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The Effects of Photographic Representations on Scores of the Stroke and Aphasia Quality of Life Scale-39 for People with Aphasia

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THE EFFECTS OF PHOTOGRAPHIC REPRESENTATIONS ON SCORES OF THE STROKE AND APHASIA QUALITY OF LIFE SCALE-39 FOR PEOPLE WITH APHASIA

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LIST OF ACRONYMS

AAC	Augmentative and Alternative Communication
ASHA	American Speech-Language-Hearing Association
CVA	Cerebrovascular Accident
HRQOL	Health-Related Quality of Life
IRB	Institutional Review Board
LSU	Louisiana State University
LSU-SLHC	Louisiana State University- Speech, Language, Hearing Clinic
M	Mean
PWA	People with Aphasia
QOL	Quality of Life
SAQOL	Stroke and Aphasia Quality of Life Scale
SD	Standard Deviation
SLP	Speech-Language Pathologist
SSQOL	Stroke Specific Quality of Life

ABSTRACT

Background: The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) survey was designed explicitly for people with aphasia (PWA). Aphasia is an acquired language disorder that may affect comprehension, expression, reading, and writing deficits. Those with severe aphasia may not be able to read the questionnaire. The literature shows that high-context color photographs accompanying text may assist PWA improve their comprehension of questions. A previous study provided face validity for a set of high-context color photographic representations of the SAQOL-39 items. The present study aimed to determine whether these photographs would aid PWA to rate the SAQOL-39 with more than text alone.

Methods: This within-subject repeated measures experiment included the independent variables for stimuli presentation, AAC-Modified or Text-Only, and three dependent variables, response time, rating consistency, and AAC-Modified helpfulness. A convenience sample of PWA between 40 and 89 years old (n=4) attended two separate 1-hour experimental sessions on different days. Stimuli were randomized by the two conditions (AAC-Modified and Text-Only) on day one and then reversed on the second day. The stimuli were presented via E-Prime on a laptop computer, which recorded responses and response time. Helpfulness was rated on a visual analog scale.

Results: Parametric and non-parametric tests indicated no significant difference in response time (t=-1.26, $p > .10$; Z = -.730, $p = .465$) between the two conditions. Consistency of ratings between the two conditions was analyzed descriptively and showed no differences between means (AAC-Modified [M = 3.64 ms, SD = 0.46]; Text-Only [M = 3.69, SD =0.42]). Finally, three of the four participants rated the AAC modifications “very helpful,” above 80% helpful, on the visual analog scale.

Discussion: Unfortunately, the sample size was too small to draw definitive conclusions about whether the photographic representations of the SAQOL-39 items are objectively helpful for PWA or not. However, the majority of participants (75%) found the pictures to be "very helpful" in assisting them to self-report their own quality of life after aphasia. Further research with a larger sample size is necessary.

INTRODUCTION

Aphasia is a neurogenic communication disorder acquired after a lesion to the language dominant (typically left) hemisphere of the brain, where language comprehension, processing, and production are stored. The most common causes of aphasia are from a cerebrovascular accident (CVA) or traumatic brain injury (TBI) (Beukelman, Fager, Ball, & Dietz, 2007, Hilari, Needle & Harrison, 2012). The site of brain lesion causes deficits in receptive and expressive language, reading and symbol comprehension, and the ability to write (Hallowell & Chapey, 2008). Strokes and aphasia affect people worldwide. In the United States alone, over two million people are living with aphasia (National Aphasia Association, 2017). In addition to physical, cognitive, and language deficits, stroke survivors experience changes in their quality of life (QOL) due to the deficits they acquire from a stroke. Changes in QOL have important implications for all rehabilitation specialists, including speech-language pathologists (SLPs).

The American Speech-Language-Hearing Association (ASHA) *Scope of Practice in Speech-Language Pathology* states that SLPs provide services to improve the QOL for the patient by improving their ability to communicate (2016). With QOL being at the forefront of patient care objectives, QOL assessments are a valuable resource for evaluating patient status in many areas. The use of QOL scales allows healthcare professionals to initiate care that is patient-centered and monitor consequences of the patient's deficits associated with reduced QOL (e.g., social withdrawal due to language deficits) (Cruise, Worrall, Hickson, & Murison, 2005). In their 2015 article, Holt-Lunstad, Smith, Baker, Harris, and Stephenson reported that social isolation, as seen in many people with aphasia (PWA), places people at an increased risk for death at an earlier age. However, the deficits in auditory comprehension and reading that PWA may display

can cause their responses to QOL scales to be unreliable or invalid (Engell, Hutter, Willmes, & Huber, 2003; Cruise et al., 2005).

Consequently, PWA are commonly omitted from QOL assessments or patient proxies (i.e., people who interact with PWA regularly [e.g., caregivers, children, or spouses]) complete ratings on behalf of their partners (McColl, 2003 as cited in Cruise et al., 2005). However, the literature demonstrates that proxies tend to rate the QOL for their communication partners with aphasia as lower than the PWA would rate themselves (Cruise et al., 2005). Due to their lower QOL scores, proxies should only be used if no other option exists. The ideal preference is for the PWA to complete the QOL measure whenever possible.

While there are a number of health-related QOL rating scales available (e.g., Short Form 36 Heath Survey, Dartmouth Cooperative Functional Assessment Charts, etc.), only two QOL scales are available for people with stroke and aphasia (Eaton, P. Young, W. Fergusson, J. E. Garrett, & J. Kolbe, 2005; Ware & Sherbourne,1992, Thelander, Hoen, & Worsley, 1994). In 2005, Cruise et al. researched 30 PWA's QOL to investigate if proxies were reliable in the recording of QOL for their partners with aphasia. The researchers examined scores on the Dartmouth Cooperative Functional Assessment Charts (COOP Charts; Eaton et. al, 2005), the How I Feel About Myself well-being scale (Thelander, Hoen, & Worsley, 1994), and the Short Form 36 Heath Survey (Ware & Sherbourne,1992), which were self-recorded by PWA. The scores were analyzed across the domains of mental health, emotional, physical, and social scores. The proxies for the PWA were given the same assessments and were instructed to complete the assessments as if they were the patient to examine how their responses compared to the PWA's responses. The researchers discovered that proxies rated the QOL of their partners with aphasia significantly lower than the PWA rated themselves. These findings suggested that proxies may

not be reliable reporters for their partners' QOL. Therefore, proxy ratings for QOL should not be used interchangeably or in place of the PWAs' QOL ratings whenever possible (Cruise et al., 2005). Proxies may be asked to answer QOL ratings when the PWA's language deficits impede their ability to comprehend or respond appropriately to QOL measures. These results suggest that there is a need for a QOL scale targeted toward PWA with more severe aphasia.

This study aims to extend a previous study using the same experimental paradigm to validate the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) with augmentative and alternative communication (AAC) modifications that may make it more useful for individuals with aphasia (Studrawa, 2015).

LITERATURE REVIEW

What is Aphasia?

Aphasia is an impairment in communication resulting from damage to the language dominant (typically left) hemisphere of the brain (Beukelman, Fager, Ball, & Dietz, 2007). The damage that causes aphasia most often is from a CVA, and presently, the survival rate post-stroke is improving. Secondary to a CVA, survivors may have residual paralysis, loss of sensation, visual impairments, deficits in swallowing, and difficulty communicating (e.g., aphasia) (Clarke, Black, Badley, Lawrence, & Williams, 1999). Aphasia can present at different levels of severity, ranging from mild to severe impairment, with 40% of all PWA categorized as having severe, chronic aphasia (Beukelman et al., 2007). Specific to aphasia, CVA survivors may have communication deficits in auditory comprehension, expressive language, reading, and writing, making aphasia a multimodal disorder (Rosenbek, LaPointe, & Wertz, 1989 as cited in Ross & Wertz, 2003). PWA have high levels of depression, be socially isolated from friends, and perform fewer activities of daily living as compared to people without aphasia (Rosenbek, LaPointe, & Wertz, 1989 as cited in Ross & Wertz, 2003). The reduction in activities of daily living was not in areas of physical activity (i.e., walking or cleaning), but in areas of communication (i.e., shopping, work, or traveling) (Hilari, 2011). Some aspects affected by the CVA may significantly improve in the time after the stroke; however, the social effects caused by communication deficits secondary to aphasia may continue (Clarke et al., 1999; Hilari, 2011). Due to continued, long term deficits, aphasia impacts many aspects of QOL.

PWA report their QOL as significantly lower than people without aphasia; however, it is unknown which areas of QOL were rated lower by the PWA (Ross & Wertz, 2003). In 2003, Ross and Wertz researched the areas in which PWA rate themselves lower than people without

aphasia. This study aimed to examine the areas of QOL that were rated lower than others so that therapy could target the problem areas. Thus, QOL would determine the direction of therapy. The study had two participant groups, each with 13 males and five females. The first group included PWA between the ages of 40 to 80 years old. The inclusion criteria for all participants were as follows: no hearing loss below 40 dB, corrected visual acuity of at least 20/100, literate in English (at least pre-CVA), and one extremity with enough movement to point. The PWA included in the study met the following additional criteria: a history of at least one stroke with the most recent one at least six months before the study, damage to the left hemisphere of the brain, and a diagnosis of aphasia with no other known communication impairments. The people without aphasia had to self-report no history of communication deficit secondary to disease or brain injury.

Each participant in the study received two QOL measures: The World Health Organization Quality of Life Instruments (WHOQOL-BREF) and the Personal Wellbeing Index (PWI; Ross & Wertz, 2003). Participants rated themselves on written forms. The researchers performed an index of determination and a degree of overlap for each item to determine which facets of QOL differed between the two groups.

Results indicated that the PWA and the people without aphasia differed in three QOL domains: independence, social relationships, and environment (Ross & Wertz, 2003). The decrease in independence was related to difficulty in performing daily tasks, getting to work, and overall mobility. The decrease in social relationships was related to decreased support from friends and decreased satisfaction with their sex lives. Finally, changes in the accessibility of information, medical health services, and overall transportation (environmental contexts) decreased QOL (Ross & Wertz, 2003). Knowing where PWA differ from people without aphasia

allows for therapy to directly focus on improving quality of life. The participant's ability to reliably self-report their QOL, therefore, allows for treatment by healthcare professionals to take into account the patients' priorities. The information may then be used to create individualized healthcare and treatment goals.

Assessment of Quality of Life for People with Aphasia

QOL is defined by the World Health Organization Quality of Life group as a person's ability to participate in life, achieve their goals, and participate in their culture and values (WHOQOL Group, 1993 as cited in Ross & Wertz, 2003). QOL scales are used to assess areas critical to the individual patient and allow them to participate in their treatment; when given autonomy over healthcare, there is an overall improvement in the patient's health (Helm-Estabrooks, Haley, &Womack, 2007). QOL assessments have been developed and adapted over many years to fit the needs of different populations. The language deficits of PWA have necessitated the development of a QOL measure that takes each specific need into account. Research has demonstrated that PWA tend to rate their QOL after stroke and aphasia closer to pre-CVA level, select the first option in a list of choices, agree with a proxy, family member, or interviewer, and ignore questions they do not comprehend (Cruise et al., 2005). These results may be attributable to the QOL assessments demanding a higher level of linguistic and cognitive functioning and processing skills than the PWA have (Cruise et al., 2005).

QOL is a subjective measure that provides the most information when it is self-reported by PWA (Ross & Wertz, 2003). As previously stated, proxy respondents for PWA have a propensity to rate the QOL of PWA as significantly lower than a self-reported measure completed by PWA (Cruise et al., 2005). Due to the rote responses, PWA tend to give on QOL

measures, the development of a measure that they could self-report became a necessity. This need led to the development of the SAQOL-39.

Health-Related Quality of Life

When beginning treatment in a healthcare setting, health-related quality of life (HRQOL) is often used to assess the patient's perspective on the impact of a disease or disorder, typically within one of four domains: mental, social, physical, and family (Hilari, Byng, Lamping, & Smith, 2003). HRQOL is a subjective measure of the person's view of his or her ability to live a life he or she finds fulfilling. Understand the patient's perspective allows for targeted rehabilitation for people after a significant medical event or diagnosis (Hilari & Smith, 2009). However, HRQOL scales are often too linguistically complex for PWA to read and comprehend, leading to difficulty, including PWA in HRQOL research (Hilari & Byng, 2001). Therefore, a QOL measure specific to the deficits seen in stroke survivors was developed.

Stroke Specific Quality of Life

The Stroke Specific Quality of Life (SSQOL) scales are HRQOL scales designed to look at the psychometric areas most affected by a stroke (Hilari & Smith, 2009). Developers of SSQOL scales often exclude PWA due to their language and communication deficits. However, some researchers suggest that PWA are the most affected by a stroke. (Hilari & Smith, 2009). These participants are prone to social withdrawal and isolation, which affects their QOL (Hilari et al., 2003), so understanding QOL is especially critical to optimal outcomes for PWA.

The *ASHA Quality of Communication Life Scale* (ASHA QCL; Paul et al., 2004) measures the impact of ineffective communication secondary to acquired communication disorders. Some might consider the QCL to be a SSQOL scale because strokes cause a wide range of communication impairments, the most common being aphasia. However, because it is limited strictly to communication deficits, it has a minimal scope. In the development of the

ASHA QCL, 85 participants (71% PWA, 16% people with cognitive-communication impairments, and 13% of people with dysarthria) were used as the normative sample for the standardization of the test (Paul et al., 2004).

The SSQOL scale was developed in 1999 by Williams, Weinberger, Harris, Clark, and Biller to make an HRQOL tool that offered insight into the deficits commonly seen in patients post-CVA. At the time, the SSQOL scale was the only QOL measure specific to stroke survivors. While other HRQOL scales included stroke, they did not accurately address the full breadth of deficits stroke patients were left with that could affect their QOL. Thus, a focus group of 34 stroke survivors was asked to identify the three areas of deficit that affected them most. From the focus group responses, 12 domains emerged: family roles, energy changes, language, mood, mobility, personality, social, self-care, thinking, upper extremity function, work, and vision. Each domain included three to 12 questions participants rated on a 5-point Likert scale. The scales rated the need for assistance to complete a task, the amount of trouble encountered when attempting a task, and feelings of agreement towards statements. The SSQOL demonstrated good reliability, validity, and responsiveness (Williams et al., 1999).

PWA were not included in the development of the SSQOL scale, resulting in poor content validity for PWA (Hilari & Byng, 2001). In 2001, Hilari and Byng began the process of developing an interview-based version of the SSQOL for people with aphasia. The initial modifications included many format changes. The authors increased the font size and the number of questions per page was reduced to make it more aphasia-friendly. The scale was changed to an interview format that allowed the interviewer to record the responses from PWA. The SSQOL scale uses two five-point Likert scales ranging from “Couldn’t do it at all” to “No trouble at all” and “Strongly agree” to “Strongly disagree. The “Strongly agree” to “Strongly disagree” was

changed to a version with yes and no to make it easier for PWA to answer, based on feedback from a focus group comprised of people with mild to moderate aphasia. Finally, negative items (e.g., 'I didn't go out as often as I would like') were hard for people with aphasia to answer, so the researchers changed the wording to a question format rather than a statement (e.g., "Did you go out less often than you would like?"). Finally, the focus group listed things they felt were missing from the scale noting the following: more on their feelings (i.e., embarrassment and frustration when communicating), effects of aphasia on their partners, access to health services, and changes in their overall attitudes post-stroke (Hilari & Byng, 2001). These changes to the SSQOL eventually led to the SAQOL-39.

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

The SAQOL-39 is a reliable and valid QOL survey for PWA and can be used to determine priorities in their treatment (Hilari, Byng, Lamping, & Smith, 2003). The QOL of PWA is reportedly impacted by many aspects of the disorder including severity, depression, other health needs, and activity levels pre- and post-CVA (Hilari, 2011). To validate the SAQOL, 95 PWA (at least one-year post-CVA, with no known cognitive decline before the CVA, and living at home pre-CVA) participated in the study. After removing participants that were not able to self-report, 83 participant responses were analyzed for reliability, validity, and consistency. In the original development of the SAQOL, 87% of the participants were able to self-report their QOL, which reduced the need for proxies to report (Hilari et al., 2003). The authors suggest that this would allow most PWA and stroke survivors to be included in clinical trials as well.

The original 53 question SAQOL demonstrated acceptable validity and reliability; however, the subdomains initially proposed in the study were not supported. Therefore, the SAQOL-39 was analyzed using factor analysis and was found to be reliable, valid, and

acceptable with good internal consistency (Cronbach's alpha = .93). According to Hilari et al. (2003), the SAQOL-39 was adopted over the SAQOL with 53 questions because the 4 factor subdomains hypothesized to be most affected by stroke remained: physical, communication, psychosocial, and energy (Hilari et al., 2003).

Thus, the SAQOL-39 is a measure that can be used to assess QOL in clinical settings to guide treatment goals and measure treatment success (i.e., as a pre- and post-treatment measure). It allows for treatment priorities to be directed by the patients' self-reported QOL (Hilari et al., 2003).

Limitations for Moderate to Severe Aphasia

Research on the QOL of participants with moderate to severe aphasia is minimal. If PWA are included in HRQOL research, people with severe aphasia are typically excluded due to the challenges that their language deficits present in research (Hilari & Byng, 2009). The receptive and or expressive language difficulties present in severe aphasia can make it difficult to report on their quality of life. Thus, if one is to obtain QOL information for people with moderate to severe aphasia, the typical practice has been to have a proxy rate their communication partner's QOL. As explained previously, proxies have a propensity to rate their communication partner's QOL lower than a PWA would rate themselves (Hilari et al., 2007).

In 2009, Hilari and Byng researched the level of QOL impairment in people with severe aphasia via proxy responses to the SAQOL-39. Due to language and reading deficits, the PWA could not report for themselves. The researchers found that people with severe aphasia had QOL ratings that were significantly lower than people with mild to moderate aphasia. However, with no self-reported measures from the people with severe aphasia, it is hard to know how much lower their QOL is due to the proxy rating, which is typically lower than self-reported measures

(Hilari & Byng, 2009). These findings represent a gap in the research for self-reported QOL for people with moderate to severe aphasia.

Augmentative and Alternative Communication Modification for People with Aphasia

Augmentative and alternative communication (AAC) systems are methods or technology that aid speech and language for people with communication deficits (Wilkinson & Jagaroo, 2004). AAC systems range from photographs that can augment communication and contextualize a conversation to devices meant to be an alternative way for people to communicate altogether. AAC systems can be used to assist adults with acquired neurological conditions, such as aphasia, to improve communicative effectiveness for increased participation in their life roles, (i.e., social communication) (Beukelman et al., 2007). These systems allow people to interact with their environments socially, which is an area that PWA have deficits. AAC systems can be used as a focal point to aid in word retrieval and add visual aids to assist the communication partner in better understanding (e.g., when explaining a recipe, PWA can use a kitchen scene to explain steps and aid in retrieval of words like refrigerator) (Beukelman et al., 2007). Some AAC interventions for PWA have focused on supporting communication using visual scenes that are contextualized (i.e., scenes that show objects in relation to one another or in relation to people) rather than isolated pictures or line drawings (Beukelman et al., 2007). Visual scenes show object sizes in relation to other objects as well as demonstrate semantic relationships between objects (Wilkinson & Jagaroo, 2004). This added context allows for the conversation to have a central point. Participants in the conversation can utilize the context for mutual understanding between all parties involved in the exchange, leading to more effective communication (Beukelman et al., 2007). The visual scenes allow for PWA to access words and organize thoughts for expressive communication while allowing communication partners to be

better understood by PWA. (Hux, Buechter, Wallace, & Weissling, 2010). Color photographs and visual scenes are often used with PWA, as well. Wilkinson and Jagaroo (2004) found that using color on AAC devices allows for an increase in visual processing and enhances short-term memory. These additions may allow PWA better access to words they want to use. One study showed that participants were able to recall more from color scenes than from black and white ones, attributed to the increase in visual processing and memory (Wichmann, Sharpe, & Gegenfurtner, 2002 as cited in Wilkinson & Jagaroo, 2004).

Secondary to aphasia, PWA can have deficits in reading comprehension that prevent their participation in activities involving written text. In Dietz, Hux, McKelevy, Beukelman, and Weissling (2009), seven PWA with comorbid deficits in reading comprehension between the ages of 28 and 79 participated in a study that examined pictorial augmentation of written narratives. All participants had aphasia secondary to a left CVA at least three months before the study. Each participant received three narratives and one of three levels of visual support (no photographs, low-context photographs, or high-context photographs). After they read the narrative, researchers asked participants series of reading comprehension questions associated with the written passage. The results found that the accuracy of the responses and time to respond to the questions increased with both low-context and high-context visual supports. The participants also indicated that the pictures were helpful and decreased task difficulty. Participants rated the high-context photographs as "very helpful" and the low-context photographs as "moderately helpful" (Dietz et al., 2009). The researchers suggested that the longer response time of the participants could be secondary to the pictorial supports enhancing the participant’s ability to access their knowledge, which led to improved information processing but increased response time. The shorter response times, for the condition group without visual

support, could have been due to the participants not understanding the narrative (Dietz et al., 2009).

Another AAC modification for PWA includes making materials aphasia-friendly, which means simplifying or augmenting written material to allow for better reading comprehension (Brennan, Worrall, & McKenna, 2005). Aphasia-friendly modifications include simplifying word choices, simplifying complex grammar, increasing font size, pictorial augmentation of written text, and increasing white space between lines of text (Pound et al., 2001 & Rose et al., 2003 as cited in Brennan, Worrall, & McKenna, 2005).

In 2005, Brennan, Worrall, and McKenna investigated the effects of different aspects of aphasia-friendly augmentation. They recruited nine people (three females and six males) between the ages of 34 and 70 years old. All participants had to meet the following inclusion criteria: native English speakers, three or more years post-stroke, mild to moderate aphasia, seven or more years of education, no history of neurologic disease before the stroke, and adequate vision to read 12-point font. The participants were asked to read six sets of passages and complete the passage with a word or phrase. The first set had no aphasia-friendly modifications and was used as a control group. The second set was a passage with simplified word choice and less complex grammar. The third set was modified by making the font larger. The fourth set was adapted by increasing the white on the page between the lines in the passages. Set five was modified using Google images and clip art chosen by one of the researchers. Finally, set six was a combination of the previous sets incorporating all aspects of aphasia-friendly material (Brennan, Worrall, & McKenna, 2005).

The participants completed multiple passages with each type of modification listed above. The results indicated that the aphasia-friendly material showed a statistically significant

increase in the overall passage comprehension for the participants. They also found a possible effect of fatigue in the participants when asked to read the third set of six passages. The entire experiment was completed in one sitting, and the PWA reported increased fatigue as the passages progressed. They also found that every modification caused a statistically significant increase in reading comprehension, except picture augmentation. The researchers suggested that the picture modification could have been considered distracting for PWA as an explanation for no statistically significant increase when the photographs alone were added (Brennan, Worrall, & McKenna, 2005). One limitation of this study was that one person chose the photographs, which brings face validity into question. The pictures chosen were low-context pictures as well. This could be a reason for the photographs alone not being reported to have a statistically significant effect on reading comprehension.

Augmentative and Alternative Communication Modifications to the SAQOL-39

As discussed earlier, the original SAQOL-39 was not validated for individuals with more severe aphasia using the text and interview format alone. Therefore, research was undertaken in the LSU Communication Outcome Research Lab in 2013 to determine whether AAC modifications could be made to the SAQOL-39 using high-context color photographic representations to augment the written text for each of the 39 questions (Brouwer, 2013). The LSU Communication Outcomes Research Lab was the first known group to examine paired visual stimuli as AAC modifications to the SAQOL-39. No recent literature searches uncovered any new research concerning the SAQOL-39.

Developing the AAC modifications involved three steps. First, three undergraduate and graduate students in the Communication Sciences and Disorders department judged 84 photographs (two photographs per question with three additional practice questions) (Brouwer,

2013). The photographs were high-context color photographs that featured at least one adult depicting the actions associated with the questions on the SAQOL-39 (Brouwer, 2013). The reviewers were also asked to comment on what they thought about the pictures in general. The judges deemed the photographs acceptable if at least two out of three reviewers agreed that there was high correspondence with the SAQOL-39 questions. If both photographs for a question received the same ratings, the researcher chose the photograph to be used (Brouwer, 2013). The results demonstrated that two out of three reviewers showed a 95% agreement between the SAQOL-39 survey questions and at least one of Brouwer's photographs (2013). The researchers included these photographs as AAC modifications to the SAQOL-39 in the next phase of the study.

Following review and selection of the visual AAC modifications, 20 healthy-aging participants (ages 65-85) rated how similar the photographs were to the SAQOL-39 questions. The monolingual English-speaking participants possessed adequate hearing and vision and had no medical history of stroke, aphasia, neurological impairment, or language impairment (Brouwer, 2013). People without aphasia were used in this study to establish the face validity of the photographs to the SAQOL-39 questions. A computer software (E-Prime 2.0) was used to track the responses to the participants and was administered via laptop computer. The instructions were explained to the participants. The picture rating used a traditional 7-point Likert Scale ranging from “very dissimilar (1)” to “very similar (7)” (Brouwer, 2013).

The results showed that the participants agreed that the selected high-context color photographs were 95% valid representations for the SAQOL-39 questions. The mean rating for all responses was 6.06. Raters judged 93% of the photographs at or above 6 in 60% of the responses.

Modifications Validated for Mild to Moderate Aphasia

In 2014, Heise-Jensen investigated the face validity of Brouwer's (2013) research with participants who had mild-to-moderate aphasia. Ten adults between the ages of 30-89 were recruited for the study (Heise-Jensen, 2014). Each participant met the following inclusion criteria: monolingual English speaker, at least one previous CVA in the left hemisphere, no language impairment prior to stroke, and no other neurologic impairment. Each participant's aphasia severity was determined by the *Boston Aphasia Severity Rating Scale* (Goodglass et al., 2001; Heise-Jensen, 2014).

Heise-Jensen (2014) used the high-context, color photographs developed in the Brouwer (2013) study referenced above. The photographs featured at least one adult depicting the actions associated with the questions on the SAQOL-39 (Brouwer, 2013). Heise-Jensen (2014) copied each question from the SAQOL-39 verbatim to the E-Prime 2.0 computer program used to present the stimuli and track responses. Similar to the Brouwer (2013) study, this experiment had each participant rate the similarity of photographs to the SAQOL-39 text using a 7-point Likert scale (ranging from "very dissimilar (1)" to "very similar (7)").

The results indicated that the overall mean rating of the similarity of the photographs was 6.40 out of 7, meaning the photographs were rated as highly similar to the written questions with which they were paired (Heise-Jensen, 2014). As in Brouwer (2013), Heise-Jensen's results indicated a strong agreement between the photographic representations and the SAQOL-39 survey questions, further evidence for the face validity of the AAC modifications made. This study included PWA across three severity levels (mild, mild to moderate, moderate). Based on the severity levels, the response times of the participants were analyzed. Participants with mild aphasia had the shortest average response time; however, people with moderate aphasia

demonstrated more rapid responses than people with mild to moderate aphasia (Heise-Jensen, 2014). This suggested that the photographs may augment the ability for people with more severe aphasia to accurately complete the SAQOL-39. The overall intra-rater reliability was 93% indicating that the participants were consistent in their ratings of the photographic representations. Due to these findings, research was needed to verify these finding with moderate to severe aphasia.

Modifications for Moderate to Severe Aphasia

Following the findings of Brouwer (2013) and Heise-Jensen (2014), Studrawa (2015) conducted a pilot study to test how well people with moderate to severe aphasia would use the SAQOL-39 with AAC modifications to rate their QOL. Four PWA (54 to 78 years of age) participated in the study. The participants met the following inclusion criteria: monolingual English speakers, no history of prior language or neurological disorders, had one or more left hemisphere stroke, aphasia severity level of moderate to severe (as determined by the *Boston Aphasia Severity Rating Scale* [Goodglass et al., 2001]), adequate hearing, adequate vision, and no color-blindness (Studrawa, 2015).

Each participant was asked to complete the experiment in two different sessions within a week of each other. In the first session, the participants completed a mix of the Text-Only version of the SAQOL-39 and the SAQOL-39 with the photographic representations, with each participant completing only one survey. In the second session, the participants were required complete the remaining questions from the opposite version of the SAQOL-39 (Studrawa, 2015). Each participant sat in front of a computer to answer the questions. The Text-Only version of the SAQOL-39 was referred to as “Experiment A” and the text with photographs was referred to as “Experiment B” (Studrawa, 2015). The experiment type was varied in the session it was presented to account for possible bias from memory of the last version of the SAQOL-39

presented to the participants (Studrawa, 2015). Practice questions were used to train the participant on how to complete the experiment on the computer. Secondary to language impairments associated with moderate to severe aphasia, Studrawa (2015) developed a level of instruction rating to record the level of cueing needed to answer the question presented to the participant. This allowed for the level of cueing used for each question to be traced in the E-Prime software and analyzed to assess if the photographs reduced the level of instruction needed for PWA to complete the survey (Studrawa, 2015).

The results indicated that the photographic context did not change the result of the QOL ratings given by the participant (Studrawa, 2015). The response time was also analyzed to determine if the photographs lower the response time for the Text-Only version versus the text plus photographs. The results indicated that the response time increased when the photographs were present (Studrawa, 2015). This could be due to the presence of an additional stimulus to attend to and process. Studrawa (2015) also noted that the participant's severity level affected their response time, where participants with more severe aphasia required more time to respond. The last question analyzed whether the photograph paired with the text reduced the amount of cueing needed by the PWA to complete the SAQOL-39 (Studrawa, 2015). The results indicated that the photographs did not reduce the level of instruction needed to complete the task. However, due to the small sample size, the results could not be generalized, and further research would be needed.

In summary, Brouwer (2013) developed photographic representations for the 39 SAQOL questions and tested them on a non-brain injured population to validate the similarities between the questions and the photographs. With high similarity, Heise-Jensen (2014) researched these photographs as they applied to people with mild to moderate aphasia further validating the

stimuli. After Heise-Jensen's 2014 study, Studrawa (2015) sought to validate the photographs in a sample with moderate to severe aphasia. To summarize, in previous studies, the AAC modifications of the SAQOL-39 have demonstrated face validity between the photographs and the questions. The AAC modifications increased participants' response times as the severity of their aphasia increased. This could be due to an increase in the amount of information presented and an increase in the complexity of processing information for each participant. The photographic modifications also did not decrease the level of cueing needed for PWA to complete the survey. Aphasia-friendly adaptations for the SAQOL-39 have face validity.

Rationale for this Study

The current literature demonstrates the need for AAC modifications of QOL scales for PWA. Previous research has examined high-context, color photographic representations and demonstrated face validity for the SAQOL-39 questions for people with differing levels aphasia severity; this face validity should allow PWA to reliably self-report their QOL (Brouwer, 2013; Heise-Jensen, 2014; Studrawa, 2015). In 2015, Studrawa examined the high-context color photographs for the SAQOL-39 in people with moderate to severe aphasia; however, the study included only four participants. The current study's purpose is to extend the Studrawa (2015) study with a larger participant sample across a broader range of aphasia severity (i.e., mild to moderate-to-severe) to examine if the photographs augment the ability for PWA to self-report QOL.

Aim of the Proposed Study

This study aimed to examine whether AAC modifications (i.e., the adding of high-context, color photographs) would enable PWA to reliably self-report their QOL better than the existing Text-Only version. This study will be a partial replication of the Studrawa (2015) study

to include a larger sample size across a broader range of aphasia severity. The research questions addressed in this study are as follows:

1. Do people with aphasia differ in their response times to the Text-Only version of the SAQOL-39 as compared to the AAC-modified condition?

Based on the literature presented above (Dietz et al., 2009), I hypothesized that participants would have longer response times when the SAQOL-39 was presented with the AAC modifications to the survey. As suggested in Dietz and colleagues (2009), the AAC modifications may allow for deeper understanding and ability to relate the information to the world, which may lead to an increase in response times.

2. For people with aphasia, what is the item agreement between the Text-Only version of the SAQOL-39 and the AAC-modified condition?

I established the null hypothesis that PWA would not differ on their responses to the Text-Only version of the SAQOL-39 and their responses to the AAC-modified condition because there is no literature to support otherwise.

3. Do people with aphasia rate the AAC Modifications to the SAQOL-39 as more helpful than the text-only version of the SAQOL-39?

Based on the literature (Dietz et al., 2009), I hypothesized that participants would rate the AAC-modified SAQOL-39 as more helpful when completing the survey as compared to the original text-only version of the SAQOL-39. The participants in the Dietz et al. (2009) study rated the high-context photographs as “very helpful” in a reading comprehension task.

METHODS

Design

This was a prospective within-group study design. The independent variables were the two conditions: AAC-Modified and Text-Only. The three dependent variables included response time (ms), consistency of responses, and helpfulness of the photographs. The Louisiana State University Institutional Review Board approved this study on November 8, 2018. See Appendix A. Informed consent was acquired before beginning the collection of data. Due to the deficits in language comprehension and reading associated with aphasia, the following precautions were taken to ensure participants understood what the study entailed: (1) the consent form was presented to the participant verbally, in writing, and simplified when needed, (2) the consent form was presented to the caregivers in addition to the participant to ensure that they too knew what the study entailed, and (3) the informed consent was written in simplified language.

Participants

I planned to recruit 25 PWA using the following inclusion criteria: (1) between the ages of 40-89, (2) monolingual English speakers, (3) had experienced one CVA in the left hemisphere of the brain, (4) literate before the CVA, (5) no prior history of neurological damage or other language disorders, (6) met criteria for mild to moderate-to-severe aphasia based on the *Boston Aphasia Severity Rating Scale* (Goodglass et al., 2001), (7) adequate hearing (aided or unaided) to follow directions, (8) able to see in color as determined by *Ishihara Test for Color Blindness* (Picjiford, 1944), and (9) adequate vision (aided or unaided), as determined by the *Rosenbaum Pocket Vision Screener* (Rosenbaum, 1982), to read the stimuli presented. Participants were excluded from the study if they were pregnant, had previous neurological damage other than CVA, or were color blind.

Sampling Procedures

The participants in this study were recruited from the LSU – Speech, Language, and Hearing Clinic (LSU-SLHC) and the surrounding community through a convenience sampling method via flyer distribution and word-of-mouth. The areas of recruitment were concentrated around Baton Rouge and included support groups for stroke survivors, support groups for PWA, and rehabilitation centers.

To determine study eligibility, the investigator obtained the age, language status, and other demographic information from the participant via telephone or in-person interview. Once eligibility was determined, participants were screened for hearing, vision, and aphasia severity. When the screenings were passed and criteria met, the study was explained to those who were eligible. Questions regarding the study were answered and written informed consent was obtained.

Four PWA (three females and one male) participated in the study. The ages ranged from 57 to 80 years of age (M = 67.5 years, SD = 9.54 years*).* Aphasia severity was determined for each participant. Three participants were found to have mild-to-moderate aphasia, and one participant demonstrated moderate-to-severe aphasia. The demographics of the participants are displayed in Table 1. In addition to the aphasia severity rating, a reading comprehension score was obtained for each participant. The participants were asked to read 10 sentences/paragraphs and answer a reading comprehension question regarding the stimulus. These sentences and paragraphs were taken from the *Boston Diagnostic Aphasia Examination- 3rd edition*, with established validity of reading comprehension (Goodglass et al., 2001). The investigator also took note whether the reading comprehension task took an excessive amount of time (above 45 minutes to complete ten questions). Reading comprehension was not an inclusion criterion

because the SAQOL-39 may be administered in an interview format. See Table 1 for all demographic information.

Table 1. Participant Demographics

ID #	Age (Years)	Sex	Aphasia Severity	Aphasia Severity Score	Reading Comprehension Score
101	57	Female	Mild-to-moderate	4	6*
102	65	Female	Mild-to-moderate	4	10
103	80	Male	Moderate	3	10*
104	68	Female	Moderate-to-severe	1.6	6
M age = 67.5 years, *SD* = 9.54					

*Reading comprehension questions (10) took over 45 minutes

Screening and Assessment Instruments

The following screening assessments were given. The investigator completed the *Boston Aphasia Severity Rating Scale* (Goodglass et al., 2001) after conversation with each participant to determine the degree of aphasia severity. During the aphasia severity tasks, hearing was also examined. Finally, vision was assessed using the *Rosenbaum Pocket Vision Screener* (Rosenbaum, 1982) and the *Ishihara Test for Color Blindness* (Picjiford, 1944). A reading comprehension section of the *Boston Diagnostic Aphasia Examination* (Goodglass et al., 2001) was given to determine the participant's reading comprehension level. The aphasia severity and vision screening and assessment measures described below have established validity and reliability.

Aphasia Severity

The investigator rated each participant's aphasia severity based on *The Boston Aphasia Severity Rating Scale*, a valid and reliable scale used by clinicians and researchers in the field of Communication Disorders (Goodglass et al., 2001). *The Boston Aphasia Severity Rating Scale* includes ratings of zero to five, obtained through unstructured and structured conversation and a picture description task. The ratings are described in Table 2 below. Two judges trained in

aphasia assessment and treatment listened to the recorded language samples and assigned the severity ratings based on phrase length, prosody, grammar, word finding, and auditory comprehension. Participants in this study had severity ratings ranging from Moderate-to-Severe to Mild-to-Moderate (1.66 to 4, respectively). As described above, two experienced raters assigned severity ratings to each participant based on unstructured and structured conversation and a picture description task. To determine inter-rater reliability, the ratings were averaged for each investigator and the averages were then compared. A 90% agreement for the severity level of the participants between the two investigators was considered acceptable.

Table 2. Aphasia Severity Ratings from the *Boston Aphasia Severity Rating Scale**

The Boston Aphasia Severity Rating Scale		
Rating	Aphasia Severity Level	Description of Characteristics
5	Mild	Minimal discernible speech handicap; the patient may have subjective difficulties that are not obvious to the listener.
4	Mild-to-Moderate	Some noticeable loss of fluency in speech or facility of comprehension, without significant limitation on ideas expressed or form of expression.
3	Moderate	The patient can discuss almost all everyday problems with little or no assistance. Reduction of speech and/or comprehension, however, makes conversation about specific material difficult or impossible.
2		Conversation about familiar subjects is possible with help from the listener. There are frequent failures to convey the idea, but the patient shares the burden of communication.
1	Moderate-to-Severe	All communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. The range of information that can be exchanged is limited, and the listener carries the burden of communication
0	Severe	No usable speech or auditory comprehension.

Hearing

The researcher judged participants' hearing based on their ability to participate in conversation and follow simple direction, aided or unaided.

Vision

The researcher screened participants using *The Rosenbaum Pocket Vision Screener* to determine visual acuity via a display card containing numbers and letters (Rosenbaum, 1982). Each participant held the card approximately 14 inches from their face, and the researcher asked that each line on the card was read aloud. Participants had to demonstrate visual acuity at 20/100 to participate in the study. They also had to pass the color blindness screening using the *Ishihara Test for Color Blindness* (Picjiford, 1944).

Materials

E-Prime

E-Prime 2.0 software suite (Psychology Software Tools, Pittsburg, PA) was used to develop and run the experiments. The software collected precise data on two of our dependent variables: response time and response ratings. E-Prime 2.0 was used to present both the Text-Only condition and the AAC-Modified condition while obtaining the Likert scale rating and the speed at which the participant responded in milliseconds. E-Prime presented the quetions in random order in each experiment. The experiment was programed by a Communication Outcomes Research Lab research assistant who had experience with E-Prime 2.0, with assistance from an E-Prime 2.0 specialist as needed.

SAQOL-39

The questions from the SAQOL-39 were copied into the computer software verbatim. The SAQOL-39 is divided into two sections with different rating scales (Hilari et al., 2003). The first section of the SAQOL-39 requests that participants rate the trouble they encounter when attempting specific tasks. The second section has questions asking for participants to respond regarding their feelings towards their productivity, family life, and social life.

Photographs

The items from the SAQOL-39 were presented using high-context color photographs developed in Brouwer's (2013) study. These photographs were found to correspond to the questions in the survey. The photographs were taken with a Nikon D40 digital camera with a Nikon AF-S DX Nikkor 55-200mm lens. The camera was set to automatic mode to take the photographs.

Likert Scales

The SAQOL-39 uses two five-point Likert scales to elicit responses from participants, rating how each item represents the participant's life post-stroke. They are asked to rate their feelings, as well as the trouble they encounter during different activities of daily living. These Likert scales were copied directly from the SAQOL-39; however, colors were applied to the background to allow for the participant to key in their answers. The original Likert scale will be presented on boxes containing different background colors (i.e., Teal, Cyan, Silver, Lime, Yellow). These scales were displayed with the photographs and with the Text-Only condition.

***Trouble Questions*.** The Likert scales for the questions regarding trouble with daily activities ranged from "I couldn't do it at all" to "No trouble at all." An example of a trouble question would be as follows: During the past week, how much trouble did you have standing? Each of the items on the Likert scale were assigned a color for the participant to record their responses. They are as follows:

1. I couldn't do it at all - Teal
2. A lot of Trouble - Cyan
3. Some trouble - Silver
4. A little trouble - Lime
5. No trouble at all - Yellow

***Feeling Questions*.** The Likert scales for questions regarding the PWA's feeling towards different activities ranged from "Definitely Yes" to "Definitely No". An example of a feeling questions would be as follows: During the past week, did you feel irritable? Each of the items on the Likert scale were assigned a color. They are as follows:

1. Definitely Yes - Teal
2. Mostly Yes - Cyan
3. Not sure - Silver
4. Mostly No - Lime
5. Definitely No – Yellow

Helpfulness Scale

A visual analog scale (VAS) was used to measure attitudes of helpfulness. According to Hayes and Paterson (1921), using a VAS is a "graphic rating method" that measures subjective characteristics and psychometric responses. The VAS used in this study was a four-inch line anchored on the left by "Not Helpful" and on the right by "Very Helpful." Each participant received the following instructions: "You have been shown statements with and without pictures. Place a mark on the line based on how helpful or unhelpful the pictures were." The participant then marked the helpfulness of the AAC-modified condition. The mark on the scale was then measured with a ruler to give the exact inches measured. Finally, the rating was converted to a percentage of helpfulness. See Figure 1.

Figure 1. Helpfulness Visual Analog Scale

Data Collection

Data were collected using a computer software program called E-Prime. This program displayed the questions from the test in written form, as well as whether questions were presented with or without the high-context color photographs, and adapted Likert scales. The software collected data on participants' responses and rate at which they respond in milliseconds. The experiments were presented to each participant on a Dell Latitude E5540 laptop computer.

Procedures

Once all participants had given informed consent and met the inclusion criteria data collection using E-Prime began. The location of the experiment was chosen by the participant. Each participant was asked to attend two sessions within a week. The participant was placed in front of a Dell Latitude laptop computer with the E-Prime software. Each session, the participant's task included questions from the Text-Only version and the AAC-Modified version of the SAQOL-39. Half of each question type was presented in each session. Each question of the SAQOL-39 was presented as a Text-Only version and as the AAC-Modified version. If the question was presented in session I with the AAC modifications, then it was presented in session II as the Text-Only version. The order of the stimuli was randomized for each participant across each session. This was done to account for a possible order effect of the questions and or participant fatigue.

Before each session, the researcher trained the participant on how the experiment worked. First, each participant received an example of the task that would be asked. Next, the participant was presented with three of the six practice questions to ensure that the tasks were understood. These questions also allowed for the participant to become familiar with the E-Prime software and the computer. Three of the practice questions were Text-Only questions and three were AAC-Modified questions. The researcher gave continuous cues to rate themselves on each item. The rating scale was explained as needed.

Task instructions for each participant were presented on the screen using the E-Prime software. The instructions were developed from three protocols: the SAQOL-39, the Brouwer (2013) protocol, and the Studrawa (2015) protocol. Like the SAQOL-39, there were two types of Likert scale response formats, and there was an introduction before each type of question (Hilari, 2003). The introduction slides for each type of question format were developed in Studrawa's 2015 study. They are presented below:

1. Overall introduction slide:

   We would like to know how you are doing with activities or feelings that can sometimes be affected by a stroke.

   Each question will ask about a specific activity or feeling.

   For each question, think about how you have been in the past week.

   Press any key to continue.

2. Introduction slide for questions about trouble with activities:

   The first set of questions ask about HOW MUCH TROUBLE you have with DAILY ACTIVITIES.

Press the key that best describes HOW MUCH TROUBLE you have had with each activity IN THE PAST WEEK.

Press any key to continue.

3. Introduction Slide for questions about problems or feelings after stroke:

The next part is about PROBLEMS or FEELINGS that some people have after their stroke.

Press the key that best describes HOW YOU FELT DURING THE PAST WEEK.

Press any key to continue.

For each question presented in the Text-Only version, the E-Prime software presented the directions, the question, and the Likert scale from the original SAQOL-39. As in Studrawa (2015), the original Likert scale was presented on boxes containing different background colors (i.e., Teal, Cyan, Silver, Lime, Yellow). For each question in the AAC-Modified version, the E-Prime software will display the directions, the question, the photograph, and the Likert scales.

The order in which the stimuli were presented to each participant was randomized. After the participant had completed the practice questions, the researcher stopped to answer any questions the participant had. Once questions were answered and the participant felt ready to continue, the SAQOL-39 experiment questions began. During each session, a total of 52 questions were presented; there are thirty-nine questions with and without AAC modifications, six questions that are repeated for reliability (three Text-Only version and three with the AAC modifications), and six practice questions (three Text-Only version and three with the AAC modifications). Questions 9, 18, and 33 (randomly selected) were repeated for reliability. The E-Prime software recorded the ratings for each question and the response time in milliseconds for each question. Pictures of the screens for each type of question are provided below:

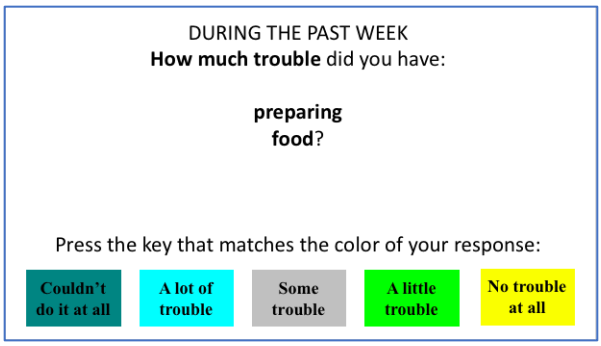

Figure 2. Screenshot of Text-Only Condition

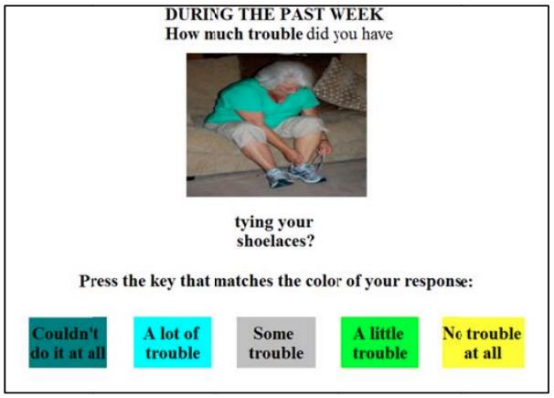

Figure 3. Screenshot of AAC-Modified Condition

The investigator gave cues to participants, as needed, based on the severity of their language impairment. Cues included repeating the directions, explaining a question's meaning, explaining the Likert scale units, and explaining a photograph. The SAQOL-39 was designed so that all of these cues listed, with the exception of explaining the photograph, were allowable.

Finally, following the second session, the participants were asked to complete the VAS to rate the helpfulness of the photographs presented in the AAC-Modified condition.

RESULTS

Parametric, non-parametric, and descriptive statistics were used to address the experimental questions based on results from SPSS v. 24. Non-parametric and descriptive statistics were required, secondary to the small sample size. A Wilcoxon Signed-Rank test was completed to compare the response times of participants in the text-only condition compared to the AAC-modified condition. The helpfulness of the photographs and the consistency of the answers between the two conditions were analyzed descriptively. Inter-rater reliability was calculated to ensure agreement between the two raters of participants' aphasia severity. The *Boston Aphasia Severity Rating Scale* (Goodglass et al., 2001) was utilized to assess the participants' aphasia severity across three situational contexts: unstructured conversation, structured conversation, and picture description.

Question 1

Do PWA differ in their response times to the Text-Only version of the SAQOL-39 as compared to the AAC-Modified condition? Response time was recorded in milliseconds (ms) using E-Prime software. See Table 3.

Using SPSS (v.24), a Shapiro-Wilk test was conducted to determine if the data was normally distributed for each condition, the AAC-Modified condition (*M = 521605.25 ms, SD = 306085.38 ms*) and the Text-Only condition (M = 557891.25 ms, SD = 354695.77 ms). Results were found to have a normal distribution for both the AAC-Modified condition (W = 0.940) and the Text-Only condition (W = 0.962). A Paired Samples T-Test was conducted to analyze the results. We hypothesized a longer response time for the AAC-Modified condition. The results of a paired samples t-test failed to support this prediction, t=-1.26, $p > 0.10$.

Although t-tests are robust for small samples, due to the very small sample size nonparametric analyses were conducted. The Wilcoxon Signed-Rank test was utilized to the compare response times between the two experimental conditions: AAC-Modified Condition and the Text-Only condition. The results of the test (a = .05) demonstrated no differences between the two conditions (z = -0.730, p = 0.465). See Table 4 regarding this information.

Table 3. SAQOL-39 Response Times (ms) by Participant and Condition

SAQOL-39 Item	Participant 101		Participant 102		Participant 103		Participant 104	
	AAC	Text	AAC	Text	AAC	Text	AAC	Text
1	20482	11470	3947	3914	9818	13456	42105	35944
2	12447	10164	5041	5596	10733	9277	48149	44711
3	13967	7021	5355	2915	12680	9571	17602	14520
4	6659	11560	4030	2101	13510	8413	11894	13462
5	10846	6657	5004	5443	12001	20346	42088	18930
6	13719	5326	1790	2598	26853	23471	8795	24075
7	15374	8071	5130	5367	18878	12941	42052	64335
8	13138	7142	3759	5125	10904	10833	12824	17228
9	15275	5503	2709	3969	11706	9082	15416	12575
10	13368	10418	3318	2710	9516	11658	35422	25697
11	8646	11056	6263	3622	12397	16008	41652	23912
12	6495	13725	5573	3516	11614	14771	13270	53818
13	5625	7699	9049	4668	7138	8842	24031	40858
14	6536	14132	4840	3504	10281	10470	22914	25227
15	7168	21759	6224	2266	8570	12516	23550	40347
16	11210	11254	5104	3277	11817	15438	13501	12555
17	6707	23435	4954	4041	10872	10699	24610	53044
18	7193	35342	4409	4355	12671	15791	22326	23675
19	12106	18486	7453	3747	9958	12715	101941	31507
20	9057	17528	3476	4573	15283	18469	28814	28469
21	12694	14421	4404	4965	9958	12702	35457	23658
22	18802	5740	2555	2728	13191	12245	15766	25110
23	52214	7715	3171	3648	10274	7591	47499	27529
24	11994	4797	2521	9844	14189	8424	47499	9335
25	10187	5230	2940	3815	11020	11558	15678	18375

(table cont'd)

SAQOL-39 Item	Participant 101		Participant 102		Participant 103		Participant 104	
	AAC	Text	AAC	Text	AAC	Text	AAC	Text
26	2480	11211	2779	3502	22237	15148	9827	14885
27	21598	10865	6781	7430	27908	14132	13219	40142
28	12130	5061	10110	3706	11979	11300	12377	14942
29	10195	9767	5190	4872	17179	8575	10555	26080
30	13481	15481	5405	5939	10406	12194	12558	12201
31	19079	15593	2592	2685	13092	11595	11901	11295
32	11123	9406	2386	2500	9699	10153	11413	15481
33	5580	11549	3927	2307	9386	10639	12255	9297
34	10269	19533	3887	3481	12142	14945	11848	16098
35	11675	17138	4541	4102	9619	11879	9293	9458
36	17140	69762	7122	6931	15243	14394	11258	31844
37	11932	24821	4326	2473	8601	10920	15471	22291
38	11675	11412	4965	3051	11599	13989	14856	14799
39	3334	28920	3042	4726	13203	16653	12938	73873

Table 4. Summary of the Wilcoxon Signed Rank Test for Response Time

		N	Mean Rank	Sum of Ranks	Test Statistic	Asymptotic Significance (2-tailed)
Text-Only-AAC-Modified Condition	Negative Ranks	2*	1.50	3.00	-0.730	0.465
	Positive Ranks	2**	3.50	7.00		
	Ties	0***				
	Total	4				

*Text-Only < AAC-Modified
** Text-Only > AAC-Modified
*** Text-Only = AAC-Modified

Further analysis was conducted to determine the effect of aphasia severity on the response time of the participant by condition. Participant 104 presented with average response times higher than the other three participants. These results are demonstrated in Table 5 below.

Table 5. Average Response Time (ms) of Each Participant in Each Condition

Participant Number	AAC-Modified Condition	Text-Only Condition
101	12400.00	14260.76
102	4617.23	4102.87
103	12772.43	12661.62
104	23708.31	26194.41

Question 2

For PWA, what is the item agreement between the Text-Only version of the SAQOL-39 and the AAC-Modified condition? Due to the limited sample size, these results were analyzed descriptively.

The responses of each participant were analyzed for differences between the two conditions, AAC-Modified (M = 3.64, SD = 0.46) and Text-Only (M = 3.69, SD = 0.42). No differences existed between the responses for the AAC-Modified condition as compared to the Text-Only condition. The responses to the SAQOL-39 items of each participant across both conditions are reported below. See Table 6.

Table 6. Summary of Responses by Each Participant in Each Condition

SAQOL-39 Item	Participant 101		Participant 102		Participant 103		Participant 104	
	AAC	Text	AAC	Text	AAC	Text	AAC	Text
1	5	4	4	4	1	3	1	2
2	5	5	4	4	2	4	2	2
3	5	5	4	3	3	4	5	5
4	4	4	4	4	3	4	5	5
5	4	4	4	4	1	4	4	3
6	4	4	4	3	3	4	5	3
7	4	4	4	4	3	5	4	4
8	5	5	4	4	5	5	5	5
9	5	5	4	4	4	4	5	5
10	4	5	3	3	1	5	3	2
11	4	4	3	3	1	5	4	3

(table cont'd)

SAQOL-39 Item	Participant 101		Participant 102		Participant 103		Participant 104	
	AAC	Text	AAC	Text	AAC	Text	AAC	Text
12	4	4	4	4	3	3	1	4
13	5	5	1	4	4	3	3	2
14	4	4	4	4	3	2	1	2
15	4	4	4	4	5	5	2	1
16	4	4	2	2	5	2	1	1
17	4	3	4	3	4	4	3	3
18	4	4	3	4	4	2	3	4
19	4	3	3	3	4	3	3	4
20	3	3	3	3	4	5	4	4
21	3	3	3	3	4	4	4	4
22	1	5	2	2	5	4	5	4
23	4	4	4	4	2	4	5	3
24	5	5	4	4	4	4	5	5
25	5	5	3	2	2	4	5	4
26	5	5	4	3	4	5	5	5
27	5	5	2	3	4	5	5	4
28	4	5	4	2	4	4	5	5
29	5	5	4	4	2	5	5	2
30	4	4	4	3	4	4	5	5
31	4	4	2	2	4	4	5	5
32	4	4	3	4	4	4	4	5
33	5	5	4	4	2	1	5	5
34	4	4	2	2	2	2	4	2
35	5	5	3	2	4	4	5	5
36	2	2	2	2	2	5	5	2
37	2	2	4	2	5	4	5	5
38	4	4	2	2	2	1	5	5
39	4	4	2	2	2	4	4	3

Next, I examined whether there was a trend in how the individual participant's ratings differed between the AAC-Modified condition and the Text-Only condition. See Table 7. Overall, there was not a trend toward one condition over the other by participants, but there were several questions where three of the four participants answered differently between the two contexts. These questions were marked with an asterisk in Table 7.

When examining the differences, I found that Participants 103 and 104 responded more inconsistently (24 and 23 times respectively) compared to Participants 101 and 102 (6 and 7 times respectively). The two more severe participants were not only more inconsistent with their responses, they also presented with higher differences in ratings between the two conditions. See Table 7.

Table 7. Differences in Response Consistency between the Text-Only and the AAC-Modified Conditions

SAQOL-39 Item	**101**	**102**	**103**	**104**
1*	1	0	-2	-1
2	0	0	-2	0
3*	0	1	-1	1
4	0	0	-1	1
5	0	0	-3	1
6*	0	1	-1	2
7	0	0	-2	0
8	0	0	0	0
9	0	0	0	0
10*	-1	0	-4	1
11	0	0	-4	1
12	0	0	0	-3
13	0	-3	1	1
14	0	0	1	-1
15	0	0	0	1
16	0	0	3	0
17	1	1	0	0
18*	0	-1	2	-1
19*	1	0	1	-1
20	0	0	-1	0
21	0	0	0	0
22*	-4	0	1	1
23	0	0	-2	2
24	0	0	0	0
25	0	0	-2	1
26	0	1	-1	0
27	0	0	-1	1
28	-1	2	0	0

(table cont'd)

SAQOL-39 Item	101	102	103	104
29	0	0	-3	3
30	0	1	0	1
31	0	0	0	1
32	0	-1	0	-1
33	0	0	1	0
34	0	0	0	2
35	0	1	0	0
36	0	0	-3	3
37	0	2	1	0
38	0	0	1	0
39	0	0	-2	1

Question 3

Do PWA rate the AAC Modifications to the SAQOL-39 as more helpful than the text-only version of the SAQOL-39?

Three of the four participants rated the AAC-modified condition above 80% helpful. One participant relied heavily on the photographs, rating them 100% helpful. One of the four participants rated the photographs below 20% helpful. The scores of each participant are resented in Table 8.

Table 8. Rating of Helpfulness of Each Participant in Inches

Participant Number	Rating (Inches)	% Helpfulness
101	3.5/4	87.50
102	0.7/4	17.50
103	4/4	100.00
104	3.25/4	81.25

Reliability

Inter-rater reliability

Inter-rater reliability was utilized to establish the participant's aphasia severity on the *Boston Aphasia Severity Rating Scale* (Goodglass et al., 2001). The raters were the Primary

Investigator and the Co-Investigator. Each rater assigned a severity rating for each of the three contexts: unstructured conversation, structured conversation, and picture description. Ratings were then compared. Raters agreed on all four participant severity ratings. For this study, the following rating scale was used: 5 (Mild), 4 and 3 (Mild-to-Moderate), 2 (moderate), 1 (Moderate-to Severe) and 0 (Severe). See Table 2 for the descriptions of each rating. Overall inter-rater reliability was found to be 100% across the four participants. This can be seen in Table 9.

Table 9. Inter-Rater Reliability for Aphasia Severity.

Participant	Rater 1	Rater 2	Percentage of Agreement
101	4	4	100%
102	4	4	100%
103	3	3	100%
104	1.6	1.6	100%
Overall Inter-Rater Reliability			100%

Intra-rater reliability

Three items from the SAQOL-39 were repeated in both contexts during each session to determine the intra-rater reliability (i.e., 6 items per session). The intra-rater reliability for participant 101 and 102 were 66.7% and 83.3%, respectively. Participant 103 was 16.7 % reliable across the experiment. Participant 104 was 50% reliable. Finally, the overall intra-rater reliability was found to be 65% across the participants. A summary of these results can be found in Table 10.

Table 10. Summary of Reliability Items by Participant and Item

Participant	Item 1 Text-Only		Item 1 AAC		Item 6 Text-Only		Item 6 AAC		Item 17 Text-Only		Item 17 AAC		Intra-Rater Reliability
	E1	E2	E1	E2	E1	E2	E1	E2	E1	E2	E1	E2	
101	4	4	4	4	5	4	5	4	4	4	4	4	66.7%
102	3	3	3	4	3	3	3	3	3	3	3	3	83.3%
103	3	3	3	4	2	1	1	2	1	2	2	4	16.7%
104	4	3	4	4	1	2	1	2	5	5	5	5	50.0%
Overall Intra-Rater Reliability													13/24 65%

*Gray indicates a difference of at least 1

DISCUSSION

This study aimed to examine whether AAC modifications of the original SAQOL-39, which were determined to have face validity (Brouwer, 2013; Heise-Jensen, 2014), would be helpful in allowing PWA to self-report their QOL. Overall, due to the small sample size, no statistically significant differences in response time were noted. The PWA who participated in this study rated their QOL similarly between the two presented conditions: AAC-Modified and Text-Only. Results showed that 75% of the participants rated the AAC modifications more helpful than the Text-Only condition. The following sections discuss the implications of the three experimental questions.

Question 1

With regards to response time, I hypothesized that the participants would demonstrate a longer response time on responses to the AAC-Modified condition based on the literature (Dietz et al., 2009). Response times were analyzed in milliseconds to determine if the AAC-Modified Condition would result in longer response times. Statistical analysis found no statistically significant differences between the AAC-Modified and Text-Only conditions using both parametric and nonparametric statistics.

In an attempt to understand the data that were acquired, descriptive analyses were completed to determine aphasia severity's effect on the response time of the participant. The average response time of the two conditions (AAC-Modified and Text-Only) were calculated for each participant. The participant with the most severe aphasia (#104) had the longest response times compared to the other three participants. Participant 102 had the lowest response time, which is not surprising since she had the highest reading proficiency. Per her comments, she did not need any assistance (photographs or verbal input) to understand the questions. It will be interesting to see if these trends remain when this study is replicated with a larger sample size.

Question 2

When measuring QOL, responses cannot be considered correct or incorrect. Therefore, changes in ratings between the two conditions were analyzed. Three of the four participants answered differently between the two contexts on seven questions. On the SAQOL-39, questions 1 through 21 ask about the participant's trouble with daily activities, while questions 22 through 39 deal with the participants' feelings about their daily life. Of the seven questions the three participants answered inconsistently, six were in the first category (i.e., trouble with daily life). The researcher did not expect ratings on the daily living pictures to be more inconsistent since the photographs were thought to represent more concrete activities as opposed to the abstract nature of the feelings questions.

When examining the differences in ratings, the two more severe participants (103 and 104) were not only more inconsistent with their responses, but also presented with higher differences between the two conditions. When their answers were not consistent, there was a higher chance of a difference higher than one, where participants 101 and 102 typically varied their answers by one on the Likert scale.

Question 3

The helpfulness rating of the photographic representation was used to assess the perceived benefits the photographs provided in completing the SAQOL-39. I initially hypothesized PWA would rate the photographs as helpful when completing the SAQOL-39 based on the previous literature (Dietz et al., 2009). The three participants that rated the helpfulness higher were the participants with the lower reading comprehension score or that took an excessive amount of time to complete the reading comprehension task. The participant who rated the AAC-modified condition as “not helpful” scored a ten of ten on the reading

comprehension task, indicating relatively spared reading comprehension abilities. This suggests that the participant did not find the photographs helpful because she was able to read well.

The participants with the lower reading comprehension scores (Participants 102 and 104) and more severe aphasia (Participants 103 and 104) rated the photographs as "very helpful." This could be because the photographs reduced the burden required to complete the SAQOL-39. The photographs presented context without requiring the participants to utilize their compensatory strategies, such as rereading, to understand the text.

Overall, the use of photographic representations was found to be helpful in allowing PWA to complete the SAQOL-39. This provides us with tool to utilize, especially with people with more severe aphasia, in order to reduce the burden of completing a written or orally administered assessment.

Study Limitations

Unfortunately, this study included only four participants. Due to the small sample size, non-parametric and descriptive analyses were used and cannot be generalized to another group. However, should data collection continue in the future, a larger sample size could lead to more generalizable findings. Again, because of the limited sample size, the range of aphasia severity was limited. Although we aimed to recruit people with mild to moderate-to-severe aphasia, I was only able to recruit people with mild-to-moderate, moderate, and moderate-to-severe aphasia.

Recruiting participants with aphasia proved difficult, although numerous steps were taken to make it easier. For example, I offered to conduct the experiment in the participant's home, so he/she would not have to come to LSU. I contacted aphasia groups in the New Orleans area and had access to the LSU Speech-Language-Hearing Clinic clients and database. While some people who declined participation did not express any specific reasons, some hesitance may have

been due to the need for the participant to attend two testing sessions. In addition, a number of people who agreed to participate became ill and could not participate. If given the opportunity to do it again, I would pursue a larger geographic area, possibly going to additional states to increase the number of participants.

Future Research

Future research should continue to examine how PWA can better self-report their QOL to assist the SLP in establishing patient-centered treatment goals. The LSU Communication Outcomes Research Lab will continue gathering data for this study until a larger sample size is achieved. Although the use of photographic representations of the SAQOL-39 items demonstrated face validity, additional information could be garnered from a study of cognitive interviews (asking people questions regarding how they completed the survey) to see how people use the picture while completing the experiment. Alternatively, it may be beneficial to use cognitive interviewing to have PWA and healthy older adults describe their rating processes for the seven pictures that had the most rating inconsistencies.

Conclusion

In this study, possibly secondary to the small sample size, AAC-modified conditions of the SAQOL-39 questions with the photographs developed by Brouwer (2013) did not show a statistically significant difference between the response times of the participants between the two conditions. It did, however, confirm that participants with more severe aphasia were not consistent overall in rating their quality of life. However, the study demonstrated that PWA found the photographic representations were very helpful in completing the SAQOL-39. Being able to measure QOL in PWA is imperative because the information is vital to SLPs for

developing patient-centered goals and treatment, leading to more valuable and functional treatment outcomes. With further research and a larger sample size, more conclusive results may aid in determining whether the AAC-modified SAQOL-39 can be used for these purposes.

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APPENDIX A. IRB Approval

ACTION ON PROTOCOL APPROVAL REQUEST

Institutional Review Board
Dr. Dennis Landin, Chair
130 David Boyd Hall
Baton Rouge, LA 70803
P: 225.578.8692
F: 225.578.5983
irb@lsu.edu
lsu.edu/research

TO: Neila Donovan
Communication Sciences and Disorders

FROM: Dennis Landin
Chair, Institutional Review Board

DATE: November 8, 2018

RE: **IRB#** 4145

TITLE: The Effects of Photographic Representations on Scores of the Stroke and Aphasia Quality of Life Scale-39 for People with Aphasia

New Protocol/Modification/Continuation: New Protocol

Review type: Full ___ Expedited _X_ **Review date:** 11/8/2018

Risk Factor: Minimal ___X___ Uncertain _____ Greater Than Minimal_____

Approved_____X_____ **Disapproved**_____

Approval Date: 11/8/2018 **Approval Expiration Date:** 11/7/2019

Re-review frequency: (annual unless otherwise stated)

Number of subjects approved: 100

LSU Proposal Number (if applicable)**:**

By: Dennis Landin, 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.
7. Notification of the IRB of a serious compliance failure.
8. **SPECIAL NOTE: When emailing more than one recipient, make sure you use bcc.**

**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*

APPENDIX B. CONSENT FORM

LSU Communication Outcomes Research Lab
Consent Form

Project Title: The Effect of Photographic Representations on Scores of the Stroke and Aphasia Quality of Life Scale-39 for People with Aphasia

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

Investigators: The following investigators are available for questions, Monday-Friday 8:00 a.m. – 4:30 p.m.

Taylor Glorioso, B.A.
Department of Communication Sciences and Disorders
Tglori2@lsu.edu
(504) 377-5332

Neila Donovan, Ph.D., CCC-SLP
Department of Communication Sciences and Disorders
Ndonovan@lsu.edu
(225) 578-3938

Purpose of the Project: To answer the question: Do pictures help people with aphasia take a test?

Number of Subjects: 100

Inclusion Criteria: Persons with aphasia from stroke. They must only speak English. They are 40-89 years old. They must be able to see and hear enough to be in the study.

Exclusion Criteria: No past problems with brain or speech. Not pregnant.

Description of the study: There are two parts to this study. Each part will take about 1 hour. You will take part 1. Within 7 days, you will take part 2. In part 1, you will see pictures and answer questions about your life now. In part 2 you will see pictures and answer questions about your life now.

Benefits: Your participation will help us make a better test.

Risks: This study will not hurt you. This study will not cause problems later.

Right to Refuse: You can stop the study any time you want. This is not a problem for us or you.

Privacy: We will keep your information secret. Your name is given a code. We use the code. No one will see any information except me and my helpers. We will lock up all information. We store results in the computer. The computer has a password. We do not use your name when we write reports.

Financial Information: This study is free. You do not pay us. We do not pay you.

I. **Signature for patient who can read the consent form:** I agree to be in this study. The researcher reviewed this form with me. She told me about the study. She answered all of my questions. I can call Taylor Glorioso or Neila Donovan if I have questions about this study. I may call Dennis Landin, Chairman, Institutional Review Board, at (225) 578-8692 or email irb@lsu.edu if I have any problems with the study. I know I get a copy of this form after I sign it. I agree to participate and acknowledge the researcher's obligation to provide me a copy of this form signed by me.

_____ _____

Signature of Participant **Date**

II. **Signature for participant who cannot read:** The participant has indicated to me that he/she is unable to read the consent form. I certify that I have read the consent form to the participant. I explained that by signing below, they have agreed to participate in the study listed above.

.

_____ _____

Signature of Reader **Date**

Institutional Review Board
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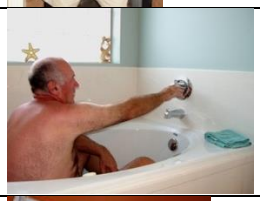
APPENDIX C. Examples of SAQOL-39 Questions and Corresponding Photographs

#	Question	Photographs
1	How much trouble did you have preparing food?	
2	How much trouble did you have getting dressed?	
3	How much trouble did you have taking a bath or shower?	
22	Did you have to write things down to remember them?	
23	Did you find it hard to make decisions?	
24	Did you feel irritable?	

VITA

Taylor Ashton Glorioso was born and raised in Metairie, Louisiana. She attended Louisiana State University where she earned her Bachelor of Arts in Communication Disorders in December of 2017. She began her Master of Arts at Louisiana State University five weeks later in January 2018. Her anticipated graduation is in December 2019. Her thesis was completed under the guidance of Dr. Neila J. Donovan. Upon graduation, Taylor plans to work as a clinical fellow speech-language pathologist in a medical setting with patients with aphasia and cognitive communication disorders.