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PRELIMINARY INVESTIGATION OF AN APHASIA-FRIENDLY VERSION OF THE PHQ-8 COMPARED TO OTHER PATIENT AND PROXY REPORTED OUTCOME

MEASURES OF DEPRESSION

By

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Bachelor of Arts, Washington State University, Spokane, WA, 2018

Thesis

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Preliminary Investigation of an Aphasia-Friendly Version of the Patient Health Questionnaire - 8 Compared to other Patient and Proxy Reported Outcome Measures of Depression

Chairperson: Catherine Off, Ph.D.

Persons with aphasia (PWA) experience post-stroke depression more frequently than stroke survivors who do not have aphasia. Currently, no patient reported outcome measures that screen for depression have been created specifically for PWA or modified to be aphasia friendly for PWA. The purpose of this preliminary study is to modify the Patient Health Questionnaire-8 (PHQ-8) to an aphasia friendly format and to assess the feasibility of administering the modified assessment compared to other patient-reported and proxy-reported outcome measures used to screen depression. This retrospective analysis examined pre- and post-treatment outcome measures of depression for seven stroke-survivors with aphasia. The Patient Health Questionnaire -8 (PHQ-8) was modified to an aphasia friendly format through simplification of questions, increased font size, addition of a calendar representation of possible responses, and addition of pictures related to the question being asked. Prior to and immediately following an intensive comprehensive aphasia program (ICAP) lasting four weeks, stroke-survivors with aphasia were administered the modified PHQ-8 (mPHQ-8). Each stroke survivor also completed the Geriatric Depression Scale (GDS) and the Modified Perceived Stress Scale (mPSS); family caregivers completed a proxy measure, the Stroke Aphasia Depression Ouestionnaire -10 (SADQ-10). The GDS and SADQ-10 were administered in their original formats. The mPSS was administered in its designed format as an aphasia friendly version of the Perceived Stress Scale. The GDS, mPHQ-8, and SADQ-10 were scored immediately before and after the summer 2019 ICAP at the University of Montana. Undergraduate research assistants not involved in the data collection and blind to research procedures rescored all outcome measures for validity and reliability purposes. Means, standard deviation, and standard error of measurement are reported for each measure. Feedback about the feasibility and ease of administration of these measures was collected from speech-language pathology clinicians immediately following pre- and posttesting, and again approximately three months later. Clinicians report that the mPHQ-8 required less modifications than the GDS, and that responses to the mPHQ-8 were perceived to be more accurate than responses to the GDS. Data from this study provides preliminary support for the use of modified depression screening tools for use with PWA.

Key words: aphasia, depression, patient-reported outcome measures, proxy outcome measures, aphasia-friendly modification, psychosocial well-being

Preliminary Investigation of an Aphasia-Friendly Version of the Patient Health Questionnaire – 8 (PHQ-8) Compared to other Patient and Proxy Reported Outcome Measures of Depression

Introduction

Due to the high prevalence of stroke-related aphasia, and the known correlation between language disorders and reduced psychosocial outcomes, depression must be accurately screened for stroke survivors with aphasia. Aphasia is a neurologic condition stemming from damage to the centers of the brain that causes impairments of language abilities across multiple modalities including speaking, reading, writing, and understanding spoken language (Simmons-Mackie, 2018). Aphasia leads to deficits in everyday communication, perceived ability to communicate, social interactions, and a number of psychosocial outcomes, all of which significantly reduces overall quality of life (Baker et. al., 2019). The prevalence of aphasia in the United States alone is currently estimated between two and four million Americans (Simmons-Mackie, 2018). Given this high prevalence, individuals with aphasia must regularly be included in all stroke related research.

Stroke survivors with aphasia are more than twice as likely to develop depression than stroke survivors without aphasia (Wang et. al., 2018; Shehata et. al., 2014; Shiggins et. al., 2018; Ferenchick et. al., 2019; Kauhanen et. al., 2000). In a study conducted by Shehata and colleagues (2014), 61 stroke survivors were assessed for depression, anxiety, and personality characteristics using the <u>Beck Depression Inventory-II</u> (BDI-II; Beck, Steer, & Brown, 1996), the <u>Hamilton</u> <u>Anxiety Scale</u> (Hamilton, 1959), and the <u>Eysenck Personality Inventory</u> (Eysenck & Eysenck , 1978) to determine the impact of aphasia on psychosocial well-being (Shehata et. al., 2014). Of these 61 individuals, 30 stroke survivors were diagnosed with aphasia. The researchers found that individuals with aphasia, on average, scored over twice as high on the BDI-II than those without aphasia. The authors concluded that depression and aphasia were linked and that depression as well as other mood disorders should be regularly screened for post-stroke (Shehata et. al., 2014). In a similar study, Kauhanen and colleagues (2000) aimed to examine the relationship between aphasia, depression, and nonverbal cognitive impairments in 106 individuals who experienced an ischemic stroke. The researchers used the Western Aphasia Battery-Revised (WAB-R; Kertesz, 2006) to diagnose the presence and severity of aphasia and used the Diagnostic and Statistical Manual of Mental Disorders III - Revised (DSM-III-R) (American Psychiatric Association, 1987) criteria to diagnose depression. Of those diagnosed with aphasia, 70% were also diagnosed with depression. In comparison, only 46% of the individuals without aphasia were diagnosed with depression. The authors concluded that due to known correlation between aphasia and depression, that more comprehensive evaluations should be completed on PWA including measures of mood and well-being (Kauhanen et. al., 2000). Given the high prevalence of co-occurring depression and aphasia, individuals post-stroke would benefit from thorough evaluations that include screening measures for depression.

Factors Contributing to Depression in Stroke Survivors with Aphasia

Aphasia and the multitude of changes it brings to a person's life including social isolation, changes in self-identity, and reduced quality of life are linked to a higher risk of poststroke depression (Baker, Worrall, Rose, & Ryan, 2019; Baker et. al., 2020; Mohr et. al., 2017; Hilari et. al., 2012). Baker and colleagues interviewed 10 PWA to better understand perspectives and experiences post-stroke related to psychosocial well-being. PWA reported that having a stroke and the onset of aphasia were traumatic events. PWA also reported that depression and other mood related changes are not frequently addressed throughout the recovery process. From these interviews, the authors concluded that PWA with mood related changes may feel isolated and their social participation and engagement declines as a result (Baker et. al., 2020). These interviews support the need to frequently and properly screen for depression and mood related changes in PWA.

Persons with aphasia also experience changes to their self-identity as they navigate life with aphasia (Baker et. al., 2019; Baker et. al., 2020; Hilari et. al., 2012). PWA who may have been the main source of income for their family must adapt to life at home, even if for a short period, and PWA who may have ran the household often go through the process of learning to accept help from others. These changes in lifestyle may negatively impact how one may view themselves and their role in life. Collectively, these changes can increase the risk of post-stroke depression. Both social isolation and changes in self-identity can lead to a reduced quality of life (Baker et. al., 2019; Hilari et. al., 2012). Quality of life for PWA is also impacted and affected by socioeconomic status post-stroke, as well as social support. These abrupt changes in the lives of PWA, and the changes in language across modalities, all ultimately increase the likelihood of co-occurring post-stroke depression.

Depression has been observed more frequently in individuals with non-fluent as opposed to fluent aphasia (Starkstein & Robinson, 1988). Out of 25 participants with aphasia who were screened three months post-stroke, major depression was diagnosed in 33% of individuals with non-fluent aphasia compared to 5% of individuals with fluent aphasia. Though the researchers hypothesized that the higher incidence of depression in non-fluent aphasia may have been due to increased awareness for persons with aphasia (PWAs) with non-fluent aphasia compared to PWAs with fluent aphasia, a difference in general lesion location was also observed between individuals presenting with fluent versus non-fluent aphasia.

The higher prevalence of depression in individuals with aphasia may also be due, in part, to the overlapping lesion location sites that lead to aphasia and those that lead to depression. Both post-stroke depression and aphasia are associated with left-hemisphere lesions (Leeds, Meara, & Hobson, 2002; Starkstein & Robinson, 1988; Watila & Balarbe, 2015). Aphasia results from a stroke that occurs near or around language centers within the left hemisphere (i.e., Wernicke's area, Broca's area, peri-sylvian region, angular gyrus, cingulate gyrus) (Yourganov et al., 2015). Similarly, depression following a stoke most commonly occurs when the lesion is near the frontal pole, the rounded most anterior portion of the frontal lobe, within the lefthemisphere (Starkstein and Robinson, 1988). Starkstein and Robinson (1988) examined the similarities between aphasia and depression in 25 stroke survivors with aphasia. These individuals were assessed using criteria in the DSM-III for presence of depression, and the Western Aphasia Battery-Revised (WAB-R) for presence of aphasia. Of the 25 observed, nine were diagnosed with major depression and six PWA were diagnosed with minor depression. Although the researchers did not find meaningful correlations between the type of aphasia and depression, a significant correlation was found between lesion location and depression. Seven individuals with depression and aphasia presented with lesions in the left frontal cortex or basal ganglia. This finding suggests that lesion location rather than aphasia type may be able to predict depression. Of the remaining ten individuals who did not present with depression, only one patient had a lesion that was in the left frontal lobe. Lesion location and involvement is important to consider as both aphasia and depression can coincide with or be caused by a left hemisphere lesion, increasing the likelihood for a comorbid diagnosis.

Separately, both depression and aphasia have been reported to have negative healthrelated impacts on overall quality of life (Leeds, Meara, & Hobson, 2002; Starkstein & Robinson, 1988; Watila & Balarbe, 2015; Simmons-Mackie, 2018; Baker et. al., 2020). With the increased likelihood of co-occurring depression and aphasia, it is necessary to screen for and identify risk factors for depression to ensure that PWA are provided with the services and supports that they need throughout their recovery.

The Impact of Co-Occurring Poststroke Depression and Aphasia

Depression directly impacts language expression as well as language recovery, resulting in an increased need to properly identify depression in individuals with aphasia (McCann & Lalonde, 1993; Watila & Balarbe, 2015; Starkstein & Robinson, 2007; Shiggins et. al., 2018; Ferenchick et. al., 2019). Individuals with aphasia are at an increased risk for social isolation, which may be worsened with a comorbid depression diagnosis. Morris, Robinson, and Samuels (1993) sought to examine the relationship between depression, introversion, and mortality following stroke. In doing so, they observed 94 patients two months after stroke, and 84 of those same patients again at 15 months post-stroke. Forty-four of these individuals had mild aphasia. All participants were assessed for symptoms of depression using the DSM-III criteria at both the two-month and 15-month assessments. Participants were also observed for signs of introversion such as living alone, being unmarried, having no reported people with whom they are close to, and or social isolation. The researchers found that individuals with depression who also exhibited signs of introversion had a 60% mortality rate. They also found that mortality rates increased with more severe depression types. In addition to mortality rates increasing for individuals' poststroke with depression, other health consequences were observed. Depression led to decreased compliance with health-care related treatment or tasks, and an increase in plasma cortisol levels.

The authors suggested that when cortisol levels rise, the immune system may be affected, causing individuals to be more prone or vulnerable to infections. This study provides evidence that depression has the potential to significantly influence a wide range of health-related outcomes.

Post-stroke depression also leads to differences in communicative patterns such as monotonous speech, reduced eye contact, and increased use of gestures that are unrelated speech (McCann & Lalonde, 1993). These changes in communication patterns, combined with language impairments associated with aphasia, may significantly hinder an individual's ability to communicate effectively, increasing the risk of social isolation, and possibly increasing the risk of mortality following a stroke.

Collectively these studies suggest that the combination of post-stroke depression and aphasia has potential to significantly reduce health outcomes and further impair successful communication, communicative participation, and quality of life. It is essential to accurately and reliably screen for post-stroke depression in individuals with aphasia throughout the rehabilitation process.

Screening for Depression Following Stroke

Though the comorbidity of depression and aphasia following stroke is well known, depression is not frequently screened for in stroke survivors with aphasia (Baker et. al., 2019). Across healthcare settings it is unclear where the responsibility for screening an individual poststroke for depression falls when there is co-occurring aphasia. In 2019, Baker and colleagues examined the roles of 39 stroke-related healthcare professionals in assessing and treating depression in PWA by including them in focused discussions. Through this study the authors found that though speech language pathologists have the training and understand how to communicate effectively with PWA, it is outside their scope of practice to truly address emotional well-being. Mental health care providers, such as psychiatrists, report that it is difficult to diagnose depression in PWA due to language impairments (Baker et. al., 2019). The authors suggested that an interdisciplinary approach to assessing and treating depression in PWA would be beneficial to bridge the gap caused by language impairments. Without training related to aphasia, an interdisciplinary approach, and the creation of aphasia friendly healthcare related materials, screening for depression in PWA will continue to be neglected.

There are several methods of screening for depression in stroke survivors. Two screening methods that are commonly used are (1) patient reported outcome measures, and (2) proxy reported outcome measures (Yesavage & Sheikh, 1986; Kroenke et. al., 2009; Leeds, Meara, & Hobson, 2004). Patient reported outcome measures (PROMs) are being used more frequently as healthcare continues to shift towards a model that places the patient at the center of all care and aims to better understand healthcare from the perspective of the patients (Yorkston & Baylor, 2019). PROMs are assessment measures that are designed to gather information directly from the patient without interpretation, significant assistance, or use of a proxy (Yorkston & Baylor, 2019). PROMs measure outcomes or variables that may change as a result of obtaining treatment, and they are designed to measure this change from the patient's perspective rather than clinician judgement or the caregiver's assessment of the patient. Several PROMs have been developed to screen for depression including the <u>Beck Depression Inventory-II</u> (BDI-II; Beck, Steer, & Brown, 1996), the <u>Geriatric Depression Scale – Short</u> (GDS; Yesavage & Sheikh, 1986), and the <u>Patient Health Questionnaire – 8</u> (PHQ-8; Kroenke et. al., 2009).

The <u>Beck Depression Inventory – II</u> (BDI -II) is a 21 – question assessment designed to measure depression severity in individuals aged 13 - 80 with a sensitivity of 0.81 and a

specificity of 0.92. The BDI-II consists of 21 questions that have four response options. These options are consistently ranked with point values zero through three, though the wording of the given responses is different for each question.

Another patient-reported outcome measure used to screen for depression is the <u>Geriatric</u> <u>Depression Scale – Short</u> (GDS; Sheikh & Yesavage, 1986). This screening tool is designed to screen for the presence or absence of depressive symptoms in adults over the age of 65 without major medical, neurological, or psychiatric conditions. When used with the population that it was designed for, the GDS has a sensitivity of 0.71 and specificity of 0.78. The GDS has a construct validity measure of r=0.83, and a test-retest reliability coefficient where r=0.84. The GDS-Short contains 15 questions on a single page (see appendix A). The GDS-Short uses a yes/no response format for all of the questions.

A third patient-reported outcome measure used to screen for depression is the <u>Patient</u> <u>Health Questionnaire-8</u> (PHQ-8; Kroenke et al., 2009). The PHQ-8 is designed to identify presence or absence of depressive symptoms as well as to document the severity of depressive symptoms. The PHQ-8 was initially designed for use in primary care populations. The PHQ-8 has a construct validity of r=0.99 and an internal reliability rating of r=0.82. This measure has only eight questions in comparison to the 21 and 15 seen on the prior two screening tools (Appendix A). As well as having fewer questions, the PHQ-8 uses the following rating scale in relation to the last two weeks for all eight questions: (1) *Not at all*, (2) *Several Days*, (3) *More than Half the Days*, and (4) *Nearly Every Day*.

The BDI-II, GDS-Short, and PHQ-8 are all valuable, psychometrically sound screening tools for depression. Unfortunately, none of these patient-reported outcome measures has been validated, normed, or adapted for use with stroke survivors with aphasia. Recently, the Research

Outcome Measurement of Aphasia (ROMA) consensus was reached during which researchers identified the <u>General Health Questionnaire -12 (GHQ-12)</u> as being the best measure to use to assess broad emotional well-being in individuals with aphasia (Wallace et. al., 2018), but no measures were identified to specifically screen for depression. The ROMA consensus also determined that the <u>Stroke Aphasic Depression Questionnaire -10</u> (SADQ-10: Leeds, Meara, & Hobson, 2004), a measure completed via proxy response, is not appropriate for screening for depression in PWA.

Screening for Depression Following Stroke in Individuals with Aphasia

Due to the health risks following a stroke, and the increased likelihood of depression cooccurring with aphasia, it is important to accurately screen for depression in stroke survivors with aphasia. While individuals with mild aphasia can typically complete self-report measures independently, those with moderate or severe aphasia often require support from a speechlanguage pathologist who can adapt the scale or use visual analogue scales to support reading comprehension of the measure. The ultimate goal of PROMs is for the PWA to independently complete the measure.

Though there are multiple patient-reported screening tools and proxy measures for poststroke depression, current patient-reported outcome measures designed to screen for depression are not aphasia-friendly (Leeds, Meara, & Hobson, 2002; Laures-Gore et. al., 2017; Rose et. al., 2011). In 2011, Rose and colleagues sought to understand exactly what aphasia friendly medical information needed to include by interviewing 40 individuals with aphasia. Through the interviews and modification of materials, a general consensus was formed that described aphasia friendly health information as follows: (1) are easy to read, (2) can be read through quickly, (3) are clear, and (4) look as though they were made by someone who understood the challenges that individuals with aphasia have with text-heavy documents. These interviews also revealed why individuals with aphasia were displeased with non-aphasia friendly written information. The participants reported that non-aphasia friendly materials contained the following: (1) large amounts of text, (2) long words, (3) information written in medical jargon, and (4) information not organized in a way that was easy to read and understand. Perspectives of PWAs should be considered when providing health related information to individuals post-stroke.

Given these findings, administering an individual with aphasia a text-heavy, hard to read depression screening measure, such as the Beck Depression Inventory- II (BDI-11), Geriatric Depression Scale-Short (GDS- Short), or the Patient Health Questionnaire-8 (PHQ-8) to fill out without assistance is not appropriate. The questions presented on the BDI-II are typed in a small font and are close together, making it challenging for an individual with aphasia to focus on one question at a time. The BDI-II also contains a long paragraph at the top with instructions, making the individual rely solely on text-based cues. The BDI-II also uses different responses for each of the 21 questions, offering no consistency and a new reading and response challenge with each answer. Similarly, one of the downsides to the GDS-Short lies in the length and complexity of the syntax of the questions being asked. From an aphasia friendly standpoint, questions need to be syntactically less complex to aid in reading and/or auditory comprehension. Another downside of the GDS-Short lies within the answers to the questions as the only options are "yes" or "no". Binary choices are often hard to make, with no option for an "in between" response. PWAs also often grammatically confuse "yes" and "no", reducing the reliability of their responses. Although the PHQ-8 incorporates a rating scale and has fewer questions, it is also not an aphasia friendly resource to use in screening for depression. The PHQ-8 contains small

font sizes, long, syntactically complex questions that target two content areas at once and relies solely on reading comprehension of text.

Due to the common difficulty of implementing text-heavy documents requiring significant reading comprehension skills for PWA, proxy screening tools were developed to be completed by a caregiver rather than the individual with aphasia (Leeds, Meara, & Hobson, 2002; Laures-Gore et. al., 2017; S. Screening Tools). Johns Hopkins University defines a proxy measure as an indirect way of measuring desired outcomes due to a barrier in a direct form of measurement (2017). One proxy measure for screening depression in individuals with aphasia is the Stroke Aphasic Depression Questionnaire -10 (SADQ-10). This measure was designed to screen for depressive symptoms in PWA by gathering information from a caregiver who has at least weekly contact with the PWA. The SADQ-10 has ten questions and uses a rating scale related to the last week (Appendix B). In 2004, Leeds and colleagues calculated the sensitivity and specificity of the SADQ-10 and found these values to be 0.70 and 0.77 respectively. These values were calculated when the cutoff for detecting depressive symptoms was set at 14 out of 30 points on the SADQ-10. Leeds and colleagues also discovered that the SADQ-10, in comparison to the GDS, was not a valid measure of depression due to a weak association between the two. Another proxy measure designed to screen for depressive symptoms in PWA is the Aphasia Depression Rating Scale (ADRS; Benaim et. al., 2004). This measure has nine areas that the proxy rates and does not follow a specified timeline. The rating scales for the nine areas are all different and have different point values (Appendix B). In 2004, Benaim and colleagues found the sensitivity and specificity of the ADRS to be 0.83 and 0.71 respectively. These values were found when the cutoff for detecting depressive symptoms was set at nine out of 32 possible

points on the ADRS. The ADRS is also designed to be completed by a caregiver who has at least weekly contact with the PWA.

Though both the SADQ-10 and ADRS have been designed with the aphasic population in mind, they both neglect to include the patient's perspective, relying solely on another person's perception of the PWA's psychosocial well-being. Proxy measures may or may not provide accurate information depending on the level of contact the caregiver has, or their own emotional influence on the answers that are given as family members and caregivers of individuals with aphasia also experience mood and communication related changes and difficulties (Shiggins et. al., 2018). While a positive correlation between language and reduced psychosocial well-being is known, the use of proxy measures in aphasia related research may account in part for the higher reported rates depression in people with aphasia (Leeds, Meara, & Hobson, 2002; Volkers et. al., 2004; Ferenchick et. al., 2019; McCann & Lalonde, 1993). For future studies, it is important to address the differences between proxy measures and patient reported outcome measures in relation to depression screening tools for people with aphasia.

Statement of Problem and Research Questions

The population of stroke survivors with aphasia continues to increase along with stroke survival rates (Simmons-Mackie, 2018), leading to an increased population of individuals who may have concomitant post-stroke depression. Due to the language-based challenges that individuals with aphasia face throughout their recovery process, unmodified (i.e., aphasia "unfriendly") depression screening measures are not an appropriate choice for screening and may lead to an incomplete understanding of the comorbidity of aphasia and depression. With the shift towards patient-centered healthcare, considering the patient's perspective whenever possible, it is then also inappropriate to deliver a proxy-reported measure to screen for depression in individuals with aphasia. Therefore, it is necessary to explore ways in which depression can be screened for in individuals with aphasia that acknowledges both patient perspectives and is modified to assist with language comprehension to ensure accuracy of responses. The purpose of this preliminary study is to modify the <u>Patient Health Questionnaire- 8</u> (PHQ-8) to an aphasia-friendly format and to assess the feasibility of administering this modified assessment to individuals with aphasia compared to other patient-reported and proxy outcome measures of depression. The following research questions were explored:

- 1. Can the PHQ-8 be modified to an aphasia-friendly format?
- 2. Can a modified PHQ-8 be administered to PWA?
- 3. What are the clinician's perspectives of administering an aphasia friendly assessment compared to other unmodified patient reported outcome measures?

Methods

Participants

Seven stroke survivors with aphasia who were accepted and enrolled into the summer 2019 Big Sky Aphasia Program – Intensive Comprehensive Aphasia Program (BSAP-ICAP) at the University of Montana were recruited to participate in this study (IRB#116-14). The seven participants included three males and four females, ranging in age from 42 years to 73 years old. All seven participants presented with chronic, non-fluent aphasia stemming from cerebrovascular accidents (CVAs). See Table 1 for a summary of patient characteristics.

Table 1

Patient Characteristics

| PWA | Age | Sex | Date of | Time Post | Educational | Type of | Lesion |
|------|-----|-----|---------|-----------|-------------|---------|-------------|
| ID | | | CVA | CVA | Attainment | Aphasia | Location |
| | | | | (Months) | | | |
| PWA1 | 65 | F | May-16 | 37 months | Law Degree | Non- | Unspecified |
| | | | | | | fluent | |
| PWA2 | 48 | F | Feb-18 | 16 months | Bachelor's | Non- | Left MCA |
| | | | | | Degree | fluent | CVA |
| PWA3 | 42 | F | Nov-18 | 7 months | Bachelor's | Non- | Left MCA |
| | | | | | Degree | fluent | Infarct |
| | | | | | | | Left ICA |
| | | | | | | | Occlusion |
| | | | | | | | Left ACA |
| | | | | | | | Occlusion |
| PWA4 | 66 | М | May-18 | 13 months | Vocational | Non- | Left MCA |
| | | | | | School | fluent | CVA |
| PWA5 | 73 | М | Jul-14 | 59 months | Vocational | Non- | Left MCA |
| | | | | | School | fluent | CVA |
| PWA6 | 63 | М | Feb-17 | 28 months | Associate | Non- | Unspecified |
| | | | | | degree | fluent | |
| PWA7 | 67 | F | Dec-17 | 18 months | High School | Non- | Unspecified |
| | | | | | | fluent | |
| | | | | | | | |

Seven graduate student clinicians enrolled in the Speech-Language Pathology Program in the School of Speech, Language, Hearing, and Occupational Sciences at the University of Montana who had been assigned to the Big Sky Aphasia Program for their summer 2019 neurological rotation were also recruited to participate in this study (IRB#116-14). The seven participants included seven females, ranging in age from 22 years to 49 years old. See Table 2 for a summary of graduate student clinician characteristics.

Table 2

| Student Clinician ID | Age | <u>Sex</u> | Education | Race/Ethnicity |
|----------------------|-----|------------|------------------|----------------|
| C1 | 49 | F | M.S. Student | Caucasian |
| C2 | 23 | F | M.S. Student | Caucasian |
| C3 | 23 | F | M.S. Student | Caucasian |
| C4 | 23 | F | M.S. Student | Caucasian |
| C5 | 24 | F | M.S. Student | Caucasian |
| C6 | 49 | F | M.S. Student | Caucasian |
| C7 | 23 | F | M.S. Student | Caucasian |

Graduate Student Clinician Characteristics

One director of the Big Sky Aphasia Program who is a nationally certified and Montana state-licensed Speech-Language Pathologist at the University of Montana was recruited to participate in this study. This participant was a 29-year-old Caucasian female with a Master's degree in Speech-Language Pathology.

Selection Criteria

All participants with aphasia were 18 years-of-age or older, presented with aphasia, and had a history of speaking, reading, and writing American English fluently. All graduate student clinicians were 18 years of age or older and had a history of speaking, reading, and writing American English fluently.

Sampling Procedure

This study includes a sample of convenience. All participants with aphasia were selfreferred or referred to the Big Sky Aphasia Program ICAP from their healthcare provider. Participants who enrolled in the BSAP ICAP were invited to participate in the study. All graduate student clinicians were assigned to the Big Sky Aphasia Program neurological rotation for their summer 2019 clinical experience by their academic and clinical advisors. Graduate student clinicians were invited to participate in the study.

Procedures

Research Design

This study retrospectively analyzed individual and group data of participants with aphasia and graduate student clinicians including: (1) pre- and post-treatment patient-reported outcome measures (PROMs) of psychosocial well-being for people with aphasia (i.e., GDS, mPHQ-8, mPSS); (2) a pre- and post-treatment proxy-reported outcome measure of psychosocial wellbeing for people with aphasia (i.e., SADQ-10); and (3) graduate student clinician and clinical supervisor feedback about the ease of administering these measures of psychosocial well-being (i.e., the GDS, PHQ-8, and mPSS). This study reflects a Phase I investigation, exploring the feasibility of administering aphasia-friendly and aphasia non-friendly patient-reported and proxy-reported outcome measures to screen for depression in stroke survivors with aphasia (Hula, Cherney, & Worrall, 2013).

Modification of the Patient Health Questionnaire-8 (PHQ-8)

The <u>Patient Health Questionnaire – 8</u> (PHQ-8) was selected to assess the presence and severity of depression due to its relative ease of administration, the omission of questions relating to self-harm or thoughts of death, and the high reported reliability and validity in comparison to other well-known depression screening tools. In its pre-modified format, however, the PHQ-8 was not aphasia friendly. Prior to administering the measures of psychosocial well-being, the PHQ-8 was modified to make it accessible to individuals with aphasia.

The (PHQ-8) was modified in a manner similar to the procedures detailed by Hunting Pompon and colleagues (2018) for the <u>modified Perceived Stress Scale</u>. The PHQ – 8 was modified in the following ways: (1) by simplifying questions while maintaining crucial, meaning-bearing components of the original wording; (2) by breaking several questions (i.e., questions three, five, and eight) into two questions due to the complexity of the original questions asked; (3) by increasing the size of the font and assigning one question to each page of the screening tool; (4) by creating a calendar representation of the four possible responses as they related to a two-week time-line (i.e., not at all, several days, more than half the days, and nearly every day); and (5) by providing real-life picture representations of the main content asked in each question to further aid in comprehension of the question. See Appendix C for the modified PHQ-8 (mPHQ-8) and related images.

Assessment Measures

As part of a comprehensive pre- and post-treatment assessment battery, each graduate student clinician, under the direct supervision of state-licensed and nationally-certified speech-language pathologists administered the <u>Modified Patient Health Questionnaire-8</u> (mPHQ-8), the <u>Geriatric Depression Scale – Short Form</u> (GDS- Short), and the <u>Modified Perceived Stress Scale</u> (mPSS) to one person with aphasia, and gave the proxy measure, the <u>Stroke Aphasic Depression</u> <u>Questionnaire – 10</u> (SADQ-10), to one family caregiver of the person with aphasia. Clinicians administered the psychosocial measures in the following order: (1) GDS-Short, (2) mPSS, and (3) mPHQ-8. The mPHQ-8 was administered immediately following the mPSS to capitalize on the similar nature and format of the screening measures. Clinicians administered the three self-report measures in the same day. Immediately following the administration of these measures, clinicians were asked to reflect upon the ease of administering the <u>Modified Patient Health</u>

Questionnaire-8 in comparison to the Geriatric Depression Scale-Short Form, and in conjunction

with the Modified Perceived Stress Scale. See Table 3 for a description of the comprehensive

assessment battery administered to all participants before and after intervention.

Table 3

Assessment Battery for BSAP ICAP Summer 2019

| Outcome Measure | <u>Type of</u> Measure | <u>Purpose</u> |
|--|---------------------------|---|
| Geriatric Depression Scale (GDS; Sheikh & | Impairment | PROM used to detect presence of |
| Yesavage, 1986) | Based | depression |
| Communicative Participation Item Bank (CPIB; | Participation | PROM used to assess how aphasia has |
| Baylor et. al., 2013) | Based | affected communication participation |
| | | across environments |
| Communicative Confidence Rating Scale for | Participation | PROM used to gather information about |
| Aphasia (CCRSA; Cherney & Babbitt, 2011) | Based | self-perceived confidence when |
| | | participating in various life tasks and |
| | | conversations |
| Modified Perceived Stress Scale (mPSS; | Impairment | PROM used to assess perceived stress |
| Pompon et. al., 2018) | Based | levels |
| Modified Patient Health Questionnaire- 8 | Impairment | PROM used to detect presence and |
| (mPHQ-8; Walter & Off, 2019) | Based | severity of depressive symptoms |
| Western Aphasia Battery - Revised, Part 1 | Impairment | Measure used to detect presence or |
| (WAB-R; Kertesz, 2006) | Based | absence of aphasia, and to determine |
| | | aphasia severity and classification |
| Raven's Coloured Progressive Matrices (RCPM; | Impairment | Used to assess non-verbal problem |
| Kertesz, 2006) | Based | solving |
| Boston Naming Test- Second Edition (BNT-2; | Impairment | Used to assess confrontational naming of |
| Kaplan, Goodglass, & Weintrub, 2001) | Based | concrete nouns of decreasing word |
| | | frequency |
| Scales of Language Rehabilitation (SLR; | Impairment | Used to assess spoken language across |
| Millman, 2010) | Based | naming, sentence production, and |
| | - • | discourse |
| AphasiaBank Discourse Protocol (MacWhinney, | Impairment | Used to assess verbal discourse |
| 2000) | Based | production across discourse genres |
| | | (conversation, picture description, story |
| | | retell) |
| Assessment of Living with Aphasia (ALA; | Participation | Used to assess aphasia-related quality of |
| Kagan et. al., 2010) | Based | lite |
| Stroke Aphasic Depression Questionnaire -10 | Impairment | Proxy reported measure used to screen |
| (SADQ10; Leeds, Meara, & Hobson, 2004) | Based | Tor depressive symptoms in the PWA |
| Communicative Effectiveness Index (CETI; | Participation | Proxy reported measure used to assess |
| Lomas et. al., 1989) | Based | communicative participation in the PWA |

Immediately after administering the measures of psychosocial well-being, the graduate student clinicians were asked to complete a paper and pencil reflection form designed to gather information related to ease of administration of the GDS-Short in comparison to the mPHQ-8. At approximately three months post-treatment, graduate student clinicians were asked the same questions via a Qualtrics survey to anonymously collect their delayed feedback. The reflection form included the following questions (see Appendix D for the "Ease of Administration" form):

(1) How easy was the administration of the GDS?

(2) How easy was the administration of the mPHQ-8?

(3) In comparison to the GDS, was the mPHQ-8 easier or harder to administer? In what ways?(4) Did the PWA appear to respond better to the mPHQ-8 or the GDS?

(5) Did administration of the mPSS before the mPHQ-8 appear to aid in comprehension of the task for the PWA? If so, in what way?

(6) Any other thoughts on the GDS, mPHQ-8, or mPSS? Comment upon the administration, the person with aphasia's reaction, the timing, and/or level of assistance required.

Data Collection & Analysis

The patient-reported outcome measures (i.e., GDS, mPHQ-8, mPSS) were administered to participants with aphasia immediately before and immediately after participating in the summer 2019 ICAP. The SADQ-10 was administered to the caregivers of the participants with aphasia at the time of testing. Scores for each of these measures were initially calculated according to the test manual by the graduate student clinicians. Undergraduate research assistants blinded to the study rescored all outcome measures for accuracy. All scores were entered into Excel. Descriptive statistics including means and standard deviations were calculated for each measure pre- and post-intervention. Outcome measure change scores from pre- to post-treatment were assessed using Standard Error of Measurement (Harvill, 1991).

Qualitative feedback from the graduate student clinicians and ICAP Director was collected immediately after pre-treatment testing (i.e., Time 1), immediately following posttreatment testing (i.e., Time 2), and again approximately three months post-treatment testing (i.e., Time 3). Graduate student clinician and Director feedback was compiled and analyzed. Feedback was organized by the time at which it was collected (i.e., Time 1, Time 2, Time 3). The feedback was then evaluated for themes to qualitatively assess the information gathered on a larger scale. See Appendix D for the "*Patient Reported Outcome Measures: Assessment of Ease of Administration*" form.

Results

Stroke Survivors with Aphasia

Descriptive statistics including means and standard deviations were calculated for preand post-ICAP scores of the GDS, PHQ-8, and SADQ-10 (see Table 4). To assess the difference between pre-treatment and post-treatment scores, standard error of measurement (SEM) was also calculated for all measures (see Tables 5-7). The calculated standard error of measurement is used in part to determine accuracy of a testing measure (Harvill, 1991), but has also been applied to assess the difference between pre- and post-treatment outcome measures in research that involves small sample sizes (e.g., Milman et al., 2014). Visual graphs were created to display individual participant data for each measure (see Figures 5-7).

Table 4

| Participant | GDS Pre-test Score | GDS Post-test Score | SADQ-10 Pre-test Score | SADQ-10 Post-test Score | mPHQ-8 Pre-test Score | mPHQ-8 Post-test Score |
|-------------|--------------------------|---------------------------|------------------------------|-------------------------------|-----------------------------|------------------------------|
| PWA 1 | 4 | 2 | 4 | 6 | 8 | 9 |
| PWA 2 | 6 | 1 | 10 | 11 | 6 | 4 |
| PWA 3 | 1 | 2 | 11 | 12 | 10 | 9 |
| PWA 4 | 7 | N/A | 14 | 7 | 6 | 9 |
| PWA 5 | 5 | 4 | 10 | 14 | 3 | 5 |
| PWA 6 | 11 | 9 | 22 | 13 | 15 | 11 |
| PWA 7 | 3 | 2 | 6 | 3 | 6 | 5 |
| Mean | 5.29 | 3.33 | 11.00 | 9.43 | 7.71 | 7.43 |
| SD | 3.20 | 2.94 | 5.86 | 4.12 | 3.86 | 2.70 |

Pre- and Post-test Scores, Means, Standard Deviations

Note: GDS=Geriatric Depression Scale; SADQ-10 =Stroke Aphasic Depression Questionnaire - 10; mPHQ-8 =Modified Patient Health Questionnaire-8; SD = standard deviation; N/A=Not Administered

Table 5

| GDS | | | GDS r- 84 | | | |
|-------------|------------------------|-------------------------|--------------|------------------------|---------------------------------------|------------------------------|
| Participant | GDS Pre- test Score | GDS Post- test Score | SEM | GDS change score | 95% CI SEM (score+/- (1.96*SEM) | 68% CI = Score +/- SEM |
| PWA 1 | 4 | 2 | 1.28 | 2 | 2.51 | * |
| PWA 2 | 6 | 1 | 1.28 | 5 | 2.51* | * |
| PWA 3 | 1 | 2 | 1.28 | -1 | 2.51 | |
| PWA 4 | 7 | N/A | N/A | N/A | N/A | |
| PWA 5 | 5 | 4 | 1.28 | 1 | 2.51 | |
| PWA 6 | 11 | 9 | 1.28 | 2 | 2.51 | * |
| PWA 7 | 3 | 2 | 1.28 | 1 | 2.51 | |
| MEAN | 5.29 | 3.33 | | | | |
| SD | 3.20 | 2.94 | | | | |

Note: GDS=Geriatric Depression Scale; SEM=Standard Error of Measurement; CI=Confidence Interval; N/A=Not Administered

Table 6

| mPHQ-8 | | | PHQ-8 r=.82 | | | |
|-------------|-----------------------------|------------------------------|----------------|---------------------------|---------------------------------------|------------------------------|
| Participant | mPHQ-8 Pre-test Score | mPHQ-8 Post-test Score | SEM | mPHQ-8 change score | 95% CI SEM (score+/- (1.96*SEM) | 68% CI = Score +/- SEM |
| PWA 1 | 8 | 9 | 1.64 | -1 | 3.21 | |
| PWA 2 | 6 | 4 | 1.64 | 2 | 3.21 | * |
| PWA 3 | 10 | 9 | 1.64 | 1 | 3.21 | |
| PWA 4 | 6 | 9 | 1.64 | -3 | 3.21 | * |
| PWA 5 | 3 | 5 | 1.64 | -2 | 3.21 | * |
| PWA 6 | 15 | 11 | 1.64 | 4 | 3.21* | * |
| PWA 7 | 6 | 5 | 1.64 | 1 | 3.21 | |
| MEAN | 7.71 | 7.43 | | | | |
| SD | 3.86 | 2.70 | | | | |

mPHQ-8 Standard Error of Measurement

Note: mPHQ-8=Modified Patient Health Questionnaire-8; PHQ-8=Patient Health Questionnaire-8; SEM=Standard Error of Measurement; CI=Confidence Interval

Table 7

| | | | SADQ-10 r=0.72 | | | |
|-------------------|------------------------------|-------------------------------|-------------------|----------------------------|---------------------------------------|------------------------------|
| Participant ID | SADQ-10 Pre-test Score | SADQ-10 Post-test Score | SEM | SADQ-10 Change Score | 95% CI SEM (score+/- (1.96*SEM) | 68% CI = Score +/- SEM |
| PWA 1 | 4 | 6 | 3.10 | -2 | 6.08 | |
| PWA 2 | 10 | 11 | 3.10 | -1 | 6.08 | |
| PWA 3 | 11 | 12 | 3.10 | -1 | 6.08 | |
| PWA 4 | 14 | 7 | 3.10 | 7 | 6.08* | * |
| PWA 5 | 10 | 14 | 3.10 | -4 | 6.08 | * |
| PWA 6 | 22 | 13 | 3.10 | 9 | 6.08* | * |
| PWA 7 | 6 | 3 | 3.10 | 3 | 6.08 | |
| MEAN | 11.00 | 9.43 | | | | |
| SD | 5.86 | 4.12 | | | | |

SADQ-10 Standard Error of Measurement

Note: SADQ-10=Stroke Aphasic Depression Questionnaire-10; SEM=Standard Error of Measurement; CI=Confidence Interval

Figure 8





Figure 9

mPHQ-8 Pre- and Post-Test Scores



Figure 10

SADQ-10 Pre- and Post-Test Scores



Clinician Feedback

Clinician feedback was collected immediately after pre-treatment testing (Time 1), immediately following post-treatment testing (Time 2), and again approximately three months post-treatment testing (Time 3) for the PHQ-8 and GDS. Feedback was collected to assess and understand clinicians perspectives of administering a modified assessment in comparison to other unmodified patient reported outcome measures. See Table 11 for clinician feedback for both the GDS and mPHQ-8.

Table 11

| Geriatric Depression | Scale | Modified Patient Health Questionnaire -8 | | |
|---|--|---|--|--|
| Positive | Negative | Positive | Negative | |
| Less options for answers | Every question had to be reworded | Simplified language increased PWA's understanding | Had to explain calendar scale multiple times | |
| Easy for clinician to administer | Client limited to two answers | Calendar representation & large text helpful | Two-part questions slightly confusing | |
| Fast responses due to yes/no format of assessment | Test could not be given in unmodified format | Allowed to respond on a scale instead of yes/no | Longer administration time | |

Qualitative Feedback about GDS and mPHQ-8 Use with PWA

A portion of the qualitative feedback was transformed into quantitative data to document the number of modifications that clinicians needed to make to the GDS and mPHQ-8 to ensure comprehension and accurate responses by the stroke survivors with aphasia. On average, clinicians used more modifications post-ICAP for the GDS, and less modifications post-ICAP

for the mPHQ-8 (see Table 12).

Table 12

Number of Modifications needed for GDS and mPHQ-8 Administration

| | | # of Modifications needed for GDS and mPHQ-8 | | | | | |
|---------------------|-------|--|------|----------|--------|---------------|--|
| | Р | re ICAP | Po | ost-ICAP | 2 Mont | ths Post ICAP | |
| Clinician ID | GDS | mPHQ-8 | GDS | mPHQ-8 | GDS | mPHQ-8 | |
| C 1 | 0 | 0 | 1 | 1 | NR | NR | |
| C 2 | 1 | 0 | 1 | 0 | 1 | 0 | |
| C 3 | 2 | 0 | 2 | 0 | 2 | 0 | |
| C 4 | 2 | 1 | N/A | 0 | N/A | 0 | |
| C 5 | 0 | 1 | 2 | 0 | 2 | 0 | |
| C 6 | 1 | 0 | 1 | 0 | 1 | 0 | |
| C 7 | 2 | 1 | 0 | 0 | NR | NR | |
| Moon | 1 1 / | 0.42 | 1 17 | 0.14 | 1 50 | 0.00 | |
| Mean | 1.14 | 0.45 | 1.1/ | 0.14 | 1.50 | 0.00 | |
| SD | 0.90 | 0.53 | 0.75 | 0.38 | 0.58 | 0.00 | |

Note: mPHQ-8=Modified Patient Health Questionnaire-8; \GDS= Geriatric Depression Scale; ICAP=Intensive Comprehensive Aphasia Program; SD=Standard Deviation; N/A=Not Administered; NR=No Response

Qualitative data was also transformed into quantitative data to determine the number of

clinicians who reported that specific tests were perceived to be more reliable than others.

Overall, clinicians reported that they perceived responses to the mPHQ-8 to be more accurate

than responses to the GDS (see Table 13).

Table 13

| | Question # 4: Which test yielded more reliable responses from PWA? | | | | | |
|------------|--|----------|-----|-----------|-----|----------------|
| | F | Pre ICAP | P | Post-ICAP | | nths Post-ICAP |
| Clinician | GDS | mPHQ-8 | GDS | mPHQ-8 | GDS | mPHQ-8 |
| ID | | | | | | |
| C 1 | 1 | 0 | 0 | 0 | NR | NR |
| C 2 | 0 | 1 | 0 | 1 | 0 | 1 |
| C 3 | 0 | 1 | 0 | 1 | 0 | 1 |
| C 4 | 0 | 1 | 0 | 1 | 0 | 1 |
| C 5 | 0 | 1 | 0 | 1 | 0 | 1 |
| C 6 | 0 | 1 | 0 | 1 | 0 | 1 |
| C 7 | 0 | 1 | 0 | 1 | NR | NR |
| Total # of | 1/7 | 6/7 | 0/7 | 6/7 | 0/5 | 5/5 |
| Clinicians | | | | | | |

Graduate Student Clinician Reports of Test Reliability

Note: mPHQ-8=Modified Patient Health Questionnaire-8; \GDS= Geriatric Depression Scale; ICAP=Intensive Comprehensive Aphasia Program; NR=No Response; PWA=People with Aphasia

Conclusions & Discussion

This preliminary study was designed to assess the feasibility of modifying and administering an aphasia friendly version of the *Patient Health Questionnaire* – 8 in comparison to other patient and proxy reported outcome measures of depression. Through this study four aims were addressed: (1) to modify the *Patient Health Questionnaire* -8 to an aphasia friendly version, (2) to administer the mPHQ-8 to seven PWA and to assess feasibility of administering this modified assessment, (3) to gather and explore perspectives from clinicians administering both the GDS and the mPHQ-8, and (4) to gather preliminary data on how the GDS, SADQ-10, and mPHQ-8 compare in terms of reliability.

Modification of the *Patient Health Questionnaire* – 8 was feasible and was done in a similar manner to the modification of the *Perceived Stress Scale* in 2018 (Pompon et. al., 2018).

Key words of each question were maintained to ensure that the modified assessment did not stray from the intended purpose of the original. The PHQ-8 was modified to be aphasia friendly in a manner consistent with previous research outlining necessary modifications for individuals with aphasia (Rose et. al., 2011). The simplified structure of each question and added visual analogue scale, as well as the additional white space on each page increased the "aphasia friendliness" of this measure. This preliminary modification could be improved upon by adding the picture representations to each page of the screening tool rather than having them as a separate document, and re-examining how to best phrase two part questions to reduce confusion for both the clinician and the individual living with aphasia.

The findings from this preliminary study suggest that it is feasible for speech-language pathology graduate student clinicians to administer the modified version of the PHQ-8 to individuals with aphasia. From the clinician's standpoint, the mPHQ-8 is favored to non-modified assessments (e.g., GDS) due to ease of administration, limited number of modifications, and what clinicians perceive to be more accurate answers from stroke survivors living with aphasia.

Clinicians reported that the mPHQ-8 required fewer modifications than the *Geriatric Depression Scale* (GDS). Clinicians reported use of modifications increased from pre to post-ICAP testing for the GDS (1.14 to 1.17 modifications), and reported modifications decreased for the mPHQ-8 (0.43 to 0.14 modifications). Overall, the use of fewer modifications for the mPHQ-8 compared to the GDS suggests that that the modification was successful and may have improved the accessibility of the PHQ-8 for the PWA (Rose et. al., 2011; Pompon et. al. 2018). During the post-ICAP testing process, PWA 4 could not complete the GDS, but they could complete the mPHQ-8, indicating that this assessment increased accessibility and was modified appropriately.

Clinicians also reported that they perceived the PWA's responses to the mPHQ-8 to be more accurate than answers to the GDS. Across the three data collection periods, the majority of clinicians (6/7, 6/7, and 5/5 respectively) reported that the mPHQ-8 reflected what they perceived to be more accurate answers than did the GDS. Only one clinician during one data collection period (1st time period) reported favoring the GDS. This preference for the mPHQ-8 by graduate student clinicians stemmed in part from the difference of response structure for each measure. The GDS limits participants to a binary response, either confirming or denying the symptom (i.e., "yes" or "no"), whereas the mPHQ-8 provides a visual analog scale, allowing participants to rate each item based on frequency. The binary "yes" or "no" response allowed on the GDS is also difficult for PWA to comprehend and respond to (i.e., PWAs often semantically confuse "yes" and "no"), leading to reduced reliability of responses (Howard et. al., 2006). The visual analogue scale on the mPHQ-8 also incorporates realistic images related to each mood addressed in order to support comprehension of the assessment for the PWA (Townsend et. al., 2007).

Clinicians commented on the value of different response options for the GDS and mPHQ-8. These responses as well as other qualitative feedback were categorized as positive or negative features of each test. Clinicians noted that the GDS could not be administered to a PWA without modification and rewording of every question. This increases the administration time and places task of modification on the clinician in the moment to adapt the test. With the mPHQ-8 clinicians reported that the modifications that were already in place increased PWA's

understanding of the assessment, and that the scale of response options was preferred to a binary response (see Table 11).

Though this study was not designed to measure or assess psychometric properties (i.e., reliability) of these assessments, preliminary data suggests that the mPHQ-8 may be measuring a more realistic change from pre-ICAP to post-ICAP than either the GDS or SADQ-10. The mean scores on the GDS and SADQ-10 change by over one point greater than the change seen on the mPHQ-8 (-1.96, -1.57, and -0.28 respectively). From pre-ICAP to post-ICAP, there is a four-week period of treatment that does not directly target psychosocial wellbeing for the PWA, and instead intensive language therapy takes place. A smaller change (-0.28), seen with the mPHQ-8, over the course of the four weeks may be more accurately capturing the psychosocial changes. Studies focused on improving psychosocial wellbeing have found small but significant effect sizes when wellbeing was directly targeted with two months or more of treatment (Weiss et. al., 2016). This indicates that one month of language treatment may not significantly affect psychosocial wellbeing, and that it may be more accurate to see smaller changes from pre to post-ICAP testing.

Overall, the data gathered from this preliminary study supports that the mPHQ-8 is preferred over the GDS from an administration perspective by clinicians. The mPHQ-8 was also able to be completed by all PWA pre- and post-ICAP, suggesting that the modifications improve accessibility to the assessment, and that pre-modified assessments are preferred to those that require in-the-moment modifications.

Limitations

This study represents a preliminary, feasibility study (i.e., Phase I research), and is not without limitations. Participants (i.e., both individuals with aphasia and graduate student

clinicians) represent a sample of convenience. As such, the assessment was only administered to individuals with non-fluent aphasia and did not include a broad range of aphasia subtypes. Due to the nature of participant selection, only seven PWA completed the measures pre- and post-treatment, limiting the ability to apply information gathered for this study to a larger population. This study also lacked control and participants were not administered the unmodified PHQ-8. Blinding measures were not in place throughout this study leading to potential bias from student clinicians during data collection periods.

Future Directions

Future studies should add elements of control to begin to explore the efficacy of administering the mPHQ-8 to individuals with aphasia (Hula et. al., 2013). Administering the mPHQ-8 to a larger sample size would aid in gathering data to validate this measure against other measurements that screen for depression, including the unmodified PHQ-8. In addition to a larger sample size, participants should be recruited to include those with fluent and non-fluent aphasia types. Participants should be randomly assigned to groups that would be administered either the mPHQ-8 or the PHQ-8. Implementing a more structured and planned research design would assist in analyzing and understanding trends in the data.

Additional modifications of the mPHQ-8 are likely to aid in improved administration of the assessment. Adding the picture representation of each question to the page would reduce manipulation of materials, easing administration from the clinician's standpoint. Removing the line "*Over the last two weeks*" from the top of every page would limit text seen by the individuals with aphasia and increase the friendliness of the assessment. The last modification would address rewording the two-part questions to decrease confusion. See appendix E for a sample of future modifications.

The current research supports both the use of modifications for individuals with aphasia and the move towards patient reported outcome measures. A modified patient reported outcome measure reduces the burden on health care professionals and allows for more participation on the part of stroke survivors with aphasia. Future modifications of the PHQ-8 as well as incorporating measures of control will continue to advance research in this area.

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APPENDIX A: Patient Reported Outcome Measures

Geriatric Depression Scale (short form)

| Ins | tru | cu | on | 5: | |
|-----|-----|----|----|----|--|
| | | | | | |

Circle the answer that best describes how you felt over the <u>past week</u>.

| Are you basically satisfied with your life? | yes | по |
|--|-----|-----|
| Have you dropped many of your activities and interests? | yes | по |
| Do you feel that your life is empty? | yes | по |
| 4. Do you often get bored? | yes | по |
| 5. Are you in good spirits most of the time? | yes | no |
| Are you afraid that something bad is going to happen to you? | yes | по |
| Do you feel happy most of the time? | yes | по |
| Do you often feel helpless? | yes | no |
| 9. Do you prefer to stay at home, rather than going out and doing things? | yes | по |
| 10. Do you feel that you have more problems with memory than most? | yes | 110 |
| 11. Do you think it is wonderful to be alive now? | yes | по |
| 12. Do you feel worthless the way you are now? | yes | по |
| 13. Do you feel full of energy? | yes | по |
| 14. Do you feel that your situation is hopeless? | yes | 110 |
| 15. Do you think that most people are better off than you are? | yes | що |
| Total Score | , | |

1 Tools

may be copied without permission

Geriatric Depression Scale (GDS) Scoring Instructions

Instructions:

Score 1 point for each bolded answer. A score of 5 or more suggests depression.

| 1. | Are you basically satisfied with your life? | yes | 80 |
|-----|---|-----|----|
| 2. | Have you dropped many of your activities and interests? | yes | no |
| 3. | Do you feel that your life is empty? | yes | no |
| 4. | Do you often get bored? | yes | no |
| 5. | Are you in good spirits most of the time? | yes | 80 |
| 6. | Are you afraid that something bad is going to happen to you? | yes | no |
| 7. | Do you feel happy most of the time? | yes | 80 |
| 8. | Do you often feel helpless? | yes | no |
| 9. | Do you prefer to stay at home, rather than going out and doing things? | yes | no |
| 10. | Do you feel that you have more problems with memory than most? | yes | no |
| 11. | Do you think it is wonderful to be alive now? | yes | 80 |
| 12. | Do you feel worthless the way you are now? | yes | no |
| 13. | Do you feel full of energy? | yes | no |
| 14. | Do you feel that your situation is hopeless? | yes | no |
| 15. | Do you think that most people are better off than you are? | yes | no |
| A | score of \geq 5 suggests depression Total Score | | |

Ref. Yes average: The use of Rating Depression Series in the Eiderly, in Posin (ed.): Clinical Memory Assessment of Older Adults, American Psychological Association, 1986 Resource Center

Depression Scale (PHQ-8)

Over the last 2 weeks, how often have you been bothered by any of the following problems? (circle one number on each line)

| Ho we | ow often during the past 2 beks were you bothered by | Not at all | Several days | More than half the days | Nearly every day |
|----------|--|---------------|-----------------|-------------------------------|---------------------|
| 1. | Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. | Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| 3. | Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. | Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. | Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. | Feeling bad about yourself, or that you are a failure, or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. | Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. | Moving or speaking so slowly that other people could have noticed. Or the opposit being so fidgety or restless that you have been moving around a lot more than usual | te — al 0 | 1 | 2 | 3 |

Scoring

If two consecutive numbers are circled, score the higher (more distress) number. If the numbers are not consecutive, do not score the item. Score is the sum of the 8 items. If more than 1 item missing, set the value of the scale to missing. A score of 10 or greater is considered major depression, 20 or more is severe major depression.

APPENDIX B: Proxy Outcome Measures

| liem | Score |
|--------------------------------------|---|
| 1. Insomnia-Middle | 0 - No difficulty 1 = Patient indicates being restless and disturbed during night/observe sleep disturbance 2 - waking during the night; any getting out of bed (except to go to bathroom) |
| 2. Anxiety-Psychic | 0 = no difficulty 1 = some tension and irritability 2 = worrying about minor matters 3 = apprehensive attitude apparent in patient's face or speech 4 = fears indicated (verbal/non verbal expression) without questioning |
| 3. Anxiety-Somatic | 0 = absent; 1 = mild; 2 = moderate; 3 = severe; 4 = incapacitating |
| 4. Somatic symptoms-Gastrointestinal | 0 = none 1 = loss of appetite but continues to eat; heavy feelings in abdomen 2 = difficulty eating (not due to arm paresis); requests/requires luxatives or medication for howels or for eactrointestinal symptoms |
| 5. Hypochondriasis | 0 = not present 1 = self-absorption (hodily) 2 = preoccupation with health 3 = frequent complaints, requests for help, etc 4 = hypochondriacal delusions |
| 6. Loss of weight | 0 = <0.5 kg weight loss/week 1 = 0.5 kg to 1 kg weight loss per week 2 = >1 kg weight loss per week |
| 7. Apparent sadness | 0 = no sadness 1 = between 0 and 2 2 = looks dispirited but brightens without difficulty 3 = between 2 and 4 4 = appears sad and unhappy most of the time 5 = between 4 and 6 6 = looks miscrable all the time: extremely descondent |
| 8. Mimic-Slowness of Facial Mobility | 0 = the head moves freely, resting flexibility on the body with the gaus either exploring the room or fixed on the examiner or on other objects of interest in an appropriate manner 1 = there may be some reduction of mobility, not easily confirmed. 2 = roduced mobility is definite but mild; gaze, often fixed, but is still capable of shifting; mimic, although monotonous, is still expressive 3 = does not move head/explore room, usually stares at floor, seldom looking at examiner; patient is slow to smile; expression is unchanging 4 = face is completely immobile and painfully inexpressive |
| 9. Fatigability | 0 = fatigability is not indicated spontaneously/after direct questioning 1 = fatigability is not indicated spontaneously, but evidence of it emerges in the course of the interview 2 = patient is distressed by fatigability in his/her everyday life (eating, washing, dressing, climbing stairs, or any physical activity the patient is usually able to do despite motor deficiency). 3 = fatigability is such that the patient must curb some activities 4 = near total reduction of activities due to overwhelming fatime. |

Table adapted from Benaim, C., Cailly, B., Perennou, D., Pelissier, J. (2004). Validation of the aphasic depression rating scale. *Stroke*, 35, 1692.

Stroke Aphasic Depression Questionnaire Hospital Version (SADQ-H 10)

Please indicate how many days of the last 7 the participant has shown the following behaviours:

1. Did he/she have weeping spells?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

2. Did he/she have restless disturbed nights?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

3. Did he/she avoid eye contact when you spoke to him/her?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

4. Did he/she burst into tears?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

5. Did he/she indicate suffering from aches and pains?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

6. Did he/she get angry?

Every day this On 4-6 days On 1-4 days Not at all this week this week this week week

7. Did he/she refuse to participate in social activities?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

8. Did he/she sit without doing anything?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

9. Did he/she keep him/herself occupied during the day?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

10. Did he/she get restless and fidgety?

| Every day this | On 4-6 days | On 1-4 days | Not at all this |
|----------------|-------------|-------------|-----------------|
| week | this week | this week | week |

C University of Nottingham 2007

APPENDIX C: mPHQ-8 Script, Score Sheet, Assessment & Images

BSAP ICAP 2019

Script for mPHQ-8

<u>Notes for Clinicians</u>: The provided score sheet is for your use only while the packet provided with one question per page is designed for the PWA to view while you read. If additional cueing is required, please first turn to the provided pictures and then to the full question if more key words are needed. The full question is provided in italics on the scoring page. If cueing is required beyond this point, please make a note of any techniques that were used on the "Assessment of Ease of Administration" form.

<u>Script</u>: This test is the Modified Personal Health Questionnaire -8. It will be asking about your feelings over the last two weeks. There are 11 questions. I will read each question to you. You can point to the answer that matches or say the words aloud. You will always have 4 choices; not at all – or zero days in the last two weeks, several days – or around 4 days of the last two weeks, more than half the days – or around 8 days of the last two weeks, and nearly every day. These are all shown on a calendar. Ready?

| Over th (Place a clients | he last two weeks, how often have you a check mark in the box that corresponds to answer} | Not at all (0) | Several Days (1) | More than half the days (2) | Nearly everyday (3) |
|--------------------------------|---|----------------------|---------------------|-----------------------------------|---------------------------|
| 1. | Had little interest in doing things "Little interest or pleasure in doing things" | | | | |
| 2. | Felt sad or hopeless "Feeling down, depressed, or hopeless" | | | | |
| 3. | A. Had trouble falling or staying asleep <u>OR</u> B. Had trouble sleeping too much "Trouble falling or staying asleep or sleeping too much" | | | | |
| 4. | Felt tired or without energy "Feeling tired or having little energy" | | | | |
| 5. | A. Had a small appetite <u>OR</u> B. Had problems overeating "Poor appetite or overeating" | | | | |
| б. | Felt bad about yourself "Feeling bad about yourself or that you are a failure ar have let yourself ar your family down" | | | | |
| 7. | Had trouble concentrating "Trouble concentrating on thins such as reading the newspaper or watching television" | | | | |
| 8. | A. Been moving or speaking slowly <u>OR</u> B. Been restless or moving more than normal "Moving or speaking so slowing that ather people could have noticed. Or the appasite, being so fidgety or restless that you have been maving around a lot more than normal" | | | | |
| | Totals | 0 | | | |

Modified Personal Health Questionnaire-8 (PHQ-8) Score Sheet for Clinician Use

Sum of above scores

Scoring guidelines for questions 3, 5, and 8: If the scores for both parts of the question differ, indicate the higher score on this sheet. For example, if the client answers 1 for 3.a. and 3 for 3.b., mark the box for a score of 3 for all of question 3. If the scores for both parts of the question are the same, mark the correct box only once.

Scoring guidelines for depression severity: Scores of 5-9 indicate mild depression, 10-14 indicate moderate depression, 15-19 indicate moderately severe depression, and scores 20 and above represent severe depression.

Scoring guidelines for major depressive syndrome: If questions 1 or 2, and 5 or more of the rest are scored at "more than half the days", then major depressive syndrome is indicated.



| | | Name: | Modified Patient Health |
|-----------|--|-------|----------------------------|
| B5AP 2019 | | Date: | ı Questionnaire- 8 (PHQ-8) |

| | | S M T W T F S | | Not at all | |
|---|--|---------------|----------|----------------|--|
| | | S M T W T F S | | Several days | |
| - | | S M T W T F S | the days | More than half | |
| | | S M T W T F S | everyday | Nearly | |

Over the last two weeks, how often have you...

Had little interest in doing things

Felt sad or hopeless

| S M T W T F S | Not at all |
|---------------|----------------------------|
| S M T W T F S | Several days |
| S M T W T F S | More than half the days |
| S M T W T F S | Nearly everyday |

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| | S M T W T F S S M T | the days eve | More than half No |
| | S M T W T F S S M T W | the days every | More than half Nea |
| | S M T W T F S S M T W T | the days everyd | More than half Nearh |
| | S M T W T F S S M T W T F | the days everyday | More than half Nearly |
| | S M T W T F S S M T W T F S | the days everyday | More than half Nearly |

Felt tired or without energy

| | S M T W T F S | | Not at all |
|--|---------------|----------|----------------|
| | S M T W T F S | | Several days |
| | S M T W T F S | the days | More than half |
| | S M T W T F S | everyday | Nearly |

Had a small appetite

| | S M T W T F S | | Not at all | |
|--|---------------|---------|--------------|--|
| | S M T W T F S | - | Several days | |
| | S M T W T | the day | More than | |
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Over the last two weeks, how often have you...

Had problems overeating

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Had trouble concentrating

| | S M T W T F S | | Not at all | |
|--|---------------|----------|----------------|--|
| | S M T W T F S | | Several days | |
| | S M T W T F S | the days | More than half | |
| | S M T W T F S | everyday | Nearly | |

Over the last two weeks, how often have you...

Been moving or speaking slowly

| | S M T W T F S | | Not at all | |
|--|---------------|----------|----------------|--|
| | S M T W T F S | | Several days | |
| | S M T W T F S | the days | More than half | |
| | S M T W T F S | everyday | Nearly | |

Over the last two weeks, how often have you...

Been restless or moving more than normal















5.b.







5. a.





mPHQ-8 Pictures

APPENDIX D: Clinician Feedback – Ease of Administration Form

Clinician Name:

Patient Initials:

BSAP ICAP 2019

Patient Reported Outcome Measures: Assessment of Ease of Administration

| Acronym | Description |
|---------|--|
| PWA | Person with Aphasia |
| GDS | Geriatric Depression Scale |
| mPHQ-8 | Modified Personal Health Questionnaire-8 |
| mPSS | Modified Perceived Stress Scale |

Client Bio: (Age & Fluent or Non-Fluent Aphasia)

Overall Assessment:

- How easy was the administration of the <u>GDS</u>?
 - How many modifications were needed?
 - What strategies did you use to modify the <u>GDS</u>?
 - What worked best?
- How easy was the administration of the <u>mPHO-8?</u>
 - Were modifications needed outside of what was provided? If so, what was needed?
 - Did the pictures and/or calendar examples for each question seem to help? In what ways?

Comparing Measures:

- In comparison to the <u>GDS</u>, was the <u>mPHQ-8</u> easier or harder to administer? In what ways?
- Did the PWA appear to respond better to the <u>mPHQ-8</u> or the <u>GDS</u>?
 - Did responses come faster during one assessment vs. the other?
 - Were responses clearer for one assessment vs. the other?
- Did administration of the <u>mPSS</u> before the <u>mPHQ-8</u> appear to aid in comprehension of the task for the PWA? In what way?

Other Thoughts:

 Any other thoughts on the GDS, mPHQ-8, or mPSS? Comment upon the administration, the PWA's reaction, the timing, and/or level of assistance required?

ŝ Z Not at all Т Ś н Ы S S Several days More than half Z н Ś Н Ы S S M T the days Ś Т ч S S M T Nearly everyday

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Had little interest in doing things



APPENDIX E: Example of Future Modifications