

CAREGIVER-PROXY AND INDIVIDUAL WITH APHASIA SELF-REPORT AGREEMENT
ON THE MODIFIED PERCEIVED STRESS SCALE AND MUTUALITY SCALE

by

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A thesis submitted in partial fulfilment of the requirements
for the degree of Master of Arts
in the School of Communication Sciences and Disorders
in the College of Health Professions and Sciences
at the University of Central Florida
Orlando, Florida

Summer Term
2019

ABSTRACT

The level of agreement proxy-caregivers have with individuals with aphasia (IWAs) on a measure of perceived stress has yet to be systematically investigated. According to the extant literature, there is less agreement on psychosocial domains between proxy-caregivers and IWAs. In addition, high levels of mutuality have been strongly associated with low levels of stress in stroke survivors; however, these studies are not been specific to IWAs. The proposed study sought to examine the degree of agreement between proxy-caregiver reports and IWAs' perceived stress using a modified stress scale specifically for IWAs. This study also examined the relationship between perceived stress and mutuality of the relationship between the caregiver and IWAs. The modified Perceived Stress Scale (mPSS), a proxy version of the mPSS, and the Mutuality Scale (MS) were administered to 12 dyads. An independent sample t-test was conducted to determine if there were significant differences in perceived stress and mutuality as reported by the caregiver, proxy-caregiver and IWA. A Pearson correlation was performed to determine the level of agreement across questionnaires. Results show a moderate correlation on mPSS ratings between the proxy-caregiver and IWA. On average, proxy ratings on the mPSS were significantly higher than reports from IWAs. There was strong agreement on mutuality among the dyads and a moderate correlation between mutuality agreement and proxy agreement. Finally, there was a moderate correlation between the caregiver's mPSS score and increased disagreement between the proxy-caregiver and the IWA's mPSS score. These findings suggest a moderate agreement on perceived stress among caregivers and IWAs. Differences in agreement on perceived stress for proxy-caregiver and IWAs were minimized when perceived mutuality between the dyads were high. Further, caregivers were more likely to overestimate the perceived

stress of IWAs when their own mPSS ratings were high. Study limitations and future directions are also discussed.

Dedicated to the millions of people living with aphasia and their family.

ACKNOWLEDGMENTS

I owe my deepest gratitude to everyone that was involved with the creation and completion of my thesis. Dr. Lauren Bislick Wilson, thank you for believing in my vision and saying yes to becoming my thesis chair. I've learned so much from you this past year, I will forever value the way you challenged me throughout this process. To Dr. Amy Engelhoven, thank you for allowing me to recruit participants from the Aphasia House, the compassion you have for your work and the people you serve has been a constant reminder that I went into the correct field. To Dr. Joshua Troche, thank you for your continued support with the data analysis, it was a crucial component in completing this research project. To Dr. Rebecca Hunting Pompon, thank you for allowing me to utilize your Modified Stress Scale and add value to the stress literature in our field. To Dr. Linda Rosa-Lugo and Ms. Ranetta Guinn, thank you, thank you, thank you. I will forever be grateful. To my parents, thank you for inspiring me to live a fearless life by always encouraging me to take on challenges I would normally stray away from. Lastly, to all of my family, friends, and professors, thank you for all of your encouraging words over the past several years I've been at the University of Central Florida.

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LIST OF ABBREVIATION

ADL: Activities of Daily Living

CVA: Cerebrovascular Infarct

HRQOL: Health-related Quality of Life

IWA: Individual with aphasia

IWAs: Individuals with aphasia

MPSS: Modified Perceived Stress Scale

MS: Mutuality Scale

PSS: Perceived Stress Scale

PSD: Post-stroke depression

PROM: Patient Reported Outcome Measures

QOL: Quality of Life

SAQOL-39: Stroke and Aphasia Quality of Life Scale-39

SF-36: Short Form-36 Health

CHAPTER ONE: INTRODUCTION

Per the American Stroke Association, nearly 800,000 individuals in the United States have a stroke every year (American Stroke Association, 2016). Individuals post-stroke experience a variety of stressful life events which lead to a decline in their quality of life (QoL), such as a deterioration in physical health, loss of independence, and a decline in social relationships (Chau, Thompson, Twon, Chang, & Woo, 2009; Hackett, Yapa, Parag, & Anderson; 2005; Patel, McKeivitt, Lawrence, Rudd, & Wofe, 2007). A common result of left hemisphere stroke is acquired aphasia, a language processing disorder (National Aphasia Association, 2018). Over two million individuals are living with aphasia in the United States (National Aphasia Association, 2018). Aphasia is characterized by a loss of language affecting the production or comprehension of speech and the ability to read or write. These linguistic deficits may range from mild anomia to an inability to participate in everyday activities that require communicative exchange. Individuals with aphasia (IWAs), post-stroke, perceive their QoL more negatively in comparison to stroke survivors without aphasia, with an increased risk in developing post-stroke depression (PSD) and higher perceived stress (Kauhanen et al, 1999; Laures-Gore, Hamilton, & Matheny, 2007).

Although there is an abundance of research behind the risk factors on developing PSD, perceived stress, as a risk factor, has been largely ignored (Moncayo-Gaete & Bogousslavsky, 2008). Work by Ostwald and colleagues, however, suggests that depression and emotional distress in the stroke population are most associated with stress (Ostwald, Swank, & Khan, 2008). When we perceive chronic stress over a long period of time, the wear and tear on the body and brain begin to have negative impacts on an individual's mental health and memory, which in

turn may affect their relationships with loved ones (McEwen & Gianaros, 2011). In addition, studies show that stress experienced by stroke survivors and their caregiver may be linked (Godwin, Swank, Vaeth, & Ostwald, 2013; Ostwald, Bernal, Cron, & Godwin, 2009).

Specifically, lower reports of stress, by both the stroke survivor and the caregiver, are associated with higher reports of mutuality, known as shared feelings between two people, whereas higher reports of stress are associated with lower reports of mutuality. The relationship between perceived stress and mutuality has not been specifically investigated in IWAs and their caregivers.

IWAs represent the subgroup of stroke survivors that may be in need of a proxy respondent due to communication breakdowns that occur at the receptive and expressive level of communication. Current research suggests proxy-caregiver and self-report agreement on subjective domains, such as psychological well-being, is much lower in comparison to objective domains such as physical ability (Chen, Hsieh, Mao, & Huang, 2007; Poulin & Desrosiers, 2008; Sneeuw, Aaronson, de Haan, & Limburg, 1997; Tooth, McKenna, & Smith, 2003). There is a level of ambiguity in subjective questionnaires that makes it difficult for proxy respondents to accurately respond the same way the responder would answer. Although not systematically examined in IWAs and their caregivers, increased mutuality between the caregiver and care receiver has been linked to an increase agreement on proxy reports (Horowitz, Goodman, & Reinhardt, 2004). Although proxy-reports will never be an exact representation of a patient, having increased knowledge on the level of accuracy on these reports can be a crucial component in refining the manner clinicians enhance progress and growth in the rehabilitative process when it is not possible to get information directly from the patient.

There is a pressing need for better understanding on the levels of agreement between IWAs and their proxies in the psychosocial domains of depression and stress. The stroke literature shows that individuals with higher mutuality in their relationships tend to have lower perceived stress. The aim of this study is to evaluate if higher mutuality between IWAs and their caregivers is associated with higher agreement on perceived stress. If this is the case, incorporating a mutuality scale would be a tool by which to gauge how effective a proxy report may be when an IWA cannot report for themselves.

CHAPTER TWO: LITERATURE REVIEW

2.1 Post Stroke Quality of Life

Multiple factors associated with an individual's physical status, level of independence, social relationships, personal beliefs, economic status, and psychological well-being impact QoL (World Health Organization; WHO, 1997). In general, QoL questionnaires used in healthcare facilities cover the domains of physical health, psychological well-being, social relationships, and environment. In regard to stroke survivors' QoL, there are a number of studies that report a reduced social network, decline in activities of daily living (ADLs), lower probability to re-enter the workforce, PSD, and reduced health-related QoL (HRQoL) as areas of concern (Astrom, Asplund, & Astrom, 1992; Chau, Thompson, Twon, Chang, & Woo, 2009; Hackett, Yapa, Parag, & Anderson; 2005; Patel, McKeivitt, Lawrence, Rudd, & Wofe, 2007). Factors associated with a poor HRQoL include depression, anxiety, irritability, older age, comorbidities, and stroke recurrence (Leach, Gail, Dewey, Macdonell, & Thrift, 2011). Unfortunately, many studies exclude IWAs due to severe linguistic impairment or only include individuals with relatively mild linguistic impairment. In some cases, proxy-respondents, such as spouses and caregivers, report for an IWA.

Of the research that has focused on IWAs, declines in QoL have been reported. For example, Hilari (2011) conducted a six-month longitudinal study comparing IWAs with stroke survivors without aphasia and found that IWAs had a significant decline in ADLs and experienced a significantly lower HRQoL. Particularly, the ADLs that were most affected were those that required socialization, such as shopping and travelling for pleasure, rather than physical activities. Other studies have shown that IWAs report reductions in friendship networks,

ADLs, HRQoL, and satisfaction in social activities, as well as higher levels of depression (Cruice, Worall, & Hickson, 2006; Hilari, Northcott, 2006; Hilari & Byng, 2009; Hilari, Wiggins, Roy, Byng, & Smith, 2003; Kauhen et al. 2000). Additionally, perceptions of QoL may differ across different aphasia profiles. For example, IWAs whose speech is characterized as non-fluent are more likely to perceive their social relationships and overall environment in a more negative manner than IWAs whose speech is characterized as fluent (Hernandez, 2016). It is unclear if this finding reflects differences in awareness across fluent and non-fluent speakers or the social implications of their expressive speech impairment. Nonetheless, the sudden changes in an IWA's QoL post-stroke has a negative effect on their psychological well-being, which can be perceived as stressful.

2.2 Stroke Survivor Stress

From the onset of recovery, stroke survivors experience stressful changes that affect different aspects of their QoL, including physical, psychological, and social function. For example, physical impairments may include deficit of movement, vision, swallowing, agnosia, hemiplegia, and apraxia, which have lasting effects on one's ability to perform ADLs. Psychological issues, such as depression have been linked to higher levels of perceived stress (Ostwald et al., 2008). With regard to social function, decreased participation in leisure activities such as shopping, hobbies, and traveling for pleasure have been reported (Hilari, 2011). Another source of stress may result from a loss of autonomy, that may lead stroke survivors to feel they are a burden to their caregiver or spouse (Hanger, Fogarty, Wilkinson, & Sainsbury, 2000).

Work by Laures-Gore and colleagues found that IWAs, compared to stroke survivors without aphasia, have higher perceived stress and may benefit from learning coping strategies such as the use of stress monitoring and tension control resources (Laures-Gore, Hamilton, & Matheny, 2007). One reason for higher reports of perceived stress in IWAs, compared to stroke survivors without aphasia, is that complete language recovery is often not possible, and may increase the chances of depression and higher levels of stress. This in turn affects multiple aspects of QoL, particularly the subjective domains, such as psychological well-being, that are more challenging to measure accurately. Bearing in mind aphasia treatments require learning and memory, stress can impede these abilities. Therefore, it is important to better understand variables that impact stress in IWAs.

2.3 Stress and Coping

Lazarus (1966) defines stress as “a relationship between the person and the environment that is appraised as personally significant and as taxing or exceeding resources for coping.” This definition encompasses the basis on which the stress and coping theory was founded. This theory created a framework that allows researchers to create and test hypothesis regarding the stress processes and its connection to physical and mental health (Folkman, 2013). In addition, the stress and coping framework has been used in psychosocial studies to explain how individuals and families adjust to the stresses that are accompanied after a chronic condition.

A potential stressful situation may be appraised or perceived as stressful if it is relevant to one’s being and has the potential to cause harm or loss. The appraisal of a life changing event by the individual and their family, in combination with their problem solving and coping responses,

are based on the impact of the stressor on their lives. Appraisal has two components: (1) objective appraisal, which determines the nature and extent of the threat or challenge; and (2) subjective appraisal, the ability for an individual or family to assess their capacity in managing the threat or challenge (Lazarus & Folkman, 1984). Appraisals have a lot of variability and are unique to every individual. What may be perceived as a stressful situation to one individual may not be as stressful to another. The situation may involve values and beliefs that are more impactful to one individual versus the other, or one may be more prepared than the other to control their emotions over the outcome.

Coping refers to the preferred process individuals use to manage stress, manage the source causing the stress, and eventually the management of sustained positive well-being. Folkman (2013) describes this process using three coping styles; (1) emotion-focused coping, (2) problem-focused coping, and (3) meaning-focused coping. Emotion-focused coping can be divided into two different strategies; adaptive strategy, such as seeking social support, and maladaptive strategy, such as blaming others. Problem-focused coping consists of strategies like seeking advice, gathering research, and problem solving. Meaning-focused coping concentrates on beliefs, such as religion, spirituality, and focusing on positive moments. An individual's coping style is highly influenced by whether the outcome is controllable or must be accepted. For IWAs and their caregivers, the new dynamic in their relationship has to be accepted.

This abrupt change in QoL can be perceived as stressful for the IWA and the caregiver. The manner in how they cope is a crucial component for their psychological well-being. However, a study by DuBay and colleagues reported that IWAs perceived to have fewer resources in how to cope with stress in comparison to those with right brain damage and

neurologically intact adults (DuBay, Laures-Gore, Matheny, & Ronski, 2011). Prolonged exposure to stress has detrimental effects in all domains of QoL and may also alter the course of recovery in rehabilitation (Code & Herrmann, 2003). Coping is unique to every individual; thus, the manner in which stroke survivors and their loved ones respond to stroke and aphasia can be different.

2.4 Stress and Depression

The relationship between depression and stress has been well documented in the general population (Bao, Meynen, & Swabb, 2008; Caspi et al., 2003; Kendle, Karkowski, & Prescott, 1999; Papp, Moryl & Willner, 1996; Paykel & Dowlatshani, 1988), with some studies specifically linking chronic stress to depression (Mazure, 1998; Tafet & Bernardini, 2003). Chronic stress, as described in McEwen's research, is defined as the cumulated load of day-to-day stress that creates psychogenic and physiological disturbances that interfere with the physiological and psychological homeostasis of the brain (McEwen, 1998, 2006). When individuals perceive stress, whether negative or positive, several regulatory systems of our brain work together to calibrate our brain back to a state of homeostasis. This allodynamic process is known as allostasis, which is crucial in maintaining homeostasis. However, when the brain continues to adapt to internal and external demands of stress over a period of time, the regulatory systems in our brain begin to malfunction causing a decrease in brain plasticity. This wear-and-tear on the body and brain over an extended period is known as allostatic load (McEwen, 1998). Researchers have discovered individual's memory and capacity to learn are affected when exposed to long term stress (Tafet & Benardini, 2003).

The stress exposure model of depression (Hammen, 1991) similar to McEwen's framework on allodynamic processes (McEwen & Gianaros, 2011), views depression as a byproduct of stressful situations over an extended period of time. Many studies are in support of this model (see Liu and Alloy; 2010); however, the majority of studies conducted have focused on episodic stress (i.e., frequent acute stress) rather than chronic stress. The emphasis on episodic stress rather than chronic stress is due the increase in factors that must be addressed, such as environmental, cognitive, and personality influences. There currently is an absence of research on chronic stress and its impact on IWAs and their caregivers as a dyad. This is an issue as chronic stress has the potential to impact a stroke survivor's rehabilitation potential, as well as the relationship between the survivor and the caregiver.

Specific to the relationship between stress and PSD, higher levels of perceived stress are shown to be predictive of depressive symptoms, independent of stroke severity (Laures-Gore & DeFife; 2013). The inverse relationship has also been reported, where PSD acts as a predictor of stress. For example, Ostwald et al. (2008) interviewed ninety-seven stroke survivors and found that predictors for stress were depression and emotional distress. Consequently, survivors that expressed less stress also displayed fewer depressive symptoms. Recently, Hunting Pompon and colleagues modified and validated the Perceived Stress Scale (Cohen & Janicki-Deverts, 2012) to be used as a measure of chronic stress in IWAs (Hunting Pompon, Amtmann, Bombardier, Kendall, 2018). This new tool will now allow clinicians to appropriately measure perceived stress in the aphasia population and obtain additional information in this area of research.

2.5 Post-stroke depression

PSD is a common psychological disorder and appears to have a larger influence on QoL than functional limitations, such as difficulty with ambulation or physical activities of daily living (ADL's) (King, 1996). Although there is not a universally accepted definition for PSD, it is clinically defined by the presences of a significant depressive state which may include crying, loss of energy, and lack of motivation (Code & Herrmann, 2003). Consequently, medications and referrals to support programs such as stroke support groups, home health agencies, and rehabilitation therapists are important in the management of PSD.

The frequency of reported PSD cases varies, with studies reporting an average of first year prevalence ranging between 17-52% (Mocayo-Gaete & Bougousslavsky, 2008). Diagnosing PSD is challenging, missed detections by non-psychiatric physicians are as high as 80% (Schubert, Taylor, Lee, Mentari, & Tamaklo, 1992). Accurately identifying PSD may be hindered by a number of circumstances, such as the presence of aphasia, agnosia, apraxia of speech, and memory disturbances, all of which can limit the capacity of a patient to express their feelings and thoughts (Moncayo & Bogousslavsky, 2008). Some studies suggest that aphasia is a risk factor for PSD (Kauhanen et al, 1999; Ouimet, Primeau, & Cole, 2001; Thomas & Lincoln; 2006), while other studies have not found a similar association (Carota, Berney, & Aybeck, 2005; Paolucci et al. 2005). With aphasia being a multi-modal impairment of language, finding a direct correlation has its challenges.

2.6 Stress and Stroke Survivor and Caregiver Mutuality

The strength of the stroke survivor and caregiver relationship, also referred to as mutuality or shared feelings between two parties, is predictive of stroke survivor stress and degree of recovery (Bhogal, Teasell, Foley, & Speechley, 2003). Mutuality is conceptualized as a positive aspect of the caregiving relationship. It describes such ideas as the degree of closeness that both the caregiver and the stroke survivor feel, the quality of pleasure and comfort resulting from the relationship, and the amount of gratitude each individual feel towards the other. Higher mutuality in a relationship has been linked to improved patient self-reported care and decreased caregiver strain; it may also act as a protective buffer in caregiving relationships (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007). On the contrary, lower mutuality among spousal caregivers has been linked with negative caregiver outcomes such as depression, anxiety, and increased stress (Halm & Bakas, 2007).

Ostwald et al. (2009) conducted a study that identified predictors of stress among stroke survivors and their spousal caregivers during the first year. In addition to finding that stress scores reported by the stroke survivor and the caregiver were correlated with each other, there was an indication that higher stress levels in spousal caregivers were predicted by poor health, being female, and being of a younger age. There was also an indication that higher levels of mutuality were strongly associated with lower levels of stress in stroke survivors.

Similarly, Godwin et al. (2013) examined the dyadic relationship between caregiver and stroke survivor mutuality and its role in determining which of the two had a greater impact on perceived stress over a year span. The authors concluded on average, the spousal caregivers had higher perceived stress and lower mutuality than the stroke survivors, indicating the spouse is

more directly influenced by the caregiving relationship. In addition, the study discovered a partner effect for the stroke survivors stress, suggesting that the stroke survivors stress has more influence on the caregiver, however, the caregiver stress is not as impactful on the stroke survivor. Thus, stroke survivor stress appears to significantly impact the caregiver. There is a paucity of research that specifically looks at the mutuality for IWAs and their caregivers. A better understanding of mutuality between the IWA and the caregiver may improve the assessment and management of perceived stress for these individuals.

2.7 Caregiver-proxy and self-report studies

Patient reported outcome measures (PROMs) are one way to assess the different domains that encompass QoL post-stroke (Hilari, Cruice, Sorin-Peters, & Worall, 2015). PROMs require stroke survivors to comprehend the question being asked of them and accurately provide their response either verbally, via gesture, or writing. A considerable amount of stroke survivors may not be able to self-report on various QoL questionnaires that are used in health facilities due to communication deficits, visual and physical impairment, fatigue, and stress (Sneeuw et al., 1997). In such cases, an individual that knows the stroke survivor well, such as a caregiver, may be asked to provide a proxy evaluation of the stroke survivor. Numerous studies have systematically assessed the validity of proxies as an alternative for stroke survivors in the assessment of QoL, ADLs (including instrumental ADLs, such as cooking and cleaning), and social participation (Chen, Hsieh, Mao, & Huang, 2007; Poulin & Desrosiers, 2008; Sneeuw, Aaronson, de Haan, & Limburg, 1997; Tooth, McKenna, & Smith, 2003). Studies have found that the level of agreement between stroke survivors and their proxies vary with more agreement

on objective measures, (e.g., ADLs), and less agreement on subjective measures (e.g., psychosocial domains in QoL questionnaires).

Very few studies have specifically looked at agreement between IWAs and proxy reports. Similar to the findings reported above, work by Cruice, Worrall, Hickson, and Murison (2005) and Hilari, Owen, and Farrelly (2007) concluded there was less agreement between people with chronic aphasia and their proxies on subjective domains (e.g., psychosocial) compared to objective domains (e.g., physical limitations). In addition, proxies reported significantly more problems than the IWA reported. Considering the lack of agreement in this area, there is a need for additional research surrounding caregiver-proxy and IWA's self-report measures, especially on subjective domains. Further, there is an absence of research looking into agreement on proxy and self-report measures on perceived stress in this population.

Additional factors that may affect agreement on proxy and stroke survivors self-reports include age, pain, and the presence of depression (Hung, Pickard, Witt, & Lambert, 2007). For example, depressed caregivers tend to underestimate the pain experienced by the stroke survivor, whereas caregivers with pain tend to overestimate pain in stroke survivors. The living situation may also impact agreement on proxy and stroke survivor self-reports. In particular, one study discovered an increase in agreement when caregivers and stroke survivors reported living together (Horowitz, Goodman, & Reinhardt, 2004). The measurement of mutuality between the caregiver-proxy and IWA could lead to a better understanding in how to increase accuracy in proxy-reports. In turn increased accuracy on proxy-reports can potentially be used by clinicians to enhance the rehabilitation process and improve the QoL for the IWA and their caregiver.

2.8 Purpose

The proposed study sought to examine the degree of agreement a caregiver has with an IWA's perceived stress using a stress scale specifically modified for IWAs (Modified Perceived Stress Scale or mPSS; Hunting Pompon, Amtmann, Bombardier, & Kendall, 2018), as well as the relationship between perceived stress and mutuality of the caregiver and stroke survivor relationship. The level of agreement a proxy-caregiver has with an IWA report on perceived stress has not been systematically investigated. According to the extant literature there is less agreement on psychosocial domains, specifically those related to depression and perceived stress, between the proxy-caregiver and IWA. In addition, high levels of mutuality have been strongly associated with low levels of stress in stroke survivors (Ostwald et al., 2009), however, these studies have not been specific to IWAs. A better understanding on what may increase proxy-report agreement when the patient is unable to communicate can be a crucial tool in improving the rehabilitation process for the IWA and their caregiver. For these reasons, the following research questions (RQ) were addressed:

1. What is the level of agreement between IWAs and their caregiver's proxy ratings on a measure of perceived stress (mPSS)? We hypothesized a moderate to high agreement on the level of perceived stress.
2. What is the level of perceived mutuality (MS) between IWAs and their caregivers? We hypothesized a moderate to high mutuality score among IWAs and their caregivers.
3. Are higher mutuality scores between the caregiver and IWAs associated with higher agreement on the mPSS? We hypothesized that higher mutuality will lead to greater agreement on the mPSS.

4. Are higher mutuality scores between the caregiver and the IWA associated with lower perceived stress scores for the IWA? We hypothesized that higher mutuality will be associated with lower perceived stress.
5. Does caregiver stress influence agreement on the proxy rating mPSS? We hypothesized that caregiver stress will have an inverse relationship with the proxy agreement on the mPSS.

CHAPTER THREE: METHODOLOGY

3.1 Research Design

A cross-sectional study was performed to determine the agreement between IWAs' self-report and proxy-caregiver report on two measures: perceived stress and mutuality. In addition, the relationship between stress and mutuality agreement was explored. IRB consent forms were provided prior to administering questionnaires.

3.2 Participants

The participant pool included 12 IWAs and their caregivers. All IWAs had the Western Aphasia Battery-Revised (WAB-R; Kertesz, 2007) or the Comprehensive Aphasia Test (CAT; Swinburn, Porter, & Howard, 2005) within six months of the study (either through the UCF Aphasia House or the Florida Aphasia Registry and Repository). Participants with aphasia were recruited from the University of Central Florida's Communication Disorders Clinic. Inclusion criteria for IWAs included a diagnosis of aphasia due to a cerebrovascular infarct (CVA) with a post-onset minimum of six months. IWAs also had to be over the age of 18. Caregivers were adults over the age of 18 and were required to live with the IWA. Exclusion criteria for the IWAs included progressive neurological disorder, non-English speaker, and self-reported alcohol or drug abuse. Exclusion criteria for the caregiver included any form of neurological disorder, non-English speaker, and self-reported alcohol or drug abuse. Caregiver data was collected via a brief assessment interview. Data regarding severity of aphasia, age, gender, ethnicity, marital status, employment status, education, and use of anti-depressant medications was collected but did not exclude participants.

3.3 Demographic Statistics

Across the 12 dyads, age ranged from 49-85 years for IWAs ($m=63.25$, $SD=11.87$; see Table 1) and 45-80 for caregivers ($m=64.33$, $SD=9.89$). IWAs were all at least six months post stroke and ranged from 7 to 209 months post injury, with an average of 67.75 months since onset ($SD=70.21$). Gender for IWAs was seven males (58%) and five females (42%), and for caregivers four were (34%) males and eight were females (66%). Of the dyads 10 were spouses (83%) and two were parent caregivers (17%). Six of the participants had the CAT administered prior to the study with an average of 50.9 for Spoken Language Comprehension, 50.4 for Written Language Comprehension, 46.8 for Repetition, 49.8 for Naming and Fluency, and 49.4 for Reading (See Table 2). Participant 5 did not have all of the sections administered due to a mild case of aphasia. Six of the participants had the WAB-R administered prior to the study with an average Aphasia Quotient (AQ) score of 64.5 and a range of 35.1-78.2 (See Table 3).

Table 1. Participants' Characteristics

Pt #	IWA age	Caregiver age	IWA gender	Caregiver gender	Relationship to IWA	Month post
1	55	54	F	M	Spouse	42
2	56	69	F	M	Spouse	178
3	72	72	F	M	Spouse	30
4	49	68	F	F	Parent	56
5	60	45	M	F	Spouse	8
6	84	80	M	F	Spouse	34
7	61	54	M	F	Spouse	69
8	77	75	M	F	Spouse	209
9	66	61	M	F	Spouse	7
10	77	65	F	M	Spouse	9
11	61	61	M	F	Spouse	132
12	48	68	M	F	Parent	96
Mean	63.83	64.33				72.50
SD	11.543	9.893				67.984

Note. Individual with aphasia (IWA); Months post-stroke (Months post)

Table 2. Comprehensive Aphasia Test (CAT) Scores

Pt#	Spoken Language Comprehension (66)	Written Language Comprehension (62)	Repetition (74)	Naming (58) & Fluency	Reading (70)
1	55	53	62	60	60
5	DNT	DNT	DNT	DNT & 31	64
8	50	51	60	55	55
10	41.5	48	52	46	4
11	64	50	43	75	64
12	44	50	17	13	UTP
Mean	50.9	50.4	46.8	49.8	49.4
SD	9.017	1.817	18.267	23.102	25.648

Note. Did not test (DNT); Unable to perform (UTP)

Table 3. Western Aphasia Battery- Revised Aphasia Quotient (WAB-R AQ) Scores

Pt #	WAB AQ Score (100)
2	78.2
3	35.1
4	68.3
6	71
7	48.2
9	86.4
Mean	64.5
SD	19.249

3.4 Measures

3.4.1 Modified Perceived Stress Scale (mPSS).

The mPSS questionnaire was utilized to measure perceived stress from IWAs and their caregivers (Hunting Pompon, Amtmann, Bombardier, & Kendall, 2018). The mPSS, a modified version of the Perceived Stress Scale (PSS; Cohen & Janicki-Deverts, 2012), was selected because it was systematically modified and normed for IWAs. The mPSS asks IWAs and their caregivers to rate the extent to which they have felt their life to be stressful during the past month. This scale consists of 10 questions regarding their feelings and thoughts, such as “In the

last month, how often were you upset when something happened that you did not expect?" The items are measured on a 5-point rating scale, (0=never, rarely, to 5= very often) with a range of 0 to 40. High scores indicate higher levels of stress. The caregiver was given the proxy version of the scale with the same questions, The questions had the caregiver rate to the best of their knowledge how they believe the IWA would have answered the questions in regard to their own perceived stress, for example, "In the last month, how often has your loved one felt stressed?"

3.4.2 Mutuality Scale (MS).

The MS was utilized to measure the positive caregiving relationship between the caregiver and the IWA (Archbold et al., 1990). The MS was selected due to its use with the stroke population and their caregivers in past studies. Both the caregiver and the IWA will answer 15 questions about their relationship, such as "How close do you feel to him or her?" The items are measured on a 5-point scale, (0=not at all to 4=a great deal). The total MS score is the sum of the individual items divided by the number of items answered. High scores indicate a more positive relationship.

3.5 Procedure

All scales were administered by the author. Participants and their caregivers were given the baseline assessment materials to complete, which includes the demographic form, MPSS, proxy-MPSS (caregivers only) and MS questionnaires. The questionnaires were completed by each IWA and their caregiver separately and were completed in approximately one 20-minute session. Order of questionnaire presentation was counterbalanced across participants. Every question was read aloud by the author and participants were encouraged to point and say their

answer aloud. When participants demonstrated difficulty understanding a question, the Communicative Support Hierarchy and Independence Rating Scale (Tucker, et al., 2012) was utilized to facilitate understanding of questions. The scale was systematically normed to be used with IWAs and provides 5 specific steps for the examiner to support participants during test item administration, such as “1. Repeat the question and choices” and “2. Simply and restate the questions” (pg. 45, Tucker et al, 2012).

3.6 Statistical Analysis

Two independent sample *t*-tests were completed to determine if significant differences existed in both proxy and IWA perceived stress and mutuality. To describe the level of agreement on the mPSS in IWAs and caregivers we made two calculations. First, to examine absolute agreement we calculated the absolute value (proxy mPSS minus IWA mPSS). Second, to describe the direction of disagreement (i.e., did the caregiver rate the IWA as being more or less stress than the IWA reported), the following calculation was performed (proxy mPSS minus IWA mPSS). A Pearson’s correlation was then performed across the following measures: (1) Caregiver MPSS, (2) IWA mPSS, (3) Proxy mPSS, (4) Absolute Agreement, (5) Direction of Disagreement, (6) Caregiver MS, and (7) IWA MS. Pearson's correlation was performed to determine if higher mutuality scores lead to better agreement on perceived stress, if higher mutuality scores between the caregiver and the IWA lead to lower perceived stress, and if greater caregiver stress lead to higher proxy scores.

CHAPTER FOUR: RESULTS

4.1 Descriptive Statistics

Please refer to Table 4 for individual data. IWAs' mPSS scores ranged from 2-15 points ($m=10.08$, $SD=1.16$) and the caregiver mPSS scores ranged from 7-21 points ($m=10.92$, $SD=5.35$). The Proxy mPSS scores ranged from 4-25 points ($m=15$, $SD=5.35$). The Direction of Disagreement scores ranged from -15 to 1 ($m=4.92$, $SD=6.27$) and the Absolute Agreement scores ranged from 1-15 points ($m= 6.75$, $SD= 4.00$). Caregiver MS ranged from 1.87-3.93 points ($m=3.24$, $SD=0.69$) and IWAs MS ranged from 2.40-4.00 points ($m=3.33$, $SD=0.56$).

Table 4. Descriptive statistics for questionnaires

Pt #	Caregiver mPSS	IWA mPSS	Proxy MPSS	Direction of Disagreement	Absolute Agreement	Caregiver MS	IWA MS
1	7	12	11	1	1	3.67	3.73
2	1	15	5	-10	10	3.93	3.60
3	9	12	18	-6	6	1.87	2.87
4	9	7	11	-4	4	3.87	3.87
5	15	7	16	-9	9	3.73	3.80
6	8	6	21	-15	15	2.67	2.60
7	7	7	15	-8	8	2.27	2.40
8	14	15	25	-10	10	2.67	2.93
9	17	14	22	-8	8	3.33	3.07
10	10	2	4	-2	2	3.73	4.00
11	21	13	17	-4	4	3.67	3.93
12	13	11	15	-4	4	3.47	3.13
Mean	10.92	10.08	15	4.92	6.75	3.24	3.33
SD	5.35	1.16	5.35	6.27	4.00	0.69	0.56

Note. Modified Perceived stress scale (mPSS); Individual with Aphasia (IWA).

RQ 1. An independent samples *t*-test and a Pearson correlation were conducted between the IWA mPSS and the Proxy mPSS for the entire sample ($n=12$) to determine the level of agreement between the IWA perceived stress and the caregiver's perception of the IWA stress.

The independent samples *t*-test was associated with a statistically significant effect between the dyad ($t(22)=-2.23$, $p=0.036$; Table 5). Results from the correlation indicated a moderate correlation ($r=0.36$, $p<0.254$; Table 6).

Table 5. Independent Samples t-test

Measure	F	t	Sig. (2-tailed)
MPSS	22	-2.23	0.036
MS	22	0.35	0.733*

Note. * $p<0.05$

Table 6. Pearson Correlation

Measure	Caregiver MPSS	IWA MPSS	Proxy MPSS	Direction of Disagreement	Absolute Agreement	Caregiver MS	IWA MS
Caregiver MPSS	1						
IWA MPSS	0.14	1					
Proxy MPSS	0.55	0.36	1				
Direction of Disagreement	0.47	-0.30	0.78	1			
Absolute Agreement	-0.15	0.09	0.49	0.44	1		
Caregiver MS	0.09	-0.05	-0.57	-0.55	-0.38	1	
IWA MS	0.17	-0.11	-0.60*	-0.54	-0.59*	0.85**	1

Note. Modified Perceived stress scale(mPSS); Individual with Aphasia (IWA). ** $p<0.01$ (two tailed). * $p<0.05$ (two tailed).

RQ 2. An independent samples *t*-test and a Pearson correlation were conducted between the IWA MS and the caregiver MS to assess the level of perceived mutuality between IWAs and their caregivers. The independent samples *t*-test was not associated with a statistically significant difference between the dyad ($t(22)=0.35$, $p=0.733$; Table 5). Results from Pearson correlation

indicated a statistically significant, strong correlation between the IWA MS and the caregiver MS ($r=0.85$, $p<0.00$; Table 6 and Figure 1).

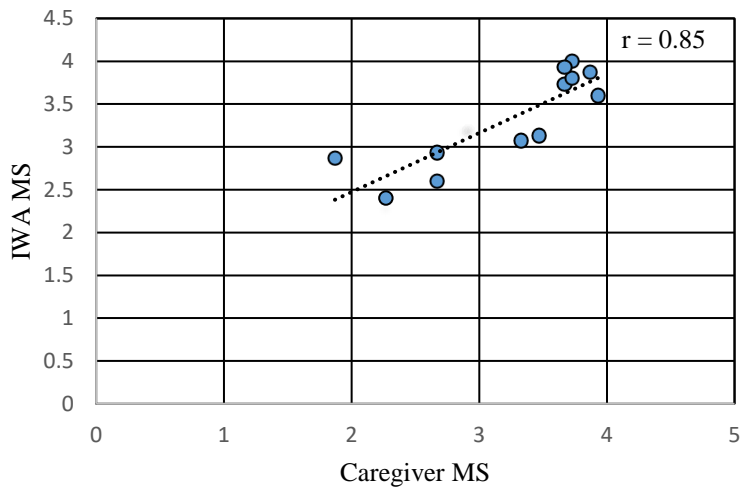


Figure 1. Scatter plot for IWA MS and Caregiver MS
This figure illustrated a significant strong correlation between IWA MS and Caregiver MS.

RQ 3. A Pearson correlation test was conducted to determine if higher agreement between the IWA and the caregiver on the mPSS correlated with higher MS. To do this, the Absolute Agreement score for the mPSS, the IWA MS, and the caregiver MS were used (see Table 2). Results show a statistically significant, moderate correlation between the IWA MS and the MPSS Absolute Agreement score ($r= -0.596$, $p<0.042$; Table 6 and Figure 2) and a moderate correlation between the caregiver's MS and the mPSS difference score ($r= -0.381$, $p<0.222$; Table 6 and Figure 3). There was a negative correlation between variables; as the mPSS Absolute Agreement score decreased, there was an increase in the MS score among the dyad.

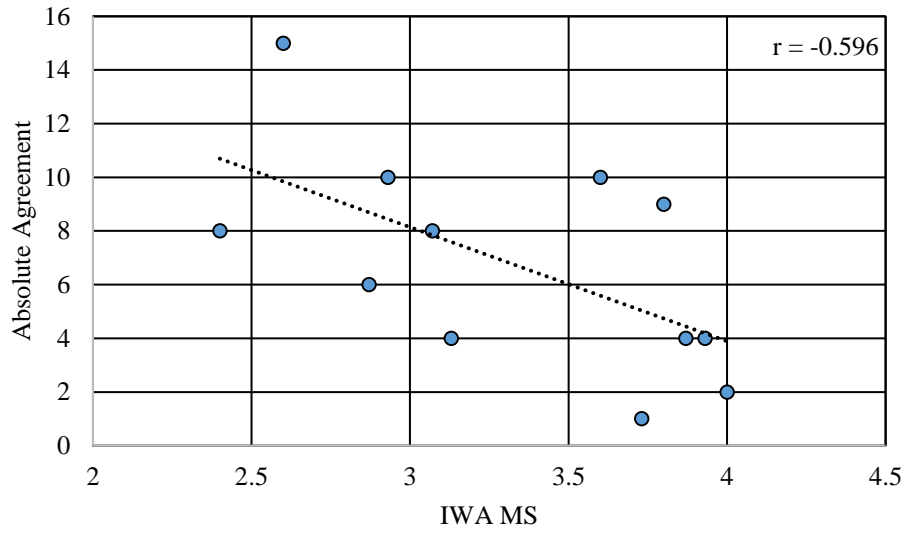


Figure 2. Scatter Plot for IWA MS and Absolute Agreement
 This figure illustrates the significant moderate correlation between IWA MS and Absolute Agreement on the Proxy-MPSS.

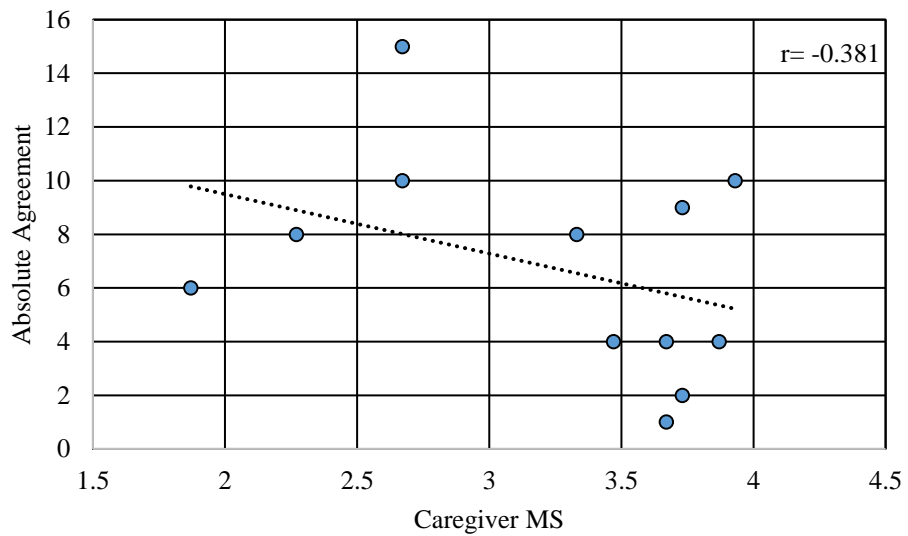


Figure 3. Scatter Plot for Caregiver MS and Absolute Agreement
 This figure illustrates moderate correlation between caregiver MS and Absolute Agreement on the Proxy-MPSS.

RQ 4. A Pearson correlation test was conducted between the mPSS and MS for both dyads to determine if higher mutuality scores between the caregiver and the IWA lead to lower perceived stress scores. Results indicated a weak correlation for the IWA ($r=-0.112$, $p<0.730$; Table 6) and a weak correlation for the caregiver ($r=0.86$, $p<0.790$; Table 6).

RQ 5. Lastly, we looked at the caregiver’s mPSS scores and the affect it had on level of agreement across the proxy-mPSS. A Pearson correlation was conducted between the caregivers mPSS score and the Direction of Disagreement Score for the mPSS. Results indicated a moderate correlation ($r=0.466$, $p<0.127$; Table 6 and Figure 4).

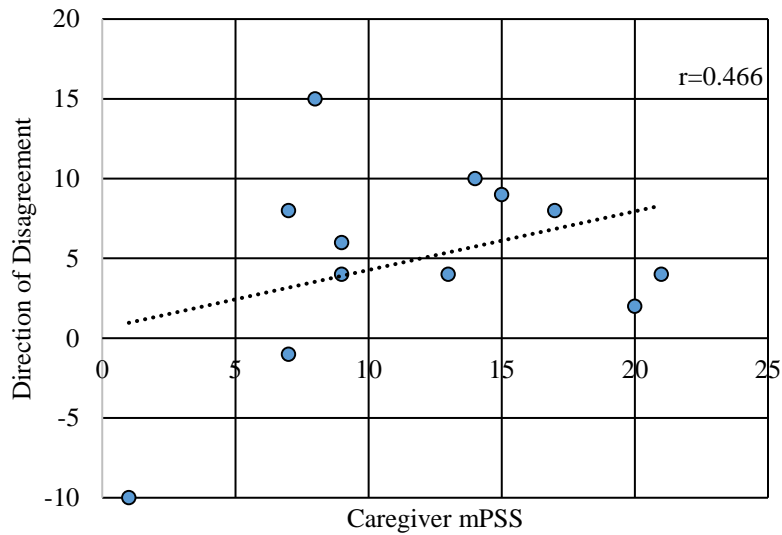


Figure 4. Scatter Plot for Caregiver mPSS and Direction of Disagreement
 This figure illustrates a moderate correlation between caregiver mPSS and Direction of Disagreement on the proxy-MPSS.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The purpose of this study was to examine the degree of agreement a caregiver has with an IWA's perceived stress using a modified stress scale for IWAs (mPSS; Hunting Pompon, et al., 2018). The relationship between perceived stress and mutuality of the caregiver and IWAs relationship was also explored. To our knowledge, this is the first study to systematically examine the level of agreement between an IWA and a proxy-caregiver on a measure of perceived stress. Past studies suggest less agreement on subjective domains, such as depression, and more agreement on objective domains, such physical abilities or limitations (Chen, Hsieh, Mao, & Huang, 2007; Poulin & Desrosiers, 2008; Sneeuw, Aaronson, de Haan, & Limburg, 1997; Tooth, McKenna, & Smith, 2003). Although proxy-reports will never be an exact representation of a patient, having an increased understanding on the level of accuracy on these reports can potentially help clinicians enhance the rehabilitation process, thus improve the QoL for the IWA and their caregiver. In the following sections we discuss the level of agreement an IWA and their caregiver had on a measure of perceived stress and the impact of mutuality and caregiver stress on this agreement.

5.2 Agreement on the mPSS

Our findings indicate moderate agreement between the IWA and their caregiver, via proxy rating, on the mPSS ($r= 0.36$). This means there was fair agreement in the way caregivers rated the perceived stress of IWAs. The proxy ratings were associated with a larger mean score on the mPSS in comparison to IWAs, which suggests that caregivers perceive the stress that

IWAs experience as higher than that reported by IWAs. These findings differ slightly from the extant literature and our hypothesis. Specifically, agreement is lower than the level of agreement in subjective domains reported in the literature for IWAs. For example, Cruice et al. (2005) reported a correlation of 0.49 in the Feelings domain, 0.54 in the Pain domain, and 0.75 in the Mental Health domain from the Short Form-36 Health Survey (SF-36). Hilari et al. (2007) reported a correlation of 0.7 in the Psychosocial domain and 0.5 in the Energy domain from the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39). Although these two studies found higher proxy agreements, they also had more participants. Therefore, it is possible agreement for the current study would have been higher if we had more power. In addition, the current study included participants that were six months or more post stroke, whereas past studies (e.g., Cruice et al., 2005; Hilari et al., 2007) only included participants who were at least 12 months post-stroke. Thus, time post onset may also be responsible for differences in findings. Interestingly, the results of Hilari et al., (2007) suggest that time post stroke influences agreement on QoL ratings between the proxy-responder and the stroke survivor, more so than the proxy-responder's mood or other characteristics. Other studies have shown the level of agreement on proxy reports increases with long-term patients as they are more stable and the dyad has had more experience with the symptoms of stroke (Pickard et al., 2004; Clarridge & Massagli, 1989).

5.3 Mutuality

Our findings show that both the caregiver and the IWA rated their mutuality high. In other words, both the caregiver and the IWA perceived a close relationship as measured by interconnectedness, love, and appreciation for one another. This finding is consistent with our

hypothesis. High mutuality may be attributed to marital status, as most of the dyads were married or partnered and living together. On average, IWAs rated their mutuality slightly higher than the caregiver. This finding is similar to Godwin et al. (2013), where caregivers were found to rate their mutuality lower than the IWA. This slight discrepancy between the IWA and caregiver mutuality rankings may be accredited to increased caregiver stress, as a result of caring for an IWA. The communication difficulties that accompany aphasia not only impact the IWA but may also increase caregiver stress. Studies show that caregivers of IWAs demonstrate increased depression, loneliness, and other psychological disorders compared to caregivers of non-aphasic stroke survivors (Ross & Morris, 1988; Christensen & Anderson, 1989; Michallet, Le Dorze, & Tetreault, 2001; Draper et al., 2007). Nonetheless, the caregivers and the IWAs in our study rated their mutuality high which is indicative of an overall positive caregiver-patient relationship as measured by the MS.

5.4 Higher Mutuality and Increased Proxy Agreement

The results suggest that as perceived mutuality for IWAs and caregivers increases the differences between the IWA's mPSS score and the caregiver proxy-mPSS score decreases. Thus, increased mutuality among pairs is associated with increased agreement on the mPSS. In other words, caregivers are more likely to accurately depict an IWA's perceived stress if the dyad perceives a closer relationship. This finding is consistent with the hypothesis. This is the first study to examine proxy ratings on stress in IWAs. The results of this study suggest that higher mutuality between the dyads is associated with greater agreement on perceived stress. Interestingly, the correlation between IWAs MS and mPSS Absolute Agreement score had more

of a significant affect (difference of 0.042) than that of the caregivers MS and mPSS Absolute agreement score (difference of 0.222). In other words, an IWA's perceived mutuality may have a greater influence on perceived stress agreement than the caregivers perceived mutuality. To date, no other study has looked to see if mutuality influences agreements on proxy reports within subjective domains. The extant literature, however, indicates that spousal caregivers have reported higher perceived stress and lower mutuality (Godwin et al., 2013) and that caregiver stress is influenced by the stress of the stroke survivor (Ostwald et al., 2009). The findings of our study imply that when an IWA perceives a healthier relationship with their caregiver, the caregiver is more likely to accurately depict the IWA's stress levels via proxy report. Overall, increased mutuality among dyads is associated with increased accuracy on the proxy-mPSS report.

5.5 Mutuality and Perceived Stress

Our findings show that higher mutuality between the caregiver and IWA did not correlate with lower perceived stress scores. In other words, the mutuality between dyads did not influence perceived stress scores for IWA and/or caregivers. This finding is not consistent with our hypothesis, as we predicted that that higher mutuality between dyads would be associated with lower perceived stress. These finding differ from Godwin et al. (2013), where higher levels of mutuality were strongly associated with lower levels of stress in stroke survivors. While this finding is not supported by the current study, we did observe this pattern for a few participants. Specifically, participants 1, 4, and 10 reported high mutuality and lower stress. All three of these participants were female, but differed across age, time post onset, and caregiver relationship, i.e.,

parent vs. spouse (see Table 1) and differed in aphasia severity based on the CAT and WAB-R (see Table 2 and 3). The study by Godwin and colleagues (2013) differs from the current study in several ways. In particular, it was a longitudinal study that followed stroke survivors at three different time frames throughout the first 12 months' post-stroke, they administered the PSS rather than the mPSS, and included 159 stroke survivors and their caregivers. The study also included individuals with left and/or right hemisphere damage and did not report presence of aphasia. The methodological differences between studies likely influenced dissimilar findings. Further, a study by DuBay et al. (2011) suggests that IWAs have fewer resources to cope with perceived stress, thus impairing their ability to successfully monitor and manage stress. Thus, mutuality may influence perceived stress differently in IWAs compared to stroke survivors without aphasia.

5.6 Caregiver Stress and Proxy Agreement

Our findings show that as caregiver perceived stress increases, so does their proxy rating on the mPSS. In other words, the higher the caregivers perceived stress, the more likely they are to overestimate the IWA perceived stress. This finding is consistent with our hypothesis and is supported in the literature. For example, Williams et al. (2006) found a relationship between caregiver stress and proxy-HRQoL for stroke survivors. Specifically, caregivers with higher stress and caregiver burden reported lower proxy-HRQoL compared to the stroke survivor. Consequently, Hung et al. (2007) found that caregivers with physical pain tend to overestimate the physical pain the stroke survivor is experiencing and that caregivers with depression tend to underestimate stroke survivor pain. These studies suggest caregiver strain, whether emotional or

physical, effect how they rate their loved ones in subjective and objective domains. Therefore, the caregivers emotional and physical state should be taken into consideration when relying on them for proxy reports. Incorporating caregiver questionnaires with proxy questionnaires may help professionals interpret the report and possibly provide additional support and education to the caregiver.

5.7 Study Limitations

This study has several limitations. First, the sample size is small ($n=12$) in comparison to similar proxy studies (e.g., $n=30$ and $n=50$), which makes it difficult to generalize these findings to all IWA and their caregivers. Further, the small sample size limits our ability to explore additional variables that may influence findings, such as age post onset or aphasia severity. Second, there was a large range of time post onset (7-209 months), whereas similar studies have only included IWA at least 12 months post-onset. Time post onset may influence results in proxy studies as dyads with greater time post onset have more experience and exposure to the symptoms of aphasia (Hilari et al., 2007). Third, the MS was not normed for IWA, but was used as it was the best option available. Most participants demonstrated comprehension of all questions when first presented verbally and visually. For those that demonstrated difficulty the Communicative Support Hierarchy and Independence Rating Scale (Tucker, et al., 2012) was done to improve their understanding. Finally, in the current study caregivers were given the mPSS rather than the PSS. The mPSS was specifically created for IWA, whereas the PSS was normed on the general population in the United States. We choose to give the mPSS to the caregivers to maintain consistencies in the language used across the dyads. However, due to the

difference in language in the mPSS, the caregivers perceived stress cannot be accurately compared to past studies that have used the PSS.

5.8 Future Directions

Future proxy studies should continue the use of the mPSS as a tool to measure perceived stress in IWA and explore additional psychosocial variables that may affect the caregiver-proxy agreement on chronic stress. Assessing chronic stress and depression in people with acquired neurogenic communication disorders continues to be a complicated mission, as they are often excluded from studies that measure psychological disorders following a stroke (Spencer, Tompkins, & Schulz, 1997). Therefore, future proxy studies with IWA as participants should include larger sample sizes and examine potential confounding or influential variables such as age, time post onset, aphasia severity, socioeconomic background, and individuals not in therapy.

Additional research into mutuality and its impact on psychological disorders post-stroke between the IWA and their caregivers should be explored. A mutuality scale that is developed and normed for people who have acquire neurogenic communication disorders can be a tool used to help individualize treatment and help counsel IWA and their caregivers or family members. Future studies may want to explore the affect support groups may have on mutuality among the dyad and the long-term management of chronic stress. In addition, it can be used as a potential tool to help provide additional insight to potential discrepancies between the caregiver-proxy and patient report in subjective domains such as depression and chronic stress.

Finally, the impact of caregiver's stress and its influence on proxy ratings for IWA should be explored in more depth, as the results of the current study suggest that caregiver stress may have a negative impact on the level of agreement on proxy ratings. In addition, severity of aphasia should be looked into as another potential factor directly impacting level of agreement on proxy ratings. Past studies have highlighted how spousal caregivers for IWA have a difficult time adjusting to their new role as a caregiver (Ross & Morris, 1989; Michallet, Le Dorze, & Tetreault, 2001). Future proxy studies should also explore the stress experienced by parent and child caregivers. Furthermore, other potential confounding variables for the caregiver, such as preexisting psychological conditions, alcohol or substance use, caregiver health, personality traits, age, and sex should be explored.

5.9 Conclusion

In conclusion, this study sought to examine the level of agreement IWAs and their caregivers had on perceived stress and the impact mutuality had on this agreement. This is the first study to explore proxy agreement on the mPSS. Findings indicate fair agreement on perceived stress among caregivers and IWAs. We found that mutuality and caregiver stress influenced agreement scores on the mPSS in these 12 participants. Specifically, differences in proxy agreement scores on perceived stress improved when perceived mutuality increased among the dyad. On average, caregiver-proxy MPSS scores tended to be higher than that reported by the IWA, particularly if their perceived stress was higher.

The results of this study provide support for the use of proxy-derived information in perceived stress. Specifically, a caregiver-proxy is likely an accurate report of an IWA's

perceived stress if mutuality between the IWA and their caregiver is high. However, this does not suggest using a caregiver-proxy when an IWA can self-report, as proxy reports do not match those of IWA perfectly. In general, disagreement in proxy scores are higher when utilizing subjective questionnaires that cover psychological disorders such as depression, anxiety, and chronic stress in IWA (Cruice et al., 2005; Hilari et al, 2007).

More research is necessary to support the validity of proxy reports, particularly in the areas of subjective domains such as chronic stress and depression. Nonetheless, the importance of including both the IWA and the caregiver in interventional research is becoming increasingly popular. Both members of the dyad are a crucial component in identifying psychological symptoms that can't be readily assessed by professionals and moreover, are a major contributor to the success of rehabilitation.

APPENDIX A: IRB HUMAN SUBJECTS PERMISSION LETTER



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board

FWA00000351
IRB00001138
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

April 30, 2019

Dear Nelson Hernandez:

On 4/30/2019, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study, Category 2
Title:	Caregiver-proxy and individual with aphasia self-report agreement on the Modified Perceived Stress Scale and Mutuality Scale
Investigator:	Nelson Hernandez
IRB ID:	STUDY00000409
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Racine Jacques, Ph.D.
Designated Reviewer

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