly around the mean.

**Item rating median.** The median ratings ranged from 5 to 7, with an average median for all items of 6.77. This indicates that the midpoint of the item ratings was in the higher end of the 7-point rating scale, suggesting strong similarity between paired photographs and SAQOL-39 items.

**Item rating mode.** The mode for all but two items was 7, with an average mode of 6.91 for all items. One item’s mode was 4. Despite this single lower mode, results show many participants rated each item as a 7.

**Mean response time.** Response time is a measure of processing speed. Responses that were more than 3 standard deviations from the mean were considered outliers and were eliminated. Mean response times for each item ranged from 9739.11 ms - 58961.67 ms. However, the maximum response time was on a practice item and may reflect the time it took the clinician to explain the task. The maximum response time on SAQOL-39 items was 39203.88 ms. The mean response time was 23711.44 ms. Some participants required assistance with
questions or made comments during the rating task which may have increased variability in response times. See Table 3.

What follows are further analyses completed of the descriptive statistics, including item-by-item frequency analysis, followed by response time analysis for aphasia severity and separate items.

**Item-by-Item Frequency Analysis**

Item-by-item frequency distributions were calculated to review participants’ ratings for each of the SAQOL-39 photograph-question pairings by noting how many participants responded with each point on the 7-point Likert scale. If the percentage of ratings $\geq 6$ was $\geq 60\%$, as in Brouwer (2013), the photograph was considered representative of the question. An item-by-item summary of mean ratings $\geq 6$ is shown in Table 4.

**Table 4. Item-by-Item Summary of Mean Ratings $\geq 6$**

![Chart](chart.png)

Based on item analysis results, 36 of the 39 total photograph-written item pairings (92%) were rated a 6 or 7 at least or more than 60% of the time. Furthermore, 33 of the 39 items (85%) were rated a 6 or 7 at least 70% of the time. Only three items were rated a 6 or 7 less than 60% of the time. Item 7 was rated a 6 or 7 by 50% of participants; item 29 was rated a 6 or 7 by 44%
of participants; item 36 was rated a 6 or 7 by 56% of participants. These three items are detailed in Appendix B. Possible reasons for lower ratings will be discussed further on.

**Response Time Analysis**

We analyzed mean RTs by aphasia severity level to determine whether mean RTs increased as aphasia severity increased. The data are summarized in Table 5.

### Table 5. Mean RTs by Aphasia Severity Level

<table>
<thead>
<tr>
<th>Severity Rating</th>
<th>Severity Description</th>
<th>Mean RT (ms)</th>
<th>Mean RT (seconds)</th>
<th>SEM RT (ms)</th>
</tr>
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<tr>
<td>5 (n = 1)</td>
<td>Mild</td>
<td>14185.67</td>
<td>14.19</td>
<td>15411.87</td>
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<tr>
<td>4 (n = 3)</td>
<td>Mild-Moderate</td>
<td>24413.77</td>
<td>24.41</td>
<td>19582.98</td>
</tr>
<tr>
<td>3 (n = 3)</td>
<td>Mild-Moderate</td>
<td>27053.63</td>
<td>27.05</td>
<td>23895.29</td>
</tr>
<tr>
<td>2 (n = 2)</td>
<td>Moderate</td>
<td>21056.74</td>
<td>21.05</td>
<td>16351.98</td>
</tr>
</tbody>
</table>

First, I found differences in mean RTs among the severity levels. As expected, the mean RT for mild aphasia (n=1) was shorter than the mean RT for any other severity level. Unexpectedly the mean RT for moderate aphasia was shorter than the mean RTs for the two mild-moderate aphasia categories. The differences could not be tested for significance since the number of participants in each category was not equal.

Item-by-item analysis of mean RTs showed that items 22, 24, and 9 had the shortest mean RTs (9739.11 ms, 11326.75 ms, and 11927.44 ms, respectively). Items 7, 31, 36, and 3 had the longest mean RTs (39203.88 ms, 31981.11 ms, 31885.78 ms, and 31430.56 ms, respectively). A summary of mean RTs by item is shown in Table 6.

The items with the shortest mean RTs were rated 7 (“picture IS the same”) by 100% of the participants. Of the longest mean RTs, items 7, 31, and 36 were rated less similar than other items (e.g. rating 4 = “picture is SORT OF the same”). However, that is not the case for item 3, which was rated 6 or 7 by 100% of participants.
Reliability Measures

**Intra-rater reliability.** Duplicate stimuli pairs were presented during the 7-point Likert scale rating task to establish intra-rater reliability among participants. On SAQOL-39 item 1, intra-rater agreement was 90%. On SAQOL-39 item 17, intra-rater agreement was 70%. On SAQOL-39 item 22, agreement was 100%. Participants who did not reliably answer all duplicate items continued to rate items on the higher end of the scale in and differed by only 1 or 2 rating response numbers. Overall intra-rater reliability was 93%, suggesting most items were rated consistently among participants.

**Inter-rater reliability.** Inter-rater reliability was established for participants’ severity ratings on the *Boston Aphasia Severity Rating Scale* by having three raters independently judge each participant’s severity level. Raters agreed on all but one participant severity ratings. One rater considered Participant 3 as a Level 4, whereas the other two raters considered this participant to be Level 3. For purposes of this study, a severity rating between 3-4 is considered
mild-moderate; therefore this is not a concerning difference in ratings. The participant that was disagreed upon was removed from data analysis regardless. Overall inter-rater reliability was calculated to be 97% across all participants as seen in Table 7.

Table 7. Inter-Rater Reliability of Aphasia Severity Levels

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<thead>
<tr>
<th>Participant</th>
<th>Rater #1</th>
<th>Rater #2</th>
<th>Rater #3</th>
<th>Percent of Agreement</th>
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<td>2</td>
<td>2</td>
<td>100%</td>
</tr>
<tr>
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<tr>
<td>10</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>100%</td>
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</table>

*Overall Inter-Rater Reliability* 97%
DISCUSSION

This study aimed to add to the content validity of photographs representing SAQOL-39 items by supporting previous research with adults (Brouwer, 2013) and exploring whether people with mild to moderate aphasia perceived the same photographs as similar to paired questions. Results supported Brouwer (2013); 92% of the photographs were rated as highly similar.

Summary of Results

Based on the results of this study, preliminary content validity for the high-context photographs designed to be representative of written SAQOL-39 items was determined to be strong. The overall mean rating of the three practice questions and 39 original SAQOL-39 questions was 6.40 on a 7-point Likert scale, indicating most photographs were rated very similar to questions they were paired with. Furthermore, the rounded means for items were ≥ 6 on all but two items (Item #7 and Item #29), which both had rounded ratings of 5. Item-by-item analysis revealed that 36 of the 39 original SAQOL-39 items (92%) were rated at least a 6 by at least 60% of participants, indicating that participants perceived the photographs to be very similar to paired items.

While overall mean ratings were high, the SEM values were variable and ranged from 0 to 1.96. Further analysis showed that the five items that had a mean rating < 6 (Items #7, 12, 29, 36, and Practice Item B), also had higher SEM values ranging from 1.09 to 1.96. Greater variability suggests these five items may have been more difficult to rate 7 (“picture IS the same”). The 40 items that had ratings ≥ 6 tended to have SEM values more tightly arranged around the mean, indicating less variability among participants’ ratings. Despite the items that deviated farther from the mean, the overall content validity of these items remained strong considering all items had a median and rounded mean ≥ 5. The mode for all items except Item
#29 was $\geq 6$, suggesting most participants considered the majority of photographs were the same as paired questions. Brouwer (2013) found that adults without aphasia also rated Item #17 and #36 as less similar than other photographs. The mean rounded rating for both items was 5 in adults without aphasia (Brouwer, 2013). While participants in the current study rated Item #17 as highly similar ($M = 6.22$), intra-rater reliability was lower for this item, suggesting more difficulties with the stimuli as seen in the previous research. Similarly, results of these studies suggest people with and without aphasia did not perceive Item #36 to be as similar as other items. Overall, these results support Brouwer (2013), suggesting people with and without aphasia perceive the majority of the photographs as highly similar to SAQOL-39 items.

Although I simplified the task and provided guided practice for each participant, many participants required additional assistance throughout the rating task. Some participants required frequent reminders that they needed to rate the similarity between the photograph and paired question rather than rate their own difficulty with the target question. For example, when prompted about an item regarding climbing stairs (Item 6), one participant commented to the investigator, “Oh I don’t have trouble with stairs anymore,” and needed to be reminded of the purpose of the rating task. The need for additional cues was unexpected, as I had not expected people with high reading comprehension scores to have difficulty with the study’s task. This may suggest an issue with working memory, as the study’s task required a higher cognitive load on working memory to remember the instructions and process the stimuli. Furthermore, based on comments, some participants rated certain items as less similar because the person in the photograph did not appear to be having trouble with the task referred to in the written question. This was understandably difficult for some people with aphasia because the wording of the
SAQOL-39 questions were designed to assess the level of trouble a person with aphasia has in each domain.

There is no way to know how the aforementioned need for frequent communication with the investigator during the experimental rating task affected mean RTs since no comparison data exist. I collected RT data with the expectation that it would provide further information about how people with mild to moderate aphasia processed the photographs and paired SAQOL-39 items. For example, the three shortest mean RTs corresponded to items that were rated 6 or 7 (“picture IS the same”) by 100% of the participants (regardless of aphasia severity). Furthermore, I thought people with more severe aphasia would have longer RTs. However, results did not bear this out. In fact, participants with moderate aphasia had slightly shorter mean RTs than those with mild-to-moderate aphasia. This might suggest the photographs did in fact provide a complete visual-linguistic concept to people with moderate aphasia who may otherwise have had more difficulty and slower processing speeds. These results merit further research.

Adults (n = 9) with mild to moderate aphasia were reliable in their ratings of items. Overall intra-rater reliability was 93%, suggesting participants rated the items consistently and the overall strong similarity was reliable. It is interesting to note that both RP #7 and RP #8 varied ratings on Item 17 by more than one rating on the 7-point Likert scale. Both participants first rated the stimuli as 7, and then rated the duplicate pair as 5. Item 17 asked about trouble with speaking; thus it was less concrete and more difficult to display photographically than more concrete items (i.e., buttoning a shirt or preparing food). This item’s lower intra-rater reliability might indicate greater difficulty for participants to questions with photographs that cannot readily capture the action (i.e., speaking). Despite differences in intra-rater reliability on duplicate stimuli pairs, most participants continued to rate the photographs in the higher end of
the 7-point Likert scale. These ratings support the overall similarity of the photographs and written items and suggest people with aphasia can understand the relationship between the stimuli.

**Study Limitations**

The current study was limited by a small sample (ultimately, $n = 9$) that was not equally represented in all aphasia severity levels. Most participants were rated mild-moderate ($n = 6$), two were rated moderate and one was rated mild. Due to the study’s small sample size and unequal groups of aphasia severity levels, significance could not be tested.

The study’s sample was further diminished by the need to remove one participant’s responses from the data analysis (see p. 29). Participant 3 did not reliably complete the task and was a clear outlier in the sample although he met all of the inclusion/exclusion criteria. This participant did not rate any of the duplicate stimuli the same, indicating poor intra-rater reliability. Furthermore, ratings varied on two of the three duplicate pairs by more than one rating (i.e., rated Item 17 as 5 and 7; rated Item 22 as 4 and 7). In addition to poor reliability, this participant demonstrated longer response times on items with a mean of 40645.72 ms per item. This participant also required the greatest deal of redirection and clarification on each item, which could be indicative of more comprehension deficits than the rest of the sample. It should be noted that a review of this participant’s clinical records indicated she had Wernicke’s aphasia, whereas most of the sample did not. Wernicke’s aphasia is characterized by more comprehension deficits, which may have been more affected in Participant 3 than in the rest of the sample. This was the only participant that raters did not agree on severity level, with two of the three raters judging severity level as a 3 and one rater judging severity level as a 4. Both 3 and 4 were considered mild-moderate aphasia, though one rater judged the severity level slightly
milder. The *Boston Aphasia Severity Rating Scale* is not a comprehensive aphasia test, and therefore, does not indicate the specific areas of impairment that may have led to Participant 3’s inconsistent performance.

On the other hand, Participant 3’s language and cognitive deficits may have been more impaired than the *Boston Aphasia Severity Rating Scale* revealed, which led to performance variations. The majority of participants were recruited from the LSU Speech Language Hearing Clinic. However, as with any outpatient setting, medical records are often incomplete. Therefore, I had no way of knowing the site of lesion that resulted in aphasia, or what premorbid and/or comorbid medical issues the participant may have had (i.e., dementia). This participant’s performance may indicate that the study’s procedures require further simplification.

**Future Research**

Results of this study support strong content validity of photographic representations of SAQOL-39 items for a small group of people with mild to moderate aphasia. However, further research is necessary with a larger sample that can better represent the different types and severities of aphasia. A larger sample with equal representation among severity levels would allow researchers to test statistical hypotheses, and be able to generalize findings. Future studies might consider a simpler interview format for the rating task. For example, a computer display along with a structured investigator-led interview might reduce the cognitive load and working memory to facilitate task comprehension. Consistent scaffolding and cueing might involve scripted dialogue (i.e., the investigator says, “Look at this picture. What do you think is happening in the picture?,” “Now look at this question. It says, ‘How much trouble did you have climbing stairs?’”, “Do you think the picture matches that question about climbing stairs? Pick a number 1 – 7 to rate how well you think the picture matches the question.”
Many participants commented that some photographs were difficult to rate because they could not discern whether the person in the photograph was having trouble with the concept in the written question. Participants appeared to understand the general concept of each photograph, but the questions that specified having “trouble” with tasks sometimes required more time, discussion with the investigator, or prompted a lower rating. It may be easier for people with aphasia to associate visual stimuli with the written questions if the stimuli more closely resemble the difficulties assessed in the SAQOL-39 questions by displaying exaggerated facial expressions and body language conveying the questions’ targeted difficulties. Future studies may consider retaking photographs to capture more facial expressions that demonstrate difficulty. Alternatively, a video stimuli format may be even more clear and beneficial to people with aphasia. For example, a short video clip of a man walking and then stopping to rest with a pained facial expression may be clearer to people with more severe aphasia when paired with SAQOL-39 Item 7, which asks, “How much trouble did you have walking without stopping to rest? Or using a wheelchair without stopping to rest?” (Hilari, 2003, p. 5). This item was particularly difficult for participants in this study to rate, as evidenced by the lower mean rating (5.13), highest SEM (1.96), longest mean response time (39203.88 ms), and lower rounded mean (5).

The use of photographs to increase accessibility of the SAQOL-39 for individuals with severe aphasia is promising. The current results indicate that with only minor adjustments this same method and images could be made usable with people with moderate to severe aphasia as well. More contextualized photographs or video stimuli along with an interview format may provide the increased assistance necessary to further establish reliability of the stimuli to represent SAQOL-39 items for people with aphasia.
Conclusion

This study established strong preliminary content validity of photographic representations of SAQOL-39 questions among a sample of adults with mild to moderate aphasia. The results support previous findings from Brouwer (2013) in which adults without aphasia rated the same photographs as highly similar to SAQOL-39 items. With further research, we may enable people with severe aphasia to independently report on their QoL. If we can provide stimuli to assist individuals with severe aphasia to independently complete the SAQOL-39, clinicians will at last be able to tailor therapy goals and activities based on their clients’ personal views of the effects aphasia has had on their QoL. The incorporation of QoL reports by people with severe aphasia will improve speech-language pathologists’ ability to complete a more thorough assessment, deliver more effective treatment, and better understand the lives of people with severe aphasia.
REFERENCES


visual scene display prototype. *Journal of Medical Speech-Language Pathology, 15*, 305-317.


### APPENDIX A: ACRONYM DICTIONARY

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<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AAC</td>
<td>Alternative and Augmentative Communication</td>
</tr>
<tr>
<td>ASHA</td>
<td>American Speech-Language-Hearing Association</td>
</tr>
<tr>
<td>BDAE</td>
<td>Boston Diagnostic Aphasia Examination</td>
</tr>
<tr>
<td>COR Lab</td>
<td>Communication Outcomes Research Laboratory</td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebrovascular attack</td>
</tr>
<tr>
<td>FAST</td>
<td>Frenchay Aphasia Screening Test</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability, and Health</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>LSU</td>
<td>Louisiana State University</td>
</tr>
<tr>
<td>LSU-SLHC</td>
<td>Louisiana State University- Speech, Language, Hearing Clinic</td>
</tr>
<tr>
<td>MCA</td>
<td>Middle cerebral artery</td>
</tr>
<tr>
<td>NIHSS</td>
<td>National Institute of Health Stroke Scale</td>
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<tr>
<td>PWA</td>
<td>Person/people with aphasia</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
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<td>RCBA</td>
<td>Reading Comprehension Battery for Aphasia</td>
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<td>SAQOL-39</td>
<td>Stroke and Aphasia Quality of Life Scale-39 items</td>
</tr>
<tr>
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<td>Stroke Impact Scale</td>
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<tr>
<td>SEM</td>
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<tr>
<td>SEM RT</td>
<td>Standard error of the mean response time</td>
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<td>Stroke Specific Quality of Life Scale</td>
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<td>RT</td>
<td>Response time</td>
</tr>
<tr>
<td>WAB</td>
<td>Western Aphasia Battery</td>
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<tr>
<td>WHOQOL</td>
<td>World Health Organization Quality of Life (e.g., The WHOQOL Group)</td>
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APPENDIX B: LOWEST RATED ITEMS

SAQOL-39 Question 7. “How much trouble did you have walking without stopping to rest?
Or using a wheelchair without stopping to rest?” (Hilari, 2003, p. 5).

<table>
<thead>
<tr>
<th>Mean Rating</th>
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Frequency Distribution of Ratings

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<table>
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| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 6+7=|%
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APPENDIX C: IRB APPROVAL

ACTION ON PROTOCOL APPROVAL REQUEST

TO: Neila Donovan
    COMD

FROM: Robert C. Mathews
    Chair, Institutional Review Board

DATE: November 11, 2013
RE: IRB# 3419

TITLE: Stroke and Aphasia Quality of Life Scale-39: Investigating Preliminary Content Validity of Picture Representations of Questions by People with Mild to Moderate Aphasia


Review type: Full ___ Expedited _X_ Review date: 11/12/2013

Risk Factor: Minimal ___ Uncertain _____ Greater Than Minimal_____

Approved___ X___ Disapproved_________

Approval Date: 11/12/2013 Approval Expiration Date: 11/11/2014

Re-review frequency: (annual unless otherwise stated)

Number of subjects approved: 20

Protocol Matches Scope of Work in Grant proposal: (If applicable)_____

By: Robert C. Mathews, Chairman

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING – Continuing approval is CONDITIONAL on:

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU’s Assurance of Compliance with DHHS regulations for the protection of human subjects*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
8. SPECIAL NOTE:
   *All investigators and support staff have access to copies of the Belmont Report, LSU’s Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb
Application for Approval of Projects Which Use Human Subjects

This application is used for projects/studies that cannot be reviewed through the exemption process.

- Applicant, please fill out the application in its entirety and include two copies of the completed application as well as parts A-E, listed below. Once the application is completed, please submit to the IRB Office for review and please allow ample time for the application to be reviewed. Expedited reviews usually takes 2 weeks. Carefully completed applications should be submitted 3 weeks before a meeting to ensure a prompt decision.

- A Complete Application Includes All of the Following:
  (A) Two copies of this completed form and two copies of part B thru F.
  (B) A brief project description (adequate to evaluate risks to subjects and to explain your responses to Parts 1 & 2)
  (C) Copies of all instruments to be used.
  *If this proposal is part of a grant proposal, include a copy of the proposal and all recruitment material.
  (D) The consent form that you will use in the study (see part 3 for more information.)
  (E) Certificate of Completion of Human Subjects Protection Training for all personnel involved in the project, including students who are involved with testing or handling data, unless already on file with the IRB. Training link: [https://php.rntraining.com/users/login.php](https://php.rntraining.com/users/login.php)
  (F) IRB Security of Data Agreement: [https://sites01.lsu.edu/wp/cred/files/2013/07/Security-of-Data-Agreement.pdf](https://sites01.lsu.edu/wp/cred/files/2013/07/Security-of-Data-Agreement.pdf)

1) Principal Investigator:
*Pi must be an LSU Faculty Member

Nelia Donovan, PhD, CCC-SLP
Rank: Associate Professor

Dept: COMD  Ph: 578-3938  E-mail: ndonovan@lsu.edu

2) Co Investigator(s): please include department, rank, phone, and e-mail for each

Lea Leise-Jensen, BS
Rank: Graduate Clinician
Dept: COMD
Phone/Email: (973) 534-9671 / lheise1@lsu.edu

3) Project Title:

Stroke and Aphasia Quality of Life Scale-39: Investigating Preliminary Content Validity of Picture Representations of Questions by People with Mild to Moderate Aphasia

4) Proposal Start Date: 10/9/13  5) Proposed Duration Months: 12 months

6) Number of Subjects Requested: 20  7) LSU Proposal #: N/A

8) Funding Sought From: N/A

ASSURANCE OF PRINCIPAL INVESTIGATOR

I accept personal responsibility for the conduct of this study (including ensuring compliance of co-investigators/co-workers) and all the documents submitted herewith. I also understand that copies of all consent forms must be maintained at LSU for three years after the completion of the project. I leave LSU before that time, the consent forms should be preserved in the Departmental Office.

Signature of PI:  Date: 9/24/13

ASSURANCE OF STUDENT/PROJECT COORDINATOR

I agree to adhere to the terms of this document and am familiar with the documents referenced above.

Signature of Co-PI:  Date: 9/24/13
IRB #
PI: Neila J. Donovan, Ph.D.
Co-Investigator: Lea Heise-Jensen, B.S.

Informed Consent Form

Project Title: Stroke and Aphasia Quality of Life Scale-39: Investigating Preliminary Content Validity of Picture Representations of Questions by People with Mild to Moderate Aphasia

Performance Site: LSU Speech, Language, and Hearing Clinic; Communication Outcomes Research Lab, in the participants' home, or a location in the community chosen by the participant

Investigators: The following investigators are available for questions, M-F 8:30 a.m. – 4:30 p.m.
Lea Heise-Jensen, B.S. Communication Disorders Dept., LSU (973) 534-9671
Neila Donovan, Ph.D. Communication Disorders Dept., LSU (225) 578-3938

Purpose of the Study: The purpose of this study is to determine if selected photographs match text statements.

Inclusion Criteria: The people chosen for this study are:
- Between 65 and 85 years of age;
- English is their first and only language;
- Have suffered 1 or more left hemisphere cerebrovascular accidents (CVA);
- Have mild to moderate aphasia;
- Demonstrate adequate vision and hearing aided or unaided; and
- Demonstrate adequate reading comprehension for the study’s tasks.

Exclusion Criteria: No history of other neurological or language disorders; currently pregnant

Description of the Study:

A. You will be asked to complete a questionnaire over the telephone to see if you might be a candidate for the study. If you qualify for the study, we will meet and you will be asked to complete a short screening process (Part A).
B. If you pass Part A, you will be given a survey to rate how closely pictures match a text statement by pushing a button on a computer keyboard. The survey may take about 1 hour to complete.
C. The entire process (Parts A and B) can be completed in one 2 hour session but may require a second session depending on the amount of time it takes you to complete the screener/survey.

Initiauls of Participant

Page 1 of 2
Benefits: There are no benefits to you for participating in the study except knowing that the information we learn may, in the future, help people who had a stroke that resulted in speech and language problems.

Risks: There are no known risks. You may take breaks as needed if you get tired.

Right to Refuse: Participation is voluntary. If you decide that you do not want to be in it, YOU CAN REFUSE AT ANY TIME as we conduct the study. There is no penalty for not being in the study. We will be glad to include you in future studies even if you decide to stop participating in this one.

Privacy: Your privacy is protected in this study. Everything about you being in the study will be kept a secret. You will be identified by a secret code, and only the people working on this study will be able to see your records. We keep all of your records in a locked file cabinet or in password-protected computer files that others cannot see. If the results of this research are published in a professional journal or meeting, you will not be identified in any way.

Financial Information: There is no cost for participation in the study, and compensation will not be provided to you for participating in the study.

Thank you for your participation!

If you have any questions about the study you can ask the examiners at any time.

Signatures:

This study has been discussed with me and all of my questions have been answered. I understand that if I have any questions, I can call the investigator, Neila Donovan, at (225) 578-3938 or co-investigator, Lea Heise-Jensen, at (973) 534-9671. I understand that if I have any questions about my rights or any concern about research, I can contact Robert C. Mathews, Institutional Review Board, at (225) 578-8692.

_________________________  ______________________
Signature of Participant                      Date
VITA

Lea Jane Heise-Jensen was born in Ringwood, New Jersey. She attended the Pennsylvania State University where she earned her Bachelor of Science degree in Psychology with a concentration in Biological and Evolutionary Sciences in May 2010. She began her Master of Arts degree in August 2012 at Louisiana State University and expects to graduate in May 2014. Her thesis was completed under the guidance of Dr. Neila J. Donovan. Upon graduation, Lea plans to work as a clinical fellow speech-language pathologist in an acute care hospital setting with a special interest in treating stroke and traumatic brain injury patients.