DEFINING THE SEVERITY OF STUTTERING

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Communicative Sciences and Disorders – Master of Arts

2024

ABSTRACT

This study examined stuttering severity by reviewing 21 formal definitions from a comprehensive review of over 500 sources in English, Spanish, and Portuguese. While all definitions are primarily focused on observable characteristics, the study emphasizes the importance of considering the internal experience of stuttering, such as the speaker's sense of "loss of control." Through an online survey, people who stutter, speech-language pathologists, and those who are both, were asked to define stuttering severity and explain the factors that influence it. Qualitative analysis of the definition of severity revealed five themes across all participants: disfluencies and visible physical tension, effective communication, affective, behavioral, and cognitive responses, adverse impact, and variability. People who stutter reported two additional themes: internal struggle and effort, and struggle may not be visible. Analysis of the factors that influence severity revealed seven themes: psychological factors, speech and language factors, situational factors, cultural factors, individual factors, speech therapy experiences, and perspectives and responses of the listeners. People who stutter reported an additional theme: force to produce speech. The results indicated that while speech speech-language pathologists who do not stutter provided important insights that largely matched the perceptions of people who stutter, they did not identify the internal experience that people who stutter reported. This study advocates for incorporating both external observations and the subjective experience to better capture the complexity of stuttering severity, fostering a more comprehensive approach.

ACKNOWLEDGEMENTS

I would like to thank my mentor, Dr. J. Scott Yaruss, for his guidance and support in this study and since I met him in 2019 in Peru. His mentorship has taught me not only how to become a better clinician and researcher, but also how to be a better human being. His passion for our field and his ability to think innovatively have been a constant source of inspiration. Gracias, Scott. Thanks to my committee members Dr. Bridget Walsh, Dr. Seth Tichenor, and Dr. Jeff Searl for their time and feedback on this project. Their expertise and insights have enriched my research and I aspire to reach the same level of expertise as them one day.

Agradezco profundamente el apoyo de mi familia, quienes han sido mi fortaleza y mi motivación para seguir adelante con mis metas en Estados Unidos y no rendirme. Les amo enormemente y les estoy infinitamente agradecida. Quiero mencionar especialmente a Antonella, mi pequeña. Espero que encuentre inspiración en mis logros y vea en ellos un ejemplo de perseverancia para alcanzar sus propias metas en el futuro. Te adoro más de lo que imaginas.

Ook wil ik Jeroen bedanken voor zijn voortdurende steun. Want toen ik de steun het meest nodig had, zelfs op afstand, stond hij altijd voor me klaar. Ik lieg niet als ik zeg dat ik het zonder jou niet had kunnen doen. Ik hou van jou met heel mijn hart. Ik ben erg dankbaar voor de aanwezigheid van jou en je familie in mijn leven. Altijd. Bedankt.

No puedo continuar sin agradecer a todos mis amigos latinos que me han apoyado en este proceso, a los que están aquí en Michigan y a aquellos en Perú y otros lados del mundo. Gracias por hacer mi vida mejor y más feliz. Espero con ansias verlos pronto nuevamente.

Finally, I want to express my gratitude to all the participants of this study who completed the questionnaire in English, Spanish, and Portuguese. I have learned a lot from their insights, and I am really grateful for that. Thank you so much. Muchas gracias. Muito obrigada.

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Introduction

Although the "severity" of stuttering has long been measured, both in research and clinical practice, there are numerous problems associated with this measure. For instance, when asked to rate the severity of a given sample, different clinicians may arrive at different severity ratings (Cordes & Ingham, 1994; Hall et al., 1987; Hulit, 2004). Also, the level of severity perceived by the clinician could differ from the level of severity perceived by the person who stutters (Adriaensens et al., 2015; Aron, 1967; Manning & DiLollo, 2017; Moïse-Richard et al., 2021; O'Brian et al., 2004). That is, a clinician may judge a speaker's stuttering to be "mild," while the speaker may judge that their stuttering is "severe".

One possible reason for these disagreements is a lack of consensus regarding the definition of stuttering severity. A review of historical and recent publications on stuttering reveals that nearly all resources address the concept of severity, but very few provide actual definitions of what is meant by severity. In fact, an extensive search of the literature revealed only a few instances in which formal definitions of stuttering severity were presented (see Table 1). Even though those definitions are certainly relevant and meaningful as descriptors of stuttering, they nevertheless reflect different aspects of the stuttering experience. The majority of the definitions provided are based on the observable characteristics, that is, the features that a listener or conversational partner might be able to observe. As Tichenor and Yaruss (2019) explained, however, stuttering can be also viewed in terms of the perceptions that speakers themselves experience internally. One way to experience this has been defined as a "loss of control" that a person experiences while speaking, and this *internal* experience may not always be perceived by other people. For example, a person might sense that a moment of stuttering is occurring or about to occur, but in order to hide their stuttering so that it is not noticeable to the

listener, they may stop talking or change the word that they say. In that case, the observer might not recognize that stuttering occurred even though the speaker would indicate that they stuttered.

Inconsistencies and uncertainties about the definition of stuttering severity are relevant because the concept is ubiquitous in both clinical settings and research settings. Clinically, severity is judged by speech-language pathologists in assessing, diagnosing, and treating the condition. Numerous assessment tools have been created for measuring stuttering severity, and many treatment approaches are focused on reducing the outwardly apparent severity of stuttering, whether directly or indirectly (Franken & Laroes, 2021; Kelman & Nicholas, 2020; Onslow et al., 2023). Moreover, countless publications and books explain how clinicians should work to reduce severity (De Sonneville-Koedoot, Stolk, et al., 2015; Fraser, 2010; Rickheit & Strohner, 2008; Rohani Ravari et al., 2022; Tarkowski, 2016; Williams, 2023). Still, most of these authorities do not define what is meant by severity.

In research, severity is measured for selecting participant samples, describing, and setting inclusion/exclusion criteria, differentiating subgroups of participants, measuring the effects of various interventions, and comparing results in longitudinal studies. For example, the participants may need to exhibit a minimum percentage of stuttered syllables or level of severity in order to participate in a study (Buzzeti et al., 2016; Carrasco et al., 2015; Costa et al., 2019; Fiorin et al., 2015; Juste et al., 2016; Neumann et al., 2005; Nogueira et al., 2015; Regacone et al., 2015; Ritto et al., 2015). Stuttering severity is also used to differentiate control and experimental groups (Andrade, 2010; Pirinen et al., 2023; Rossi et al., 2014); it is commonly used as a dependent or independent variable (Abdul Waheed et al., 2022; Adriaensens et al., 2015); and in comparison over the time (De Sonneville-Koedoot et al., 2015). Nevertheless, the vast majority of research has not actually defined what severity is.

There is a clear gap in the literature with respect to the definition of the severity of stuttering, and this gap has consequences for both clinical and research endeavors. For that reason, this study aimed to specify the definition of stuttering, while accounting for the perspectives of both listeners (clinicians and researchers) and people who stutter.

Literature Review

Definitions of stuttering severity

The first part of this study examined definitions of stuttering severity. Inclusion criteria involved searching sources that were published on peer-reviewed articles, books, and thesis, in English, Spanish, and Portuguese. The literature review was conducted in multiple languages to access information that may not be present in the English-language literature, and to ensure an understanding of the topic from diverse cultural perspectives. This examination included the terms "severity," "severe," "stuttering," "stammering," "disfluency," "dysfluency," "severidad," "gravedad," "severo," "tartamudez," "disfemia," "disfluencia," "severidade," "gravidade," "gagueira," "gaguez," anywhere in the text. In other words, all the sources that used the concept of severity in relation to stuttering were examined, with no additional filters based on the content. Those terms were located through a search of the Michigan State University Library system (which searches 1249 databases), as well as PubMed, the ASHA Wire, Biblioteca de la Pontificia Universidad Católica del Peru, Google Scholar, and SciELO. Based on the extensive literature review of more than 500 sources, 21 formal definitions of severity in the context of stuttering were found: 19 in English, 1 in Spanish, and 1 in Portuguese. Table 1 summarizes the definitions from these various publications.

Table 1. Definitions of stuttering severity

Definitions of stuttering severity	
Authors and year	**Definitions**
Spurlock (1966, p. 1)	"Severity is a way of quantifying the extent of abnormality or degree of interference with the normal speech process. To say that one stutterer is more severe than another is to say that he appears to be more abnormal than the other"
Young (1970, p. 300)	"Stuttering severity is a perceptual dimension measured by processing judgments extracted from observers"
Conture (1990, p. 2)	"Severity of stuttering refers to the subjective, rather holistic, judgment of the degree of stuttering exhibited by a stutterer, usually expressed in terms of mild, moderate or severe and relates to the stutterer's problem as a whole but can also be applied to separate instances of stuttering (cf. Sherman & McDermott, 1958)"
Kell et al. (2009, p. 2749)	"Stuttering severity was defined as the percentage of stuttered syllables according to the guidelines by Boberg & Kully (1994)"
Kuniszyk-Jozkowiak (1995, p. 14)	"Stuttering severity defined as the number of errors characteristic of stuttering, such as: repetitions, insertions, blockades etc. per 100 syllables"

Table 1 (cont'd)

Shapiro (1999, p. 14)	"Severity of stuttering is a judgment based on objective measurement of the degree of stuttering demonstrated by a person who stutters"
Ruscello (2001, p. 174)	"Based on the work of Martin et al. (1984) perceived severity of stuttering is a rating of 'natural and unnatural' speech to the degree of deviancy"
Zebrowski & Kelly (2002, p. 16)	"Severity of stuttering is a global judgment based on listener's perceptions of the frequency, type, and duration of disfluent speech, as well as the presence or absence of associated behaviors"
Klassen (2002, p. 98)	**"**Severity is the seriousness of the stuttering, including its length, and behaviors such as avoiding eye contact, grimaces, etc."
Neumann et al. (2003, p. 191)	Stuttering severity was defined by subjects' percentage of disfluent syllables in four speaking situations (talking with the therapist; overt reading; making a tele-phone call to an unknown person; interviewing people on the street).
Giraud et al. (2008, p. 191)	**"**Stuttering severity was defined as the percentage of stuttered syllables in four different speaking situations (speaking to a therapist, reading, phoning, speaking to a passer-by")

Table 1 (cont'd)

Correa (2010, p. 204)	"Stuttering severity, that is, the degree of difficulty in temporal motor control of speech (…) To determine the degree of severity of the participants' stuttering, a scale was used whose score is divided into four components (Yairi & Ambrose, 1999; Jakubovicz, 1997): frequency and duration of disfluencies, tension and secondary behaviours" "Severidade da gagueira, ou seja, ou grau de dificuldade do controle motor temporal da fala (…) Para determinar o grau de severidade da gagueira dos participantes foi utilizada escala cuja pontuação divide-se em quatro componentes (Yairi e Ambrose, 1999; Jakubovicz, 1997): frequência e duração das disfluências, tensão e fenômenos secundários"
Shapiro (2011, p. 11)	"Severity of stuttering refers to the degree of stuttering demonstrated by a person who stutters"
O'Brian et al. (2011, p. 88)	"Typical stuttering severity was defined as the severity of your speech for the majority of the day"

Table 1 (cont'd)

Pertijs et al. (2014, p. 164)	"Stuttering severity is a measure based on the objective measurement of stuttering behaviour, such as stuttering frequency, duration of stutter moments, the type of dysfluencies and secondary behaviours"
Boyle (2015, p. 4)	"The disruption in your speech that you think is noticeable on the surface for the majority of the day. It does not refer to the impact of the disorder as a whole on your life"
Neumann et al. (2018, p. 122)	"Stuttering severity, defined as percentage of stuttered syllables (%SS)"
Berrospi et al. (2018, p. 27)	"Degree to which speech is affected (...) the degree of severity is determined according to the percentage of stuttered syllables in their verbal communication, according to Salgado (2008)" "Grado en que se ve afectada el habla (…) el grado de severidad se determina según el porcentaje de sílabas tartamudeadas en su comunicación verbal, según Salgado (2008)"
Guitar (2019, p. 156)	"Severity: generally, a measure of the impediment to communication caused by the stuttering. This may be an overall impression or a compilation of stuttering frequency and duration as well as other behaviors that impede communication."

Table 1 (cont'd)

Yairi & Seery (2021, p. 194)	"The level of disruption in the delivery of continuous speech"
Zebrowski et al. (2022, p. 4)	"Is the description of the degree to which stuttering interferes with typical speaking/communication. The degree of severity ranges from not very serious (i.e., mild) to quite serious (i.e., severe). Specifically, stuttering severity is often indexed by an overall or composite score that may be based on several measures. For example, the Stuttering Severity Instrument, fourth edition (SSI-4) determines stuttering severity by considering the following measures: (1) *frequency* of instances of stuttering (stuttered disfluencies), (2) the average *duration* of the three longest instances of stuttering, and (3) the *quantity* and *quality* of associated nonspeech behaviors (see the explanation later)"

These cited definitions have long been used by researchers and clinicians to form part of their theoretical framework and treatment practices. Even though these definitions include important aspects of the stuttering experience, two main issues arise. First, these definitions reveal a lack of *consensus* on how the severity of stuttering should be defined. Some define severity as a measure of frequency and duration, others as the level of disruption, while others define severity as the degree of natural or unnatural speech, and still others define stuttering

severity based on different factors. These differences in definition are problematic because the absence of a consensus may negatively affect both treatment and research. For example, research has shown that when speech-language pathologists need to determine a severity rating after analyzing the same recording of a person's speech, there may be differences in the results they obtain (Cordes & Ingham, 1994; Hall et al., 1987; Hulit, 2004), which could be influenced because there is not an agreement on what is stuttering severity and what exactly they are assessing. Additionally, in research, it is challenging to interpret, replicate, and compare results if there is no standard definition. For that reason, there is a need for a consensus on the definition to develop accurate research and effective intervention.

The second problem with the existing definitions of stuttering severity is that most are primarily focused *on characteristics that a listener might perceive*, such as the number of disfluencies and physical movements, but not on the internal experience of stuttering. There is a common tendency to take for granted that certain types of observable disfluencies and stuttering are the same thing; however, stuttering encompasses much more than just what observers can notice about the way people talk (Johnson et al., 1963). When people stutter, speakers have reported to have "a feeling" inside them (Emerick & Hamre, 1972), which was described by Perkins (1990) as a sense of "loss of control" while speaking (see also Tichenor and Yaruss, 2019).

What listeners observe is *not* the feeling of losing control. Instead, they observe the physical reactions as a person tries to regain control and continue to speak. In that regard, the severity of the overt characteristics of stuttering as commonly defined fails to capture the essence of stuttering, that internal essence that can be ultimately judged by the person who stutters (Alm, 1997; Tichenor & Yaruss, 2019).

Assessment of stuttering severity

Severity is a concept used by most clinicians in the assessment of stuttering, because it allows them to have quantitative data, it can help to establish the effectiveness of treatment, and it is used to determinate if a person's speech meet the diagnostic criteria for stuttering (Eve et al., 1995; Guitar, 2019). Current ways to assess stuttering severity can be divided into two approaches: assessments from the clinician's perspective and assessments from the person who stutters perspective. The first one asks the clinicians to rate severity according to the way they observe the person who stutters, while the second one asks the person who stutters to assess their own severity.

Other measures that may be relevant to the speaker's experience is the impact of stuttering in their lives, which has been examined in the *Wright & Ayre Stuttering Self-Rating Profile* (WASSP; Wright & Ayre, 2000), and the *Overall Assessment of the Speaker's Experience of Stuttering* (OASES; Yaruss & Quesal, 2006). Those assessments do not provide a stuttering severity measure. Instead, they are focused on the impact of stuttering in the life of the person who stutters. For this study, the authors are focused on severity, so measures of impact are not further discussed.

Assessment of severity from the perspective of the clinician

Numerous assessments have been created for measuring stuttering severity. Among the first severity measures described in the stuttering literature was the Iowa Scale of Severity of Stuttering (Lewis & Sherman, 1951). This scale goes from zero to seven, where the number zero indicates no stuttering and seven indicates the most severe stuttering (Sherman, 1952; Spurlock, 1966). It asks the observer (clinician, clinical student, mother, father, etc.) to describe and analyze the sample(s) of speech and the situation in which the rating was made. It considers the

amount of stuttering and tension, the duration of disfluencies, the patterns of disfluencies, and the number of stuttering-associated body movements (Johnson et al., 1963).

Current measures include the *Test of Childhood Stuttering (TOCS)* by Gillam et al. (2009), and the widely known *Stuttering Severity Instrument*, 4th edition(SSI-4) by Riley (2009). The TOCS (Gillam et al., 2009) is an assessment that evaluates the fluency and stuttering behaviors of children ages 4 to 12 years. To assess severity, the clinician asks the child to complete four speech fluency tasks: name 40 pictures as quickly as possible, produce sentences with the same syntactic structure as the clinician, answer questions about pictures, and tell a story that corresponds to the pictures presented. For each of the four speech fluency tasks, clinicians obtain a raw score, which matches a scale from Typical Fluency to Severe Disfluency. The TOCS also includes The Observational Rating Scale, which is a sheet completed by the clinician, teachers, parents, or caregivers. In this scale, the adult is asked to think about the child's speech in the last two months, read the statements provided, and rate from 0 to 3, where 0 is never and 3 is often. It is divided into two: the Speech Fluency Rating Scale and the Disfluency-Related Consequences Rating Scale. The first scale assesses the occurrence of repetitions and duration of stuttering events, among others. For that scale, scores will match a severity ranking from Typical Fluency to Severe Disfluency. The second scale, the Disfluency-Related Consequences Rating Scale, assesses tension and body moments while speaking. Scores on that scale will cores from 0 to 6 are considered Typical Consequences, and above 6 are considered Greater Than Typical Consequences. Additionally, clinicians can analyze the speech rate, disfluency duration, associated behaviors, stuttering frequency, and speech naturalness. Clinicians are suggested to use this data to describe the pretreatment status, assess changes over

time, and identify specific goals for intervention, such as reducing the frequency of stuttering or the associated behaviors.

The SSI-4 is a norm-reference stuttering assessment for children and adults that is used for clinical and research purposes (Riley, 2009). It measures the frequency of stuttering events, the duration, and the physical behaviors. It asks the clinician to record speech samples from an in-depth interview with the person who stutters, direct observation of the person's speech, and reading tasks, depending on the age of the child. The instructions for the SSI-4 recommend getting speech samples beyond the clinic, which could be at home, at work, at school, or on the telephone. Once the clinicians obtain the speech samples, they evaluate the frequency, duration, and physical movements. The frequency is the percentage of stuttered syllables, which is obtained by counting the total number of syllables and stuttered syllables, or by using the Computerized Scoring of Stuttering Severity that comes in the assessment. The value obtained matches a task score from 2 to 18. To assess duration, the clinician is asked to measure the length of the three longest stuttering events. The number of seconds obtained matches a scale score from 2 to 18. Videotapes are considered useful for getting information about physical behaviors, such as facial, head, or extremities movements. Those movements are scored from 0 to 5, where 0 is None and 5 is "Severe and Painful Looking." The values of each of the three areas are added together to generate a total overall score. The number obtained match a severity equivalent, which could be Very Mild, Mild, Moderate, Severe, or Very Severe.

Although the Iowa Scale of Severity of Stuttering, the TOCS, and the SSI-4, are among the most common assessments designed to measure the severity of stuttering, none actually defines what severity is. Additionally, all are focused on the *observable characteristics* of

stuttering behaviors, and not on what constitutes stuttering from the perspective of the speaker, which may be the feeling of losing control.

There are numerous problems with assessing only or primarily observable characteristics of stuttering. For example, stuttering can occur without easily detectable overt characteristics (Naylor, 1953), due to tricks and distractions that the person who stutters can use to hide stuttering (Constantino et al., 2017). These strategies render the stuttering behavior "covert" – that is, the speaker may successfully hide the moments of stuttering by changing the words, pretending to forget what they were saying, or staying in silence (Douglass et al., 2019). Even though people might not notice a moment of stuttering due to these covert strategies, speakers may still experience negative impact, including feelings of anxiety and depression (Sønsterud et al., 2022). Thus, though the number of overt characteristics of stuttering may be minimal, the real severity and impact of stuttering may be high (Douglass et al., 2019). Another concern with assessments that focus only on surface behaviors is that a potential client may not achieve the "requirements" to be diagnosed as stuttering, even though they experience the sensation of losing control in their speech.

Research has also shown that people who stutter may experience physical movements or tension that are not easily visible to clinicians. Tichenor et al. (2017) conducted a study in which 10 adults who stutter and two board-certified specialists in stuttering evaluated two speaking samples of each adult using the SSI-4. In all cases, the degree of tension reported by the speakers who stutter was higher than that observed by the expert clinicians. In part, this occurred because the speakers experienced tension in parts of the body that clinicians could not identify, such as the chest, abdomen, and throat. As it is possible to observe, a stuttering severity assessment that

is based solely on the clinician's perspective may not be entirely valid, potentially affecting the correct diagnosis and treatment.

Assessment of severity from the perspective of the person who stutters

Clinicians have also developed severity ratings based on the self-reports of people who stutter. Those questions are considered important to provide sample behaviors and to assess the person's perspective of their stuttering (Manning & DiLollo, 2017). Different ways to self-assess the severity of stuttering have been developed over the years. The first studies on this topic were in the 90s by Naylor and Aron. Naylor (1953) conducted a study in which 24 adults who stutter were trained to use a 9-point severity rating scale, from 1 (least severe stuttering) to 9 (most severe stuttering), in a recorded reading task (63 seconds). Similarly, Aron (1967) asked 46 adults who stutter to complete a reading task and then rate themselves on a 9-point scale, from 1 (no stuttering) to 9 (very severe stuttering), in terms on visible behaviors. They rated their severity immediately after the reading and 30 minutes later, by listening to the audiotape.

Current ways to assess self-severity are similar. For example, O'Brian et al. (2004) used a Self-Rating Stuttering Severity Scale as a clinical tool with 10 people who stutter. The 10 participants made a 5-minute audio recording of themselves speaking in 6 different scenarios. They had to rate themselves for each situation, on a scale from 1 to 9, where 1 meant No stuttering and 9 Extremely severe stuttering.

Another assessment is the Subjective Screening of Stuttering (SSS), which is a self-report measure developed by Riley et al. (2004). This assessment has 3 areas: perceived stuttering severity, level of internal or external locus of control, and reported word or situation avoidance. It includes 8 questions to be answered on a 1 to 9 scale. For the first area, Perceived stuttering severity, people who stutter has to answer how would they score their speech during the session,

and how would they score their speech with close friends, authority figures, and on the telephone, all during the last week. For those questions, 1 is equivalent to "relative relatively fluent" and 9 to "severe stuttering."

Overall, self-severity ratings have been considered a useful clinical tool because they complement the traditional stuttering severity measures provided by the speech pathologist (O'Brian et al., 2004). However, there are two main problems with these measures. The first one is that these ratings, even though they are from the perspective of people who stutter, are also primarily based on the observable characteristics of stuttering. They do not consider the sense of losing control while speaking, and they have been more used as a secondary tool to validate the overt measures realized by clinicians (Guntupalli et al., 2006). The second problem is that these self-ratings of stuttering severity also have not defined what is meant by severity. In other words, the field does not have an agreement on what is meant by the severity of stuttering for speech-language pathologists, and we do not know what the severity of stuttering is for people who stutter.

Treatment of stuttering severity

The severity of stuttering has been used widely as a primary outcome measure in different treatment approaches, through assessments like the SSI-4 or self-reports (Andrews & Ingham, 1971; Blomgren et al., 2005). Current stuttering therapy programs that rely on various types of severity measures include the Camperdown Program, the Lidcombe Program, the Palin Parent-Child Interaction Therapy Approach, and the Restart-DCM Program, among others.

Therapy programs directly focused on reducing stuttering severity

The Camperdown Program is a behavioral treatment for people who stutter older than 12 years old, by O'Brian et al. (2018), which has a pre-defined goal of achieving a stuttering

severity rating of 0. This approach uses the Stuttering Severity Scale, a scale used to quantify overt stuttering behaviors from 0 to 8, where 0 is no stuttering and 8 is extremely severe. The purpose of this scale is to collect measures during the day-to-day talking and compare severity during and after treatment. In the session, the clinician engages in a recorded conversation with the client, they listen to the recording together and immediately assign a stuttering severity score. Differences between the clinician's and client's scores are discussed in order for the clinician to understand how clients view their speech. During the first weeks, the procedure of obtaining the severity is repeated until there is agreement between the client and the clinicians, defined as having no differences of more than one point on the scale value. The number obtained in the Stuttering Severity Scale is assigned to a rating, where a score of 1 is extremely mild, 2-3 is considered mild, 4-5 is considered moderate, 6-7 is considered severe, and 8 is considered extremely severe. Clients are expected to continue with the program until they achieve a severity score of 0-1. Thereafter, they move on to generalization activities, in which they are expected to maintain the 0-1 severity score by practicing in controlled speaking activities and everyday conversations, without avoiding situations and while using fluency techniques. After that, the frequency of therapy is reduced progressively, and the client is discharged when they have the skills to monitor their speech, and control stuttering and it is variability while maintaining a stuttering severity score of 0 to 1.

Another program directly focused on reducing the severity of stuttering is the Lidcombe Program. This is a behavioral treatment for children who stutter under the age of 6, and, in some cases, for older children (Onslow et al., 2023). In this program, parents and clinicians use a Severity Rating Scale from 0 to 10, where 0 is no stuttering, 1 is extremely mild stuttering, and 10 is extremely severe stuttering. The procedure of obtaining the severity is repeated until there

is an agreement between the parents and the clinicians, defined as having no differences of more than one scale value. Parents are asked to rate the severity of their child every day, either as one number that represents the whole day, or including speaking situations such as talking at dinner or in public settings. The goals of the program are twofold: the child to not stutter or almost not stutter, and to be able to maintain it for a long time (O'Brian et al., 2013; Subasi et al., 2022). To assess that severity, parents should keep using the Severity Rating Scale for over a year. If the severity of stuttering increases, then the family is supposed to contact the clinician to manage stuttering again (Onslow et al., 2023).

Both the Camperdown Program and the Lidcombe Program have a primary goal of reducing the severity of observable stuttering behavior, which is assessed through severity rating scales. Even though both approaches have research that supports their effectiveness in reducing severity (Carey et al., 2010, 2012; Cocomazzo et al., 2012; Hearne et al., 2008; O'Brian et al., 2003, 2008, 2013, 2023; Rohani Ravari et al., 2022; Subasi et al., 2022), there are important aspects to highlight regarding how severity is approached. First, severity has been described in terms of frequency and physical movements, but severity itself has not been defined. This means that there are descriptions of how stuttering can occur, and the notion of stuttering severity is recognized, but there is no specific definition of what exactly severity is. This reinforces the fact that there is a need to define the severity of stuttering. Second, even though stuttering severity is assessed by people who stutter, as the authors recognized, that severity is assessed and treated in terms of the overt stuttering behaviors, and not the internal experience of feeling out of control. This is problematic because, as has been mentioned above, stuttering is an internal experience that not always can be seen. In that regard, it is possible to conclude that emphasizing in the overt characteristics rather than the internal experience could give the message that it is more

important how stuttering looks for others than how it feels for the person who stutters. It is also true that there is no research that focuses on how to treat stuttering having as the core the sense of loss of control while speaking, neither for children nor adults. For that reason, future research should also study how to treat the severity from the person who stutters' inner experience of loss of control.

Therapy programs less focused on reducing stuttering severity

The Rotterdam Evaluation Study of Stuttering Therapy Randomized Trial – Demands and Capacities Model (RESTART – DCM) is a treatment program for preschool children who stutter, ages 2 to 6 (Franken & Laroes, 2021). During the assessment, this program uses the SSI-4 to determine the severity of the child. Additionally, clinicians gather information regarding the perceived severity and burden of stuttering, through a visual analogue rating scale (VAS -score). During treatment, parents are asked to start a logbook, in which they track the severity using the scale that is part of the Lidcombe Program, or the 8-point scale of Yairi and Ambrose (1999), where 0 is normal and 7 is very severe. Parents can score severity daily or use a score for the entire past week. The severity obtained helps the clinician decide if the child should target speech more directly, with the expectation that the child spontaneously changes their speech behavior due to the exercises worked in therapy. However, fluency in speech is not the main goal. This program also teaches the child that stuttering is okay and work towards having positive attitudes regarding communication.

Another approach that is less focused on reducing stuttering severity is the Palin Parent-Child Interaction Therapy for Early Childhood Stammering (Palin PCI), for children before 7 years old (Kelman & Nicholas, 2020). This approach assesses stuttering behaviors, with the goal of establishing severity through the analysis of a video-recorded speech sample. The clinician

obtains information about the percentage of stuttering syllables, duration, number of repetitions, tension, avoidance behaviors, physical movements, and rate of speech. In order to do this, it is recommended to use standardized assessments such as the SSI-4 (Riley, 2009) or TOCS (Gillam et al., 2009) explained in previous sections. In case other clinicians do not have access to these measures, a subjective assessment is suggested to determine if the child's stuttering is categorized as mild, moderate, or severe. This subjective assessment should be based on the frequency of stuttering, the type of stuttering, and the quantity of physical struggle and tension related to stuttering. This approach also uses the Palin Parent Rating Scale (Palin PRS) by Millard and Davis (2016). This is a 19-item questionnaire that provides the clinician with information regarding the *parent's* perspective of the stuttering severity, their current knowledge, their confidence on how to support their kid, and the impact of stuttering on the child and them. Section 2 of the questionnaire is called "The severity of stuttering and parent concern". It asks seven questions, four related to stuttering severity and three to parent concerns, to be answered on a 0-10 scale. Numbers close to 10 reflect the best scenario for the family. Stuttering severity is reassessed during treatment to assess progress. However, it is not the most important factor in therapy. As the authors explain, the goal is for the child and the family to understand that it is okay to stutter. They promote being open and talk about stuttering, build confidence, desensitize, and work with thoughts and emotions.

Both RESTART – DCM and Palin PCI are approaches with scientific evidence (De Sonneville-Koedoot et al., 2015; De Sonneville-Koedoot, Adams, et al., 2015; De Sonneville-Koedoot, Stolk, et al., 2015; Millard et al., 2009, 2018; Millard & Davis, 2016; Onslow & Lowe, 2019), which uses stuttering severity as a part of their assessment and treatment. However, they do not account for severity as the main factor in therapy. In similar ways, both agree that there is

nothing wrong with stuttering and state that clinicians should prioritize communication attitudes. Nevertheless, even though stuttering severity is not the main goal of treatment, it is important to mention that when it is assessed and treated, it is in terms of what is observable. For preschool children, clinicians may prefer this because many times children in that range of age are not aware of stuttering, and in those who are, clinicians try to include their perspectives by asking them questions related to their speech, such as if they feel tension and where they feel it. However, it is considered that with a clear definition of the severity of stuttering and which dimensions constitute and influence severity, clinicians would be able to improve and get more precise information, which will allow them to enhance assessment and therapy.

Uses of stuttering severity in research

The severity of stuttering has been used in stuttering research for several purposes. Researchers have used this term as an inclusion or exclusion criteria, to differentiate subgroups of participants, to measure the effects of different interventions, and to compare interventions in longitudinal studies. For instance, the participants needed to have a minimum percentage of stuttered syllables or level of severity in order to participate in the study, using assessment tools like the SSI-4 (Buzzeti et al., 2016; Carrasco et al., 2015; Costa et al., 2019; Fiorin et al., 2015; Juste et al., 2016; Neumann et al., 2005; Nogueira et al., 2015; Oliveira et al., 2014; Regacone et al., 2015; Ritto et al., 2015).

Stuttering severity is also used to differentiate control and experimental groups (Andrade, 2010; Pirinen et al., 2023; Rossi et al., 2014); as a dependent or independent variable (Abdul Waheed et al., 2022; Adriaensens et al., 2015; Picoloto et al., 2017); and to compare treatment approaches over the time (De Sonneville-Koedoot et al., 2015). However, the vast majority of research has not defined what severity is.

One study that did define severity was conducted by Boyle (2015). This study examined the relationship of social support, empowerment, self-help support group participation, and group identification on the quality of life in adults who stutter. Measures included demographic and stuttering-related parameters, which included a self-rating severity. This self-rating was assessed through a 9-point Likert scale in eight different conversational situations, where a high score indicated more severe physical stuttering. For this study, participants were provided with the following definition of stuttering severity: "the disruption in your speech that you think is noticeable on the surface for the majority of the day. It does not refer to the impact of the disorder as a whole on your life". The goal of providing a definition was to ensure that the participants received a similar concept of what the author meant by severity and to reduce the potential overlap between the severity perceived and other psychological scales.

Even though some authors have defined severity and their studies provide us with valuable information to understand the stuttering experience, similar issues as mentioned in the previous section arise: there is no consensus on the definition of stuttering severity in research, and all the definitions are from the listener's perspectives. In that regard, it is considered that researchers would benefit more if they assessed the severity of stuttering in a broader way than just what is observable. For example, it could be concluded that excluding participants who do not reach a number of stuttering events established to participate in the study could impact the results because it excludes the experiences of another important group of people who stutter. Additionally, it may be feasible to infer that research that has as a goal to assess the efficacy of a treatment approach, having as a factor for success the reduction of the severity after therapy, in terms of what is observable, could perpetuate and reinforce the idea that it is better to hide

stuttering moments from others, even if that unintentionally lead people who stutter to stutter covertly in order to reach those standards.

Finally, it is important to highlight that the literature review revealed an absence of studies that look into defining stuttering severity. As a response to this gap in research, this study is focused on understanding this concept from a variety of perspectives.

Summary and Study Aim

Stuttering severity is a term used widely in stuttering assessment, treatment, and research. However, an extensive literature review demonstrated that there have been just a few instances in which it has been clearly defined. Additionally, those definitions reveal a lack of consensus on what is meant by severity, and the majority of them are based on the observable characteristics of stuttering, such as frequency and body movements. Nevertheless, stuttering is an internal experience that can be described as a sense of loss of control while speaking that only sometimes can be perceived by others. If a person changes the word or avoids talking, the others will not notice a stuttering moment, even though the person could affirm that it occurred.

The purpose of this study is to define stuttering severity taking into account the perspectives of both people who stutter and professionals. It is considered that by incorporating the perspectives of people who stutter the field gains a deeper understanding of severity, while the perspectives of professionals ensure that it is used in terms of evidence-based practice.

Method

The first part of this study included a literature review of peer-reviewed articles, books, and thesis, in English, Spanish, and Portuguese, to find and examine definitions of stuttering severity. The terms searched included “severity,” “severe,” “stuttering,” “stammering,” “disfluency,” “dysfluency,” “severidad,” “gravedad,” “severo,” “tartamudez,” “disfemia,” “disfluencia,” “severidade,” “gravidade,” “gagueira,” “gaguez,” anywhere in the text. After an extensive review, 21 formal definitions of stuttering severity were found: 19 in English, 1 in Spanish, and 1 in Portuguese. Table 1 in the literature review section summarizes the definitions from these various publications.

The lack of definitions and consensus led to the second part of this study, creating a questionnaire to gather information on perspectives of the severity of stuttering. In order to do that, the study included two groups of participants: adults who stutter and speech-language pathologists. The first group included adults who currently or have ever considered themselves to stutter. The second group included speech-language pathologists who currently or ever have had clients who stutter in their caseload. There was an option to indicate if a participant is both a person who stutters and a speech-language pathologist.

Inclusion criteria for both groups also included being over 18 years old and speaking English, Spanish, and/or Portuguese. Participants were recruited from December 2023 to January 2024, using snowball and convenience sampling, through personal contacts of the authors, and flyers posted on the social media accounts of stuttering organizations and stuttering centers globally (Appendix A).

Participants completed a Qualtrics survey through the website of the Michigan State University Spartan Stuttering Laboratory. It started with a consent form (Appendix B),

explaining the purpose of the study, potential benefits and risks, information regarding privacy and confidentially, and what participants were expected to do. The consent form explained that the purpose was to gather input on how people define and perceive stuttering severity. No personal information was requested, with the exception of the email address, which was optional, because it could help researchers if they wanted to follow up with questions if needed.

Demographic data was collected, including age, racial identity, ethnicity, and country of birth. For people who stutter, information about prior speech therapy and self-help/support group participation was requested. For speech-language pathologists, information about years of experience and if stuttering was their area of expertise was asked. This data was used to describe the study participants. All participants were asked to answer three open-ended questions about stuttering severity (Appendix C). The same questions were asked to both groups so that answers could be compared. A definition of stuttering severity was not provided, so that participants could provide their own responses in an unbiased manner. In order to gather a variety of perspectives, the questionnaire was available in English, Spanish, and Portuguese. Prior to full data collection, the questionnaire was tested in the three languages by one person who stutters (English speaker), one speech- language pathologist (Spanish speaker), and one person who is both a person who stutters and a speech-language pathologist (Portuguese speaker). The goal of the pilot testing was to identify and correct possible ambiguities or errors. The results of this testing indicated that no revisions or edits were needed.

A total of 400 participants completed the questionnaires in English, Spanish, or Portuguese. Of these, 115 responses were in English, and these are the responses that were analyzed in this study. Responses in Spanish and Portuguese will be examined at a later date. Within the sample of the English-speaking participants, 47 were people who stutter, 50 were

speech-language pathologists, and 18 were both people who stutter and speech-language pathologists. No follow-up questions were included in the study. Participant demographic information of people who stutter can be found in Table 2.

Table 2. Demographic data – People who stutter

Demographic data – People who stutter	
Demographic variable	**% or range**
Age (years)	8 – 75 years old
Racial identity	
- American Indian or Alaskan Native	0%
- Asian	10.87%
- Black or African American	0%
- Native Hawaiian or other Pacific Islander	0%
- White	65.22%
- Other	10.87%
- Prefer not to say/missing data	13.94%
Ethnicity	
- Not Hispanic or Latino	78.26%
- Hispanic or Latino	6.52%
- Prefer not to say/missing data	15.22%
History of stuttering therapy	
- Yes	80.43%
- No	8.70%
- Prefer not to say/missing data	10.87%
History of self-help or support groups	
- Yes	80.43%
- No	8.70%
- Prefer not to say/missing data	10.87%
Country/continent of birth	
- United States	32.61%
- North America (not the United States)	4.35%
- South America	0%
- Europe	34.78%
- Asia	10.87%
- Africa	2.17%
- Oceania	0%
- Prefer not to say/missing data	15.22%

Participant demographic information of speech-language pathologists can be found in Table 3.

Table 3. Demographic data – Speech-Language Pathologists

Demographic data – Speech-Language Pathologists	
Demographic variable	**% or range**
Age (years)	23 – 68 years old
Racial identity	
- American Indian or Alaskan Native	0%
- Asian	6.52%
- Black or African American	0%
- Native Hawaiian or other Pacific Islander	0%
- White	86.96%
- Other	4.35%
- Prefer not to say/missing data	2.17%
Ethnicity	
- Not Hispanic or Latino	80%
- Hispanic or Latino	8%
- Prefer not to say/missing data	10%
Stuttering as an area of expertise	
- Yes	70.59%
- No	9.80%
- Prefer not to say/missing data	19.61%
Years of practice	1 - 50 years
Country/continent of birth	
- United States	50.98%
- North America (not the United States)	1.96%
- South America	1.96%
- Europe	13.73%
- Asia	5.88%
- Africa	0%
- Oceania	0%
- Prefer not to say/missing data	21.57%

Participant demographic information of people who stutter who are also speech-language pathologists can be found in Table 4.

Table 4. Demographic data – Speech-language pathologists who stutter

Demographic data – Speech-language pathologists who stutter	
Demographic variable	**% or range**
Age (years)	21– 69 years old

Table 4 (cont'd)

Racial identity	
- American Indian or Alaskan Native	0%
- Asian	16%
- Black or African American	0%
- Native Hawaiian or other Pacific Islander	0%
- White	64%
- Other	0%
- Prefer not to say/missing data	20%
Ethnicity	
- Not Hispanic or Latino	80%
- Hispanic or Latino	0%
- Prefer not to say/missing data	20%
History of stuttering therapy	
- Yes	83.33%
- No	16.67%
- Prefer not to say/missing data	0%
History of self-help or support groups	
- Yes	83.33%
- No	16.67%
- Prefer not to say/missing data	0%
Stuttering as an area of expertise	
- Yes	86.96%
- No	0%
- Prefer not to say/missing data	13.04%
Years of expertise	0.5 – 26 years
Country/continent of birth	
- United States	61.11%
- North America (not the United States)	5.56%
- South America	0%
- Europe	16.67%
- Asia	22.22%
- Africa	0%
- Oceania	0%
- Prefer not to say/missing data	0%

A thematic analysis was conducted on responses to the three open ended questions in Appendix C. A narrative comparison of the thematic analysis to the literature review project on existing definitions of stuttering severity was then completed. Thematic analysis is a method to identify, analyze, and report patterns (themes) found in the data (Braun & Clarke, 2006). This

study used an internet-based administration in order to increase the number of participants and to get responses from a variety of experiences and backgrounds (Tichenor & Yaruss, 2019).

The first author, who is a person who stutters, answered the questions first, in order to reduce unintentional bias and a possible inclination of researchers to interpret the participant's responses through the lens of their own experience (Creswell, 2013). Answers indicated that from her perspective, stuttering severity is the intensity in which a person responds to the sense of loss of control while speaking, which is not always visible to others. Some aspects or areas that constitute stuttering severity include awareness, reactivity (tension, struggle), regulation, and spontaneity. Factors that influence severity include personal reactions to the sense of loss of control (cognitive, emotional, behavioral), environmental factors, and variability.

To analyze the data, the six steps proposed by Creswell (2013) were followed: Step 1: organize and prepare data for analysis. Step 2: read and observe all the data and get general ideas about what was mentioned by the participants. Step 3: start data coding, which includes organizing relevant data according to the objective of the investigation. Step 4: use decoding and generate categories, and then use the codes found previously to group them by similarity into themes or categories, which will be the main study findings. Step 5: describe the topics and narratively describe the results of the analysis depending on the objective of the research and the topics found. Step 6: interpret the results, and compare the information found with what is raised in the literature. The researcher can mention if the findings confirm what was raised in the research or if they differ from them, as well as raise new questions for future research.

Data were evaluated in terms of "themes," and, in the descriptions below, quotes from each group are included to illustrate these themes. This study used a triangulation approach in order to enhance the trustworthiness and validity of the findings. Triangulation is a way to

explore different perspectives on the same phenomenon (Fusch & Ness, 2015). The participants include clinicians and people who stutter, and, as the authors suggested, it is important to keep in mind that contradictory results could be obtained. However, it is the responsibility of the researchers to interpret the findings in a way in which they can demonstrate the richness of the information obtained from the data. Saturation analysis was not conducted because the data included a very large sample and participants from different backgrounds, which supports the idea that the themes and subthemes reflect a deep understanding of the topic and is credible (Fusch & Ness, 2015).

In conclusion, this study aimed to combine the perspectives of both clinicians and people who stutter. Through a qualitative study, and a survey distributed online on different internet platforms, researchers explored the concept of stuttering severity. The findings are expected to improve the use of this concept, which is widely used in the assessment, treatment, and research of this condition.

Results

Three open-ended questions were included in the survey to explore and analyze the concept of stuttering severity. The analysis results are presented in two main sections. The first section focuses on the analysis of questions 1 and 2, the definition and components of stuttering severity; the second section focuses on question 3, the factors that influence stuttering severity. This division is based on the similarity of responses to the first two questions, with the purpose of enhancing the clarity and organization of the findings.

Definition and Components of Stuttering Severity

A compilation of all the themes across all the participants regarding the definitions and components of stuttering severity is presented in Table 5. Many themes resonated consistently across all the three participants groups; thus, they are addressed first. However, distinct patterns depending upon whether the respondent was a person who stutters were also observed. Particularly, there were two distinct themes exclusively observed in the responses of individuals who stutter, encompassing both those who were speech-language pathologists and those who were not. Those particular themes are presented separately.

Table 5. Definition and components of stuttering severity

Definition and components of stuttering severity		
People who stutter	**Speech-language pathologists who Stutter**	**Speech-language pathologists**
Internal Struggle and Effort	Internal Struggle and Effort	
Struggle May Not Be Visible	Struggle May Not Be Visible	
Disfluencies and Visible Physical Tension	Disfluencies and Visible Physical Tension	Disfluencies and Visible Physical Tension

Table 5 (cont'd)

Effective Communication	Effective Communication	Effective Communication
Affective, Behavioral, and Cognitive Responses	Affective, Behavioral, and Cognitive Responses	Affective, Behavioral, and Cognitive Responses
Adverse Impact	Adverse Impact	Adverse Impact
Variability	Variability	Variability

People who Stutter, Speech-Language Pathologists who Stutter, and Speech-Language Pathologists

Analysis of questions 1 and 2 revealed five themes exploring the concept of stuttering severity: (a) Disfluencies and Visible Physical Tension; (b) Effective Communication; (c) Affective, Behavioral, and Cognitive Responses; (d) Adverse Impact; and (e) Variability. Some responses did not fit with the other themes, so these were collected into a Miscellaneous category.

Disfluencies and visible physical tension

Participants defined stuttering severity as the degree of visible disruption in the fluency of speech, including factors such as the frequency, duration, and types of stuttering events. Stuttering events themselves were defined as observable behaviors such as blocks, prolongations, and repetitions. Severity also includes physical concomitant behaviors, body movements, and outward tension during moments of stuttering.

People who stutter:

> Participant 25 (P25): *I have generally defined stuttering severity by the frequency and intensity of physical struggle* combined with the frequency and intensity of avoidance behaviors.
>
> P37: *I would define stuttering severity using a combination of factors, for example, stuttering types and durations, physical tension…*

Speech-language pathologists who stutter:

> P100: *How frequently someone stutters, duration of stuttering, and physical concomitants.*
>
> P102: *Primary characteristics = ratio of stuttering vs. fluent speech, how much interjections or other non-stuttering-like disfluencies are used, length of stuttering moments. Secondary behaviors = distinct lack of eye contact, excessive hand/body movements, etc.*

Speech-language Pathologists:

> P55: *I define stuttering severity based on frequency, duration, and physical concomitant behaviors as outlined by the SSI.*
>
> P56: *I define stuttering severity as how pronounced the stutter sounds/looks to a listener.*
>
> P59: *I define stuttering severity as the number of repetitions, blocks, and/or prolongations in samples of a person's speech taken over time.*
>
> P85: *One meaning is the degree of disruption/distraction of stutter events on speech delivery (severity of dysfluency).*

Effect on communication

Stuttering severity is related to the freedom the person who stutters feels in expressing themselves and their ability to communicate openly. In that regard, a greater severity means that it is harder for the person to say what they want to say.

People who stutter:

> P28: *I personally define stuttering severity as how well a person finds him/herself able to communicate what s/he wants to say.*
>
> P29: *I define it as* (…) *the amount that stuttering has on their ability to communicate in a way they would like to…*
>
> P30: *I define stuttering severity as the degree to which it limits a person in expressing themselves.*

Speech-language pathologists who stutter:

> P95: *The amount of freedom a person feels to speak. So, to which amount can he/she say exactly what he wants -and when- to say.*
>
> P107: I define stuttering severity by a combination of how often and how much someone stutters (in terms of physical concomitants) as well as life impact *(if someone avoids a lot or is not saying what they want to say).*

Speech-Language Pathologists:

> P57: *I really define severity based on* (…) *how severely it limits allowing a person to say what they want to say.*
>
> P71: *I define stuttering severity as the level at which it affects communication.* Although the main signs of stuttering include repetition, block, or any kind of avoidance, in *my view it can be measured based on its effects on communication.*

P83: I define stuttering severity as how much the stuttering negatively impacts one's life. *Is the stuttering preventing this person from communicating in certain settings, or saying what they would like to say?*

Affective, Behavioral, and Cognitive Responses

Stuttering severity also involves the impact on an individual's emotional, cognitive, and behavioral dimensions. This includes the degree to which stuttering affects feelings, thoughts, attitudes, and confidence, among others. It involves examining how often they feel that way, thoughts and reactions related to stuttering, how much of the time they think about the way they speak, what do they think, and how intrusive those thoughts are. In that regard, a greater negative affective, behavioral, and cognitive responses equals a greater severity.

People who stutter:

P22: *The emotions you feel when communicating or anticipating speaking. The greater the negative emotions you feel about speaking (before and after) are a good barometer of stuttering severity.*

P39: *Severity: as it influences my life, my thoughts, my willingness to talk, and* how I behave.

Speech-language pathologists who stutter:

P98: I think some of those different things include (but are not limited to):

- How good or bad someone feels about the way they speak

- How often do they feel that way about the way they speak

- How much of the time they think about the way they speak…

P99: *The amount of negative thoughts or feelings that I experience after moments of stuttering.*

Speech-language Pathologists:

P52: *I define stuttering severity to the tune of how much (or how little) the affective, behavior, and/or cognitive aspects of stuttering* may (or may not be) holding a person back from saying exactly what they want to say, when they want to say it.

P54: *I define stuttering severity as a culmination of the affective, behavioral, and cognitive components of the condition. Stuttering severity includes the person's thoughts and feelings related to stuttering…*

P92: *Are they so embarrassed/ anxious/ frustrated about their stuttering* that they shut down in class/ refuse to speak.

Adverse Impact

Stuttering severity involves how much stuttering limits the speaker's participation in different activities, including what are they doing (or not doing) because of previous experiences associated with stuttering. This involves evaluating the level of negative influence across various life areas, including daily living situations, relationships, and future plans.

People who stutter:

P19: *I relate stuttering severity to how it affects your daily living.*

P22: *I define stuttering severity as the impact of stuttering on one's everyday life. The negative emotions, limitations,* and the real-world environment *that effects that negatively impact their ability to participate in everyday life activities.*

P23: *I define stuttering severity as the level of limited personal and social activities with other people, which could influence my quality of life as a person who stutters.*

P27: I would define severity as the level of disfluency and *level of impairment in daily life that the stutter causes.*

Speech-language pathologists who stutter:

P99: *Participation in activities (speaking related mostly) is impacted by their stuttering.*

P100: *I define stuttering severity as how much stuttering hinders our lives.*

P102: *Participation and activity limitations (i.e., what are they doing or not doing because of stuttering).*

P109: The second factor would be how the individual experiences stuttering, that is, how much does stuttering affect them in all aspects of life? *How limiting is the stuttering to their quality of life? Participation in work, hobbies, and socialization?* In short, I define stuttering as both the severity of overt characteristics (primary and secondary behaviors) and the i*mpact it has on an individual's life.*

Speech-language Pathologists:

P48: *I define stuttering severity as the level at which a person's life is negatively impacted. How much does the stigma of stuttering negatively impact the person's participation and satisfaction across the many facets of their life.*

P79: *I would define severity according to how it affects the client's ability to function in their daily activities, work, school, and interactions with others.*

P88: *I define stuttering (stammering) severity as how much stammering impacts the* person who stammers well-being and *participation across different situations.*

P89: *Th*e most important indicator of severity is how it affects the person who stutters in life. E.g., *do they avoid participation in things they would otherwise do due to their stutter.*

Variability

Stuttering severity varies both within and between individuals. Within an individual, stuttering severity varies based on the context in which speech occurs, and the self-perspective of the speaker. And, different people experience stuttering severity differently. Notably, every component of stuttering severity varies. (Note that additional information regarding factors that influence severity and variability are presented in the analysis of the question 3, under the section "Factors that influence stuttering severity.")

People who stutter:

> P7: *Stuttering severity should be defined in different contexts, as different contexts lead to different fluency experiences (talking to yourself isn't the same as talking to an audience).*
>
> P32: *I would say the severity depends on personal experience. One might call themselves a person with a severe stutter, while someone with the same 'stutter frequency' might not experience the stutter to be severe. People who are good at avoiding their stutters to be heard by their listeners (coverts) could still have a 'severe' stutter, while nothing is noticeable to outsiders.*

Speech-language pathologists who stutter:

> P104: *This can vary from person to person over physical, emotional, and cognitive.*

Speech-Language Pathologists:

> P79: *Variability of any of the components.*

Miscellaneous Responses

Some participants indicated that they avoid using the term severity because it is necessarily or inherently focused on observable characteristics, such as the number of syllables stuttered, and thereby missing the internal experience. They also stated that the term severity

assumes that stuttering must be fundamentally negative, limiting it to only negatives or the absence of negativity.

People who stutter:

> P26: *I prefer pronounced as it is less judgmental…*
>
> P40: *I no longer really think in terms of stuttering severity. It is too complicated to explain to somebody what people can mean when they say this. In the past, I interpreted stuttering severity as the frequency or percentage in which stuttering moments happened in a conversation, as this is what was recorded in speech therapy. But this no longer seems like a helpful measure in any way.*

Speech-language pathologists who stutter:

> P107: *I choose to avoid using the term 'severity' as I think a general/layperson understanding would assume it refers to observable symptoms so I think it can too easily be understood in different ways (…) But I think the term severity has become increasingly problematic as I've moved towards viewing stuttering as a difference rather than a disorder. Severity carries a strong implicit negative (…) I also have an issue with the term 'severity' because it doesn't make space for anything positive. It only allows for negatives or the absence of negativity (…). There's a huge assumption built into the term stuttering severity that stuttering MUST be bad. There's no shred of possibility of anything good in it.*

Speech-Language Pathologists:

> P44: I *would not define severity as it relates to stuttering because I disagree with the concept and connotations of it being used to rate or count the amount of stuttering as %*

syllables stuttered. I feel there is more value in considering the impact on the person and how it affects their well-being and quality of life.

P60: *I don't define severity. I talk about stammering more or less / increase or decrease…*

Other participants declined to define stuttering severity. Instead, they defined the "impact" of stuttering.

P52: *Impact on the individual who is stammering: Their physical experience and their psychological response.*

P74: The i*mpact of stuttering can be: - physical, when people report tiredness and physical tension leading to being exhausted after talking - emotional, when anxiety, stress, and strong emotions have an effect on the person before, during, and after conversations - cognitive, when "fight or flight" attitudes lead to thoughts considered as having a negative impact on the person's self-confidence – social, when stigma around stuttering is high and family or work environment have attitudes impeding the person's ability to live the life he/she wants.*

Themes Unique to People Who Stutter

Analysis of questions 1 and 2 revealed two themes that were exclusively reported by people who stutter (including those who are speech-language pathologists and those are who are not): (a) Internal Struggle and Effort and (b) Struggle may not be visible.

Internal Struggle and Effort

Stuttering severity is the degree of the internal struggle and physical or mental effort involved in navigating moments of being stuck, either in attempt to hide the moment of being suck, in an attempt to escape from the moment of being stuck, or in an attempt to talk even

though they feel stuck. In that regard, the more the internal struggle and effort, the more severe stuttering is.

People who stutter:

> P1: *Severity for me means how much you struggle with your own stuttering. So not how much you hear, but how big is the struggle inside.*
>
> P16: For me, severity is the noticeable attributes of the stutter and *the effort taken to communicate appropriately.*
>
> P26: *How long and intense someone is stuck in their words.*

Speech-language pathologists who stutter:

> P96: *Stuttering severity relates to the degree to which the speaker is forcing sound...*
>
> P102: We base our diagnosis on the *frequency and intensity of stuttered events (...) By intensity I mean, how "stuck" the person feels they are. A more severe stutter requires more mental and physical effort to move past, to get unstuck, than a less severe stutter. Very mild stuttering may require little effort or attention, while severe stuttering might require great amounts of both.*

Struggle may not be visible

The speaker's sense of internal struggle is not always visible to others; however, it becomes evident when manifested through audible and/or visible behaviors, particularly when the person is forcing speech. A more severe stutter requires greater mental and physical efforts to navigate moments of being stuck. Covert stutterers, individuals who experience few interruptions but frequent avoidance strategies such as word substitutions, may not appear severely affected by overt stuttering, but can still be impacted by their condition. This was demonstrated in the following quotes:

People who stutter:

> P26*: Individuals who have very few interruptions with little struggle but exhibit a high frequency of avoidance (word substitutions, circumlocutions, etc.), so-called covert stutterers, may not be considered severe in terms of overt stuttering but may be severely impacted.*
>
> P34: *People who are good at avoiding their stutters to be heard by their listeners (coverts) could still have a 'severe' stutter, while nothing is noticeable to outsiders.*

Speech-language pathologists who stutter:

> P102: *We base our diagnosis on the frequency and intensity of stuttered events. These events might result in disfluencies, but they might not… The more severe stutter requires more mental and physical effort to move past, to get unstuck, than a less severe stutter…*
>
> P96: *The greater the amount of forcing, the more audible and visual features will accompany that moment…*

Summary of Definitions and Components of Stuttering Severity

According to the participants in this study, stuttering severity encompasses the degree of internal struggle and physical or mental effort involved in navigating moments of being stuck, either in an attempt to hide the moment of being stuck, in an attempt to escape from the moment of being stuck, or in an attempt to talk even though they feel stuck. The speaker's sense of internal struggle is not always visible to others; however, it becomes evident when manifested through audible and/or visible behaviors, particularly when the person is forcing speech. A more severe stutter requires greater mental and physical effort to work through moments of being stuck.

Stuttering severity, when it is visible, includes disruptions in speech fluency and the frequency, duration, and types of dysfluencies, including blocks, prolongations, and repetitions, along with accompanying physical manifestations and tension. It includes the speaker's perceived freedom in communication, in which greater severity denotes higher difficulty in expressing oneself openly. Additionally, stuttering severity involves emotional, cognitive and behavioral dimensions, and the adverse impact that it has on one's life. Stuttering severity varies across individuals, contexts, and perspectives.

Factors that influence stuttering severity

This section provides an analysis of question 3, which centers on participants' perceptions regarding the factors that influence stuttering severity. Themes common across the three groups of participants are presented first. One theme was apparent only in the responses of participants who stutter (including both those who were speech-language pathologists and those who were not), so this theme is presented separately.

People who Stutter, Speech-Language Pathologists who Stutter, and Speech-Language Pathologists

Analysis of the question 3 revealed seven themes regarding the factors that influence stuttering severity, across all groups of participants: (a) Psychological Factors; (b) Speech-Language Factors; (c) Perspectives and Responses of the Listeners; (d) Speech Therapy Experiences; (e) Situational Factors; (f) Culture Factors; and (g) Individual Factors. A compilation of all the themes across all the participants regarding the factors that influence stuttering severity is presented in Table 6.

Table 6. Factors that influence stuttering severity

Factors that influence stuttering severity		
People who stutter	**Speech-language pathologists who stutter**	**Speech-language pathologists**
Force to produce speech	Force to produce speech	
Psychological Factors	Psychological Factors	Psychological Factors
Speech and Language Factors	Speech and Language Factors	Speech-Language Factors
Perspectives and Responses of the Listeners	Perspectives and Responses of the Listeners	Perspectives and Responses of the Listeners
Speech Therapy Experiences	Speech Therapy Experiences	Speech Therapy Experiences
Situational Factors	Situational Factors	Situational Factors
Cultural Factors	Cultural Factors	Cultural Factors
Individual Factors.	Individual Factors.	Individual Factors.

Psychological factors

Various psychological factors influence stuttering severity. Examples include emotional states, such as mood, stress, anxiety, uncertainty, and fear of being perceived as a person who stutters; personal attributes, such as personality, confidence, resilience, temperament, coping skills, self-advocacy, and self-image; reactions, such as feelings and thoughts about stuttering; and other factors such as mental and spiritual well-being.

People who stutter:

P2: *Mood/confidence in how you go about stuttering.*

P6: *Stress, anxiety, feeling unsure of yourself.*

P13: *The biggest factor for me was fear...Fear of being seen as a person who stutters.*

P16: *Personality, thought patterns.*

P25: *The stutterer's self-image.*

P37: *Dependent on an individual's temperament.*

Speech-language pathologists who stutter:

P87: *Feelings and thoughts (shame, doubt, negative self-talk).*

P94: *Anxiety.*

P101: *Related to the person's tolerance of hearing themselves stutter.*

P102: *The person who stutter's current physical, emotional, mental, and spiritual health.*

P104: *Having a firm foundation of self-advocacy, coping, and resilience to navigate spaces where stuttering is not understood or acceptable.*

Speech-language pathologists:

P88: *Temperament and personality.*

P92: *It can be affected by the emotions that arise in someone during communication. It can also be influenced by the ways of coping with stuttering.*

P100: *Feeling that there is something wrong with them, anxiety surrounding speaking/fear of judgment, etc.*

Speech and language factors

Several factors related to speech and language influence stuttering severity. Examples include using multiple languages, speech tasks, encountering challenging letters or words, utterance length, language proficiency, speech rate, so-called "feared" words, perceived speech fluency, and more.

People who stutter:

P3: *The number of repetitions at a particular syllable, the state of our mouth, and facial expressions when we get a blockage (when we get stuck on a syllable).*

P6: *Talking in a second or third language.*

P10: *Speech tasks.*

P19: *Letter or word.*

Speech-language pathologists who stutter:

P91: *Linguistic, paralinguistic,* and social *factors.*

P92: *Words prone to stutter* (…), *perceived fluency of speech.*

P100: *It can be a lot of factors like rate of speech (…), the language that I speak.*

Speech-language pathologists:

P69: *Linguistic factors are obvious like initial word position, length of the utterance.*

P73: *Language - if someone is using language which is in their remit they might have less severe stuttering, especially in children.*

P85: *What does the overt struggle look like.*

Perspectives and responses of the listeners

Various perspectives and responses of the listener influence stuttering severity. Examples include the reactions of people in the individual's environment such as parents, friends, and colleagues, which include the thoughts, beliefs, attitudes, and moods of listeners. Additionally, the perceptions of stuttering in childhood by parents or caregivers can impact severity.

People who stutter:

P16: *Reactions of people around us, mostly parents, but also friends, colleagues, etc.*

P25: *Attitude/mood of the listener.*

P32: *Parent/caregiver*/SLP perception *of their stuttering at an early age can influence the relationship a child has towards their stuttering.* If a child was in a setting that praised fluency and presented consequences when stuttering occurred, then that child might develop a negative relationship towards their stuttering. This starts to develop their "iceberg" that can be carried into adulthood which influences increased stuttering severity.

Speech-language pathologists who stutter:

P99: *Supportive and unsupportive people.*

P104: *Children who stutter' parents' ability to regulate with child/or provide a safe space to stutter/live into the identity of the person who stutters.*

Speech-language pathologists:

P42: *Negative/positive responses from others.*

P46: *Reactions of the environment to the way the person who stutters speaks.*

P52: *Parental support, reactions of others, and peer acceptance.*

P73: *Thoughts and beliefs (and ultimately physical actions or words) held by those in the lives of a person who stutters that can positively or negatively impact a person who stutters view of themselves.*

Speech therapy experiences

Speech therapy can influence the severity of stuttering positively or negatively. Some respondents emphasized the importance of speech techniques to facilitate smoother stuttering and reduce severity, while others were against a focus on fluency, noting potential negative effects such as decreased self-confidence or enjoyment in speaking. According to these participants, early perceptions of stuttering, particularly in environments that praise fluency and

penalize stuttering, can shape a negative relationship with stuttering, potentially increasing its severity in the long term. Additionally, delayed intervention may increase the severity of both the emotional and physical aspects of stuttering, in comparison to those who received therapy earlier.

People who stutter:

> P32: *SLP perception of their stuttering at an early age can influence the relationship a child has towards their stuttering. If a child was in a setting that praised fluency and presented consequences when stuttering occurred, then that child might develop a negative relationship towards their stuttering. This starts to develop their "iceberg" that can be carried into adulthood which influences increased stuttering severity.*
>
> Participant 39: *I think the later a child receives help and support the more difficult the task of combating the emotional and physical responses to stuttering.*

Speech-language pathologists who stutter:

> P104: *If in speech therapy, working with an SLP who provides/facilitates holistic care, NOT just focused on fluency shaping.*

Speech-language pathologists:

> P41: *Their use of strategies to help them stutter more easily.*
>
> P54: *Focusing too much on fluency or using various techniques, antiquated speech therapy that doesn't educate the person and improve self-confidence and enjoyment in speaking.*
>
> P56: *The understanding and deployment of the strategies required to help support fluency.*

P74: *Experiences in Speech-Language Therapy - fluency therapy may have a negative impact if a child perceives stammering negatively or as 'failing to improve' in speech therapy.*

Situational factors

The situation a person is in and the activity they are completing affect the severity of stuttering: some situations are more challenging and therefore are associated with higher stuttering severity. This relationship differs for each individual. For example, stuttering severity increases during high-pressure situations like job interviews or phone conversations, particularly when speaking to unfamiliar individuals or in noisy environments. Factors such as background noise and unfamiliarity can also contribute to variations in stuttering severity. Additionally, the composition of the audience and the speaker's comfort level with the situation play important roles, with stuttering severity often escalating in group settings or when interacting with challenging individuals.

People who stutter:

P11: *Situation, e.g., will be worse in job interview rather than speaking to friend. Often worse on phone.*

P23: *Unfamiliarity.*

P31: *Background noise (…), situations where I'm a long way out of my comfort zone.*

Speech-language pathologists who stutter:

P92: *Challenging situations, challenging people.*

P100: *Stuttering severity can be impacted by environmental factors such as the person you are talking to and the situation you are in.*

P102: *Factors may include the environment or situation (work, work conference, conversational interactions with time-pressure expectations, family or close friends, small vs large social groups), the individual the person is speaking with (closer relationships vs. acquaintances, the position of the communication partner such as a boss, subordinate, customer service representative, or police officer, etc.)*

Speech-language pathologists:

P76: *Stuttering can be affected by different communicative situations. It may be easier to speak one to one with another speaker while in a group situation, stuttering may increase (...) Talking on the phone may be more difficult for some people. Unfamiliarity with given situations.*

Cultural factors

Cultural factors and community support influence stuttering severity. These include societal attitudes towards stuttering, exposure to diverse stuttering groups, media representation impact, and government regulations on support. Stigma, discrimination, and bullying within family, social circles, schools, and workplaces also play a role.

People who stutter:

P9: *Cultural and social attitudes.*

P30: *How society views stuttering, exposure to other diverse groups of stuttering, government regulations on what's needed to gain support in different countries.*

P34: *Would be influenced by stigma, faced with family, and other parts of their social life, and school, and work.*

Speech-language pathologists who stutter:

P98: *Environment (family, school, daycare, work, hobbies), society.*

P104: *If the child/child's family or person is connected to any stuttering support groups/community, representation in the world, media, books, etc.*

Speech-language pathologists

P51: *Community/support factor: a person's stuttering severity may be affected by their level and type of support. This could be from community or family support. Culture- A person's stuttering severity is very likely to be impacted by their culture, specifically how their society views disability. Communities embracing the medical model of disability may empower people who stutter to experience the condition in a positive light. Contrarily, people living in societies that abide by the medical model of disability may experience more severe stuttering due to participation restrictions.*

P74: *Culture and societal views of stammering (...), bullying, discrimination and stigma about stammering.*

Individual factors

Individual factors influence the severity of stuttering, from external circumstances to internal states. Financial circumstances, daily stress, mental and physical health, and tiredness all contribute to the severity of stuttering experienced. Additionally, life problems, co-occurring conditions, medication, gender dynamics, and potential genetic and neurological components also influence stuttering severity. In that regard, stuttering severity appears to fluctuate day to day, hour to hour, minute to minute, or based on the situation, reflecting the variability of its manifestation.

People who stutter:

P16: *Financial circumstances.*

P17: *Tiredness, depression, sleep deprivation, and life problems.*

P18: *Your health at that moment.*

P26: *Daily stress, overall mental health, physical health (feeling good in your body, makes you feel more confident which could affect the stuttering experience).*

P31: *The balance of men to women I'm talking to.* The more men, the more I stutter. Not sure why.

P34: *It also would matter if they had other disabilities or disorders. For example, the negative impact of stuttering may increase for someone with ADHD who struggles with rejection sensitivity dysmorphia.*

Speech-language pathologists who stutter:

P92: *Unpleasant memories related to past speaking experiences.*

P103: *I imagine there is a genetic and neurological component.*

Speech-language pathologists:

P58: *Physical health (healthy/sick, tired/alert), medication.*

P63: *Changing - job, places to live.*

P80: *Stuttering severity seems like it could change day to day, hour to hour, minute to minute, or based on the situation. I'd say it could depend on external factors such as communication partners, environment, stress, feelings, anxiety, mood, physical needs such as being tired/hungry, etc.*

Theme Unique to People Who Stutter

Analysis of question 3 revealed that one theme was exclusively reported by people who stutter, including both those who are speech-language pathologists and those are who were not: Force to produce speech.

Force to produce speech

Participants who stutter highlighted that one factor that influences stuttering severity is the degree of force applied to produce speech during moments of feeling stuck, along with the motivation that drives that force. Additionally, the internal reactions to stuttering were noted to amplify their intensity.

People who stutter:

P4: *The ability to get out of the blockage and continue speaking.*

P12: *The difficulty in controlling it by persons who stutter.*

P21: *The more I want to be fluent, the more I stutter.*

Speech-language pathologists who stutter:

P101: *How much the person is forcing sound out at that moment is the key factor related to severity. Forcing sound out relates to how much the speaker wants to be done with that speaking situation (e.g., related to perceptions of what the listener thinks; related to the person's tolerance of hearing themselves stutter).*

P103: *Also, some people may react to their stuttering more than others, increasing intensity (...). Also, it seems the more one reacts to stuttering the more frequently they stutter too.*

Summary of Factors that Affect Stuttering Severity

Various factors influence the severity of stuttering. This includes the degree of force to produce speech, as well as the motivation that drives that force. Psychological factors, such as emotional states, personal attributes, reactions, and mental and spiritual well-being, could also influence stuttering severity. Apart from that, speech-language factors, such as speech rate, and multilingualism; situational factors; like the situation in which the person is in; cultural factors, including stigma and discrimination; and individual factors, such as financial circumstances and

daily stress, also contribute to the decrease or increase of stuttering. Additionally, the perspectives and responses of the listeners influence stuttering severity, which includes their thoughts, beliefs, and attitudes. Finally, participants mentioned that speech therapy experiences can either influence severity positively or negatively, according to the perspectives on fluency strategies.

Discussion

This section includes an examination and analysis of the findings, as well as an important consideration and key aspects of the participants. Additionally, it mentions the limitations of the study and future directions.

Analysis of results

This study addressed the challenges in defining stuttering severity. The first part of the study involved a comprehensive review of over 500 sources in English, Spanish, and Portuguese to determine how various authorities in the field have defined stuttering severity. Analyses revealed 21 formal definitions of stuttering severity. For instance, Kuniszyk-Jozkowiak (1995, p. 14) mentions "stuttering severity defined as the number of errors characteristic of stuttering, such as: repetitions, insertions, blockades, etc. per 100 syllables," Klassen (2002, p. 98) explained that, "severity is the seriousness of the stuttering, including its length, and behaviors such as avoiding eye contact, grimaces, etc." Yairi and Seery (2021, p. 194) stated that stuttering severity is, "the level of disruption in the delivery of continuous speech."

Another important finding of the literature review is that some of the well-known assessments of severity, such as the Iowa Scale of Severity of Stuttering, the TOCS, and the SSI-4 did not define stuttering severity. They provided information on how it should be measured but did not a definition of what exactly it is. This highlighted the need for a definition of stuttering severity to ensure consistency and accuracy in clinical and research practices.

While the 21 definitions provide us valuable insights regarding how severity might be conceptualized, two main issues arise. First, a consideration of all of these definitions reveals a lack of consistency or consensus on how severity should be defined. For some authors, severity is the measure of frequency and duration, while for others, is the amount of overt stuttering

moments a person exhibits, including speech and body movements, and others define stuttering severity based on different factors. The second problem is that nearly all of the definitions are focused on the observable characteristics of stuttering that a listener might perceive, such as the disfluencies and physical characteristics of moments of stuttering. In contrast, when people stutter, they have reported to have "a feeling" inside them (Emerick & Hamre, 1972), described by Perkins (1990) as a sense of "loss of control" while speaking (see also Tichenor and Yaruss, 2019). In that regard, stuttering severity as commonly defined may not capture the internal essence of stuttering, that sensation that can only be judged by the person who stutters (Alm, 1997).

To further explore the ways in which stuttering is or might be defined, the study gathered the perspectives of people who stutter and speech-language pathologists, as well as those who are both. Participants were asked to define stuttering severity and explain the factors that influence it. People who stutter and speech-language pathologists defined the severity of stuttering as the degree of disruptions in speech fluency, including factors like frequency, duration, and types of stuttering events. These definitions involve visible physical behaviors and body movements, and affective, behavioral, and cognitive dimensions. Participants also highlighted that stuttering severity can reflect the extent in which the person limits their communication, the adverse impact stuttering has in their lives, and the variability that severity has.

The first common theme, stuttering severity defined as disfluencies and visible physical tension, is similar to findings in existing literature. Zebrowski and Kelly (2002, p. 16) stated that "severity of stuttering is a global judgment based on listener's perceptions of the frequency, type, and duration of disfluent speech, as well as the presence or absence of associated behaviors."

Similarly, Pertijs et al. (2014, p. 164) mentioned that "stuttering severity is a measure based on the objective measurement of stuttering behavior, such as stuttering frequency, duration of stutter moments, the type of dysfluencies and secondary behaviors." This demonstrates that the field shares a common agreement on this first aspect regarding how stuttering is defined.

As previously mentioned, the concept of stuttering severity includes more aspects in addition to just the number or nature of speech disfluencies. However, the 21 definitions identified in the first part of this study are focused primarily on those observable disfluencies and physical tension that might be visible to a listener. In that regard, there is a contradiction between the current literature and the findings of this study. According to the literature, stuttering severity is related to speech disfluencies, but for people who stutter and speech-language pathologists in this study, severity includes broader aspects. One possible explanation for this discrepancy is that the definitions found in the literature reflect perspectives that historically have been focused on speech, while contemporary understandings of severity have broadened the perspectives to a more holistic approach, adding factors such as the adverse impact and cognitive and emotional responses, among others. Future research should study these viewpoints further and explore the broader, multifaceted nature of stuttering severity.

People who stutter added another theme to these descriptions: the degree of *internal* struggle and physical and mental effort required to talk. They indicated that this struggle may sometimes be visible to others and sometimes kept internalized. Interestingly, while speech speech-language pathologists who do not stutter provided important insights about severity that largely matched the perceptions of people who stutter, they did not identify the internal experience that people who stutter reported. In other words, while speech-language pathologists did identify observable aspects of stuttering severity, such as the disruptions in the speech, they

did not fully recognize the significance of the internal struggle and effort required to talk that was described by those who stutter.

This is relevant because the comprehensive review of definitions of severity conducted in the first part of this project revealed that severity is defined and evaluated only in terms of observable behaviors. Current approaches are therefore failing to fully capture the experience of stuttering severity reported by individuals who stutter. Clinicians and researchers could benefit from listening to the voices of people who stutter who can share first-hand experiences with stuttering and factors that maybe previous research has not investigated.

Moreover, in the analysis of factors that influence stuttering severity (Question 3), people who stutter and speech-language pathologists highlighted a range of consistent factors. These included psychological factors, speech-language factors, situational factors, cultural factors, individual factors, speech therapy experiences, and perspectives and responses of the listeners. Again, however, the participants who stuttered added another theme. They explained that stuttering severity is influenced by the degree of force to produce speech while feeling stuck, and the motivation that drives that force. As with the two previous questions, speech-language pathologists did not identify these internal aspects of stuttering severity, despite the majority of them being professionals with stuttering as their area of expertise. This again highlights the fact that there is a gap between the clinical and research understanding and the experiences of individuals who stutter, which demonstrates the need for research focused on stuttering from the perspectives of those who live with it.

Another important finding from these analyses is the number of factors that influence stuttering severity. Analysis of the themes demonstrated that severity can be influenced by the force required to produce speech, the motivation that drives that force, psychological factors,

situational factors, cultural factors, individual factors, speech therapy experiences, and perspectives and responses of the listeners. In contrast, the most common assessments designed to measure the severity of stuttering, such as the Iowa Scale of Severity of Stuttering, the TOCS, and the SSI-4, typically provid a level of severity based on 3 or 4 speech tasks of a few minutes each. These may not adequately represent the complexity of stuttering severity due to the numerous factors that influence it and cause it to fluctuate rapidly. Indeed, one of the key themes identified from this study is the variability of stuttering severity, yet current measures of stuttering do not fully account for this variability. Consequently, relying on a small number of speech tasks in restricted settings may result in an incomplete understanding of stuttering severity for an individual speaker. Future research should look into ways to develop an assessment that accounts for the diverse factors that influence stuttering severity, according to how impactful are each factor for each person who stutters.

An important consideration about these participants

It is critical to note that participants who are both people who stutter and speech-language pathologists demonstrated a deep level of insight and sophistication in their responses. This could be attributed to their professional training and expertise, as well as their personal experiences with stuttering, which allowed them to perceive different aspects of this complicated concept of severity. This facilitated having more profound answers that contributed and enriched these research findings. At the same time, this introduces a potential confound in the data, as these respondents might have had insights that are not common within the general population of people who stutter.

Moreover, the biggest proportion of individuals who stutter had previously received stuttering therapy and/or participated in support groups. This is relevant because their responses

may have been influenced by their previous interventions. Such influences could have shaped their perspectives about how severity should be viewed, in comparison who those who have not accessed any therapy or support group. An example of this it is shown in the following quote:

> P22: *I define stuttering severity as the impact of stuttering on one's everyday life. The negative emotions, limitations, and the real-world environment that effects that negatively impact their ability to participate in everyday life activities.*

Additionally, a substantial number of participants were speech-language therapists who specialize in stuttering. Again, their experience and expertise in the field also introduce potential biases and limit the generalization of the results to bigger populations. For instance, some of the answers to the questions include very sophisticated analyses, reflecting the high level of understanding and specialization about stuttering, as it is showed in the next quote:

> P51: *Community/support factor: a person's stuttering severity may be affected by their level and type of support. This could be from community or family support. Culture- A person's stuttering severity is very likely to be impacted by their culture, specifically how their society views disability. Communities embracing the medical model of disability may empower people who stutter to experience the condition in a positive light. Contrarily, people living in societies who abide by the medical model of disability may experience more severe stuttering due to participation restrictions.*

Future studies should include groups of people who stutter and professionals who have less involvement in the stuttering community, to have a more generalizable understanding of how people presently define stuttering severity and how might be defined in the future.

Limitations

While this research offers valuable insights into the severity of stuttering, it is crucial to recognize and address its limitations. One of these is that it was conducted through an online survey, which may have limited participants in fully expressing their insights. Many participants did enter a considerable amount of text into the response fields, but a face-to-face interview could still have provided more detailed and deeper answers. Another limitation of the study is that, as with most qualitative research, there is a risk of bias on the researcher due to the knowledge and experiences (Nowell et al., 2017), such as being a person who stutters. Even though this was addressed by answering the questions before the participants and asking neutral questions, analytical bias is always a risk that should be considered.

Future directions

The results of this study offer valuable insights and important opportunities for future research. For instance, the 21 definitions of stuttering severity identified could receive a more comprehensive examination, which could include classifying these definitions into groups to gather more clarity on the diverse conceptualizations on the topic.

Moreover, as noted in the method, data were not only collected from English-speaking participants. Approximately 300 responses were also collected from people who speak Spanish or Portuguese. These data will be analyzed in the future, and this will provide broader perspectives and a bigger understanding of the concept of stuttering severity. Such analyses will allow the researchers to conduct cultural comparisons across the different populations.

In addition, future studies can address the specific themes that participants identified in this study. For instance, future studies could gather deeper insights into what the internal struggle and effort that people who stutter feel means and it is influence on stuttering severity, since there

are few studies on the topic. Apart from that, this study was conducted on adults who stutter and professionals, but future studies should consider the perspectives of younger people who stutter to know it their experiences and make comparisons over time. And, people who do not have advanced knowledge about stuttering should also be involved, to determine whether the unique expertise of this participant group affected the findings.

Final Conclusions

The purpose of this study was to increase understanding of the concept of stuttering severity as perceived by people who stutter and by speech-language pathologists. Results demonstrate that for all participants stuttering severity involves broader aspects than speech disfluencies, and that numerous factors influence stuttering severity. Although speech-language pathologists who do not stutter provided valuable insights that aligned the perspectives of individuals who stutter, they did not recognize the internal experiences reported by people who stutter. This highlights the fact that there is a gap between the clinical and research understanding and the experiences of individuals who stutter, which demonstrates the need for research focused on stuttering from the perspectives of those who live with it.

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APPENDIX A: RECRUITMENT FLYERS

Figure 1. Flyer in English

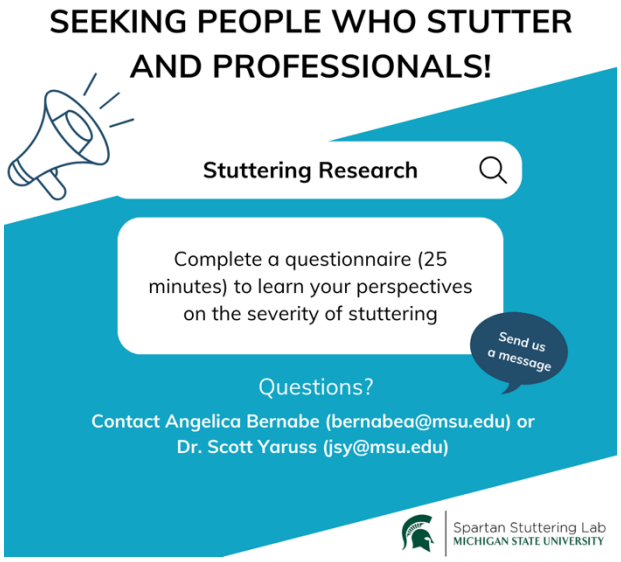
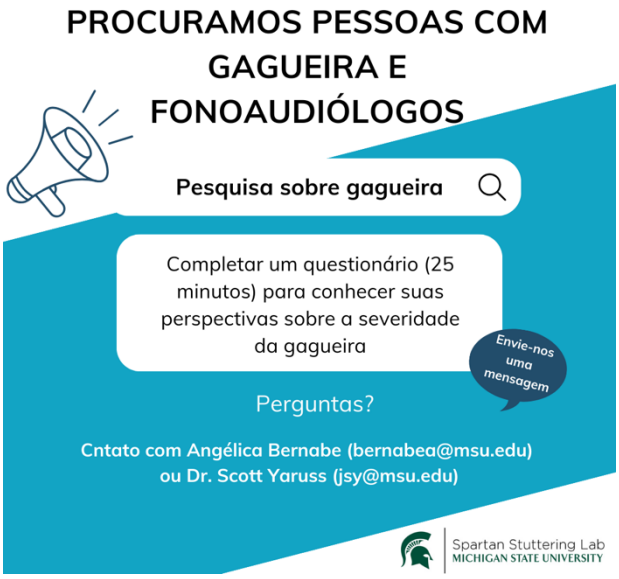


Figure 2. Flyer in Spanish

Figure 3. Flyer in Portuguese



APPENDIX B: CONSENT FORM

Study Title: Defining the severity of stuttering

Background and Purpose of the Study

The purpose of this study is to learn more about how people who stutter and professionals view the concept of stuttering severity.

WHAT YOU WILL DO

You will be asked to provide answers to a survey about your perspectives regarding the severity of stuttering. Your participation in this study will require about 25 minutes.

POTENTIAL BENEFITS

Though you will not directly benefit from your participation in this study, your response will help clinicians, researchers, and other people who stutter better understand your experiences of stuttering.

POTENTIAL RISKS

There are minimal foreseeable risks associated with participation in this survey. The primary risk is a breach of confidentiality. We will take every precaution to guide your privacy by ensuring that your personal information will not be released publicly or shared with anyone. The other possible risk is that some of the questions may cause you to feel uncomfortable. You will not be required to answer any question that you do not wish to answer.

PRIVACY AND CONFIDENTIALITY

Information about you (including name and demographic information) will be kept confidential to the maximum extent allowable by law. Data will be stored on a secure, password-protected server at MSU. The only people who will have access to this server will be people directly involved with the research study and the University's Institutional Review Board (IRB).
All survey item responses will be de-identified for analysis, and no personally identifiable information will be included in any presentations or publications resulting from this study.
All data will be collected via the internet and responses will be anonymized. Results of this study will be made available to you and anyone who completes this survey. A link will be sent via email when the study is completed.

Your rights to participate, say no, or withdraw
Participation is voluntary.
You have the right to say no.
You may change your mind, discontinue, and withdraw from the study at any time.
You may choose not to answer specific questions or to stop participating at any time.

COSTS AND COMPENSATION FOR BEING IN THE STUDY

There is no cost to you, or compensation provided for this suervey. We appreciate your time and your responses so that we can learn more about your perspectives on stuttering severity.

Contact Information

If you have concerns or questions about this study, such as scientific issues, or to report an injury, please contact the researcher or the faculty supervisor:

- Angelica Bernabe; bernabea@msu.edu

- Prof. J. Scott Yaruss, PhD, CCC-SLP BCS-F, F-ASHA (Lab Director) jsy@msu.edu

Michigan State University Spartan Stuttering Laboratory
1026 Red Cedar Road, Oyer Building, MSU, East Lansing, MI 48824
If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI, 48910

DOCUMENTATION OF INFORMED CONSENT
Please select your choice below. You may print a copy of this consent form for your records. Clicking "Agree" indicates that:

- You have read the above information
- You are voluntarily agree to participate
- You are 18 years of age or older
- If you choose to provide your email address, you also agree to receive email notices about future surveys from the Spartan Stuttering Laboratory

APPENDIX C: SURVEY QUESTIONS

English

1. How would you **define** "severity" as it relates to stuttering? If you are a person who stutters, we are not asking about the severity of your stuttering; instead, we want to learn about how you define severity of stuttering. You may choose to initiate your answer with the phrase "I define stuttering severity as..."
2. Do you think that stuttering severity is made up of different **components**? If so, please list and describe what those components are.
3. Do you think that stuttering severity can be affected by different **factors**? If so, please describe what those factors are.

Spanish

1. ¿Cómo **definiría** la "**severidad**" en relación a la **tartamudez**? Si eres una persona con tartamudez, **no** estamos preguntando por la severidad de tu tartamudez; en cambio, queremos saber cómo tú defines la severidad. Puede optar por iniciar su respuesta con la frase **"Defino la severidad de la tartamudez como..."**
2. ¿Cree que la severidad de la tartamudez está constituida por diferentes **componentes**? En ese caso, por favor, enumere y describa cuáles son.
3. ¿Cree que la severidad de la tartamudez puede ser afectada por diferentes **factores**? En caso sea afirmativo, por favor, describa cuáles son esos factores.

Portuguese

1. Como você **definiria** "severidade" no contexto da gagueira? Se você é uma pessoa que gagueja, **não** estamos perguntando sobre a severidade da sua gagueira; em vez disso, queremos saber como você define a severidade da gagueira. Você pode optar por começar sua resposta com a frase **"Eu defino a severidade da gagueira como..."**
2. Você acredita que a severidade da gagueira é constituída por diferentes **componentes**? Em caso afirmativo, por favor, liste e descreva quais são esses componentes.
3. Você acredita que a severidade da gagueira pode ser afetada por diferentes **fatores**? Em caso afirmativo, por favor, descreva quais são esses fatores.