EVALUATING HEALTH-RELATED QUALITY OF LIFE IN AFRICAN-AMERICANS WITH APHASIA

by

DAVETRINA SELES GADSON

(Under the Direction of Patrick Finn)

ABSTRACT

Health-related quality of life (HRQL) provides insight into the impacts of a health condition on an individual's ability to lead a fulfilling life. Previous research has identified determinants of HRQL in stroke survivors with aphasia, including communication, mobility, mental/emotional health, role, and social functioning. However, the extent to which these determinants are quantified in African-Americans with aphasia is unknown. Building upon previous research, this study attempts to gain a better understanding of HRQL in African-Americans and the role of social support and social network on HRQL in this population. Specifically, the aim of this study was to explore the determinants of HRQL in a homogenous sample of African-Americans which included stroke survivors with aphasia (PWA), stroke survivors without aphasia (PSA) and successfully aging/healthy adults with no history of neurological injury (SAH).

This study used a cross-sectional case control descriptive research design. A total of 39 male and female African-American adults participated in the study, with 13 participants included in each group (PWA, PSA, and SAH). Participants completed one language assessment and four patient reported outcomes that assessed HRQL, perceived social support, and social network. The patient-reported outcomes for HRQL included both a condition-specific measure, the Stroke and Aphasia Quality of Life Scale-39g (SAQOL-39g), and a generic measure, EuroQol-5D (EQ-5D).

Results indicated that PWA reported a significantly lowered overall HRQL than PSA and SAH adults on the SAQOL-39g. On the generic measure of HRQL, PWA reported a significantly lower overall HRQL than SAH adults, but no difference in overall HRQL was noted between PWA and PSA on the EQ-5D. PWA demonstrated significantly lower reports in specific domains related to communication and social HRQL than both PSA and SAH. A moderator regression analysis revealed that aphasia did not affect HRQL differently depending on social support or social network. Overall PWA reported a worse HRQL than PSA even when their physical abilities, role functioning, and mental/emotional health were comparable. Implications and limitations are discussed.

INDEX WORDS: aphasia, health-related quality of life, African-American, stroke survivor

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DEDICATION

This study is dedicated to African-American stroke survivors with and without aphasia, caregivers, speech-language pathologists, and my ancestors who paved the way for me to pursue a higher education.

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Chapter 1

Introduction

Chapter one is comprised of the significance of the problem, study purpose, background, and significance to speech language pathology. A conceptual model is described. Research aims and hypothesis of this study are explained.

Problem Statement

Stroke is the leading cause of long-term disability in Americans and is twice as likely to occur in African-American men and women than in Caucasians or any other ethnic minority group (Benjamin, Blaha, & Chiuve, 2017; CDC, 2017). Stroke costs are estimated at 34 billion dollars per year, including health services, medication, and employment absence (CDC, 2017). Adult stroke survivors often experience residual disabilities, participation limitations, and a host of personal, social, and economic hardships (Burns et al., 2018; Walsh et al., 2015) that contribute to stroke costs. Of these survivors 25% to 50% will be diagnosed with chronic aphasia (Flowers et al., 2016; Gialanella, Bertolinelli, Lissi, & Prometti, 2010). Approximately 2.5 million Americans who are currently living with aphasia (Hardy, Lindrooth, Peach, & Ellis, 2018; NAA, 2016a) often experience lower health-related quality of life (HRQL) as a result of changes in psychosocial, physical, and communication functioning (Hilari, 2011; van Mierlo et al., 2014)

Aphasia is a major health problem with highly variable rates of linguistic recovery (Hilari, Needle, Harrison et al., 2012). In most cases, language skills do not return to pre-stroke ability, which creates a new normal for stroke survivors with aphasia in navigating day to day speech interactions. The restriction of communication on human functioning not only impacts the individual but the individual's family and the community. The root of the issue is that aphasia not only affects communication but also psychological factors, such as self-identity, personal relationships, and social roles (Hilari 2011; Hilari et al., 2012; van Mierlo et al., 2014). However, these factors are often ignored in traditional medical approaches that value the practitioner's view over the patient's perspective. Moreover, research that describes the interaction of aphasia on biological, psychological, and social factors in African-Americans with and without aphasia is lacking.

The present study will evaluate HRQL in African-Americans with aphasia to better understand HRQL within this population and the role of social support and social network. This investigation will be the first cross group comparative study to capture self-reports not only in people with aphasia but also among African-American stroke survivors without aphasia, and successfully aging African-Americans who present without a history of neurological injury.

Study Objective

The major objective of this study is to examine HRQL in African-Americans with aphasia and evaluate the role of two components that relate to social functioning–social networks and perceived social support. This evaluation is important because African-Americans' lived experiences, recovery, and health conditions differ from that of any other ethnic group (Boan et al., 2014; Hardy et al., 2018). This research study will attempt to identify the factors that support and/or hinder well-being and social functioning that are unique to this group and responsible for improving client-centered care for PWA. Consistent with research recommendations poised by Burns et al. (2018), this study will explore real-world contributors to disability through the use of both a clinician-reported assessment and patient-reported measures that survey personal and environmental factors. This study will be the first attempt to bridge the gap in our clinical and research knowledge base as it pertains to the HRQL in African-American stroke survivors.

Research Questions

1. Is there a significant difference in health-related quality of life in African-Americans with aphasia, African-Americans with history of stroke but no aphasia, and successfully aging or healthy African-Americans with no known history of neurological injury?
2. Does aphasia affect health-related quality of life differently depending on social support?
3. Does aphasia affect health-related quality of life differently depending on social network?

Background

In the United States, more than 795,000 individuals will experience stroke annually and of these approximately 140,000 die (CDC, 2017) while roughly 180,000 stroke survivors will acquire aphasia (NIDCD, 2017). Stroke is the fifth leading cause of death in Americans, and a major cause of long-term disability in adults (CDC, 2017). Disparities in the delivery of health care, hospitalization rates, health outcomes, frequency of stroke occurrence, stroke recovery, healthcare literacy, and service provision are noted between African-Americans and Caucasians (Boan et al., 2014; Burns et al., 2018; Fiscella, Franks, Gold, & Clancy, 2000). African-Americans are twice as likely to have recurrent strokes, have the highest death rate due to stroke (CDC, 2017), and are more likely to experience strokes at a younger age than whites or any other ethnic population (CDC, 2017, Ellis et al., 2018; Hardy et al., 2018).

One contributing factor for increased stroke occurrence in African-Americans may be linked to pervasive chronic medical conditions. Chronic medical conditions like hypertension and diabetes are common in African-Americans and may influence stroke occurrence (Sacco et al., 2001). The presence of hypertension, in particular, is high in African-Americans regardless of geographic location (Sacco et al., 2001) and is the most cited reason for the higher occurrence of stroke in this population in addition to poor medical management (HHS, 2015).

The U.S. Department of Health and Human Services Office of Minority Health identifies Black/African American, American Indian/Alaska Native, Asian American, Hispanic/Latino, and Native Hawaiian and Pacific Islander ethnic groups as minority populations (HHS, 2015). Throughout the U.S., social determinants, such as socioeconomic status, access to healthcare, health insurance, and environmental barriers have contributed to health disparities among racial/ethnic groups (Hardy et al., 2018; Osypuk et al., 2017; Toivanen, 2012). For example, the U.S. Census Bureau reported the median Black household income at $40,258 which is lower than that of all racial groups, with Hispanics at $50, 486, Caucasians at $68,145, and Asians at $81, 331 (U.S. Census Bureau, 2018a). Access to care through insurance coverage revealed that 56.5% of African-Americans possessed private health insurance, 44.1% used government insurance like Medicaid or Medicare, and 10.0% were uninsured (US Census Bureau, 2018b).

Social determinants of health are conditions in the environment in which people are born, live, learn, and worship that affect health and quality of life outcomes (ODPHP, 2014). This means there is an unequal distribution of and access to resources, such as prevention services, money, education, and healthy neighborhoods which continues to influence health disparities and chronic conditions (Toivanen, 2012; WHO 2008). For example, when minorities have fewer opportunities to pursue higher levels of education, receive comparable wages, and live or work in positive environments (Toivanen, 2012), these barriers detract from healthy living and influence social determinants of health which ultimately contributes to health disparities. In addition, stroke mortality and morbidity occur more in individuals who are exposed to geographic disparities and are of lower socioeconomic status (Osypuk et al., 2017; Toivanen, 2012).

Aphasia

Aphasia is caused by damage to the language centers of the brain localized in the left hemisphere and is most often a consequence of stroke (NAA, 2016). Aphasia is a loss of language not intellect. The National Aphasia Association (2016) reports that over 2 million Americans are living with aphasia, a condition that is more common than Parkinson’s disease and muscular dystrophy. Recent post-hospital discharge information estimated that diagnosis of acute aphasia ranges from 18-38% (Ellis, Hardy, Lindrooth, & Peach, 2018), and this number is slightly lower than previously reported estimates of post-hospital discharge rates of 25-40% of individuals acquiring post-stroke aphasia (NAA, 2016). Aphasia types are often classified in one of the two main categories of fluent and nonfluent or receptive and expressive aphasia. People with receptive aphasia may have difficulty understanding speech production if Wernicke’s area is affected but are able to produce fluent speech, although their speech may lack content and organization (Gyorfi & Rebek-Nagy, 2015). On the other hand, people with expressive aphasia may have difficulty producing fluent speech if Broca’s area is affected but are able to understand spoken language without difficulty; therefore, receptive language skills are intact. In addition to these linguistic deficits, PWA may also experience difficulty with nonlinguistic tasks such as visuospatial perception and calculation.

The extent of the neurological lesion caused by a stroke impacts the type and severity of aphasia (Ellis et al., 2018), and recent evidence supports gender differences as a contributing factor as well (Ellis et al., 2018; Giroud et al., 2017). Recent reports that investigated aphasia predictors post-stroke found that older age and gender influenced the likelihood of aphasia (Ellis & Urban, 2016).

Quality of Life

The World Health Organization (WHO) defined QOL as:

> Individuals' perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment (WHO Quality of Life Assessment Group, 1993, p. 153).

Quality of life is a broad multidimensional concept that encompasses domains, such as jobs, housing, health, environment, and culture (WHO, 2001). In contrast, health-related quality of life (HRQL) is an individual's perception of his or her ability to lead a reasonably satisfactory life given the impact of a disability on their health (Berzon, Hayes, & Shumaker, 1993; Hilari, Cruice, Sorin-Peters, & Worrall, 2015; Hilari, Needle, & Harrison, 2012). Although there is no consensus on the definition of health-related quality of life (HRQL), scholars agree that HRQL is multidimensional and comes from "within the skin" attributes (Bell, Bombardier, & Tugwell, 1990) that are determined by the client and cannot be viewed by an observer. This construct, in addition to QOL, has become a key indicator for stakeholders to determine if intervention is both effective and client-centered. In general, QOL is a broader term that encompasses HRQL and non-HRQL components.

Health-related quality of life.

HRQL refers to an individual's ability to function and his or her perceived well-being in physical, mental/emotional, family, and social domains of life in the presence of a health condition (Berzon et al., 1993; Hilari et al., 2015; van Mierlo et al., 2014). A growing body of literature within both medical and rehabilitation sciences has described the key aspects of HRQL as including five dimensions: physical, social, mental (e.g., cognition or psychosocial), emotional (e.g., affect or mood), and role (e.g., ability to work) (Fayers & Machin, 2007; Mansoor et al., 2016). Although terminology is often used interchangeably, HRQL should be considered a narrower perspective of QOL because the focus of HRQL is on physical, psychological, and social functioning (Carod-Artal, 2009a; van Mierlo et al., 2014). An individual's HRQL is often measured by his or her capacity to perform daily activities and social roles (Doward & McKenna, 2004; Guyatt, Feeny, & Patrick, 1993; Hilari, Wiggins, Roy, Byng, & Smith, 2003b) and is typically self-reported along multiple dimensions. For purposes of this study, HRQL is operationally defined as an individual's self-perception and satisfaction with his or her communication; physical, mental/emotional role; and social functioning in the presence of a chronic health condition or without a chronic health condition.

The need to understand HRQL among African-Americans is guided by historical evidence of healthcare disparities related to this population. These disparities have contributed to stroke reoccurrence, long-term disability, and adherence to treatment programs within this population. However, little information on African-American stroke survivors with aphasia is available. Research on stroke survivors with aphasia and without aphasia has identified differences between the two groups in areas related to communication, activity participation, psychosocial behaviors, role/identity, and social support (Hilari, 2011; Hilari et al., 2012; Hilari et al., 2015; Katona et al., 2015). Although these factors are well-known contributors to HRQL in people with aphasia, there is no information on HRQL specific to African-American stroke survivors with aphasia. Previous research studies either had an African-American sample size 7%-13% (Hilari et al., 2003b; Hilari, 2011) or did not specify ethnic group as part of the descriptive statistics.

This dissertation study will attempt to contribute to the body of literature and the practitioners' awareness of HRQL in African-Americans with aphasia and identify the role of social network and social support on HRQL in this population. The information collected from stroke survivors with aphasia (PWA), stroke survivors without aphasia (PSA), and successfully aging/healthy adults without neurological injury (SAH) may support speech pathology services and identify HRQL factors that are unique to this population.

Disability Framework

The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) framework theorizes the relationship between impairment, activities, participation, and contextual factors such as environment and personal influences on ??? (Burns et al., 2018, WHO, 2002). The ICF is both a conceptual framework and classification system whose overall aim is to provide a unified and standard language for the description of health and health-related states (Threats, 2008; WHO, 2001 p. 3). The ICF framework is most useful because it helps to move the client from a passive recipient of treatment to the center of care by describing the impact the health condition has on his or her ability to lead a fulfilling life (Threats, 2008) or the impact of the disease on physical, mental, and social components (Hilari et al., 2003b). Furthermore, the ICF provides a universal language for practitioners to communicate human functioning and restrictions that are associated with health conditions across disciplines (Ross & Wertz, 2005).

Much of the available literature on the ICF emphasizes the individual's health experience to be an interaction between the health condition and social, personal, and environmental factors (Wade & Halligan, 2003). This position supports the progressive shift in healthcare from a disease focus or medical model to a biopsychosocial model that includes the person-perspective and social influences (Alford et al., 2015) such as HRQL. Although the ICF is not an assessment tool or theoretical model, the framework has been credited with increasing the client's and practitioner's understanding of rehabilitation goals. (Simmons-Mackie & Kagan, 2007; Threats, 2012).

The ICF framework was adopted by the American Speech and Hearing Association (ASHA) in 2001 to help practitioners "develop functional goals" and facilitate "collaborative practice" (ASHA, 2016 p. 2; Threats, 2012). In clinical speech-language pathology, the ICF framework has been incorporated into evaluation and intervention procedures in aphasia, motor speech, dementia, and cognitive communication disorders (Dykstra, Hakel, & Adams, 2007; Hopper, 2007; Larkins, 2007; Simmons-Mackie & Kagan, 2007; Threats, 2008). The ICF framework plays an important role in aphasia rehabilitation in the context of quality of life. To help educate practitioners on the connection of the ICF framework to aphasia management, Simmons-Mackie and Kagan (2007) adapted the ICF model to the Framework for Outcome Measurement (FROM). This association helped to better illustrate the connection of the ICF framework to assessment and intervention practices using a universal language. For example, the ICF impairment category was linked to anomia and auditory comprehension deficits, whereas the activity/participation category was linked to difficulty using the telephone or limitations in social engagement (Simmons-Mackie & Kagan, 2007). Most notably, these scholars advocated approaches that would improve assessment and treatment practices that would help individuals to live successfully with aphasia (Kagan et al., 2008; Simmons-Mackie & Kagan, 2007; Wallace, 2010).

Stroke disability is often viewed from a life course perspective (Burns et al., 2018; Simmons-Mackie & Kagan, 2007). The goal of the ICF framework is to sustain functional health (Threats, 2008), by ensuring intervention practices have real-world value on human functioning. Social policy and program evaluations continue to use the ICF framework to monitor disability costs and insurance reimbursements (WHO, 2002). In order for SLPs to join the global conversation related to outcome research and rehabilitation practices, practitioners must adopt the ICF framework to describe the impact of communication disorders on life participation.

Significance to Speech Language Pathology

The value in understanding the HRQL in African-Americans is important because only the individual knows how aphasia impacts his or her daily living. Previous research has identified differences in HRQL among stroke survivors with and without aphasia, however ethnicity among the groups have been predominantly white or not disclosed as part of participant demographics. As explained earlier in the text, it is clear that social determinants contribute to stroke recovery, health related quality of life, and successful aging. As a result, previous research that has identified predictors of HRQL or described HRQL in stroke survivors with and without aphasia has not been able to confidently speak to these factors in African-Americans with aphasia. In order to advance clinical practices that consider HRQL, there is a need to better understand the chronic disability of aphasia within this population (Thorpe et al., 2016). This research study will begin to fill the gap by describing HRQL in a homogenous sample of African-Americans. Additionally, this study will extend the body of literature by examining the role of social support and social network on HRQL.

Purpose of the Study

This dissertation study evaluates the patient perspective on communication, mental/emotional health, physical, role and social functioning in the presence of a chronic disability. The aim of this project is to describe HRQL in African-Americans with aphasia. In addition to extend the research by evaluating aspects of social functioning by using a combination of different support indicators (Hilari et al., 2003b) in terms of social support and social network on HRQL within this population.

Chapter 2

Review of the Literature

An extensive literature search was performed with online databases: PsycINFO, Medline, Web search engines from the American Speech-Language-Hearing Association, Google Scholar, and PubMed (1980 to 2019). All searches were performed using the key terms “quality of life”, “well-being”, “health related quality of life”, “attitudes and communication”, “psychosocial’, and “health-status”, cross-referenced with “aphasia”, “African-American stroke”, “minority stroke”, African-American health related quality” of life”, “African-Americans with aphasia”. Edited books and published scales also were hand searched.

As mentioned throughout the introduction, a gap exists in the literature describing HRQL in African-American stroke survivors with aphasia. Therefore, the literature review is inclusive of HRQL in stroke survivors with and without aphasia, in addition to aphasia in African-Americans.

Health-Related Quality of Life

Health-related quality of life (HRQL) refers to the overall components of quality of life and considers the impact of a health condition on a person’s ability to lead a fulfilling life (Hilari, 2011; Vincent-Onabajo, Hamzat, Owolabi, 2015). HRQL is self-reported and comes from “within the skin” because only the individual knows how he or she feels (Bell, Bombardier, & Tugwell, 1990). Although there is no consensus on a single definition of HRQL, most scholars agree that it is multidimensional.

Ross and Wertz (2003) were early investigators of the concept of quality of life in PWA. In their study, they examined 24 facets of QOL proposed by the WHO to determine which facets differed between 18 PWA and 18 PSA as measured by the World Health Organization Quality of Life (WHOQOL)-BREF. Ethnicity was not identified. The results revealed facets within three domains to distinguish QOL in PWA and PSA— level of independence, social relationships, and environment. Level of independence was viewed as the ability to perform daily activities, to get around, and to work. The social relationship domain included satisfaction with support received from friends and the individual's sex life. The environment domain included accessibility of information, health services, and transportation (Ross & Wertz, 2003).

Simmons-Mackie and Kagan (2007) also supported the findings of Ross and Wertz (2003) with regard to the dynamic interaction of QOL components in PWA. These scholars recommended that intervention strategies collectively address the ICF components— Impairment, Activities and Participation, Environment, and Personal Factors —in order to maximize recovery throughout all stages of aphasia. Based on this endorsement the use of comprehensive assessments that utilize disease specific elements and patient-reported measures is warranted by both clinicians and researchers (Bose, McHugh, Schollenberger, Buchanan, 2009).

Parallel to categories of the ICF, determinants of HRQL in people with aphasia are reported across ICF domains to provide information regarding well-being, psychosocial behaviors, social functioning, quality of life, and community participation. The influence of communication on functional autonomy and social participation is seen across the continuum from healthy to disabled (Wallace et al., 2017).

Health-related quality of life is assessed through the use of patient-reported outcome (PRO) measures (Hilari & Byng, 2009; Threat, 2012). Patient-reported means the information comes directly from the patient without the practitioner or family input regarding accuracy (Yorkston & Baylor, 2019) These measures are beneficial in aphasia management because they help capture the patient's responses to life satisfaction in the presence of a disability in various contexts (Ellis & Peach, 2017). More recently, PROs have served to support Speech-Language Pathologists (SLPs) with goal setting and knowledge transfer of innovative treatment practices (Rodriquez et al., 2013; Worrall et al., 2011). Patient-reported measures differ from clinician-reported measures in that the patient's perspective in the specified domain area is the targeted response with no judgement from the administrator in terms of accuracy.

The use of the ICF framework will alert practitioners to the factors that are most meaningful to the client. Many SLPs have debated if aphasia therapy should target impairment-based or functional treatment approaches. In a qualitative descriptive study Worrall et al. (2011) conducted semi-structured in-depth interviews with 50 stroke survivors with aphasia; ethnicity was not identified. Nine broad categories of preferred goals were derived from the data: return to pre-stroke life; communication; information; speech therapy and other health services; control and independence; dignity and respect; social leisure and work; altruism and contribution to society; and physical function and health. These goal areas identified by PWA are linked to each domain of the ICF. This evidence justifies the need for practitioners to use the ICF framework to better capture goals across the spectrum that target the desires and perspectives of PWA.

Previous consideration regarding the use of PROs in clinical and research arenas has prompted questions about the reliability of an instrument for capturing information objectively and providing standardized results. A considerable amount of literature has been published on the benefit and reliability of PROs for adequately capturing the patient's perspective across severity levels in PWA (Berzon, et al., 1993; Doward & McKenna, 2004; Eadie et al., 2018; Hilari et al., 2003b; Threats, 2012, Yorkston & Baylor, 2019). A systematic review that compared the psychometric properties of PROs that measure HRQL in PWA was completed by Gadson, Marshall, & Franic (in preparation). The goal of this review was to determine whether one or more available instruments were appropriate for use as a measure of HRQL in aphasia with consideration of severity levels, settings, and administration purpose (research or clinical). Eight condition specific instruments were found to demonstrate adequate psychometric properties' in regard to conceptual and measurement model, reliability, content validity, construct validity, interpretability, responsiveness, and interpretability for use in PWA (Gadson, Marshall, & Franic, in preparation). Given the widespread evidence on incorporating the patient perspective within the plan of care, clinicians that continue to use clinician-reported measures in isolation jeopardize shared decision making between the practitioner and the client in therapy (Swinburn et al., 2018).

For purposes of this study HRQL is defined as the subjective perception of the individual's reflection on five domains — communication, physical, mental/emotional, role, and social functioning. This review will synthesize the evidence regarding components of HRQL in stroke survivors and healthy aging adults to understand the extent to which these five factors influence an individual's ability to lead a fulfilling life.

Health-related Quality of Life in People with Aphasia

Scholars have identified several predictors for HRQL in people with aphasia (PWA). Hilari, Needle, and Harrison (2012) conducted a systematic review of quantitative and qualitative studies that classified predictors for HRQL in PWA. The determinants included verbal communication/language, participation in activities, body function, physical/mobility, positive/personal outlook, in/dependence, emotional/mental health, social functioning (social network, perceived social support, living alone), optimism and ability to look to the future and set goals, self-identity/role (Moeller & Carpenter, 2013), home and health, accessibility to information, environment and minimal structural and attitudinal barriers (Hilari et al., 2012). These determinants have consistently suggested that HRQL is poorer in people who report lower evaluation in these areas. A study by Hilari et al. (2003b) evaluated the predictors of HRQL in 83 people with chronic aphasia, 13% of the sample identified as Black. Health-related quality of life was measured using the Stroke and Aphasia Quality of Life Scale-39, and results of this study revealed that emotional distress, social participation, communication disability, and comorbidities were significant predictors of HRQL. Cognition, age, and social support were not significant predictors of HRQL. However, the study recommended that future research should further examine of the role of social support on HRQL using a combination of support indicators such as social network and perceived social support (Hilari, 2003b). A study by Carod-Artal and Egido (2009a) also identified causal factors like depression or high emotional distress, aphasia severity, comorbid medical problems, and age to be predictors of poor functional recovery in stroke patients and associated with poorer HRQL as assessed by generic HRQL measures. Given the multiple determinants and overlap, the five most frequently cited domains associated with HRQL—communication, physical, role, social, and mental/emotional health —were chosen for further exploration within this population.

Communication

Language functioning describes the extent to which an individual is able to communicate spontaneous thoughts and ideas fluently, understand spoken language, repeat words and phrases, and execute word finding skills. As result of damage to the left hemisphere of the brain, stroke survivors with language impairment or difficulty in these areas have aphasia (NAA, 2016; NIDCD, 2017). The severity of language functioning is most often judged by the individual's ability to perform linguistic language tasks associated with reading, writing, word fluency, repetition, and auditory comprehension of words and sequential commands. The standard for language remediation is to improve communication (Spreen & Risser, 2003). Communication occurs when knowledge, information, or feelings are exchanged between at least two people

(Eadie et al., 2006; Spreen & Risser, 2003). Although communication is inclusive of language, the two terms are often differentiated in that communication refers to the transfer of information, most often through a conversational exchange (Eadie et al, 2006). For the purposes of this study the terms are not mutually exclusive and will be used interchangeably. Severity of communication disability is a significant predictor of HRQL with higher communication disability resulting in poorer quality of life (Hilari et al., 2003b).

Communication functioning is deemed influential in stroke survivors' self-perception of their HRQL (Cruice, Hill, Worrall, & Hickson, 2010a; Hilari et al., 2012). Deficits in verbal and functional communication (Bose et al., 2009; Cruice, Worrall, Hickson, & Murison, 2003; Moeller & Carpenter, 2013; Spaccavento et al., 2014) and severity of aphasia (Koleck et al., 2017; Nagayoshi, Iwata, & Hachisuka, 2008) often contributed to the individual's independence (Cruice et al., 2010a; Moeller & Carpenter, 2013). Furthermore, the stroke survivor's ability to participate in social and work-related activities (Cruice, et al., 2010a; Hilari, 2011) had an impact on the individual's psychosocial well-being (Constantinidou, Prokopiou, Nikou, & Papacostas, 2015; Cruice, Worrall, & Hickson, 2003; Spaccavento et al., 2014) and self-identity (Moeller & Carpenter, 2013).

Treatment research has begun to highlight specific techniques, activities, and service delivery models that support communication and HRQL. For example, Rodriguez et al. (2013) examined the secondary influence of service delivery models like an intensive, comprehensive aphasia program on activity/participation in addition to impairment function in 11 people with chronic aphasia; ethnicity was not identified. This study aimed to estimate the magnitude of influence that the treatment effects had on language impairment, functional communication, and communication-related quality of life domains (Rodriquez et al., 2013). The treatment model included individualized treatment based on neuroplasticity principles, group sessions with a focus on communication-based challenges, and computer-based treatment that targeted impairment-based skills. Results yielded positive outcomes among PWA in functional communication, enhanced life participation, and communication-related quality of life.

Physical

Physical functioning includes mobility and the individual's ability to walk, move, and perform personal care. An individual's physical ability contributes to his or her independence in carrying out activities of daily living (ADLs) or with transportation (Spreen & Riser, 2003). The physical domain also considers the presence of hemiplegia that results in limited functioning of the right arm, hand, leg or any upper extremity motor function weakness that negatively influences HRQL (Koleck, et al., 2017; Nichols-Larsen, Clark, Seringue, Greenspan, & Blanton, 2005).

The inability to use upper and lower extremities is important because it contributes to functional limitations and activity restrictions (Hilari et al., 2009). Stroke survivors identified physical functioning as a major contributor to HRQL because it interfered with mobility (Cruice et al., 2010a; Hilari, Needle, Harrison, 2012; Franzén-Dahlin, Karlsson, Mejhert, & Laaska, 2010; Ross & Wertz, 2003) and work capacity (Ross & Wertz, 2003).

Social

Social functioning as a broad concept was identified in PWA to be a major contributor to HRQL (Cruice et al., 2003; Eadie et al., 2018; Hilari et al., 2003) and includes opportunities that allowed for leisure (Cruice et al., 2010a), community related activities, perceived social support (Eadie et al., 2018), and personal interactions with friends and family (Spaccavento et al., 2014). The extent to which social functioning contributes to HRQL requires further research. This ambiguity is due to the use of various terminology in the literature to describe the multiple layers of social functioning.

Some of the various terminology used to describe the social component include: social participation, social influence, social integration, social support, social network, and social isolation. For example, Hilari and Northcott (2006) described social functioning as encompassing perceived social support from friends and family in addition to actual support received from friends and family. Social relationships are considered a key element of successful aging (Petersen et al., 2016) and also referred to as social network (Kelly et al., 2014). Social network is frequently linked to the individual's experience with social isolation, whereas social domain broadly refers to the social participation or social limitations the individual experiences as a result of the neurological injury. Social integration is defined to include the individual's existing social ties (Heaney & Israel, 2002, Kelly, Patel, Narayan, Prabhakaran, & Cunningham, 2014). This is different from social influence, which is exerted through the behavior observation of others and includes support within ones' social network or the number of persons within the social network that increased or decreased post stroke (Heaney & Israel, 2002). Social influence is differentiated from perceived social support, in that social support is consciously provided by the sender (Heaney & Israel, 2002). There is agreement among some scholars to classify characteristics of social functioning into two main pillars: social support and social relationships (Heaney & Israel, 2002). This investigator agrees with this classification and extends the classification to include social participation (Kelly et al., 2014) as a frequently identified component of social functioning. Therefore, the specific components of social functioning that are responsible for changes in HRQL requires further research.

Social network refers to the "web of social relationships that surround the individual" (Heaney & Isreal, 2002 p. 185). It is important to HRQL because relationships with family and friends can help reduce social isolation, which is frequently identified in PWA. Social isolation has been described as a quantitative construct, which arises from a deficit in social contact

(Petersen et al., 2016). Social network may include family, friends, co-workers, church members, and organizational constituents (e.g. sorority/fraternity members) (Kelly et al., 2014). These types of social companionships contribute to the individual's social network because they reference the individual's feelings of community inclusion and sense of identity (Hilari & Northcott, 2006). Researchers have suggested that social network is a predictor of social isolation (Lubben, et al., 2006); therefore, social isolation and social network should not be considered unrelated. Social isolation defined in this context broadly includes the loss of friendships or engagement and integration in one's social circle. This type of isolation has also been known to be a determinant of poor health and found to create neurobiological changes (Dhand, Luke, Lang, & Lee, 2016). There is evidence in the literature that PWA often experience social isolation and difficulty maintaining friendships more than non-aphasic individuals as a result of communication challenges (Hilari et al., 2012). Social isolation in individuals was gauged by measuring the quantity of family and friends the individual engaged with as part of a social relationship (Lubben et al., 2006). For example, a question such as "how many relatives do you see or hear from at least once a month" is aligned with measuring the size of the individual's social network (Lubben et al., 2006). Overall social networks are links between people that may or may not provide social support (Heaney & Israel, 2002).

Social support refers to the functional content of relationships and any support given outside a formal setting that utilizes various supportive behaviors (Heaney & Israel, 2002; Kruithof, van Mierlo, Visser-Meily, van Heugten, Post, 2013). As a determinant of HRQL, social support includes factors related to social life integration, social health, and perceived social support (Hilari & Northcott, 2006; Langford, Maloney, & Lillis, 1997). Social support can be distinguished from other social relationship functions because social support is always intended (by the sender) to be helpful (Heaney & Israel, 2002). Some scholars have divided social support into four categories that are also described as supportive behaviors or acts: emotional support, instrumental support, informational support, and appraisal support (Heaney & Israel, 2002; Langford et al., 1997). In reference to these four categories, emotional support is most often investigated and demonstrates a strong relationship to HRQL in contrast to information, instrumental, or appraisal (Kruithof et al., 2013). Given the novel nature of identifying which aspects of social support contribute to HRQL, Kruithof et al., (2013) recommended that future research measure social support by source and/or type via instruments such as the Medical Outcomes Social Support Survey (MOSS-SS). Perceived social support is different from social network that quantifies support, in that perceived social support explores the accessibility and quality of support an individual has available to them for various circumstances. For example, support types may include informational support (e.g. someone to give you good advice about a crisis), tangible support (e.g. someone to help with daily chores if you were sick), affectionate support (e.g. someone who hugs you), and positive social interaction (e.g. someone to have a good time with) (Sherbourne & Stewart, 1991). Perceived social support does not focus on the number of people in the individual's social circle but the availability of types of support an individual has within his or her network.

Social participation refers to the participation in community-related and activities of daily of living. It has been identified as an important determinant of HRQL, especially within the first year of stroke recovery (Vincent-Onabajo et al., 2015). Participation limitations as a determinant of HRQL encompass limitations in activities of daily living, social activities, and community participation (Hilari, 2011), in addition to the functional limitations surrounding work-related activities, personal activities, domestic, travel, and hobbies (Cruice et al., 2010b).

Exploring the range of social participation, Wallace (2010) examined life participation in 40 people with chronic aphasia in two regions of the U.S. (Ohio and Hawaii), 30% self-identified as African-American. The Profile of Functional Activities and Life Participation (PFALP) was used to “assess the need of therapy, the reason for therapy (life participation goals) and the disciplines most appropriate to target the goal” (p. 437). Individuals were assessed in his or her home or a university speech and hearing clinic. PFALP pictographic materials were used to support communication strategies and to decrease the need for a proxy. The study found that PWA across regions judged 20% of all their activities in the life participation profile as impaired, which indicated a moderate participation restriction in areas that mattered most to the clients. Qualitative reports revealed intrinsic and extrinsic factors contributing to participation restrictions were aphasia, difficulty communicating with strangers, and accessibility barriers. PWA expressed the desire for psychological counseling and motivational coaching to decrease life participation restrictions. Overall, this study supports that aphasia in the societal context involves communicating and interacting with others (Papathanasiou & De Bleser, 2003).

The body of evidence supporting the ongoing role of social functioning in PWA has been established; however, there is a gap in the literature with regard to identifying the specific aspects of social functioning that are the most influential for HRQL. Social functioning requires further research because the concept of social functioning is described in the literature through various terminology with multiple layers. It is important to tease apart this domain because an individual’s actions are embedded in his or her social networks and may serve as an important determinant of health (Kelly et al., 2014). This study will focus on the two elements of social functioning mentioned above, perceived social support and social network, to examine the influence of these elements on HRQL. These two elements of social functioning were chosen in alignment with research recommendations by Hilari et al. (2003b) to explore a combination of different support indicators such as social support and social network.

Role

Role functioning as a determinant of HRQL addressed an individual's level of independence with regard to ADLs and work mobility (Cruice et al., 2010a; Hilari et al., 2012; Moeller & Carpenter, 2013; Ross & Wertz, 2003). Role functioning included activities that took place in the workplace or home (e.g., homemaker) and includes paid or unpaid employment (e.g., volunteer) (Eadie et al., 2006).

Emotional/Mental

Emotional functioning or emotional distress as a predictor of HRQL in stroke survivors encompasses emotional health, spiritual well-being (Hilari et al., 2003b; Kim, Heinemann, Bode, Slivva, King, 2000), and emotions surrounding the ability to perform the activities of daily living and work (Cruice et al., 2010b). Individuals with aphasia experience higher rates of psychological distress such as depression, participation limitations in social and community-related activities, and social isolation (Hilari, 2011; Moeller & Carpenter, 2013; Ross & Wertz, 2003). Although part of emotional health (Cruice et al., 2003; Kim et al., 2000), depression was often categorized separately as a major determinant of HRQL in PWA (Constantinidou et al., 2015; Cruice et al., 2003; Cruice et al., 2010; Hilari et al., 2009). In addition to emotional functioning, mental health was described to include nervousness, anxiety and psychological distress (Crichton et al., 2016; Cruice et al., 2010b; Hilari et al., 2003). Ways to support emotional distress in PWA include working on self-esteem and confidence. This can help affect the patient's motivation and response to rehabilitation (Hilari et al., 2003b).

Psychosocial functioning is under the umbrella of emotional health and a key determinant of HRQL in PWA. It includes information about one's belief system, mood, energy, and well-being. Elements of this domain include having a positive outlook and attitude coping skills (Cruice et al., 2010b; Moeller & Carpenter, 2013), ability to find/accept a new identity (Sarno, 2007), psychosocial factors, and attitudinal barriers (Hilari et al., 2012). As PWA experience neurological injury, mental components or cognitive changes may contribute to psychological well-being (Spaccavento et al., 2014). Scholars have identified components of mental function that contribute to the self-perception of HRQL in PWA including cognitive decline (Hilari et al., 2003) and cognitive health (Constantinidou et al., 2015), sensory body functioning (Cruice et al., 2010b), and home arrangements or living conditions (e.g., alone or spouse) (Hilari et al., 2012; Nagayoshi et al., 2008). Notably, home arrangement was important for older adults (Cruice, et al., 2010a).

Ross, Winslow, Marchant, and Brumfit (2006) examined the effects of treatment activities and service delivery models in the context of group intervention on communication, psychological well-being, and life participation in people with aphasia. The results of this study revealed the use of a social model approach promoted conversational changes related to life participation, in addition to changes in psychological well-being such as increased motivation to engage in conversational exchanges. This finding supports previous research that found group conversation to be beneficial to social participation and functional communication (Ross et al., 2006). These outcomes are essential to the body of research that examines HRQL in stroke survivors with aphasia because they target major predictors like psychological well-being, functional communication, and life participation in addition to language impairment to support comprehensive recovery.

Health-related Quality of Life in People without Aphasia

A number of studies have found differences between PWA and people without aphasia (PSA) that contribute to the individual's self-report of life satisfaction (Hilari, 2011; Ross & Wertz, 2003). These studies often compare PWA and PSA or PWA and non-neurologically impaired or healthy adults to better understand the variance in reports. Hilari (2011) investigated the predictors of HRQL in stroke survivors with and without aphasia. The sample size was 87 (*n*=55 without aphasia; *n*=32 with aphasia), with male and female adults ranging in age from 18 to 91. The sample included African-Americans with aphasia (6%), ischemic and hemorrhagic stroke types, and participants with non-specified co-morbid conditions. The results of this study found that PSA reported better independence, well-being, and social participation, while PWA reported a lower performance in well-being, social participation, and independence which contributed to a poorer HRQL. In addition to these elements, higher incidences of depression and social isolation were reported in PWA than stroke survivors without aphasia.

To learn more about the personal experiences of minority stroke survivors through the lens of the participant, Balakrishnan et al. (2017) examined the quality of life in 17 urban minority stroke survivors. Sixty-five percent of the sample size was Black /African-American. The study used Photovoice, a qualitative method, which places data collection in the hands of the participant. The Photovoice technique has been used to study the experiences of marginalized communities to better understand the facilitators of and barriers to emotional and physical recovery. This technique allows participants to capture, present, and narrate their lived experiences through photography. The pictures were discussed in group sessions. Through a grounded theory approach and content analysis, the central theme was explored, and a three-stage conceptual framework with subthemes was established. The three-stages and subthemes were initial stroke experience (acknowledgement and avoidance), coping strategies (integration versus isolation), and long-term adaptation. A common theme among the stroke survivors was "a journey to recovery of adaption to life after stroke" (p. 3). Notably, all participants reported emotional barriers such as feelings of depression, social isolation, and frustration. Successful transition between the stages was greater when stroke survivors acknowledged new challenges and reported more positive reflections on personal experiences and social integration. Stroke survivors who presented with difficulty transitioning between the recovery stages displayed avoidance behaviors toward new challenges, reflected negatively on personal experiences, and were socially isolated. Minority stroke survivors were more isolated when physical and emotional barriers, which influenced coping mechanisms, were ignored. Although this study did not report whether any of the minority stroke survivors had aphasia, it confirms the vital role that social functioning, optimism, and mental/emotional health have on stroke recovery in minority communities.

Similarly, a qualitative study documenting the lived experiences, quality of life, and coping skills in 10 African-Americans with primary stroke in south Florida found physical and speech impairments contributed to the individual's independence and self-care (Johnson, 2014). Both males and females reported the desire to return to pre-stroke life. Overall, there seems to be evidence of the need for more stroke education and healthcare literacy in the African-American community to decrease the occurrence of stroke.

In summary, among the studies completed comparing HRQL in stroke survivors with and without aphasia, key differences between the groups that contributed to HRQL were the changes of or limitations in functional communication (Bose et al., 2009; Cruice et al., 2003; Moeller & Carpenter, 2013; Spaccavento et al., 2014), psychological well-being (Cruice et al., 2003; Cruice et al., 2005; Spaccavento et al., 2014), physical functioning (Bose et al., 2009; Cranfill & Wright, 2010; Crichton et al, 2016; Cruice et al., 2010b; Hilari & Byng, 2009; Moeller & Carpenter, 2013), social functioning and relationships (Cruice et al., 2010b; Hilari et al., 2003; Moeller & Carpenter, 2013; Ross & Wertz, 2003), participation limitations (Hilari, 2011; Moeller & Carpenter, 2013), depression (Constantinidou et al., 2015; Cruice et al., 2003; Cruice et al., 2010b; Hilari et al., 2003) and environmental barriers that limit accessibility to information, transportation, or health services (Ross & Wertz, 2003). Initial stroke type (Nichols-

Larsen et al., 2005), risk of stroke reoccurrence, general health (Cruice et al., 2010b), and comorbidities like diabetes and depression (Hilari et al., 2003; Nichols-Larsen et al., 2005) were also identified as determinants of HRQL.

Figure 1 displays the contributors to HRQL in PWA within the ICF disability framework. The health condition is aphasia, and in the impairment category, physical limitations, cognitive decline, and communication disability contribute to HRQL in PWA. Activity limitations that correlate with components of HRQL in PWA include changes in role functioning, work mobility, and participation in ADLs. The participation restrictions that contribute to a poorer HRQL in PWA include changes in community participation, social support, and social participation. Environmental factors that contribute to a poorer HRQL in PWA include accessibility to information, environment and structural barriers, comorbidities, and social isolation. Finally, personal factors that contribute to a poorer HRQL in PWA are mental/emotional health, positive/personal outlook, optimism, education, and age. Situating the contributors to HRQL in PWA within the ICF disability framework is beneficial in showing the connection between a health condition and its restrictions on an individual’s ability to lead a fulfilling life and helping practitioners with rehabilitation goal setting.

Figure 1. Contributors of health-related quality of life in PWA

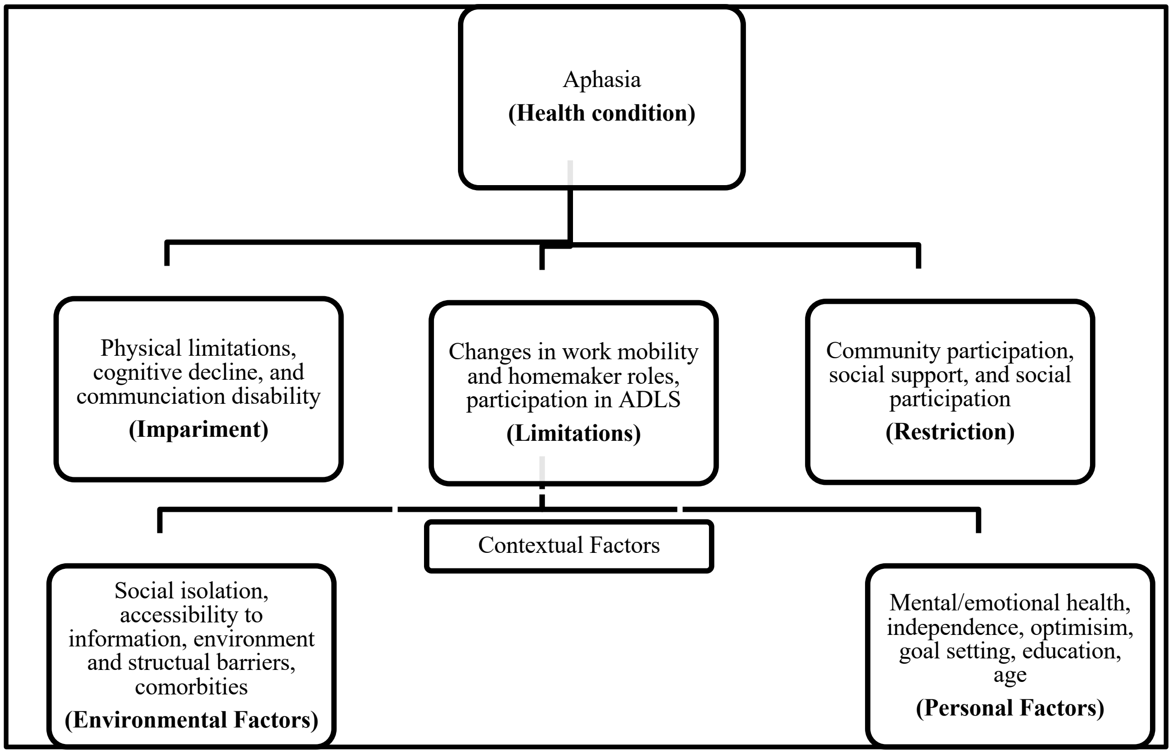

Figure 1. Contributors of HRQL in PWA outlined in the WHO ICF disability conceptual framework. Aphasia as a health condition causes impairment, limitations, and restrictions in the individual's health and health state which interacts with contextual factors related to daily functioning. This list is not all inclusive of the contributors of HRQL to PWA.

Finally, some studies found demographic variables contributed to the individual's perception of HRQL. Demographics such as education, gender (Constantinidou et al., 2015; Hilari & Northcott, 2006), age (Cranfill & Wright, 2010; Cruice et al., 2010a,b; Hilari, 2003), and socioeconomic status (Lima et al., 2014) were noted among both PWA and PSA as impacting HRQL. Although not consistently identified throughout the literature, gender differences were noted in social network size and level of education. Women who self-reported a lower level of education and a smaller social network size also demonstrated a poorer quality of life (Constantinidou et al., 2015).

Collectively, these studies outline the critical role of HRQL in stroke survivors with and without aphasia. There is a growing body of literature that consistently acknowledges the difference in HRQL between individuals with language impairment and those without. Among those determinants are communication, mental/emotional health, physical functioning, social functioning, and role/self-identity. It is for these reasons that this study will further explore these concepts of HRQL in African-Americans.

African-Americans with Aphasia

There is limited knowledge available on the HRQL in African-Americans with aphasia. The bulk of evidence presented thus far has mostly been identified in Caucasians; as stated in the introduction, African-American representation was less than seven percent of the sample in most studies. The inclusion of the African-American perspective as it relates to HRQL and aphasia is important because health disparities and stroke reoccurrence plague this population (Balakrishnan et al. 2017). This section of the literature review focuses on studies that were centered on HRQL components in stroke survivors with aphasia. African-American representation in the sample had to be 50% or higher.

In a descriptive cross-sectional study Jackson (2013) explored the emotional distress in first-time stroke survivors with aphasia. In a sample of 16 PWA, 50% identified as African-American. Factors related to emotional/mental health such as apathy, anxiety, and depression were described in this sample. As social isolation is a determinant of HRQL, this component was examined using the Lubben Social Network Scale (LSNS-6). The majority of PWA (87.5%) presented with scores representative of no isolation, whereas 12.5% of PWA stroke survivors were at high risk of isolation. The results revealed that emotional distress in PWA impaired functional recovery and cognition. Additionally, the impact on the emotional/mental domain exacerbated functional disability and intensified social isolation in these first-time stroke survivors with aphasia. In addition to these factors, higher healthcare cost was also noted. Moving the research forward, this study incorporated the biopsychosocial model to help highlight the interrelated social, physiology, and psychological factors of stroke recovery. In fact, the benefits of the biopsychosocial model have been credited to better explain the relationship between health restrictions or illnesses, social adaptation, and psychological health (Alder, 2009; Engel, 1977, Gyorfi & Rebek-Nagy, 2015; Wade & Halligan, 2017), however, in a critique of this study, Johnson (2014) did not partition the results or other demographic variables collected like income and education by race. This missing piece contributes to the gap in the literature related to identifying HRQL characteristics that are unique to African-Americans.

A qualitative study by Mahendra and Spicer (2014), investigated the perception and lived experiences with access to SLP services in five African-Americans with aphasia. Participants were three females and two males ranging in age from 46 to 83 years old. Education level ranged from high school diploma to bachelor's degree, and the annual household income ranged from <$25,000 to $100,000. All participants had private or public health insurance; however, most reported paying out of pocket for speech therapy services because of insurance non-reimbursement. Interview responses were analyzed and grounded in phenomenological inquiry then grouped into four thematic categories: perceived ideal result of therapy, clinician attributes or behaviors deemed helpful, clinician attributes or behaviors deemed unhelpful, and advice to SLPs working with diverse clients. Overall, participants agreed on the need for more access to speech therapy services and expressed frustrations with locating services within their communities. African-Americans with aphasia desired SLPs to be more knowledgeable regarding working with diverse clients in order to improve communication within various contexts. Similarly, to Worrall et al. (2011), findings of this study reported that overall PWA desire aphasia information, access to more services, and more speech therapy.

Knowledge pertaining to the components of HRQL in African-Americans may provide practitioners with insight into which domains are most supportive for speech and language therapy. This information could help link impairment-based treatment approaches to contexts that are inclusive and considers the individual’s current position in life. Because of the minimal information available on the components of HRQL in African-Americans with aphasia, it is important to understand HRQL within this population. The reason is that research has identified healthcare disparities within this minority group that may hinder stroke recovery, such as educational level, access to care, and comorbid conditions (Ellis et al., 2008).

Purpose and Hypotheses

The purpose of this study was to explore HRQL, social network, social support, and language functioning in African-American stroke survivors with aphasia. No available research on HRQL presents a homogenous sample of African-American stroke survivors with aphasia, and only limited research is available on the language performance and social functioning in African-Americans with aphasia. An understanding of the components of HRQL in African-Americans with aphasia may support aphasia rehabilitation by centering impairment and activity-based interventions within a context that considers an individual’s personal and environmental factors. Health disparities in African-Americans may influence stroke recovery and participation in activities of daily living (Osypuk, Ehntholt, Moon, Gilsanz & Glymour, 2017).

The gap in the literature exposes the limited available knowledge on the characteristics that are uniquely attributable to African-Americans even though this group is twice as likely to experience a stroke than any other ethnic group. This study will begin to fill the gap. Three research questions and two main hypotheses guided this study.

Research questions

1. Is there a significant difference in health-related quality of life in African-Americans with aphasia, African-Americans with history of stroke but no aphasia, and successfully aging or healthy African-American adults?

   H1: There are no overall differences in health-related quality of life among stroke survivors with aphasia in comparison to those stroke survivors without aphasia and successfully aging/healthy adults.

   H2: Are there domain differences in health-related quality of life among stroke survivors with aphasia in comparison to those stroke survivors without aphasia and successfully aging healthy adults.
2. Does aphasia affect health-related quality of life differently depending on social support?
3. Does aphasia affect health-related quality of life differently depending on social network?

Chapter 3

Method

This chapter describes the methods for evaluating the health-related quality of life in African-Americans with aphasia and for exploring the differences in HRQL in a homogenous population. The study design, setting, sample, human subjects protection measures, data collection techniques, study instruments, and data analysis are discussed. The methods of the study were approved by the Institutional Review Board (IRB) of the University of Georgia. In order to protect the identities of the participants and their confidential information, the research data were de-identified and safeguarded through the use of pseudonyms. Participants were recruited by use of printed and electronic advertisements.

Research Design

A cross-sectional case control design was used in this descriptive research study to explore language, health-related quality of life, and social functioning among stroke survivors with aphasia, stroke survivors without aphasia, and healthy/successfully aging adults without neurological injury. This design is considered the appropriate for comparing different groups at a single point in time. For this study HRQL is operationally defined to include five domains: communication, physical, mental/emotional, role (e.g., homemaker, self-care, work mobility) and social functioning.

Participants and Other Persons Involved in this Research

Participants

A total of 39 self-identified African-American/Black adults were recruited for the study. Group A included adult stroke survivors with aphasia, subsequent to a left hemisphere stroke. A total of 13 participants, including seven males and six females, were in this group and coded as people with aphasia (PWA). Group B included participants with a history of stroke but without the diagnosis of aphasia. A total of 13 participants, including four males and nine females, were in this group and coded as people without aphasia (PSA). Group C included adults who had no known history of neurological disease process and were deemed successfully aging or healthy adults. A total of 13 participants, seven males and six females, were in this group and coded as successfully aging healthy (SAH). Participants were matched as closely as possible in terms of age, education, and socioeconomic status (Ulatowska et al., 2001). The study used a rolling recruitment process in that as participants were recruited and consented, as data collection took place. The stroke survivors with aphasia were recruited first, followed by recruitment of the PSA matched as closely as possible to PWA in terms of age, gender, education, and socioeconomic status. The SAH adults were recruited last and matched as closely as possible to PWA in terms of age, gender, education, and socioeconomic status (Table 1).

Table 1

Characteristics of the sample population

	Total sample N=39	People with aphasia *n*= 13	People without aphasia *n*= 13	Successfully Aging or Healthy *n*= 13
Characteristics	N (%)	*n* (%)	*n* (%)	*n* (%)
Gender				
Male	21 (53.8)	6 (46.2)	9 (69.2)	6 (46.2)
Female	18 (46.2)	7 (53.8)	4 (30.8)	7 (53.8)
Age				
Mean [SD]	62.4 [11.10]	62.7 [13.57]	62.9 [10.65]	61.7 [9.58]
Co-morbid conditions				
None	10 (25.6)	3 (23.1)	2 (15.4)	5 (38.5)
HTN	11(28.2)	3 (23.1)	3 (23.1)	5 (38.5)
DM	3 (7.7)	1 (7.7)	--	2 (15.4)
CA	1 (2.6)	--	1 (7.7)	--
HTN & DM	10 (25.6)	3 (23.1)	7 (53.8)	--
= 2 conditions	3 (7.7)	3 (23.1)	--	--
> 3 conditions	1 (2.6)	--	--	1 (7.7)
Time post stroke				
N/a	13 (33.3)	--	--	--
< 6 months	6 (15.4)	5 (38.5)	1 (7.7)	--
6 months- 1 year	2 (5.12)	2 (15.4)	--	--
> 1 year	18 (46.2)	6 46.2)	12 (92.3)	--
	6 (15.4)	4 (30.8)	1 (7.7)	1 (7.7)
Education	6 (15.4)	4 (30.8)	2 (15.4)	--

< 12 years	27 (69.2)	5 (38.5)	10 (76.9)	12 (92.3)
= 12 years				
> 12 years				
Household Income				
< $ 25,000	10 (25.6)	6 (46.2)	4 (30.8)	--
$25,000- $50,000	6 (15.4)	1 (7.7)	3 (23.1)	2 (15.4)
$50, 000- $ 75, 000	15 (38.5)	3 (23.1)	4 (30.8)	8 (61.5)
> $75, 000	8 (20.5)	3 (23.1)	2 (15.4)	3 (23.1)
Caregiver				
None	23 (59.0)	7 (53.8)	8 (61.5)	8 (61.5)
Care receiver	11 (28.2)	6 (46.2)	5 (38.5)	--
Care provider	5 (12.8)	--	--	5 (38.5)
Language WAB-R Overall Score	90.31 (14.75)	74.80 (17.14)	97.77 (1.51)	98.32 (1.35)

Note. HTN= Hypertension=, DM= Diabetes=, CA =Cancer, WAB-R=Western Aphasia Battery

Prior to their participation in the study, adults were required to meet all of the following inclusion criteria:

Self-identifies as African-American or Black and were:

(a) successfully aging/healthy adults over the age of 18 who were free from neurological disease process (i.e. dementia, traumatic brain injury)

(b) adults over the age of 18 without aphasia but with neurological injury (i.e. stroke) time post onset greater than three months

(c) adults over the age of 18 with mild to moderate aphasia as a result of neurological injury (i.e. stroke) time post onset greater than three months

People with aphasia and with concomitant speech disorders, such as apraxia or dysarthria were included in the study. Inclusion criteria for time of stroke was greater than three months which is supportive of a chronic aphasia classification (Spaccavento et al., 2014) and previous timeframes of HRQL measurement in stroke survivors with and without aphasia (Cruice et al., 2003; Cruice et al., 2010a, b; Franzén et al., 2010; Hilari, 2011; Sarno, 1997). Exclusion criteria omitted adults with psychiatric problems and dementia because these chronic conditions may additionally impact speech, language, and quality of life (Ulatowska et al., 2001). Additionally, adults who required a legal representative for consent were also excluded from the study. Lastly, stroke survivors with severe aphasia were excluded because of the potential impact on comprehension and the ability to provide self-consent for participation in the study.

Language Functioning and Aphasia Severity

Participant groups were categorized based on the inclusion criteria in addition to language performance. The clinician-reported assessment that measured language functioning and classified aphasia severity was the *Western Aphasia Battery-Revised (WAB-R).* The WAB-R Aphasia Quotient (AQ) has been used in African Americans with aphasia and normal African-American adults (e.g., Ellis & Peach, 2017; Ulatowska et al., 2001) to measure body structure and function at the impairment level of the ICF. The WAB-R is a comprehensive assessment designed to diagnose aphasia severity through evaluation of language performance in the areas of spontaneous speech, auditory comprehension, repetition, and naming (Shewan & Kertesz, 1980). An understanding of the potential variability between PWA and PSA can be best achieved by comparing the population within the group versus between group comparisons (Thorpe et al., 2016). Dialectal variations in phonology, morphology, and articulation were accepted in the repetition and spontaneous speech portions of the WAB-R. The following characteristics of African-American English Vernacular were considered—omission of noun plural (e.g. “no if and or but), substitution /θ/ and /ð/ for /d/, /f/, syllable addition (e.g. detergents), and final consonant deletion.

Aphasia severity was categorized using the following criteria: WAB-R AQ scores between 0 to 31.2 indicates severe aphasia, scores between 31.3 to 62.5 indicate moderate aphasia, scores between 62.6 to 93.7 indicate mild aphasia, and scores between 93.8 to 100 indicate no aphasia (Ellis & Peach, 2017; Ellis & Urban, 2016; Perdersen, Vinter, & Olsen, 2004).

Student Research Assistants

Student research assistants were recruited from undergraduate cohorts and participated in an independent research seminar, that was taught by this lead investigator for the Fall and Spring semester of 2018-19. A group of 10 research assistants was trained in the Fall 2018, and two students continued through the Spring 2019. All students completed the CITI training as required for all researchers at the University of Georgia. The course trained students on the research protocol and offered additional preparation in aphasia communication partner training, service provision for culturally and linguistically diverse groups, and training on dialectal variations in African-American English Vernacular (Craig, Thompson, Washington, & Potter, 2003; Roseberry-McKibbin & Hedge, 1995; Simmons et al., 2017; Threat, 2010; Wallace, 1996). Students were paired in groups of two for data collection and alternated assessment leader roles. Student research assistants were assigned to specific participant groups based on the student's ability to manage the research protocol, use aphasia communication partner strategies, and apply cultural training principles. Both student accessors collected participant responses independently. Responses were then checked for interrater agreement between the student accessors and the lead investigator. Reviews of audio/video recording were completed for assessment fidelity. The lead investigator who is a licensed clinical speech-language pathologist was present and provided direct supervision.

Setting

The study took place across the South Atlantic United States (U.S.) (Georgia, North Carolina, Maryland, District of Columbia). Data collection occurred through face-to-face interviews that were audio or video-taped for assessment fidelity. Participants were scheduled according to times that were convenient and at locations that were also convenient to each participant. These locations included personal homes, nursing homes, speech and hearing clinics, and churches. Participants were recruited through referrals from medical clinics, speech language pathologists, and flyers that were posted on social media and throughout their communities.

Sample Size

An a priori power analysis was conducted to determine the estimated sample size that was warranted to determine when an effect is present. Small (0.20) to medium (0.50) effect sizes were identified from the meta-analysis of literature on aphasia (Flowers et al., 2016; Robey, 1998) and based on the post-acute stage (three to twelve months) and chronic stage (over twelve months) in clinical outcomes. The minimum level of power that was acceptable for statistical analysis was .80 (Robey, 1998; Flowers et al., 2016). An alpha level of 0.05 was established as significance level. Based on the meta-analysis of aphasia literature (Flowers et al., 2016; Robey, 1998) and effect size calculations, the moderate effect size was established at 0.35, and this conservative estimate was used to determine an a priori sample size of 28 participants in each group. A sample size of 28 was considered a large number to obtain within a single site study for people with aphasia and even a larger number to obtain in African-Americans with aphasia (Bose et al., 2009; Jackson, 2013; Mahendra & Spicer, 2014). Large sample sizes of this magnitude in aphasia research are infrequent because of the influence of expressive and receptive language impairments that restrict the participants’ responses or comprehension of research protocol and outcome measures. Additionally, physical immobility such as paralysis or paresis may prevent survivors without mobility independence from participating in research, because of walking and transportation problems. Lastly, the comorbidity of depression in PWA may impact endurance, cognitive flexibility, and motivation or desire to participate. Recent research involving African-American stroke survivors with and without aphasia has ranged in sample size from five to ten participants (Johnson, 2014; Mahendra & Spicer, 2014). Moreover, larger sample sizes in aphasia research, especially with funding sources, are often recruited from multiple sites with participation from several speech-language pathologists and/or researchers. Traditionally, larger research studies specific to health-related quality of life in aphasia present data with less than 7% minority representation (Ellis & Peach, 2017; Ellis et al., 2018; Northcott, Marshall, & Hilari, 2016). This research study will help identify preliminary differences in HRQL in African-Americans across the life span from healthy to disabled.

Data Collection Procedures

Data collection began after approval was received from the Internal Review Board (IRB) between October 2018 and February 2019. Potential subjects were recruited for the study by the principal investigator, speech-language pathologists, occupational therapists, and physical therapists. After a referral, participants were screened for eligibility via telephone or in person. If the potential participant met inclusion criteria via screening protocol, he or she was invited to participate in the study, and an appointment was scheduled for face to face data collection.

An organizational chart was created to outline outcome measures and other data collection sources. The history intake form included questions that gathered information on socioeconomic status, neurological history, and previous speech therapy (Appendices B, C, D). At the initial meeting with the stroke survivor, informed consent proceeded Either a written consent form or pictograph consent form was used to support comprehension and facilitate individualized consent (Appendices E, F). Individuals who required assent were not included.

The history intake form was completed by the researcher or by the participant after informed consent and clarification were provided as needed. Instruments that were selected for use encompassed domains in the ICF and were chosen based on the following criteria: a) psychometric characteristics b) utilization within the literature specific to African-Americans c) appropriateness for a person with aphasia d) instrument practicality or administration burden (time to administer the assessment). The following measures were administered in the order listed: Western Aphasia Battery-Revised (WAB-R), Stroke and Aphasia Quality of Life Scale (SAQOL-39g), Euro-Qol (EQ-5D), Medical Outcome Studies Social Support Survey (MOS-SSS), and the Lubben Social Network Scale-6 (LSNS). The Western Aphasia Battery-Revised (WAB-R) was used to classify language performance among the groups. Patient-reported measures were paired with visual aids in order to enhance auditory comprehension as necessary. The visual aids were used in conjunction with standardized test instructions as appropriate for each participant. The estimated completion time for the research protocol varied among category groups—people with aphasia ~45-120 minutes, and people without aphasia required ~30-60 minutes, and successfully aging/healthy adults required ~20-45 minutes.

Study Variables

The outcome measures that were used in this study to measure HRQL and language severity were aligned with the ICF framework. Both patient-reported and clinician-reported outcome measures were influential in capturing the impact of a health condition on body function, activity/participation/ and contextual factors such as personal and environmental. The ICF framework as an international scientific tool, aligns with this study, in that it will help examine the elements of HRQL; and identify facilitators and barriers to the individual's participation in society (Threats, 2010).

Health-related quality of life: Condition-Specific

The *Stroke and Aphasia Quality of Life Scale (SAQOL-39g)* is a condition-specific measure of HRQL. The Stroke and Aphasia Quality of Life Scale is a 39-item, patient reported outcome measure that was categorized into three domains (physical, psychosocial, and communication). All questions were rated on a 5-point scale, and the score of each individual item ranged from 1 to 5, and a higher score indicated better HRQL (Hilari et al., 2009). The SAQOL-39g is conceptually appropriate to target all five HRQL domains that were outlined for this study: communication, physical, mental, role, and social functioning. The SAQOL-39g was developed in 2001 by modifying the Stroke-Specific Quality of Life Scale (SS-QOL), that sought to produce a more communication friendly scale. The psychometric properties of SAQOL-39g have been tested on a large number of stroke survivors who did not have chronic aphasia through a series of related studies of all which included its developer (Hilari, 2011; Hilari & Byng, 2009, Hilari & Northcott, 2006) and was judged to have good internal consistency (α=.92-.98).

The presentation of the SAQOL-39g was paired with visual aids as needed in order, to support auditory and reading comprehension (Appendix L). Clarification of question content was provided as warranted to support comprehension.

Health-related quality of life: Generic

The *EuroQol-5D.* The EQ-5D is a generic preference-based measure of health status that is widely used in clinical research, observational studies, and health surveys and is a standardized non-disease, specific, patient-reported outcome measure that describes the value of HRQL in five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D is conceptually appropriate to target four out of the five HRQL domains outlined for this study: physical, mental, role, and social functioning. Each dimension includes five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. Numeral scores range from 1 to 5 described the respondent's health state. The EQ-5D-5L was developed by the EuroQol group in 2005 in order to improve ceiling effects and sensitivity of the previous version EQ-5D-3L, which was developed in 1990. Clarification of question content was provided as warranted to support comprehension.

Social support

The *Medical Outcome Study Social Support Survey (MOS-SSS)* measures the perceived availability of functional social support. This 19-item patient-reported outcome measure consists of five separate social support subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction, and an overall functional social support index. All questions are rated on a 1 to 5-point scale and a higher score indicates more perceived social support (Sherbourne & Stewart, 1991). The MOSS-SS has been used in people with aphasia and healthy adults with chronic conditions, such as hypertension and diabetes (Hilari & Northcott, 2017; Hilari & Northcott, 2006; Hilari, et al., 2003b) and demonstrated good internal consistency (α = .91-.97) and validity (Sherbourne & Stewart, 1991). The presentation of the MOSS-SS was paired with visual aids as needed to support auditory and reading comprehension. The presentation of the MOSS-SS was paired with visual aids as needed in order, to support auditory and reading comprehension (Appendix M). Clarification of question content was provided as warranted to support comprehension.

Social isolation

The Lubben Social Network Scale (LSNS) is a patient-reported outcome measure that is used to assess social isolation in adults. The LSNS has been used across health conditions among the elderly and with caregivers (Levy-Storms & Lubben, 2006; Lubben et al., 2006). This instrument was originally developed in 1988 and was revised in 2002 to include an abbreviated version (LSNS-6) and an expanded version (LSNS-18) (Lubben et al., 2006) All questions were scored on a scale ranging from 0 to 5 with six responses available (0 = none; 1 = one; 2 = three or four; 4 = five to eight; 5 = nine or more) with the summed responses equating to the number of social contacts. The LSNS-6 ranges in score from 0 to 30 and higher scores represent more social engagement while lower scores indicate a smaller social network among family and friends. A total score of 12 or lower indicates a high risk for social isolation (Jackson, 2013; & Lubben et al., 2006). The LSNS-6 has been used in PWA and demonstrated good reliability for measuring social isolation judged at (0.83−.089) (Jackson, 2013). In order to support auditory and reading comprehension, the presentation of the LSNS-6 was paired with visual aids as needed (Appendix N). Clarification of question content was provided as warranted to support comprehension.

Sample characteristic variables

Previous research has identified consistent factors that were associated with health disparities among minorities. Demographic factors, such as education, annual income, health comorbidities, and access to healthcare insurance were “essential for drawing inferences, identifying extraneous variables, and recognizing validity threats” (Jackson, 2013). These variables were collected in this sample of African-Americans in order to consider aspects of health that are distinctive and consistent to this population.

Each stroke survivor provided the following demographic information: education, annual income, comorbidities, and level of access to healthcare, these factors have been noted to contribute to health disparities in African-Americans. This information was important because socioeconomic status has been linked to stroke mortality (Howard et al., 2007) and inevitably contributes to stroke recovery. In addition, these demographic variables have been reported to be different within black and white communities (Landrine, & Corral, 2009; Osypuk et al., 2017) and vital to stroke occurrence and prevention.

Risk factors and comorbidities

Risk factors and comorbidities contribute to health disparities among minority populations and place individuals at greater risk for long-term disability. Classifying these risk factors in this population was important in order to help draw inferences toward identifying extraneous variables (Jackson, 2013). Comorbidities were self-reported and were specific to (1) hypertension (HTN) (2) diabetes mellitus (DM)(3) coronary heart disease (4) chronic respiratory disease. These variables were known to cooccur in stroke survivors and frequently occurred in African-Americans in isolation without stroke. Hypertension which is also known as high blood pressure is an identified risk factor for ischemic and hemorrhagic stroke types (Jackson, 2013; Roger et al., 2010). Hypertension is often referred to as the silent killer and is the leading cause of stroke in African-American men and women (CDC, 2018). Diabetes impairs the body's ability to produce or respond to hormone insulin and is 77% higher among African-Americans than any other ethnic group (Shiyanbola, Ward, & Brown, 2018). Type 2 diabetes is more common in African-Americans and is a significant risk factor for initial stroke (Krzyaniank et al., 2011). Coronary heart disease is a common heart disorder that increases risk of stroke (CDC, 2018). occurs when plaque builds up on the arteries, which in turn blocks the flow of oxygen-rich blood to the brain (CDC, 2018).

Previous research has identified that individuals who have high blood pressure in addition to diabetes are at an increased risk for stroke (CDC, 2018). Also stroke mortality in African-Americans in the Southeast has been primarily linked to a higher prevalence of hypertension and diabetes (Howard et al., 2007). Because of this information, an additional variable code (6) was created to identify the frequency of individuals who presented with both comorbidities' hypertension and diabetes. Moreover, as African-Americans are at a higher risk of health disparities, two additional variable codes were created in order to determine the frequency of any other combination of more than one condition, (7) two conditions and (8) 3 or more conditions.

Education

Education was self-reported and classified into three categories (1) less than 12 years, (2) twelve years, and (3) greater than twelve years. This information is an important characteristic trait that relates to health, quality of life, and role. Education likely grants access to a higher income, which likely influences the community in which one lives, and the health stimuli that one experiences.

Annual income

Annual Income was self-reported and classified into four categories (1) less than $25,000, (2) $25,000-50,000, (3) $50-75,000, (4) greater than $75,000. Annual income is important because higher incomes presumably provide greater access to neighborhoods with better grocery stores, hospitals, recreation, and environmental spaces. Individuals had to seek healthcare in the communities in which they reside in (Landrine & Corral, 2009), and neighborhood disparities in healthcare quality among blacks and whites have reflected differences between the groups. For example, Osypuk et al. (2017) analyzed neighborhood differences in post-stroke mortality within a large data set as part of the Health and Retirement Study. Results indicated that individuals experienced better or lower post-stroke mortality rates when a higher percentage of the neighborhood was white (Osypuk et al., 2017). Neighborhoods are sustained by annual income; therefore, black communities with lower monetary revenue may have fewer hospitals that have advanced technology services, such as imaging or specialists, such as like cardiac surgeons. A lack of these resources may promote missed opportunities for early intervention (Landrine & Corral, 2009) or prevention.

Health insurance

Health insurance was self-reported and collected with response to the question "Do you have health insurance? (1) Yes (2) No. Individuals were invited to share the type of health insurance (i.e. private or government). Access to healthcare plays a pivotal role in prevention, management, and recovery. This information was collected because previous research identified that lower access to prevention services and specialty areas, such as speech pathology are visible within the African-American community (Mahendra & Spicer, 2014). Access to health insurance plays a role in ability to obtain health services.

Data Analysis

Data was systematically collected and categorized for analysis purposes. Given the descriptive nature of this research study, the dependent variable is referred to as the *outcome variable,* and the independent variable is referred to as the *predictor variable* (Schiavetti, Metz, & Orlikoff, 2011). The outcome variable is health-related quality of life, and the predictor variables are people with aphasia, people without aphasia, and successfully aging/healthy adults. Additional co-variates include language, perceived social support, and social isolation/social network.

A reliability analysis was performed to assess the internal reliability of all scales in this study. Descriptive statistics for each group PWA, PSA, and SAH were formulated across all variables. Using SPSS version 25, analyses were conducted to test for associations between the criterion and classification variables and covariates. An Analysis of Variance (ANOVA) test was used to compare the means of the three classification groups PWA, PSA, and SAH. The ANOVA is considered a robust test and most appropriate for statistical analysis in this study because of its ability tolerate potential violations of normality assumption (Agresti & Finlay, 1997; Field, 2013; Kazdin, 2016). ANOVA as an omnibus test will provide insight into the variability of the data but will not disclose the specific groups that are responsible for the differences. For this reason, additional post hoc comparisons were completed to determine which significant relationships exist between the variables.

A post hoc comparison analysis was used to test the two hypotheses. The Bonferroni and the Scheffe are appropriate for this study, in that the Bonferroni has power with smaller comparisons and is good for control over Type 1error (Field, 2013). However, the Scheffe has been recommended for use in studies with fewer than two degrees of freedom (Mi & Sampson, 1993). For this reason, the Scheffe post hoc analysis was used to test the hypotheses.

A Moderator analysis regression model was used to determine whether social support or social network are moderators or predict HRQL in PWA. Hayes' PROCESS Model 1 was used evaluate the role of social support and social network on HRQL. Moderation analysis is most appropriate to determine the combined effect of two variables on another (Field, 2013). All variables were centered to the mean fixed value to account for multicollinearity problems caused by interaction terms (Field, 2013; Hayes, 2018). Multicollinearity occurs when two or more variables have a very close linear relationship (Field, 2013). This relationship may cause problems in how well the classification or predictor variable predicts the outcome variable. (Field, 2013; Kazdin, 2016).

An a priori alpha level of 0.05 was used to assess statistical significance. Data were entered into an excel spreadsheet by one research assistant then counterchecked by the second research assistant, followed by countercheck by the lead investigator before statistical analysis. The SPSS computer package (version 25) was used to analyze the data.

Summary

This chapter described the methodological process of the study, including the study design, setting, sample size, data collection methods demographic variables (risk and comorbidities, access to healthcare, annual income, education), instrument psychometric properties, and data analysis. In summary, the research aim of this project was to describe HRQL in Africans-Americans with aphasia and identify the role of social network and social support on HRQL.

Chapter 4

Results

This chapter provides the results of the study, which are presented in four sections. The first section reports reliabilities of the clinician-reported and patient-reported outcome measures. The second section describes the participants' characteristics within all three groups: people with aphasia (PWA), people without aphasia (PSA), and successfully aging/healthy (SAH) adults. The third section presents the descriptive statistics for the study variables. The final section reports the findings that are associated with the research questions and hypotheses.

Evaluation of Reliability

Reliability analyses were conducted to measure the consistency of the instruments and data collection. Cronbach's alpha was calculated to provide the internal reliability for each scale (Field, 2013). A reliability coefficient greater than or equal to 0.70 was deemed acceptable for group level decision making and comparison (Scientific Advisory Committee, 2002). Table 2 shows the multi-item scale coefficient alpha estimates for all scales that were used in the study. The internal consistency reliability estimates were greater than 0.70 for four out of five of the outcome measures: the Western Aphasia Battery-Revised (WAB-R) (Cronbach's $\alpha = 0.89$), Stroke and Aphasia Quality of Life Scale-39g (SAQOL-39g) (Cronbach's $\alpha = 0.79$), and Euro-Qol-5D (EQ-5D) five-dimension scale (Cronbach's $\alpha = 0.76$). The Medical Outcome Study Social Support Survey (MOSS-SS) had the highest reliability out of all the measures with a (Cronbach's $\alpha = 0.90$). The Lubben Social Network Scale 6 item scale (LSNS-6) reliability was slightly lower, with a (Cronbach's $\alpha = 0.68$).

Table 2

Reliability Estimates of Scales

Scale	Scale Items	Coefficient Alpha
Western Aphasia Battery	4	0.89*
Stroke and Aphasia Quality of Life Scale-39g	3	0.79*
Euro-Quol-5D	5	0.76*
The Medical Outcome Study Social Support Survey	5	0.90*
Lubben Social Network Scale	2	0.68

Note: * indicates the instrument met reliability standards Cronbach's ($\alpha > 70$).

Assessment fidelity was monitored throughout data collection via video recording, audio recording, and direct observation (Richardson, Hudspeth Dalton, Shafer, & Patterson, 2016). Interrater agreement between the student accessors and the lead investigator was completed on 15 randomly selected participants, in that video or audio recordings were reviewed, and the participant's response was compared to the recorded response on the data collection sheet. The student research assistants and the lead investigator administered language and HRQL measures to all groups. The lead investigator who is a licensed clinical speech-language pathologist was present and provided direct supervision at least 90% of the time.

Participants' Characteristics

A total of 39 African-American men (53.8%) and women (46.2%) participated in the study. They ranged in age from 33 to 79 ($M = 62.4 \pm 11.10$) and were composed of three groups of 13: people with aphasia (PWA), people without aphasia (PSA), and successfully aging healthy adults with no history of neurological disease (SAH). The total sample characteristics are presented first and are followed by descriptive characteristics for each group (Table 1). The total sample achieved a language performance mean score of 90.31 (*SD* = 14.75) with a range of 43.6 to 100 as measured by the Western Aphasia Battery-Revised (WAB-R). Ninety-seven percent of the population sample reported access to private or government health insurance, with 20% having both types of insurance coverage. The majority of individuals earned \$50,000-75,000 (38.5%); 25.6% reported incomes <\$25,000; 20.5% reported incomes greater than \$75,000; and 15.4% reported an income range between \$25,000-\$50,000. Comorbid conditions were present throughout the sample; however, only four out of the six health conditions were self-reported in this population. No individuals reported chronic respiratory disease or coronary artery disease. Sixty-four percent of individuals reported a diagnosis of hypertension (HTN), and within that group, 28.2% also reported a history of diabetes mellitus (type unspecified) (DM). Approximately 7.7% of individuals reported a history of DM in isolation. Twenty-five percent of the sample population was free from comorbid health conditions. The majority of stroke survivors (84.6%) reported a left hemisphere stroke, with 46.2% post stroke greater than one year. Sixty-two percent of African-Americans reported a level of education to be greater than 12 years; it should be noted that level of education more than 12 years is not synonymous with highest level of education achieved.

People with aphasia

The sample of PWA (*n* = 13) self-reported a left-sided stroke and ranged in age from 33 to 79 (*M* = 62.7, *SD* = 13.57). People with aphasia demonstrated a language performance mean score of 74.80 (*SD* = 17.14) as measured by the WAB-R. Aphasia types were diverse across the group and included five stroke survivors with Anomia, four stroke survivors with Broca's, two stroke survivors with Transcortical Motor, one stroke survivor with Conduction, and one stroke survivor with Wernicke's aphasia (Kertesz & Poole, 1974). Approximately 46.2% reported time post stroke onset to be greater than one year, followed by 38.5% with stroke occurrence of fewer than 6 months at the time of this study. The prevalence of comorbid conditions in PWA varied in report as 23.1% reported no comorbid conditions, 23.1% reported HTN in isolation, 23.1% reported HTN and DM and 23.1% reported a combination of at least two premorbid conditions. The majority of PWA (38.5%) reported an education level beyond 12 years, followed by an equal distribution of 30.8% for education of fewer than 12 years and equal to 12 years. Approximately 46.2% of PWA reported a household income below $25,000; 23.1% reported a household income range of $50,000-75,000 and more than $75,000. Forty-six percent of PWA reported caregiver support with activities of daily living (ADLs). All 13 PWA reported access to speech and language services throughout stages of recovery.

People without aphasia

The PSA sample (*n* = 13) ranged in age from 34 to 78 (*M* = 62.9, *SD* = 10.65) and reported a history of a left-sided stroke (69.2%). PSA achieved a mean language score of 97.77 (*SD* = 1.51) as measured by the WAB-R. Ninety-two percent of stroke survivors without aphasia experienced his or her stroke at least a year prior. Fifteen percent of stroke survivors without aphasia reported no history of comorbidities, while 23.1% reported a history of hypertension only. The highest combination of hypertension and diabetes was found in this group with 53% of PSA diagnosed with both risk factors. The majority of PSA (76.9%) reported an education level beyond 12 years. For PSA, the household income was mostly divided between individuals who earned below $25,000 (30.8%) and $50,000-75,000 (30.8%). The majority of stroke survivors without aphasia did not have a caregiver (61.5%); however, 46.2% used caregivers for support with ADLs. A little over half (53.8%) of PSA stroke survivors received post-stroke speech and language services. One PSA reported the need for post-stroke speech and language services; however, administrative errors delayed referral for the service, which prompted the individual to initiate self-therapeutic tasks to restore communication.

Successfully aging/healthy adults

The sample of SAH (*n* = 13) confirmed no history of stroke or other neurological disease and ranged in age from 41 to 73 (*M* = 61.7, *SD* = 9.6). Successfully aging/healthy adults achieved a language score of *M* = 98.32 (*SD* = 1.35) as measured by the WAB-R. Thirty-eight percent of SAH adults were free from targeted health conditions. However, the presence of HTN in this group was proportionately large at 38.5% while history of DM was at 15%. Hypertension and DM combined was noted in 7.7% of the sample population. The majority of SAH adults reported an education level of more than 12 years. Sixty-one percent of successfully aging adults reported an annual household income range of $50,000-75,000, which was followed by 23.1% with an income of more than $75,000, and 15.4% reported a range of $25,000-50,000. The majority of individuals reported no use of a caregiver (61.5%); however, 38.5% reported that they functioned in a caregiver role to individuals with a stroke or intellectual disability. Four of the SAH participants were caregivers to stroke survivors who also participated in the study.

Study Variables

Mean scores, standard deviations, and ranges for the summed study variables are displayed in Table 3. Health-related quality of life was captured by condition-specific and generic outcome measures. The Stroke and Aphasia Quality of Life (SAQOL-39g) condition- specific measure is a 5-point scale in which a higher score indicates a better HRQL. The total sample demonstrated a mean score of 3.98 (*SD* = 0.78) with a score range of 2.4 to 4.9. People with aphasia achieved an overall mean score of 3.32 (*SD* = .74), followed by PSA (*M* = 3.94, *SD* = 0.56) and SAH (*M* = 4.70, *SD* = 0.19). The Euro-Qol (EQ-5D) is also on a 5-point scale, but a lower score indicates a better HRQL on this generic instrument. The total sample achieved a mean score of 9.51 (*SD* = 4.03) with a score range of 5 to 20. People with aphasia reported an HRQL mean of 11.00 (*SD* =

3.94), while PSA achieved a group mean of 11.38 (*SD* = 4.03). Successfully aging/healthy adults presented with an overall HRQL mean score of 6.15 (*SD* = 1.21).

Table 3

Descriptive Statistics for Study Variables

Variable	Minimum Score	Maximum Score	Total Sample (N=39)	People with aphasia (*n*=13)	People without aphasia (*n*=13)	Successfully Aging Healthy (*n*=13)
HRQL						
SAQOL-39g	2.4	4.9	3.98 (.78)	3.32 (.74)	3.94 (.56)	4.70 (.19)
EQ-5D	5	20	9.51 (4.03)	11.00 (3.94)	11.38 (4.03)	6.15 (1.21)
Social Support MOS-SSS	1.4	5.0	4.02 (0.92)	3.85 (.99)	3.88 (1.09)	4.36 (0.58)
Social network LSNS-6	2	29	17.69 (6.32)	17.85 (7.77)	17.92 (6.80)	17.31 (4.44)

Note. SAQOL-39g- Stroke and aphasia quality of life scale, EQ-5D-EuroQol 5D, MOSS-SSS- Medical Outcome Study Social Support Survey, LSNS-6- Lubben Social Network

Social support and social network were the specific components of social functioning measured in this study. The Medical Outcome Study Stroke Survey Scale (MOSS-SS) captured perceived social support among the groups which is evaluated on a 5-point scale, with a higher score indicative of more social support. The total sample scores ranged from 1.4 to 5.0 with an overall sample mean at 4.02 (*SD* = .921). People with aphasia reported an overall mean score of perceived social support at 3.85 (*SD* = .99). The overall mean score of social support for PSA was 3.88 (*SD* = 1.09), followed by SAH participants who presented with a total mean score of

4.36 (*SD* = .58). The Lubben Social Network Scale (LSNS-6) captured the self-report of social network size among the groups. A higher score is indicative of more social engagement, whereas a score of 12 or lower delineates "at risk" for social isolation (Lubben et al., 2006). The total sample scores ranged from 2 to 29 with an overall sample mean of 17.69 (SD = 6.32). People with aphasia presented with a mean score of 17.85 (*SD* = 7.77). People without aphasia presented an overall mean score of 17.92 (*SD* = 6.80). Social network as judged by the SAH group reported an overall mean score of 17.31 (*SD* = 4.44).

Bivariate analyses showed a Spearman's rank order correlation among the total sample between HRQL and comorbid conditions, as well as between HRQL and education. There was a strong, negative correlation between the SAQOL-39g and comorbid conditions (*r*(36) = -.439, *p* = .005) and a positive correlation between SAQOL-39g and education (*r*(36) = .487, *p* = .002). There was a strong positive correlation between the EQ-5D and comorbid conditions (*r*(36) = .409, *p* = .010) and strong negative correlation for education (*r*(36) = -450, *p* = .004).

Test of the Hypotheses

The objective of this study was to (a) evaluate the differences in HRQL in African-Americans with aphasia, without aphasia, and successfully aging/healthy normal adult African-Americans, (b) determine the effect of social support on HRQL, and (c) determine the effect of social network on HRQL. An analysis of variance (ANOVA) and multiple regression were performed to answer the research questions and test the hypotheses. The ANOVA tested the group means among PWA, PSA, and SAH performance on the five outcome measures. A Scheffe post-hoc comparison identified specific group variances and tested the hypotheses. Multiple regression models were performed to identify the determinants of HRQL in PWA and test the moderating effect of social support and social network on HRQL.

Research Question 1. Is there a significant difference in health-related quality of life in African-Americans with aphasia, African-Americans with history of stroke but no aphasia, and successfully aging or healthy African-American adults?

H1: There are no differences in HRQL among stroke survivors with aphasia in comparison to those stroke survivors without aphasia and successfully aging/healthy adults.

H2: There are no domain differences in HRQL among stroke survivors with aphasia in comparison to those strokes survivors without aphasia and successfully aging healthy adults.

ANOVA. H1: An ANOVA analysis revealed statistically significant ($p = .05$) group means differences in overall HRQL among the group. The significant differences were found between the groups as indicated by the SAQOL-39g, F (2,36) = 20.71, $p < .001$; EQ-5D overall score, F (2,36) = 9.98, $p < .001$ (Table 4). Therefore, the null hypothesis can be rejected and accept the alternative hypothesis that overall HRQL is different in people with aphasia compared to people without aphasia and successfully aging adults.

Table 4

ANOVA results of study variables (overall)

Variable	*df*	*SS*	*MS*	F	*p*
SAQOL-39g	2, 36	12.50	6.25	20.71	.001**
EQ-5D	2, 36	220.97	110.49	9.98	.001**

Note. ** indicates significant at $p < .001$. Variable Names: SAQOL-39g = Stroke and Aphasia Quality of Life Scale, EQ-5D = Euro-Qol-5D

Post Hoc Comparison. Scheffe post-hoc analysis revealed an overall mean decrease in HRQL as rated by the SAQOL-39g (M = -1.38, 95%, CI [-1.93, 0.84] $p < .001$) and the EQ-5D (M = 4.85, 95%, CI [1.57, 8.12], $p = .002$) between PWA and SAH adults. Overall mean decrease in HRQL as rated by the SAQOL-39g (*M* = -.623, 95%, CI [-1.17, -.073] *p* = .023 between PWA and PSA.

ANOVA. H2: An ANOVA analysis revealed statistically significant (*p* = .05) group mean differences in domain-specific HRQL among the group (Table 5). The significant differences were found between the groups as indicated by the SAQOL-39g in physical, *F* (2,36) = 11.74, *p* < .001; communication, *F* (2,36) = 40.48, *p* < .001; psychosocial, *F* (2,36) = 7.34, *p* = .002 domains. Significant differences in domain-specific HRQL as measured by the EQ-5D were found in mobility, *F* (2,36) = 6.29, *p* = .005; self-care (role), *F* (2,36) = 7.28, *p* = .002; and usual activities (social), *F* (2,36) = 5.74, *p* = .007. Therefore, the null hypothesis can be rejected and accept the alternative hypothesis that domain-specific HRQL is different in people with aphasia compared to people without aphasia and successfully aging adults.

Table 5

ANOVA results of study variables (domain)

Variable (HRQL domain)	*Df*	*SS*	Mean Squares	F	*p*
SAQOL-39g					
Physical (physical, role, social)	2, 36	12.93	6.47	11.74	.001**
Communication (communication, social)	2, 36	30.50	15.25	40.48	.001**
Psychosocial (mental/ emotional, social)	2, 36	8.89	4.44	7.34	.002*
EQ-5D					
Mobility (physical)	2, 36	16.77	8.39	6.29	.005*
Self-care (role)	2, 36	13.74	6.87	7.28	.002*

Usual Activities (social)	2, 36	12.67	6.33	5.74	.007*
Pain/discomfort	2, 36	2.21	1.10	1.18	.318
Anxiety/depression (mental/emotional)	2, 36	4.98	2.49	2.42	.103

Note. ** indicates significant at $p<.01$, $^*p<.05$. Variable Names: SAQOL-39g = Stroke and Aphasia Quality of Life Scale, EQ-5D = Euro-Qol,

Post Hoc Comparison. H2: Individual domains of the HRQL revealed significant differences in PWA when compared to PSA and SAH. On the SAQOL-39g, Scheffe post-hoc analysis revealed a mean decrease in the physical domain of HRQL as rated by the SAQOL-39g between PWA and SAH (-1.32, 95%, CI [-2.06, -0.59], $p < .001$) and the EQ-5D (1.31, 95%, CI [0.15, 2.46], $p = .024$). Significant differences in the communication domain of HRQL were noted between PWA and SAH (-2.04, 95%, CI [-2.64, -1.43], $p < .001$), as well as between PWA and PSA ($M = -1.65$, 95% CI [-2.26, -1.05]) $p < .001$). The psychosocial domain of the SAQOL-39g includes elements of mental/emotional/and social HRQL components. People with aphasia compared to SAH demonstrated significant mean differences ($M = -1.17$, 95%,CI [-1.94, -0.40], $p < .001$) in mental/emotional/and social components of HRQL as measured by the SAQOL-39g. However, no significant differences in the psychosocial domain were found between PWA and PSA ($M = -0.60$, 95%, CI [-1.39, 0.18], $p = 0.16$). As measured by the EQ-5D, significant differences in role functioning ($M = 1.08$, 95%, CI [.10, 2.05], $p = .027$) and social functioning ($M = 1.08$, 95%, CI [.03, 2.05] $p = .044$) were noted between PWA and SAH. However, no significant differences in role ($M = -3.08$ -1.26, .65), $p= 1.00$) or social functioning ($M = -2.31$ -1.26, 0.80), $p = 1.00$) were noted between PWA and PSA as measured by the self-care and usual activities domains of the EQ-5D. No significant differences were found between PWA, PSA, or SAH in the mental/emotional domain via the EQ-5D as measured by anxiety/depression or pain/discomfort components.

Therefore, we can reject the null hypothesis and accept the alternative hypothesis that there are differences in HRQL domains between stroke survivors with aphasia in comparison to strokes survivors without aphasia, and successfully aging healthy adults.

Research Question 2. Does aphasia affect health-related quality of life differently depending on social support? Two models will address this question.

Model 1 Social Support x Health-related quality of life via SAQOL-39g. The predictor variables were PWA, PSA, and SAH (groups) and social support (MOSS-SS). The outcome variable was HRQL in terms of communication, physical, and psychosocial domains as measured by the SAQOL-39g. The interaction term was groups x social support. Table 6 shows the linear model of predictors of HRQL via the SAQOL-39g on social support. There is a significant relationship between HRQL and the groups $b = -.64$, 95%, CI [-0.86, -0.43], $t = -6.03$, p < .001. There was no interaction effect of social support on HRQL $b = -0.82$, 95%, CI [-1.95, .30], $t = -1.49$, p = .15, indicating that aphasia does not affect HRQL differently depending on social support as measured by the SAQOL-39g.

Table 6

Linear model of predictors of HRQL via SAQOL-39g on Social Support

	b	SE (HC3)	*t*	*p*
Groups	-0.64 [-0.86, 0.43]	0.11	-6.03	.001 **
MOSS-SS (centered)	0.46 [-1.62, 2.55]	1.03	0.45	0.65
Groups x MOSS-SS (centered)	-0.82 [-1.95, 0.30]	0.55	-1.49	0.15

Note. $^{**}p < .001$ indicates significant MOSS-SS= Medical Outcome Study Social Survey, SAQOL-39g = Stroke and Aphasia Quality of Life Scale

Model 2 Social Support x Health-related quality of life via EQ-5D. The predictor variables were PWA, PSA, and SAH and social support (MOSS-SS). The outcome variable was HRQL in terms of mobility, self-care, usual activities, anxiety/depression, and pain/discomfort as measured by the EQ-5D. The interaction term was groups x social support. Table 7 shows the linear model of predictors of HRQL via the EQ-5D on social support. There is a significant relationship between HRQL and the groups *b* = -.4.70, 95%, CI [-7.19, -2.21], *t* = -3.83, p < .001. There was no interaction effect of social support on HRQL via EQ-5D *b* = 1.59*,* 95% CI [-7.24, 10.43], *t* = 0.37, p = 0.72, indicating that perceived social support does not moderate the relationship of HRQL as measured by the EQ-5D.

Table 7

Linear model of predictors of HRQL via EQ-5D on Social Support

	b	SE (HC3)	*t*	*p*
Groups	-2.32 [0.93, 3.71]	0.69	3.39	. 001**
MOSS-SS (centered)	-0.80 [-19.19, 17.59]	9.06	-0.09	0.93
Groups x MOSS-SS (centered)	1.59 [-7.24-10.43]	4.35	0.37	0.72

Note. **p < .001 MOSS-SS= Medical Outcome Study Social Survey, EQ-5D= EuroQol- 5 Dimensions

Research Question 3: Does aphasia affect quality of life differently depending on social network? Two models were used to address this question.

Model 3 Social Network x Health-related quality of life via SAQOL-39g. The predictor variables were PWA, PSA, and SAH and social network (LSNS-6) the outcome HRQL as measured by the SAQOL-39g. The interaction term was groups x social network. Table 8 shows the linear model of predictors of HRQL via the SAQOL-39g on social network. There is a significant relationship between HRQL and the groups *b* = 1.39, 95% CI [1.01, 1.78], *t* = 7.39, p < .001. There was no interaction effect of social network on HRQL via SAQOL-39g *b* = 0.0*,* 95% CI [-0.06, 0.05], *t* = -0.18, p = 0.86, indicating that an individual's social network size does not moderate the relationship of HRQL as measured by the SAQOL-39g in PWA.

Table 8

Linear model of predictors of HRQL via SAQOL-39g on Social Network

	b	SE (HC3)	*t*	*p*
Groups	-0.70 [-0.95, -0.45]	.12	-5.64	.001**
LSNS (centered)	0.02 [-0.08, 0.12]	0.41	0.41	0.69
Groups x LSNS (centered)	0.0 [-0.06, 0.05]	0.03	-0.18	0.86

Note. **p < .001 LSNS-6 = Lubben Social Network Scale, SAQOL-39g = Stroke and Aphasia Quality of Life Scale

Model 4 Social Network x Health-related quality of life via EQ-5D. The predictor variables were PWA, PSA, and SAH and social network (LSNS-6) to the outcome HRQL as measured by the EQ-5D. The interaction term was groups x social network. Table 9 shows the linear model of predictors of HRQL via the EQ-5D on social network. There is a significant relationship between HRQL and the groups *b* = -4.83, 95% CI [-7.13, -2.54], *t* = -4.28, p < .001. There was no interaction effect of social network on HRQL via EQ-5D *b* = -0.07*,* 95% CI [-0.35, 0.21], *t* = -0.50, *p* = 0.62, indicating that an individual's social network size does not moderate the relationship of HRQL as measured by the EQ-5D.

Table 9

Linear model of predictors of HRQL via EQ-5D on Social Network

	b	SE (HC3)	*t*	*p*
Groups (centered)	2.42 [1.06, 3.79]	.67	3.61	. 001**
LSNS (centered)	0.11 [-0.49, 0.70]	0.29	0.37	0.71
Groups x LSNS	-0.07 [-0.35, 0.21]	0.14	-0.50	0.62

Note. **p < .001 LSNS-6 = Lubben Social Network Scale (LSNS-6), EQ-5D = EuroQol- 5 Dimensions

The previous models (1 to 4) investigated whether aphasia affected HRQL differently depending on social support or social network. There was no moderation effect, indicating that social support and social network do not moderate HRQL. However, there was a significant group difference in HRQL. Table 10 and Table 11 display the final regression models of HRQL differences among the groups.

Multiple Regression Analysis

Table 10 displays the summary of the regression model for the HRQL differences via the condition-specific measure, SAQOL-39g. There was a statistically significant difference between the groups in overall HRQL as measured by the SAQOL-39g. PWA had a lower HRQL than SAH adults (ß = .688, p < .001) and between PWA and PSA (ß = -.383, p = .018). Table 11 displays the summary of regression model for HRQL differences via the generic measure EQ-5D. There was a statistically significant difference in overall HRQL between PWA and SAH (ß

= -.755, p < .001). There was no significant difference in the HRQL between the PSA and PWA (ß = .049, p = .713) as measured by the EQ-5D.

Table 10

Multiple Regression Model for HRQL via the SAQOL-39g

Variable	B	SE B	β
PWA vs SAH	3.36	.754	.688**
PWA vs PSA	-1.87	.754	-.383**

Note. **p < .001 SAQOL-39g= Stroke and Aphasia Quality of Life Scale

Table 11

Multiple Regression Model for HRQL via the EQ-5D

Variable	B	SE B	β
PWA vs SAH	-.715	.124	-.755**
PWA vs PSA	.046	.124	.049

Note. **p < .001 EQ-5D= EuroQol- 5 Dimensions

Summary

This chapter presented evidence of reliability of measures, descriptive statistics of the sample population, and results of the statistical hypothesis testing and research questions. All measures were deemed adequately reliable except the LSNS-6. The two statistical hypotheses were supported in that there are differences in overall HRQL between PWA, PSA, and SAH. There were also differences within the five individual domains of HRQL specifically in terms of communication and social functioning among the groups. No significant interaction effect was found for social support or social network on HRQL, indicating that these elements of social functioning do not moderate the effect on HRQL.

Chapter 5

Discussion

The purpose of this study was to evaluate HRQL in African-American stroke survivors with aphasia as a group and compare those findings to those for African-American stroke survivors without aphasia as well as to those for successfully aging/healthy adults. This chapter presents the results of the study, clinical implications, and limitations of the current research.

Findings of the Study

This study used a homogenous sample population of African-Americans in order to better understand the HRQL in PWA. The use of patient-reported outcome measures that align with the ICF framework was beneficial in that this disability framework has established roots in both clinical and research practices for aphasia management (Threats, 2008; Threats, 2012; Wallace, 2010; Worrall et al., 2011). The decision to use instruments that capture an individual’s lived experience in the presence of a health condition like aphasia allows for greater focus on areas that are important to the client. This study will contribute to the aphasia literature by administering the EQ-5D and SAQOL-39g to people with aphasia, people without aphasia, and successfully/healthy aging adults within a homogenous sample. The generic and condition specific HRQL measure has proven beneficial in identifying different but equally important aspects of lived experiences for PWA (Bose et al., 2009; Whitehurst et al., 2015). This emerging area of interest in speech-language pathology has the potential to help move the field forward by assisting clinicians in adopting a universal language to classify and treat communication disorders. Given the preliminary nature of this study and limited available research that documents HRQL in African-American stroke survivors, the EQ-5D and SAQOL-39g were useful for comparing HRQL across conditions and ethnicities.

Overall differences in HRQL were found between people with aphasia (PWA), people without aphasia (PSA), and successfully aging/healthy adults (SAH) in both overall and domain-specific HRQL dimensions. There is a conceptual overlap in the condition-specific SAQOL-39g and generic EQ-5D measures of HRQL. The use of two HRQL measures was strategic in that only the SAQOL-39g captures the role of communication in life satisfaction and social participation. Overall differences in HRQL were noted between PWA in comparison to PSA and SAH groups; however, these differences varied between the groups. Overall, PWA reported a lower HRQL than PSA and SAH as measured by the SAQOL-39g. However, overall differences in HRQL as measured by the EQ-5D found lower reports in PWA and PSA when compared to SAH. This discrepancy could be related the SAQOL-39g's inclusion of communication ability as a separate dimension in addition to questions that were integrated into the mental/emotional and social domains.

In agreement with previous research which identified lower HRQL in PWA compared to PSA (Hilari, 2011; Ross & Wertz, 2003; Northcott, Marshall, & Hilari, 2016), this study also found significant differences in communication and social domains of HRQL between PWA, PSA, and SAH via the SAQOL-39g. However, differences in the social domain as measured by the *usual activities* dimension of the EQ-5D only revealed significant differences between PWA and SAH, and between PSA and SAH. No differences were found between PWA and PSA, which may further support the influential role of communication in terms of social participation.

The physical component of HRQL as measured by the SAQOL-39g and EQ-5D revealed significant differences in mobility for PWA and PSA when compared to SAH. No significant differences in physical functioning were reported between PWA and PSA. Likewise, significant differences in role functioning were found between PWA and PSA compared to SAH as measured by the *self-care* component of the EQ-5D. However, no significant differences were noted in role functioning via the EQ-5D between PWA and PSA.

The mental/emotional component of HRQL identified a significant decrease in well-being between PWA and SAH as measured by the *psychosocial* component of the SAQOL-39g. This was the only group difference found in the mental/emotional domain as the EQ-5D identified no significant variance between groups as measured by the *anxiety/depression* dimension. This discrepancy could be related to the narrower assessment of mental/emotional health by the SAQOL-39g, in which questions focus on cognition and feelings that relate to identity, social participation, and family burden. One plausible reason as to why no significant differences were identified among the groups via the EQ-5D on emotional/mental health is that the generic instrument is not sensitive to contexts that are unique to HRQL in individuals with aphasia. This assumption is in agreement with previous research by Kagan, Simmons-Mackie, Victor, Whitehurst, & Hoch, 2015) that found the EQ-5D to be useful for generic health economics but not sensitive to contexts that are important to PWA.

In this study, PWA reported a larger social network than successfully aging adults but not larger than that of stroke survivors without aphasia. This study examined two aspects of social functioning more closely — social support and social network. Perceived social support as measured by the MOSS-SS did not reveal significant differences among the groups. Although PWA reported a lower perceived social support than PSA and SAH, these differences were not judged to be significant. Social network size has been linked to social isolation. As measured by the LSNS-6, no significant differences were noted in social network size among the groups. An overall score of 12 or less indicates risk for social isolation (Lubben et al., 2006), all of the groups in this study presented with overall social network scores greater than 17. Although PWA reported a higher social network than PSA, the difference was not judged to be significant. These results of the study align with previous evidence that found a limited change across participants regarding social network and perceived social support (Attard, Loupis, Togher, & Rose, 2018). It is possible that the lack of difference among the groups regarding social support and social network could be related to the traditional cultural values in the African-American community (Wallace, 1993). These values foster community through social relationships (Tang, Jang, Rauktis, Musa & Beach, 2017), and resources of love, support, services, communication, and money (Blake & Darling, 2000). Regardless of the individual's health condition, the approach of the African-American community is to continue to offer social support through a strong social network.

Finally, in agreement with previous literature which found that social functioning positively contributed to HRQL in individuals with aphasia (Carod-Artal, 2000; van Mierlo et al., 2014), this study attempted to tease apart the multidimensional concept. A moderator analysis was performed in order to evaluate the interactions between the groups and to determine if perceived social support or social network predicted HRQL. The was no significant interaction between the level of support that one received and his or her HRQL as measured by both the SAQOL-39g and EQ-5D. In terms of social network, no significant interaction was noted between the level of engagement and HRQL as measured by both SAQOL-39g and EQ-5D. These findings suggested that aphasia does not affect HRQL differently depending on perceived social support or social network size.

The results of this study concur with previous reports that communication (Cruice et al., 2010a; Hilari et al., 2012); social participation (Hilari, 2011; Vincent-Onabajo et al., 2015); and role functioning (Moeller & Carpenter, 2013; Ross & Wertz, 2003) contribute to a lower self-perceived HRQL in PWA.

Strengths and Limitations

The study has multiple strengths that contribute to the preliminary work in this area. First, the study included a homogenous sample of African-Americans with aphasia, without aphasia, and successfully aging adults. This is the first known cross group comparative study using all African-American participants to evaluate HRQL by comparing domains within the same population. Second, the study included African-Americans from both rural and urban environments across four states, providing a wider perspective of HRQL within the population. Third, the study included PWA across recovery periods, from individuals currently receiving speech and language therapy to individuals in the maintenance stage of therapy.

The study also has several limitations that warrant consideration. First, the research sample was small sample size of participants, which limits generalizability across the population. Second, the study only included people with mild to moderate aphasia. The exclusion of individuals with severe aphasia prevents a wide-ranging view of HRQL across severity levels. Third, a formal method for recording and analyzing anecdotal reports was not included in this design. Fourth, the report of health conditions was not medically verified and only considered the participant's self-report. In addition, some comorbid conditions, such as chronic respiratory disease and coronary heart disease, could have been present in the sample but unknown to the participant because of the medical terminology used by the investigator. For example, sleep apnea is under the umbrella term *chronic respiratory disease*. However, examples of chronic respiratory diseases were not shared with the participants, which could have affected self-disclosure. Fifth, inter-rater reliability was not performed with language classification instrument. Finally, a limitation of the study is the use of the social network scale, LSNS-6. This assessment did not meet group level reliability as measured by Cronbach's alpha. This limitation could have influenced statistical significance.

Future research should consider a mixed-method approach to capturing HRQL in African-Americans. Throughout the data collection, participants within all the groups shared stories of resilience, spirituality, and hope as factors that lead to recovery or healthy living. These elements were not captured through the design that was used for this study. Future research also should use lay terms along with medical terminology to support healthcare literacy.

Clinical Implications

Aphasia in its chronic phases is best addressed by examining the limitations on activities that relate to daily living and the individual effects on participation in society (Holland, 1998; Wallace, 2010). The evidence from this study suggests that African-Americans with aphasia experience a lower HRQL than African-Americans without aphasia and successfully aging/healthy African-American adults. Although varying in degree, the differences in communication, physical, emotional/mental health, role (e.g., self-care, homemaker), and social functioning are affected as a result of aphasia. In African-Americans with aphasia, additional factors, such as education and comorbid health conditions, contribute to HRQL. These types of environmental and personal features may be identified through the ICF framework and such features may provide SLPs with better insight into the impact of these contextual factors on human functioning within this population. Given the influence of the social determinants previously discussed on health, the contextual factors of the ICF that examine environment and personal factors are valuable for practitioners in determining therapeutic practices to use with African-Americans with aphasia. This information provides insight into the barriers to or facilitators of individual's presence in society (Threats, 2010).

The ultimate goal of aphasia rehabilitation is a social one as communication is key to social participation (van de Sandt-Koenderman, Meulen, & Ribbers, 2012); therefore, aphasia management, regardless of ethnicity, should include the patient's perspective in order to capture the context that matters most to the individual. It should no longer be considered best practice to treat individuals with aphasia, especially African-Americans, without capturing the subjective meaning of the disability in their lives. Clinician-reported outcomes that measure impairment-based function are necessary for aphasia rehabilitation; however, SLPs should avoid using these measures in isolation as they may exhibit cultural bias (Wertz & Ross, 1997) and inadvertently omit the psychological components of language.

The U.S. healthcare system is in a progressive shift toward a stricter protocol for insurance reimbursement for outpatient services through therapy caps (ASHA, 2019; Wallace, 2010). These therapy caps may impact service delivery or duration of treatment; therefore, assessment and intervention practices that utilize the ICF framework may better maximize recovery better throughout all stages of aphasia (Simmons-Mackie and Kagan, 2007). Although there were no significant differences in household income among this sample, PWA reported a lower income than PSA and SAH with most anecdotal reports revealing changes in income as a result of the stroke. As stated by Mahendra and Spicer (2014), African-Americans with aphasia reported obligations to pay out of pocket for services despite health insurance coverage. Therefore, if PWA have lower incomes, have to pay out of pocket for services, and only receive impairment-based therapy, SLPs may contribute to mental/emotional distress by limiting appropriate services within fixed time frames. This research has supported that African-Americans perceive themselves as having a good social support and social networks. In addition, PWA experience lower levels of social functioning as a result of communication challenges. There is ample room for practitioners to embed impairment-based language treatment into functional contexts that matter to the client, such as volunteering. Volunteering has been recognized as a meaningful activity that provides role identity and emotional support within the African-American community (Tang et al., 2017).

The overall objective of speech and language therapy is to enhance well-being and improve functional outcomes for individuals with communication disorders (ASHA, 2016); therefore, therapeutic interventions should be personally relevant and culturally appropriate (Simmons-Mackie et al., 2017; Wallace, 1996). Best practices for SLPs should challenge practitioners to expand their knowledge of cultural issues that are unique to diverse populations and adapt their clinical approaches such that those approaches are more inclusive (Wallace, 1996). Speech language pathologists have acknowledged the importance of HRQL in aphasia rehabilitation; however, most have reported concerns with assessment and ways to incorporate HRQL into treatment (Hilari et al., 2015).

An important part of this study is advocacy for outcome measurement systems that document the patient experience. Patient-reported measures in addition to clinician outcome measures help stakeholders make informed decisions about healthcare-related choices (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015; Frattali, 2013). This project showed the feasibility of incorporating the patient perspective into the evaluation process by demonstrating the practicality and minimal administrative burden of four patient-reported outcome measures. Outcome measures that target arbitrary performance on contextual tasks does not provide practitioners or clients with information about real-life functional gains (Threats, 2008).

Conclusion

The findings of this study support previous research that identified communication, physical, mental/emotional, role, and social functioning as significant predictors of HRQL in people with aphasia (PWA). This project embodies the realistic components that target multiple factors in aphasia rehabilitation by examining disability through the lens of the client. In alignment with future research recommendations to systematically study aphasia outcomes and social networks that affect race/ethnicity (Ellis & Peach, 2017), evidence from this study has presented an authentic perspective of aphasia in African-Americans. For example, a significant decrease was noted in social functioning as measured within HRQL between PWA and SAH adults, and this information alludes to the importance of social communication as a marker for successfully aging or normal function within this population. In contrast, minimal HRQL differences were noted between PWA and PSA, which may indicate that in this population, language is the major determinant of a positive HRQL as opposed to mental/emotional health, role, social or physical functioning.

With regard to treatment of stroke survivors with aphasia, research has established that the desired goals for both clients and caregivers are to improve communication, increase life participation and independence, and improve emotional well-being (Wallace et al., 2017). This study confirmed that African-American stroke survivors with and without aphasia experience lower psychosocial health than African-Americans without a history of neurological injury. Understanding the determinants of HRQL domains in PWA will help SLPs develop treatment goals that are more closely related to the individual (Cranfill & Wright, 2010). Therefore, there is a need to structure therapy in such a way that considers language within contexts that are important to the client may produce more clinically significant outcomes within this population.

One factor that may be outside the scope of practice for SLPs but influential in the role of rehabilitation is the rate of HTN and other health problems that are present within African-Americans. In order to help curb the stroke mortality epidemic, SLPs may facilitate prevention methods through healthcare literacy, which will promote knowledge acquisition that surrounds medication administration, nutrition, and advocacy with medical physicians. However, in order to do so, SLPs must be knowledgeable about these components within the African-American community and open to practices that facilitate the patients' perspectives on rehabilitation. As indicated by Mahendra and Spicer (2014), practitioners and researchers should help reduce health disparities by providing education and delivering services that promote participation in the community and utilization prevention services. These types of novel tasks may be best initiated through theories that support human functioning and behavior change, such as social cognitive theory. With a large body of evidence supporting the role of HRQL in aphasia management, the transition to practices that place the patient in control of his or her recovery can occur now.

Finally, the growing body of research suggests that a social model of care, such as the biopsychosocial approach, may be more appropriate for management of aphasia in the later stages of recovery (Ross & Wertz, 2003). This study also recommends this type of method to maximize results. As African-Americans may maintain subjective well-being through social support and engagement in social roles (Tang et al., 2017), structuring language therapy in these contexts may be beneficial. Social network and social support can enhance an individual's ability to access new contacts and information that help with problem solving (Heaney & Israel, 2002). Consistent determinants of HRQL have been identified in stroke survivors with aphasia, and PWA have requested that SLPs be more culturally sensitive (Mahendra & Spicer, 2014). It is imperative that practitioners' listen to clients regarding their stroke recovery to ensure treatment practices contribute clinical significance.

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Appendix A

Reflection of the Process

"Know from whence you came. If you know whence you came there are absolutely no limitations to where you can go" (James Baldwin). I wanted to ensure that I was culturally sensitive and knowledgeable about the experiences that have shaped health-related quality of life in African-Americans. I realized that before I could make judgements or inferences regarding an individual's desire to participate in research or share his or her subjective perception about his or her life satisfaction, I had to "know where I came from, to understand where I was going". To better understand the plight of African-Americans in the United States, I visited historic sites that taught me about our culture, history, and perseverance: The "Sweet Auburn District", Civil Rights Museum, the African-American Research Library, the Martin Luther King Center in Atlanta, GA, and the National African-American Museum in Washington, DC. These experiences gave me information, determination, and optimism.

As I reflect on the process that allowed me to enter the homes and lives of people with aphasia, people without aphasia, and of successfully aging/healthy adults, I am filled with pride— that a community with a history of struggle, a history of socioeconomic disadvantages, and a history of health disparities is so strong. I noticed that for many homes similar types of items were in display from pictures of Jesus to pictures of former president Barak Obama. I noticed similarities in the communities across the states, the neighborhoods in these communities were plagued with food deserts with only fast food pit holes that contribute to the health problems. The neighborhoods lacked walkability, environmental quality, and access to green space all factors associated with psychological well-being and physical health. The absence of these neighborhood characteristics in African-American communities only perpetuate the problem of an unhealthy lifestyle within this population. I acutely began to understand that the major contributors to the frequency of comorbid conditions and the reoccurrence of stroke in African-Americans were, in part, a result of their community.

A noteworthy observation shared anecdotally from some participants was the paternalistic relationship with healthcare providers. For example, some successfully aging adults reported the major responsibility was on the physician to ensure comorbid conditions were managed (e.g. “they know the medicine I need”; “it’s hard to change my eating habits”; “they say exercise, I’m old”). I was surprised by this paternalistic frame of thought, especially given the history of distrust by African-Americans with regard to separate and unequal medical provisions, unethical research practices, and government relationships. It is common for most practitioners, SLPs included, not to be adequately educated on factors unique to the population that they serve. However, given the limited research available perhaps the situation is not the practitioners fault; perhaps the patients should assume more responsibility for fostering their own care. African-Americans must begin to help practitioners manage their care not just through medication adherence but with lifestyle changes. If we fail to do this, then in the words of Dr. Barbara Sizemore, “black people still don’t get it”.

The African-American community is full of history, resilience, and courage. I appreciated the many times across the states when I was offered words of encouragement, food, gifts, and hugs from complete strangers. The pride in the participants’ eyes and joy in their voices when they prematurely congratulated me on the completion of the doctoral degree filled me with purpose. As an African-American woman, speech-language pathologist, and clinical researcher, they were happy to meet me, and I was just as happy to meet them.

Appendix B

HISTORY INTAKE FORM

People with Aphasia Intake Form
Health-related quality of life in African-Americans
University of Georgia

Name: ______________________________________ Sex: ☐ M ☐ F Age : ________

Phone Number: ____________________ Native Language: _____________________

Present/Former Occupation: ____

<u>Medical History</u>

Neurological Diagnosis:

____

Side of stroke: ☐ Right ☐Left Side of Hemiparesis (weaker side): ☐ None ☐ Right ☐Left

Date of stroke:

____

Premorbid Handedness: ☐Right ☐Left ☐Ambidextrous

Neglect: ☐None ☐Right ☐Left

Hemianopia (loss of visual field): ☐None ☐Right ☐Left

Comorbid Health Conditions: ☐ Hypertension ☐ Diabetes ☐ Coronary Heart Disease

☐ Cancer ☐ Chronic Respiratory Disease

Other Medical/Neurological Diagnosis:

____

<u>Communication/Social History</u>

Have you previously received Speech and Language therapy? ☐ Yes ☐No If, yes when was your last treatment session?

____

How often did you receive speech and language therapy?

____

Communication strengths and weakness:

____

Are you caregiver? ☐ Yes ☐No If, yes please list the disability type (i.e. stroke)

Do you have a caregiver? ☐ Yes ☐No If, yes please list the relationship type (i.e. spouse)

Demographic Information

What is the highest level of education achieved? ☐ <12 years ☐ =12 years ☐ >12 years

What is your household income?

☐ < $25,000 ☐ $25,000-50,000 ☐ $50,000-75,000 ☐ $>75,000

Do you have health insurance? ☐ Yes ☐No If, yes please list provider type (i.e. Medicare)?

Appendix C

HISTORY INTAKE FORMS

People without Aphasia Intake Form
Health-related quality of life in African-Americans
University of Georgia

Name: ____________________________________ Sex: ☐ M ☐ F Age : ________

Phone Number: ____________________ Native Language: _____________________

Present/Former Occupation: ____

Medical History

Neurological Diagnosis:

____

Side of stroke: ☐ Right ☐Left Side of Hemiparesis (weaker side): ☐ None ☐ Right ☐Left

Date of stroke:

____

Premorbid Handedness: ☐Right ☐Left ☐Ambidextrous

Neglect: ☐None ☐Right ☐Left

Hemianopia (loss of visual field): ☐None ☐Right ☐Left

Comorbid Health Conditions: ☐ Hypertension ☐ Diabetes ☐ Coronary Heart Disease

☐ Cancer ☐ Chronic Respiratory Disease

Other Medical/Neurological Diagnosis:

____

____
_

Communication/Social History

Have you previously received Speech and Language therapy? ☐ Yes ☐No If, yes when was your last treatment session?

____

Communication strengths and weakness:

____

Are you caregiver? ☐ Yes ☐No If, yes please list the disability type (i.e. stroke)

Do you have a caregiver? ☐ Yes ☐No If, yes please list the relationship type (i.e. spouse)

Demographic Information

What is the highest level of education achieved? ☐ <12 years ☐ =12 years ☐>12 years
What is your household income? ☐ < $25,000 ☐ $25,000-50,000 ☐ $50,000-75,000 ☐ $>75,000
Do you have health insurance? ☐ Yes ☐No If, yes please list provider type (i.e. Medicare)?

Appendix D

HISTORY INTAKE FORMS

Successfully-Aging Intake Form
Health-related quality of life in African-Americans
University of Georgia

Name: ______________________________________ Sex: ☐ M ☐ F Age : ________

Phone Number: ____________________ Native Language: _____________________

Present/Former Occupation: ____

Medical History

Comorbid Health Conditions: ☐ Hypertension ☐ Diabetes ☐ Coronary Heart Disease ☐ Cancer ☐ Chronic Respiratory Disease

Other Medical/Neurological Diagnosis:

____

____

Communication/Social History

Have you previously received Speech and Language therapy? ☐ Yes ☐No If, yes when was your last treatment session?

____

Communication strengths and weakness:

____

____

Are you caregiver? ☐ Yes ☐No If, yes please list the disability type (i.e. stroke)?

____

Demographic Information

What is the highest level of education achieved? ☐ <12 years ☐ =12 years ☐>12 years

What is your household income? ☐ < $25,000 ☐ $25,000-50,000 ☐ $50,000-75,000

☐ $>75,000

Do you have health insurance? ☐ Yes ☐No If, yes please list provider type (i.e. Medicare)?

Appendix E

WRITTEN CONSENT FORM

UNIVERSITY OF GEORGIA
CONSENT FORM
"Evaluating health-related quality of life in African-Americans with aphasia"

Researcher's Statement

We are asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Principal Investigator:	**Patrick Finn PhD CCC-SLP** **Communication Sciences and Disorders** **706-542-4572**
Co-Investigator:	**Davetrina Seles Gadson MS CCC-SLP** **Communication Sciences and Disorders** **706.215.1270**

Purpose of the Study

The **purpose** of this research is to understand how the health conditions and quality of life in African-Americans are affected after a stroke. You are being asked to participate in the study if you fall into one of the following categories:

- You have a history of a stroke with aphasia (language impairment).
- You have a history of a stroke but do not have aphasia (language impairment).
- You have no known history of a stroke or other neurological injury and are considered a healthy or successfully aging participant.

Study Procedures

If you agree to participate, you will be asked to …

- Attend a one-time data collection appointment to assess language functioning (aphasia type/severity), health-related quality of life, and social functioning.

- You will complete an intake form that will ask questions about your health and demographics, assessment of language functioning, and four assessments that capture your individual perspective on your health condition and quality of life.

- This assessment will take approximately 1-2 hours. Time will vary depending on participant category.
- If you become tired or fatigued, you will be allowed to take breaks as often as you wish.
- Assessments and meetings with researchers will be videotaped to ensure accuracy in data collection.

Risks and discomforts

- Your participation in this study involves no known physical or legal risks. Loss of privacy is a social risk that could result from breach of confidentiality.
- People with aphasia may experience some discomfort or stress answering questions about their health condition, quality of life, and social functioning.

Benefits

- There are no direct benefits for participation.
- Anticipated benefits from this study will provide information on the predictors of health-related quality of life in African-Americans. This evidence may promote client-centered care to improve rehabilitation and overall well-being.

Audio/Video Recording

Video/audio recording devices will be used to document participant responses and ensure accuracy in data collection. Video recordings will be kept under password protected encryption or locked file cabinet.

Please provide initials below if you agree to have this interview video/audio recorded or not. You may still participate in this study even if you are not willing to have the interview recorded.

_______I do not want to have this interview recorded.
_______I am willing to have this interview recorded.

Privacy/Confidentiality

- You will be assigned a unique code made up of letters and numbers. This code will be used on all data collection forms used in this study. The key that links your real name to your code will be destroyed 90 days after all data collection is complete.
- All data used for research purposes will be coded, and names will not be included in any presentations or publications. The results of this study will be confidential and will not be released in an individually identifiable form without prior written consent unless required by law.
- All audio and videotapes will be locked in a filing cabinet in the Think Tank Laboratory of the Department of Communication Sciences and Special Education at the University of Georgia, to which only the investigators will have access.
- All audio and videotapes will be destroyed 90 days after all data collection is complete.

Taking part is voluntary

- Your participation, of course, is voluntary, but would be greatly appreciated. You may choose not to participate or to withdraw your consent at any time without penalty or loss of benefits to which you are otherwise entitled.
- If you decide to stop or withdraw from the study, the information/data collected from or about you up to the point of your withdrawal will be kept as part of the study and may continue to be analyzed.

If you have questions
The main researcher conducting this study is Davetrina Seles Gadson MS CCC-SLP under the guidance of Patrick Finn, PhD at the University of Georgia. Please ask any questions you have now. If you have questions later, you may contact Davetrina S. Gadson at sgadson@uga.edu or at 706.215.1270

If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

Name of Researcher	Signature	Date
Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

Appendix F

PICTOGRAPH CONSENT FORM

1785

The University of Georgia

College of Education

Department of Communication Sciences and Special Education

Consent Form

I, ________________________ ________________________, agree to participate in the research study entitled, “Evaluating health-related quality of life in African-Americans with Aphasia”, conducted by Davetrina Seles Gadson MS CCC-SLP and Patrick Finn, PhD, CCC-SLP from the Department of Communication Sciences and Special Education at the University of Georgia.

I understand that my participation is voluntary.

I understand that I can stop taking part without giving any reason, without any penalty or loss of benefits to which I am otherwise entitled (e.g., future or ongoing services available through the UGA Speech and Hearing Clinic, if applicable).

The **purpose** of this research is to understand how health-related quality of life is affected after a stroke. If I choose to participate in this study, I will be asked to do the following:

1. Attend a one-time assessment appointment to test language functioning (aphasia type/severity), health-related quality of life, and social functioning.

x 1

2. This assessment will take approximately 2 hours. I may become tired or fatigued, but I will be allowed to take breaks as often as I wish.

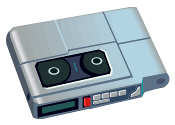
= 2 Hours,

= ✓

My participation in this study involves no known physical, social, or legal risks.

DANGER! = 0

All assessments and meetings with researchers may be videotaped and/or audiotaped.



Privacy and Confidentiality

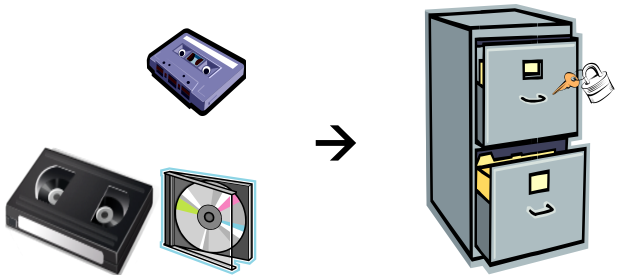
The results of this study will be confidential and will not be released in an individually identifiable form without my prior consent unless required by law or in order to protect my welfare.

- All data used for research purposes will be coded, and names will not be reported. My name will not be used on any documents collected as part of my participation in this study, nor will I be identified by name on any presentations or publications of the data.

John Smith → ~~John Smith~~ → JS

- All of the results of the tests will be kept totally private.

- All audio and videotapes will be locked in a filing cabinet in the Think Tank Laboratory of the Department of Communication Sciences and Special Education at the University of Georgia, to which only the investigator will have access.



- All data and recordings will be kept confidential, and will not be released in any identifiable form without my prior consent except as may be required by law. Only the researchers and research assistants assigned to this study will be able to view these records for the purpose of data analysis.

- I can ask for any tape to be destroyed at any time and for any reason.

____

Any questions regarding any aspect of this study can be directed towards Davetrina Seles Gadson MS CCC-SLP [(706) 215-1270, sgadson@uga.edu].

The investigator will answer any further questions about the research, now or during the course of the project.

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

Name of Researcher	Signature	Date
Name of Participant	Signature	Date

Please sign both copies of this form. Keep one and return the other to the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu

Appendix G

LSNS-6

LUBBEN SOCIAL NETWORK SCALE – 6 (LSNS-6)

FAMILY: Considering the people to whom you are related by birth, marriage, adoption, etc...

1. How many relatives do you see or hear from at least once a month?
0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

2. How many relatives do you feel at ease with that you can talk about private matters?
0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

3. How many relatives do you feel close to such that you could call on them for help? 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

FRIENDSHIPS: Considering all of your friends including those who live in your neighborhood

4. How many of your friends do you see or hear from at least once a month? 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

5. How many friends do you feel at ease with that you can talk about private matters? 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

6. How many friends do you feel close to such that you could call on them for help? 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

Appendix H

EQ-5D

Under each heading, please check the ONE box that best describes your health TODAY.

MOBILITY

I have no problems walking	☐
I have slight problems walking	☐
I have moderate problems walking	☐
I have severe problems walking	☐
I am unable to walk	☐

SELF-CARE

I have no problems washing or dressing myself	☐
I have slight problems washing or dressing myself	☐
I have moderate problems washing or dressing myself	☐
I have severe problems washing or dressing myself	☐
I am unable to wash or dress myself	☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	☐
I have slight problems doing my usual activities	☐
I have moderate problems doing my usual activities	☐
I have severe problems doing my usual activities	☐
I am unable to do my usual activities	☐

PAIN / DISCOMFORT

I have no pain or discomfort	☐
I have slight pain or discomfort	☐
I have moderate pain or discomfort	☐
I have severe pain or discomfort	☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

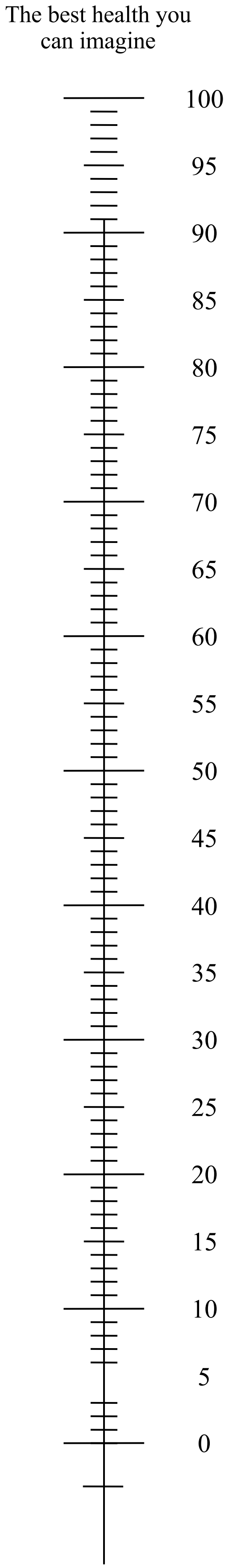
I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

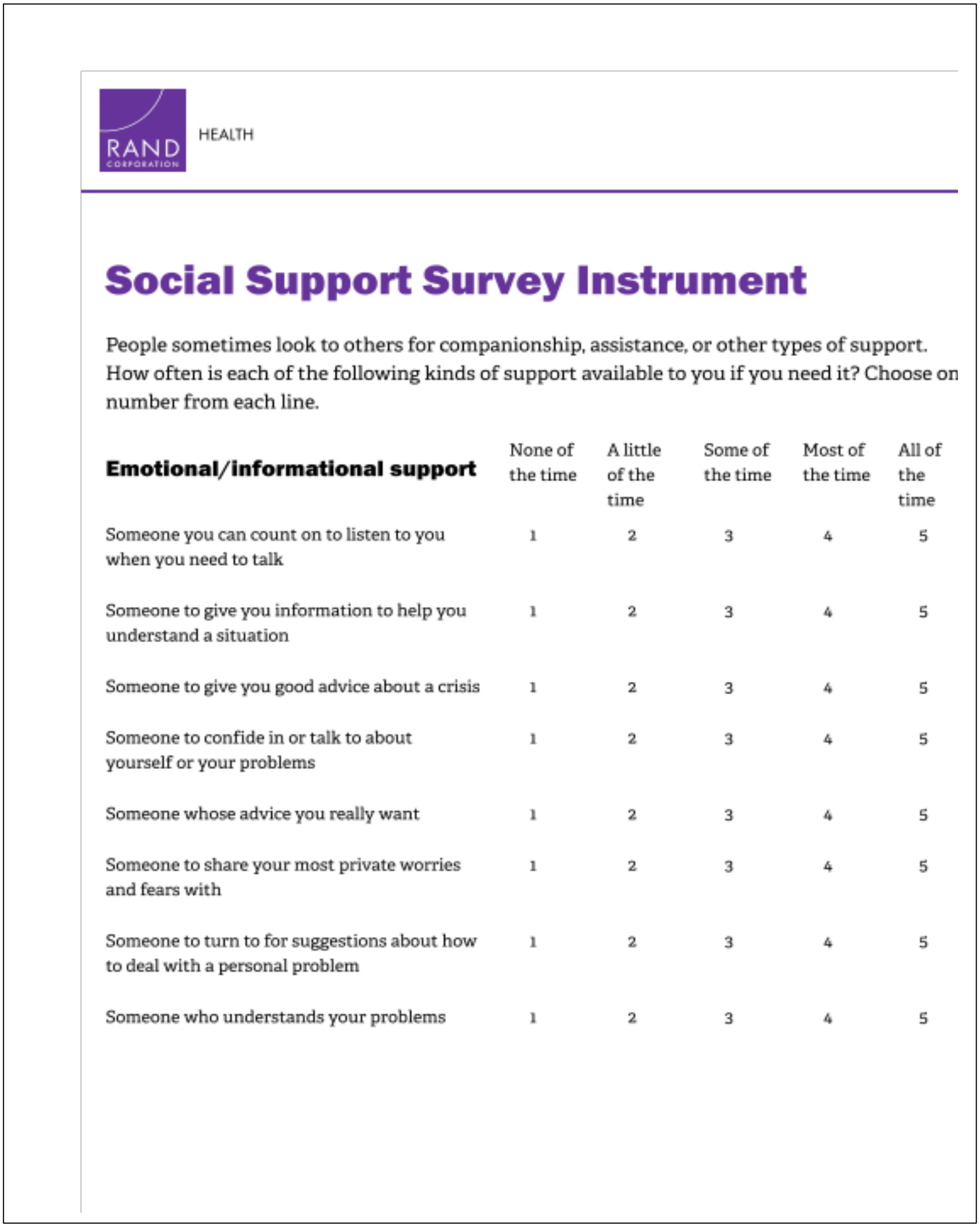


YOUR HEALTH TODAY =

☐

Appendix I

MOS-SSS



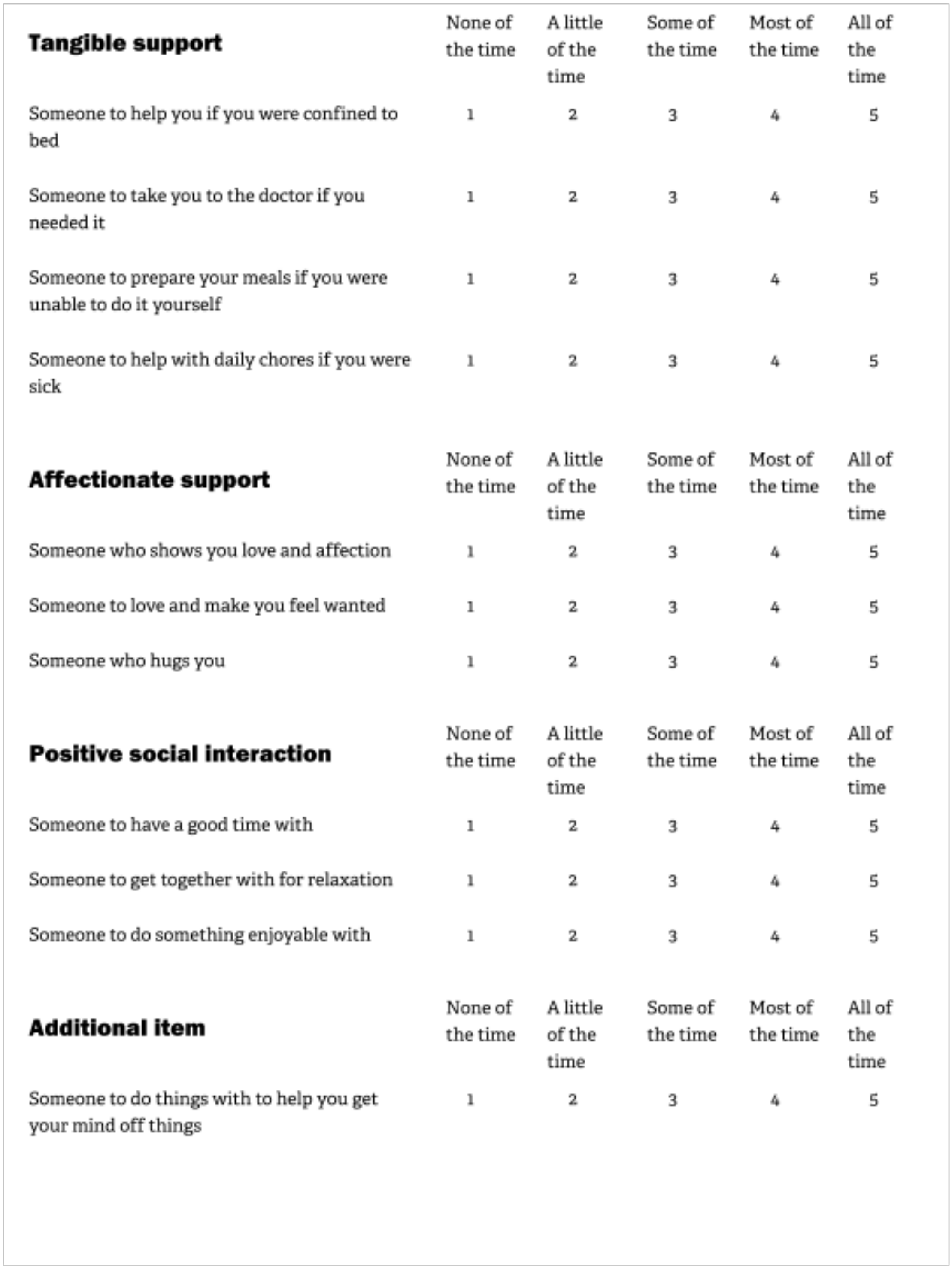
RAND CORPORATION

HEALTH

Social Support Survey Instrument

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Choose on number from each line.

Emotional/informational support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5



Tangible support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5

Affectionate support	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5

Positive social interaction	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5

Additional item	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to do things with to help you get your mind off things	1	2	3	4	5

Appendix J

SAQOL-39g

Item ID	How much trouble did you have (Repeat before each item or as necessary)	Couldn't do it at all		Some trouble	A little trouble	No trouble at all	Domains		
							Physical	**Comm.**	**Psycho-social**
SC1.	preparing food?	1	2	3	4	5			
SC4.	getting dressed?	1	2	3	4	5			
SC5.	taking a bath or shower?	1	2	3	4	5			
M1.	walking? (If respondent can't walk, circle 1 and go to question M7)	1	2	3	4	5			
M4.	keeping your balance when bending over or reaching?	1	2	3	4	5			
M6.	climbing stairs?	1	2	3	4	5			
M7.	walking without stopping to rest or using a wheelchair without stopping to rest?	1	2	3	4	5			
M8.	standing?	1	2	3	4	5			
M9.	getting out of a chair?	1	2	3	4	5			
W1.	doing daily work around the house?	1	2	3	4	5			
W2.	finishing jobs that you started?	1	2	3	4	5			
UE1.	writing or typing, *i.e. using your hand to write or type*?	1	2	3	4	5			
UE2.	putting on socks?	1	2	3	4	5			
UE4.	doing buttons?	1	2	3	4	5			
UE5.	doing a zip?	1	2	3	4	5			
UE6.	opening a jar?	1	2	3	4	5			
L2.	speaking?	1	2	3	4	5			
L3	speaking clearly enough to use the phone?	1	2	3	4	5			
L5.	getting other people to understand you?	1	2	3	4	5			
L6.	finding the word you wanted to say?	1	2	3	4	5			
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5			

Item ID	Did you <u>(Repeat before each item or as necessary)</u>	Definitely yes	Mostly yes	Not sure	Mostly no	Definitely no	Physical	**Comm.**	**Psycho-social**
T4.	have to write things down to remember them, *(or ask somebody else to write things down for you to remember)?*	1	2	3	4	5			
T5.	find it hard to make decisions?	1	2	3	4	5			▨
P1.	feel irritable?	1	2	3	4	5			▨
P3.	feel that your personality has changed?	1	2	3	4	5			▨
MD2.	feel discouraged about your future?	1	2	3	4	5			▨
MD3.	have no interest in other people or activities?	1	2	3	4	5			▨
MD6.	feel withdrawn from other people?	1	2	3	4	5			▨
MD7.	have little confidence in yourself?	1	2	3	4	5			▨
E2.	feel tired most of the time?	1	2	3	4	5			
E3.	have to stop and rest often during the day?	1	2	3	4	5			
E4.	feel too tired to do what you wanted to do?	1	2	3	4	5			
FR7.	feel that you were a burden to your family?	1	2	3	4	5			▨
FR9.	feel that your language problems interfered with your family life?	1	2	3	4	5		▨	
SR1.	go out less often than you would like?	1	2	3	4	5			▨
SR4.	do your hobbies and recreation less often than you would like?	1	2	3	4	5			▨
SR5.	see your friends less often than you would like?	1	2	3	4	5			▨
SR7.	feel that your physical condition interfered with your social life?	1	2	3	4	5	▨		
SR8.	feel that your language problems interfered with your social life?	1	2	3	4	5		▨	▨
	SAQOL-39 Mean score	Add all items and divide by 39				▨	▨	▨	
	Physical score	(SC items+M items+W items+UE items+SR7)/17					▨		
	Communication score	(L items+FR9+SR8)/7						▨	▨
	Psychosocial score	(T5+P items+MD items+FR7+SR1+SR4+SR5)/11							▨

Appendix K

Organizational Chart

WHO-ICF	Instrument	Info	Scoring/ Range of Scoring	Number of Test Items	Time (lowest) estimate	Clinical and Research Question(s)
		Stroke survivors with aphasia				
Body Structure and Function	Western Aphasia Battery-Revised Auditory Quotient (WAB-R) AQ*	measures of oral language production/ comprehension			30 - 45 minutes	• Spontaneous Speech • Auditory Comprehension • Repetition • Naming • Word Finding • Predictors of life participation
Participation/ Activities/ Contextual	Stroke and Aphasia Quality of Life Scale (SAQOL-39g)	Assessment of health-related quality of life (HRQL)	1-5/ Varies with subtest (4)	39	20-30 minutes	• Physical, Communication, and Psychosocial domains of HRQL. • Predictors of life participation or social functioning.
Participation/ Contextual/ Activities	EuroQuol (EQ-5D)	Generic and preference-based measure of HRQL	Likert scale/overall health 0-100	5	5-15 minutes	• Ability to compare across conditions. • Predictors of life participation and social functioning
Participation/ Contextual	Medical Outcomes Social Support Survey (MOSS)	Source and Type of Perceived Social Support	1-5/higher score more perceived social support	18	10-20 minutes	• Predictors of perceived social support are significantly associated with HRQL •
Participation/ Contextual	Lubben Social Network Scale-6 items scale (LSNS-6)	Social engagement including family and friends	0-5 /0-30 Higher score more social engagement	6	5-15 minutes	• Predictors of HRQL
Body Structure and Function/ Contextual	Case History	Premorbid Information			Send home in packet	• Predictors of HRQL • Multimorbidity and outcomes • Employment
		Stroke survivors without aphasia				
Body Structure and Function	WAB-R AQ*	Measures of oral language production /comprehension			20-30 minutes	• Spontaneous Speech • Auditory Comprehension • Repetition • Naming • Word Finding • Predictors of life participation
Participation/ Contextual	SAQOL-39g	Assessment of health-related quality of life	1-5/varies with subtest (4)	39	15-20 minutes	• Physical, Communication, and Psychosocial domains of HRQL. • Predictors of life participation and social functioning
HRQL	EQ-5D	Generic and preference-based measure of HRQL	Likert scale/overall health 0-100	5	5-10 minutes	• Ability to compare across conditions. • Predictors of life participation or social functioning.
Social Support	MOSS	Source and Type of Social Support	1-5/higher score more perceived social support	18	10-15 minutes	• Predictors HRQL.
Participation/ Contextual	LSNS-6	Social engagement including friends and	0-5 /0-30 Higher	6	5 -10 minutes	• Predictors of HRQL

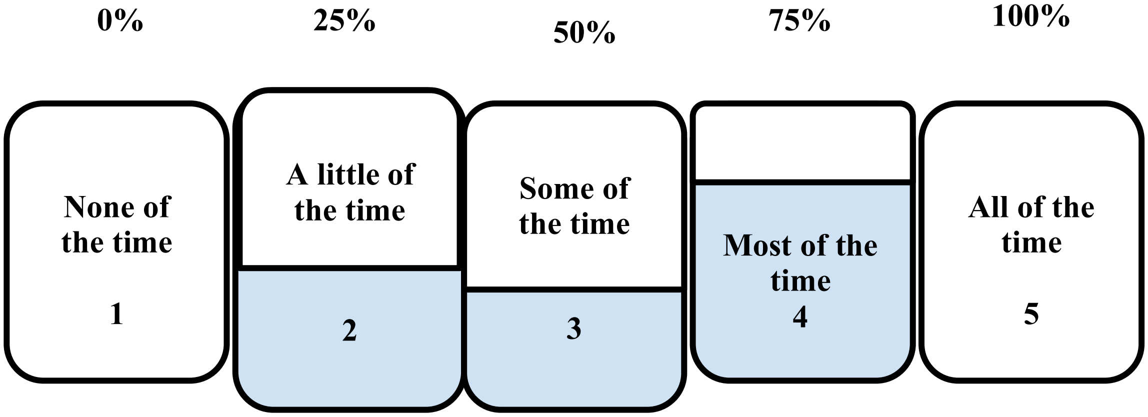
		family	score more social engagement			
Body Structure and Function/Contextual	Case History	Premorbid information			Send home in packet	• Predictors of HRQL • Multimorbidity and outcomes • Employment
	Successfully aging peers (no neurological injury)					
Body Structure and Function	WAB-R AQ*	Measures of oral language production/ comprehension			15-30 minutes	• Spontaneous Speech • Auditory Comprehension • Repetition • Naming • Word Finding • Predictors of life participation
Participation/ Contextual	SAQOL-39g	Assessment of health-related quality of life	1-5/varies with subtest	39	10-15 minutes	• Physical, Communication, and Psychosocial domains of HRQL.
HRQL	EQ-5D	Generic and preference-based measure of HRQL	Likert scale/overall health 0-100	5	5-10 minutes	• Ability to compare across conditions. • Predictors of life participation or social functioning.
Social Support	MOSS	Source and Type of Social Support	1-5/ higher score more perceived social support	18	5-10 minutes	• Predictors of perceived social support are significantly associated to HRQL.
Participation/ Contextual	LSNS-6	Social engagement including friends and family	0-5 /0-30 Higher score more social engagement	6	5-10 minutes	• Predictors of HRQL
Body Structure and Function/Contextual	Case History	Successfully Aging			Send home in packet	• Predictors of HRQL • Multimorbidity and outcomes • Employment

Appendix L

Visual Aid for SAQOL-39g

Appendix M

Visual Aid for MOS-SSS



Appendix N

Visual Aid for LSNS-6