Readability of patient-reported outcome questionnaires for use with persons who stutter

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**Abstract**

Objective: The purpose of this study was to examine the readability of several published patient-reported outcome (PRO) questionnaires for use with persons who stutter, and to compare the readability results to existing data about average reading levels for English-speaking adults living in the United States.

Method: Published PRO questionnaires were identified that are traditionally completed by persons who stutter in a self-administered format.

Results: The results of this study demonstrate that many of the PRO questionnaires exceeded the fifth to sixth grade reading levels recommended by health literacy experts.

Conclusions: The clinician should consider the average reading level needed to understand a particular PRO questionnaire when administering it to a patient or their proxy. Likewise, developers of PRO questionnaires should consider reading level of respondents and include information about this when reporting psychometric data.

**Educational objectives:** The reader will get an overview over the literature on patient-reported outcome (PRO) questionnaires and their use with persons who stutter and will be able to: (1) define readability, (2) describe how reading levels are determined for a given PRO questionnaire, (3) list the strengths and limitations of readability assessment in the evaluation of persons who stutter and (4) analyze the role of readability assessment in future PRO questionnaire development.

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1. Introduction

Examination of the stuttering treatment outcomes literature reveals that most studies to date have focused primarily or exclusively on changes in the observable characteristics of stuttering, with relatively little consideration given to the broader consequences of the disorder experienced by the speaker (Yaruss, 2010, p. 191). Stuttering is associated with increased mental health problems and potentially lowered quality of life (Craig, Blumgart, & Tran, 2009). Thus, assessment protocols should also include patient-reported outcome (PRO) measures to gage fully the impact of stuttering (Yaruss, 2000). PRO measures are patient-derived instruments that measure any aspect of a patient’s health status (USFDA, 2009; Valderas & Alonso, 2008).

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Many PRO questionnaires are available to help gather potentially relevant clinical information about the personal impact of stuttering on the speaker’s well-being (for review see Yaruss, 2010). Franic and Bothe (2008) examined the psychometric properties of many of the fluency-related PRO questionnaires using measurement standards related to item information, versatility, practicality, breadth and depth of health measure, reliability, validity and responsiveness. Franic and Bothe (2008) reported that none of the available instruments met more than 8 of the 15 measurement standards assessed, and cautiously recommended a few specific questionnaires for use in group-level decision making vs. individual-level decision making. Franic and Bothe (2008) conclude, in part, that the development of a well-validated PRO questionnaire for use with persons who stutter would fill several gaps in the existing stuttering measurement literature, would support an evidence-based approach to the assessment and treatment of stuttering, and would serve critical needs in stuttering research and theory development (p. 70). Likewise, Cummins (2010) argues in his review of fluency disorders and quality of life, that there is a host of theoretical and methodological issues to consider when interpreting the literature in this area. Chief among these is how the constructs “quality of life” and “health-related quality of life” are defined (pp. 164–165), which underlies how measures of such constructs are developed and then ultimately interpreted.

As described in Franic and Bothe (2008), and supported in Cummins (2010), many PRO questionnaires do not meet all of the current standards for the development of an instrument established by the Scientific Advisory Committee of the Medical Outcomes Trust (SACMOT) (2002) and the U.S. Food and Drug Administration (USFDA) (2009). The document produced by the SACMOT lists eight attributes (p. 195) as the principal foci for instrument review: (1) the conceptual and measurement model; (2) reliability; (3) validity; (4) responsiveness; (5) interpretability; (6) respondent and administrative burden; (7) alternative forms and (8) cultural and language adaptations and translations. Within these attributes, the SACMOT established specific review criteria based on existing standards and evolving practices in the behavioral science and health outcomes fields. Respondent burden was defined as, “...the time, effort, and other demands placed on those to whom the instrument is administered” (p. 202). One criterion for evaluating respondent burden was, “...the reading comprehension level needed for all population groups for which the instrument is intended” (p. 202). It is of note that in the literature reporting the development of these fluency-related questionnaires, there is no description of readability assessment.

The 2003 National Adult Literacy Survey revealed that the average reading comprehension level of an English-speaking adult in the United States is estimated to be at the seventh- or eighth-grade level (Kutner, Greenberg, Jin, & Paulson, 2006). To facilitate health literacy, health-related materials targeted to adults should be written at the fifth- or sixth-grade reading level (Weiss & Coyne, 1997). The most common approach to determining the reading comprehension level required for a given document is to assess its readability (Dubay, 2004). The poor readability of patient-related documents in communication sciences and disorders has been reported in recent years (Atcherson, Zraick & Brasseux, 2011; Hester & Stevens-Ratchford, 2009; Zraick & Atcherson, 2011; Zraick, Atcherson, & Ham, 2011).

When the reading level of a PRO questionnaire is too high, patients may reject the questionnaire, may provide missing or partial information, or may complete the questionnaire with responses that are incongruent with their health status. Difficult-to-read questionnaires therefore impose an unfair respondent burden (see e.g., SACMOT, 2002). If this is the case, then treatment planning and outcomes based on responses to such PRO questionnaires may be tenuous (ASHA, 2008). Therefore, the purpose of this study was to examine the readability of widely known PRO questionnaires for use with persons who stutter. It focuses on the direct question, “At what grade level is a particular stuttering-related PRO questionnaire readable?”.

2. Method

A search was conducted to identify published PRO questionnaires related to stuttering (e.g., Andrews & Cutler, 1974; Brutten, 1997; Healey, 2007a,b; Johnson, Darley, & Spiroterbach, 1952; Wolpe, 1967; Yaruss & Quesal, 2010; Yaruss, Coleman, & Quesal, 2010; Yaruss, Quesal, & Coleman, 2010) (see Table 1). Any questionnaire designed to be administered in an interview- or open-ended style was excluded. Many of the questionnaires are psychometrically sound (Franic & Bothe, 2008). However, any questionnaire that lacked sufficient psychometric data was not excluded either because of popularity of the tool or because of their perceived potential.

Readability of each document was assessed using the Windows-based software Reading Calculations version 7.5 (Micro Power and Light Co., Dallas, TX). This program is able to assess readability of documents using nine different, widely used and popular readability formulas. Unfortunately, there is no standard for choosing readability formulas (Breese & Burman, 2005). For this study, we chose the FORCAST (Caylor, Sticht, Fox, & Ford, 1973), Flesch Reading Ease (Flesch, 1948), and Gunning FOG (Gunning, 1952) formulas. Of the three, the FRE formula is considered to be the most widely and heavily used (Ley & Florio, 1996); however, the FORCAST formula is most appropriate for this study as it focuses on functional literacy and is typically used in evaluating adult questionnaires, forms, lists, many websites, tests and job materials not in narrative or prose-like form. What makes FORCAST different from other readability formulas is that it ignores the number of sentences, their lengths, and any hard punctuation (Redish, 2000), though many PRO questionnaires do use complete sentences for items. The FORCAST formula has a 0.66 correlation (Dubay, 2004) with performance on a standardized comprehension reading test (e.g., McCaul & Crabbs, 1961), and it has been demonstrated to correlate highly with other readability formulas (Caylor et al., 1973). For these reasons, the Flesch Reading Ease (FRE) and the FOG formulas were also considered for comparison.

The FRE formula is typically used with reading materials written for adults, it is considered to be the most widely used formula, and has been incorporated into the popular Microsoft® Word® software. Rather than reporting reading grade level,
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