

Assessing Stuttering Severity from the Perspective of People Who Stutter

J. Scott YARUSS

Michigan State University, East Lansing, MI USA
jsy@msu.edu

1. Introduction

Stuttering severity has traditionally been measured based on the observations of listeners. For example, the *Stuttering Severity Instrument* (SSI; Riley, 2009) combines observer ratings of the frequency and duration of stuttered disfluencies with observer ratings of physical concomitant behaviours. Other measures ask observers to rate severity on various scales, for example, from 0 (no stuttering) to 9 (severe stuttering) (e.g., O'Brian et al., 2004).

Although widely used, such measures do not easily account for the variability of stuttering (e.g., Constantino et al., 2016) or the fact that people who stutter routinely report that stuttering involves experiences that cannot be readily observed by conversational partners. For example, Tichenor et al. (2017) showed that people who stutter experience physical tension in parts of the body that are not visible (e.g., the abdomen), and Tichenor and Yaruss (2018, 2019a; see also the work of Constantino, 2017, and Douglass, 2019) showed that people routinely employ strategies to hide stuttering. Such findings indicate that external observations of stuttering are likely to underestimate what speakers actually experience, and this raises important but unanswered questions about the *validity* of most common measures of stuttering severity.

More fundamentally, Tichenor and Yaruss (2019b) reported that people who stutter experience a sensation during stuttering that can be described as “being stuck” or “losing control” (see Perkins, 1990). Existing assessments are not well-suited to measuring these internal states, suggesting again that current practices fail to accurately describe severity as experienced by people who stutter. Importantly, several authors *have* suggested the use of self-ratings of stuttering severity (e.g., O'Brian et al., 2004), though, again, such measures still focus on overt behaviours rather than internal states and sensations.

The purpose of the presentation described in this extended abstract was to describe the current status of a new, in-development tool for measuring stuttering severity *from the perspective of people who stutter*. The assessment is specifically designed to account for (a) how people experience the moment of stuttering (e.g., Tichenor & Yaruss, 2019b) and (b) the variability that is inherent to the speaker's experience of stuttering. The draft version of the measure, tentatively called the “Comprehensive Assessment of Stuttering Severity” (CASS) at the time of the presentation, examines the speaker's perception of being stuck, combined with the perception of tension, struggle, and effort, as well as feelings of spontaneity, smoothness, and fluency. The goal is for clinicians and researchers to be able to supplement (or perhaps even replace) their current listener-based assessments with a validated assessment that reflects what the speaker is actually experiencing during the moment of stuttering.

2. Method

The CASS was developed following procedures similar to those used in the creation and validation of the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES; Yaruss & Quesal, 2006, 2016). The first version of the CASS was developed for adults (ages 18 and above), though preliminary work has already been done on versions for adolescents (ages 13-18), school-age children (ages 7-12), and younger children (ages 3 to 6). The presentation described in this extended abstract focused only on the draft adult version of the CASS, as this is the version for which the largest number of participants have been recruited.

Development of the draft version of the CASS described in this presentation involved the creation of an initial set of potential test items based on a detailed review of existing literature on the moment of stuttering, combined with input from people who stutter regarding how they experience the moment of stuttering. The initial items were combined into a set of Qualtrics surveys using various formats so that different presentation modes could be explored. (For example, one draft form used a response matrix to collect responses to items within a section, while another draft form used individual items to collect responses.)

These initial items and forms have been subjected to a first round of data collection using different response scales and form organizations or layouts. Respondents have also been asked for their opinions about the wording and clarity of test items. Based on these preliminary results, revisions to the item wording, anchors, and format

have been completed, and additional drafts of the form have been created. This process of form creation followed by pilot testing will be repeated in an iterative and ongoing fashion until respondents indicate that the items are clearly worded and easy to answer, and until data analyses affirm the reliability and validity of the tool. As of this writing, the draft CASS for adults contains 60 items, each measured on 5-point scales, examining constructs such as the sensation of feeling stuck, the presence of physical struggle, and the perception of effort, as well as a sense of spontaneity, naturalness, and smoothness in speech.

Larger-scale data analyses are being conducted as part of the ongoing survey-based research conducted through the Spartan Stuttering Center (e.g., Tichenor & Yaruss, 2019a, 2019b, and others). All of these studies (including the current investigation) have been judged to be exempt from institutional review by the Michigan State University Human Research Protection Program Office of Regulatory Affairs under Statute 45 C.F.R. 46.101(b)(2) of the Federal Policy for the Protection of Human Subjects. Preliminary data presented in this extended abstract for adults who stutter are covered under this exemption.

3. Results

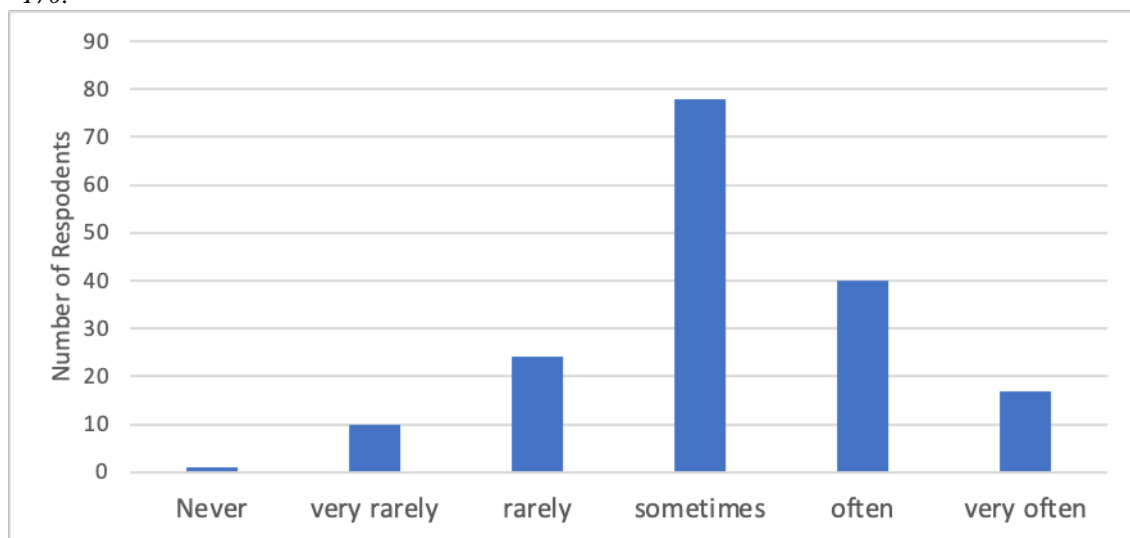
As of this writing, data have been collected from more than 175 adults who stutter. Additional data are forthcoming, and the ultimate sample size will be determined by preliminary data analyses.

The mean age of participants who provided age information ($N = 137$) was 41.5 years (range 18 to 84 years; $SD = 18.1$ years). Ninety participants reported that they were male and 44 reported that they were female. This reflects a 2:1 Male-to-Female ratio, which lower than is typically seen. This distribution difference will be addressed through ongoing data collection to ensure that respondents in the standardization sample reflect the commonly understood makeup of the population of people who stutter.

Initial analyses of item characteristics and debriefing questions demonstrate that speakers are able to make meaningful judgments about their experience of the moment of stuttering, and that the items in the draft CASS accurately describe the participants' self-reported experiences during stuttering. Further analyses have revealed that the measure is sensitive to variations across situations.

To illustrate this, Figure 1 shows the participants' responses to a sample item that asks how often speakers experience a feeling of being "stuck" when talking (mirroring language used by adults who stutter in Tichenor & Yaruss, 2019b).

Figure 1. Responses to trial item about how often speakers experience a feeling of being "stuck" when talking. $N = 170$.



Additional analyses, which are ongoing, will examine sensitivity to change over time (including test-retest reliability assessment over short periods of time, as well as measures of sensitivity to changes over larger periods of time and before/after treatment). Studies will also compare how speaker perception and listener perceptions differ. Ongoing analyses will also explore how self-ratings of stuttering severity relate to self-ratings of adverse impact of stuttering, as measured via the OASES and other relevant measures. Comparisons of self-rated severity to listener-rated severity (through both X-point scales and measures such as the SSI) will also be conducted, so that the specific constructs involved in severity assessment (including validity) can be explored.

4. Discussion

Initial analyses suggest that it is possible for people who stutter to provide data on how they experience the moment of stuttering, and that these data can provide a meaningful reflection of their perceived severity of stuttering. The presentation described in this extended abstract reflected a work in progress. Ongoing analyses offer promise that a future version of the tool will be able to provide valid and reliable measure of the severity of stuttering that accounts for speakers' internal states. This will have significant implications both for clinical work (e.g., by allowing a shift away from measures of percent syllables stuttered for assessing treatment outcomes) and research (e.g., for evaluating studies that attempt to differentiate groups of people who stutter based on severity). Findings should also lead to an improvement in the validity of measures of severity by incorporating the speaker's experiences of the moment of stuttering. Ultimately, it is hoped that such measures will supplement existing measures of the impact of stuttering (e.g., the OASES) so that clinicians and researchers will be able to gain a comprehensive view of speakers' experiences both withing the moment of stuttering and across the broader life experience of stuttering.

Disclosures

Financial: J. Scott Yaruss is co-author of the CASS and co-owner of Stuttering Therapy Resources, Inc. (STR), which will publish the finalized CASS. He is also co-author of the OASES, which is published by STR.

Nonfinancial: None.

References

- Constantino, C. D., Manning, W. H., & Nordstrom, S. N. (2017). Rethinking covert stuttering. *Journal of Fluency Disorders*, 53(October 2016), 26–40. <https://doi.org/10.1016/j.jfludis.2017.06.001>
- Douglass, J. E., Constantino, C., Alvarado, J., Verrastro, K., & Smith, K. (2019). Qualitative investigation of the speech-language therapy experiences of individuals who covertly stutter. *Journal of Fluency Disorders*, 61(August), 105713. <https://doi.org/10.1016/j.jfludis.2019.105713>
- O'Brian, S., Packman, A., & Onslow, M. (2004). Self-Rating of Stuttering Severity as a Clinical Tool. *American Journal of Speech-Language Pathology*, 13(3), 219–226. [https://doi.org/10.1044/1058-0360\(2004\)023](https://doi.org/10.1044/1058-0360(2004)023)
- Perkins, W. H. (1990). What is Stuttering? *Journal of Speech and Hearing Disorders*, 55(3), 370–382. <https://doi.org/10.1044/jshd.5503.370>
- Riley, G. D. (2009). *Stuttering Severity Instrument for Children and Adults* (4th ed.). Pro-Ed.
- Tichenor, S. E., Leslie, P., Shaiman, S., & Yaruss, J. S. (2017). Speaker and Observer Perceptions of Physical Tension during Stuttering. *Folia Phoniatica et Logopaedica*, 69(4), 180–189. <https://doi.org/10.1159/000486032>
- Tichenor, S. E., & Yaruss, J. S. (2018). A Phenomenological Analysis of the Experience of Stuttering. *American Journal of Speech-Language Pathology*, 27(3S), 1180–1194. https://doi.org/10.1044/2018_AJSLP-ODC11-17-0192
- Tichenor, S. E., & Yaruss, J. S. (2019a). Group Experiences and Individual Differences in Stuttering. *Journal of Speech, Language, and Hearing Research*, 62(12), 4335–4350. https://doi.org/10.1044/2019_JSLHR-19-00138
- Tichenor, S. E., & Yaruss, J. S. (2019b). Stuttering as Defined by Adults Who Stutter. *Journal of Speech, Language, and Hearing Research*, 62(12), 4356–4369. https://doi.org/10.1044/2019_JSLHR-19-00137
- Yaruss, J. S., & Quesal, R. W. (2006). Overall Assessment of the Speaker's Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment. *Journal of Fluency Disorders*, 31(2), 90–115. <https://doi.org/10.1016/j.jfludis.2006.02.002>
- Yaruss, J. S., & Quesal, R. W. (2016). *Overall Assessment of the Speaker's Experience of Stuttering*. Stuttering Therapy Resources, Inc.