

2013

Finding similarities between photographs and the Stroke and Aphasia Quality of Life Scale - 39 (SAQOL-39) items

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FINDING SIMILARITIES BETWEEN PHOTOGRAPHS AND THE STROKE AND
APHASIA QUALITY OF LIFE SCALE - 39 (SAQOL-39) ITEMS

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
Ashley Renee Brouwer
B.A., Louisiana State University, 2011
May 2013

ACKNOWLEDGEMENTS

There are a number of people I would like to take the time to thank for their invaluable guidance, advice, and support. I would first like to thank Dr. Neila J. Donovan for her tremendous support throughout the process of my master's thesis. This thesis would not have been possible without her enthusiasm, positive attitude, and confidence in me. Secondly, I would like to thank Mrs. Shannon Farho who so graciously volunteered to serve as the photographer for this thesis project. Her amazing eye for photography was an invaluable asset to the quality of the photographs used in this study. In addition, I would like to thank the actors and actresses who volunteered to be photographed for this study along with all of the participants who volunteered to take part in this study. Likewise, an incredible amount of thanks goes out to Dr. Brittan Barker and Annie Schubert who assisted with the E-Prime programming to administer the rating task. In addition, thank you to Dr. Janet Norris for serving on my thesis committee. Finally, thank you to Gabrielle Becnel, undergraduate volunteer in the Communication Outcomes Research (COR) lab, who assisted me with several tasks throughout the process of this study.

I would also like to thank my parents, fiancé, and sister who whole-heartedly supported me throughout this entire journey. I would not have made it this far without your continuous support and encouragement!

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ABSTRACT

Background: *The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39)* is a valid, reliable quality of life (QoL) assessment for PWA (Hilari, 2003; Hilari, Byng, Lamping, & Smith, 2003). However, individuals with severe aphasia are unable to use it because their ability to comprehend the text is too severely impaired for accurate self-report (Hilari & Byng, 2009; Hilari et al., 2003; Hilari, Owen, & Farrelly, 2007). Proxy respondents often report on QoL measures for these individuals; however, studies suggest differences between proxy-reported and self-reported scores in less severe populations (e.g., Cruice, Worrall, Hickson, & Murison, 2005; Engell, Hütter, Willmes, & Huber, 2003; Hilari et al., 2007). Therefore, proxy-reported scores may not be reliable substitutes (Cruice et al., 2005). Incorporating images may increase accessibility of text to individuals with severe aphasia by drawing upon intact visuo-spatial abilities (Dietz, Hux, McKelvey, Beukelman, & Weissling, 2009; Dietz, McKelvey, & Beukelman, 2006; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski, Korpijaakko-Huuhka, & Klippi, 2008).

Objective: This study assessed similarities between high-context, colored photographs and SAQOL-39 questions.

Methods: This study employed a non-experimental, within-group design. Twenty individuals between 65-85 with no history of aphasia completed a 7-point Likert scale rating task wherein they rated the degree of similarity between photographs and SAQOL-39 questions. Three expert reviewers evaluated the photographs before being used as stimuli.

Results: Results of the 7-point Likert scale rating task revealed a mean rating of 6.06 (range 5.05 – 6.70) for all 42 photograph-question pairings (i.e., three training items plus 39 items). Thirty-nine of the total 42 photographs (93%) were rated ≥ 6 at least 60% of the time. Thirty-seven of the 39 actual scored SAQOL-39 questions (95%) were rated ≥ 6 at least 60% of

the time. The mean standard error of the mean (SEM) for all 42 photographs was 1.44. The average mode was 7.00, and the average median was 6.74.

Conclusion: Results indicated that photographs were rated as being similar to SAQOL-39 questions. Further research is warranted to evaluate if the photographs enhance accessibility of the SAQOL-39 to individuals with severe aphasia allowing for self-report.

INTRODUCTION

Aphasia is an acquired neurogenic communication disorder that affects expressive and receptive language abilities (Chapey, 2008; Papathanasiou, Coppens, & Potagas, 2013). While aphasia is considered a language-based communication disorder, other aspects of an individual's life may be concomitantly affected as a result of the disorder (Cruice, Worrall, Hickson, & Murison, 2003; Ross & Wertz, 2003). Ross and Wertz (2003) determined the main factors that distinguished people with aphasia (PWA) from people without aphasia based on the 24 components of quality of life (QoL) suggested by the WHOQOL Group (1996). The researchers discovered that PWA had significantly lower scores on the standardized QoL assessments compared to people without aphasia. These results suggested that aphasia affected several functional skills in addition to those affected by stroke alone, which may have accounted for the lower scores. Therefore, it is essential to assess QoL from the PWA's perspective to discover which specific areas are negatively affected by aphasia, especially in light of the literature that has demonstrated subjective information may not be evident to an observer (Cruice, Worrall, Hickson, & Murison, 2005; Engell, Hütter, Willmes, & Huber, 2003; Hilari, Owen, & Farrelly, 2007). Further supporting the need to assess QoL in PWA are the American Speech-Language-Hearing Association (ASHA) practice guidelines for speech-language pathologists (SLPs). According to ASHA's (2007) *Scope of Practice in Speech-Language Pathology*, SLPs must work "to optimize individuals' ability to communicate and swallow, thereby improving quality of life" (p. 3).

The SAQOL-39 is a valid, reliable, and comprehensive QoL assessment specifically designed for PWA (Hilari, 2003; Hilari, Byng, Lamping, & Smith, 2003). However, individuals with severe aphasia are unable to use it successfully because their ability to comprehend the

SAQOL's text is too severely impaired for accurate self-report (Hilari & Byng, 2009; Hilari et al., 2003, 2007, 2009). Proxy respondents often report on QoL measures for severely impaired PWA; however, some studies suggest that proxy-reported scores differ when compared to self-reported scores in less severely impaired populations (e.g., Cruice et al., 2005; Engell et al., 2003; Hilari et al., 2007). Therefore, proxy-reported scores may not be reliable substitutes for self-reported scores (Cruice et al., 2005).

Previous research suggests that the incorporation of images may increase accessibility of text to individuals with severe aphasia by drawing upon intact visuo-spatial abilities (Dietz, Hux, McKelvey, Beukelman, & Weissling, 2009; Dietz, McKelvey, & Beukelman, 2006; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski, Korpijaakko-Huuhka, & Klippi, 2008). As a result, supplementing the SAQOL-39 with images should be explored to discover if this provides the support needed to allow for individuals with severe aphasia to self-report.

In a previous study, Deroche (2011) looked at the degree of symmetry between 31 SAQOL-39 (Hilari, 2003) questions and 31 selected *Life Interests and Values* cards (L!V cards; Haley, Womack, Helm-Estabrooks, Caignon, & McCulloch, 2010). She could not find appropriate pictures in the L!V cards for eight items. Eighteen individuals between the ages of 65 and 82 years participated in the study and determined if these line drawings would be a good match for the 31 selected SAQOL-39 items. Participants were native monolingual English speakers; with no history of stroke, neurologic or neurogenic disease, or traumatic brain injury; had adequate vision; and could read at a fifth-grade level. Participants rated the degree of symmetry on a 5-point Likert scale with the anchors "1 = does not match at all" and "5 = matches exactly" (Deroche, 2011). Results indicated: 7/31 images were judged symmetrical, 9/31 images were judged not symmetrical, and 2/31 images were judged somewhat symmetrical.

A relationship could not be determined for 13/31 images due to variable ratings. Therefore, only 23% of the total L!V cards were considered to be adequate, symmetrical representations of the 31 selected SAQOL-39 questions. Based on the poor overall symmetry between the L!V cards and the SAQOL-39 items, Deroche (2011) recommended further research using images specifically developed to represent the SAQOL-39 items. She did not recommend the specific medium in which the pictures should be developed (i.e., line drawings or photographs)

Deroche's study was among the first to explore the idea of pairing the SAQOL-39 items with images to increase accessibility to PWA. She began the process using older adults without language disorders to establish face validity of the images. Her inconclusive results provided a springboard for further research on this topic because we currently do not have a way to assess QoL of severely impaired PWA. I concluded that the use of different images should be explored to see if they would be a better fit for the SAQOL-39 questions. A review of the literature suggested that high-context, colored photographs in particular help to establish context for PWA (Dietz et al., 2009; Dietz et al., 2006; McKelvey, Hux, Dietz, & Beukelman, 2010; Wilkinson & Jagaroo, 2004). Dietz et al. (2009) described high-context photographs as "those depicting people interacting with each other, the natural environment, and/or the central action of the scene in such a way as to reveal independently any relations among the people and objects (e.g., a photo of fans cheering as they watch a sporting event)" (Dietz et al., 2009, p. 1055; Dietz et al., 2006). Therefore, I opted to use high-context, colored photographs in this study.

The current study is a partial replication of Deroche (2011). This study's aim is to answer the following experimental question: What are the perceived similarities between selected colored, high-context photographs and SAQOL-39 questions as judged by 20 older individuals between the ages of 65-85 years on a 7-point Likert scale rating task?

REVIEW OF LITERATURE

Aphasia is an acquired neurogenic communication disorder that affects expressive and receptive language abilities (Chapey, 2008; Papathanasiou, Coppens, & Potagas, 2013). One or all language forms may be impaired including verbal expression, auditory comprehension, reading, writing, and signing. Likewise, any element of language can be affected including phonology, morphology, syntax, semantics, and/or pragmatics (Papathanasiou et al., 2013). Stroke is the most common cause of aphasia, resulting in about 80,000 new cases of aphasia in Americans each year. Currently, about one in every 300 people residing in the United States has aphasia, totaling approximately one million people (Chapey, 2008; National Institute on Deafness and Other Communication Disorders, 2010).

Quality of Life and Health-Related Quality of Life

The World Health Organization Quality of Life Group (WHOQOL, 1996) defined QoL as, "...individuals' perceptions of their position in life in the context of the culture and value systems where they lived and in relation to their goals, expectations, standards and concerns" (p. 354). A number of factors may affect QoL including health, mental state, independence level, relationships, environmental influences, and individual beliefs (Berzon, Hays, & Shumaker, 1993; The WHOQOL Group, 1996). While aphasia is considered a language-based communication disorder, other aspects of an individual's life may be concomitantly affected as a result of the disorder (Cruice, Worrall, Hickson, & Murison, 2003; Ross & Wertz, 2003). Health-related quality of life (HRQoL) specifically focuses on the effect of an individual's health status on their QoL and life satisfaction (Hilari & Byng, 2009). Hilari & Byng (2009) suggested that HRQoL in PWA may be affected by "their emotional well-being, the severity of their communication disability and their activity levels" (p. 194).

QoL and aphasia. Ross and Wertz (2003) sought to determine the main factors that distinguished PWA from people without aphasia based on the 24 components of QoL suggested by the WHOQOL Group (1996). Participants included 18 PWA ranging from ages 48-79 years and 18 people without aphasia ranging from ages 41-75 years. Participants with aphasia were at least 6 months post-stroke, sustained damage to the left hemisphere, and had no other disease(s) that affected communication. Participants without aphasia had a negative history of brain injury and no other disease(s) that affected communication. QoL instruments included the *World Health Organization's Quality of Life Instrument, Short Form* (The WHOQOL Group, 1998a, 1998b) and the *Psychosocial Well-Being Index* (Lyon et al., 1997). The *World Health Organization's Quality of Life Instrument, Short Form* is a shortened version of the original *World Health Organization's Quality of Life Instrument*, a generic QoL assessment that probes 24 factors affecting QoL. The *Psychological Well-Being Index* consists of 11 items specific to aphasia administered in a non-standardized format. The participants completed both written questionnaires from their perspectives. Administrators provided additional assistance (e.g., interview-based administration, repetition, rephrasing, examples) if the individual had difficulty completing the measures independently.

Results indicated that PWA had significantly lower scores on the standardized QoL assessments compared to people without aphasia. The main differences between PWA and people without aphasia related to: (1) level of independence (activities of daily living, mobility, ability to work); (2) social relationships (support from friends and family, sex life); and (3) environment (access to information, transportation, health-related services). These results suggested that aphasia affected several functional abilities thus hindering the PWA's ability to function as they once did prior to aphasia. Therefore, it is essential to assess QoL from the

PWA's perspective to discover these specific areas negatively affected by aphasia especially since subjective information will not be evident to the observer.

Further supporting the need to assess QoL in PWA is the American Speech-Language-Hearing Association (ASHA) practice guidelines for speech-language pathologists (SLPs). According to ASHA's (2007) *Scope of Practice in Speech-Language Pathology*, SLPs must work "to optimize individuals' ability to communicate and swallow, thereby improving quality of life" (p. 3). Thus, assessing QoL is necessary so that SLPs operate within their professional scope of practice (ASHA, 2007). For those SLPs who have adopted the premise that the primary goal of aphasia treatment is to enhance QoL, assessing QoL is mandatory (Simmons-Mackie & Kagan, 2007; Worrall & Holland, 2003).

The World Health Organization's International Classification of Functioning, Disability and Health Model

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) is "a standard language and framework for the description of health and health-related states" (WHO, 2002, p. 2; WHO, 2001). More specifically, ASHA defines the WHO's ICF model as the framework that SLPs should use to plan assessment and treatment of communication disorders (ASHA, n.d.). The ICF framework is a biopsychosocial model that combines the traditional medical model, which is centered on diagnosis and treatment to remedy the impairment, and a social model, which recognizes disability as the result of social and environmental problems (WHO, 2002). The ICF has two main components: (1) Functioning and Disability and (2) Contextual Factors. Functioning and Disability components include body functions, body structures, and activities and participation. Contextual Factors include environmental factors and personal factors (Threats, 2005). All of these factors incorporated into the ICF model encourage healthcare professionals to view the individual as a whole rather than

from an approach centered on diagnosis (Cruice, 2008; WHO, 2002). This is critical since “diagnosis alone does not predict service needs, length of hospitalization, level of care or functional outcomes” (WHO, 2002, p. 4). Other aspects of an individual’s unique situation need to be considered in order to plan their care and intervention appropriately (WHO, 2002).

The ICF and QoL. Although the ICF has been adopted as the theoretical model for assessment and planning in communication disorders, the ICF does not directly incorporate QoL (Cruice, 2008; Kagan et al., 2008; Simmons-Mackie & Kagan, 2007). In response to the absence of QoL in the ICF, Kagan et al. (2008) created another model, the *Living with Aphasia: Framework for Outcome Measurement (A-FROM)*, to link the ICF and QoL. This model contains four overlapping circles—participating in life situations; personal identity, attitudes and feelings; severity of aphasia; and communication and language environment—that overlap to encompass the center of the model entitled “living with aphasia”. The A-FROM model puts QoL as affected by aphasia at the center of the model to emphasize its importance. However, this model limits the ability of SLPs to communicate with other rehabilitation professionals because it has such a narrow focus – PWA. The author also recommended its use in aphasia centers, specifically, rather than general medical facilities such as hospitals and rehabilitation centers. While the A-FROM may be applied in these settings in the future, its current focus is limited (Kagan, 2011). Therefore, in this study, I recognize the ICF model (per ASHA mandate) but incorporate a measure of QoL into my assessment repertoire.

Cruice (2008) presents support for both sides of the ICF-QoL argument suggesting that while the ICF does influence professionals to practice from a more client-centered, “holistic” approach, the ICF framework and QoL are different from one another. She emphasized that, “The ICF framework helps us to structure what the individual *can* and *cannot* do; quality of life

reminds us to consider *who* the individual is, what he or she *wants* in life, and *who he or she wants to be*” (p. 48). In addition, although Threats (2005) suggested some degree of overlap between QoL and the ICF, he reported that the ICF was meant to assess objective, observable behaviors. Therefore, QoL measures are still needed to gather subjective reports of QoL from the perspective of the patient (Cruice, 2008). Cruice (2008) specifically suggested QoL as the starting point in practice.

Incorporating self-report QoL measures into an ICF assessment and treatment repertoire not only provides the SLPs with a model to better understand the disabling factors associated with aphasia, but it also enhances service-delivery (Buck, Jacoby, Massey, & Ford, 2000; The WHOQOL Group, 1996). Without self-reported QoL measures, the true effects of aphasia on a person’s life remain hidden. QoL is highly subjective and unless the patient reports his own QoL, relying on an outsider’s perspective may be misleading and result in inappropriate or unnecessary interventions (Berzon et al., 1993). In addition, integrating the PWA’s perspective on QoL allows that person to play a role in goal-setting and intervention planning in areas that are important to him (Kagan et al., 2008; WHO, 2002). According to ASHA’s 2005 Position Statement on evidence-based practice compiled by the Joint Coordinating Committee on Evidence-Based Practice (ASHA, 2005), the clinician’s consideration of the needs and perspectives of the patient is one of the three critical elements of evidence-based practice. Furthermore, the Joint Coordinating Committee on Evidence-Based Practice suggested that incorporating evidence-based practice is vital to increase funding for research projects and to increase clinicians’ reimbursement for SLP services (ASHA, 2004). Therefore, implementing evidence-based practice may benefit not only clients who will have input into the treatments they

receive, but also clinicians who may be able to justify reimbursement for a wider range of service provision.

Generic and Stroke-Specific QoL Measures

The need for self-reported QoL measures has been established and deemed necessary in order for SLP services to be in line with ASHA's practice guidelines. QoL measures are essential so that professionals can center goals on improving aspects of an individual's QoL based on the person's perspective (Kagan et al., 2008). Furthermore, QoL measures are needed to determine treatment efficacy in order to improve health care services for patients (Buck et al., 2000; The WHOQOL Group, 1996). While various generic QoL measures exist in the field of speech-language pathology, few are geared specifically to PWA.

A review by Buck, Jacoby, Massey, and Ford (2000) evaluated generic QoL measures employed in stroke research and condition-specific QoL measures. Fifteen generic measures met the criteria for search terms and eligibility as defined by the authors. Of these 15, nine were eliminated due to use in only a single study and/or questions centered on only one aspect of QoL. Of the remaining six generic QoL measures, only two measures had established reliability, validity, and responsiveness to change. These two were the *Sickness Impact Profile* (Bergner, Bobbitt, Carter, & Gilson, 1981) and the *Nottingham Health Profile* (Hunt et al., 1980). Although sound QoL measures, they do not take into account stroke-specific conditions that affect QoL (Buck et al., 2000).

Ten condition-specific QoL measures met the criteria for consideration. Of these 10, however, only seven were stroke-specific. Of the seven stroke-specific QoL measures, only one measure had been used in more than one study— the *Frenchay Activities Index* (Holbrook & Skilbeck, 1983). While appropriate for individuals affected by stroke, it was designed to probe

activity levels prior to stroke. Therefore, Buck et al. (2000) deemed it an incomplete QoL measure.

As a result of the findings, the authors concluded that no patient-centered, comprehensive QoL assessment specific to stroke existed. The authors addressed the need for a psychometrically strong stroke-specific QoL measure created on patient-centered experience. They concluded by citing two stroke-specific QoL measures under development in 1999: the *Stroke-Specific Quality of Life Scale* (SS-QOL; Williams, Weinberger, Harris, Clark, & Biller, 1999) and the *Stroke Impact Scale- Version 2.0* (Duncan, Wallace, Lai, Johnson, Embretson, & Laster, 1999). While a further published analysis on the *Stroke Impact Scale* demonstrated reliability, validity, and sensitivity to change in a stroke sample, it was not created based on a sample solely of PWA (Duncan et al., 1999). The SS-QOL, however, was modified for an aphasia-specific population and standardized on PWA (Hilari & Byng, 2001; Hilari et al., 2003). Details are described below.

The Stroke Specific Quality of Life Scale (SS-QOL)

Williams and colleagues (1999) created the *Stroke Specific Quality of Life Scale* (SS-QOL) to measure QoL in stroke patients. The authors set out to create a valid and reliable stroke-specific QoL measure that demonstrated response to change over time. To begin, one author interviewed 34 individuals who had suffered ischemic strokes to determine the top three areas affected most by stroke to establish domain and item content validity. From the 12 most common responses, 78 items were created and tested on a sample of 72 stroke patients. Exploratory factor analysis (EFA), Cronbach's α , and change in mean from 1-month to 3-months post-stroke were used in item reduction, and 29 of the original 78 items were eliminated. The reduced 49-item version demonstrated high internal reliability across all domains ($\alpha \geq 0.73$).

Construct validity was also acceptable for most domains. Most domains demonstrated moderate responsiveness to change from 1 to 3 months post-stroke. The authors concluded that the initial version of the SS-QOL demonstrated promising reliability, validity, and responsiveness to change; however, they recommended future studies incorporate larger sample sizes with more cases of severe stroke.

Adapting the SS-QOL for aphasia. Hilari and Byng (2001) altered the 49-item SS-QOL to create an aphasia-specific QoL measure for individuals with mild to moderate receptive aphasia. They modified the SS-QOL in multiple stages, beginning with SS-QOL wording changes, piloting the modified version with 12 PWA, revising further based on pilot data, and finally pre-testing with 18 PWA (Hilari & Byng, 2001). Initial layout modifications included increasing font size and presenting fewer questions per page. They also changed to an interview-administered format rather than a self-rating format. The authors shortened lengthy questions and bolded key words. Twelve individuals with mild to moderate aphasia then participated in pilot testing to evaluate various response formats. Results indicated that agree-disagree and comment formats were the most difficult while yes-no and a visual “x” or checkmark were easiest. The authors eliminated negative questions because they were too difficult for participants to understand. In addition, a response format was created for the second part of the questionnaire that included the options: “definitely yes/mostly yes/neither yes nor no/mostly no/definitely no” (p. 89). Statements indicating a new set of question topics (i.e., family and social life) and practice questions were also added.

After the above changes were made, the modified SS-QOL was tested on 18 PWA. All participants indicated that the questionnaire probed all areas affected by stroke. Seventeen of the 18 participants were able to complete the modified SS-QOL. One participant was unable to

reliably self-report and scored a 6/15 on the receptive portion of the *Frenchay Aphasia Screening Test* (FAST) (Enderby, Wood, & Wade, 1987). Individuals can score from 0 to 15 on the receptive portion, which consists of 10 oral commands and five written commands that increase in complexity. The lower the score, the more severe the aphasia (Hilari et al., 2007). The authors concluded that individuals scoring 7 or higher on the receptive portion of the FAST could complete the SS-QOL version specific to PWA.

Results of this study (Hilari & Byng, 2001) indicated that individuals with mild to moderate receptive aphasia could successfully complete a modified version of the SS-QOL (i.e., SAQOL) for aphasia. This, however, was only the initial stage of development as acceptability, reliability, and validity still needed to be tested to establish the psychometric properties of the new assessment (Hilari & Byng, 2001).

In 2003, Hilari, Byng, Lamping, and Smith tested the acceptability, reliability, and validity of the SAQOL. Ninety-five of 116 eligible PWA participated in this study. Twelve, however, were eliminated because they could not self-report due to severe language impairments. The receptive score on the FAST for these individuals, as in Hilari & Byng (2001), was less than 7. As a result, 83 individuals with mild to moderate aphasia participated in this study. They were included in the study if they met the following inclusion criteria: aphasia as a result of stroke, at least 12 months post-stroke, no history of other strokes or mental health problems, and living at home prior to the stroke. Participants completed the assessment at home or at a speech and language therapy clinic.

The initial 53-item SAQOL encompassed the 49 SS-QOL items plus four aphasia-specific items. Psychometric evaluation of the 53-item SAQOL indicated good internal consistency ($\alpha = 0.93$), negligible missing data, small floor/ceiling effects, and high test-retest

reliability for overall score (intraclass correlation coefficient [ICC] = 0.98) and the 12 individual subdomains (ICC = 0.84 - 0.99). Eleven questions had high skewness, and four subdomains had low internal consistency (≤ 0.70). Forty-eight of the 53 items loaded highly on the general component as measured by principal components analysis (PCA). Within-scale analyses indicated moderately to highly correlated subscale scores with overall score ($r = 0.39 - 0.73$) except for vision ($r = 0.26$). Convergent and discriminant validity were also established by comparing the SAQOL to six other similar measures. Construct validity was established for all but four subscales (thinking, mood, family roles, and social roles).

These results established the reliability, validity, and acceptability of the SAQOL; however, the authors cited weak support for the current subdomain structure. In an attempt to strengthen and tighten the subdomains, the authors needed to shorten the current version to reflect the subdomains most associated with aphasia resulting from stroke. Development and testing of the shortened version is described below.

Psychometric testing of the SAQOL-39. Based on the results above (Hilari et al., 2003), the authors removed 14 items to create a shortened form of the 53-item SAQOL in the same study. Results indicated little missing data and small floor/ceiling effects, good internal consistency for scale ($\alpha = 0.93$) and subscale scores ($\alpha = 0.74$ to 0.94), and good test-retest reliability for scale (ICC = 0.98) and subscale scores (ICC = 0.89 to 0.98). Four items were skewed. Acceptable intercorrelations between subscale scores ($r = 0.10$ - 0.47) and between subscale and overall scores ($r = 0.38$ - 0.58) were found via within-scale analyses. Results indicated good convergent and discriminant validity for the physical, communication, and energy subscales. Additionally, results indicated good discriminant and adequate convergent validity for the psychosocial subscale.

This analysis established the SAQOL-39 as a valid, reliable, and acceptable aphasia-specific QoL measure for individuals with mild to moderate aphasia with a tighter subdomain construct compared to the SAQOL (Hilari et al., 2003). This development was significant because QoL in PWA could now be assessed more accurately and appropriately using a measure specific to aphasia and standardized on PWA.

The ASHA Quality of Communication Life Scale and The Assessment for Living with Aphasia

Upon further review of the literature, another QoL measure appropriate for PWA is the *ASHA Quality of Communication Life Scale* (ASHA QCL) (Paul et al., 2004). The ASHA QCL is specific to the effect of a communication disorder on QoL which is highly appropriate given the deficits caused by aphasia. The ASHA QCL, however, included a mixed sample for field testing: 71% PWA, 16% individuals with cognitive-communicative impairments, and 13% people with dysarthria (Paul et al., 2004). While these three populations have communication disorders that may affect QoL, the similarities between them and aphasia may be negligible. The ASHA QCL also focuses exclusively on communicative aspects of QoL; therefore, it is not a comprehensive HRQoL assessment, like the SAQOL-39, that covers other aspects of QoL affected by aphasia caused by stroke (Bose, McHugh, Schollenberger, & Buchanan, 2009).

In addition to the ASHA QCL, the only other assessment appropriate for PWA is the *Assessment for Living with Aphasia* (ALA) (Kagan et al., 2008). This assessment is relatively new, and an abstract from the 1st Canadian Stroke Congress suggested psychometrically strong properties based on testing results (Kagan, Simmons-Mackie, Rowland, Victor, & Huijbregts, 2010). However, the complete published study on its reliability and validity is not yet available (The Aphasia Institute, n.d.; Kagan et al., 2007, 2008). This assessment may be appropriate for assessing QoL in PWA for this study; however, since the peer-reviewed research report

describing the sample, reliability measures, and validity measures used is unavailable, the only appropriate instrument known to date is the SAQOL-39. In addition, the SAQOL-39, along with six other stroke-specific measures, was included in a more recent review of stroke-specific QoL instruments in 2007 (Geyh, Cieza, Kollerits, Grimby, & Stucki, 2007). Among all seven stroke-specific QoL assessments that met the criteria for inclusion based on the ICF model, the only one specific to PWA was the SAQOL-39.

In summary, the SAQOL-39 is currently the most promising QoL assessment for PWA based on the fact that it was developed on a sample comprised solely of PWA and specifically created for PWA. It can be completed reliably by individuals with mild to moderate receptive aphasia (Hilari & Byng, 2001). With the SAQOL-39, aspects of QoL specifically affected by aphasia could now be discovered and implemented into intervention planning.

Proxy Reports on the SAQOL-39

Although the SAQOL-39 is a valid and reliable measure specifically for PWA, individuals with severe aphasia have been eliminated from the validity and reliability studies because they cannot comprehend the written text (Hilari & Byng, 2009; Hilari et al., 2003, 2007, 2009). As a result, the authors established a receptive cutoff score on the FAST as less than 7 out of 15 for PWA who could self-report and those who could not (Hilari et al., 2007). In cases where a PWA scores lower than 7, proxy-reporters are used to gauge the severe PWA's QoL (Hilari & Byng, 2009). Proxy reporters might include spouses, close relatives, or anyone who knows the PWA well. The QoL assessment is filled out according to the proxy's perception of the PWA's QoL (Hilari & Byng, 2009). While such an alternative approach exists, modifications to the SAQOL-39 should be considered to allow individuals with severe aphasia the opportunity to self-report. This is essential since QoL is best measured by the individual

himself not via proxy (Berzon et al., 1993; Kagan et al., 2008; Rautakoski et al., 2008). The very definition of QoL developed by the WHOQOL Group (1996) emphasizes measurement of QoL from the perception of the individual himself. Thus, QoL, by definition, cannot be judged objectively from another's perspective.

A study conducted by Hilari, Owen, and Farrelly (2007) looked at the level of agreement between SAQOL-39 self-reported scores and proxy-reported scores. Fifty pairs of PWA and proxy-reporter participated in this study. To qualify, the PWA had to (1) have aphasia as a result of stroke, (2) be ≥ 6 months post-stroke and stable, (3) have a score $\geq 7/15$ on the receptive portion of the FAST, and (4) nominate a proxy respondent. The SAQOL-39 was administered to the PWA via face-to-face interviews. Proxy respondents answered the SAQOL-39 questions via telephone interview.

The results showed that proxies tended to rate the PWA significantly poorer than the PWA actually rated themselves. Differences in score were statistically significant for overall scores, and on the communication, physical, and psychosocial domains. Although statistically significant, however, the overall effect sizes of the differences were small (0.2) to moderate (0.5). This indicated that the bias of proxy-reported scores compared to self-reported scores was small to moderate. Therefore, the authors concluded that a proxy-rater who knows a PWA well can serve as a reliable substitute in the event that the PWA cannot self-report on the SAQOL-39.

Despite conclusions made by the authors, the study had limitations (Hilari et al., 2007). To begin with, the first author of the study was the creator of the SAQOL-39 which may interject bias into the results and interpretation. In addition, overall means and scores on three of the four domains of the SAQOL-39 were significantly different between proxy respondents and PWA. The authors suggested that "proxy scores may not necessarily be a good indicator of the

self-report scores at the individual level” (Hilari et al., 2007, p. 1074). Likewise, the authors reported overall small to moderate effect sizes. The smallest effect size noted was 0.2 for the energy domain. Effect sizes were much higher for overall score (0.5) and for the physical (0.4), psychosocial (0.4), and communication (0.5) domains. Therefore, results should be interpreted cautiously since smaller effect sizes would have indicated more negligible bias of proxy-reported scores compared to self-reported scores thus strengthening the reliability of proxy-reported scores. Additionally, the authors recognized their sample size ($n = 50$) as a limitation to the study, noting that a larger sample would have been more favorable (Hilari et al., 2007).

Based on the study limitations described above, the reliability of proxy-reported scores on the SAQOL-39 is questionable. This study, along with other studies that have compared various proxy-reported scores to self-reported scores in stroke-specific and populations with aphasia, found lower agreement on subjective domains of QoL compared to objective domains (Cruice et al., 2005; Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997; Engell et al., 2003; Hilari et al., 2007). Dorman et al. (1997) found poor agreement between proxy respondents and 130 stroke patients on social functioning, pain, overall HRQoL, and psychological functioning domains of the *EuroQoL* (The EuroQol Group, 1990) assessment. In an aphasia-specific study, Engell et al. (2003) found low correlations between proxy-reported and self-reported scores on cognitive, language, and psychosocial domains using a pictorial version of the *Aachen Life Quality Inventory* (Hütter, 2001; Hütter & Gilsbach, 1996; Hütter & Würtemberger, 1997) with 24 PWA and written version with 24 proxy respondents. Likewise, Cruice et al. (2005) found significant differences on proxy-reported and self-reported scores in PWA using a global QoL rating, the *Short-Form-36 Health Survey* (Ware & Sherbourne, 1992), the *Dartmouth COOP Charts* (Nelson, Landgraf, Hays, Wasson, & Kirk, 1990; Nelson et al.,

1987), and the *How I Feel About Myself (Well-being Scale)* (Hoen, Thelander, & Worsley, 1997; Ryff, 1989; Thelander, Hoen, & Worsley, 1994). Effect sizes were moderate ($d = 0.5$) to large ($d = 0.8+$) on global QoL, physical functioning, general overall health, pain, and vitality domains.

In addition to poor agreement on subjective domains of QoL assessments, proxy respondents tend to rate individuals as more severely affected than those individuals would rate themselves in certain categories (Cruice et al., 2005; Dorman et al., 1997; Engell et al., 2003; Knapp & Hewison, 1999). Therefore, proxy-reported scores cannot serve as reliable substitutes for self-reported scores from PWA since their scores do not parallel PWA's on all domains (Cruice et al., 2005). Proxy-reported evaluations are not a true representation of QoL in PWA compared to self-reported evaluations.

QoL in Individuals with Severe Aphasia

Because individuals with severe aphasia cannot self-report on the SAQOL-39, their perspective on their own QoL remains unknown (Hilari & Byng, 2009). As a result, Hilari & Byng (2009) suggested that there is still much to be learned about QoL in individuals with severe aphasia since current information about their QoL is minimal. Such knowledge is crucial so that SLPs may tailor interventions appropriately in conformance with ASHA's practice guidelines (ASHA, 2007) and evidence-based practice guidelines (ASHA, 2004, 2005).

In an attempt to learn more about the QoL of individuals with severe aphasia, Hilari and Byng (2009) explored the relationship between proxy-reported scores of individuals with severe aphasia and proxy-reported and self-reported scores of individuals with mild to moderate aphasia. Participants included 12 individuals with severe aphasia who were unable to self-report (i.e., FAST score < 7) in Hilari et al. (2003). Participants nominated a proxy respondent to complete the SAQOL-39 for them. The authors specified that the proxy "had to be in daily face

to face contact with the person with aphasia” (Hilari & Byng, 2009, p. 196) for a minimum of two years. Most proxies were friends and relatives of the PWA; one proxy was a “key worker” (p. 198). Since the proxies interacted with the PWA on a daily basis, their scores were likely more reliable than someone who did not know the PWA very well (e.g., health care provider, distant relative).

Results indicated that individuals with severe aphasia had lower QoL scores, as measured by proxy-report on the SAQOL-39, compared to those with mild to moderate aphasia. There were no significant differences between proxy-reported and self-reported scores for individuals with mild to moderate aphasia. Large effect sizes ($d = 0.92$ to 1.22) were found between proxy-reported severe scores and proxy- and self-reported mild to moderate scores for overall score, physical domain, and communication domain. Energy and psychosocial domains had small to moderate effect sizes ($d = 0.28$ to 0.64).

This study suggested that the QoL in individuals with severe aphasia is significantly lower than in mild to moderate aphasia. The results of this study, however, are only as reliable as the proxy-reported scores of the individuals with severe aphasia (Duncan et al., 2002). Therefore, they should be interpreted cautiously since proxy respondents tend to rate PWA as more severely affected than PWA rate themselves (Cruice et al., 2005; Engell et al., 2003). Not having self-report data from the individuals with severe aphasia was a weakness in this study, but such data was not available. However, since scores for individuals with severe aphasia were significantly different than *both* self-reported and proxy-reported scores of individuals with mild to moderate aphasia, the results of this study carry some weight since discrepancies may have leveled out across both comparisons. Nonetheless, this study uncovered some aspects of the QoL of individuals with severe aphasia. However, until we can discover a way to obtain their

perspectives on QoL, the picture is incomplete. As a result, the authors suggested the need for additional research to focus on learning and understanding more about QoL specifically in individuals with severe aphasia (Hilari & Byng, 2009).

In summary, QoL is most accurately measured from a person's perspective rather than via proxy (Berzon et al., 1993; Kagan et al., 2008; Rautakoski et al., 2008). The very definition of QoL implies that it must be subjectively rated based on the PWA's perspective, not an external perspective (The WHOQOL Group, 1996). Any deviation from self-reported QoL scores (i.e., proxy-reported scores) presents room for error; therefore, increased efforts to allow all individuals to self-report need to be made (Berzon et al., 1993).

Furthermore, it is essential that accessibility to QoL measures be enhanced for persons with severe aphasia since limited self-report information on their QoL is available (Hilari & Byng, 2009; Kagan et al., 2008; Rautakoski et al., 2008). Since most measures require adequate verbal and written receptive and expressive abilities, individuals with severe aphasia are at a disadvantage due to the severity of their receptive and expressive deficits (Hilari & Byng, 2009; Rautakoski et al., 2008). Therefore, our assessments in their current format are inaccessible to individuals with severe aphasia (Rautakoski et al., 2008). Regardless, these individuals should be allowed to assess their own QoL no matter the severity of their aphasia since QoL is best assessed by the individual himself (Kagan et al., 2008). Although Kagan and colleagues (2008) insist upon assessing QoL regardless of aphasia severity, doing so remains an enormous challenge because few studies have demonstrated that any QoL measure is valid or reliable for individuals with severe aphasia (Rautakoski et al., 2008). For this reason, there is a clear need to develop or alter QoL assessments for individuals with severe aphasia (Cruice et al., 2005; Rautakoski et al., 2008).

Increasing Accessibility of Text to PWA via “Aphasia-Friendly” Modifications

Throughout the literature, researchers use the term “aphasia-friendly” to describe adaptations to print material to make text more accessible to PWA (Pound, Parr, Lindsay, & Woolf, 2000; Rose, Worrall, & McKenna, 2003). Aphasia-friendly adaptations may include using: (1) simpler words and shorter sentences; (2) larger, standard font; (3) increased white space; and (4) relevant pictures (Brennan, Worrall, & McKenna, 2005; Rose et al., 2003).

Aphasia-friendly formatting to increase accessibility of information to PWA has been successful in previous studies (Egan, Worrall, & Oxenham, 2004; Rose et al., 2003). In response to inaccessible Internet training manuals for PWA, Egan et al. (2004) tested the effectiveness of aphasia-friendly Internet training manuals with 20 PWA. Using the aphasia-friendly formatted *Aphasia Handbook* (Parr, Pound, Bing, & Long, 1999) and other adapted resources as a guide, the authors created a manual specifically for PWA that incorporated 10 different modifications including simplified instructions, large font, increased white space, and pictures, to name a few. Each PWA was assigned a personal tutor as well. Results indicated significant changes on 12 Internet tasks (e.g. connect to Internet, favorites/bookmarks, send email, reply to email, print, etc.) from pre- to post-test as rated by the tutors. Twelve of the 20 PWA reported ability to use the Internet training manual independently at post-training. The results suggested that with tools adapted for PWA, text and information becomes more accessible. This study, however, did not have a control group. Therefore, the degree of the effectiveness of the adapted manual compared to the original manual is unknown.

Likewise, Rose et al. (2003) looked at the effectiveness of aphasia-friendly formatted health brochures in response to the inaccessibility of current brochures to PWA. Format alterations included simpler words, shorter sentences, larger standard font, increased white space,

and relevant pictures. Twelve PWA ranging from mild to moderately-severe participated in the study. Each participant responded to questions from two original brochures and two aphasia-friendly brochures on different health-related topics. Results from pre- to post-test indicated significantly higher scores from both formats; however, comprehension was 11.2% higher for aphasia-friendly brochures compared to original brochures. The confidence rating of the participants' answers to comprehension questions as judged by the participants was also higher for aphasia-friendly brochures. There was no significant correlation between aphasia severity and aphasia-friendly effectiveness; however, a scatter plot suggested that those with mild-moderate aphasia benefitted more from the aphasia-friendly formatting compared to those with more severe aphasia. In summary, this study, along with Egan et al. (2004), supported the use of aphasia-friendly formatting to increase accessibility of text to PWA.

Use of images. Regarding aphasia-friendly formatting, several researchers showed that specifically pairing images with text may increase accessibility to PWA (Dietz et al., 2009; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski et al., 2008). Elmore-Nicholas & Brookshire (1981) found that adding pictures to a verbal comparative sentence task resulted in increased comprehension of sentences compared to the task with no pictures in 10 PWA. Meanwhile, Engell et al. (2003) suggested that a pictorial version of the *Aachen Life Quality Inventory* (Hütter, 2001; Hütter & Gilsbach, 1996; Hütter & Würtemberger, 1997) was highly accessible to PWA giving them to opportunity to self-report on the adapted measure. Likewise, Rautakoski et al. (2008) found that adapting the *Communicative Effectiveness Index* (Klippi, Korpijaakko-Huuhka, & Lehtihalmes, 1994; Lomas et al., 1989) and the “Use of Different Communication Methods” to include pictures resulted in increased accessibility of the instruments to 35 individuals with moderate to severe aphasia, thus allowing them to self-report.

Furthermore, Dietz et al. (2009) found that reading passages supplemented with photographs resulted in increased comprehension of text compared to paragraphs with no images in 7 PWA. Lastly, in an article suggesting ways to make healthcare services more accessible to PWA, Kagan and LeBlanc (2002) specifically recommended that paramedics and medical professionals use pictographs when interviewing PWA in the pre-hospitalization stage of illness. They also suggested health care professionals use pictographs to support educational materials about stroke and aphasia diagnoses, and doctors use them when interacting with PWA (Kagan & LeBlanc, 2002).

In summary, several studies have cited the effectiveness of pairing images with text to increase accessibility to PWA (Dietz et al., 2009; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski et al., 2008). Some of these studies will be described in more detail in the sections to follow.

Pictorial version of a QoL assessment. A study by Engell, Hütter, Willmes, and Huber (2003) looked at the effectiveness of a pictorial version of the *Aachen Life Quality Inventory* (ALQI; Hütter, 2001; Hütter & Gilsbach, 1996; Hütter & Würtemberger, 1997), a German adaptation of the *Sickness Impact Profile* (SIP; Bergner et al., 1981). The ultimate goal of the study was to create a pictorial version of the ALQI that could be accessible to individuals with severe aphasia to allow them to self-report. A total of nine females with aphasia, 17 males with aphasia, and 24 proxies participated in this study. Characteristics of the PWA included: (1) aphasia resulting from stroke; (2) an average duration of aphasia of 1 year; (3) an age range of 26-69 years; and (4) 17 patients with non-fluent aphasia types and nine with fluent aphasia types.

Images were simple line drawings paired with short phrases above the image depicting the main message of the statement. The response format consisted of a ‘thumbs up’ image paired with the text “yes, that’s true” and a ‘thumbs down’ image paired with the text “no, that’s not true” (Engell et al., 2003, p. 385). If the participant selected the ‘thumbs up’ image indicating agreement with the statement, the PWA then reported the degree of the burden by choosing: (a) straight-lined, neutral face, “doesn’t matter”; (b) frowning face, “bad”; or (c) frowning face with tear drops, “very bad” (Engell et al., 2003, p. 385). Using a 5-point scale, 21 SLP students judged the degree of similarity between the adapted pictorial items and the equivalent written items of the ALQI. The mean similarity rating was 3.7 with a range of 3.3-4.3.

The study then proceeded, and PWA completed the pictorial version. The administrator read the headings aloud to the individual and monitored the assessment to ensure the participant completed it in its entirety. Proxies completed the original, written version of the ALQI. Results indicated that the pictorial version of the ALQI had variable psychometric properties. Internal consistency was good across total score, main subtests, four of nine individual physical and psychosocial categories, and cognition for patients and proxies. The acceptable point of internal consistency ($\alpha \geq .70$) was not met for five of the nine individual physical and psychosocial categories or for language. When proxy-reported scores and self-reported scores were compared, results indicated significant correlations between scores for total score and the physical subscale. However, psychosocial, language, and cognitive scores as reported by the PWA and their proxy differed. Among these categories, proxy respondents reported more complaints than the PWA. These findings paralleled the trends in proxy-reported comparison studies that showed the same discrepancies (Cruice et al., 2005; Dorman et al., 1997;

Duncan et al., 2002; Engell et al., 2003; Hilari et al., 2007; Knapp & Hewison, 1999). This study provided further support to assess QoL from the PWA's perspective rather than from proxy perspective since scores were not equivalent.

Overall, the results of this study suggested that PWA may be able to reliably self-report on QoL measures with pictures (Engell et al., 2003). However, there were limitations to the measures used in the study. The psychometric properties of the pictorial assessment were not robust and need to be further verified to ensure the validity of this QoL measure for PWA. In addition, the sample consisted of less severe PWA who were mostly independent. Therefore, accessibility to pictorial versions of QoL assessments in individuals with more severe aphasia is still unknown.

Pictorial assessments used with individuals with moderate to severe aphasia. A study by Rautakoski, Korpijaakko-Huuhka, and Klippi (2008) explored the ability of individuals with moderate to severe aphasia to reliably self-report on adapted self-assessments. Fifty-three PWA and 52 proxy respondents participated in this study; however, only 35 pairs of data were fully completed and used for results interpretation. Of the 35 PWA, 14 were female and 21 were male. They ranged in age from 26 to 65 years ($M = 53.9$ years; $SD = 9.3$ years). Participants were recruited from a Finnish Stroke and Dysphasia Association program specifically for individuals with moderate to severe disorders who needed augmentative and alternative means of communication. Seventy-four percent of the participants scored ≤ 2 on the *Boston Diagnostic Aphasia Examination* (Goodglass & Kaplan, 1972) severity scale (range = 0-5) indicating more severe types of aphasia, although the authors emphasized that no participants were excluded.

In this study, a Finnish version of the *Communicative Effectiveness Index* (Klippi et al., 1994; Lomas et al., 1989) was supplemented with Picture Communication Symbols©

(Mayer-Johnson, LLC., 1981-2007) to increase accessibility to PWA by reducing the language demands of the text. The “Use of Different Communication Methods”, “an investigator-constructed questionnaire” (Rautakoski et al., 2008, p. 1277) was also administered. Both assessments used a 10-centimeter Visual Analogue Scale as the response method.

Results indicated that responses from PWA and proxies on the “Use of Different Communication Methods” were consistently parallel on all 3 administrations. Responses from PWA were reliable and paralleled responses of proxy respondents in the second and third administration of the *Communicative Effectiveness Index* (total of 3 administrations). Differences were only significant during the first administration. This trend, however, was similar to previously reported proxy respondent trends wherein the proxy rated the PWA as more severely affected than the person rated himself on certain domains (Cruice et al., 2005; Engell et al., 2003). This further supports the need to rely less on proxy-reported perceptions of QoL and to focus more on adapting QoL measures for PWA to self-report.

Reliability of the *Communicative Effectiveness Index* was acceptable as internal consistency measured by Cronbach’s alpha test was high for all three administrations. Reliability of the “Use of Different Communication Methods” was lower but still acceptable ($\alpha > .70$). Therefore, psychometric properties of both assessments were strong. The authors concluded that the adapted version of the *Communicative Effectiveness Index* allowed for individuals with moderate-severe aphasia to reliably self-report. The *Communicative Effectiveness Index*, however, only contains questions pertaining to communication in various situations (Rautakoski et al., 2008). It is not a comprehensive QoL assessment. Regardless, the results support the idea that self-report assessments can be modified to make them more aphasia-friendly to allow individuals with severe aphasia the opportunity to self-report.

Conflicting literature for use of pictures alone. While some studies suggest incorporating images to enhance readability and comprehension (Dietz et al., 2009; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski et al., 2008), others suggest that incorporating images alone with text may hinder comprehension (Brennan et al., 2005). Brennan et al. (2005) looked at the effect of aphasia-friendly principles separately and all together compared to control paragraphs. Nine individuals, 3 females and 6 males, with mild to moderate aphasia participated in this study. Thirty paragraphs across three grade levels (fifth, sixth, seventh) were used and consisted of the following modifications: a) five paragraphs with no modifications; b) five paragraphs with simplified vocabulary and syntax; c) five paragraphs with large print; d) five paragraphs with increased white space; e) five paragraphs with relevant pictures; and e) five paragraphs with all aphasia-friendly modifications listed above. Thus, the study consisted of 90 paragraph probes total. Two sessions were used to gather data to avoid participant fatigue. Scores across each paragraph type were compared to determine the modification that resulted in the greatest comprehension increase.

Results indicated that modifications at the sixth grade level increased comprehension the most and included: (1) simplified vocabulary and syntax alone, (2) large print alone, (3) all four aphasia-friendly modifications, and (4) increased white space alone. Incorporating Microsoft ClipArt and Google Image Search images alone did not result in significant increases in comprehension. Incorporation of all aphasia-friendly modifications, however, did result in a 32% increase in comprehension compared to no modifications at all.

While this study suggested that images alone did not lead to the greatest increases in comprehension, the combination of aphasia-friendly principles was still supported (Brennan et al., 2005). Moreover, there were limitations to the study. This study included a small sample

size ($n = 9$) which did not include individuals with severe aphasia who may have benefitted more from text supported by pictures. In addition, the images used in this study had limitations that decreased their effectiveness. The authors suggested that sometimes the image used was not the most accurate representation of the text, and that at times, the images “may have been distracting” (Brennan et al., 2005, p. 706). Therefore, the images were not as carefully selected as the images used in previous studies that demonstrated positive results. The authors suggested that hand-drawn illustrations or photographs may have been more effective. The use of hand-drawn line drawings proved effective in the study described previously (Engell et al., 2003). Therefore, the use of photographs should be explored since this type of medium may be more helpful when paired with text.

Use of photographs. A study by Dietz et al. (2009) looked at the effect of photographs on reading comprehension in seven individuals with chronic aphasia between the ages of 28 and 79 years. The participants’ *Western Aphasia Battery Aphasia Quotients* ranged from 19.2 to 65.7 (Kertesz, 1982). All participants were classified as having Broca’s aphasia.

The stimuli consisted of two different levels of photographs: (a) high-context photographs and (b) low-context photographs. High-context photographs were defined as “those depicting people interacting with each other, the natural environment, and/or the central action of the scene in such a way as to reveal independently any relations among the people and objects (e.g., a photo of fans cheering as they watch a sporting event)” (Dietz et al., 2009, p. 1055; Dietz et al., 2006). Low-context photographs were defined as those that “serve primarily to identify persons or objects (e.g., a portrait of a person in front of plain background)” (Dietz et al., 2009, p. 1055; Dietz et al., 2006). Photographs for the study were selected from personal albums and Internet images.

Each participant was presented with (a) a reading passage paired with two high-context photographs, (b) a reading passage paired with two low-context paragraphs, and (3) a reading passage paired with no images. The three reading passages contained the same total number of words, average words per sentence, average characters per word, Flesch Reading Ease, and Flesch-Kincaid Grade Level (Flesch, 1948).

Results indicated that the participants had a significantly higher percent correct [$Z(7,2) = -2.041; p \leq .04$] for the comprehension questions when the passage was paired with high-context photographs ($M = 5.57, SD = 2.57$) than with the low-context photographs ($M = 4.29, SD = 1.98$) or no photographs at all ($M = 4.57, SD = 2.23$). The participants answered significantly more questions correctly when paragraphs were supported with high-context photographs compared to low-context photographs. They also answered more questions correctly in the high-context compared to no-context condition, but the difference barely reached significance. There was no significant difference between the low-context photographs and no-context condition. Participants also rated image helpfulness using a 5-point Likert scale. All participants found the high-context photographs helpful while only 5 of the 7 found the low-context photographs helpful. Five of the 7 commented that images would have been helpful in the no-context condition.

While the results suggest the incorporation of high-context imagery to enhance comprehension, the authors warned that the results should be interpreted cautiously since changes in reading comprehension were minimal. Nonetheless, the results of Dietz et al. (2009) suggested that incorporating photographs may be a way to increase comprehension of written material in PWA. It is likely that the incorporation of photographs, specifically those rich in context, compensate for language impairment in PWA by drawing upon relatively intact

visuo-spatial abilities and establishing context for the PWA (Dietz et al., 2006). They provide a non-linguistic way to compensate for linguistic deficits in PWA (McKelvey, Dietz, Hux, Weissling, & Beukelman, 2007).

High-context photographs. A study by McKelvey, Hux, Dietz, and Beukelman (2010) further supported the use of high-context photographs as an aid for PWA. Eight individuals with severe aphasia (M age = 61 years; SD = 24 years) who were, on average, 4 years, 8 months, post-stroke (SD = 6.28 years; range = 0.33 - 19.58 years) participated in this study. The tasks involved having the PWA select the correct picture to match a verbalized target word given: (a) personally relevant, contextualized photographs; (b) non-personally relevant, contextualized photographs; and (c) noncontextualized, iconic images (i.e., Boardmaker symbols; Mayer-Johnson, 2006). Contextualized photographs followed the guidelines of high-context photographs as indicated by Dietz et al. (2006, 2009). Results revealed higher accuracy on the word-picture matching task when using contextualized photographs compared to noncontextualized, iconic images. While accuracy was strongest when using personally-relevant photographs (M = 95.83%; SD = 7.07), an increase in accuracy was still present when using non-personally relevant photographs (M = 52.5%; SD = 33.89) compared to noncontextualized, iconic images (M = 34.17%; SD = 37.62;). Therefore, high-context photographs are further supported in comparison to other medium options. While I recognize the value of personally-relevant photographs based on the results of this study, this would inhibit the universality of the SAQOL-39 since stimuli would be specific to one individual. The task of personalizing the SAQOL-39 for each PWA would also be unfeasible. However, the value of personally-relevant photographs should be considered when exploring daily augmentative-alternative communication (AAC) options for these individuals with severe aphasia.

Adapting the SAQOL-39

In terms of specifically adapting the SAQOL-39 into an “aphasia-friendly” assessment for individuals with severe aphasia, we propose the missing link is the incorporation of images to support the text in order to allow for individuals with severe aphasia to self-report. Several studies support the use of aphasia-friendly formatting (Egan et al., 2004; Rose et al., 2003), specifically the incorporation of pictures to increase accessibility of text to PWA (Dietz et al., 2009; Elmore-Nicholas & Brookshire, 1981; Engell, et al., 2003; Rautakoski et al., 2008). It is likely that the incorporation of photographs, specifically those rich in context, with the text of the SAQOL-39 items will draw upon intact visuo-spatial abilities and help to establish context for the PWA compared to text alone (Dietz et al., 2006). However, no one to date has explored whether or not photographs will enhance patients’ self-report on the SAQOL-39.

Furthermore, the incorporation of photographs to support the SAQOL-39 to increase accessibility to individuals with severe aphasia should be explored to allow patients the opportunity to self-report on their QoL. If possible, every PWA should have the opportunity to provide their own perspective on their QoL regardless of their aphasia severity (Kagan et al., 2008; The WHOQOL Group, 1996). As Rautakoski and colleagues (2008) reported, “Clients are the best estimators of their own life situation” (p. 1269). Likewise, Rautakoski and colleagues suggested that individuals with moderate to severe aphasia could reliably self-report if measures are adapted to meet their needs. Finally, although ASHA has established practice guidelines (ASHA, 2007) and evidence-based practice guidelines (ASHA, 2004, 2005) that necessitates SLPs incorporate a QoL measure in their assessment repertoires, a portion of clients cannot be assessed using the SAQOL-39 in its current form because it is not adapted to meet their needs.

Pairing the SAQOL-39 with *Life Interests and Values Cards*. In a previous study, Deroche (2011) looked at the degree of symmetry between 31 SAQOL-39 (Hilari, 2003) questions and 31 selected *Life Interests and Values Cards* (L!V cards; Haley, Womack, Helm-Estabrooks, Caignon, & McCulloch, 2010). The study aimed to determine if these line drawings would be a good match for the SAQOL-39 items as judged by normal aging individuals between 65 and 85 years old. Twenty individuals between the ages of 65 and 82 years participated in the study; however, two participants were eliminated because they did not understand the task. Participants were native monolingual English speakers; with no history of stroke, neurologic or neurogenic disease, or traumatic brain injury; had adequate vision; and could read at a fifth-grade level. Participants rated the degree of symmetry on a 5-point Likert scale with the anchors “1 = does not match at all” and “5 = matches exactly” (Deroche, 2011).

Results indicated an intra-rater reliability of 70%. Seven of the 31 images were perceived to be symmetrical while nine of the 31 images were judged not symmetrical. Two of the 31 images were judged to be somewhat representative of the questions. Finally, no relationship could be determined based on the results of 13 of the 31 images due to low agreement rate among raters. Therefore, only 23% of the total L!V cards were judged to be adequate, symmetrical representations of the SAQOL-39 questions.

Qualitative comments from participants suggested that modifications to the images should be made in order to enhance symmetry between the text and the image. Most comments centered on the following themes: facial expressions should be “sad” or “confused,” body postures should be depicted to suggest “tiredness” and “fatigue,” and certain objects and people should be altered in the pictures (p. 32). Based on the results of this study, Deroche

recommended further research in this area since overall symmetry between the L!V cards and the SAQOL-39 items was low.

Deroche's study was the first known to explore the idea of pairing the SAQOL-39 items with images to increase accessibility to PWA. She first began the process with a sample of older adults without language disorders to establish the face validity of the stimuli she had chosen by studying a normal-aging sample. This was essential before moving onto the more complicated process of determining the face validity of the stimuli for individuals with language disorders. Her study provided a springboard for further research in this area because the results were inconclusive. Based on participant input, she suggested finding different images that might be more representative of the SAQOL-39 questions.

Rationale for Current Study

Deroche's (2011) study serves as the impetus for the current study. Based on the supporting literature for pairing text with images to enhance readability (Dietz et al., 2009; Elmore-Nicholas & Brookshire, 1981; Engell et al., 2003; Rautakoski et al., 2008) and the results of Deroche's 2011 study, I will pair a different set of images with the SAQOL-39. I will use descriptive statistics, including mean, standard error of the mean, median, and mode, to summarize the collected data.

Aim of the Study

The current study is a partial replication of Deroche (2011). This study's aim is to answer the following experimental question: What are the perceived similarities between selected colored, high-context photographs and SAQOL-39 questions as judged by 20 normal-aging individuals between the ages of 65-85 years on a 7-point Likert scale rating task?

METHODS

Design

This exploratory study employed a non-experimental, within-group design. The study was approved by the Louisiana State University (LSU) Institutional Review Board prior to participant enrollment and data collection. As in Deroche (2011), I began by having normal-aging individuals rate the similarities between photographs and SAQOL-39 questions to determine if the photographs were a good match. This is an essential first step before incorporating them into a measure created for PWA. PWA will need the photographs to accurately match the questions in order to benefit from the visual support meant to reduce the language demands of the text (Deroche, 2011). This is vital since studies have cited poor picture representations as the possible source for ill results on image-supported text studies for PWA (Brennan et al., 2005).

Participants

I recruited participants through a convenience sampling method using flyers that were displayed at the LSU Speech Language Hearing Clinic and senior citizen centers. In addition, I recruited participants using word-of-mouth advertisement. I included participants in this study if they met the following criteria: (1) between 65 and 85 years old; (2) native monolingual English speaker; (3) no history of or evidence of stroke, neurologic or neurodegenerative disease, and/or brain injury; (4) adequate vision as measured by the *Rosenbaum Pocket Vision Screener* (Rosenbaum, 1982); (5) hearing ability aided or unaided adequate for purposes of the study; (6) ability to read at least a fifth grade reading level passage as measured by the *Dynamic Indicators of Basic Early Literacy Skills* (DIBELS; Good & Kaminski, 2007); (7) ≤ 10 on the *Geriatric*

Depression Scale (Sheikh & Yesavage, 1986; Yesavage et al., 1983); and (8) ≥ 26 on *The Montreal Cognitive Assessment* (MoCA; Nasreddine, 2003-2013; Nasreddine et al., 2005).

I first gathered age, language, and history from potential participants. If the participant met these criteria, I administered the remaining screening items (i.e., vision screener, informal hearing screening, DIBELS passage, *Geriatric Depression Scale*, and the MoCA). If the individual met all of the inclusion criteria, I explained the purpose of the study along with the tasks involved. All participants completed an informed consent form prior to completing the 7-point Likert scale rating task and received a copy to keep. A total of 20 individuals, 14 females and 6 males, met the inclusion criteria. Fifteen percent of the participants were African American, and the remainder were Caucasian. Table 1 displays the demographic information.

Table 1. Demographic Information for Study Participants

Participant Number	Age in Years	Sex	Race
1	70	Male	Caucasian
2	65	Female	African American
3	66	Male	Caucasian
4	81	Female	Caucasian
5	67	Female	Caucasian
6	81	Female	Caucasian
7	85	Male	Caucasian
8	77	Female	African American
9	70	Female	Caucasian
10	69	Female	Caucasian
11	75	Female	Caucasian
12	85	Female	African American
13	78	Male	Caucasian
14	67	Female	Caucasian
15	74	Male	Caucasian
16	66	Male	Caucasian
17	75	Female	Caucasian
18	66	Female	Caucasian
19	75	Female	Caucasian
20	73	Female	Caucasian

M age = 73.25 years (*SD* = 6.43 years)

Materials

Photographs. High-context, colored photographs were taken specifically for the purpose of this study. While line drawings may have been appropriate, a professional artist would have needed to be hired to illustrate a new set of images based on the suggestions made by the participants in Deroche's 2011 study. Given the limited financial resources and time for this thesis, commissioning drawings was not a feasible option. Therefore, older individuals from the Baton Rouge area volunteered to be photographed in high-context settings. The primary investigator and I also posed in photographs that needed a small group. An amateur photographer, who also worked in the LSU Department of Communication Disorders, took the photographs. Photographs were taken using a Nikon D40 digital camera in automatic mode with a Nikon AF-S DX Nikkor 55-200mm lens.

Expert review. A group of expert reviewers (LSU COMD undergraduate and graduate students) reviewed a total of 84 photographs. For the purpose of review, two photographs were selected for each SAQOL-39 question and three training items. Individual photographs were presented via a laptop computer to simulate the experimental display of the photographs. Each reviewer rated whether each photograph represented the SAQOL-39 question using a binary choice "yes" or "no" response on a form. Each photograph was judged independently. For example, if the expert reviewer circled "yes" for the first photograph option for question #4, the expert reviewer did not have to circle "no" for the second photograph option for question #4. Each expert reviewer was also allowed to write any comments for the photographs they rated.

If 2 of 3 expert reviewers agreed that a photograph was representative of the question, it was selected for inclusion into the experimental task. In the event that both photograph options were rated representative, I selected the photograph to be included in the experimental task.

In 38 of the 39 SAQOL-39 questions, at least one of the two photographs received a “yes” by at least 2 of the 3 reviewers. Two of the three sample questions received a “yes” by at least 2 of the 3 reviewers. This resulted in two questions wherein either photograph option did not receive a “yes” by at least 2 of the 3 reviewers. The photographer retook photographs for these questions. These photographs did not undergo a second expert review, but the photographer incorporated the input from the expert reviewers given in the comment section of the initial review.

Procedures

A computer-administered, 7-point Likert scale rating task was used to gather the 20 participants’ judgments regarding the similarity between each photograph and SAQOL-39 question pair. I created the program using E-Prime 2.0 software (E-Prime, 2005). Each participant completed the rating task independently using a Dell Latitude D820 laptop computer at a site chosen by the participant. Data collection sites included participants’ homes, a coffee shop, and senior citizen centers.

To begin, the participant was seated in front of the laptop. Participant characteristics including age, participant number, and sex were entered into the program by the researcher before the task began. The task began with instructions displayed in black font, Times New Roman, point 24, bold against a white screen. The directions read:

1. Look at the photo.
 2. Read the question below it.
 3. Decide how similar the photo is to the question.
 4. Respond by pressing the number on the keyboard.
- 1 = very dissimilar
4 = somewhat similar

7 = very similar

Press SPACEBAR to continue.

Three practice questions, two of which were directly from the SAQOL-39 manual and one which I developed, were included at the beginning of the 7-point Likert scale rating task to ensure that the participant understood the question-photograph pairing, the rating scale, and how to enter their rating using the keyboard. The participant was introduced to the practice questions by the following script which was displayed on the screen in black font, Times New Roman, point 24, bold against a white screen:

First, you will begin with some practice questions.

Press SPACEBAR to continue.

Administration of the three practice questions then began. The photograph was displayed at the top of the screen with the SAQOL-39 question directly below it and the 7-point Likert scale below the question. All SAQOL-39 questions were displayed in black font, Times New Roman, point 19, bold against a white screen. All photographs were sized to fit the allotted space on the screen. After the participant marked his or her response for the displayed photograph-question pairing, the next pairing then immediately and automatically appeared on the subsequent screen. Upon completion of the three practice questions, the screen displayed the following message:

Good job!

You have completed the practice.

Please let Ashley know you are ready to move on.

I answered any questions pertaining to the task before moving onto the 7-point Likert scale rating task involving the remaining SAQOL-39 questions. After answering any questions, the task continued with the screen displaying the following directions:

Now you will rate more pictures.

Remember, your job is to decide how similar the photo is the question.

Enter your rating using the numbers on the keyboard.

1 = very dissimilar

4 = somewhat similar

7 = very similar

Press SPACEBAR to begin rating.

Administration of the remaining 39 questions from the SAQOL-39 then began. The computer screen layout mirrored the practice question layout as described above. All SAQOL-39 questions were copied directly from the manual and were presented in random order for each participant to control for fatigue effects. No stimuli pairs were repeated.

Data Analysis

After 20 participants completed the 7-point Likert scale rating task, I extracted the data using E-DataAid 2.0 (E-Prime, 2005). The data was then exported to Microsoft Office Excel 2007 where I organized it for purposes of this study's data analysis procedure. I calculated mean rating, standard error of the mean, median, mode, and mean response time for each question using the pre-programmed Excel formulas.

RESULTS

Experimental Question

This study's purpose was to answer the following experimental question: What are the perceived similarities between selected colored, high-context photographs and SAQOL-39 questions as judged by 20 normal-aging individuals between the ages of 65-85 years on a 7-point Likert scale rating task?

Descriptive Statistics

The mean rating, standard error of the mean (SEM), median, mode, and mean response time (in milliseconds) were calculated for each SAQOL-39 question using pre-programmed Excel formulas. The mean rating for each question was also rounded up to the nearest whole number if the number following the decimal was $\geq .50$. It was rounded down to the nearest whole number if the number following the decimal was $< .50$. This was done so that mean ratings would more closely represent the whole number values of the 7-point Likert scale used for the experimental rating task. Dual entry by an undergraduate student in the LSU Communication Outcomes Research (COR) Lab was done to ensure accuracy of the calculated values. Results are displayed in Table 2.

Mean rating. Mean ratings for the photograph-question pairings ranged from a minimum of 5.05 to a maximum of 6.70 with an overall mean rating of 6.06 (i.e., 1 = very dissimilar, 4 = somewhat similar, 7 = very similar). The mean ratings for each photograph-question pairing were also rounded to the nearest whole number according to the method described above. With the exception of four photographs, all photographs had a mean rating ≥ 6 when the mean ratings were rounded. The overall rounded mean was 6, indicating that most photographs were rated as being similar to the SAQOL-39 questions.

Table 2. Summary of Descriptive Statistics

SAQOL- 39 Question No.	Mean Rating	Standard Error of the Mean	Median	Mode	Mean Response Time (ms)	Rounded Mean
1	5.75	2.00	7.00	7.00	15172.30	6
2	6.25	1.16	7.00	7.00	11696.05	6
3	5.50	2.14	6.50	7.00	20089.50	6
4	6.15	1.18	7.00	7.00	10880.40	6
5	6.15	1.66	7.00	7.00	15050.25	6
6	5.95	1.64	7.00	7.00	12438.45	6
7	6.35	1.46	7.00	7.00	19489.95	6
8	6.00	1.26	7.00	7.00	11433.45	6
9	6.65	0.75	7.00	7.00	10332.20	7
10	5.60	2.01	6.00	7.00	13300.25	6
11	5.75	1.48	6.00	7.00	16964.55	6
12	5.55	1.79	6.00	7.00	15444.00	6
13	5.85	1.84	7.00	7.00	12929.25	6
14	6.40	1.27	7.00	7.00	10063.15	6
15	6.40	0.99	7.00	7.00	11708.75	6
16	6.00	2.18	7.00	7.00	16868.65	6
17	5.35	1.73	5.50	7.00	18998.85	5*
18	5.65	2.16	7.00	7.00	15028.65	6
19	6.05	1.23	7.00	7.00	14074.20	6
20	5.90	1.33	7.00	7.00	19289.55	6
21	6.00	1.62	7.00	7.00	22085.65	6
22	6.65	0.88	7.00	7.00	9019.35	7
23	6.35	1.27	7.00	7.00	13518.65	6
24	5.40	1.67	6.00	7.00	12710.60	5*
25	6.40	0.99	7.00	7.00	14813.70	6
26	6.00	1.26	7.00	7.00	14592.50	6
27	6.50	1.40	7.00	7.00	10521.55	7
28	6.15	1.50	7.00	7.00	14561.75	6
29	5.75	1.86	6.50	7.00	13669.05	6
30	6.65	0.75	7.00	7.00	15670.55	7
31	6.70	0.73	7.00	7.00	11717.55	7
32	6.45	1.00	7.00	7.00	12457.95	6
33	6.45	1.10	7.00	7.00	16756.15	6
34	6.00	1.21	6.50	7.00	17900.65	6
35	6.45	1.47	7.00	7.00	14016.80	6
36	5.05	2.33	6.00	7.00	31731.80	5*
37	6.15	1.57	7.00	7.00	15548.70	6
38	6.30	0.98	7.00	7.00	19927.45	6
39	5.80	1.47	6.50	7.00	20546.05	6
Sample A	6.15	1.63	7.00	7.00	35845.90	6
Sample B	5.10	1.83	4.50	7.00	28387.70	5*
Sample C	6.70	0.57	7.00	7.00	28528.30	7
Means	6.06	1.44	6.74	7.00	16328.11	6

Note: * = received < 6 rounded mean

Standard error of the mean. The standard error of the mean (SEM) for each individual question-photograph pairing ranged from 0.57 to 2.33. The mean SEM for all 42 pairings was

1.44. The variable SEM values indicated that some ratings were distributed closer to the mean while others were dispersed further away from the mean. An analysis of the SEM values revealed that 19 of the 27 (70%) total photographs with a raw mean rating ≥ 6 had an SEM ≤ 1.44 , which was the mean SEM for all 42 question-photograph pairings. The remaining 8 of the 27 photographs (30%) with a raw mean ≥ 6 had an SEM > 1.44 . For the 15 total photographs with a raw mean rating < 6 , one of these photographs (7%) had an SEM ≤ 1.44 . The remaining 14 of the 15 (93%) total photographs with a raw mean < 6 had an SEM > 1.44 .

This analysis indicated that, overall, the majority of the photographs (70%) with mean ratings ≥ 6 had an SEM that was *less than or equal to* the mean SEM of all 42 question-photograph pairings (SEM = 1.44). The remaining 30% of the photographs with mean ratings ≥ 6 had an SEM that was greater than the mean SEM (SEM = 1.44). In contrast, the majority of photographs (93%) with mean ratings < 6 had an SEM that was *greater* than the mean SEM of all 42 question-photograph pairings (SEM = 1.44). Seven percent of the photographs with mean ratings < 6 had an SEM that was less than or equal to the mean SEM (SEM = 1.44).

Overall, this indicated that the 27 higher rated photographs (i.e., those with a mean rating ≥ 6) had an SEM that was less than or equal to the mean SEM for all 42 question-photograph pairings (SEM = 1.44). The calculated SEM for these 27 photographs was 1.22, a difference of -0.22 compared to the mean SEM. The 15 lower rated photographs (i.e., those with a mean rating < 6) had an SEM that was greater than the mean SEM for all 42 question-photograph pairings (SEM = 1.44). The mean SEM for these 15 photographs was 1.82, a difference of +0.38 compared to the mean SEM. This analysis indicated that, most of the time, the higher the mean rating, the lower the SEM. The individual ratings of these photographs tended to be more closely situated around the mean rating, indicating less variability among the 20 ratings.

Median. The average median for all 42 photographs was 6.74, with a range of medians from 4.50 to 7.00. Following the grouping of the photographs as described above, the 27 photographs with mean ratings ≥ 6 had an average median of 6.98, which was +0.24 than the average median for all 42 photographs. The 15 photographs with mean ratings < 6 had an average median of 6.3, which was -0.44 than the average median for all 42 photographs. Despite the average median of these 15 photographs being lower than the overall median and median of the 27 photographs, the median was still above 6, indicating that the midpoint of the ratings was still at the higher end of the 7-point Likert scale.

Mode. The average mode for all 42 photographs was 7.00. In fact, for all 42 photographs, the mode was 7.00, indicating that most participants rated each photograph as a “7” on the 7-point Likert scale.

Mean response time. The mean response time was 16328.11 milliseconds (16.3 seconds) with some photographs requiring shorter and longer response times. Response times, however, may have been affected if the photograph-question pairing prompted questions or comments.

Item-by-Item Frequency Ratings

Item-by-item frequency distributions were also calculated by reviewing each participant’s rating for each individual SAQOL-39 question. If the percentage of ratings of a 6 or 7 was $\geq 60\%$, as in Deroche (2011), the photograph was determined to be very similar to the question. Results are displayed in Table 3 and Figure 1.

Table 3. Item-by-Item Frequency Distribution

Question No.	1	2	3	4	5	6	7	6 + 7 = %
1	2	0	0	3	2	0	13	65%
2	0	0	0	3	2	2	13	75%
3	3	0	0	1	3	3	10	65%
4	0	0	0	3	3	2	12	70%
5	1	0	1	1	1	2	14	80%
6	1	0	0	3	2	2	12	70%
7	1	0	0	0	3	1	15	80%
8	0	0	0	4	3	2	11	65%
9	0	0	0	0	3	1	16	85%
10	2	1	0	1	1	6	9	75%
11	0	1	0	4	2	4	9	65%
12	1	1	0	4	0	6	8	70%
13	1	1	0	3	0	3	12	75%
14	0	1	0	1	0	4	14	90%
15	0	0	0	2	1	4	13	85%
16	3	0	0	0	0	2	15	85%
17	1	1	0	3	5	3	7	50%
18	3	0	0	1	1	4	11	75%
19	0	0	0	4	2	3	11	70%
20	0	0	0	5	3	1	11	60%
21	1	0	0	3	1	3	12	75%
22	0	0	0	1	2	0	17	85%
23	0	0	1	2	1	1	15	80%
24	1	0	1	4	3	4	7	55%
25	0	0	0	1	4	1	14	75%
26	0	0	0	4	3	2	11	65%
27	1	0	0	0	1	2	16	90%
28	1	0	0	1	2	4	12	80%
29	2	0	0	1	3	4	10	70%
30	0	0	0	1	0	4	15	95%
31	0	0	0	1	0	3	16	95%
32	0	0	0	2	1	3	14	85%
33	0	0	1	1	0	4	14	90%
34	0	0	0	4	2	4	10	70%
35	1	0	0	1	0	2	16	90%
36	3	1	1	3	0	3	9	60%
37	1	0	0	2	1	3	13	80%
38	0	0	0	1	4	3	12	75%
39	0	1	0	3	4	2	10	60%
Sample A	1	0	1	1	0	4	13	85%
Sample B	1	0	2	7	1	1	8	45%
Sample C	0	0	0	0	1	4	15	95%

Table 3. The frequency distribution of ratings is summarized above. Note that the rating anchors of “1” indicated that the photograph and question were “very dissimilar” while “7” indicated a “very similar” relationship. A rating of “4” indicated the photograph and question were “somewhat similar.”

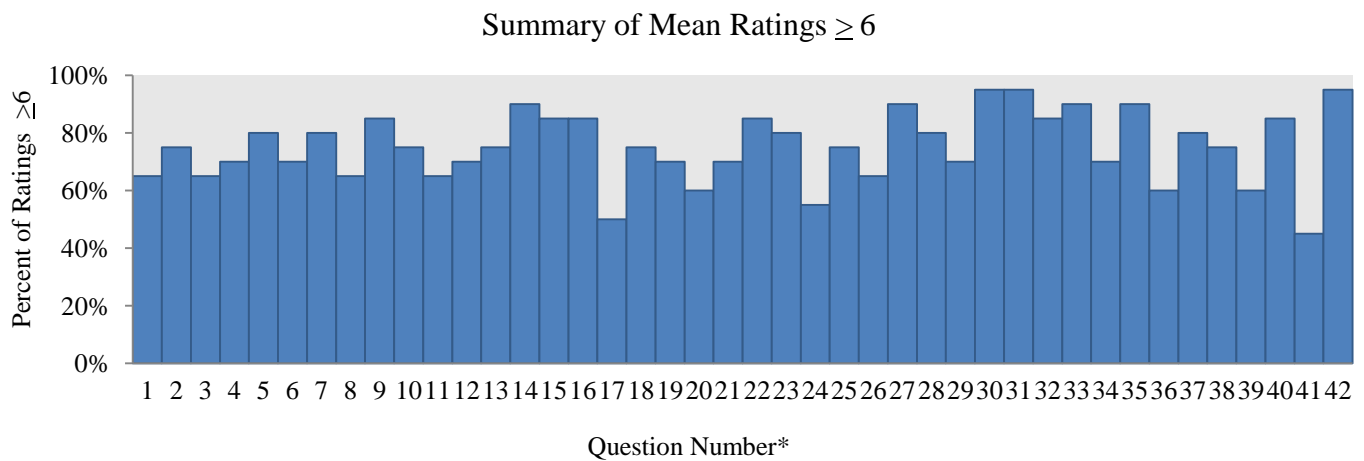


Figure 1. Summary of Mean Ratings ≥ 6

**Note: 40 = "Sample A"; 41 = "Sample B"; 42 = "Sample C"*

Item-by-item frequency ratings analysis. Based on the results, 39 of the 42 total photographs (93%) were rated a 6 or 7 at least or more than 60% of the time. Three of the 42 photographs (7%); question #17, question #24, and Sample B; were rated a 6 or 7 only 50%, 55%, and 45% of the time, respectively.

DISCUSSION

Summary of Results

Based on the results of this study, the validity of the high-context photographs taken to represent the SAQOL-39 questions was determined to be high considering that the overall mean rating of the 42 photographs was 6.06 on a 7-point Likert scale. The rounded mean ratings for all but 4 questions (Question #17, #24, #36, and Sample B) were ≥ 6 . In addition, 39 of the 42 photographs (93%) were rated a 6 or 7 $\geq 60\%$ of the time, as per the method used in Deroche (2011). Of the three total photographs receiving a 6 or 7 rating $< 60\%$ of the time, one was a photograph for a sample question rather than a scored SAQOL-39 test item. As a result, 37 of the actual 39 SAQOL-39 questions (95%) were rated a 6 or 7 $\geq 60\%$ of the time.

Although mean ratings were high, the SEM values were variable. Some photographs had higher SEM values which suggested that ratings were not as tightly arranged around the mean. Some SEM values, however, were low suggesting that most ratings fell closer to the mean. An analysis of individual SEM values revealed that the 27 photographs with a mean rating ≥ 6 had a smaller SEM than the 15 photographs with a mean rating < 6 . This indicated that the individual ratings of the higher rated photographs were more closely situated around the mean compared to the lower rated photographs. Despite their overall higher SEM, however, the strength of these 15 photographs was justified by a strong overall median of 6.3 and a strong overall mode of 7.00.

Results of this study indicated that, on a whole, the photographs taken were similar and representative of the SAQOL-39 questions as judged by 20 typically-aging individuals. As compared to the results of Deroche (2011), these results are more conclusive because 93% of the photographs were rated “similar” to the question (i.e., rated a 6 or 7 $\geq 60\%$ of the time). Deroche’s data, on the other hand, showed that only 7 of the 31 (23%) picture-question pairings were determined to be symmetrical. Some might argue that asking typically aging individuals to

rate the similarity of pictures and questions on a measure QoL in people with post-stroke aphasia is not the way to establish face validity. However, PWA will need the photos to accurately match the questions in order to benefit from the visual support meant to reduce the language demands of the text (Deroche, 2011). This is vital since studies have cited poor picture representations as the possible source for ill results on image-supported text studies specifically for PWA (Brennan et al., 2005). As a result, this goal of establishing face validity was achieved via studying a normal-aging sample before moving onto a sample of PWA.

Study Limitations

An analysis of participant gender revealed a higher female ($n = 14$) to male ($n = 6$) ratio of participants in this study. In addition, no duplicate pairs were rated during the 7-point Likert scale rating task, thus the intra-rater reliability is unknown. Furthermore, some participants misinterpreted the wording of the questions taken from the SAQOL-39 manual and thought they were to rate their *own* level of difficulty based on each question's first-person wording. In addition, the question prompt, "How much trouble did you have..." (Hilari, 2003, e.g., p.4) sometimes led participants to rate the similarity of the photograph and question based on how much *trouble* the person in the photograph appeared to be experiencing. While their thinking was sensible, the PWA who complete the SAQOL-39 are able to choose from a range of responses, including "No trouble at all" (Hilari, 2003, e.g., p. 4). Therefore, when this occurred, participants were re-instructed to rate the similarity of the photographic activity or situation compared to the question rather than judging the amount of difficulty that the model in the photograph was experiencing.

Finally, I recognize that the SAQOL-39 questions could have been depicted in photographs in many different ways. However, I worked to depict each question in the most

representative way in an attempt to reduce bias, such as including expert reviewers in picture selection prior to the experiment.

Future Research

My results justify the need for future research to investigate if these photographs provide the additional support needed for individuals with aphasia—from mild to severe—to complete the SAQOL-39 independently thereby reducing the need for proxy raters. If the photographs increase accessibility of the SAQOL-39 to individuals with severe aphasia, we would be able to obtain their unique perspectives on how severe language disorders have actually affected their QoL. As a result, speech-language pathologists could work toward helping these individuals improve aspects of their QoL by tailoring treatment to each patient's specific needs. Ultimately, service delivery would be enhanced (ASHA, 2004; Buck et al., 2000; The WHOQOL Group, 1996), and SLPs would be practicing more in line with their scope of practice (ASHA, 2007).

Conclusion

In conclusion, every individual, no matter the severity of their aphasia, should be given the opportunity to self-report on their QoL. The results of this study have paved a path for others to discover if the missing link to assessing QoL in individuals with severe aphasia is the incorporation of images. Until we are able to assess QoL in all individuals affected by aphasia, this multi-faceted puzzle remains incomplete. However, when our goal is finally reached, the field of speech-language pathology will truly be revolutionized.

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APPENDIX A: ACRONYM DICTIONARY

A-FROM	Living with Aphasia: Framework for Outcome Measurement
ALA	Assessment for Living with Aphasia
ALQI	Aachen Life Quality Inventory
ASHA	American Speech-Language-Hearing Association
ASHA QCL	American Speech-Language-Hearing Association Quality of Communication Life Scale
COR Lab	Communication Outcomes Research Lab
DIBELS	Dynamic Indicators of Basic Early Literacy Skills
FAST	Frenchay Aphasia Screening Test
HRQoL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability, and Health
L!V	Life Interests and Values cards
LSU	Louisiana State University
MoCA	Montreal Cognitive Assessment
PWA	Person/people with aphasia
QoL	Quality of life
SAQOL	Stroke and Aphasia Quality of Life Scale (53-item version)
SAQOL-39	Stroke and Aphasia Quality of Life Scale- 39 items
SLP	Speech-language pathology/pathologist
SS-QOL	Stroke Specific Quality of Life Scale
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life (e.g., The WHOQOL Group)

APPENDIX B: IRB APPROVAL

Project Report and Continuation Application

(Complete and return to IRB, 131 David Boyd Hall, Direct questions go to IRB Chairman Robert Mathews 578-8692.)



Institutional Review Board
 Dr. Robert Mathews, Chair
 131 David Boyd Hall
 Baton Rouge, LA 70803
 P: 225.578.8692
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IRB#: 3146 Current Approval Expires On: 10/11/2012
 Review Type: Expedited Risk Factor: Minimal
 PI: Nella Donovan Dept: COMD Phone: 578-3938
 Student/Co-Investigator: **Ashley Brouwer

Project Title: A survey of selected picture representations of the stroke and aphasia quality of life scale-39 items

Number of Subjects Authorized: **20 **New M.A. student completing thesis. Requesting continuation of this study to replicate it with 10 different subjects.

Please read the entire application. Missing information will delay approval!

IRB Security of Data Agreement: <http://research.lsu.edu/files/item26774.pdf>

I. PROJECT FUNDED BY: N/A LSU Proposal #: N/A

II. PROJECT STATUS: Check the appropriate blank(s) and complete the following:

- 1. Active, subject enrollment continuing; # subjects enrolled: 10 **See above note, requesting continuation to replicate study with 10 new subjects with some changes to protocol.
- 2. Active, subject enrollment complete; # subjects enrolled: _____
- 3. Active, subject enrollment complete; work with subjects continues.
- 4. Active, work with subjects complete; data analysis in progress.
- 5. Project start postponed; date: _____
- 7. Project cancelled: no human subjects used.
- 6. Project complete; end date: _____

III. PROTOCOL: (Check one).

- Protocol continues as previously approved
- Changes are requested*
 --List (on separate sheet) any changes to approved protocol.

IV. UNEXPECTED PROBLEMS: (did anything occur that increased risks to participants):

---State number of events since study inception: 0 since last report: 0
 ---If such events occurred, describe them and how they affect risks in your study, in an attached report
 ---Have there been any previously unreported events? Yes/No: _____

V. CONSENT FORM AND RISK/BENEFIT RATIO:

Do new knowledge or adverse events change the risk/benefit ratio? Yes/No: NO
 Is a corresponding change in the consent form needed? Yes/No: NO

VI. ATTACH A BRIEF, FACTUAL SUMMARY of project progress/results to show continued participation of subjects is justified; or to provide a final report on project findings.

VII. ATTACH CURRENT CONSENT FORM (only if subject enrollment is continuing); and check the appropriate blank;

- 1. Form is unchanged since last approved -Purpose of the study, description of the study, investigators, signatures, and risks sections altered
- 2. Approval of revision requested herewith: (Identify changes) -Inclusion criteria added

Signature of Principle Investigator: Nella Donovan Date: 8/24/12

IRB Action:	<input checked="" type="checkbox"/> Continuation approved; <input type="checkbox"/> Disapproved <input type="checkbox"/> File Closed	Approval Expires: <u>9/4/13</u>
Signed:	<u>[Signature]</u>	Date: <u>9/5/12</u>

Print Form

ACTION ON PROTOCOL APPROVAL REQUEST



Institutional Review Board
Dr. Robert Mathews, Chair
131 David Boyd Hall
Baton Rouge, LA 70803
P: 225.578.8692
F: 225.578.6792
irb@lsu.edu | lsu.edu/irb

TO: Neila Donovan
COMD

FROM: Robert C. Mathews
Chair, Institutional Review Board

DATE: April 17, 2013
RE: IRB# 3146
TITLE: A survey of selected picture representations of the stroke and aphasia quality of life scale-39 items

New Protocol/Modification/Continuation: Modification

Brief Modification Description: Number of subjects increased from 30 to 40

Review type: Full Expedited **Review date:** 4/17/2013

Risk Factor: Minimal Uncertain Greater Than Minimal

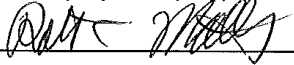
Approved **Disapproved**

Approval Date: 4/17/2013 **Approval Expiration Date:** 9/4/2013

Re-review frequency: (annual unless otherwise stated)

Number of subjects approved: 40

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.
7. Notification of the IRB of a serious compliance failure.
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>*

VITA

Ashley Renee Brouwer was born in LaPlace, Louisiana and graduated from Saint Charles Catholic High School in 2007. After graduation, she attended Louisiana State University where she earned her Bachelor of Arts degree in Communication Disorders in May 2011. She began her Master of Arts degree in August 2011 and will graduate in May 2013. Her thesis was conducted under the guidance of Dr. Neila J. Donovan. Upon graduation, Ashley plans to work as a clinical fellow speech-language pathologist in a hospital setting in Baton Rouge, Louisiana.