

Respondent Burden and Readability of Patient-Reported Outcome Measures for People With Aphasia

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Purpose: Patient-reported outcome measures (PROMs) for persons with aphasia (PWA) are commonly used to measure various outcomes. Persons with aphasia commonly present with language deficits that can likely increase respondent burden. Elements that contribute to respondent burden include readability, design, and formatting methods. The aims of this study were to determine how PROMs for PWA rate in level of respondent burden and on readability levels. **Method:** Irwin's 2012 review of PROMs for PWA was used for inclusion criteria and additional PROMs developed after 2012 were identified. This method resulted in 14 PROMs, which were rated on proposed respondent burden criteria and also underwent a readability analysis. **Results:** Six PROMs achieved a 7 or higher with the proposed 10-point respondent burden measure, indicating lower respondent burden. Eight PROMs met the nationally recommended reading level of sixth grade. **Conclusions:** Results indicated that the several PROMs available for PWA fail to minimize respondent burden. **Key words:** *aphasia, health literacy, PROMs, readability, respondent burden*

APHASIA is a multimodal impairment of language stemming from damage in regions of the brain central to language processing (McNeil & Pratt, 2001). Aphasia typically impacts an individual's ability to

participate in life activities and maintain relationships, roles, and identity. These drastic and chronic changes may heighten stress, decrease mood, and diminish a person's sense of well-being. In 2001, the World Health Organization (WHO) proposed a framework to assimilate health and functioning into the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). The purpose of the ICF is to provide a standard language and model to describe health and health-related situations, inclusive of body functions, structures, activities, participation, and disabilities, with consideration of personal and environmental factors. The adoption of the WHO-ICF framework helped propel an emphasis on patient-centered care across health care disciplines, and motivated specific models of holistic patient care, such as *Living with Aphasia: Framework for Outcome Measurement* (A-FROM, Kagan et al, 2008). Although clinical services for aphasia have traditionally focused on ameliorating language impairments through clinician-led

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approaches, patient-centered care has become common and foundational to assessment and treatment of impairment and/or daily life function.

PATIENT-REPORTED OUTCOME MEASURES AND APHASIA

An emphasis on the patient beyond pathology and impairment provoked new methods of measurement to capture the patient's perspectives and experiences. For speech-language pathologists (SLPs), this meant moving beyond assessments of linguistic and cognitive-linguistic impairment to measures of patient-reported attitudes, appraisals, and activities. Patient-reported outcome measures (PROMs) are self-report instruments that capture an individual's perspectives of their own health, well-being, participation, and/or quality of life. Patient-reported outcome measures uniquely quantify and document perspectives and experiences that are not externally observable by the clinician (Cohen & Hula, 2020), and can drive patient-centric practices (Burns et al., 2015). As such, these measures are well-suited for use across health care disciplines including speech-language pathology (Ross, 2006) and reflect current trends in clinical practice.

A growing literature describes PROMs as an important component of patient ownership and self-advocacy in health care (Fung & Hays, 2008), including in the communication disorders disciplines (e.g., Cohen & Hula, 2020; Irwin, 2012; Ross, 2006; Wallace et al., 2020). Patient-reported outcome measures are usually written questionnaires that require adequate literacy skills and cognitive abilities to understand and respond to measure questions. People with aphasia (PWA), unlike individuals with typical communication abilities, encounter unique barriers when completing these measures (Babbitt & Cherney, 2010). Concomitant acquired reading impairment can impede access to and comprehension of written information in roughly 68% to 80% of PWA (Brookshire et al., 2014; Wilson et al., 2007).

Cohen and Hula (2020) proposed PROM respondents with communication impairments fit into one of three categories: (1) those who can independently complete any PROM without modification or supports; (2) those who cannot complete any PROM (regardless of modification or supports) due to significant cognitive-linguistic impairment; or (3) those who can access cognitively and linguistically simple portions of PROMs with some modification and support.

Patients with more severe impairment may require assistance to complete a PROM. The assistance of a proxy reporter (e.g., a family member or caregiver) may be sufficient for individuals with no communication impairment (Hauer et al., 2021). However, proxy respondents for PWA tend to overestimate impairment and the degree of disagreement between patient and proxy appears to correlate with stroke severity (Baylor et al., 2017; Oczkowski & O'Donnell, 2010). In addition to ethical considerations (Kothari & Kirschner, 2006), PWA may prefer autonomy over relinquishing control to a proxy reporter (Babbitt & Cherney, 2010).

Several PROMs have been designed for PWA (Irwin, 2012; Wallace et al., 2020). For example, the Assessment for Living with Aphasia (ALA; Simmons-Mackie et al., 2014) assesses activity, participation, and quality of life in PWA using graphics, simple language, and administrative supports. Similarly, the Aphasia Impact Questionnaire (AIQ; Swinburn et al., 2018) uses culturally sensitive line drawings to help the respondent reflect on the effect aphasia has on their life.

Patient-reported outcome measures that require greater cognitive and/or linguistic processing may be more difficult and less accessible for PWA. Given the variable comprehension and expression barriers of aphasia, the challenges with proxy reports, and the limited number of PROMs developed for individuals with communication limitations, it is important to evaluate the appropriateness of PROMs for PWA via measure attributes.

PROM ATTRIBUTES

The Medical Outcomes Trust Scientific Advisory Committee (SAC) reviewed measures of health, well-being, and quality of life, and identified eight attributes to assess patient measures: reliability, validity, responsiveness, interpretability, respondent and administrative burden, alternative forms, and cultural and language adaptations (Aaronson et al., 2002). Within these attributes, respondent burden is defined as the “time, effort, and other demands placed on those to whom the instrument is administered” (p. 196). The readability of the measure contributes to increased or decreased respondent burden. The SAC defines this element of burden as “the reading and comprehension level needed for all population groups for which the instrument is intended” (p. 202; Aaronson et al., 2002).

Respondent burden

Completing a questionnaire requires respondents to execute four proposed processing stages: (1) comprehension of the questionnaire instructions and questions; (2) recall of autobiographical information from memory; (3) use of a solution-based decision process to formulate a response; and (4) determination of the appropriate response option (Jobe, 2003). A well-developed PROM informs the respondent what is expected of them, provides clear response options, and overall, improves the respondent’s motivation to complete the measure. Outcome measures that are simply presented and include fewer visual distractions, less unnecessary or redundant information, and a natural reading flow (e.g., left to right reading) help reduce the cognitive demands required by the respondent. Similarly, response entry (i.e., circled, marking a box, pointed to and administrator-scored) can affect data collection. Measures that include these empirically tested formatting elements can yield valid outcome data and reduce respondent burden (Mullen et al., 2000).

Some attributes of respondent burden have been considered with measures used with PWA. Tucker et al. (2012) published aphasia-friendly design modifications for several assessments, including the 36-item Short Form Medical Outcomes Study (Ware et al., 1997), the Activity Card Sort (Baum & Edwards, 2008), the Stroke Impact Scale (Duncan et al., 2003), and the Reintegration to Normal Living Index (Wood-Dauphinée et al., 1988). These modifications included one question per page, 24-point Arial font, use of white space, and increased character spacing. People with aphasia with a range of severity levels demonstrated improved participation on these assessments with aphasia-friendly design modifications, though continued research is necessary to determine how these modifications may affect the validity of the resulting data (Tucker et al., 2012).

Respondent burden includes mode of PROM administration, which can also contribute to measure validity. Many PROMs are developed for self-administration; however, most PROMs for PWA are designed for assisted administration by the examiner that may include contextual and/or visual supports (e.g., reading the questions aloud, rephrasing questions, and use of gestures; for examples see Baylor et al., 2017, and Hunting Pompon et al., 2018). Measure platform may also contribute to respondent burden. For example, computer adaptive testing may be designed to meet response patterns whereas paper-based forms do not (Rolstad et al., 2011).

Questionnaire length and required administration time have been examined with some conflicting results related to respondent burden. Although Rolstad et al. (2011) reported a weak association between PROM length (i.e., number of pages of the questionnaire) and respondent burden, administration time of 15 min or less has been recommended for health surveys (Franic & Bothe, 2008; McHorney & Tarlov, 1995). This time parameter was also recommended in a more recent discussion of PROM administration for PWA (Gadson et al., 2020). It is important to consider the

relationship between PROM length and the context of administration (Francis et al., 2016).

Assessment of respondent burden

As of now, there are no formal parameters to assess respondent burden in PROMs in general or specific to the needs of PWA. Evaluating the clinical utility and suitability of a PROM for a specific population includes the time and training required to administer the measure (e.g., Clinical Utility Scale; Burton & Tyson, 2015). Informally, respondent burden can be assessed by comparing a measure to evidence-based parameters, such as formatting methods to improve data collection (Mullen et al., 2000).

Readability

A widely studied element of respondent burden is readability. Readability has received considerable attention in recent communication sciences and disorders literature (e.g., Abou-Diab et al., 2019; Slavych et al., 2013; Zraick et al., 2012). Readability is known as “the ease with which a person can read and understand written materials” (Freda, 2005, p. 152), and incorporates style of writing (Klare, 1976), degree of clarity (Hargis et al., 1998), characteristics of the intended reader (McLaughlin, 1969), and the intended purpose of the text (DuBay, 2004). Respondents may stop reading or misunderstand the material if it surpasses their abilities (DuBay, 2004). Readability is sensitive to a variety of lexical and syntactic factors such as number of words, number of polysyllabic words, sentence length, and syntactic complexity (e.g., use of passive vs. active voice), as well as nonlinguistic factors such as document layout, typography, illustration use, and personal motivation to read (Hayden, 2008). Further, Doak et al. (1996) reported that readability is highly influenced by an individual’s perception of the degree of reading difficulty in any given document.

Although the U.S. national adult reading literacy level was estimated to be at the seventh to eighth-grade level (Kutner

et al., 2007), health-related materials and information are often written at a fifth- or sixth-grade reading level to promote health literacy (Doak et al., 1996). The SAC advised that PROMs for a general patient population should be written at an accessible reading level because administering a questionnaire that exceeds a patient’s reading level can affect the measure’s validity (Aaronson et al., 2002). When considering the reading level criterion, the target population should be considered (e.g., underlying cognitive and/or linguistic deficits; Francis et al., 2016; Reeves et al., 2013). Notably, many PROMs used in clinical speech–language pathology are written beyond a fifth-grade reading level (e.g., Doak et al., 1996; Slavych et al., 2013; Zraick et al., 2012), despite readability evidence and recommendations (Stefu et al., 2021). However, PROMs included in these studies were developed for clinical populations without language impairment (e.g., persons with swallowing disorders; Zraick et al., 2012); therefore, the impact of PROM reading level on PWA is unspecified.

Assessment of readability

Common readability evaluative techniques include cloze tasks (i.e., replace certain words with blank spaces and have participants guess which word may best complete the sentence), pre- and postcomprehension tests, analysis of extant vocabulary, and readability formulae (Albright et al., 1996). Given their simplicity, objectivity, and ease of use, readability formulae are widely used tools that produce results equivalent to reading grade levels (Wong & Levi, 2017) and are useful in clinical, educational, and research contexts (McInnes & Haglund, 2011). Some widely used readability formulae include the Flesch Reading Ease and Flesch–Kincaid (F-K) formulae, both of which examine sentence length and syllable number within a sample but use different calculations to arrive at a resulting reading level.

When the reading level of the PROM is mismatched with the reading level of the respondent, the PROM may not fully capture or

reflect the perceptions and experiences it is designed to capture; therefore, the measure may not yield valid response data (Nicholson et al., 2016; Zraick et al., 2012). Difficulties with readability can lead to inaccurate response selection or nonresponse, reduced motivation and engagement in the measurement process, and a negative experience overall. These risks to measure utility are reflected in the research literature; lower literacy skills are predictive of a person's refusal to complete a questionnaire (Martin et al., 2021).

Alternatively, attending to reading level and respondent burden during PROM development also improves the validity of the resulting data. Specifically, addressing PROM burden criteria can improve reading comprehension, response ease, and overall participation, and reduce dependence on assistance as well as invalid or nonresponses (Mullen et al., 2000). Reduced burden leads to PROMs that quantify the effects of impairment on participation, emotional well-being, and/or quality of life with a high degree of validity.

RESEARCH QUESTIONS/PURPOSE

Respondent burden has been scantily addressed in the speech-language pathology literature. Respondent burden of PROMs used with PWA is critical for clinicians and researchers to consider when selecting measures and interpreting their results. The primary purpose of this research was to identify PROMs designed to measure emotional well-being, participation, and/or quality of life variables, and evaluate both respondent burden and readability of these PROMs. Specifically, this study was guided by the following research questions:

1. What is the level of respondent burden of PROMs for PWA that measure emotional well-being, participation, and/or quality of life?
2. What are the readability levels of PROMs for PWA that measure emotional well-being, participation, and/or quality of life?

METHODS

Measure identification

Irwin (2012) reviewed PROMs specifically validated for PWA and reported what he believed to be the best developed instruments to assess quality of life and communication following stroke, impairments due to stroke, and aphasia. These instruments included the Burden of Stroke Scale (BOSS; Doyle et al., 2003), Stroke and Quality of Life Scale (SAQOL-39; Hilari et al., 2003), American Speech-Language-Hearing Association (ASHA) Quality of Communication Life Scale (ASHA-QCL; Paul, 2017), Communication Disability Profile (CDP; Swinburn & Byng, 2006), Communication Outcome After Stroke Scale (COAST; Long et al., 2008), and Communication Confidence Rating Scale for Aphasia (CCRSA; Cherney et al., 2011). This review was used in the present study to identify PROMs commonly used within the context of speech and language service delivery for PWA. Since this review, additional PROMs have been developed and validated for PWA; therefore, we conducted an additional literature search for measures published between 2013 and 2021. Measures were identified using three search terms: (1) "patient report," "patient-reported outcomes," or "patient perception"; and (2) "aphasia"; and (3) one or more of the following terms (or variations thereof): "communication," "life participation," "attitudes/awareness," "normality," "emotional well-being," "quality of life," and/or "health-related quality of life" (Wallace et al., 2017; Whitehurst et al., 2015). Measures were included if they were validated for PWA and measured emotional well-being, communicative participation, and/or quality of life; elicited responses directly from PWA, not via proxy (Doyle et al., 2013); developed with consideration of WHO's ICF guidelines (ASHA, 2016) and/or the *Life Participation Approach to Aphasia* (Kagan & Simmons-Mackie, 2007); and published in a peer-reviewed academic journal (see Figure 1).

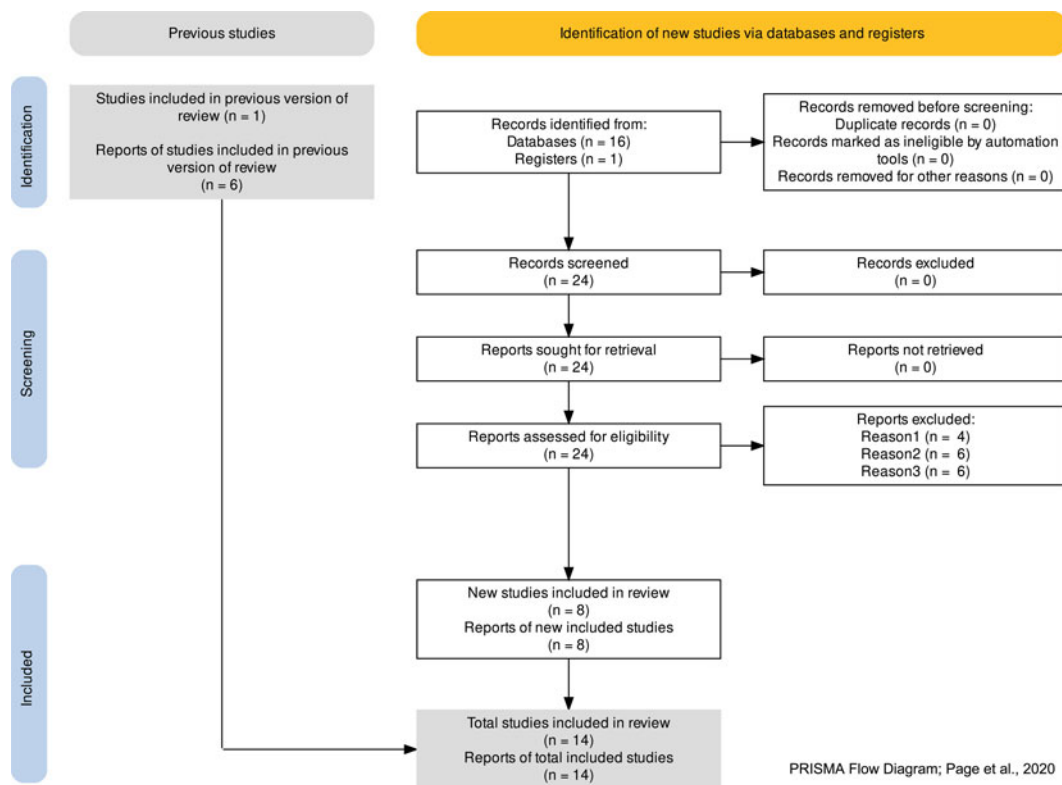


Figure 1. Burden and readability (Page et al., 2020). This figure is available in color online (www.topicsinlanguage disorders.com).

Patient-reported outcome measures were excluded from review if they were published prior to 2012 but not addressed in Irwin’s (2012) review; published following 2012 but did not meet inclusion criteria; the measure did not address self-perception or -report of emotional well-being, communicative participation, and/or quality of life; lacked evidence of validity; or designed without consideration of WHO’s ICF guidelines (ASHA, 2016) or the *Life Participation Approach to Aphasia* (Kagan & Simmons-Mackie, 2007). For example, the Faces Pain Scale (Hicks et al., 2001) has been used with PWA and this information has been published (e.g., de Vries et al., 2017). Thus, this scale populated in the initial search, but was excluded because it did not address communication, quality of life, and/or health-related quality of life. See Supplemental Digital Content Table 1 (available at: <http://links.lww.com/TLD/A85>)

for a list of PROMs that were populated with the search terms but excluded from the analysis.

Measure evaluation procedures

Respondent burden

To evaluate respondent burden of the selected PROMs, we adapted the Clinical Utility Scale (Burton & Tyson, 2015), which describes health literacy modifications for PWA, and combined this scale with the recommendations for reducing respondent burden in PROMs for PWA (Rose et al., 2003, 2011a; 2011b) along with additional recommended psychometric properties of health-related PROMs (Aaronson et al., 2002; Mullen et al., 2000). Thus, the resulting framework for PROM evaluation included 10 elements: (1) readability (at or below a sixth-grade reading level); (2) pictorial supports for questions

(e.g., line drawings and contextual images); (3) pictorial supports for response (e.g., line drawings, contextual images, and pictorial anchors); (4) layout: left indent or organized layout (i.e., instructions and questions were indented to the left of the page or were in an organized layout); (5) layout: no grid or tables; (6) font size of 14 or higher; (7) font type was sans serif; (8) instructions were included; (9) practice items were available; and (10) white space was included (i.e., at least 35% of white space, margins should be at least 0.5–1 inch and text and visuals should be limited for optimal accessibility to the content; Centers for Disease Control & Prevention, 2009; Rose et al., 2003; 2011a). See Supplemental Digital Content Appendix A (available at: <http://links.lww.com/TLD/A85>). Each PROM was evaluated with the adapted respondent burden rating scale and given 1 point for each of the 10 criteria present in that PROM. Patient-reported outcome measures with higher scores suggest reduced respondent burden; those with lower scores suggest increased burden.

Readability

Although readability is reflected in a limited way in the adapted respondent burden scale, a more thorough assessment of readability was conducted. Readability Studio software standard edition for macOS (Oleander Software, Ltd., 2013) was used to analyze the readability of the selected PROMs. The PROM instructions (if available) were included in the analysis of the overall measure. We selected four readability formulae used to analyze health information: the Simple Measure of Gobbledygook (SMOG; Hedman, 2008; Ley & Florio, 1996; McLaughlin, 1969), the Flesch-Kincaid Grade Level Formula (F-K; Fry, 1968), Gunning FOG (FOG; Gunning, 1969), and FORCAST (Caylor et al., 1973). Additionally, parameters in the software were defined for “nonnarrative, fragmented text,” “sentence split by extra spacing/illustrations,” and “left-aligned text” to ensure the analyses were sensitive to a variety of text formats and presentations. See Supplemental Digital Content

Table 2 (available at: <http://links.lww.com/TLD/A85>) for a description of each formula, the algorithm of each, and how the output is obtained.

Procedures

This study was motivated by a preliminary readability analysis of the PROMs that met inclusion and exclusion criteria conducted by the third author (Gray, 2019). In the current study, the first author reanalyzed readability and only the results from the current analysis were utilized. Additionally, an evaluation of burden was independently completed by the first author and the second author using the adapted respondent burden rating scale.

RESULTS

Selected PROMs for PWA

Upon review, 24 records were screened and assessed for eligibility. Several measures were subsequently excluded upon further review if they did not meet the inclusion and exclusion criteria (see Supplemental Digital Content Table 1, available at: <http://links.lww.com/TLD/A85>). In addition to the six measures identified by Irwin, eight additional measures were ultimately identified for evaluation for the current study (see Supplemental Digital Content Table 3, available at: <http://links.lww.com/TLD/A85>).

PROM evaluation

Fourteen PROMs were analyzed to determine the: (1) level of respondent burden and (2) estimated reading grade level of each PROM.

Respondent burden

Six of the selected 14 PROMs scored at the higher end of the 10-point evaluation scale (score of 7–10 of 10; ASHA-QCL, Aphasia Communication Outcome Measure [ACOM], ALA, AIQ-21, COAST, and Modified Perceived Stress Scale [MPSS]) indicating less respondent burden. The COAST and the ALA met all 10 criteria; the ASHA-QCL met nine of 10 criteria; the ACOM and the AIQ-21 met eight

Table 1. Proposed measures of respondent burden

PROM	MR	PS?	PSR	LI/O	NG	FS	FT	II	PI	WS	Total
ASHA-QCL	1	0	1	1	1	1	1	1	1	1	9
ACOM	0	0	1	1	1	1	1	1	1	1	8
AIQ-21	1	1	1	1	1	0	1	1	0	1	8
ALA	1	1	1	1	1	1	1	1	1	1	10
BOSS	0	0	0	1	1	0	0	1	0	0	3
CDP	1	0	0	1	1	1	1	0	0	1	6
CCRSA	0	0	1	1	1	0	1	0	0	0	4
COAST	1	1	1	1	1	1	1	1	1	1	10
COMACT	1	0	0	0	1	0	0	0	0	0	2
CPIB-SF	0	0	0	0	0	0	1	1	0	0	2
MPSS	1	0	1	1	1	0	0	1	1	1	7
QLQA	0	0	0	0	0	0	0	0	0	0	0
SAQOL	1	0	1	1	0	0	0	1	1	1	6
SOCACT	0	0	0	1	1	0	0	0	0	0	2

Note. ACOM = Aphasia Communication Outcome Measure; AIQ-21 = Aphasia Impact Questionnaire-21; ALA = Assessment for Living with Aphasia; ASHA-QCL = American Speech-Language-Hearing Association Quality of Communication Life Scale; BOSS = Burden of Stroke Scale; CCRSA = Communication Confidence Rating Scale for Aphasia; CDP = Communication Disability Profile; COAST = Communication Outcome After Stroke Scale; CPIB-SF = Communication Participation Item Bank-SF; FS = font size; FT = font type; II = instructions included; LI/O = left indented and/or organized; MPSS = Modified Perceived Stress Scale; MR = met readability; NG = no grid; PI = practice items; PROM = patient-reported outcome measure; PS? = pictorial supports for questions; PSR = pictorial supports for responses; QLQA = Quality of Life Measurement and Outcome in Aphasia; SAQOL = Stroke and Quality of Life Scale; SOCACT = Social Activities Checklist; WS = white space.

of 10 criteria; and the MPSS met seven of 10 criteria. The criteria most frequently met by these PROMs included having a layout with a left indent and no grid. The criterion least frequently met by these PROMs included the use of pictorial supports. The results of each measure’s evaluation are presented in Table 1.

Readability

Analyses yielded a high degree of variability in reading grade level across F-K, Gunning FOG, FORCAST, and SMOG formulae, ranging from 2.6 (COAST and Communication Activities Checklist [COMACT] via F-K) to 17.4 (CCRSA via FOG). This variability in results was expected, given the disparity in validating comprehension criteria among formulae (Caylor et al., 1973; DuBay, 2004; Gunning, 1969). Eight of the 14 selected PROMs had a sixth-grade reading level or below: the ASHA-QCL with an average reading level of 6.1; the AIQ-21 with an average reading level of 6.6;

the ALA with an average reading level of 6.8; the CDP with an average reading level of 6.4; the COAST with an average reading level of 5.9; the COMACT with an average reading level of 5.9; the MPSS with an average reading level of 5.1; and the SAQOL with an average reading level of 5.9 (Table 2).

DISCUSSION

Patient-reported outcome measures are typically brief, accessible measures designed to capture the perspectives and experiences of the patient. When using PROMs with PWA, clinicians must consider whether each PROM is comprehensible and accessible for the patient. In the present study, we identified PROMs commonly used with PWA and assessed the (1) level of respondent burden of PROMs for PWA that measure emotional well-being, participation, and/or quality of life and (2) readability levels of these PROMs. Specifically, we evaluated respondent burden

Table 2. Reading grade level of overall measure

Questionnaire	F-K	FORCAST	FOG	SMOG	Average
ASHA-QCL	2.9	8.7	5.7	7.1	6.1
ACOM	5.1	10.6	7.1	8.1	7.7
AIQ-21	3.8	9.4	5.8	7.4	6.6
ALA	4	9.7	6.7	7.1	6.8
BOSS	5.9	10.1	9	9.3	8.5
CDP	3.3	10.2	5.5	6.6	6.4
CCRSA	10.8	12.3	17.4	13.3	13.4
COAST	2.6	8.3	5.8	7.1	5.9
COMACT	2.6	9.4	5.3	6.6	5.9
CPIB-SF	7.2	10.4	11	10.7	9.8
MPSS	2.5	10.7	2.3	4.9	5.1
QLQA	5.5	10.7	8.5	8.5	8.3
SAQOL	3.2	9.9	4.4	6.4	5.9
SOCACT	6.7	10	8.9	9	8.6

Note. ACOM = Aphasia Communication Outcome Measure; AIQ-21 = Aphasia Impact Questionnaire-21; ALA = Assessment for Living with Aphasia; ASHA-QCL = American Speech-Language-Hearing Association Quality of Communication Life Scale; BOSS = Burden of Stroke Scale; CCRSA = Communication Confidence Rating Scale for Aphasia; CDP = Communication Disability Profile; COAST = Communication Outcome After Stroke Scale; CPIB-SF = Communication Participation Item Bank-SF; F-K = Flesch-Kincaid; MPSS = Modified Perceived Stress Scale; QLQA = Quality of Life Measurement and Outcome in Aphasia; SAQOL = Stroke and Quality of Life Scale; SMOG = Simple Measure of Gobbledygook; SOCACT = Social Activities Checklist.

using an adapted respondent burden scale and assessed readability using several widely used readability formulae. Six of the 14 selected measures had more relative attributes of reducing respondent burden, indicating improved ease of measure completion. Eight of the 14 selected measures were written at a sixth-grade reading level or lower, indicating better relative readability compared with other measures.

Respondent burden

Each PWA has a unique set of linguistic and cognitive abilities. Patient-reported outcome measure design and format elements can facilitate or inhibit PROM comprehension for PWA and can, therefore, enhance or diminish measure validity. Measures with elements such as clear instructions and practice items can reduce respondent burden and increase patient participation in data collection. Similarly, practice items can allow respondents to familiarize themselves with procedures and response mode (Kramer & Schwartz, 2017).

Patient-reported outcome measure with attributes that diminish respondent burden included characteristics like left indented and/or organized layout, appropriate font size, use of instructions, and increased white space (e.g., ALA, ASHA-QCL, AIQ-21, ACOM, COAST, and MPSS). Several of the PROMs that scored in the mid to lower end of the burden scale omitted features that reduced respondent burden, such as pictorial supports for questions and/or responses, increased font size, inclusion of practice items, and greater relative white space (e.g., BOSS, Quality of Life Measurement and Outcome in Aphasia [QLQA], Communication Participation Item Bank [CPIB], Social Activities Checklist [SOCACT], and COMACT). The CPIB included a grid, which decreases white space and may require increased visual decoding and processing effort (Mullen et al., 2000). Further, the CPIB's rating scale may be cognitively demanding; score numbers appear below the response choices and do not appear to correspond with the choices (e.g., "3" below "not at all"). A PWA might look for the simplest

representation for their response choice and select the number instead of the words or phrase associated with the response choice, compromising the resulting score. The scale that represented the highest degree of respondent burden (0) was the QLQA, as none of the criteria were met.

Readability

Results indicated that six of the included PROMs were written at a reading grade level higher than recommended for the average adult for health-related materials (sixth-grade reading level; Doak et al., 1996), and eight PROMs fell within the target reading grade level (Doak et al., 1996). These measures include the ASHA-QCL, AIQ-21, ALA, CDP, MPSS, COAST, COMACT, and SAQOL. These measures appear to suit readability standards, though even *lower* reading grade levels may be warranted for PWA. As the measure with the lowest reading grade level, the MPSS questions were relatively short in length, used simple phrasing, and asked about a single problem that the respondent had to process. The MPSS questions also used active voice without embedded elements, which is easier for PWA to understand, thereby increasing its readability (Grodzinsky, 2000; Meyer et al., 2012). For example, the first question states: *In the last month, how often were you upset when something happened that you did not expect?* Only five words in this example item had two syllables and this sentence had an average reading level of 6.4.

The remaining six measures had readability ratings equivalent to seventh grade or above. The CCRSA had the highest average reading grade level (13.4) and included several stimulus items with multiple words over three syllables. For example, the final question states: *How confident are you that you can participate in conversations about your finances?* This sentence had an average reading level of 12.8 and contained four words with three or more syllables. Sentences with more complex and lengthy words contribute to higher reading grade level and lower overall readability. Interestingly, several of the

PROMs with relatively high reading grade level are also commonly used outcome measures in clinical research (e.g., Attard et al., 2018; Kiran et al., 2018).

It is important to note that nearly all the PROMs evaluated in the current study were validated with communicative supports in place, such as an interview-style administration, reading the questions aloud, explaining or rephrasing questions, use of gestures and drawings, scripts, writing key words, use of Tucker's cueing hierarchy (Tucker et al., 2012), and/or clarification of responses. Several PROM validation studies acknowledged that, although these supports were suitable for mild-moderate aphasia profiles, future research is needed to understand the modifications needed for more severe aphasia types (i.e., SOCACT, COMACT, and SAQOL-39). Although these supports are helpful in the administration of PROMs to PWA, there are many PROMs that would also benefit from additional modifications/adaptations to make them more accessible to PWA (e.g., formatting changes, using an interview-style administration, reading the questions aloud, explaining or rephrasing questions, use of gestures and drawings, scripts, and writing key words).

Implications and recommendations

The readability and respondent burden of several PROMs examined in this study may indicate that these measures may not be fully comprehensible or accessible for an individual with language impairment, although these measures are widely used by SLPs. As discussed, PROM attributes that increase respondent burden and reading difficulty may result in invalid measure data. Invalid measure data not only impact the clinician's understanding of the patient, but also influence third-party reimbursement. Patient-reported outcome measures are increasingly used as measures of clinical care, including in the insurance reimbursement process. Reimbursement can reflect provider performance, patient engagement and outcomes, and collaborative decision-making. If the PROM is

not a valid representation of the patient's perspectives or experience, it may not be an appropriate measure of clinical care or outcomes.

To address these issues, there are steps the clinician and clinical researcher can take to improve PROM utility and validity, including careful PROM selection, consideration of PROM development evidence, minor and specific modification, and strategies to support administration.

PROM selection

Clinicians and researchers alike should select, evaluate, and administer PROMs that fit their patient's needs and produce valid data (Basch et al., 2015; Kocher et al., 2010; Squitieri et al., 2017). For individuals with linguistic impairments, the selected PROMs would have been developed or modified and validated for the target population. Clinicians can also evaluate PROMs for level of respondent burden by using the consolidated respondent burden criteria implemented in the present study. Selecting PROMs that use formatting elements consistent with currently published evidence will support the validity of collected data (Tucker et al., 2012).

Consideration of PROM evidence

Some PROMs that have been validated for use with PWA but do *not* have commercially or readily available aphasia-friendly versions for clinical use should report the specific modifications made in the validation studies. Clinicians can review the published modification and administration information to help identify the appropriate communicative supports to suit the needs of the individual PWA. This information ideally includes clear instructions regarding response modality to ensure the collected data are reliable. For example, the validation research of the CPIB for PWA explicitly states that clinicians should be prepared to provide communication supports in the administration of this PROM to PWA. The authors also provided information about the amount of assistance needed given a WAB-R clinical profile. This information is not consistently provided in all PROM development

studies. Publishing specific information on administration, communicative support options, and ideally, an aphasia-friendly version of the validated PROM may reduce respondent *and* administrator burden as well as improve reliability of these outcome measures.

PROM modification

Researchers and clinicians may consider minor modifications to currently available PROMs. The Patient-Reported Outcomes Measurement Information System (PROMIS) reports that some specific and minor modifications are allowable without invalidating the measure (though may require PROM developer permission), such as underlining, bolding, or italicizing contextually appropriate content for emphasis. Other more significant modifications, such as altering response items or adding instruction, may invalidate the PROM. The guidance provided by the PROMIS is contingent on how the modified measure is used (i.e., clinical versus research purposes). Researchers should test modifications prior to implementation to the target population for validity and reliability, and any modifications to PROMIS measures that are intended to be published must first have permission from the measure's authors. Researchers and clinicians are advised to consult PROM developers when considering most modifications, and proceed with extreme caution (HealthMeasures, 2021).

PROM administration support

Tucker et al. (2012) outlined a process to systematically administer and support PROMs for respondents with communication limitations. These recommendations include use of personal interviewing to gather qualitative responses from respondents, simultaneous auditory and visual presentation of questions, and provision of no more support than the PWA requires for accurate response (Tucker et al, 2012). A five-step hierarchy of supportive cues may be used by clinicians or researchers to systematically support administration. Specifically, if the respondent's initial response is unclear or absent, the clinician can provide the following support:

(1) repeat the question and response options as written, (2) restate the question more simply, (3) reintroduce the response options with examples and restate the question, (4) add a yes/no choice with individual response options (considered maximal cueing), and then (5) move on to the next question (Tucker et al, 2012, p. 45).

Future directions

PROM development

When developing PROMs or other materials for PWA, researchers/developers should adhere to the recommendations for readability of health literature for the adult population (Aaronson et al., 2002), as well as consider several other broad recommendations to accommodate PWA and others with communication limitations. In addition to developing measures with an appropriately low reading level and format-related elements to decrease respondent burden, a description of these attributes can be included in development publications and measure manuals. Conducting cognitive interviews during PROM development or modification (DeWalt et al., 2007), a standard practice in measure development, can yield specific information about the clarity, accessibility, and validity of each element of the PROM with a sample from the target population, as well as other knowledgeable experts (e.g., clinicians and caregivers). For examples of this approach, see Baylor et al. (2013) and Hunting Pompon et al. (2018). Finally, computerized adaptive testing methodology, through item response theory, in the evaluation, development, or modification of PROMs for PWA, can improve “measurement efficiency” (Cook et al., 2005, p. 1701) and reduce respondent burden.

PROM evaluation criteria

An evidence-based set of criteria for the reading level and format of PROMs and other materials used with PWA is an important direction for future research. Ideally a collaborative pursuit, this research could build upon previous evidence of readability and re-

spondent burden and examine the degree to which the related elements influence measure validity. The resulting recommendations could inform discussion and stimulate consensus among clinicians and aphasiologists, and guide development of PROMs for PWA as well as other assessment, treatment, and educational materials. Put differently, without an agreed-upon approach to PROM development and evaluation for PWA, PROM validity and clinical relevance may continue to vary. Furthermore, clinicians may continue to make unverified modifications to PROMs to facilitate administration at the risk of collecting compromised data. It would be beneficial to survey clinicians to determine what modifications or communicative supports they offer patients during PROM administration. By following an established set of guidelines, researchers and developers can create PROMs suitable to the abilities of many PWA and usable in a variety of contexts.

Limitations

This research included several limitations. First, the adapted respondent burden scale has not been used previously in the evaluation of respondent burden. Further examination, discussion, and established consensus of this or a similar scale are warranted among clinicians and researchers. Second, some of the measures evaluated included less than the prescribed word count for accurate reading grade level estimation. Most of the selected readability formulae require a minimum sample of 100 words to create an accurate reading grade level estimate. In the case of the SMOG, a minimum sample size of at least 300 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 disproportionately. The results provide a preliminary assessment of readability but should be interpreted with caution. Finally, of the 14 measures identified for this study, two were not originally developed for PWA. The CPIB was initially developed for patient populations with

speech disorders but not language impairment. In a subsequent study, however, the use of the CPIB with PWA was examined and the authors found that those with a mild form of aphasia (i.e., score of 80+ on the WAB-R) were likely to complete the CPIB with little to no assistance, whereas those with scores lower than 50 may have significant challenges completing the CPIB (Baylor et al., 2017). In short, with increasing aphasia severity levels, increased support was needed to complete the questionnaire. The MPSS is a version of the Perceived Stress Scale (PSS; Cohen & Janicki-Deverts, 2012) that has been modified and validated for PWA (Hunting Pompon et al., 2018). The PSS was originally developed for general but not aphasia-specific clinical populations to determine perception of chronic stress.

CONCLUSIONS

Some PROMs commonly used with PWA have a high degree of respondent burden and exceed the recommended reading level for health-related materials, which likely impacts the validity of these measures' resulting data. Until these measures are modified to fit the cognitive-linguistic abilities of many PWA, they require careful administration and interpretation in both clinical and research contexts. Ultimately, PROMs that are appropriate for PWA will more accurately capture the psychosocial, participation, and/or quality of life experiences of these patients and allow for more individualized treatment planning and accurate assessment of both rehabilitation and functional outcomes.

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