Readability of Patient-Reported Outcome Measures for Persons with Aphasia

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READABILITY OF PATIENT-REPORTED OUTCOME MEASURES FOR PERSONS WITH APHASIA

by

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ABSTRACT

The relationship between positive health outcomes in persons with aphasia (PWA) and person-centered care is highlighted by personally-relevant information obtained directly from the PWA. Such is often facilitated via patient reported outcome measures (PROMs). In order to provide accurate responses to PROMs, PWAs must to read, comprehend, formulate and generate answers to a variety of questions. PROMs designed for other clinical populations assessed/treated by speech-language pathologists have been found to be largely unreadable. Despite the significant role of PROMs in assessment and management of aphasia, no study to date has examined the readability of these measures. Four readability formulae were applied to identified PROMs for PWAs. These formulae estimate readability in terms of reading grade level and provide additional, quantitative information regarding textual elements such as syllable, word, and sentence length, complexity, and frequency. Fourteen PROMs were identified, per review of extant literature. A Macintosh-based readability software program was used to perform readability analyses. Additional metrics of clinical utility were applied to the selected measures via the Clinical Utility Scale. Results indicate that, on average, PROMs designed for PWAs are written at an eighth-grade reading level which is discordant with fourth-to-sixth reading grade level recommendations set forth by health literacy experts. Scores derived from the Clinical Utility Scale highlight the disconnect among measures that are easy to implement but are unreadable. Further analysis indicates that syllable-, word-, and sentence-level complexities can also impact the difficulty of analyzed texts. Results of the present study are consistent with prior PROM analyses performed across a variety of clinical populations assessed/treated by speech-

language pathologists. Clinical implications and limitations of the present study are discussed as well as directions for further research.

Dedicated to my parents

Linda and Michael Gray

To the moon and back

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LIST OF ABBREVIATIONS

ACOM: Aphasia Communication Outcome Measure

AIQ-21: Aphasia Impact Questionnaire-21

ALA: Assessment for Living with Aphasia

ASHA: American Speech-Language Hearing Association

ASHA QCL: ASHA Quality of Communication Life Scale

BOSS: Burden of Stroke Scale

COMACT: Communication Activities Checklist

CCRSA: Communication Confidence Rating Scale for Aphasia

COAST: Communication Outcome After Stroke Scale

CPIB: Communication Participation Item Bank

CUS: Clinical Utility Scale

DQ: Disability Questionnaire

F-K: Flesch-Kincaid

FOG: Gunning FOG Index

MPSS: Modified Perceived Stress Scale

PWA: Person with aphasia

QLQA: Quality of Life Measurement and Outcome in Aphasia

SMOG: Simple Measure of Gobbledygoodk

SOCAT: Social Activities Checklist

SAQOL-39: Stroke and Aphasia Quality of Life Scale

CHAPTER ONE: INTRODUCTION

1.1 Statement of the Problem

When working to assess and treat individuals with neurologic impairment, including those with aphasia, the American Speech-Language Hearing Association (ASHA) characterizes speech-language pathologists as being responsible for: a.) development/implementation of person-centered plans of care for those with communication difficulties; b.) using personally-relevant life situations to facilitate both communication and participation; and c.) ensuring those with aphasia participate in life through collaboration with other health professionals and family members (ASHA, 2016). An individual with aphasia's goals for treatment and self- perception of abilities are intrinsic to the clinical decision-making process when aiming to merge clinical practice and patient-centered service delivery. Such is subject to breakdown if patient-provider communication is not effective (Burns, Baylor, Morris, McNalley, & Yorkston, 2012). No two persons with aphasia (PWAs) are alike, with impairment-type and severity spanning a wide spectrum. Thus PWAs can be easily, though inadvertently, alienated from being active stakeholders during the clinical decision-making process (Hallowell, 2016).

The essence of this challenge lies within of *how* clinicians and healthcare providers promote communication with PWAs (Burns, et al., 2012). Communication is facilitated via written communication in many instances. However, individuals vulnerable to comprehension difficulties are at-risk to misunderstand health information that is too complex (Kanj & Mitic, 2009). Written health communication is only as effective as the degree to which its target audience can read, interpret, and apply the incorporated information (Hoffman & Worrall, 2004).

ASHA describes health literacy as the ways in which health information is accessed and understood by the user. Health-related literacy skills are used to make meaningful health decisions and to engage stakeholders such as patients and caregivers within the healthcare decision-making process (ASHA, 2016). Frequently, the potential to which written information can be interpreted and understood by its intended audience is measured by an estimate of the material's reading grade level (Paasche-Orlow & Wolfe, 2007). Aleligay, Worrall and Rose implemented a readability analysis of written health education materials acquired by PWAs following stroke in 2008. Their results indicated that most of these health education materials were written at a ninth-grade reading level. No significant difference was found in the readability of written health education information distributed by speech-language pathologists versus those distributed by other health providers (Aleligay, et al., 2008). Such results are discordant with fifth- to sixth-grade reading level recommendations described in Doak, Doak and Mead's 1996 seminal work addressing literacy skills among average American adults. If these documents are unreadable for the general American adult population who have *not* experienced neurologic insult, these documents have the potential to be *more* challenging for those with aphasia to access and interpret (Aleligay, et al., 2008). In addition to health education materials, speech-language pathologists distribute written materials intended to collect valuable information regarding personal goals for treatment and perceptions of communication from PWAs. PROMs are essential to constructing and maintaining appropriate plans of care (Kagan, et al., 2008). The relationship between the degree a PWA can interpret and respond to information presented in these PROMs raises questions regarding the validity of these results.

1.2 Purpose of the Study

The primary purpose of this investigation is to gauge the estimated reading grade level of PROMs designed for PWAs. PROMs are necessary tools which objectively measure the effectiveness of therapeutic interventions in a manner most intrinsic and personal to the PWA (Kagan, et al., 2008). Across clinical specialties and patient populations, many available PROMs used by speech-language pathologists do not align with fifth-grade reading level recommendations, as established by Doak, Doak, and Mead in 1996 (Atcherson, Richburg, Zraick, & George, 2013; Kelly-Campbell, Atcherson, Zimmerman, & Zraick, 2012; Pace, Atcherson, & Zraick, 2012; Slavych, Engelhoven, & Zraick, 2013; Zraick, Atcherson, & Ham, 2012). However, studiest to date have examined clinical populations whose primary morbidity is not traditionally expected to impact language comprehension (i.e., individuals who stutter (Zraick, Atcherson, & Brown, 2012) or individuals with swallowing disorders (Zraick, Atcherson, & Ham, 2012). PROMs, whose results are clinically valuable, demand that users have a requisite ability to visually process and accurately comprehend linguistic information, compose answers, and respond across a variety of modalities in order to fully convey their perception of provided clinical services/intervention. Current readability statistics, when conceptualized as a potential barrier to effective implementation of PROMs, may underestimate the impact readability has upon PWAs. Knowledge of the readability levels for PROMs designed for PWAs is a critical element for consideration when conceptualizing and qualifying these measures' results.

1.3 Research Questions

1.) What are the current reading levels of PROMs designed to measure life participation and/or quality of life in PWA?

2.) What are specific elements of these PROMs that may impede readability?

1.4 Significance of the Study

Person-centered care and optimal health outcomes for PWA has been established as a well-documented relationship within the aphasiology literature (Epstein, Fiscella, Lesser, & Strange, 2010; McGilton, et al., 2018; Wallace, et al., 2017). Collecting data that is both reliable and valid directly from patients is a substantial element in the construction of treatment objectives and is addressed by PROMs designed for PWA (Reeves, et al., 2018). The readability of the measures themselves can potentially be impacted by the degree to which PWA can access these measures. Not only have PROMs designed for other clinical populations served by speech-language pathologists been determined to be overwhelmingly unreadable (Kelly-Campbell, et al., 2012; Pace, et al., 2012; Slavych, et al., 2013; Zraick, et al., 2011), patient education materials designed for PWAs have also been found to hold a high degree unreadablility (Aleigay, et al., 2008). No study to date has determined the degree to which PROMs designed for PWA are readable, even though the importance of these PROMs has been well-established.

1.5 Limitations of the Study

1.) Readability formulae produce only estimates of reading levels necessary for comprehension of a given text. These results do not provide a complete picture of reader

comprehension and do not fully account for the unique ways in which individuals approach and access text (Friedman & Hoffman-Goetz, 2006; Doak, et al., 1996).

2.) Readability is contingent upon visual characteristics such as: font size, use of bullet points, use of graphics, formatting, and placement of images as well as personal characteristics such as: motivation to read, relevance of language to the individual, and cultural competence (Atcherson,, DeLaune, Hadden, Zraick, Kelly-Campbell, & Minaya, 2014). These are not quantifiably captured by readability formulas.

3.) Readability formulas are not sensitive enough to: a.) account for word familiarity of the individual reader or b.) capture semantic nuances which may be perceived by readers from culturally and linguistically diverse perspectives (Bailin & Grafstein, 2001).

4.) Readability formulas base calculations of complexity upon sheer length. However, complexity can be confounded by a variety of other factors such as use of passive versus active voice or use of embedded clauses (Leroy, Helmreich, & Cowie, 2010).

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview

Speech-language pathologists, as members of an interdisciplinary healthcare team, are often adjured by extant academic literature to adopt a patient-centered approach to clinical intervention for adults who have acquired neurologic communication disorders, such as aphasia (Kagan & LeBlanc, 2002). Speech-language pathologists may seek to incorporate a patient-centered approach into clinical practice by setting personally relevant goals for PWAs which can include elements such as validation of personal narrative and reengagement in life participation activities. To measure the efficacy of clinical practice, in terms of these goals, PROMs prove to be a valuable component of a robust battery for outcome assessment when administered appropriately (Kagan, et al., 2008).

Past investigation has revealed that many of the available PROMs used by speech-language pathologists in the clinical setting are written beyond a fifth-grade reading level, in direct contradiction of recommendations set forth by health literacy experts (Atcherson, et al., 2013; Doak, et al., 1996; Kelly-Campbell, et al., 2012; Pace, et al., 2011; Slavych, et al., 2013; Zraick, et al., 2011). However, this finding encompasses PROMs primarily designed for clinical populations with normal language abilities (e.g., persons with swallowing disorders (Zraick, et al., 2012) or persons who stutter (Zraick, et al., 2012). PROMs, by nature, require patients to read and comprehend linguistic information, formulate answers, and respond appropriately in order to fully convey their perception of clinical services and intervention provided. Thus, current readability statistics, when viewed as a potential barrier to effective use of PROMs, may

underestimate the impact readability has upon those with aphasia. Knowledge of the readability of PROMs designed for PWA is a crucial piece of information clinicians must consider when qualifying and critically analyzing results derived from these measures.

2.2 Prevalence of Aphasia

Thompson and den Ouden (2008) conceptualize aphasia as a disruption in language processing following insult to the brain, most commonly in the form of a left hemisphere cerebral vascular attack (CVA). Aphasia may also manifest itself following neurologic insult, such as a traumatic brain injury (TBI), or concomitantly alongside an array of neurologic injury/disease such as tumor and progressive disease, such as primary progressive aphasia (PPA). Aphasia is something which affects every 1 in 250 people in the United States (NIDCD, 2015). In 2015, the National Institute on Deafness and Other Communication Disorders (NIDCD, 2015) estimated that approximately 1 million people are living with aphasia in the United States. Englter and colleagues (2006) note that aphasia following stroke is most common in older adults rather than younger adults and, while 15 percent of those younger than 65 years of age experience aphasia following a stroke, these numbers nearly triple to 43% when examined in those older than 85 years of age.

The effects of aphasia are often spectral in severity and can encompass impairment in some or, more frequently, all areas of language. Language can best be conceptualized as a three-dimensional structure. Levels of linguistic functioning transverse five different domains (i.e. syntax, semantics, morphology, phonology, and pragmatics). These parameters operate across

four different modalities of language (i.e. auditory comprehension, verbal expression, reading, and writing). Performance of different linguistic tasks requires simultaneous activation of specific domains across modalities and PWA may experience impairment in linguistic functioning at any point across these levels and modalities. For the purposes of syndrome-based aphasia type classification, however, deficits in linguistic processing used to differentiate subtypes of aphasia are limited to four primary categories: comprehension of spoken language, naming, word finding, and speech fluency. Difficulties in one or many categories directly impact an individual's ability to use language as a fulcrum to leverage participation in life activities.

Although syndrome-based approaches to aphasia type classification categorize linguistic deficits based upon overt errors made by the individual, it is important to note that effects of aphasia are not isolated to one modality or level of linguistic processing. To illustrate, errors associated with lexical retrieval are colloquially referred to as a word-finding deficit or anomia. However, such retrieval can be parsed into two classifications: impairment in the *sublexical* or *lexical* routes of linguistic processing. The sublexical path of linguistic processing is one underscored by implicit interpretation of phoneme-grapheme relationships whereas the lexical path of linguistic processing is underscored by conceptual knowledge projected upon a phonemic pattern (Blumstein, 1994; Lecours & Lhermitte, 1969). Dell, Schwartz, Martin, Saffran, & Gagnon (1997) point out that lexical retrieval requires activation and bidirectional interaction of lexical knowledge across semantic, word, and phonemic levels. A breakdown occurring at any of these three levels may lead to characteristics that can outwardly be perceived as a word-finding deficit even though the breakdown is occurring at the phonemic level (Dell et al., 1997). That is

to say that, even though a PWA presents with a specific deficit, the outward presentation of the deficit may be a byproduct of a deeper breakdown in linguistic processing.

In keeping with the idea that aphasia results from a linguistic processing impairment, it is important to understand that PWA often have additional difficulties beyond receptive and expressive oral language. Often, PWA experience acquired reading (alexia) and writing (agraphia) difficulties. Alexia, in particular, is a major concomitant difficulty that can impede residual literacy skills in adults with aphasia. Alexia is defined as an acquired reading difficulty (Brookshire, Wilson, Nadeau, Rothi, & Kendall, 2014). Beyond this cursory definition, Wilson, Rothi, Nadeau, and Kendall, found that, of 41 PWA, 80% presented with alexia despite a wide range in aphasia-type and severity amongst the sample population (2007). Brookshire and colleagues confirmed this finding in 2014, citing that, of 99 PWA, 68% presented with alexia. Severity of aphasia was found to predict oral reading performance. However, beyond these conclusions, more study is needed to confirm the relatively high prevalence of alexia in PWA (Brookshire et al., 2014).

2.2.1 Aphasia Classification

The manifestation of aphasia varies greatly, both terms of impairment of specific language functions and severity. Because of this high level of variation, aphasia is historically classified based upon impairment of specific verbal expression abilities (Davis, 2007). This classification hierarchy is known as a neo-associationist taxonomy and was first fully and comprehensively described by Geschwind in 1970 and subsequently by Goodglass and Kaplan in

1972. Since its inception, it is one of the most widely used and accepted approaches to classifying stroke survivors with symptoms of aphasia, gripping mainstream clinical aphasiology for nearly three decades (Tesak & Code, 2008). This taxonomy is founded upon the hypothesis that a correspondence between the local of brain lesion and the anticipated deficit in language function exists (Goodglass & Kaplan, 1972).

Aphasia-type classification is broadly divided into two categories: fluent aphasia and nonfluent aphasia. Fluent aphasia simply implies that speech production is relatively fluent while linguistic meaning is relatively impaired. Fluent aphasia is classically divided into four additional subtypes. For those whose language comprehension is relatively intact, classifications extend to what is known as conduction aphasia and anomic aphasia. Composite characteristics of conduction aphasia include those individuals who have fluent aphasia, have relatively intact language comprehension, and have word finding difficulty. Composite characteristics of anomic aphasia include those individuals who have fluent aphasia, have relatively intact language comprehension, and have relatively good word repetition/word-finding. For those whose language comprehension is relatively impaired, classification extend to what is known as Wernicke's aphasia and transcortical sensory aphasia. Composite characteristics of Wernicke's aphasia include those individuals who have fluent aphasia, have impaired language comprehension, and have trouble repeating words or phrases. Composite characteristics of Transcortical Sensory aphasia include those individuals who have fluent aphasia, have relatively intact language comprehension, and have relatively good word repetition/word-finding (Goodglass & Kaplan, 1972).

On the opposite end of the spectrum, nonfluent aphasia is characterized by effortful production of speech. For those who have relatively intact language comprehension, subtypes include those who have problems repeating words or phrases-Broca's type aphasia--and those who have strong repetition skills but experience comprehension deficits--transcortical motor aphasia. For those who are known to have severely impaired abilities in both receptive and expressive language, their impairment is typically referred to as Global aphasia (Goodglass & Kaplan, 1972).

These classifications of aphasia should be stipulated with caution, as impairments classically characterized as a specific type of aphasia describe observable deficits but can often fail to fully pinpoint the *root* of breakdown. For example, Broca's type aphasia, as described above, is typically reflective of relatively intact auditory comprehension abilities. This does not, in turn, mean that an individual has fully preserved auditory comprehension skills. Thus, an individual may have a nonfluent type of aphasia and still experience problems in comprehension of auditory or written information. Dell and colleagues cite instances of individuals with Broca's type aphasia and impaired, agrammatic output to also have an impairment of sentence-processing (1997). This sentence processing impairment was found to extend to auditory comprehension of syntactic units. Caramazza, Capasso, Capitani, and Miceli confirm this finding, noting that auditory comprehension abilities in individuals with Broca's type aphasia can fall along a spectrum (2005).

Recent trends in aphasiology have called the approach of aphasia-type classification into question, citing concerns in the taxonomy's validity and clinical utility (Kasselimis, Simos,

Peppas, Evdokimidis, & Potagas, 2017). Aphasia type classification is typically determined through language assessment using commonplace batteries such as the Boston Diagnostic Test for Aphasia (BDAE; Goodglass & Kaplan, 1972) or the Western Aphasia Battery (WAB; Kertesz, 1982). Particularly, this traditional classification often fails to capture the unique language characteristics within the individual, as observed across large proportions of patients (Marshall, 2010). In fact, a recent study from Kasselimis and colleagues (2017) found that classical lesion-to-syndrome classification could not be confirmed in 63.5% of stroke patients. Thus, a deficit-based approach as opposed to a syndrome-based approach to assessment of aphasia assessment has gained recent momentum as a more efficacious approach to clinical assessment of aphasia (Vukovic, 2018).

To clarify, a syndrome-based approach to aphasia-type classification is the dominant trend within aphasiology—associating location of focal brain lesion to the expected impairment in linguistic functioning. As described above, this syndrome-based approach classifies aphasia in terms of functioning in fluency, auditory comprehension, naming, and word-finding. General terms such as 'comprehension' and 'fluency' can often overlook specific breakdowns in functioning and this specific approach often does not encompass the specific deficits faced by a large proportion of PWAs (Marshall, 2010). Basso, Lecours, Moraschini, and Vanier (1985) point out that, in many cases, a lesion-to-syndrome correspondence does always predict an individual's presentation of impairment. The report instances in which fluent aphasia is noted following anterior lesions, nonfluent aphasia following posterior lesions, and aphasia following lesions entirely beyond the perisylvian zone for language altogether. A deficit-based approach to

classification of aphasia, on the other hand, situates language within social and pragmatic environments and allows the reality of specific impairment of the individual to guide classification of aphasia type rather than the anticipated impairment of the individual (Howard, Swinburn, & Porter, 2010).

2.2.2 Neurolinguistic Reading Routes and Alexia

One particularly significant breakdown which can underscore the efficacy of written comprehension is that of alexia. This breakdown in the interface of visual and phonological processing is highly vulnerable to any overt disruption to oral reading and reading comprehension. Each mechanism taxes a different component of linguistic processing – be it receptive versus expressive or auditory versus visual. As is consistent with aphasiology literature at large, Cherney describes a shift in thinking of alexia in terms of a treating an individual based upon their difficulties rather than treating an individual based upon predicted deficits due to anatomic lesions (2004). Due to the inextricable relationship between linguistic processing systems, treatment of oral reading often can further improve other language modalities, such as auditory comprehension (Beeson & Insalaco, 1998).

Reading difficulties, additionally, are not limited to visual, semantic, or phonological processing routes. Breakdowns in cognitive processes such as short-term memory can also impact reading (Berndt, Mitchum, & Price, 1991). Importantly, difficulties in reading do not simply impact linguistic skills in isolation. Such skills are indirectly taxed when clinicians attempt to gain additional information, such as psychosocial or environmental information, about

the day-to-day functioning of the individual with aphasia. As such, assessment is not one-size-fits-all and requires customization to meet the individual with aphasia's specific needs.

2.3 Patient-Reported Information

To provide a well-illustrated picture of a PWA's residual language abilities within the context of WHO's International Classification of Functioning, Disability, and Health (ICF; Kagan et al., 2008) framework, standardized assessment cannot stand alone. In keeping with ASHA's position taken in *Preferred Practice Patterns for the Profession of Speech-Language Pathology: Spoken and Written Language Assessment*, assessment of adults with communication impairments should consider components of WHO's ICF framework as it relates to the individual (2004). To capture this information, a patient or their caregiver should be asked to report pieces of information that are crucial to forming an appropriate diagnosis and/or management plan. Such patient-report information envelops: relevant case history information (i.e. education level, socioeconomic or cultural background, and medical status), language modalities causing concern, contexts which elicit communicative frustration, and personal goals for communicative functioning (ASHA, 2004).

2.4 Patient-Centered Care

Satisfaction level of the patient is a linchpin element for treatment efficacy in language rehabilitation for PWA and should, therefore, guide service delivery. Such considerations contribute to the concept of patient-centered care. Patient-centered care for adults with

communication impairments should seek to: identify the individual's communication skills; use strategies intended to maximize the effectiveness of patient-provider interactions; identify patient-prioritized outcomes that reflect personal goals for life participation; measure treatment efficacy via measures that reflect priorities and values identified by the patient; and integrate the above information continuously throughout assessment and treatment of the individual (Lawrence & Kim, 2011).

As stated above, WHO's ICF framework emphasizes a person-centered approach to goal setting. In 2010, Worrall and colleagues investigated the relationship between goals set forth by ICF and goals self-identified by PWAs. Semi-structured interviews were conducted with 50 individuals with aphasia following stroke and coded using ICF. Results revealed that, of the nine wide categories of goals that were determined, all goals were linked back to components of ICF. The vast majority of identified goals were linked to life participation activities as it relates to leisure, work, and social activities. Specifically, these PWA wanted further educational materials about their stroke, aphasia, and services available to them. They also wanted strategies for increased independence, to help others, and to be treated with respect. A similar methodology was followed to interview 48 caregivers of PWA. Their goals largely revolved around inclusion in the rehabilitation process

These identified goals can be situated within a person-centered framework for clinical decision-making. Leach provides an excellent differentiation between clinician- and patient-driven models for decision-making (2010). A therapist-driven model for clinical decision-making stands on quantitative, standardized assessment data to pinpoint the individual's degree

of impairment. In this model, the clinician ultimately determines the patient's goals and sets the treatment course. In direct contrast, the model for clinician-driven clinical decision revolves around the patient's self-identified wants and needs. This includes involvement during introduction to the goal-setting process; identification of treatment priorities; formal diagnostic assessment; shared goal-setting; and selection of treatment approach (Leach, 2010).

2.4.1 Cost-Benefit of Patient-Centered Care

The importance of patient input during the medical treatment and rehabilitation is one which reaches both individual and systematic levels of the healthcare system. To this extent, patients who report positive health outcomes as a result of patient-centered implementation of care have been shown to have: less symptoms during medical facility stays, lower rates of recidivism to medical facilities following discharge, higher rates of treatment regimen adherence, overall faster rates of recovery, and more positive reports of emotional health during follow-up (Epstein, et al., 2010). These findings are accentuated when viewed in light of the extant cost of stroke upon the American medical system. In 2017, the U.S. Center for Disease Control reported that treatment of stroke costs the American medical system approximately 34 billion dollars annually. Further, stroke is the number one cause of long-term disability, creating further medical expenses associated with long-term care and rehabilitation (Benjamin, Blaha, Chiuve, Cushman, Das, Deao & Jimenez, 2017). Thus, clinical-decision making rooted in patient centered care has the potential to not only benefit the individual but to financially benefit the American medical system at large.

In 2012, Hersh and colleagues point out that patient-centered objectives must not only be shared, monitored, accessible, relevant and transparent but also be evolving and relationship-centered. Given the clinical and financial value of patient-centered care, it is reasonable to expect that healthcare providers would be incentivized to promote this approach to clinical decision-making. However, measuring outcomes that result from treatment as informed by these goals are subject to variation among clinicians and leave want for a set of core outcomes to better inform treatment development (Wallace, Worrall, Rose, & LeDorze, 2014). Curiously, the current state of inconsistency in expected outcomes of individuals who engage in treatment driven by personal goals for communication and life participation are increasingly difficult to justify for reimbursement (Brown & Vickers, 2015).

2.4.2 Patient-Reported Outcome Measures

One common solution to bridge the gap between patient-centered care and reimbursement focuses upon quantifiable outcomes resultant from isolated impairments is the use of PROMs to track progress, growth, and changes in quality of life (Hilari, et al., 2015) and should be folded into patient centric practices (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015). Growing literature describes a PROM as an important component of ownership and self-advocacy in health care (Fung & Hays, 2008)—this has been studied in clinical populations such as persons with dysarthria or persons with dysphonia (Branski, et al., 2010). However, The Scientific Advisory Committee of Medical Outcomes Trust points out that a key aspect for both the reliability and validity of questionnaires—like PROMs—is that the document be written at a

reading level comprehendible by the intended proxy (Aaronson, et al., 2002). A number of PROMs have also been designed for PWAs (de Riesthal & Ross, 2015). However, PWA, unlike other disciples whose morbidities do not typically include impaired linguistic reception/expression, encounter unique barriers when accessing and using these measures (Babbitt & Cherney, 2010).

2.5 Life Participation Approach to Aphasia

Within the realm of aphasiology, the Life Participation Approach to Aphasia (LPAA) is a hallmark biopsychosocial service-delivery model rooted in patient-centered care and built upon the principles of WHO's ICF framework. It is a model which evaluates its outcomes, in part, through changes in quality of life and improvements in life participation. LPAA holistically acknowledges the life effects of living with aphasia—empowering the patient to build goals for and actively engage in the rehabilitation process as a means to return to a fulfilling life. The arm of LPAA sweeps across the various stages of stroke recovery and, by extension, medical care settings with which PWA interact. Stage of management aside, LPAA is an approach which hinges upon the degree to which aphasia impinges upon the execution of the PWA's involvement in activities of choice. This appraisal is classified via four broad domains—participation, impairment, environment, and personal factors (Duchan, Linda, Garcia, Lyon, & Simmons-Mackie, 2001).

What makes LPAA unique is its commitment to outcome-driven service delivery (Kagan & Simmons-Mackie, 2007). That is, backward design is employed to ensure that a one-to-one

correspondence exists between the person with aphasia's desired treatment outcomes and the treatment approaches that are subsequently employed to achieve the given outcomes (Holland & Forbes, 2013). As Worrall and colleagues note, the clinical value of LPAA and communication participation has gained traction within academic literature, with programmatic call for further clinical emphasis upon self-perception-based objectives for therapy (2010). Despite the theoretical need for a paradigm shift within clinical treatment of aphasia, the concrete operationalization of person-centered intervention remains under-implemented and under-represented within the clinical community of aphasiologists (Collis & Bloch, 2012).

Torrence, Baylor, Yorkston and Spencer (2016) sought to better understand this disparity, distributing an online questionnaire which a.) presented cases for dysarthria, aphasia, and laryngectomy, asking respondents to build goals and describe therapeutic activities for the given goals and b.) gauged facilitating and discouraging factors to participation focused intervention via open-ended questions. The survey was distributed to and returned by 66 speech-language pathologists who work with adults with neurogenic communication disorders. Results revealed that, while many speech-language pathologists touched on participation when building goals, only 50% of respondents provided goals that placed participation squarely at the forefront of their treatment. The majority of respondents noted that a great many barriers impede implementation of participation-focused treatment such as: productivity expectations, setting limitations, and the need for a diverse array of outcome measures.

Development of PROMs for PWAs have mirrored a trend within the medical community at large—a shift from 'volume to value' characterized by Rao in 2015. The term *value* being

patient-perception of treatment efficacy while *volume* being ability-based treatment efficacy (Porter, 2010). Patient-reports have been set forth as a recommended means for outcome measures by "policy makers and funding sources" (Kagan, et.al, 2008, p. 270). Thus, PROMs have become a necessary means of outcome measurement in a robust evaluation of treatment efficacy for PWA. Most commonly, PROMs take the form of a written questionnaire which can pose an issue as the presentation of this material in a written format requires uses to possess adequate literacy skills in order to understand the measure.

2.6 Literacy

Literacy, as defined by the National Assessment of Adult Literacy (NAAL), involves the skills essential to access, comprehension, and interaction with orthographic information (Baer, Kutner, Sabatini, & White, 2009). Literacy skills are crucial to an individual's daily function—helping them to engage with and better understand the world around them. Given the crucial role of literacy skills, rigorous study conducted over the past 30 years has aimed at gauging the literacy skill level that exists among adult Americans (Brizius & Foster, 1987). National data gleaned from the NAAL indicates that the average English-speaking American adult reads at an eighth grade reading lev). Kutner and colleagues went on to affirm these findings in 2007, concluding that only 43% of adults possess skills classified as "basic reading abilities"—otherwise known as those skills needed to generate answers to simple questions after reading a given brochure. Two years later, Baer and colleagues gave further context to the NAAL's finding

that the average adult reads at the eighth grade reading level, concluding that one in seven adults do not have literacy skills needed to read beyond a first-grade reading level (2009).

Another survey of adult literacy, the International Adult Literacy Survey, in-part examined the literacy skills of a nationally-representative corpus of 230 English speaking adults living in the United States. Kirsch and colleagues analyzed this data to find that no more than 50% of these participants had the skills necessary to comprehend complex written information (2001). The findings from the afore mentioned, nationally-representative surveys fit within a vein of research stemming from the 1980's which seeks to confront what is known as a 'national literacy crisis' (Parker, Ratzan, & Lurie, 2003).

2.7 Health Literacy

An outgrowth of the discussion surrounding the 'national literacy crisis' described by Parker and colleagues (2003) is a concept known as *health literacy*. Health literacy, defined by Ratzan and Parker, is known as "the skills essential for an individual to obtain, process, and understand basic health information necessary for the individual to make appropriate health-related decisions" (p. 278; 2000). In 2010 *Healthy People* submits the idea that readability is a key component of optimal health communication (U.S. Department of Health and Human Service). Health literacy is a broad term that includes print literacy (health information that is read) and oral literacy (the health information that is discussed) (Berkman, Davis, & McCormack, 2010). Currently, it is recommended that health-related materials are at their most

optimal potential for patient comprehension when written at a fifth or sixth-grade reading level (Doak, et al., 1996).

Health literacy extends beyond skills needed to make health-related decisions and addresses the intricacy of healthcare system navigation. Age, ethnicity, occupation, socioeconomic level, degree of social support, native language, visual and hearing acuity, cognitive skill level and education are all elements that influence the ways in which an individual accesses medical care and rehabilitation (Paasche-Orlow & Wolfe, 2007). Such factors serve as filters that color the knowledge, skills, and level of motivation an individual brings with them when interacting with a given healthcare system (Williams, Davis, Parker, & Weiss, 2001). To efficiently interact with a given healthcare system, patients must use their health literacy skills to determine: a.) how to initiate care when a medical need becomes apparent; b.) how to communicate needs effectively; c.) how to engage in self-care; and d.) how to self-monitor outcomes. At any of these points, low health literacy skills can cause a break-down which can cause a chain-reaction, affecting other points along the healthcare continuum (Paasche-Orlow & Wolfe, 2007).

Health literacy, it should be cautioned, is not a monolith. Alternately, it both influences and is influenced by a variety of health-related factors. Kraemer, Wilson, Fairburn, and Agras (2002) differentiate such components of health literacy as ‘moderators’ and ‘mediators’. Moderators are known as individual skills which underscore the overall concept of ‘health literacy’ while mediators are known as the outcomes effected by health literacy. Such considerations lead Squires, Peinado, Berkman, Boudewyns, and McCormack (2012) to

construct a framework highlighting individual components of health literacy and their respective impact upon patient health outcomes.

2.7.1 Health literacy in the Communication Sciences and Disorders Literature

Published studies addressing health literacy in communication sciences and disorders include those examining: health communication and health literacy skills of African American Vernacular English (AAVE) speakers (Hester & McCrary, 2011), newborn hearing screening brochures (Nicholson et. al., 2016), cleft palate patient education literature (Kahn & Pannbacker, 2000), central auditory processing disorders (Atcherson, et al., 2013), hearing aid user guides (McMullan, Kelly-Campbell, & Wise, 2018), audiologic self-report assessment tools (Kelly-Campbell, et al., 2012), swallowing disorders (Slavych, et al., 2013), dysphonia PROMs (Zraick & Atcherson, 2012), and consumer materials accessible on the ASHA website (Atcherson et al., 2014).

Gaining momentum in the past decade, health literacy has broken into the communication sciences and disorders literature, paralleling study of this topic within general health (Hester & Stevens-Ratchford, 2009; Zraick & Atcherson, 2012). ASHA asserts that speech-language pathologists are charged to ensure communication is effective and that communication is intrinsic to human rights. As such, health literacy is an important component in maintaining the dignity and well-being that comes with patient-centered care (2010).

2.7.2 Health Literacy and Persons with Aphasia

Existing literature examining health literacy modifications for PWAs has been limited to exploration of written health education materials. Specifically, this program of research encompasses content and design characteristics for patient education materials (Rose, Worrall, Hickson, and Hoffman, 2011a), principles of design for patient education materials (Rose, Worrall, Hickson, and Hoffman, 2012), degree of comprehension of written health education materials for PWAs (Rose, Worrall, & McKenna, 2010), and readability of written health education materials intended for PWAs (Aleigay, et al., 2008). The consensus within this body of literature is that written materials modified in terms of both content and design promote ease of comprehension and can help PWAs access health-related activities such as patient education and participate in clinical decision-making and/or treatment. (Rose, Worrall, & McKenna, 2003; Aleligay, Worrall, & Rose, 2008; Rose, et al., 2011a; Rose, et al., 2011b; and Tomkins, Siyambalapitiya, & Worrall, 2013).

To better understand what PWAs expect from health-related materials as it relates to person-centered care, qualitative study has been devoted to identifying overt themes in these expectations. In 2013, a phenomenological qualitative study using semi-structured interviews of 50 PWAs, Tomkins and colleagues assert that PWAs most frequently want: a.) information emphasizing free and open communication; b.) information presented with dignity and respect; and c.) information that fosters control and independence (Tomkins, et al., 2013). These three umbrella themes confirm the findings of Rose and colleagues' qualitative investigation conducted two years earlier. This phenomenological study specifically examined 40 PWAs and

their perception of formatting characteristics contained within stroke and aphasia education material. Results from this study showed that participants consistently indicated they want information that is simple and straightforward, easy to understand, that can be read easily and quickly, is aesthetically appealing and well-formatted, is clear, and looks as though it was developed by someone understanding of aphasia (2011a)—all of which can be measured via a robust battery of readability measures.

One such readability study exists. In 2008, Aleligay and colleagues collected 114 patient education materials distributed to PWAs and analyzed them via three readability measures—Flesch-Kincaid, Fry, and SMOG. Results not only revealed that the average reading grade level of the study's corpus was at a ninth-grade reading level, but there was also no significant difference in the readability of documents distributed by speech-language pathologists and other health professionals. These results indicate that not only are these written health materials not properly modified to account for the health literacy skills and reading abilities of those with aphasia, but these education materials are not written at a level that is accessible to the average American adult (Doak, et al., 1994), which may in fact be the PWA's spouse or caregiver.

2.8 Readability

Readability captures the quality that "makes some texts easier to read than others" (DuBay, 2004, p. 3) and is known as "the ease with which a person can read and understand written materials" (Freda, 2005, p. 152). Readability is intricate concept impacted by a text's style of writing (Klare, 1976), degree of clarity (Hargis, Hernandez, Hughes, Ramaker, Rouiller,

& Wilde, 1998), characteristics of the intended reader (McLaughlin, 1969), and the intended purpose of the text (DuBay, 2004). These elements determine the likelihood a text will be understood by its reader. When material is written at a level that is too difficult, the receiver may stop reading the material (Dubay, 2004).

Since the early 20th century, researchers have sought to quantify readability—developing an array of mathematic formulas which estimate the necessary reading comprehension level the consumer must possess to understand the given written material (Albright et al., 1996). Readability is sensitive to a variety of linguistic factors such as number of words, number of polysyllabic words, sentence length, and use of passive versus active voice as well as nonlinguistic factors such as document layout, typography, illustration use, and personal motivation to read (Hayden, 2008).

2.8.1 Measuring Readability

Given the diversity of the aforementioned features, no universal readability formula exists to capture all quantifiable elements of a given text. Readability can be objectively measured across a variety of techniques such as Cloze tasks, pre- and post- comprehension tests, analysis of extant vocabulary, or via readability formulas (Albright et al., 1996). Given their simplicity, objectivity, and ease of use, readability formula are popular tools in that their results are easy to conceptualize as reading grade levels (Wong & Levi, 2017) and they are translatable to functional use and formal research alike (Mcinnes & Haglund, 2011).

A variety of readability formulae exist—the gradation among formulas often being subtle. Readability formulas that superficially look at similar textual elements can approach score calculation differently. To illustrate, the Flesch Reading Ease (FRE) and Flesch-Kincaid (F-K) formulas examine sentence length and syllable number within a sample. However, the FRE formula bases its calculations upon average sentence length and average syllables per word while the F-K formula bases its calculations upon total words, syllables, and sentences within a sample. Therefore, a variety of readability formulas should be employed to gain a comprehensive picture of readability.

2.8.2 Readability Formulae

More than 1,000 academic studies have been published utilizing or relating to over 200 readability formulas, inherently lending itself to "strong theoretical and statistical validity" (p. 2, DuBay, 2004). Yet, just as with all purely quantifiable measurements, important elements (including those conceptualized above as 'nonverbal' elements like visual layout or use of illustrations) often fall outside of the scope of readability formulae. Thus, readability formulae are limited in that they correlate but cannot fully measure comprehension (Redish, 2000). Included below are advantages and disadvantages adapted from Kahn and Pannbacker, 2000.

For the purposes of this study, four readability formulae will be employed to ensure a robust picture of readability. All formulae were selected on the grounds that they are: a.) formerly used to analyze written health information distributed to PWA (Aleligay, et al., 2008) or b.) are used to analyze readability of PROMs distributed to other populations within the field

of medical speech-language pathologist and audiology (Atcherson, et al., 2013; Kelly-Campbell, et al., 2012; Pace, et al., 2011; Slavych, et al., 2013; Zraick, et al., 2011). The full mathematical formula and description of intended use for each readability measure can be found in Table 1.

Table 1 Readability Formulae

Formula Name	Formula Description
Flesch-Kincaid Grade Level (F-K)	F–K = 0.39 (TW/TSEN) + 11.8 (TSYL/TW) – 15.59
Gunning FOG Index (FOG)	GL = 0.4 (ASL + PHW)
FORCAST	GL = 20 – (N/10)
Simple Measure of Gobbledygook (SMOG)	SMOG grade = 3 + Square Root of Polysyllable Count, Count 10 sentences in a row from the beginning, middle, and end of the text, for a total of 30 sentences. Then count every word with three or more syllables in each group, even if the word appears more than once. Calculate the square root of the number from the previous count of words, round off to the nearest 10, and then add three to the calculated number to find the SMOG grade level estimate.

Note. RE = Readability ease; ASL = Average sentence length; ASW = Average number of syllables per word; TW = Total words; TSEN = Total number of sentences; TSYL = Total number of syllables; PHW = Percentage of hard words; GL = Grade level

No standard consensus readability formula selection exists—an inherent limitation in and of itself (Breese & Burman, 2005). However, each of the selected formulas are listed by the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality (AHRQ) as useful and common measures of readability (Badarudeen & Sabharwal, 2010). These formulae include: The Simple Measure of Gobbledygook (SMOG; Hedman, 2008; Ley & Florio, 1996; McLaughlin, 1969), the Flesch Kincaid Grade Level Formula (F-K; Frye, 1968), Gunning FOG (FOG; Gunning, 1969), and FORCAST (Caylor, Sticht, Fox, & Ford, 1973).

2.8.2.1 SMOG

The SMOG formula is one commonly used for analysis of health literature (Ley & Florino, 1996). Specifically, Fitzsimmons, Michaels, Hulley, and Scott cite SMOG as an integral tool for analyzing readability of materials specifically intended for healthcare consumers (2010). SMOG calculates readability based upon polysyllabic word count and sentence length. Unlike formulas described below, SMOG was validated using a 100 percent criterion—causing scores to be one or two grades higher than Flesch-Kincaid readability tests (DuBay, 2004). SMOG is validated from grades three to 19 with D'Alessandro and colleagues noting reduced accuracy for materials scoring below the sixth-grade reading level (2001).

2.8.2.2 Gunning FOG

This formula, too, is popular in healthcare as well as business industries (Zraick, et al., 2012; Gunning, 1969). FOG calculates readability based upon words that are two or more

syllables in length (also referred to as 'hard words'). Validated using the same reading tests (the McCall-Crabbs) as SMOG, FOG was developed using a 91% accuracy criterion, rather than a 100% accuracy criterion. Thus, FOG scores typically fall slightly lower than SMOG results but slightly higher than many other standard readability formulae (DuBay, 2004).

2.8.2.3 Flesch-Kindaid Grade Level (F-K)

The Flesch-Kincaid Grade Level formula is intended for use as a general assessment of readability and is designed to appraise adult-level text. Traditionally developed through the U.S. Navy, F-K is known as the most common readability formula (Fitzsimmons, et al., 2010). It is important to realize that, compared to validating comprehension criterion of SMOG and FOG, F-K was validated on respondents' comprehension of only 75% or more of the written material. Further, D'Alessandro and colleagues contest that F-K is further limited in that it is not sensitive to material that is written beyond the 12^{th} grade level (2001).

2.8.2.4 FORCAST

FORCAST is unique in that it is specifically designed to assess readability of lists, forms, and questionnaires. With a focus upon functional literacy, this formula does not account for punctuation—an element that is used differently within the context of forms and questionnaires rather than narrative texts (Caylor, et al., 1973; Zraick, et al., 2012). Another unique feature of FORCAST is that it does not use sentence-length measurement, in keeping with its designation for non-narrative texts like forms and quizzes (Atercherson, Zraick, & Brasseux, 2011). Of the

four selected readability formulas used for analysis, FORCAST is reported to have the lowest validating comprehension criteria—66% accurate performance on test of reading comprehension (DuBay, 2004).

2.9 Psychometric Properties of Patient-Reported Outcome Measures

Beyond the fundamental question of how readable a written outcome measure is, PROMs are most frequently scrutinized in terms of their psychometric properties. In broad terms, the psychometric adequacy of a given measure is often conceptualized in terms of a.) how valid a measure is eliciting accurate information from respondents and b.) how reliable a measure is in eliciting consistent information across and/or among respondents (Cherney, Babbitt, Semik, & Heinemann, 2011). However, additional psychometric elements are often useful in creating a more holistic image beyond the sheer content of the measure and lend insight to the degree to which the measure can be easily implemented among the clinical population and/or in the clinical setting for which it was intended. Such elements include a measure's acceptability (Cardoso et al., 2018); feasibility/practicality (Tyson & Brown, 2014); and versatility, breadth, and depth (Franic, Bramlett, & Bothe, 2005).

These additional psychometric markers speak not only to a tool's saliency for its intended population but also to its ease of implementation within a clinical setting. Without a broader understanding of these psychometric markers, a measure that is adequately reliable and valid may simultaneously pose too many barriers to be practical or feasible for clinical use (Franic, Bramlett, & Bothe, 2005). Such barriers can include cost, time for administration, respondent

burden, degree of support necessary for response, and required administrator training (Burton & Tyson, 2014; Cardoso et al., 2018; Franic, et al., 2005).

2.9.1 Quantification of Psychometric Properties

When attempting to capture peripheral psychometric properties beyond reliability and validity, descriptive statistics are often used to quantify various elements of questionnaire. However, recent efforts within the broader community of rehabilitation literature have sought to streamline this effort. In 2014, Tyson and Brown described and employed the Clinical Utility Score – a validated method to measure the psychometric element of feasibility in PROMs examining mood disorders in patients who have experienced stroke. The Clinical Utility Score is calculated based upon necessary time to administer a given measure, training required to administer the measure, initial costs for clinical implementation, and recurring costs for clinical implementation (p. 5; Burton & Tyson, 2014). Each measure is assigned a score based upon these elements ranging from zero (low clinical utility) to six (high clinical utility). This measure, when applied to patient-reported outcomes for PWAs, can help to differentiate between measures that fall into a confusion matrix to describe ease of use from both clinician and patient perspectives.

CHAPTER THREE: METHODS

3.1 Overview

This chapter describes the methods through which PROMs designed to assess life participation/quality of life in PWAs were analyzed. The present analysis has been performed through the University of Central Florida (UCF). The present analysis is a project submitted for fulfillment of requirements for a Master of Arts degree and does not involve human subjects, as outlined by UCF's Institutional Review Board. This analysis has sought to: a.) retrieve current PROMs available to measure various dimensions of the experience of PWAs, in terms of communication and b.) investigate elements and levels of readability of these PROMs. In terms of literature review, this study will analyze: a.) PROMs published prior to 2012, as outlined through and described by Irwin in 2012 and b.) PROMs published following 2012 which are both clinically useful and explicitly designed for PWAs in terms of aspects contributing quality of life and/or life participation. Thirteen PROMs were chosen for the present analysis, including: the Assessment for Living with Aphasia (ALA; Simmons-Mackie, et al., 2014), Aphasia Impact Questionnaire-21 (AIQ-21; Swinburn et al., 2018), ASHA Quality of Communication Life Scale (ASHAQoCL; Paul, 2017), Burden of Stroke Scale (BOSS; Doyle, et al., 2003), Communication Confidence Rating Scale for Aphasia (CCRSA; Cherney, Babbitt, Semik, & Heinemann, 2011), Communication Outcome After Stroke Scale (COAST; Long, Hesketh, Paszek, Booth, & Bowen, 2008), Disability Questionnaire (DQ; Howard, Swinburn, & Porter, 2010), Quality of Life Measurement and Outcome in Aphasia (QLQA; Spaccavento, et al., 2014), Stroke and Aphasia Quality of Life Scale (SAQOL; Hilari, Byng, Lamping, & Smith, 2003),

Communication Activities Checklist (COMCAT)/Social Activities Checklist (SOCAT; Aujla, Botting, Worrall, Hickson, & Cruice, 2016), and Modified Perceived Stress Scale (MPSS; Hunting-Pompon, Amtmann, Bombardier, & Kendall, 2018). In terms of readability analysis, the study will analyze selected PROMs via four readability formulae: Flesch-Kinciad (F-K; Kincaid, Fishburne, Rogers, & Chissom, 1975), Simple Measure of Gobbledygook (SMOG; McLaughlin, 1969), Gunning-FOG (Gunning, 1969), and FORCAST (Caylor, et al., 1973).

3.2 Literature Search

Irwin's 2012 review of PROMs, published through ASHA's Special Interest Group 2 for Neurogenic Communication Disorders, examines PROMs designed specifically for PWAs. Membership of ASHA's Special Interest Group 2 for Neurogenic Communication Disorders spans a robust array of aphasiologists, ranging from academic researchers to clinical practitioners. Thus, the vision of this organization is to coordinate the best possible degree of clinical services to those with communication disorders which are neurogenic in nature (ASHA, 2018). For these reasons, the target audience of Irwin's 2012 review reaches those who are most readily empowered to use PROMs with person's with aphasia across clinical and research practice settings and those who seek to support language rehabilitation for individuals with aphasia.

Irwin's 2012 review is used as a guidepost to identify PROMs commonly used within the context of speech and language service delivery for PWAs in the present study. One major limitation of this review is that, while clinically relevant to language rehabilitation in individuals with aphasia, it was published seven years prior to the present study. In the time between the

paper's publication and the present query, additional PROMs have been designed and validated specifically for individuals with aphasia. To better capture these PROMs, an additional literature search was conducted, and results are included below.

3.2.1 Inclusion Criteria

PROMs were included in the present analysis, given the following criteria was met:

1. Measures published prior to 2012:
    a. Must be addressed by Irwin's review of PROMs for PWAs (2012).
2. Measures published following 2012:
    a. Must be retrieved via a database provided through the University of Central Florida's Libraries System. Relevant, communication sciences and disorders education databases include:
        i. Access Medicine
        ii. Alt-HealthWatch
        iii. Annual Reviews
        iv. ASHA Evidence Maps
        v. Elsevier Clinical Key
        vi. Cochrane Library
        vii. EBSCOhost Education Source, EBSCOhost Health Source, and EBSCHO Medline
        viii. MedlinePlus

ix. Natural Medicines Comprehensive Database

x. ProQuest PILOTS

xi. REHABDATA

xii. SAGE Journals and SAGE Research Methods

xiii. Science Direct

xiv. Springer LINK

xv. Web of Science

xvi. Wiley Online Library

xvii. WorldCat (FirstSearch).

b. Must have been published between the years 2013 and 2019.

c. Must be identified directly via a combination of three search terms:

i. "Patient report", "Patient reported outcomes", or "Patient perception"

ii. "Aphasia"

iii. One or more of the following terms (or variations thereof):

1. "Communication" (Wallace, et al., 2017)
2. "Life Participation" (Wallace, et al., 2017)
3. "Attitudes/awareness" (Wallace, et al., 2017)
4. "Normality" (Wallace, et al., 2017)
5. "Emotional wellbeing" (Wallace, et al., 2017)
6. "Quality of life" (Whitehurst, et al., 2015)

7. "Health related quality of life" (Whitehurst, et al., 2015)

3. The measure is directly validated, as described by the authors, to measure an individual with aphasia's perception of their communication as it relates to life participation or quality of life. As such, this implies the measure is designed to accommodate for the needs specific to those with communication impairments as a result of aphasia (Dalemans, Wade, van den Heuvel, & de Witte, 2009).
4. The measure is determined by its designing authors to be both valid and reliable.
5. The measure is published in a peer-reviewed, academic journal.
6. The measure elicits responses (be it verbally, gesturally, or via writing) directly from PWAs, not a proxy (Doyle, et al., 2013).
7. The measure is theoretically driven by or is designed with consideration of either/both:
    a. WHO's ICF guidelines (ASHA, 2016)
    b. Life Participation Approach to Aphasia (Kagan & Simmons-Mackie, 2007)

3.2.2 Exclusion Criteria

PROMs were excluded in analysis, given the following:

1. The measure is published prior to 2012 but is not addressed in Irwin's review of PROMs (2012).
2. The measure is published following 2012 but does not meet inclusion criteria.
3. The measure is not designed specifically to measure the self-perception of the individual with aphasia's a.) quality of life; b.) degree of participation in life activities; c.) or aspect thereof, as directly described by the authors.
4. The measure has not been found to be valid and/or reliable.
5. The measure was designed without consideration of WHO's ICF guidelines (ASHA, 2016) or the Life Participation Approach to Aphasia (Kagan & Simmons-Mackie, 2007).
6. The measure elicits responses from proxy respondents such as family members or caregivers.

3.3 Search Results and Classification

Thirty measures were identified (see Appendices A and B). The following four were excluded because the measure did not address communication, quality of life, and/or health related quality of life:

1. Faces Pain Scale (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001)
2. Fatigue Severity Scale (Michael, Allen, & Macko, 2006)
3. Verbal Rating Scale (Aicher, Peil, Peil, & Diener, 2012)

4. Visual Analog Scale (Aicher, et al., 2012)

Six were excluded because LPAA and/or WHO's ICF guidelines were not considered during development of the measure:

1. European Quality of Life – 5 Dimension (van der Gaag, Smith, Davis, Moss, Cornelisu, Laing, & Mowels, 2005)
2. Functional Outcome Questionnaire for Aphasia (Gluekauf, Blonder, Ecklund-Johnson, Maher, Crosson, & Gonzalez-Rothi, 2003)
3. General Health Questionnaire-12 (Hilari, Owen, & Farrelly, 2007)
4. Long-Term Conditions Questionnaire (Kelly, Potter, Hunter, Gibbons, Fizpatrick, 2015)
5. Patient-Reported Evaluation of Cognitive State (Patchick, Horne, Woodward-Nutt, Vail, Wood, & Bowen, 2015)
6. Southhamptom Stroke Self-Management Scale (Boger, Hankins, Demain, & Latter, 2015)

Six were excluded because the measure was published prior to 2013 and was not included in Irwin's 2012 review:

1. The Communicative Effectiveness Index (Lomas, Pickard, Bester, Elbard, Finlayson, & Zoghaib, 1989).
2. International Quality of Life Assessment; SF-36 Health Survey (Ware, Snow, Kosinski & Gandeck, 1997).
3. Stroke Aphasic Depression Questionnaire (Lincoln, Sutcliffe, & Unsworth,

2000).

4. Stroke Impact Scale (Duncan, Bode, Lai, Perera, & Glycine, 2003).
5. Stroke Self-Efficacy Questionnaire (Jones, Partridge, & Reid, 2008).
6. Utrect Scale for Evaluation of Rehabilitation-Participation (van der Zee, Priesterbach, van der Dussen, Kap, Schepers, Visser-Meily, & Post, 2010).

Selected measures include:

1. ASHA Quality of Communication Life Scale (ASHAQoCL; Paul, 2017)
2. Aphasia Communication Outcome Measure (ACOM; Hula et al., 2015)
3. Aphasia Impact Questionnaire-21 (AIQ-21; Swinburn et al., 2018)
4. Assessment for living with Aphasia (ALA; Simmons-Mackie et al., 2014)
5. Burden of Stroke Scale (BOSS; Doyle, et al., 2003)
6. Communication Activities Checklist (COMCAT; Aujla, et al., 2016)
7. Communication Confidence Rating Scale for Aphasia (CCRSA; Cherney, et al., 2011)
8. Communication Outcome After Stroke Scale (COAST; Long, et al., 2008)
9. Communication Participation Item Bank (CPIB; Baylor et al., 2017)
10. Disability Questionnaire (DQ; Howard, et al., 2010)
11. Modified Percieved Stress Scale (MPSS; Hunting-Pompon, et al., 2018).
12. Quality of Life Measurement and Outcome in Aphasia (QLQA; Spaccavento, et al., 2013).
13. Stroke and Aphasia Quality of Life Scale (SAQOL; Hilari, et al., 2003)

14. Social Activities Checklist (SOCAT; Aujla, et al., 2016)

3.3.1 ASHA QoCL

The ASHA QoCL is an 18-item measure, developed by Paul in 2005, and is designed to examine communication quality of life in individuals with aphasia (Eadie, Kapsner-Smith, Bolt, Sauder, Yorkston, & Baylor, 2018). This measure elicits responses across personal, environmental, and life participation situations via a vertical Likert scale modified by black-and-white line drawings. As noted by Eadie and colleagues in 2006, this measure, while both reliable and valid, was found to be slightly less reliable than results from the BOSS.

3.3.2 ACOM

The Aphasia Communication Outcome Measure (ACOM; Hula, et al., 2015) is a 59-item measure of communicative functioning which the authors submit as "the ability to engage in common, everyday behaviors, tasks, activities, and life situations that involve understanding and/or producing spoken, written, and/or non-verbal messages, signs, and symbols" (p. 720; Doyle et al., 2008). This scale was found by authors to be both valid and reliable based upon responses of over three hundred individuals with aphasia (Hula et al., 2015).

3.3.3 AIQ-21

The AIQ-21 (Swinburn et al., 2018) is a measure comprised of 21 questions spanning domains of emotional well-being, communication, and participation. As a whole, the measure

was determined by its authors to have sufficient internal reliability and concurrent validity. The measure was developed in partnership with a number of PWAs and validated solely within an aphasia population. This measure is described as an outgrowth of the Communication Disability Profile (Swinburn, Byng, & Firenza, 2006) and is offered up by its authors as a more concise, compact questionnaire with similar objectives to those originally outlines within the Communication Disability Profile.

3.3.4 ALA

The ALA (Kagen et al., 2014) is a PROM that is rooted in LPAA WHO's ICF-driven Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagen et al., 2008). This 45-item assessment is unique in that it provides respondents with aphasia-friendly modifications to support both question comprehension and participant response. This measure was determined by its authors to be both reliable and valid. It was normed using a sample of 101 PWAs with severity ranging from mild to severe.

3.3.5 BOSS

The BOSS (Doyle et al., 2004) is a measure comprised of three scales that measure limitations in cognitive activity, physical activity, and psychological distress. This 64-item measure quantifies the 'burden' of stroke via a five-point scale of response which reflects the degree to which the respondent perceives effects of their stroke in terms of satisfaction, participation, and affective disruptions. The validating population was comprised completely of PWAs three, six, and 12 months post-stroke. Doyle and colleagues have determined the BOSS as reliable, valid, and sensitive to change (2004).

3.3.6 COMACT

The COMACT (Aujla, et al., 2016) was developed in tandem with the SOCACT to determine communication and social activities as it relates identity and engagement in PWAs following stroke. Items are subdivided into scales addressing reading, writing, listening, and talking. This 43-item checklist, following a preliminary investigation among a population of 30 individuals with chronic aphasia ranging in severity from mild to moderate, was found to be both valid and reliable.

3.3.7 CCRSA

The CCRSA (Babbitt, Heinemann, Semik, & Cherney, 2011) is a measure of communication in terms of self-perception of confidence. The CCRSA is a 10-item derivative of the Quality of Communication Life scale, specifically used to assess an individual's perception of their skills to express oneself and understand others. Through Babbitt and colleagues' investigation, this scale has been found to be reliable and valid (2011) and was validated during a two-part pilot study utilizing sample populations of 21 then 47 PWAs.

3.3.8 COAST

The COAST (Long, et al., 2008) examines a stroke survivor's perception of their degree of communication and participation following stroke. This 20-item measure was designed with

the intent of being a more feasible outcome measure in comparison to currently available PROMs during the time of design with a significant reduction of total items, reducing respondent burden. This measure was validated through a randomized clinical trial of 102 individuals between four- and 12-months post-stroke. Participants were either those with aphasia (60), dysarthria (15), both (15), or an unspecified presentation (12). Such results were determined by the measure's authors and found to be both valid and reliable (Long, et al., 2008).

3.3.9 CPIB

The CPIB, while initially validated in clinical populations with voice and motor speech disorders, was validated among PWAs (Baylor, et al., 2017). The measure was initially designed to quantify communication participation across a variety of contexts in persons with neurogenic, voice, and communication disorders resultant from head and neck cancer (Baylor, et al., 2013; Baylor et al., 2014). Further effort was made to point out the CPIB's strong roots to both WHO's ICF and A-FROM guidelines. While the entire, 46-item bank was validated among PWAs in 2017 (specifically, 110 individuals with aphasia were included as respondents), the authors note that administration of all 46 items to a PWA is likely not appropriate for implementation in a clinical setting. Instead, the authors state the 10-item short form is 'preferable and sufficiently accurate' (p. 866; Baylor et al., 2017). Baylor and colleagues found that participants with WAB-R scores lower than 50 required assistance to complete the measure while participants with WAB-R scores higher than 80 required only occasional assistance. The CPIB was found to be valid and reliable, though the correlation between CPIB and ASHA-QCL was moderate. The 10-

item CPIB form was used for this analysis, as it has been determined by its authors as optimal for clinical use among PWAs.

3.3.10 DQ

The DQ is designed to examine the impact of aphasia upon life participation, measuring impact across four categories: emotions, participation, activities, and external influences. This is an outgrowth of an initial iteration called the Communication Disability Profile which was a stand-alone PROM initially authored by Swinburg & Byng (2006). These items were revised and incorporated as a subtest of the Comprehensive Aphasia Test (CAT; Howard, Swinburn, & Porter, 2010), which was found by its authors to be both reliable and valid.

3.3.11 MPSS

The MPSS is a 10-item measure specifically addressing chronic stress associated with living with aphasia as it relates to and potentially impacts quality of life. The MPSS conceptualizes stress in terms of anxiety, resilience, and depression was validated among 72 PWAs. Authors suggest the MPSS as valid and reliable, with limitation to the present study, and conceptualize the MPSS as a useful, emergent measure of persistent stress among PWAs (Ponpom et al., 2018.

3.3.12 QLQA

The QLQA is also a 37-item measure designed to measure quality of life among individuals with acute and chronic aphasia. Its items address emotional and social dimensions of language loss. The measure was administered to 146 PWAs and 37 neurotypical control subjects. This measure was found to be both valid and reliable by its authors and yielded results which were sensitive to aphasia severity (ranging from mild to severe) (Spaccavento et al., 2014).

3.3.13 SOCACT

The SOCACT (Aujla, et al., 2016) is a 20-item checklist measure, validated in conjunction with the COMACT. It contains items addressing formal, informal, and leisurely activities. A preliminary investigation was conducted among 30 individuals living with chronic aphasia. The population's range of severity extended from mild to moderate, with a mean participant age of 70 years old. This measure, in addition to the COMACT was found to be both valid and reliable.

3.3.14 SAQoL-39

SAQoL-39 is a 39-item measure that examines quality of life across physical, communication, psychological, and energy domains. While this measure examines communication-related quality of life, it also seeks to provide a larger picture of health related quality of life in individuals with aphasia. This measure has been found to have good

acceptability, test-retest reliability, and construct validity by Hilari and colleagues in 2003 within a population of 95 individuals with chronic aphasia.

3.4 Readability Analysis

In order to complete a full analysis of relevant, selected PROMs (Readability Studio, produced through Oleander Software, Ltd., 2013) were used to assess textual elements and readability of each selected measure. Each selected measure was converted to an electronic .docx file and divided into the following sections:

1. Instructions (if present)
2. Response items
3. PROMin its entirety (including instructions, items, response method)

Each section was uploaded within Readability Studio software. Readability Studio software allows for simultaneous analysis of a given text via multiple readability formulae. Results include both readability formulae scores as well as a breakdown of various elements of the given measure. Such breakdowns include number and frequency of polysyllabic words, sentence count, and syllable count.

3.4.1 Analysis Procedure

The analysis followed these steps:

1. Open Readability Studio (Oleander Software, 2013).

2. Create “New Project” by clicking “Create New Project” button.
3. Copy text from electronic .docx document in electronic document and paste into the text dialogue box.
4. Ensure document language is set to “English”.
5. Define the parameters of the document, including: “Non-narrative, fragmented text”, “Sentence split by extra spacing/illustrations”, and “Left-aligned text” to describe document composition and layout.
6. Ensure SMOG, FORCAST, FOG, and F-K formulae are selected for analysis.
7. Ensure all text, including fragmented sentences, are included in the analysis report.
8. A score report for the given measure will be generated, outlining each readability formula score and textual element breakdown produced.
9. Such steps will be repeated for each specific file, as dictated by the above literature search.

3.4.2 Psychometric Analyses

In order to quantify the clinical utility of the afore described PROMs, each measure was rated using the Clinical Utility Scale (Tyson & Brown, 2014). Such ratings and additional data describing the method of response included for each measure is outlined in Appendix C. Each measure, depending upon the method through which it was obtained, was rated in terms of initial

accessibility, recurring expense, and the need for skilled administration. Given that each measure is designed/researched by and distributed for speech-language pathologists, it is assumed that 'specialist' training is necessary for administration of the given measure.

Administration time, unless otherwise described by the validating author, is estimated by applying a range of 30 – 40 seconds per question and multiplying that range by the number of questions. Of course, it is known that each individual with aphasia approaches each question with a unique set of linguistic and cognitive abilities which may require additional time for response. Such acknowledges breakdowns in visual attention, auditory attention, cognitive flexibility, planning, and application of short-term and/or working memory which are known to commonly co-occur in individuals with aphasia (Murray, 2012). Consistently applying a set time constraint per question allows this aspect of the Clinical Utility Scale to reflect time changes due to sheer volume of response items, indicative of respondent burden. As the sheer number of items a PWA encounters increases, so does the demand upon these cognitive-linguistic systems vulnerable for breakdown (Murray, 2012).

3.5 Statistical Analyses

A descriptive statistical analysis was conducted to account for nuances between specific elements contributing to reading grade level scores. Such elements include average reading grade level, average number of syllables per word, ratio of complex words to novel complex words, and ratio of total words to novel words.

CHAPTER FOUR: RESULTS

4.1 Introduction

Fourteen PROMs were analyzed to: a.) determine the estimated reading grade level of PROMs for PWAs and b.) identify elements of these documents that can contribute to potential misunderstanding. In terms of estimated reading grade level, scores and results are divided according to analyzed sections: PROM instructions (if available—not all PROMs provided explicit instructional scripts for clinicians to read prior to/during administration); PROM response items; overall measure. Tables 2, 4, and 6 provide readability scores calculated for each selected formula across each selected PROM. Specifically, Table 2 addresses PROM instructions, Table 4 addresses PROM response items, and Table 6 addresses the PROM as a whole. Tables 3, 5, and 7 provide descriptive statistics (mean, median, range, and standard deviation). Specifically, Table 3 addresses descriptive statistics calculated for PROM instructions, Table 5 addresses descriptive statistics calculated for PROM response items, and Table 7 addresses descriptive statistics calculated for each PROM as a whole. Following this analysis, textual elements concerning syllabic, word, and sentence complexities are described and compared for each measure in Table 8. Finally, Clinical Utility Scores, which give additional psychometric information were provided for each measure in Table 9.

Overall, the average estimated reading grade level of each PROM fell outside of the optimal range described by Doak, Doak, and Mead in 1996. No document, on average, was written below a sixth grade level. However, the Modified Perceived Stress Scale and the Aphasia Impact Questionnaire were written *within* a sixth-to-seventh reading grade level. It is important

to note that these two measures were published between 2018 and 2019 and are modifications of previously developed scales. These results are encouraging and suggest that calls within the literature to ensure patient access in outcome measurement are being heard. The potential relationship between average reading grade level and year of publication are discussed further in this chapter.

4.1.1 Readability: Instruction

Ten of thirteen measures which explicitly provided instructions to guide measure administration, are listed in Tables 2 and 3. Instructional scripts within these PROMs are designed to be read *to* patients and comprehended auditorily by the patients. Nonetheless, patients are expected to apply this auditory information to written measures, thus the complexity of this information is a crucial variable for eliciting accurate target responses from respondents. Table 2 reveals readability results for each measure across four formulae. As is consistent with previous descriptions within broader readability literature, scores derived from readability measures validated using a lower criterion of respondent comprehension (i.e., F-K and FORCAST) tend to trend lower than measures with a more rigorous criterion of respondent comprehension (i.e., Gunning FOG and SMOG).

Table 2. Readability Statistics of PROM Instructions

PROM	F-K	FORCAST	GUNNING FOG	SMOG
ACOM	8.4	9.9	8.2	10.2
AIQ-21	3.6	8.1	6.3	7.6
ASHA-QCL	5.6	8.9	8.1	8.8
ALA	3.9	8.2	6.2	7.6
CCRSA	9.1	9.4	11.3	12.2
COAST	5.3	8.5	6.1	8.8
CPIB	11.2	9.9	13.4	14.2
DQ	4.3	8.4	5.2	6.8
MPSS	3	8.1	5.5	7.6
SAQOL-39	6.3	9.3	7.8	8.6

Table 3 provides information regarding the mean, median, range, and standard deviation taken from F-K, FORCAST, Gunning FOG, and SMOG calculated grade levels. The average reading grade level scores across measures ranges from 6.1 – 12.2, which exceeds fourth to sixth grade reading level recommendations for health-related materials (Doak, Doak, & Mead, 1996). It is important to note that measures ~~scoring~~ falling, on average, ~~to be~~ within a sixth-to-seventh

grade reading level (AIQ-21, ALA, and MPSS) were published within the last five years, whereas measures that scored higher were published earlier. As a general finding, measure instructions were, on average, written at an eighth-grade reading level.

Table 3. Descriptive Statistics of PROM Instructions

PROM	Average	Median	Range	Standard Deviation
ACOM	9.2	9.2	8.2-10.2	1.0
AIQ-21	6.4	7.0	3.6 – 8.1	2.0
ASHA-QCL	7.9	8.5	5.6 – 8.9	1.5
ALA	6.5	6.9	3.9 – 8.2	1.9
CCRSA	10.5	10.4	9.1 – 12.2	1.5
COAST	7.1	7.3	5.3 – 8.8	1.7
CPIB	12.2	12.3	9.9 – 14.2	2.0
DQ	6.2	6.0	4.3 – 8.4	2.3
MPSS	6.1	6.6	3.0 – 8.1	2.3
SAQOL-39	8.0	8.2	6.3 – 9.3	1.2

4.1.2 Readability: Measure Items

Analysis of response items across thirteen measures are listed in Tables 4 and 5. Number of response items range anywhere from 10 questions to 64 questions – yielding a wide range of response burden for the patient. While addressing concomitant cognitive deficits that can often underscore individuals with aphasia's level of linguistic functioning is outside the scope of the present study, the degree of sustained attention required to respond to a 10-question measure

versus a 64-question measure should not be overlooked. Further consideration of response burden as a complicated partner to readability will be discussed in Chapter 5. Table 4 reveals readability results for each measure's response items across four readability formulae.

Table 4. Readability Statistics of PROM Items

PROM	F-K	FORCAST	GUNNING FOG	SMOG
ACOM	7.4	10	10.7	10.5
AIQ-21	3.8	8.2	5.8	7.2
ASHA-QCL	5.2	8.8	6.7	8.7
ALA	3.9	9.4	6.7	7.6
BOSS	8.7	8.8	12.4	12.1
COMACT	2.9	9	4.8	6.6
CCRSA	9.1	9.6	13.1	12.7
COAST	6.3	7.9	9.1	10
CPIB	10.1	10.7	13.8	13.5
DQ	4	7.7	6.1	7.4
MPSS	5.5	7.4	7.8	6.9
SOCACT	7.9	9.5	10.3	10
SAQOL-39	6.9	9	8.3	8.4

Table 5 provides information regarding the mean, median, range, and standard deviation taken from F-K, FORCAST, Gunning FOG, and SMOG calculated grade levels. The average reading grade level scores for each measure ranges from 5.8 – 12, which exceeds fourth- to sixth-grade reading level recommendations for health-related materials (Doak et al., 1996). On average, PROM response items are written at an eighth-grade reading level, consistent with the average reading grade level of measure instructions. As such, response items and measure instructions do not have an overt degree of difference, in terms of reading grade level.

Table 5. Descriptive Statistics of PROM Items

PROM	Average	Median	Range	Standard Deviation
ACOM				
AIQ-21	6.3	6.5	3.8 – 8.2	1.9
ASHA-QCL	7.4	7.7	5.2 – 8.8	1.7
ALA	6.9	7.2	3.9 – 9.4	2.3
BOSS	10.5	10.5	8.7 – 12.4	2.0
COMACT	5.8	5.7	2.9 – 9.0	2.6
CCRSA	11.1	11.2	9.1 – 13.1	2.1
COAST	9.7	10.3	6.3 – 10	1.5
CPIB	12	12.1	10.1 – 13.8	1.9
DQ	6.3	6.5	3.8 – 98.2	1.9
MPSS	6.9	7.2	5.5 – 7.8	1.0
SOCACT	9.4	9.8	7.9 – 10.3	1.1
SAQOL-39	8.1	8.4	6.9 – 9.0	0.9

4.1.3 Readability: Overall Measure

Analysis of response items across thirteen measures are listed in Tables 6 and 7. Such analysis is most reflective of realistic linguistic demands that accompany these measures – often with oral instructions being delivered simultaneously with reading tasks. While both tax different linguistic modalities, they require adequate integration for successful, accurate completion of a given measure. Table 6 indicates readability results for each measure's response items across four readability formulae.

Table 6. Readability Statistics of PROMs

PROM	F-K	FORCAST	GUNNING FOG	SMOG
ACOM	7.7	10	9.9	10.4
AIQ-21	3.7	8	6.1	7.6
ASHA-QCL	5.5	8.9	7.6	8.9
ALA	4.9	8.5	6.6	8.4
BOSS	7.5	10.2	9.4	10.7
COMACT	3.5	9.2	4.9	7
CCRSA	10.1	9.7	11.8	13
COAST	5.9	8.2	7.6	9.5
CPIB	11.6	10.2	13.7	14.6
DQ	4.1	7.9	5.8	7.3
MPSS	3.4	7.9	5.7	7.6
SOCAT	7.6	9.6	9.8	10.4
SAQOL-39	8.8	9.3	9.6	9.5

Overall, PROMs are written at an eighth-grade reading level, consistent with analyses of these measures' response items and instructions. Table 7 provides information regarding the mean, median, range, and standard deviation taken from F-K, FORCAST, Gunning FOG, and SMOG calculated grade levels, similar to information provided for PROM response items and

instructions. Such results indicate that, as is consistent with prior analysis, average reading grade level scores far exceeds fourth- to sixth-grade reading level recommendations for health-related materials (Doak, Doak, & Mead, 1996).

Table 7. Descriptive Statistics of PROMs

PROM	Average	Median	Range	Standard Deviation
ACOM	9.5	10.0	7.7 – 10.0	1.2
AIQ-21	6.4	6.9	3.7 – 8.0	1.9
ASHA-QCL	7.7	8.3	5.5 – 8.9	1.6
ALA	7.1	7.5	4.9 – 8.5	1.7
BOSS	9.5	9.8	7.5 – 10.7	1.4
COMACT	6.2	6.0	3.5 – 9.2	2.5
CCRSA	11.2	11.0	9.7 – 13.0	1.5
COAST	7.8	7.9	5.9 – 9.5	1.5
CPIB	12.5	12.7	10.2 – 14.6	2.0
DQ	6.3	6.7	4.1 – 7.9	1.7
MPSS	6.2	6.65	3.4 – 7.9	2.1
SOCACT	9.4	9.7	7.6 – 10.4	1.2
SAQOL-39	9.3	9.4	8.8 – 9.6	0.4

4.1.4 Readability: Textual Elements

Mirsa and colleagues (2013) go beyond preliminary reading grade level estimation and describe average sentence length, syllabic complexity and choice of voice as important factors

which have the power to underscore or even confound readability (~~2013~~). Table 8 includes calculated data addressing each of these elements.

Table 8. Textual Elements of PROMs

PROM	Average Sentence Length	Average Number of Syllables per Word	Instances of Passive Voice
ACOM	9.2	1.6	0
AIQ-21	10.5	1.3	0
ASHA-QCL	10.3	1.4	0
ALA	10.6	1.4	2
BOSS	11.7	1.6	0
COMACT	7.6	1.4	0
CCRSA	17.1	1.6	0
COAST	13.4	1.3	0
CPIB	19.9	1.6	0
DQ	11.1	1.3	0
MPSS	10.4	1.3	0
SOCACT	10	1.6	0
SAQOL-39	20.5	1.4	0

Building upon Mirsa and colleagues' (2013) findings, it is important to conceptualize syllabic complexity in more detail. Table 9 describes word-level complexity in terms of total number of complex words (i.e., words with three or more syllables), percentage of complex words when compared to total number of words and percentage of unique complex words when compared to total number of complex words.

Table 9. Word-Level Complexities

PROM	Number of Complex Words	Percentage of Complex Words	Percentage of Unique, Complex Words
ACOM	33	13.3%	70%
AIQ-21	116	16%	37%
ASHA-QCL	37	9.4%	56.8%
ALA	107	7.6%	55%
BOSS	176	14.9%	23.3%
COMACT	22	6.1%	95.5%
CCRSA	41	16%	43.9%
COAST	43	8.7%	58%
CPIB	27	19.4%	70.4%
DQ	32	4%	45%
MPSS	24	5.2%	66.7%
SOCACT	71	15.1%	33.8%
SAQOL-39	39	5.8%	51.2%

4.2 Psychometric Elements

As described in the literature review, psychometric markers can indicate the ease with which PWA interpret and respond to a measure's items. Burton and Tyson (2014) approach this

picture of psychometric utility from a clinician's perspective via the Clinical Utility Scale —a quantitative descriptor of a measure's cost, time, and training necessary for administration. Each Clinical Utility Scale score is listed in Table 10, as well as the number of response items, an indicator of respondent burden (Cardoso et al., 2018; Franic, Bramlett, & Bothe, 2005).

Table 10. Clinical Utility

PROM	Clinical Utility Score	Number of response items
ACOM	3	67
AIQ-21	3	21
ASHA-QCL	2	18
ALA	0	45
BOSS	3	64
COMACT	3	43
CCRSA	5	10
COAST	3	20
CPIB	5	10
DQ	2	32
MPSS	5	10
SOCACT	3	20
SAQOL-39	2	39

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The objective of the present study was to a.) determine and b.) describe the readability of PROMs designed for and commonly used in assessment of PWAs. Reading grade levels were determined for fourteen frequently used PROMs, including: ASHA-QCL, ACOM, AIQ-21, ALA, BOSS, COMACT, CCRSA, COAST, CPIB, DQ, MPSS, QLQA, SAQOL, and SOACT. Reading grade levels were determined across four formulae: F-K, FORCAST, Gunning FOG, and SMOG. The results of the present analysis align with similar analyses of PROMs across other clinical populations treated by speech-language pathologists (Atcherson, et al., 2013; Kelly-Campbell, et al., 2012; Pace, et al., 2012; Slavych, et al., 2013; Zraick, et al., 2012). This long program of research indicates that PROMs designed for individuals with communication difficulties far exceed fifth grade reading recommendations for average, American adults (Doak, et al., 1996). Discussed below are results of the present study, followed by sections describing clinical implications and limitations of the present analysis. Finally, indications for further study/research are outlined.

5.2 Readability

On average, results of the present analysis indicate that PROMs selected for this study are written at too high of a reading grade level for the average American adult. This disparity is

exacerbated by the receptive/expressive linguistic difficulties encountered by PWAs. Specifically, the PROMs were written at an average eighth grade reading level, three grade levels higher than Doak and colleagues' recommendation of a fifth-grade reading level for written health materials (1996). The average reading grade levels of these measures do not squarely fall at or below the target fifth grade reading level described by Doak and colleagues. However, these results are encouraging, given Rose and colleagues' previous analysis of PWA-acquired patient education materials in 2008 and Abou-Diab, Moser, and Atcherson's most recent analysis of internet-based patient education materials in 2019. Both analyses indicate that patient education materials designed for PWAs are written: a.) between one-to-three grade levels higher than PROMs selected for the present study and b.) three-to-five grade levels higher than the target reading level of written health materials for the average American (Doak, et al., 1996).

Examining each measure individually, four PROMs have an average reading grade level falling between 5.0 – 6.9. Such scores fall within +/- one reading grade level of the target reading grade level submitted by Doak and colleagues (1996). These measures include the AIQ-21 with an average reading grade level of 6.3; the ALA with an average reading grade level of 6.9; the COMACT with an average reading grade level of 5.8; and the MPSS with an average reading grade level of 6.9. These measures were published between 2016 and 2019 and reflect a long history of research within aphasiology and the broader community of communication sciences and disorders addressing health literacy and readability as a potential barrier to patient access (Azios, Bellon-Harn, Dockens, & Manchaiah, 2017; Bedaiwi, Alfaraj, & Pines, 2018). The exception to this trend is the ALA, which is the only PROM that is a direct product of the A-

FROM framework (Kagan, et al., 2008), efforts toward aphasia-friendly printed materials (Brennan, Worrall, & McKenna, 2005), and principles of Supported Conversation for Persons with Aphasia (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). In addition to low readability scores, the ALA and MPSS use graphics to support comprehension and ease response burden (Rose et al., 2011a).

Three measures were found to have an average readability rating equivalent to a high school reading grade level (ranging from 9.0-12.0+) or beyond. These measures include: the BOSS with an average reading grade level of 10.5; the CCRSA with an average reading grade level of 11.1; the CPIB with an average reading grade level of 12.1; and the SOCACT with an average reading grade level of 9.4. Surprisingly, many of these PROMs are frequently used outcome measures within academic study (e.g., Attard, Loupis, Togher, & Rose, 2018; Kiran, et al., 2018; Rogalski, et al., 2016). Further, the CCRSA and CPIB are important contributions to the PROM community as they are some of the few measures that specifically examine communication confidence and communication participation rather than general quality of life (Baylor et al., 2017; Cherney et al., 2011b).

The content of each selected PROM was analyzed in terms of all relevant information to which the responded/PWA would likely have to read, understand, and synthesize to produce appropriate, accurate responses. This information included PROM instructions, response items, and the measure's overall content (including instructions, response items, and response scales). Such analysis yielded a high variability in reading grade level across F-K, Gunning FOG, FORCAST, and SMOG formulae, ranging anywhere from 2.9 (COMACT via F-K) to 13.8

(CPIB via SMOG). This variability in results was expected, given the disparity in validating comprehension criteria among formulae (Caylor et al., 1973; DuBay, 2004; Gunning, 1969).

Scores derived from the FORCAST formula are a metric specifically addressing functional literacy of *non-narrative* text. FORCAST is the only readability formula known to specifically address questionnaires such as PROMs (Caylor et al., 1973) and determines readability without the consideration of sentence length. The average reading grade level rating for each FORCAST calculation, across measures, fell at a ninth-grade level, one reading grade level higher than the overall average reading grade level across measures. Such points out that, in terms of non-narrative text, the study's analyzed PROMs are written at too high of a reading grade level for the average American adult to successfully access. If these questionnaires are written at a level too high for the average American adult, they are likely written at a level too high for an American adult who experiences expressive/receptive language difficulties resultant from stroke or other neurologic insult. Thus, are these measures truly valid in their collection of empirical data (Zriack & Atcherson, 2012)?

Breakdown in comprehension of and response to PROMs can occur across a variety of levels. A breakdown in comprehension of instructions can affect the way in which the PWA interprets, and subsequently responds to, the measure's items. A breakdown in comprehension of response items can impact the manner in which the PWA responds and/or the validity of the data extracted from responses. An individual analysis of each of these elements was performed. Results indicate there was no significant difference in the average reading grade level of measures' instructions versus measures' response items. Nonetheless, the average readability

levels of these PROMs are generally too high for their intended audience. If the readability of the PROM is incongruent with the reading grade level of the individual, the PROM cannot fully capture the data it is designed and developed to capture (Nicholson et al., 2012).

Some of the unique benefits of PROMs for PWAs is the ease with which the measures can be accessed by the PWA and clinician alike. Sheer readability of a PROM is not the only contingent factor influencing a speech-language pathologist's selection of diagnostic materials (Hilari et al., 2015). The likelihood with which a PROM will be implemented in clinical diagnosis/treatment of aphasia is often influenced by the ease with which the speech-language pathologist can access the measure, the price attached to the measure, and the time it takes to administer the measure. A questionnaire that is 10 questions in length, free for download, and can easily be accessed (i.e. via an open-domain internet source rather than through a heavily-licensed publishing company) may more frequently be selected by a clinician rather than a measure that is 50 items in length, is over $150.00 to purchase, and requires specialist training.

For this purpose, the clinical utility of each selected PROM was determined (Tyson & Brown, 2014). Interestingly, some of the most difficult PROMs, in terms of readability, were ones with the best clinical utility. The CPIB and CCRSA are the best examples of this mismatch in readability versus utility. These measures are both easily accessible, short, and free for use. Yet, they are written at a high school reading grade level and beyond. Such is concerning if clinicians are opting for measures that are clinically useful, but difficult for a PWA to process, interpret, and respond. Ideally, a measure is *both* clinically useful and readable. For example, the

Modified Perceived Stress Scale was found to be short, quick to administer, free to access, and to have an overall readability score just slightly above a sixth-grade reading level.

Finally, textual elements of each measure were determined. Encouragingly, average syllabic complexities of each PROM were determined and found to not exceed 1.6 syllables per word. This finding indicates that, as a general trend, vocabulary selected for these measures are not overly long. While all polysyllabic words should not be entirely removed from PROMs, it is potentially helpful to point out high frequency polysyllabic words vulnerable to misunderstanding (Nicholson et al., 2012). This is acutely true for measures which hold a high percentage of unique, complex words, like the CPIB. On the other hand, average sentence length was found to be exceedingly high and to have a direct relationship with high average reading grade levels. For example, the SAQOL-39 had an average of 20.5 words per sentence and an average reading grade level slightly above the ninth grade. In contrast, the MPSS had an average of 10 words per sentence and an average reading grade level slightly above the sixth grade.

5.3 Clinical Implications

The clinical utility and feasibility of PROMs is relatively high (Worth, Hammersley, Nurmatov, & Sheikh, 2012). These measures are often simple in layout, easy to implement, not cost prohibitive, and add additional depth/dimension to a speech-language pathologist's clinical picture of a PWA. To fully embrace the patient-centered service delivery model at the core of ASHA's standards for best-practice, PROMs are essential in determining a PWA's personal

goals for treatment and perception of communication capabilities. However, these measures are often textually based, delivered via ink and paper, and require intermittent, supplemental clarification, as delivered by the speech-language pathologist. In order for a PWA to comprehend, process, and provide appropriate responses to PROM items, the measure must be written at a level the PWA can understand. One of two things can change to mitigate this incongruence: the health literacy skills of the PWA or the health literacy demands of the PROM. With one-size-fits-all measures comes the vulnerability to gather incomplete, partial, or inaccurate responses, influencing the validity of the data derived from the PROM itself (Nicholson et al., 2012).

The above results are situated within the broader context of available trends in aphasiology. Inherently, PROMs are designed for PWAs by researchers and clinical specialists who study aphasia. These measures are especially validated using PWA participants. The underlying assumption that underscores these measures is that they account for receptive and expressive linguistic difficulties experienced by the user, the PWA (Irwin, 2012). Yet, on average, these PROMs are written at an eighth-grade reading level which is three grade levels higher than fifth grade reading level recommendations for *neurotypical adults* (Doak et al., 1996). Such results are especially troubling, as Brookshire and colleagues point out that 68% of individuals with aphasia experience some degree of alexia (2014).

Recent work from Abou-Diab, Moser, and Atcherson parallel findings from this present study (2019). Abou-Diab and colleagues investigated both readability and user-friendliness of patient education materials available on the internet designed for those with aphasia. It should be

noted that all selected PROMs for the present study have been published in peer-reviewed, academic journals (2019). Often, web-based materials do not undergo the same level of scrutiny. Nonetheless, Abou-Diab and colleagues found that these internet patient education materials for PWAs were written at an average tenth grade reading level (2019).

5.4 Limitations

Perhaps the most important limitation of the present analysis is the use of readability as a primary measuring stick to determine the likelihood a PWA will grasp concepts presented in PROMs. Language impairment-type among PWAs does not follow a developmental trajectory; the final linguistic skill acquired during language development is rarely the first to experience impairment. Instead, persons who experience neurologic insult are left with missing links within their own personal chain of linguistic processing which may hold some semblance of lesion-to-deficit correspondence but are otherwise unpredictable in manifestation. As such, readability measures do not account for the individual, unique, and intrinsic need of each PWA.

A variety of other variables aside from reading grade level and clinical utility often impact the likelihood to which a PWA may comprehend written text. 'Aphasia-friendly' modifications to written information have attempted to mitigate the cognitive-linguistic load that accompanies reading comprehension by making exaggerated modification to the design characteristics of a document (Rose et al., 2011b; Rose et al., 2012). Yet, guidelines for modification of written text to hold loose consensus within the broader aphasiology community

(Wilson & Read, 2016). From a domain-specific standpoint, Rose and colleagues have sought to investigate design preferences of PWAs when seeking to modify written health education materials (2011a). Participants indicated a preference for emphasis of key points, simple typography, use of color, use of graphics, and simplified layout/increased use of white space. However, this investigation does not bridge the gap between preference and performance and further research is necessary to determine if these modifications of written health information improve a PWA's *comprehension* of these materials (Rose et al., 2011a). Nonetheless, readability formulae are mathematical calculations which only examine word- or sentence-level elements of a text and fall short of capturing the qualitative elements of a document such as use of graphics or simplified layout.

Another limitation of the study can be found within the use of F-K and FOG readability formulae. These measures often skew lower than SMOG because their criteria for comprehension are lower than 100%. As such, the results of these formulae can be misleading to the untrained eye. On average, F-K and FOG run between one and three grade levels lower than SMOG. The objective of a PROM is not to ensure 75% comprehension (the validating comprehension level of F-K). If a PWA only comprehends 75% of the information provided in a PROM, this may also impact the validity of the data gathered from the measure. Unfortunately, SMOG does not capture an analysis of the textual elements that F-K and FOG capture. Thus, an average score calculated across each selected readability formula was emphasized throughout the study because it is most holistically reflective of reading grade level across word- and sentence-level complexities (Ley & Florino, 2007).

One final limitation of the present analysis was the occasional sample which carried less than the prescribed word count for accurate reading grade level estimation. The majority of the selected readability formulae require a minimum sample of one hundred words to create an accurate reading grade level estimate. In the case of SMOG, a minimum sample size of at least three hundred words is recommended for the most accurate results. Without appropriate sample size, high-frequency words of a certain length or syllabic complexity can impact the reading grade level estimate unfairly. While the PROMs, from a holistic perspective, carried enough words for analysis, sub-analysis of instructional scripts alone carried enough words for analysis, particularly via SMOG. In these instances, an asterisk was placed next to the score. These scores still hold a valid, though limited, role within the discussion of readability of instructional scripts versus measure items but should be interpreted with caution.

5.5 Directions for Further Study

The view of a measure's readability is sincerely narrowed with a consideration of only reading grade level. Readability formulae results are less of a hard-and-fast picture of readability and more of an estimation tool to point out potential difficulties with comprehension. As discussed above, many elements of a document, beyond the text, are important to consider when revising a PROM. Use of illustrations, pictures, and graphics/graphic organizers can simplify the presentation of information and can augment the effect of simplified readability (Nicholson et al., 2012; Rose et al., 2011a; Rose et al., 2012). Yet, Wilson and Read (2016) find that font style

and typography tend to have a significant impact upon comprehension of highly readable texts that use of graphics do not. Such highlights the intense variability of recommendations for appropriate content, readability, and design modifications for PWAs. Use of a qualitative cognitive interview technique with PWAs and clinicians alike would yield first-hand, specific information regarding what each individual appreciates or does not like about PROMs. This discussion could be expanded to encompass a comparison of PROMs found to have a low and high average reading grade level and contribute to consideration as PROMs are developed or modified to address low health literacy skills exacerbated by the linguistic deficits that accompany aphasia.

Please note that, while the present study's results indicate the need for a systemic movement toward plain language in PROMs for PWAs, it does not mean that PROMs should be simplified without appreciation for and direct study of a PWA's actual comprehension of the text. In other words, revision of these PROMs should not be an arbitrary attempt to condense and simplify. While PROMs should include simple, straight-forward plain language, revision of these PROMs to achieve plain language should not include a sanitization of all complex or polysyllabic words (Atcherson et al., 2013). Instead, it may be helpful for the administrator to review and highlight high-frequency, complex, and potentially misunderstood words. An over-simplification of language can often change the author's intended meaning of the instruction or response item (Stableford & Mettger, 2007).

Beyond word- and sentence-level modifications to PROMs, perspectives of PWAs are an essential consideration to account for when seeking to modify PROMs appropriately for PWAs.

Tucker outlines an optimal process through which general quality of life PROMs should be modified for PWAs. These recommendations include: use of personal interviewing to garner direct responses from PWAs; provision of concrete response methods including Likert scales or yes/no questions; simultaneous auditory and visual presentation of questions; use of simplified written materials which include increased use of white space, large fonts, and single-item segmentation of information; provision of no more support than the PWA absolutely requires for accurate response (Tucker, Edwards, Mathews, Baum, & Connor, 2012). Such consideration should be extended to the process through which future researchers modify PROMs appropriately for PWAs and their caregivers. Results of the present analysis indicate that PROMs designed for PWAs are, on average, written at too high of a grade level. What remains unknown are readability levels of PROMs designed for PWAs' caregivers. Such is reflective of calls within the literature which point to both the potential benefit and the notable ambiguity extended to caregiver perspectives when determining perception of communication abilities and quality of life (Saigle et al., 2019).

A simple, standard screening method through which clinicians can estimate a PWA's *current* level of literacy for health-related information may be of benefit when a clinician goes to select appropriate PROM assessment measures for patients/clients. One such measure exists within the public health sector and is called the Rapid Estimate of Adult Literacy in Medicine (Davis, et al., 1993). It is primarily used by physicians and other health professionals to determine if a patient experiences difficulty with health literacy or has a low level of health literacy. This tool is a seminal measure within the public health sector because, in part, it has a

high degree of clinical utility. The measure is easily accessible and is intended to be administered in a one-to-two-minute time span (Davis, et al., 1993). While the REALM has been implemented in research for PWAs and their caregivers (Eames, Hoffmann, Worrall, Read, & Wong, 2010), further validation among PWA participants is necessary to determine if the measure in its entirety is valid and reliable for PWAs or if a modification of this measure would increase its usefulness when implemented across populations with variation in aphasia classification and severity.

Some investigation has been extended to the use of REALM as a supplementary measure to gauge literacy levels in PWAs (Eames et al., 2010; Hoffman & McKenna 2006; Rose, Worrall, & McKenna, 2003). Yet, REALM or any other measure has not been applied for the express purpose of generating a reading level recommendation for the average PWA, as Doak and colleagues have for the average American adult (1996). This type of recommendation would be especially helpful as researchers seek to generate health-related measures and materials written at an appropriate reading level *for PWAs*. Given the close relationship of aphasia and acquired alexia, further study should include application of REALM to PWAs with and without alexia (Brookshire et al., 2014). Such data would provide further detail regarding the need of those with both aphasia and alexia and suggest the need for additional modifications necessary for these individuals to access and understand written health information.

Additionally, readability has been applied to current approaches to script training in PWA populations (Kaye & Cherney, 2016). In Kaye and Cherney's investigation of script training in aphasia, the authors utilized a series of scripts which were graduated in terms of textual

complexity and readability ranging from low to high difficulty (2016). They found that the use of these script templates, graded in terms of textual complexity and readability, was an appropriate approach to script training for PWAs and that, regardless of severity of aphasia, low complexity scripts were read by participants with increased accuracy. This same concept can be extended to the use of PROMs in assessment and management of aphasia and warrants further investigation.

A dichotomy exists in the potential approaches to addressing low health literacy skills exacerbated by linguistic deficits—approaches can include a compensatory approach or a rehabilitative approach. The majority of the above directions for research approach the mitigation of barriers to patient access to PROMs from a compensatory perspective. In other words, how can the measure be modified to accommodate the needs of the PWA? Emergent approaches to treatment of alexia have pointed out the necessity of generalization of reading skills to functional, everyday activities (Purdy et al., 2018; Webster, Connor, Horner, McCormac, & Potts, 2013). These approaches for treatment of alexia remain emergent and focus upon general reading comprehension skills. Domain-specific literacy skills, understandably, have received slim to no attention within the literature. In other words, how can the health literacy skills of PWAs be *improved*, or rehabilitated, to ensure that PWAs have adequate literacy skills to work through health-related barriers to life participation. Given that the effects of aphasia are inextricably linked to an individual's overall health status (Hilari & Byng, 2009), it is curious that a focused, specific intervention protocol has not been developed to build *domain-specific* literacy skills.

Rehabilitation of domain-specific literacy skills is something which has received recent, spotty inquiry and primarily addresses digital literacy skills (Menger, Morris, & Salis, 2016; Moffatt, Pourshahid, & Baecker, 2017). However, domain-specific literacy skills like financial and health literacies are necessary components of re-initiation of functional life activities. Further, financial and health literacies are known to be highly associated with cognitive functioning in older age populations (Wilson, James, Bennett, & Boyle, 2017). Despite the potential benefits of building these skills in individuals with aphasia, these skills have historically been an incidental target in therapies rather than a primary focus and described more commonly as functional therapeutic activities (Duchan et al., 2001). Thus, development of a health literacy centric approach to intervention would not only be a functional approach to treatment of linguistic deficits in those with aphasia but would closely align to principles outlined through LPAA and WHO's ICF framework (Kagan & Simmons-Mackie, 2007).

5.6 Conclusion

The average reading grade level of PROMs designed for PWAs commonly used by aphasiologists and speech -anguage pathologists who assess and treat aphasia was estimated using four formulae frequently used to estimate readability within the field of communication sciences and disorders (Slayvich et al., 2013). These formulae were applied to fourteen PROMs commonly used to assess PWAs; the formulae include: F-K, Gunning FOG, FORCAST, and SMOG. FORCAST is the readability formula that most closely aligns with the nature of PROMs,

as it is designed specifically to address nonnarrative text structures, such as questionnaires. Readability formulae like F-K and Gunning FOG, while frequently used within the literature (Abou-Diab, et al., 2019; Kaye & Cherney, 2016), were found to have a high variability in scores when applied to PROMs and suggest limited utility, as they were validated using a lower criterion of comprehension than that of SMOG.

Across the four selected formulae, the average reading grade level of the analysis's selected measures was at an eighth-grade reading level. This is discordant with the fourth-to-sixth grade level recommendations set forth by health literacy experts (Doak et al., 1996). While some individual measures fell just slightly outside of these recommendations, these measures were found to have significant barriers to clinical utility/implementation including ease of access, cost of implementation, and administration time/respondent burden. Such indicates the need for development of more PROMs for PWAs that are short, use plain language, and are easily implementable in clinical settings.

Encouragingly, newer, more recently developed measures such as the Modified Perceived Stress Scale (Pompon, et al., 2018) come closer to achieving this balance of clinical utility and plain language. This momentum should not be lost as further PROMs are developed to target specific areas of life participation, general quality of life, and health related quality of life. Such consideration is imperative to the process of gather reliable, valid, and useful information regarding a PWA's perception their communication abilities, quality of life, and improvement following skilled treatment. To best align assessment and management of aphasia with the patient-centered guidelines set forth by ASHA, WHO and aphasiologists (ASHA, 2016; Kagan

& Simmons-Mackie, 2007), PROMs must be adequately readable and accessible to clinicians and PWAs alike.

APPENDIX A: MEASURE INCLUSION CRITERIA

Measure name:_____

Rater:_____

Criteria:

- Measure is published during or prior to 2012 and cited in Irwin's review of PROMs for PWAs (2012).

OR

- Measures published following 2012:
    - Retrieved via a University of Central Florida's Libraries System database.
    - Published between the years 2013 and 2019.
    - Identified directly via a combination of three search terms:
        - "Patient report", "Patient reported outcomes", or "Patient perception"
        - "Aphasia"
        - One or more of the following terms (or variations thereof):
            - "Communication" (Wallace, et al., 2017)
            - "Life Participation" (Wallace, et al., 2017)
            - "Attitudes/awareness" (Wallace, et al., 2017)
            - "Normality" (Wallace, et al., 2017)
            - "Emotional wellbeing" (Wallace, et al., 2017)
            - "Quality of life" (Whitehurst, Latimer, Kagan, Palmer, Simmons-Mackie, & Hoch, 2015)

        - "Health related quality of life" (Whitehurst, Latimer, Kagan, Palmer, Simmons-Mackie, & Hoch, 2015)
    - Directly validated in PWA populations (Dalemans, Wade, van den Heuvel, & de Witte, 2009).
    - Determined to be both valid and reliable.
    - Published in a peer-reviewed, academic journal.
    - Elicits responses (be it verbally, gesturally, or via writing) directly from PWAs, not a proxy (Doyle, et al., 2013).
    - Theoretically driven by or is designed with consideration of either/both:
        a. WHO's ICF guidelines (ASHA, 2016)
        b. Life Participation Approach to Aphasia (Kagan & Simmons-Mackie, 2007).

APPENDIX B: PSYCHOMETRIC DESCRIPTORS

Name of measure:_____

- Number of questions:_____
- Response method:_____
  - Description of response method:
  - Visual supports available? YES / NO
  - If indicated via likert scale, description of scale:
- Validation using SCA for response: YES / NO

Clinical Utility Scale Score

Adapted from: (Tyson & Brown, 2014)

TIME TO ADMINISTER	2 5 or less min.	1 6-10 min	0 11 or more min.
INITIAL COST	2 Freely available	1 Cost < $128.98*	0 Cost > $128.98* or unavailable
ADDITIONAL COST		1 No additional cost	0 Additional cost or unavailable

SPECIALIST TRAINING		1 No specialist training required	0 Specialist training required
TOTAL SCORE**			

Maximum: <u>6 points</u> - higher scores denote GREATER clinical utility.

**Denotes currency conversion from British pound to American dollar, conversion completed January 5th, 2018.*

***PROMs scoring 4 or less are EXCLUDED from study.*

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