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**Factors Influencing Communication Quality of Life in Persons with Aphasia:
Results and Implications**

by

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A Thesis

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Abstract

Problem: Deficits in verbal and nonverbal communication can lead to persons with aphasia (PWAs) feeling socially isolated, resulting in lower quality of life (Cruice et al., 2003). Various assessments have been developed to measure communication quality of life (CQoL) as well as overall quality of life (QoL); however, it is unclear which aspects of PWAs' lives are specifically influencing the outcomes. Past studies have considered how aphasia influences QoL (Ross & Wertz, 2003), and more recently, the impacts aphasia has on CQoL have been analyzed (Bose et al., 2009). With the development of new measures, it is important to determine which assessment will yield effective outcomes in persons with different profiles of aphasia. The ASHA-FACS and ASHA-QCL are two measures that are commonly used in the assessment of CQoL with different response recording systems. Each have been separately studied with regards to other QoL measures to determine which measure will provide a more unique representation of CQoL in persons with aphasia. The purpose of the current study is to determine how the ASHA-FACS and ASHA-QCL correlate with each other, and if the participants' factors of post-onset period, aphasia severity level, cognitive functioning, and therapy received will impact these outcomes.

Procedure: Twenty-one people with aphasia with ages ranging from 47 to 91 years old (mean= 67 years, SD= 11.4) and post-onset periods ranging from two months to fourteen years (mean= four years, four months; SD= 2.9) participated in the study. Each individual completed six assessments, including both standardized and criterion referenced measures (WAB-R, CLQT, SAQOL-39, ASHA-FACS, ASHA-QCL, and CCRSA). In addition, participants completed a demographics questionnaire which included questions about when their stroke occurred (post-onset period) and the type and duration of therapies they had received. Assessments were conducted over two sessions to prevent fatigue and the order of presentation in the two sessions was randomized across the participants to control for order effects of test administration. The assessments were analyzed using a correlation matrix to determine the strength of relationships between each of the measures. ANOVAs were used to compare QoL and CQoL outcome scores for participant groupings based on time post-onset, aphasia severity, cognitive functioning, and therapy received.

Findings: The ASHA-QCL and ASHA-FACS were found to have large positive correlations with each other, however, the ASHA-QCL had more positive correlations with other QoL measures than the ASHA-FACS. Some of the factors examined including aphasia severity, cognitive limitations and therapy received each had a significant influence on either QoL or CQoL. These factors should be considered when planning treatment for PWAs. Selection of QoL and CQoL measures should be based upon the PWA's profile and personal factors to ensure the measure will be sensitive to identifying areas of the individual's life that have been compromised due to having aphasia.

Keywords: Aphasia, Stroke, Quality of Life, Communication Quality of Life, Cognitive Deficits

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Chapter 1: Introduction

Background

Communication is defined as the exchanging of information, ideas, needs, and mutual understanding in either verbal or nonverbal ways (Tompkins, 2012). This sharing of information is a crucial component for interacting and developing relationships with others. When an individual's communication is impaired, they may feel disengaged or detached from outside environments due to their inability to share ideas or receive information. One such common communication impairment in adults is aphasia.

Aphasia is a language impairment that results from a lesion or damage in the brain generally caused by a stroke. It is characterized by deficits in expressive and receptive language abilities and can lead to impairments within the communication modalities of speaking, listening, reading and writing. The location and extent of the lesions in the brain typically determine which aspects of communication modalities are affected and how severe the individual's deficits are, respectively (Papathanasiou & Coppens, 2017). Depending on the modalities affected and the location of the lesions, different types of aphasia are recognized, and these are broadly classified into expressive and receptive aphasias.

Broca's aphasia is a type of expressive aphasia that results from a lesion in an area of the left frontal lobe of the brain called Broca's area, which is responsible for programming and controlling speech production (Papathanasiou & Coppens, 2017). Broca's aphasia is characterized by non-fluent and effortful speech. Individuals with this type of aphasia have impairments in verbal expression, repetition, writing, oral reading, articulation, sentence production and suprasegmental elements of speech. Their receptive language is relatively better

than their expressive language, and their speech is telegraphic, or consisting of mainly content words with few function words (Broca's Aphasia; American Speech-Language-Hearing Association, ASHA, n.d.). For example, when describing a picture scene with a family in a park, a person with Broca's aphasia might say "boy, run, dog". This would be an example of omitting function words (e.g. "is", "the") that are typically used when speaking. People with Broca's aphasia may have agrammatism, which refers to an impairment at the level of the syntax and may result in the individual producing ungrammatical sentences. Common errors include omission of pronouns, prepositions, articles, and other function words (Mehri & Jalaie, 2014).

Wernicke's aphasia is a receptive type of aphasia, that results from a lesion in an area of the left temporal lobe called Wernicke's Area, which is responsible for comprehension of speech and language (Wernicke's Aphasia; National Aphasia Association, 2015). Wernicke's aphasia is characterized by fluent speech, normal prosody and intact articulation. This type of aphasia causes impairments in repetition, written expression, reading comprehension, naming, and auditory comprehension. Individuals with Wernicke's aphasia are said to have paragrammatism, which results in omissions or substitutions of grammatical morphemes when they are speaking (e.g. "The man run" instead of "the man is running") (Helm-Estabrooks, Albert, and Nicholas, 2014). Their sentences typically lack content and consist of neologisms (meaningless, nonsense words), which is referred to as 'jargon speech' (Papathanasiou & Coppens, 2017). The individual is unable to detect their own communication errors, making it hard for listeners to understand them.

Conduction aphasia is a milder form of the receptive aphasia that results from a lesion in the arcuate fasciculus. This is a band of fibers that connects Wernicke's and Broca's areas and

allows for communication between the two areas of the brain. Wernicke's aphasia is characterized by good comprehension, with impairments in repetition and word finding. Conduction aphasia differs from Wernicke's aphasia and is characterized by impairments in naming on confrontation (i.e. labeling an object or image when presented), writing, and increased difficulty programming the movements of oral and facial structures. Global aphasia is a type of aphasia characterized by severe impairments with all language functions, as well as the inability to control and plan motor movements. As the name implies, individuals with this type of aphasia have severe difficulties in all aspects of communication including auditory comprehension, verbal expression, reading comprehension and written expression. They may also have right-sided sensory loss or right hemiplegia (Papathanasiou & Coppens, 2017).

Overall, aphasia can impact various dimensions of communication within both verbal and non-verbal modalities. These deficits create a communication barrier for the person with aphasia (PWA) and have a significant effect on his or her interactions with others, because it requires more effort to access and retrieve words and understand what others are saying. The reduced language abilities may negatively impact the PWA's social life including their social networks, social activities, relationships with others, and social support (Bose et al., 2009; Hilari & Byng, 2009; Hilari, Needle, & Harrison, 2012). An individual's social involvement relates to internal factors of self-acceptance, personal growth and development (Cruice et al., 2003). Therefore, the impact aphasia has on one's ability to communicate, can significantly influence the PWA's quality of life, communication quality of life, and the quality of life of people they are close with.

Brumfitt (1993) discussed clinical issues regarding the impact aphasia has on an individual and their sense of self. The abrupt onset of aphasia can impact the individual, as many

aspects of their personality and lifestyle have changed. Some experiences, such as ordering food at a drive-through restaurant, might pose new challenges for the person with aphasia. The impaired communication abilities extend into those needed for everyday interactions, such as understanding intent, appreciating humor in jokes, and expressing one's feelings (Brumfitt, 1993). Aphasia is an invisible problem and the way other people react to the person with aphasia (i.e. their spouse and/or other caregivers) shapes how they view themselves. For example, if the spouse or caregiver behaves as if the individual is severely handicapped, this could discourage the person with aphasia. It is also important that the PWA maintains friendships, as these relationships may help the individual cope with the negative consequences associated with aphasia (Davidson et al., 2008). If there is continuity in the treatment and interactions others have with the person with aphasia, they will still feel competent and adequate, as they did pre-stroke (Brumfitt, 1993).

Social Isolation and Depression

After a stroke, PWAs might have less confidence in their speaking abilities or anticipate that they will make a mistake, and this is often referred to as "linguistic anxiety" (Gainotti, 1997). To reduce this fear and anxiety, the individual might avoid social situations (Cahana-Amitay et al., 2011). A survey conducted by the National Aphasia Association to PWAs in 1988 found that 70% of respondents felt that others avoided talking with them because of communication difficulties and 90% of the people who responded reported feeling socially isolated. PWAs may naturally become less social after their stroke because communicating effectively becomes difficult (Brumfitt, 1993; Cahana-Amitay et al., 2011; Code & Herrmann, 2003; Cruice et al. 2010). When compared to control subjects on quality of life (QoL) measures,

PWAs have been found to score lower in the socialization and activities subdomains (Bose et al., 2009; Cruice et al., 2003; Pallavi, Perumal, & Krupa, 2018). These subdomains directly ask questions about the individual's participation in social situations (e.g. social outings, making phone calls, and others) and whether they engage in these activities as often as they like, or if they would prefer to do it more often. The reduced scores in these areas demonstrate that PWAs are not participating fully in everything that they would want to do. Sometimes the reduced socialization may be due to exclusion from social groups. Previous studies have found that PWAs have fewer friends, fewer social networks, and less socialization within the work setting (Davidson et al., 2008; Herrmann & Wallesch, 1989). Additionally, people with severe aphasia report being excluded from activities and social outings more often than those with milder forms of aphasia (Hilari, Needle, & Harrison, 2012). Worrall et al. (2011) interviewed PWAs to determine which parts of their life were most impacted by aphasia and what the patients' goals were. An overall trend was found in PWAs wanting to socialize more with family, friends and coworkers. These findings confirm that PWAs have the basic desire to communicate and socialize with others in their community.

Reduced socialization can impact PWAs' lives significantly, as they are not interacting with people and their environment as much as they would like. This could lead to depression, because there have been significant life changes that do not allow the individual to engage in the same activities (Code & Herrmann, 2003). In fact, PWAs have a higher depression rate (62% at one year post-onset) when compared to other stroke survivors (34% at greater than six months post-stroke) (Hilari, Needle, & Harrison, 2012). Various studies have found that when a PWA has negative thoughts or feelings such as those associated with depression, this can impact their

recovery outcomes, whereas those people who have grieved and are ready to improve their speech will have more success (Cahana-Amitay et al., 2011; Code & Herrmann, 2003; Hilari, Needle, & Harrison, 2012). Post-stroke depression and anxiety may depend somewhat on the PWA's support system, post-onset period, and career. People who are in the acute stage post-stroke, might have a different level of depression, when compared with those who are greater than six months post-onset (Gainotti, 1997). This can be attributed to the individual not fully understanding how aphasia will impact their life in the acute stages. In summary, social participation and depression intertwine and should be monitored for PWAs.

Measuring Quality of Life

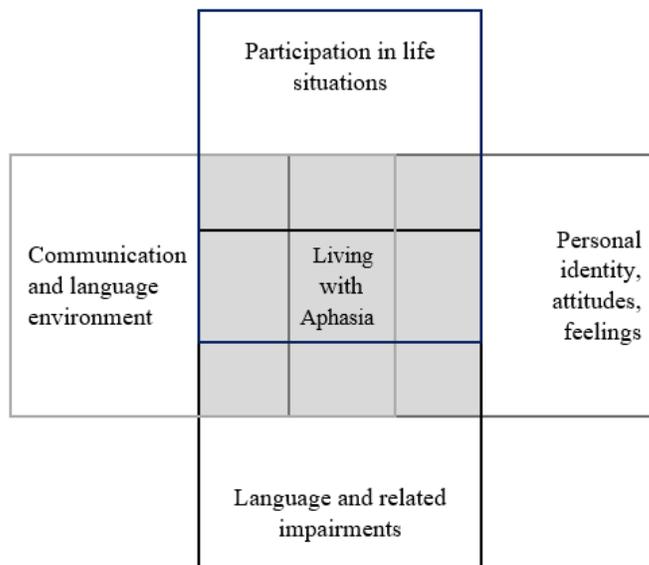
Aphasia's impact on social interactions can compromise the individual's quality of life (QoL). The World Health Organization (WHO) defines QoL as an individual's "perceptions of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards and concerns" (p.354). Past research suggests that PWAs experience a reduced QoL due to the loss of function that they once had (Spaccavento et al., 2013). They may no longer be able to participate in social events, communicate their basic needs and wants, or enjoy listening to jokes or stories. Losing these abilities impacts the PWA as well as their family and friends. To capture such pervasive effects of the disabilities (e.g. aphasia), beyond themselves, the WHO International Classification of Functioning, Disability and Health (WHO-ICF, 2001) proposed a theoretical framework that focuses on the factors that contribute to the individual's overall health status. This framework considers activities and participation in daily life and emphasizes quality of life by considering contextual, personal, and environmental factors. This is an all-inclusive approach to understanding aphasia and it also

recognizes the impact aphasia has on the people who work with and care for the individual (Papathanasiou & Coppens, 2017).

Consistent with the WHO model, Kagan (2011) described a more recent framework, Living with Aphasia: Framework for Outcome Measurement (A-FROM), that focuses on the health and well-being of PWAs. This model includes four overlapping domains that contribute to living with aphasia. The four domains pertain to participation in life situations, communication and language environment, language and related impairments, and personal identity, attitudes, and feelings. This model visually demonstrates how all parts of the person's life are overlapping and can affect one another (Figure 1; Kagan, 2011).

Figure 1

Living with Aphasia: Framework for Outcome Measurement (A-FROM)



This model offers a holistic approach to working with PWAs because their reduced language abilities do not stand alone and can impact other overlapping areas such as their self-

esteem. A lower self-esteem might result in reduced participation in everyday activities due to fear of not being understood or having word finding difficulties with unfamiliar people.

Various studies have sought to determine which areas of Quality of Life (QoL) are most impacted by aphasia. Cruice et al., (2010) asked PWAs six open-ended questions to determine which areas of QoL were predominantly impacted by aphasia. The category “activities” was mentioned often by participants, as they reported that no longer being able to do certain activities compromised their QoL and sometimes they had to accept a new way of doing specific activities. Other areas that impacted their QoL were verbal communication difficulties, relationships with family and friends (i.e. not being able to say familiar peoples’ names), and both physical mobility limitations and cognitive functioning limitations. Other studies have compared QoL between PWAs and control participants. These studies have consistently found that PWAs have reduced QoL when compared to controls, often in regard to their social life or activities, and communication confidence (Bose et al., 2009; Hilari, Needle, & Harrison, 2012; Pallavi, Perumal, & Krupa, 2018; Ross & Wertz, 2003; Spaccavento et al., 2013). These results align with previously discussed studies demonstrating that aphasia impacts all areas of life, including both communication related activities and personal factors, such as confidence in oneself.

A large study completed in Canada examined the QoL of 66,193 participants with various diseases and conditions. Aphasia was found to have the largest negative impact on QoL, because it limits the individual’s ability to communicate with friends, family, doctors and others in the community (Lam & Wodchis, 2010). In this study, aphasia had a larger negative impact on QoL than both cancer and Alzheimer’s disease combined, with the reasoning being that the PWAs felt helpless when trying to request help or express wants to care providers in the hospital. These

findings demonstrate a need for increased awareness about the negative impacts of aphasia and the need for continued use of QoL instruments to allow health care professionals to check on PWAs' overall well-being.

Theoretical frameworks such as the previously discussed WHO and A-FROM have brought QoL to the forefront in aphasia rehabilitation and they have become a vital part in both assessment and treatment of aphasia. There have been a number of standardized and criterion referenced tools developed to assess various modalities and linguistic processing problems in aphasia. Specifically, modalities such as speaking, auditory comprehension, reading, and writing, can be assessed to determine where the breakdown in communication is occurring. Standardized assessments such as the Western Aphasia Battery-Revised (WAB-R) or the Boston Diagnostic Aphasia Evaluation (BDAE) are used to measure the breakdown in such modalities and also to measure the treatment outcomes. These assessments provide an accurate representation of the PWA's current language level and identify which modalities are impacted by aphasia. Linguistic processing tests such as the Psycholinguistic Assessments of Language Processing in Aphasia (PALPA), Verb and Sentence test, Arizona Battery for Reading and Spelling (ABRS), and others focus on cognitive linguistic processing of language at all levels including phonology, morphology, syntax, and semantics.

More recently, various assessments have been developed to measure the impact of aphasia beyond the linguistic levels of impairment and help clinicians identify which domains in QoL are diminished for clients with aphasia. Some of these assessments include the American Speech-Language Hearing Association's Quality of Communication Life Scale (ASHA-QCL), ASHA's Functional Assessment of Communication Skills (ASHA-FACS), Communicative

Activities Checklist (CAC), Communication Activities of Daily Living (CADL), Social Activities Checklist (SAC), Social Network Analysis (SNA), and the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) (Morrow-Odom, Moser, & Neils-Strunjas, 2017). These assessments use survey questions specifically to determine the QoL of the individual and often incorporate participation domains from the WHO-ICF framework. When QoL is regularly assessed, it provides important information about the PWA's deficit areas and ability to cope, and helps the clinicians understand the overall well-being of the individual beyond just aphasia.

Use of accurate assessment guides the clinicians in estimating the outcome bars for rehabilitation goals in order to increase functional autonomy within multiple environments and with various communication partners (Spaccavento et al., 2013). Planning rehabilitation for the PWA must involve the individual and family's preferences as well as the clinician's expertise to determine therapy targets that will result in the most benefits and gains for the person with aphasia. The Life Participation Approach to Aphasia (LPAA; Chapey et al., 2000) is an approach that involves the re-engagement in life for PWAs and provides supports to both the individual who had a stroke and others affected by the communication disorder. This approach allows the PWAs and people they are close with to make decisions about what should be targeted in therapy to reduce the consequences of aphasia and help the individual return to an active life (Chapey et al., 2000). To provide accurate and efficient rehabilitation, the Speech-Language Pathologists will need to evaluate where deficits are occurring, within the realms of both communication and QoL of PWAs.

When evaluating a client with aphasia, the Speech Language Pathologist may be unsure of whether or not to assess QoL, and which assessment they should choose. In 2017, sixty-two

Speech-Language Pathologists (SLPs) completed surveys regarding which QoL assessments they use and if they view assessment of QoL to be important (Morrow-Odom, Moser, & Neils-Strunjas, 2017). Most SLPs viewed it as being extremely important (63%) or very important (30.5%). The professionals surveyed reported using the CADL most often of the published measures, but others used informal measures such as observations or interviews. Many respondents indicated that they had been told about the importance of assessing QoL in graduate school but may not have been introduced to specific measures. The clinicians also reported that they assessed QoL in people with severe or profound aphasia less often than people with a moderate level of aphasia severity. Several of these findings demonstrate the need for comparing QoL assessments to provide a clear understanding of what each assessment measures and which aphasia profile each assessment is best suited for (Morrow-Odom, Moser, & Neils-Strunjas, 2017).

One study by Ross and Wertz (2003) compared quality of life for people with and without aphasia. Nineteen participants with aphasia and nineteen control participants were assessed. The researchers used two measures, the World Health Organization Quality of Life Instrument Brief Version (WHOQOL-BREF) as a general QoL measure and the Psychosocial Well-being Index (PWI) as a disease-specific measure for aphasia. PWAs differed most from the controls in their activities of daily living, and both of the QoL measures used were found to be equally sensitive in measuring positive feelings, mobility, personal relationships and leisure activities. The WHOQOL-BREF was more sensitive in identifying differences in self-esteem and activities of daily living, while the PWI was more sensitive in detecting differences in spirituality/religion/personal beliefs. This study is an important contribution to aphasia

rehabilitation research because it compared two QoL measures to determine the sensitivity of each. These results can be used when deciding which assessment to administer, as this study found specific personal attributes that were measured by each questionnaire.

QoL has become a growing research topic because it is a crucial aspect of therapy when planning treatment for the total well-being of PWAs. Given that there are a number of QoL and communication quality of life (CQoL) measures to choose from, it is important to understand when to use each assessment. Previous research has mainly focused on QoL for overall health, such as psychosocial and social well-being, rather than communication QoL specifically. Within the field of communication sciences and disorders, there have been survey style measures developed to consider communication specific QoL. The American Speech-Language-Hearing Association developed both the ASHA-Functional Assessment of Communication Skills (ASHA-FACS) and the ASHA-Quality of Communication Life Scale (ASHA-QCL). Each of these measures use different response scoring systems and ask distinct questions related to everyday communication abilities and challenges that PWAs may encounter. The ASHA-QCL is used to measure difficulty of performance to see how PWAs perceive the specific communication tasks to be more challenging post-stroke (Eadie et al., 2006). Similarly, the ASHA-FACS was developed to determine how deficits in various communication modalities impact performance in everyday activities (Frattali et al., 1995). These measures developed by ASHA have been compared to QoL measures in previous research (Bose et al., 2009; Hilari & Byng 2009) however, information on when to use each of these measures is still missing.

A 2009 study compared the ASHA-QCL to the SAQOL-39 to determine which domains on the scales were most impacted by aphasia and how the two scales relate (Bose et al., 2009).

Nineteen PWAs with ages ranging from twenty-seven to seventy-nine years (mean= 65.3 years) and ranging from 8-155 months post-onset (mean= 42.2 months) were assessed with the ASHA-QCL and SAQOL-39. There were nineteen age and gender matched control participants that were also assessed. A correlation was found between the socialization/activities sub-domain of the ASHA-QCL and the communication sub-domain of the SAQOL-39. These results emphasize the need for communication in life participation. The high correlation makes it clear that socialization and involvement in activities may be compromised when communication deficits are present. The researchers found that both instruments measured different things; the SAQOL focused on overall QoL, while the ASHA-QCL was more sensitive to detecting how the communication disorder impacts the client's QoL (Bose et al., 2009). This shows how crucial it is that a well-developed CQoL measure is used when assessing a PWA to establish a more accurate representation.

Factors that Contribute to Quality of Life

When measuring PWAs' QoL, it is important to consider any cognitive limitations they have and if that contributes to their QoL. Recent studies have used the Cognitive Linguistic Quick Test (CLQT) along with QoL measures to determine if relationships exist between cognitive abilities and QoL (Chiou & Yu, 2018; Nicholas, Hunsaker, & Guarino, 2017). Both of these studies found that specifically the CLQT symbol trails subtest was highly correlated with language scores, communication confidence and QoL measures. This subtest resembles cognitive tasks that may be used in everyday life situations such as using cognitive flexibility to switch attention, visual attention, and working memory. The cognitive skills needed for switching attention can be related to everyday tasks such as preparing a meal from a recipe, or shopping,

which each require many steps of monitoring to check for progress and impending revisions. Therefore, the results indicate that PWAs may experience difficulty with cognitive tasks, thus interfering with their life participation

Furthermore, Nicholas, Hunsaker, and Guarino (2017) found the severity of language and severity of cognitive abilities to be highly related and predictive of QoL scores. Given the results of these studies, it is important to consider how PWAs' reduced language abilities may be interrelated with their lower scores on cognitive tasks. Additionally, some studies have looked specifically into which areas of executive functioning are impaired, and how this impacts PWAs' language processing and QoL. When completing language tasks, it is important that the individual attends to the language stimuli to accurately process them. Some researchers have discovered that PWAs may have deficits in arousal, which impacts their ability to attend to a stimulus for a long period of time, or allocate their attention efficiently and accurately (McNeil, Odell, & Tseng, 1991; Tseng, McNeil, & Milenkovic, 1993). These impairments in attention can make everyday tasks such as grocery shopping, listening to conversations, and following news stories on TV more strenuous for PWAs.

Another executive functioning skill that could be impacted when a person has aphasia is problem solving (Purdy & Koch, 2006). Problem solving is a skill that allows individuals to identify an issue and find ways to address the issue by generating multiple solutions. When a language breakdown occurs, it requires the individual to use problem solving skills to communicate effectively, whether they describe the word they are thinking of (circumlocution), write or type the words they are trying to say, or gesture. A deficit in this cognitive skill could make communication more difficult. It is also important to consider patient goals, as they relate

to their QoL, and determine if PWAs feel like their QoL has been impacted specifically by cognitive impairments. Cruice et al. (2010) interviewed 30 PWAs and they identified cognitive function limitations as being a contributor to lower QoL. This demonstrates that PWAs in this study were aware of their cognitive deficits, and these deficits made simple tasks more challenging.

Another factor to consider when measuring QoL is the severity of aphasia. The individual may be completely nonverbal, or speak fluently without much content, and this impacts their interactions with others. Hilari and Byng (2009) researched health-related QoL (HRQoL), or the impact a health state has on one's QoL, in 83 participants with aphasia. The PWAs' report of HRQoL was compared to their proxies' (close family or friend) report of HRQL by using the SAQOL. The ASHA-FACS was also used to measure the individual's communication ability level or the amount of assistance they need with communication tasks. After comparing the results, it was found that HRQoL for people with severe aphasia was worse than HRQoL for people with mild to moderate aphasia. Other studies have had similar findings, concluding that aphasia severity level has an impact on QoL ratings, and people with more severe aphasia have lower QoL scores, when compared to people with milder forms of aphasia (Bose et al., 2009; Hilari, Needle, & Harrison, 2012; Spaccavento et al., 2013). These findings demonstrate the importance of considering aphasia severity level as a variable that impacts QoL in PWAs. The previously mentioned study by Morrow-Odom, Moser, and Neils-Strunjas (2017) found that SLPs assess the QoL of people with severe aphasias less often than those with mild aphasia. These findings conflict with the needs of PWAs, as the people with more severe aphasia should

have their QoL monitored, because they might have more difficulty verbally expressing their needs or emotions (Lam & Wodchis, 2010).

Another area that should be considered as a factor in QoL for PWAs is their post-onset period (i.e. the time since their stroke occurred). Many studies reviewed above (Bose et al., 2009; Chiou & Yu, 2018; Hilari & Byng, 2009; Nicholas, Hunsaker, & Guarino, 2017) reported participant's post-onset periods but did not include differing lengths of post-onset periods as a key factor when reporting the results of their study. Cruice et al. (2010) set inclusion criteria requiring participants to have greater than ten months post-onset, however, the amount of time post-onset was again not considered as a factor relating to QoL when drawing conclusions. Nicholas, Hunsaker, and Guarino (2017) indicated that there is a need for studying post-onset periods because QoL could change significantly over time, due to the PWA and their family's adjustment and acceptance of the consequences of aphasia. In their study, many participants were several years post-onset and possibly reported higher QoL ratings than acute participants would, due to having accepted the way their life is post-stroke. This is consistent with what individuals reported when interviewed about their life experiences post-stroke. Kirkevold (2002) interviewed nine stroke survivors with varying lengths of post-onset periods and found a common theme that participants reported having the most difficulty transitioning from a rehabilitation facility to living on their own and accepting a new life with a disability.

Other studies have specifically separated chronic and acute aphasia participants, to compare their different profiles. When investigating response to behavioral treatment in aphasia, Moss and Nicholas (2006) found that people at or below one year of post-onset had a greater response to treatment than those that were one or more years of post-onset. It was also found that

people can continue to make smaller progress as far as twelve years post-onset, but there may be a slight decline in response to treatment after eight years post-onset. This information is beneficial in understanding how to group PWAs based on their post-onset period and how effective treatment will be in each amounts of time post-onset. Another study found a difference in the QoL between acute and chronic participants. Spaccavento et al. (2013) assessed 147 PWAs and 37 control subjects with the quality of life questionnaire for aphasics (QLQA). The researchers concluded that people with severe and acute aphasia had lower QoL ratings than those individuals with mild and chronic aphasia. However, the researchers did not specifically report how many months post-onset the “acute” participants were. Given these points, post-onset period is a factor that should be studied further when assessing people for QoL and CQoL.

When exploring QoL in PWAs, the total amount and type of therapy they have received have also been found to play a role. Few studies have specifically measured this variable, especially in relation to QoL. Bhogal et al. (2003) found that intensive aphasia therapy resulted in improved outcomes for PWAs, but there was no relation to how this impacts QoL. A recent study considered how group therapy impacts QoL, by using the SAQOL-39 to assess PWAs before and after group therapy (Lima et al., 2018). The overall findings were that participants reported higher ratings on the communication and physical domains of SAQOL-39 after receiving group therapy. Communication improved further if the caregiver or spouse was present during the therapy sessions. The outcomes of these limited number of research studies are promising; however, more information is needed to understand how different amounts and types of therapy impact PWAs' QoL.

Statement of Purpose

While there are many studies on the overall QoL in PWAs, studies on CQoL have been more recent. Furthermore, the measures used to capture CQoL across clinical settings are also widely varied. As described before, these variations are due to multiple factors such as the clinician's training, familiarity with the tool, and lack of access to CQoL measures (Morrow-Odom, Moser, & Neils-Strunjas, 2017). The purpose of this study is to determine if correlations exist between the outcomes of commonly used QoL and CQoL measures (e.g. ASHA-FACS, ASHA-QCL, CCRSA, SAQOL-39) and if the factors of post-onset period, aphasia severity level, cognitive functioning, and therapy received influence the quality of life (QoL), communication quality of life (CQoL), and confidence levels in persons with aphasia (PWAs).

Bose et al., (2009) compared different QoL and CQoL measures and the results of this study were helpful in understanding what each assessment measures. Speech-Language Pathologists can refer to the results from the 2009 study when deciding on which general QoL measure to use. However, it would also be helpful for the practicing clinicians to know which measure(s) would be most effective in determining the CQoL of the clients that they serve. Hence, the current study aims to compare the ASHA-FACS and ASHA-QCL, because these measures have not been compared in the past. It will be useful to know how these tools will measure up with each other and with other overall QoL measures such as the SAQOL-39 and communication confidence levels as measured by the CCRSA. Each of the measures may not be uniformly influenced by factors such as post-onset periods and aphasia severity level, and this information will be beneficial for practicing clinicians to understand when selecting measures to use with their clients. Additionally, each of the QoL and CQoL assessments measure responses

differently using a variety of rating scales with varying lengths of administration time. Therefore, there is a need to determine the effectiveness of the CQoL assessment tools and if one tool turns out to be more effective than the others, it can have a considerable impact on clinical practice.

There has been significant research on why QoL is an important factor to consider when planning treatment for PWAs. Also, there is research about PWAs improving communication before and after one-year post-onset of aphasia (Moss & Nicholas, 2006), but there is limited information about the changes in CQoL for individuals who are several years post-onset versus individuals in the sub-acute periods. Thus, in the present study, the independent variables include post-onset periods, aphasia severity levels, cognitive functioning and amount and type of therapy received. Each of these factors will be analyzed to determine how they impact the dependent variables of QoL and CQoL outcomes in PWAs specifically measured by the ASHA-QCL, ASHA-FACS, SAQOL-39 and CCRSA. The following research questions will be explored:

1. Do the outcomes of ASHA-FACS and the ASHA-QCL correlate with each other and with other measures of QoL and confidence, such as the SAQOL-39 and CCRSA respectively; and will one of them provide a more unique representation of QoL and CQoL in PWAs?
2. Do QoL and CQoL differ in the various groups of PWAs with different lengths of post-onset time?
3. Will QoL and CQoL be differentially influenced by the severity of aphasias?
4. Will the PWAs' cognitive impairments differentially influence the outcomes of the QoL and CQoL measures?

5. Will the therapy treatment types and intensities differentially influence the outcomes of the QoL and CQoL measures?

The null hypotheses are as follows:

1. The ASHA-FACS and ASHA-QCL will yield no differences in the outcomes in PWAs' CQoL and have no correlations with measures of overall QoL (SAQOL-39), and confidence levels (CCRSA).
2. Lengths of post-onset time, aphasia severities, cognitive impairments, and type and duration of therapy received will each have no influence on the QoL and CQoL measures.

Chapter 2: Methodology

The purpose of this study was to determine if correlations exist between the outcomes of commonly used QoL and CQoL measures (e.g. ASHA-FACS, ASHA-QCL, CCRSA, SAQOL-39) and if the factors of post-onset period, aphasia severity level, cognitive functioning, and therapy received influence the quality of life (QoL), communication quality of life (CQoL), and confidence levels in persons with aphasia (PWAs).

Participants

Prior to the initiation of the recruitment process, the St. Cloud State University (SCSU) Institutional Review Board (IRB) approved the research study design and all protocols. Participants were recruited from various organizations in Central Minnesota including non-governmental organizations (NGOs) and other independent associations. These included three Minnesota Connect Aphasia Now (MnCAN) locations, St. Cloud Hospital's Stroke Support Association, and the St. Cloud State University (SCSU) Speech-Language and Hearing Clinic. At all locations described above, participants and their caregivers were given a detailed description in writing of the research procedures and the impact the research will have on the participants. Interested participants who met the following criteria were included in the study: (1) who had aphasia as a result of a stroke, and (2) who were willing to spend approximately two hours over two days to complete all assessments and questionnaires. People with self-reported diagnoses of psychiatric conditions, other types of brain damage, or a stroke that did not result in aphasia were excluded from the present study. Eligible participants were contacted, and informed consent was obtained from all participants, prior to all data collection. Additionally, some participants receiving therapy through SCSU were willing to share their medical files, and they

initialed a portion of the informed consent form that allowed the researcher to access specific information from their medical files regarding the nature of the stroke and speech-therapy that they had received.

The current study included twenty-one persons with aphasia (PWAs) with ages ranging from 47 to 91 years (mean= 67 years, SD= 11.4) and post-onset periods ranging from two months to fourteen years (mean= four years, four months; SD= 2.9). There were ten males and eleven females (twenty Caucasian, one African American) that participated in this study, and all participants lived in their personal residences. Additional demographic information for all participants is summarized in Table 1. Participants had a variety of aphasia types and severity levels but were all able to answer questions independently.

Table 1

Participant demographics

Participant Number	Age	Gender	Time Post-Onset	Type of Aphasia	Severity
1	76	M	2-3 years	Anomic	Mild
2	62	M	1-2 years	Broca's	Very Severe
3	50	F	6+ years	Conduction	Mild
4	67	F	6 mos.- 1 year	Anomic	Mild
5	51	F	3-4 years	Conduction	Mild
6	58	F	3-4 years	Wernicke's	Very Severe
7	78	F	3-4 years	Conduction	Moderate
8	69	M	1-2 years	Anomic	Mild
9	47	M	4-5 years	Broca's	Moderate
10	71	F	1-2 yeas	Anomic	Moderate
11	69	M	5-6 years	Anomic	Mild
12	58	M	6+ years	Conduction	Mild
13	56	F	5-6 years	Broca's	Severe
14	81	F	4-5 years	Anomic	Mild
15	75	F	5-6 years	Anomic	Mild
16	91	F	2-3 years	Conduction	Moderate
17	70	M	6+ years	Anomic	Mild

18	81	M	**	Anomic	Mild
19	70	M	6+ years	Anomic	Mild
20	60	M	5-6 years	Global	Moderate
21	65	F	< 6 months	Anomic	Mild

** Participant had multiple strokes and was not included in the post-onset analyses.

Assessments

Various types of assessments including standardized, criterion-referenced, and rating scales as well as a demographics questionnaire (Appendix C) were used to gather patient information. Each participant was assessed with a variety of measures to evaluate their language abilities, cognitive abilities, functional communication skills, QoL, communication QoL (CQoL), and communication confidence. Assessments were conducted over two sessions to prevent fatigue and the order of presentation in the two sessions was randomized across the participants to control for order effects of test administration. Specifically, one half of the participants were tested using the WAB-R; ASHA-FACS; and SAQOL-39 on the first day and the CLQT; ASHA-QCL; and CCRSA on the second day. The other half of participants received CLQT; ASHA-QCL; and CCRSA on the first day, and WAB-R; ASHA-FACS; and SAQOL-39 on the second day. Each assessment is summarized in detail below.

Western Aphasia Battery-Revised (WAB-R). The WAB-R (Kertesz, 2007) was used to determine the severity, type of aphasia and assess the participants' linguistic and nonlinguistic language abilities. This is a standardized assessment that is used as a diagnostic tool to identify the type and severity of aphasia as well as the location of the lesion in the brain. The WAB-R has the following eight subtests: spontaneous speech, auditory verbal comprehension, repetition, naming and word finding, reading, writing, apraxia, and constructional, visuospatial and calculation. The subtests are used to calculate three different scores including a language

quotient (LQ), cortical quotient (CQ), and aphasia quotient (AQ). Only the AQ was used for the purposes of this study because it is an accurate measure of language ability. This assessment is a valid and reliable measure and has intra- and inter-rater reliability, high internal consistency and test re-test reliability. The WAB-R fulfills both content- and face-validity criteria. The WAB-R highly correlates with the Neurosensory Center Comprehensive Examination for Aphasia (NCCEA), indicating good construct validity (Shewan & Kertesz, 1980).

Cognitive Linguistic Quick Test (CLQT). The CLQT (Helm-Estabrooks, 2001) was administered to assess participants' cognitive abilities. The CLQT has ten tasks, five of which require minimal language use, and five nonverbal tasks that require no language use. Cognitive assessments that rely on use of verbal or language skills may not reflect the proper functioning in PWAs due to their language deficits. Previous studies have therefore used only the nonverbal subtests of the CLQT to determine the cognitive status of PWAs (Chiou & Yu, 2018; Nicholas, Hunsaker, & Guarino, 2017). Similar to previous studies, the present study used only the following five subtests of nonverbal cognition to determine the participants' cognitive abilities: symbol cancellation, symbol trails, design memory, mazes, and design generation. The CLQT is standardized and has proven to be a reliable measure. A non-linguistic cognition index score was calculated and used for determining cognitive abilities of PWAs in this study. This score is found by grouping individuals based on their age (two age groupings: 18-69; 70-89); and identifying whether scores fall in the category of within normal limits (49-39; 49-30), mild cognitive deficits (28-25; 29-18), moderate cognitive deficits (24-20; 17-11) or severe deficits (19-0; 10-0).

American Speech-Language-Hearing Association Functional Assessment of Communication Skills for Adults (ASHA-FACS). The ASHA-FACS (Frattali et al., 1995) was

administered to measure the participants' functional communication abilities and determine how these coincide with communication quality of life. This measure consists of forty-three total items divided into the following four domains: social communication, communication of basic needs, reading/writing/number concepts, and daily planning. The participants answered questions using a rating scale of one to seven, one indicating "does not" and seven indicating "does". The numbers from one to seven have increasing levels of independence beginning with "does with maximal assistance" working up to "does with minimal assistance". This assessment has been validated to be used with individuals who have experienced either right- or left-hemisphere strokes, dementia or traumatic brain injury (Frattali et al., 1995).

American Speech-Language-Hearing Association Quality of Communication Life Scale (ASHA-QCL). The ASHA-QCL (Paul et al., 2004) was used to assess the participants' QoL pertaining to communication. This measure consists of eighteen items, each with a line drawing and five-point likert rating scale. This measure provides valuable information about how aphasia has impacted the participants' relationships, interactions, communication, life participation, and overall quality of life. The ASHA-QCL has proven to be a valid measure to determine quality of communication life for adults with neurogenic communication disorders (Paul et al., 2004).

Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39). The SAQOL-39 (Hilari et al., 2003) was used to assess participants' overall QoL. This measure consists of thirty-nine items with questions pertaining to "self-care, mobility, upper-extremity function, work, vision, language, thinking, personality, mood, energy, family and social roles" that are scored using a five-point rating scale (Hilari et al., 2003, p.7). The SAQOL-39 has proven to be a relevant

measure for stroke survivors, and has test-retest reliability, internal consistency and construct validity (Hilari et al., 2003).

Communication Confidence Rating Scale for Aphasia (CCRSA). The CCRSA (Babbitt et al., 2011) was used to assess participant's communication confidence level which relates to communication quality of life. This measure includes ten items, and participants respond to specific questions using a ten-point rating scale, with zero indicating not confident, and one hundred indicating very confident. The CCRSA was shown to be psychometrically sound for recording communication confidence through participant self-report, when administered to forty-seven PWAs (Babbitt et al., 2011).

Procedure

The assessments were presented to participants in a controlled randomized order, and administration was divided into two separate sessions, one hour each day. All assessments were administered by the graduate student researcher, in face-to-face meetings with the participant in the SCSU clinic, a quiet public location (e.g. community library or a small coffee shop), or at their personal residence. If a participant had been assessed with the WAB-R within the past six months, they had the option of releasing their assessment results to the researcher, rather than being reassessed. Assessments were scored by the graduate student researcher, and all results were tabulated into an excel spreadsheet.

Data Analysis

A correlation matrix was completed to compare the ASHA-FACS, ASHA-QCL, SAQOL-39 and CCRSA. Each of the SAQOL-39 subscores were included in the correlation matrix to identify the relationships between the measures and subdomains (SAQOL-39 mean

score, physical subdomain, communication subdomain, and psychosocial subdomain). Pearson's correlation coefficient was used to determine the strength of the relationships between each of the measures.

To examine the independent variables of post-onset period, aphasia severity level, cognitive abilities, and therapy received, participants were grouped separately based on each of the outcomes. The variable of post-onset period was measured by having participants check a box on the demographics questionnaire to indicate which increment of time best described how long it has been since their stroke occurred. The options included on the demographic questionnaire were <6 months, 6 months-1 year, 1-2 years, 2-3 years, 3-4 years, 4-5 years, 5-6 years and 6+ years. This provided a categorical value that would make data analysis more feasible. After collecting the data from participants, it was determined that there would be two groups compared to one another: <6 months – 4 years (n=10) and 4 – 6+ years (n=10). One participant who had multiple strokes was excluded from the post-onset analyses due to the lack of measurable and reliable data on the length of time since their stroke had occurred.

For aphasia severity level, the participants were grouped by their AQ scores into groups of mild, moderate, severe and very-severe. The scores that fall within these categories are indicated in the WAB-R manual and are as follows: 0-25 is very severe, 26-50 is severe, 51-75 is moderate, and 76-100 is mild. Due to the limited number of participants in each of these categories, the groups were combined further to get a larger sample size and tests were run with only two groups (mild [n=13] vs. moderate, severe and very severe [n=8]). The variable of cognition was measured by the CLQT non-linguistic score, and this assessment includes a classification system for the severity of cognitive deficits. Participants' scores can be described

as within normal limits, mild, moderate or severe. The assessment has two scoring levels, one for individuals 16-69 years old, and one for individuals 70-89 years old. In the present study, eleven participants scored in the “within normal limits” category, indicating they have no cognitive deficits measured by the assessment. The remaining ten participants scored in the “mild” category for cognitive impairments. These two groupings were used to determine if cognitive deficits play a role in QoL or CQoL.

The last independent variable examined was the amount and type of therapy received. There is a wide variety of therapies and intensities practiced within the field of communication sciences and disorders, therefore, type of therapy was divided into three categories: individual therapy, group therapy, and intensive therapy programs. On the demographic questionnaire, participants checked a box next to each of the three therapy types they had received and indicated the amount of therapy that they received (measured in hours). Participants either wrote the amount of hours received on the sheet (often with help from a family member/caregiver), or noted how many hours per session, how many sessions per week, and how many weeks each of their therapy programs lasted, which allowed the graduate student researcher to calculate the hours. Most participants had received individual therapy; therefore, they were divided into two groups: less than 100 hours of individual therapy (n=11) and 100 hours or more of individual therapy (n=9). For group therapy, participants were divided into three groups: 0 hours of group therapy (n=6), less than 100 hours of group therapy (n=7), and 100 or more hours of group therapy (n=7). They were also further combined into two groups; less than 100 hours of therapy (including the 0 hours group) (n=13) and 100 or more hours of therapy (n=7) to determine if there would be more statistical significance with an increased sample size.

The last type of therapy, intensive aphasia therapy, is not as commonly received as the other two types of therapy. The intensive aphasia therapy program specifically measured in this study was the program offered in Maple Grove, Minnesota. This is a four week program that participants attend for three and a half hours a day, five days a week. Participants were divided into two groups for this variable: 0 hours of intensive therapy received (n=11) and more than 0 hours or some intensive therapy received (n=9). For each of the independent variables examined, Cohen's d index of effect sizes was also used to compare the magnitude of differences in the groups mean scores. These various variables and participant groupings were selected in order to analyze QoL outcome data and study how each factor and assessment correlated with one another.

Chapter 3: Results

The present chapter outlines the results of all of the participants' performance on the various test measures administered which include the ASHA-FACS, ASHA-QCL, CCRSA and the SAQOL-39. This study determined if correlations exist between the outcomes of commonly used QoL and CQoL measures (e.g. ASHA-FACS, ASHA-QCL, CCRSA, SAQOL-39) and if the factors of post-onset period, aphasia severity level, cognitive functioning, and therapy received influenced the quality of life (QoL), communication quality of life (CQoL), and confidence levels in persons with aphasia (PWAs). The findings related to each research question are outlined in detail below.

Research Question 1: Do the outcomes of ASHA-FACS and the ASHA-QCL correlate with each other and with other measures of QoL and confidence, such as the SAQOL-39 and CCRSA respectively; and will one of them provide a more unique representation of QoL and CQoL in PWAs?

Each participant was administered the four measures (ASHA-FACS, ASHA-QCL, SAQOL-39 and CCRSA). The assessments were scored, and a correlation matrix was used to determine if the assessments measure similar aspects of an individual's QoL and CQoL. The outcomes are displayed in Table 3.1.

Table 3.1*Relationships Between the Four Scales*

	ASHA- FACS	ASHA- QCL	CCRSA	SAQOL- 39 Mean	SAQOL- 39 Physical	SAQOL- 39 Comm.	SAQOL- 39 Psych.
ASHA- FACS	1	.549**	.644**	.316	.432	.239	-.002
ASHA- QCL	.549**	1	.773**	.594**	.304	.794**	.425
CCRSA	.644**	.773**	1	.694**	.444*	.533*	.578
SAQOL- 39 Mean	.316	.594**	.694**	1	.760**	.608**	.792**
SAQOL- 39 Physical	.432	.304	.444*	.760**	1	.188	.289
SAQOL- 39 Comm.	.239	.794**	.533*	.608**	.188	1	.452*
SAQOL- 39 Psych.	-.002	.425	.578**	.792**	.289	.452*	1

** Significant at the 0.01 level (2 tailed); *Significant at the 0.05 level (2-tailed)

Table 3.1 includes the correlation coefficients (Pearson's r) or the strength of relationship between the measures with asterisks denoting p-values. The CCRSA correlated with all other measures and had the strongest correlations with the ASHA-QCL. Additionally, the CCRSA had strong correlations with other measures in the following order: SAQOL-mean score, ASHA-FACS, SAQOL-39 psychosocial subdomain, SAQOL-39 communication subdomain, and lastly the SAQOL-39 physical subdomain. The SAQOL-39 Mean score had large positive correlations with most of the measures, with the strongest correlations to its own subtests (specifically SAQOL-39 physical, SAQOL-39 psychosocial), then the CCRSA, then SAQOL-39 communication, and lastly the ASHA-QCL. The SAQOL-39 mean score had no statistically

significant relationship with the ASHA-FACS. The ASHA-QCL had the most significant correlations with the SAQOL-39 communication subdomain, then the CCRSA, SAQOL-39 mean score, and lastly the ASHA-FACS. This indicates that the ASHA-QCL was highly correlated with all other measures of communication but had no correlations with the SAQOL-39 psychosocial subdomain or physical subdomain. The ASHA-QCL was found to specifically correlate with only measures of communication, which differs from the correlations the CCRSA has with other measures. This implies that the ASHA-QCL is more closely associated with CQoL rather than overall QoL. The ASHA-FACS had large positive correlations with the CCRSA and ASHA-QCL but failed to significantly correlate with the SAQOL-39 mean score or subdomains. In summary, the ASHA-FACS and ASHA-QCL were found to have significant correlations with each other, although the ASHA-QCL had stronger correlations with other QoL and confidence measures such as the SAQOL-39 and CCRSA.

Research Question 2: Do QoL and CQoL differ in the various groups of PWAs with different lengths of post-onset time?

The participants' post-onset periods were grouped into the following two categories: <6 months – 4 years and 4 years – 6+ years. Each group had ten PWAs, and one PWA was excluded because they had multiple strokes, resulting in the lack of a measurable time post-onset. An ANOVA was used to compare the two groups' outcomes on each of the QoL and CQoL measures. There were no significant differences found between the two groups at the levels of $p < .05$ or $p < 0.10$ on any of the QoL or CQoL measures. Effect sizes were calculated to determine if there was a strong relationship between variables, and a medium effect size ($d = 0.58$) was found on the SAQOL-Psychosocial subdomain between participants with more recent strokes

and those with older strokes. The group of PWAs with a post-onset of <6 months – 4 years had a lower mean score ($M= 2.91, SD= 0.51$) when compared to the mean of the PWAs who were 4 years – 6+ years post-onset ($M= 3.36, SD= 0.98$). The SAQOL-Psychosocial subdomain includes questions about the individual's confidence, if they feel withdrawn from others, and other personal factors. The group with less time post-onset had lower scores possibly because they might have increased difficulty with acceptance of their communication disorder, due to it being a more recent diagnosis.

Research Question 3: Will QoL and CQoL be differentially influenced by the severity of aphasia?

Two separate ANOVAs were completed to answer this question. One ANOVA had PWAs separated into three groups based on their Western Aphasia Battery-Revised (WAB-R) score. These groups were mild, moderate and severe-very severe. However, this grouping resulted in only two participants in one category, which limited the ability to make statistical comparisons. Therefore, a second ANOVA was used to determine if differences would occur when the participants were grouped into only two groups: mild versus moderate, severe and very-severe. When divided into two groups, there was a significant effect of aphasia severity on SAQOL-39 mean score results at the $p<.05$ level for the conditions [$F(1, 19) = 6.99, p= .016$]. The mild group had a significantly higher mean score ($M= 3.82, SD= 0.44$) when compared to the moderate, severe and very-severe group ($M= 3.2, SD= 0.63$). There was also a significant effect of aphasia severity on SAQOL-39 communication sub-domain results at the $p<.05$ level for the two conditions [$F(1, 19) = 6.42, p= .020$]. Again, the group of participants with mild aphasia had a higher mean score ($M= 3.65, SD= 0.57$) when compared to the moderate, severe

and very-severe group ($M= 2.8, SD= 0.99$). Additionally, there were significant findings at the $p<.10$ level between the groups' scores on the ASHA-QCL [$F(1, 19) = 3.281, p = .086$]. The participants with mild aphasia scored significantly higher ($M= 70.73, SD= 11.07$) than people with moderate, severe or very-severe aphasia ($M= 61.75, SD= 10.96$). These results demonstrate that aphasia severity impacted both QoL and CQoL in the participants, with those with less severe aphasia having higher ratings of QoL and CQoL. Furthermore, it shows that both the SAQOL-39 and ASHA-QCL measures are sensitive to detecting these differences in groups of PWAs and identified that certain measures do not result in scores that reflect aphasia severity. Specifically, the ASHA-FACS did not detect differences between groups based on aphasia severity level. Effect sizes were also calculated, and significant findings are included in Table 3.2 below.

Table 3.2

Effect Sizes of Aphasia Severity on Outcome Measures

Assessment	Group 1: Mild	Group 2: Moderate, Severe and Very-Severe	Effect Size (<i>d</i>)	Descriptive Term
ASHA-FACS	$M= 5.95, SD= 0.83$	$M= 5.65, SD= 0.99$	0.32	Small
ASHA-QCL	$M= 70.73, SD= 11.07$	$M= 61.75, SD= 10.96$	0.82	Large
CCRSA	$M= 31.15, SD= 5.84$	$M= 26.63, SD= 5.83$	0.77	Medium
SAQOL-39 Mean	$M= 3.82, SD= 0.44$	$M= 3.2, SD= 0.63$	1.13	Large
SAQOL-39 Physical	$M= 4.27, SD= 0.57$	$M= 3.71, SD= 0.98$	0.7	Medium
SAQOL-39 Communication	$M= 3.65, SD= 0.57$	$M= 2.8, SD= 0.99$	1.06	Large
SAQOL-39 Psychosocial	$M= 3.38, SD= 0.83$	$M= 2.81, SD= 0.6$	0.78	Medium

In all cases, the mild group had higher mean scores when compared to the more severe group, which implies that aphasia severity impacted QoL and CQoL negatively for PWAs in the present study.

Research Question 4: Will the PWAs' cognitive impairments differentially influence the outcomes of the QoL and CQoL measures?

The PWAs were assessed with the five nonverbal subtests of the CLQT to determine their cognitive functioning abilities. Eleven participants had scores in the category of "Within Normal Limits" and the remaining ten participants had a "Mild Impairment". These two groups were included in an ANOVA to determine if they had significantly different scores on the QoL and CQoL measures. The results showed a statistically significant difference between groups on ASHA-QCL outcomes at the level of $p < .10$ [$F(1, 19) = 3.604, p = .073$]. The participants that had cognitive abilities "within normal limits" had a higher overall mean score ($M = 71.64, SD = 10.07$) when compared to the scores of the individuals with a "mild impairment" ($M = 62.55, SD = 11.86$) on the ASHA-QCL. The ANOVA also revealed significant effects of cognitive abilities at the level of $p < .10$ on the CCRSA outcomes [$F(1, 19) = 3.046, p = .097$]. The CCRSA outcomes were consistent with ASHA-QCL outcomes with those participants that scored "within normal limits" having a higher mean score ($M = 31.55, SD = 5.41$) when compared to the "mild impairment" group ($M = 27.1, SD = 6.26$). These results confirm previous research, indicating that even mild cognitive impairments may impact CQoL (Chiou & Yu, 2018; Nicholas, Hunsaker, & Guarino, 2017). There were no significant findings on the QoL specific measures (SAQOL-39 mean and subdomains). This demonstrates that when comparing

the CQoL measures (ASHA-QCL and ASHA-FACS), the ASHA-QCL is more sensitive to identifying differences in groups of PWAs based on cognitive functioning.

Research Question 5: Will the therapy treatment types and intensities differentially influence the outcomes of the QoL and CQoL measures?

Participants completed a structured demographics questionnaire that included boxes to mark for the type of speech and language therapy received (individual, group, intensive) and corresponding lines to indicate the number of hours the individual attended therapy. During data analysis, the participants were divided into groups that received no therapy, less than 100 hours, or more than 100 hours (100+ hours) of therapy for each of the three types of therapy. The number of PWAs and division of groups varied by type of therapy, and these are outlined in Table 3.3 below.

Table 3.3

Participant Groupings for Each Type of Therapy

Type of Therapy	Amount of Therapy Received	Number of participants
Individual therapy (two groups)	Less than 100 hours	11
	100+ hours	9
Group therapy (three groups)	No therapy	6
	Less than 100 hours	7
	100+ hours	7
Group therapy (two groups)	Less than 100 hours	13
	100+ hours	7
Intensive therapy (two groups)	No therapy	11
	Therapy	9

As outlined in table 3.3 above, participants were grouped into both three groups and two groups for group therapy during the ANOVA analysis. The group that received no therapy was

combined with the group that received less than 100 hours of therapy for a second analysis to determine if findings would change with two larger groups rather than three smaller groups.

The two groups compared for individual therapy were participants who received less than 100 hours of therapy and those that received 100 or more hours of therapy. There were significant findings for the effects of individual therapy on CCRSA results at the $p < .05$ level [$F(1, 18) = 6.680$ $p = .019$]. The group that received less than 100 hours of therapy, had a significantly higher mean score ($M = 32.55$, $SD = 4.57$) when compared to participants that received 100 or more hours of individual therapy ($M = 26.33$, $SD = 6.18$) on the CCRSA. This indicates that those participants who received over 100 hours of therapy had significantly lower levels of confidence. There were also significant findings for the effects of individual therapy on SAQOL-39 communication outcomes at the $p < .05$ level [$F(1, 18) = 9.304$ $p = .007$]. The group that received less than 100 hours of therapy had a significantly higher mean score ($M = 3.8$, $SD = 0.427$) when compared to the group that received 100 or more hours of therapy ($M = 2.82$, $SD = 0.958$). These findings show a trend that participants who received less individual therapy had higher scores on the CQoL and QoL outcome measures. However, these individuals were already very high functioning and had a stroke with less severe language deficits, as measured by their WAB-R aphasia quotient. Therefore, the higher functioning individuals possibly needed less therapy overall when compared to other groups.

There were no significant findings when comparing the amount of group therapy participants received and the outcomes on QoL and CQoL measures. Effect sizes were calculated with participants divided into three groups and they are summarized in Table 3.4 below.

Table 3.4*Group Therapy Effect Sizes*

Assessment	Group 1 No therapy	Group 2 <100 hours	Group 3 100 + hours
ASHA-FACS	$M= 5.95, SD= 0.93$	$M= 5.7, SD= 0.83$	$M= 5.96, SD= 1.04$
ASHA-QCL	$M= 71.25, SD= 9.69$ **($d= 0.86$)	$M= 63.64, SD= 7.9$ **($d= 0.86$)	$M= 69.21, SD= 15.94$
CCRSA	$M= 31.67, SD= 4.41$ ** ($d= 0.97$)	$M= 27.71, SD= 3.68$ ** ($d= 0.97$)	$M= 30.14, SD= 8.9$
SAQOL-39 Mean	$M= 3.47, SD= 0.34$ *($d= 0.50$)	$M= 3.61, SD= 0.24$ *($d= 0.50$)	$M= 3.64, SD= 0.99$
SAQOL-39 Physical	$M= 3.58, SD= 0.53$ **($d= 1.63$)	$M= 4.37, SD= 0.43$ **($d= 1.63$)	$M= 4.04, SD= 1.08$
	*($d= 0.54$)		*($d= 0.54$)
SAQOL-39 Communication	$M= 3.78, SD= 0.58$ *($d= 0.75$)	$M= 3.2, SD= 0.93$ *($d= 0.75$)	$M= 3.16, SD= 0.95$
	*($d= 0.79$)		*($d= 0.79$)
SAQOL-39 Psychosocial	$M= 3.15, SD= 0.77$	$M= 2.94, SD= 0.55$ *($d= 0.58$)	$M= 3.43, SD= 1.05$ *($d= 0.58$)

Note. d = effect size; * denotes medium effect size between comparison groups; ** denotes large effect size.

Participants who received no group therapy had higher outcomes on the ASHA-QCL and CCRSA measures when compared to the participants who received some group therapy. However, participants who received no therapy scored lower on the SAQOL-39 physical subdomain when compared to the participants that received less than 100 hours of therapy. These results show that people who have not attended group therapy already have higher CQoL, possibly indicating that they do not need the group therapy. However, those individuals who received no group therapy have lower SAQOL-39 physical subdomain ratings, indicating they are less mobile than those who received some group therapy. Therefore, they may not have the ability to attend group therapy due to physical limitations.

There were statistically significant findings for the effects of intensive therapy on SAQOL-39 physical outcomes at the $p < .10$ level [$F(1, 18) = 3.073, p = .097$]. The group of participants who did not receive intensive therapy had a higher mean score on the SAQOL-39 physical subdomain ($M = 4.28, SD = 0.59$) when compared to the group that received intensive therapy ($M = 3.7, SD = 0.89$). This is possibly because those people who received intensive therapy, may have more severe symptoms overall, including physical limitations such as right-sided weakness.

In brief, the most significant results of this study are as follows:

1. The CCRSA was the only measure to have statistically significant correlations with all other assessment test measures.
2. The ASHA-QCL and ASHA-FACS had strong positive correlations with each other.
3. When compared to the ASHA-FACS, the ASHA-QCL was correlated with a higher number of other QoL and CQoL measures, indicating that it has high levels of content and criterion validity.
4. The ASHA-QCL was the only measure sensitive to detecting differences in PWAs based on severity of aphasia, cognitive functioning, and amount and type of therapy received (three of the four factors tested).
5. There is a relationship between the time since the onset of aphasia and psychosocial well-being in PWAs.
6. PWAs with more severe aphasia have lower QoL and CQoL.
7. Even mild cognitive deficits in PWAs influenced ASHA-QCL and CCRSA scores negatively.

8. The amount of therapy received yielded variable effects on QoL and CQoL outcomes, indicating a complex relationship within the sub-variables

Chapter 4: Discussion

This study aimed to compare various quality of life (QoL) and communication quality of life (CQoL) measures, and to determine which factors significantly contribute to lower QoL and CQoL in persons with aphasia (PWAs). There were two null hypotheses that were tested, and they are as follows:

1. The ASHA-FACS and ASHA-QCL will yield no differences in the outcomes in PWAs' CQoL and have no correlations with measures of overall QoL (SAQOL-39), and confidence levels (CCRSA).
2. Lengths of post-onset time; aphasia severities, cognitive impairments, and therapy received will each have no influence on a variety of QoL and CQoL measures.

Each of these hypotheses will be discussed regarding the specific research questions, and relationships between the variables will be detailed below.

Research Question 1: Do the outcomes of ASHA-FACS and the ASHA-QCL correlate with each other and with other measures of QoL and confidence, such as the SAQOL-39 and CCRSA respectively; and will one of them provide a more unique representation of QoL and CQoL in PWAs?

The ASHA-FACS and ASHA-QCL were found to have large positive correlations with each other. In previous research, each tool has individually been used with the SAQOL-39 but they have not yet been compared to each other. Bose et al. (2009) found the ASHA-QCL overall mean and socialization/activities subdomain to be highly correlated with the SAQOL-39 communication subdomain. This is consistent with the correlations found in the present study. Also, the ASHA-FACS was used with the SAQOL-39 in previous research, however, each

measure served a separate purpose (Hilari & Byng, 2009). The SAQOL-39 was administered to measure health-related QoL and the ASHA-FACS was used as a measure of communication abilities for PWAs. In the present study, the ASHA-FACS did not significantly correlate with any of the SAQOL-39 subdomains, yet it was sensitive to finding differences in groups based on the amount of individual therapy received. The ASHA-FACS had positive correlations with the ASHA-QCL and CCRSA, but these were not as strong as the correlations existing between the ASHA-QCL and other measures including the CCRSA and SAQOL-39 communication subdomain. The ASHA-QCL was more sensitive and revealed differences between groups based on aphasia severity level, cognition, and therapy received.

Each questionnaire asks different questions, with distinct wording, making the PWAs' responses unique for each measure. When comparing specific items on each measure based on the variance of z-scores, the ASHA-FACS had two items with lower scores, while the ASHA-QCL had one item with a higher score. The ASHA-FACS items with lower scores were Question 5: "Exchanges information on the phone (e.g. answers questions, provides information)"; and Question 12: "Understands conversations when they occur in noisy or distracting situations (e.g. a crowded cafeteria)". The ASHA-QCL item with a higher score was Question 10: "I see the funny things in life."

The ASHA-FACS questions that received lower scores address specific situations that present challenges for PWAs and other individuals with communication deficits. The ASHA-QCL does not have questions that specifically ask about noisy situations but does include a question about using the telephone. On the ASHA-QCL, participants responded with a higher rating for Question 9: "I use the telephone" when compared to their rating for the ASHA-FACS

Question 5: “Exchanges information on the phone (e.g. answers questions, provides information)”. Therefore, the wording used on each assessment plays a role in how participants respond to the question. Overall, the ASHA-QCL generally includes questions about how easy it is to communicate, how active the PWAs are in their home (e.g. using phone, TV, doing chores, etc.) and asks about their everyday communication interactions. In addition, the ASHA-QCL includes question 10, which participants often responded positively to and the ASHA-FACS did not have a comparable item that received many positive responses.

The large positive correlations between the ASHA-FACS and ASHA-QCL indicate that they have a linear relationship (if one measure’s total score increases, the other measure’s score will also likely increase). However, the two measures differed in that the ASHA-QCL was more sensitive to detecting differences among PWAs based on their aphasia severity level, cognition level and therapy received. This is consistent with findings from the 2009 study by Bose et al., in which the ASHA-QCL highly correlated with a patient’s aphasia severity level. The present study provides new evidence revealing that the ASHA-QCL can be used to detect differences among PWAs based on their cognitive level and therapy received. It is also important to note that the ASHA-QCL has eighteen items with a visual analog scale and line drawings, and the ASHA-FACS has forty-three items with a rating scale of one to seven in small print. Both measures are valid and reliable, however, during this study, participants were observed to complete the ASHA-QCL more easily. The ASHA-QCL has one question per page with larger print and participants were able to point to an area on the line that represented their life experiences, rather than assigning a number from one to seven to represent their abilities. The ASHA-QCL is designed for PWAs to self-report how difficult a variety of situations are for them; therefore, it

should require minimal to no support from the clinician or caregiver (Eadie et al., 2006). In contrast, the PWAs in this study were observed to have challenges completing the ASHA-FACS. The participants often required assistance reading each item and needed a straight edge to line up the question with the rating scale.

The present study's findings regarding the measures' sensitivity are comparable to the 2009 study by Bose et al. In the 2009 study, researchers compared the SAQOL-39 and ASHA-QCL measures and found that the ASHA-QCL was finer tuned to detecting differences in QoL specifically related to communication. Bose et al. (2009) found positive relationships between the SAQOL-39 communication subdomain and ASHA-QCL socialization/activities subdomain, implying that there is an overlap between communication and socialization. The ASHA-QCL mean score also correlated with the SAQOL-39 communication subdomain, confirming that the ASHA-QCL measure is capturing communication QoL for PWAs rather than overall QoL (Bose et al., 2009). The present study found that the ASHA-QCL correlates with the ASHA-FACS, CCRSA, SAQOL-39 mean score and SAQOL-39 communication subdomain. The ASHA-QCL had a relationship with all measures of communication but not measures of other areas of QoL (i.e. SAQOL-39 physical and psychosocial subdomains). This is consistent with previous research and expands the number of measures the ASHA-QCL has positive correlations with.

Research Question 2: Do QoL and CQoL differ in the various groups of PWAs with different lengths of post-onset time?

The present study had no statistically significant findings when comparing the groups of <6 months – 4 years and 4 years – 6+ years on the QoL and CQoL measures. This indicates that collectively, the participants in this study did not personally rate their QoL and CQoL more

negatively when in the acute phase, or more positively when they were several years post-onset. Yet, a medium effect size ($d= 0.58$) was found when comparing the more recent post-onset group to the increased time post-onset group on the measure of the SAQOL-39 psychosocial subdomain. This demonstrates that if there was a greater number of individuals in each of the groups analyzed, there would most likely be significant differences between the two groups.

The individuals with a more recent post-onset had lower scores, indicating they may have negative thoughts and feelings about their life changes and communication difficulties. This substantiates previous research that has emphasized the need for PWAs to have time to accept their diagnosis and life changes (Nicholas, Hunsaker, & Guarino, 2017). Previous research has found that when people with aphasia experience a stroke and lose their ability to communicate effectively, they need time to cope. The life changes resulting from a stroke require the individual to relearn how to interact with the world, which requires more effort and may result in frustration (Nicholas, Hunsaker, & Guarino, 2017). Therefore, the findings in the present study further support that PWAs need time to grieve their loss of communication.

There is minimal research on the impacts of time post-onset as it relates to perceived QoL and CQoL for PWAs. Previous studies have considered post-onset depression and anxiety (Cahana-Amitay et al., 2011; Code & Herrmann, 2003; Hilari, Needle, & Harrison, 2012). In the past, researchers have often grouped participants intentionally to show significant differences between groups. For example, in one study PWAs with less than six months post-onset were grouped and their levels of depression and anxiety were compared to PWAs with greater than six months post-onset (Gainotti, 1997). Using this method to group participants allows researchers to contrast the psychological differences between people in the acute phase post-stroke versus those

in the sub-acute to chronic phase of post-stroke. However, this limits the results and does not provide information about how time post-onset impacts QoL and CQoL for PWAs with varying lengths of time post-stroke (e.g. one year post-stroke, five years post-stroke, ten or more years post-stroke). Spaccavento et al. (2013) used the quality of life questionnaire for aphasics (QLQA) to measure various aspects of QoL in PWAs. The researchers considered how the time post-onset influences the PWAs “functional and communicative autonomy” (p. 35). In the 2013 study, it was found that PWAs who had a post-onset period of up to three months had lower QoL ratings when compared to participants with a post-onset period of greater than three months. PWAs were divided into categories with acute classified as three months or less, and chronic classified as greater than three months. The researchers gathered data on the differences between the two groups, however their findings were not specific enough to find how QoL changes overtime. The present study did not have significant results for this specific research question, yet there was a medium effect size found between the two groups, with only ten participants in each group. This indicates there is a need for different groupings, with a larger number of participants in each group to find true patterns and implications of post-stroke recovery time.

Research Question 3: Will QoL and CQoL be differentially influenced by the severity of aphasia?

Increased aphasia severity levels were found to have a negative effect on scores on the SAQOL-39 Mean, SAQOL-39 Communication Sub-domain, and ASHA-QCL measures. When divided into two groups, PWAs demonstrated significant differences based on severity level for the SAQOL-39 mean, SAQOL-39 communication subdomain and the ASHA-QCL measure. On all measures, participants with more severe aphasia had significantly lower scores than

participants with less severe aphasia. The outcomes on these measures are consistent with the findings of previous research. A 2009 study by Bose et al. revealed strong correlations between aphasia severity and the ASHA-QCL socialization/activities subdomain, SAQOL-39 psychosocial subdomain and SAQOL-39 communication subdomain. The 2009 study had a sample size of $n=19$, which is similar to the present study's sample size ($n=21$), and the researchers also considered other variables including months post-onset, education level, and participant age, however these variables did not have any significant findings.

A study completed in 2012 identified which factors are predictive of health-related QoL (HRQoL) in PWAs (Hilari, Needle, & Harrison, 2012). The researchers completed a systematic review of fourteen research articles and found that amongst other variables, the level of language impairment (aphasia severity) was predictive of lower HRQoL (Hilari, Needle, & Harrison 2012). A different study analyzed the psychometric properties of the quality of life questionnaire for aphasics (QLQA) and considered variables that contribute to changes in scores (Spaccavento et al., 2013). 147 PWAs were classified as having either mild aphasia or severe aphasia based on their scores on the Aachen Aphasia Test (AAT). Spaccavento et al. (2013) found that people with more severe aphasia had significantly lower QoL scores when compared to the group of PWAs with mild aphasia. The present study substantiates the evidence found in previous studies implying that aphasia severity has a negative impact on QoL. The current study also found that aphasia severity impacts CQoL, which was specifically measured by the ASHA-QCL. Additionally, there was a relationship between aphasia severity and cognition, with 75% of the participants ranging from moderate to very-severe having mild cognitive impairments. Participants with severe or very-severe aphasia also had lower ratings of communication

confidence on the CCRSA measure. These findings adds to the existing evidence that linguistic level processing and cognitive abilities are intertwined (Lee & Pyun, 2014; Nicholas, Hunsaker, & Guarino, 2017) and demonstrate the need for considering PWAs' communication confidence as it relates to aphasia severity and cognitive abilities.

In the present study, the ASHA-QCL was highly correlated with the CCRSA, and PWAs with significantly lower scores on the ASHA-QCL also had significantly lower scores on the CCRSA. The ASHA-FACS did not share these similarities, which implies that between the two measures, the ASHA-QCL is more sensitive in identifying the PWAs who have lower levels of communication confidence. A previous study found that an individual with aphasia may choose to engage in certain communication situations based on how confident they feel (Babbitt & Cherney, 2010). This shows how communication confidence for PWAs can impact the ways they interact with others in their community. Another study considered how the various types of aphasia and severity levels impact scores on the CCRSA (Babbitt et al., 2018). The researchers found that PWAs with different types and severities of aphasia seem to have similar outcomes on the CCRSA and each made improvements in communication confidence after receiving therapy (Babbitt et al., 2018). These findings demonstrate the importance of measuring communication confidence levels as well as linguistic and cognitive variables and prove that Speech-Language Pathologists can provide treatments that increase PWAs' level of communication confidence.

Research Question 4: Will the PWAs' cognitive impairments differentially influence the outcomes of the QoL and CQoL measures?

PWAs with a mild cognitive impairment scored significantly lower than PWAs with typical cognitive functioning on both the ASHA-QCL and the CCRSA. There were no

significant findings when comparing group scores on either the ASHA-FACS or SAQOL-39 assessments. The QoL measures were unable to detect group differences based on cognitive impairments, therefore these participant's cognitive impairments specifically impacted their communication experiences (and not only the overall well-being) as measured by the CQoL measures. Previous research has found that reduced cognitive and language abilities are highly related to QoL outcomes (Chiou & Yu, 2018; Nicholas, Hunsaker, & Guarino, 2017). Nicholas, Hunsaker, and Guarino (2017) assessed twenty-eight PWAs with a language measure (Boston Diagnostic Aphasia Examination -Third Edition; BDAE-3), cognitive measure (CLQT) and QoL measure (SAQOL) to determine if aphasia severity and cognitive limitations predicted QoL outcomes. The researchers found that lower scores on specific cognitive subtests (symbol trails, design memory, and mazes) correlated with lower QoL scores. Similarly, Chiou and Yu (2018) assessed thirty-three PWAs for their language abilities (WAB-R), nonverbal cognition (CLQT-cog), communication confidence (CCRSA), and life participation (Assessment for Living with Aphasia-Revised; ALA-R). In the 2018 study, PWAs' cognitive abilities impacted their communication confidence levels, which changed the way they viewed themselves.

Cognitive tasks that require cognitive flexibility, working memory and sustained attention may be especially difficult for these individuals. PWAs with mild cognitive deficits in the present study had reduced CQoL, implying that they may have challenges with the cognitive demands required for language processing. For example, it may be especially difficult for PWAs to adapt to changes in the conversation topic or understand language and contribute to a conversation with relevant information and insight. Both the production and understanding of language requires cognitive effort and sustained attention (McNeil, Odell & Tseng, 1991; Tseng,

McNeil & Milenkovic, 1993), which may pose a challenge for PWAs. It is important to consider not only QoL, but also CQoL because it is directly related to how PWAs' communication abilities impact their everyday interactions. As indicated in the A-FROM model, (Figure 1), linguistic abilities and cognitive functioning have overlapping areas and interconnect with PWAs' level of communication confidence. Overall, the presence of cognitive deficits can make communication more effortful and less enjoyable for the PWA, resulting in reduced CQoL.

Research Question 5: Will the therapy treatment types and intensities differentially influence the outcomes of the QoL and CQoL measures?

PWAs who received fewer hours of individual, group or intensive therapy all had higher scores on a variety of QoL and CQoL measures. There were significant differences between those who received little or no therapy and PWAs who received more therapy. A comparison of WAB-R scores found that PWAs who received less therapy in general had less severe language deficits. For individual therapy, people who received less therapy had significantly higher scores on all the measures except the SAQOL-39 physical and psychosocial subdomains. This indicates that there were not significant differences in the group scores on the two subtests based on the amount of therapy received.

For group therapy, there was a medium effect size when comparing the no therapy group to the less than 100 hours group on the ASHA-QCL, and a large effect size when comparing the same two groups on the CCRSA outcomes. In both cases, the no therapy group had high scores, with the less than 100 hours group having lower scores, and the greater than 100 hours group having high scores again (comparable to no therapy). These outcomes may be due to PWAs comparing themselves to others in group therapy, especially in the beginning stages, and

potentially feeling as though their communication skills are inferior. One possible explanation for PWAs' higher CQoL ratings even though they have not received group therapy is because they may not be comparing themselves to other PWAs. Also, PWAs who have attended some group therapy may compare themselves to other PWAs and see them making progress, which could lead to a slightly reduced CQoL. Finally, PWAs who have attended group therapy for a longer period of time may have increased CQoL because they have made connections with other group members and potentially made gains in their linguistic abilities.

Additionally, people who received no group therapy had lower mean scores on the SAQOL-39 physical subdomain when compared to the participants that received less than 100 hours of therapy. This implies that people who did not attend group therapy also may have physical limitations such as right-sided weakness, therefore they could be less likely to be referred to a group therapy setting due to physical restraints.

The other measures (ASHA-FACS and SAQOL-39 mean, communication and psychosocial subdomains) did not have medium or large effect sizes or significant findings. Therefore, a positive relationship may exist between group therapy and CQoL, with a weaker relationship existing between group therapy and QoL. This supports previous research that has shown that even just ten sessions of group therapy can be effective in improving CQoL factors such as attitude towards communication and functional communication (Brumfitt & Sheeran, 1997). In the present study, participants who did not attend group therapy had higher levels of CQoL, and lower SAQOL-39 physical subdomain ratings. These findings possibly indicate that this group of PWAs had higher CQoL and did not need group therapy or did not attend group therapy due to their physical limitations.

For intensive therapy, the no therapy group had a significantly higher mean score on the SAQOL-39 physical subdomain when compared to the group that received some therapy. A potential reason for this difference is that PWAs who received intensive therapy may have more severe impairments overall, including physical functioning and language skills. PWAs involved in intensive aphasia programs are often referred because they will benefit from more therapy to improve a plateau period in their progress or have certain language impairments that could improve with more therapy. The participants in the present study who received intensive therapy also had physical limitations such as right sided weakness. However, the distinction between those who received intensive therapy and those that did not is limited in this study because there is only one program in the state and participants may not have attended due to its location rather than the necessity of the intensive language therapy. Overall, the results of therapy types and durations should be considered when planning intervention. For example, PWAs starting group therapy might have lower communication confidence and might need extra support to transition into the new experience. Each of the factors examined in this study are interrelated and should be considered when determining therapy types and durations to best meet each PWAs' needs.

In summary, the ASHA-FACS and ASHA-QCL assessments were highly correlated, but the ASHA-QCL was more sensitive in identifying differences in groups of PWAs. Therefore, the first null hypothesis can be rejected. Furthermore, aphasia severity influenced both QoL and CQoL outcomes. The presence of cognitive limitations impacted performance on CQoL outcome measures but not overall QoL measures, which supports previous research about the interconnectivity between linguistic processing, cognitive abilities and communication confidence. Finally, the type and duration of therapy received influenced outcomes on various

QoL and CQoL measures. The different lengths of post-onset time did not have a significant impact on QoL or CQoL outcome measures, most likely due to the small sample size in the present study. Therefore, the second null hypothesis can be rejected for one of the four factors (aphasia severity), and further evidence is needed to fully reject the null hypothesis in regard to the other factors.

Clinical Implications

When treating a patient with any type or severity of aphasia, it is important to consider how aphasia has impacted their CQoL in addition to QoL. The individual's life participation should be considered by evaluating the physical impairments, activity limitations and participation restrictions consistent with the WHO-ICF model. Numerous studies have found evidence of cognitive deficits and aphasia severity level significantly impacting QoL and CQoL, therefore clinicians should create interventions that are functional for improving everyday challenges that PWAs encounter. This study also confirmed the importance of using QoL and CQoL measures to identify factors in PWAs' lives that are compromised or not as enjoyable as they previously were. Standardized assessments provide the numbers and percentages for various categories of functioning, while QoL and CQoL measures consider real life situations that the clinician might not otherwise ask about or consider when planning treatment. Finally, the ASHA-QCL was identified as an effective measure that is sensitive to detecting differences between various profiles of PWAs. It is quick and easy to administer, making it a useful measure to use with a variety of PWAs.

Study Limitations

Limitations to this study include a relatively small sample size, lack of control participants, limited access to participants and an overlap of therapies the participants received. This study included twenty-one PWAs with a range of deficits however, a larger sample size (thirty to forty PWAs) would increase the size of comparison groups. PWAs were divided into groups for each of the variables examined (post-onset period, aphasia severity, cognitive deficits, and therapy received) and these were often small (four to seven people in a group), reducing the statistical significance and generalizability of the results. In addition, it would have been beneficial to include a control group to investigate how the variables differentially influence PWAs' QoL and CQoL compared to matched control participants. A control group would ensure the results can be attributed to QoL and CQoL as a result of aphasia and related factors, not due to extraneous variables such as age or geographical region of the participants.

There were limitations when recruiting PWAs due to hospital, nursing home and government policies that do not permit facilities to provide personal information or invite researchers to converse with patients. Therefore, the present study did not examine PWAs' living environment as one of the factors contributing to QoL and CQoL, as all of the participants lived in their personal residences. Also, the inability to record the interviews or assessment administration limited the efforts to establish intra- and inter-rater reliability, which will need to be considered if the study is replicated. Finally, the amount and type of therapy each of the participants received were not discrete but were blended and overlapping. Some participants received different amounts of individual, group and intensive therapy, while others received only group or only individual therapy with varying amounts of total sessions. There was no information regarding the therapy approaches used with the participants, which may have an

impact on QoL and CQoL, as well as overall therapy outcomes. The lack of distinction between groups made analysis of this data challenging, as it was difficult to determine which therapy can be attributed to QoL and CQoL outcomes.

Recommendations for Future Research

Future research is needed to consider other variables that contribute to QoL and CQoL in PWAs. Factors such as living environments, personality type and occupations are potential areas that could be evaluated to examine how they influence PWAs' QoL and CQoL. The comparison of PWAs' living environments would provide useful information about how QoL and CQoL varies for people living in an acute hospital setting, nursing home, assisted living facility, or personal residence. PWAs' personality type and occupation pre-stroke may also have an influence on how the individual views their QoL and CQoL. For example, careers that require public speaking, or people who are extraverted and gain energy by interacting with others may feel the negative impacts of aphasia in a different way when compared to individuals with other careers or personality types.

Additionally, future research should have a larger sample size and include a control group. In this study it was found that overall, people who received no group therapy had lower scores on a physical rating scale (SAQOL-39 physical subdomain). Future research could consider how teletherapy impacts QoL and CQoL for PWAs who have physical limitations and are unable to attend as many therapy sessions. It would also be interesting to learn if group teletherapy (video conference call) can improve the lives of PWAs, or if it would be too challenging to organize. Another factor that was not considered in the present study due to the small sample size is how aphasia severity level might correlate with the amount of treatment

received. This would be an important variable to consider, however the sample size would need to be larger and group therapy types would need to be more distinguishable. Lastly, psychosocial aspects of QoL and CQoL and relationships with both PWAs' ages and post-onset periods should be further examined in future studies. PWAs of different ages and post-onset periods are at different levels of acceptance, and this should be analyzed to determine how it influences their everyday activities and self-image.

Conclusion

The present study supports previous research and contributes new information to the factors that influence QoL and CQoL in PWAs. The findings that increased aphasia severity and cognitive deficits negatively influence QoL and CQoL were consistent with previous research. The participants who had a stroke more recently, had lower scores on the SAQOL-39 psychosocial subtest, indicating that the amount of time post-onset is an important factor that contributes to PWAs' mindset and attitude about aphasia. PWAs' communication confidence should be considered when planning therapy, as the amount and type prescribed might differ based on the individual's personal factors. Reduced communication confidence might influence therapy outcomes, and this should be monitored and considered early in the stages of therapy planning. The comparison of QoL and CQoL measures revealed various correlations, with the CCRSA and ASHA-QCL being correlated to most of the other measures. Additionally, the ASHA-QCL was sensitive to identifying significant differences in groups across most variables, which suggests it is a useful tool for clinicians to use when working with PWAs. When intervention planning, the clinician should consider multiple factors of a PWA's life, including those covered in the present study as well as others examined in previous studies. Researchers

should continue to analyze other elements that contribute to QoL and CQoL in PWAs to ensure speech-language pathologists maintain high quality and efficient therapy services.

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Appendix A: IRB Approval



Institutional Review Board (IRB)

720 4th Avenue South AS 210, St. Cloud, MN 56301-4498

Name: Hannah Judovsky
Email: hmrodness@stcloudstate.edu

IRB PROTOCOL DETERMINATION: Expedited Review-1

Project Title: Factors that influence quality of life and communication quality of life in people with aphasia: Results from two measures

Advisor Grama Rangamani

The Institutional Review Board has reviewed your protocol to conduct research involving human subjects. Your project has been: **APPROVED**

Please note the following important information concerning IRB projects:

- The principal investigator assumes the responsibilities for the protection of participants in this project. Any adverse events must be reported to the IRB as soon as possible (ex. research related injuries, harmful outcomes, significant withdrawal of subject population, etc.).

- For expedited or full board review, the principal investigator must submit a Continuing Review/Final Report form in advance of the expiration date indicated on this letter to report conclusion of the research or request an extension.

-Exempt review only requires the submission of a Continuing Review/Final Report form in advance of the expiration date indicated in this letter if an extension of time is needed.

- Approved consent forms display the official IRB stamp which documents approval and expiration dates. If a renewal is requested and approved, new consent forms will be officially stamped and reflect the new approval and expiration dates.

- The principal investigator must seek approval for any changes to the study (ex. research design, consent process, survey/interview instruments, funding source, etc.). The IRB reserves the right to review the research at any time.

If we can be of further assistance, feel free to contact the IRB at 320-308-4932 or email ResearchNow@stcloudstate.edu and please reference the SCSU IRB number when corresponding.

IRB Chair:

Dr. Benjamin Witts
 Associate Professor- Applied Behavior Analysis
 Department of Community Psychology, Counseling, and Family Therapy

IRB Institutional Official:

Dr. Latha Ramakrishnan
 Interim Associate Provost for Research
 Dean of Graduate Studies

OFFICE USE ONLY

SCSU IRB# 1871 - 2399

1st Year Approval Date: 3/18/2019

1st Year Expiration Date: 3/17/2020

Type: Expedited Review-1

2nd Year Approval Date:

2nd Year Expiration Date:

Today's Date: 3/29/2019

3rd Year Approval Date:

3rd Year Expiration Date:

Appendix B: PWA Informed Consent Form

Consent to Participate

You are invited to participate in a research study about quality of life and communication in persons with aphasia (PWAs). This study is being done by Hannah Judovsky for a thesis project at St. Cloud State University, under the guidance of Dr. Rangamani.

Background Information and Purpose

As a person with aphasia, you or your family may have noticed some changes in your overall life participation and quality of life since the stroke occurred. The aim of this study is to identify which factors contribute to quality of life and communication quality of life outcomes, and which of the two assessment measures (ASHA FACS and ASHA QCL) will better reflect the communication quality of life in different groups of PWAs. The factors examined will include time since the onset of stroke, living environments, aphasia severity, and cognitive abilities.

Procedures

If you agree to be part of the research study, you will be asked to complete the following assessments:

1. Two tests, which include a short form of the Western Aphasia Battery-Revised Test (WAB-R) and parts of the Cognitive Linguistic Quick Test.
2. Four questionnaires including the American Speech-Language-Hearing Association Functional Assessment of Communication Skills for Adults (ASHA FACS); American Speech-Language-Hearing Association Quality of Communication Life Scale (ASHA QCL); Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39); and the Communication Confidence Rating Scale for Aphasia (CCRSA).
3. A short demographic information form.

Testing will take approximately 2.5 to 3 hours to complete and will be divided into two separate sessions. If willing, you may sign a release of information form to provide the researchers with access to medical information about your stroke.

If you have been assessed with any of the 6 assessments listed above within the last year at the SCSU Speech language hearing clinic, you may consent to giving us access to these assessment records by providing your initials. If you have been tested elsewhere, we will provide you a release form (standard clinical protocol of the SCSU Speech Language Hearing clinic) to sign and allow us permission to request your assessment results from the clinic/hospital/medical center that you were assessed at. The location's procedures for releasing assessment information will be followed to maintain confidentiality.

Please initial here if you allow us to access your previous assessments: _____

Risks and discomforts

There are no known anticipated risks for participants involved in this study.

Benefits of the study:

The results of this study will expand the research in the field about what factors influence quality of life (QOL) and communication quality of life (CQOL) in PWAs in different living environments and with different post-onset time periods. Additionally, it will provide useful information about how the two CQOL measures (ASHA FACS and ASHA QCL) compare to one another and if one measure should be used over the other measure with certain PWAs. Speech-Language Pathologists can use this information to plan assessment and intervention that will be the most beneficial for their client with aphasia. They can create functional goals that will increase the PWA's communication quality of life and help the individual return to an engaged lifestyle.

Confidentiality

All data collected will be kept confidential. The signed consent will be the only identifiable data collected. All tests' and questionnaires' results will be coded using secret codes of random letters and numbers. Your name or other personal information will never be used. All your documents will be kept in a secure location.

Participation/Withdrawal

Participating in this study is completely voluntary. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University, or the researcher. If you decide to participate, you are free to withdraw at any time without penalty.

Research Results

If requested, we can give you the research results after the study is completed.

Contact Information:

If you have questions about this research study, you may contact the primary investigator Hannah Judovsky by email at hmrodness@go.stcloudstate.edu or the faculty advisor Dr. Rangamani by email gnrangamani@stcloudstate.edu or by phone (320) 308-5769. Results of the study can be requested from the researcher or may be accessed after it is published at the St. Cloud State University Repository.

Acceptance to Participate

Your signature indicates that you are at least 18 years of age, you have read the information provided above, and you have consented to participate.

Name (Printed)

Signature of Participant / Power of Attorney

Date

Appendix C: PWA Demographics Questionnaire

Date: _____ Participant Initials: _____

Aphasia Demographics Questionnaire

1. Gender

- Male Female

2. Date of birth (mm/dd/yyyy)

____/____/____

3. Race

4. Current living environment

- Nursing home Assisted living
 Personal residence Other: _____

5. Stroke Information

- Left side of the brain Right side of the brain
 Blood clot in the brain Bleeding in brain

6. Aphasia type (if known)

7. When did the stroke occur?

- <6 months
 6 months – 1 year
 1 year – 2 years
 2 years – 3 years
 3 years – 4 years
 4 years – 5 years
 5 years – 6 years
 6 or more years

8. Indicate therapies received and length of time:

- One on one (individual therapy): Dates received: _____
 _____ hours per session _____ sessions per week _____ total number of weeks
- Group therapy: Dates received: _____
 _____ hours per session _____ sessions per week _____ total number of weeks
- Intensive Aphasia Therapy: Dates received: _____
 _____ hours per session _____ sessions per week _____ total number of weeks

Appendix D: PWA Recruitment Flyer



ST. CLOUD STATE UNIVERSITY

Department of Communication Sciences and Disorders
720 4th Ave. S, St. Cloud, MN 56301-4498
T 320.308.2092/F 320.308.6441
stcloudstate.edu/csd

DO YOU HAVE APHASIA?

*You are invited to participate in a research study on
improving quality of life in stroke survivors*



As part of this study you will be asked to do the following:

1. Take part in testing that includes two test batteries and a few surveys.
2. The testing will last approximately 2-3 hours. This will be conducted in two sessions over two different days.
3. We can come to your location or you can come to our on-campus clinic.

Your participation in this study will help speech-language pathologists provide improved services to promote quality of life in stroke survivors.

Thank you for your participation!

Questions? Contact us:

Graduate Student Researcher: Hannah Judovsky, BS

Email: hmrodness@go.stcloudstate.edu

Supervisor: G. N. Rangamani, Ph.D., CCC-SLP, BC-ANCDS

Email: gnrangamani@stcloudstate.edu Phone: 320-308-5769