Title: Stuttering as Defined By Adults Who Stutter

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Abstract

Purpose: Numerous frameworks and definitions have sought to differentiate what behaviors and experiences should be considered as a part of *stuttering*. Nearly all of these efforts have been based on the perspectives and beliefs of conversational partners and listeners. This outside-in approach to defining stuttering lacks validation from people who live with the condition.
Method: In this study, 430 adults who stutter participated in a qualitative exploration of the term *stuttering*. Data were analyzed thematically to determine speakers' perspectives about moment of stuttering and the overall experience of stuttering in their lives.
Results: To adults who stutter, the term *stuttering* signifies a constellation of experiences beyond the observable speech disfluency behaviors that are typically defined as stuttering by listeners. Participants reported that the moment of stuttering often begins with a sensation of anticipation, feeling stuck, or losing control. This sensation may lead speakers to react in various ways, including affective, behavioral, and cognitive reactions that can become deeply ingrained as people deal with difficulties in saying what they want to say. These reactions can be associated with adverse impact on people's lives. This inter-related chain of events can be exacerbated by outside environmental factors, such as the reactions of listeners.
Discussion: Data from this survey provide novel evidence regarding what stuttering means to adults who stutter. These data are used to update the adaptation of the World Health Organization's *International Classification of Functioning, Disability, and Health* as it applies to Stuttering (Yaruss & Quesal, 2004) to better account for the complex and individualized phenotype of stuttering and to develop a definition of the experience of stuttering that is based not only on the observations of listeners but also on the impact of stuttering on the lives of adults who stutter.

1.2 LITERATURE REVIEW

The term *stuttering* can have different meanings depending on the context in which it is used. It often indicates a family of speech behaviors that are judged to be atypical in some way, such as part-word repetitions, prolongations, or blocks (Conture, 1990; Wingate, 1964; Yairi, Watkins, Ambrose, & Paden, 2001). The term can also be used more broadly to indicate a condition a person has or a label they are given (W. Johnson, Darley, & Spriestersbach, 1963; Williams, 1957; Yaruss & Quesal, 2004), or to refer to a collective experience that people share (Perkins, 1990; Tichenor & Yaruss, 2018; Williams, 1957). These varied meanings of the term account for multiple experiences and perspectives: those of people who stutter, those of researchers and clinicians, those of conversational partners, and those of the public as a whole.

Likewise, numerous systems for classifying speech disfluencies have been proposed (Conture, 1990; Cordes & Ingham, 1995; Gregory, 1986; W. Johnson, 1959; Teesson, Packman, & Onslow, 2003; Wingate, 1964; Yairi & Ambrose, 1992; see review in Yaruss, 1997b). Notably, all of these common classification schemes are based on the perceptions of listeners. That is, existing classifications seek to identify the specific behaviors that are judged to be stuttering based on the observations of speech-language pathologists, family members, or conversation partners. To account for ambiguity in these observations, current terminology hedges the judgment about what constitutes stuttering behaviors, stating that disfluent speech behaviors are either *stutter-like* or *non-stutter-like* (Yairi, 2013; Yairi & Ambrose, 1999, 2005). These terms acknowledge that listener and observer "judgements can be rather fluid" (Yairi, 2001, p. 587) and that the distinction between stuttered and nonstuttered behaviors—as judged by listeners—is not consistent or clear-cut.

Differences between these meanings and perspectives regarding stuttering can create confusion about how the term is being used at a particular time or in a particular context. This confusion can lead to challenges in clinical and research practice. For example, clinicians may use the term *stuttering* to refer to certain behaviors that are addressed in therapy (for discussion of more-overt vs more-covert behaviors, see Constantino, Manning, & Nordstrom, 2017; Douglass, Schwab, & Alvarado, 2018; Murphy, Quesal, & Gulker, 2007; Tichenor & Yaruss, 2019). At the same time, clinicians may use the term more holistically to describe the overall impact of living with the condition (Yaruss & Quesal, 2004). Many researchers also use the term to indicate frequency thresholds as inclusion criteria for research subjects or as benchmarks relating to recovery or persistence (see Chow & Chang, 2017; Yairi & Ambrose, 1999). Research has shown, however, that the occurrence of stuttering behaviors is highly variable (cf. Constantino, Leslie, Quesal, & Yaruss, 2016; Costello & Ingham, 1984; K. Johnson, Karrass, Conture, & Walden, 2009; Yaruss, 1997a). As a result, individuals might meet threshold criteria in one situation or on one day but not in another situation or day. Moreover, a significant portion of children may have been classified as recovered according to listener-based definitions of stuttering even though they may (a) consider themselves to be stuttering when asked and (b) demonstrate negative impact associated with stuttering despite the presence of seemingly fluent speech (Franken, Koenraads, Holtmaat, & Van der Schroeff, 2018). Clearly, understanding how both listeners *and* speakers define the term stuttering is critical to addressing fundamental issues about the stuttering disorder, such as when it occurs, whether it persists, and how to treat it.

Some of this ambiguity might be resolved if the field had a better understanding of what the term “stuttering” means to *people who actually live with stuttering*. In the early 1980s, Perkins began to explore a speaker-based definition of stuttering, stating, “an indisputable reality

for people who consider themselves to be stutterers is that they feel as if they lose control of their speech when they stutter" (Perkins, 1983, p. 247). He defined stuttering as a "temporary overt or covert loss of control of the ability to move forward fluently in the execution of linguistically formulated speech" (Perkins, 1984, p. 431). Various prominent researchers in the field responded to this definition of stuttering as a "loss of control" (Perkins, 1990, p. 376) with varying levels of skepticism and concern. Bloodstein (1990) said, "If I hear someone stutter, the fact that the speaker might not call it stuttering doesn't change my perception" (p. 392). Other researchers questioned whether this relocation of the definition of stuttering from the listener to the speaker solved the problem of reliably observing stuttering behaviors (see Ingham, 1990; Martin & Haroldson, 1986; Smith, 1990). Indeed, concerns regarding the reliability of stuttering measurement remain to this day (see for discussion, Bainbridge, Stavros, Ebrahimian, Wang, & Ingham, 2015). Though subsequent research endeavors have attempted to improve the observational skills and training of clinicians in detecting stuttering behaviors (e.g. Bothe, 2008; Cordes & Ingham, 1994; Cordes, Ingham, Frank, & Ingham, 1992; Ingham & Cordes, 1997; Yaruss, 1998b), the idea that stuttering is something *experienced* by speakers and only sometimes observed has persisted (Brocklehurst, 2013; Guntupalli, Kalinowski, & Saltuklaroglu, 2006; Jackson, Quesal, & Yaruss, 2012; Quesal, 2010; Tichenor & Yaruss, 2018). Before the field will be able to achieve resolution regarding the reliability of listeners' judgements of stuttering, therefore, it will first be necessary to better understand what *speakers* actually experience during the moment of stuttering. Although a growing number of researchers are using person-centered qualitative methods to explore various aspects of speakers' life experiences of stuttering (Bricker-Katz, Lincoln, & Cumming, 2013; Jackson et al., 2012; Plexico, Manning, & DiLollo, 2010; Tetnowski & Damico, 2001; Trichon & Tetnowski, 2011), such perceptions have

not routinely been incorporated into researchers' or clinicians' definitions of the moment of stuttering itself.

Tichenor and Yaruss (2018) conducted a qualitative exploration and analysis of what the *moment of stuttering* means to adults who stutter. The purpose of the study was to further specify and systematically categorize the collective experiences of adults who stutter. Results indicated that the speaker's experience of the moment of stuttering involves more than just the production of repetitions, prolongations, and blocks that are often viewed as the hallmark of stuttering behavior (see Wingate, 1964). Instead, adults who stutter reported that the moment of stuttering often begins with a sense of anticipation—the awareness or fear that a disruption in speech may soon occur (Arenas & Zebrowski, 2017; Brocklehurst, Lickley, & Corley, 2012; Garcia-Barrera & Davidow, 2015; Jackson, Yaruss, Quesal, Terranova, & Whalen, 2015; Martin & Haroldson, 1967). Respondents indicated that, for themselves as speakers, the moment of stuttering *also* includes physical, cognitive, and emotional aspects, such as tension, anxiety, and fear. In other words, people who stutter did not endorse the commonly used differentiation between so-called "core" behaviors of repetitions, prolongations, and blocks, as compared to the "secondary" physical or negative reactions. Although these components *can* be differentiated, this distinction appears to be artificial: it is not how adults who stutter experience stuttering. To them, these behaviors, emotions, and perceptions are all part of their overall experience of the moment of *stuttering*.

Respondents in the Tichenor and Yaruss (2018) study also indicated that the moment of stuttering involves a sensation or feeling of losing control (Perkins, 1983, 1990). Respondents discussed the loss of control either as a perception that they do not have a well-formed plan for continuing to speak (in other words, they experience stuttering as a moment in which they know

what they want to say but are unable to execute that intention) or that their agency in the conversation is lost. Thus, for people who stutter, the moment of stuttering encompasses various experiences beyond those that can be directly observed by listeners. Note that this also appears to be true for other aspects of the condition, such as physical tension or struggle behavior. For example, research evidence shows that people who stutter report experiencing more locations and greater degrees of physical tension in parts of the body that expert observers cannot perceive (Tichenor, Leslie, Shaiman, & Yaruss, 2017). Thus, even aspects of the stuttering behavior that are widely accepted to be "part of the moment of stuttering" are not fully accessible to observers.

These responses from people who stutter indicating that stuttering involves more than just the production of speech disfluencies are consistent with Yaruss and Quesal's (2004) adaptation of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF; WHO, 2001) to stuttering. Specifically, their use of the ICF model shows how the adverse impact of stuttering can be described in terms of the stuttering behavior *in addition to* affective, behavioral, and cognitive reactions by the speakers; the reactions of others; the difficulties people have in communicating; and the ways in which stuttering leads to adverse impact (see also, Yaruss & Quesal, 2006). Recent work raises questions, however, about whether the way in which the model accounts for the experience of stuttering is consistent with the reports from individuals who stutter.

Although findings from Tichenor and Yaruss (2018) provide important insights into the nature of the moment of stuttering as perceived by people who stutter, a number of questions remain. Most important among these is whether the results from the qualitative study can be generalized. The sample size for Tichenor and Yaruss (2018) was relatively large for an in-person qualitative study (N = 13), but the population of people who stutter is large and

heterogeneous. Specifically, the vast majority of participants in Tichenor and Yaruss (2018) had histories of therapy and participation in self-help/support; thus, it is not clear how representative the findings are to the population of people who stutter, given that the majority do not participate in self-help/support and many in the broader population have not had (recent) therapy. It is also not clear whether people who stutter define the term *stuttering* (perhaps referring to the condition as a whole) differently from *moment of stuttering* (perhaps referring to the instance or behavior associated with stuttering), as many researchers have historically done (see discussion in Martin & Haroldson, 1981). It is therefore necessary to explore whether commonly used definitions of stuttering, including descriptions of the observable behaviors (see Gregory, Campbell, Gregory, & Hill, 2003; Gregory & Hill, 1999; Wingate, 1964, 2001; Yairi, 1996; Yairi & Ambrose, 1992; Yairi, Ambrose, & Niermann, 1993; Yairi, Ambrose, Paden, & Throneburg, 1996; Yairi et al., 2001), as well as descriptions of the experience of stuttering (Yaruss & Quesal, 2004, 2006), are actually meaningful for adults who stutter. Therefore, this study sought to determine whether adults who stutter view stuttering similarly to the ways that researchers and clinicians view the condition. The primary purposes of this study were to determine 1) what the term *stuttering* means to a large sample of adults who stutter and 2) whether speakers define the term *moment of stuttering* differently from the term *stuttering*.

2.0 METHOD

2.1 Participants and Procedures

This study was conducted in conjunction with a broader survey designed to examine the experiences of adults who stutter. Several open-ended questions were included in the survey in order to allow a thematic analysis of speakers' definitions of the terms *stuttering* and *moment of stuttering*. A total of 638 people opened the link for the survey and agreed to the consent form.

Of those, various respondents were excluded for not completing any portion of the survey past the consent form, being younger than 18 years of age, or not completing the open-ended questions presented in the survey. In total, 430 adults who stutter (18 years or older) completed the open-ended questions described in detail below. Demographic data, including age at the time of the survey, age of stuttering onset, history of participation in self-help/support and speech therapy, ethnicity, and country of residence were collected from the majority of participants; some demographic data were missing for questions occurring at the end of the survey due to attrition (i.e., participants not completing the entire longer survey). Subjects self-reported a wide range of occupations: 13% indicated they were undergraduate, graduate, or post-doctoral students; 7% indicated they were speech-language pathologists (SLPs); 5% indicated that they were engineers; and smaller numbers of respondents indicated that they were professors or researchers (2%) or in some form of business (2%). The remaining occupations were varied (e.g. management, nursing, sales, self-employed, informational technology, construction, retired, unemployed, handyman). Most respondents in the sample were from the United States of America, with the second highest portion coming from Europe. The demographic characteristics of the participants are presented in Table 1.

Participants were recruited using a mix of snowball and convenience sampling, using research registries from previous studies, personal contacts of the authors, word-of-mouth, social media outlets, and national and international stuttering associations to encourage a broad sampling of adults who stutter from different backgrounds and with different experiences (see Boyle, 2013, 2017, 2018; Boyle, Beita-Ell, Milewski, & Fearon, 2018; Boyle & Fearon, 2018).. The survey was conducted via the Internet using Qualtrics (Qualtrics, 2018). All respondents self-reported to be people who stutter and completed an informed consent prior to receiving and

completing the survey. The study was deemed to be exempt from institutional review by the Michigan State University Human Subjects Research Protection Office under statute 45 CFR 46.101(b) 2.

For this study, participants were asked to complete two open-ended questions: 1) How would you define the term "stuttering?" 2) How would you define the term "moment of stuttering?" No specific definitions or follow-up questions were included in the study, to allow the themes to emerge from the data naturally, without bias about what the researchers might think that the terms mean.

2.2 Qualitative Inquiry in Stuttering Research

Several recent studies in stuttering have used theoretically grounded lines of qualitative inquiry, such as phenomenology, to explore the experiences of people who stutter (Bricker-Katz et al., 2013; Jackson et al., 2015; Plexico et al., 2010; Tichenor & Yaruss, 2018). Thematic analysis was used in this study to attach meaning to textual data and to group these data based on shared or similar meanings, thus giving a picture of the underlying structure of the participants' responses (Braun & Clarke, 2006). Most qualitative studies in stuttering research have taken an interview-based approach, in which individuals are asked a series of questions or participate in an open-ended discussion about their experiences. One exception was the study by Jackson et al. (2015), in which participants completed open-ended and Likert-scale questions via email. In other fields, use of the internet for qualitative research is growing, as it provides access to difficult-to-study or rarer populations, while increasing the breadth and heterogeneity of respondents (Aselton, 2012; Neville, Adams, & Cook, 2016; Rodham & Gavin, 2006). In this study, internet administration of open-ended questions was used to expand the number of

participants and to encourage response from a broad range of adults who stutter with different experiences and backgrounds.

2.3 Data Analysis

Data analysis followed the suggestions by Braun and Clarke (2006), while adhering to broader qualitative principles (Creswell, 2013). Specifically, a bottom-up approach was adopted to allow the participants' responses to drive and create meanings; no top-down theoretical structure was imposed on the data to allow for a rich description and exploration of all possible meanings. The first author (a person who stutters) began by describing his answers to the questions in an attempt to acknowledge, set aside, and account for his own personal experiences. This is an important step in qualitative research, because it helps to reduce unintentional bias and a tendency for research to interpret participant responses in terms of their own experiences (Creswell, 2013).

Textual data were downloaded from Qualtrics (Qualtrics, 2019), saved as plain text files, and imported into RQDA (Huang, 2016), a qualitative analysis package developed for the R statistical computing package (R Core Team, 2019). The first author then read all of the responses to obtain a broad understanding of the data (Braun & Clarke, 2006). Misspellings or coding errors were adjusted, as needed. For example, because RQDA requires plain text ASCII files, punctuation and other symbols were initially removed but manually placed back in to improve readability. Through subsequent readings, initial codes comprised of phrases or sentences that highlighted the participants' experience were collected. A list of significant statements was collected, grouped, clustered, and re-clustered into meaning units and initial themes (Braun & Clarke, 2006). Emerging themes were then reviewed, clustered into themes, and re-named as meanings were more clearly seen.

2.5 Credibility

Themes reported and described here come from all data collected. No saturation analysis was conducted given that the data came from a very large sample (see Fusch & Ness, 2015). The large sample size, varied backgrounds of participants, and consistency of themes supports the idea that the responses and themes are credible. Consistent with established reliability procedures in qualitative research (Syed & Nelson, 2015), the second author re-coded 20% of the samples and analyzed them in the same way as the first author. The second author's codings contained the same themes and sub-themes, though with a slightly different structure. The significant statements and broad categories discussed below were then arranged and re-arranged based on multiple discussions among authors to form a final structure of the themes and subthemes. For example, the first author initially coded Cognitive, Emotional, Behavioral, and Affective Reactions as one large theme with numerous sub-themes, while the second author coded them individually as separate themes. A consensus was formed by combining Affective/Emotional while leaving Cognitive and Behavioral as separate themes, respectively.

3.0 Results

Analyses revealed 1,143 significant statements for *Stuttering* and 689 significant statements for *Moment of Stuttering* across the responses from the 430 participants. These significant statements were combined into meaning units by similarity, culminating in 28 initial and broad categories for *Stuttering* and 10 categories for *Moment of Stuttering*. These initial categories were further iteratively combined based on common ideas to form themes and sub-themes (Creswell, 2013). A list of themes and sub-themes is shown in Table 2, and the themes are described in detail in the sections below. The quotes represent examples of statements within specific themes and sub-themes; participant numbers are based on the entire original sample of

638 individuals who completed the consent, though the data for this study reflect only the responses of the 430 individuals who completed the survey. Most of the quotes include more text than needed to represent the theme itself; however, the quotes are included in longer form in order to supply the context for the respondents' answers. Pertinent portions of the quotes are italicized to highlight their relevance to support the theme in which they are presented, though multiple themes are often present in the same utterance. This is expected, because respondents did not conceptualize or experience stuttering as a unitary construct. Because of this overlap in the experience of stuttering, some examples highlight more than just the theme or sub-theme it falls within. Not every instance of a statement supporting a theme or sub-theme is included; rather, specific quotes are used to "bring in the voice of the participants" and to provide concrete evidence in support of themes (Creswell, 2013, p. 219).

3.1 Preliminary Analyses: Differentiating Moment of Stuttering vs. Stuttering

Analysis of themes revealed that respondents did not differentiate the term *moment of stuttering* from the term *stuttering*, as researchers in the field have typically done. The concept of the moment of stuttering contained one unitary theme of temporality (e.g., *a time of* disfluency, *a time of* struggle, *a time of* anticipation, etc.). According to adults who stutter, then, the *moment of stuttering* is simply the point in time when speakers experience all of the various components and aspects reflected in the broader term *stuttering*. Put differently, adults who stutter view stuttering itself as a multifaceted experience encompassing many different behaviors, reactions (e.g. feelings, thoughts, and behaviors), limitations, and negative consequences; the moment of stuttering is simply *when* those experiences occur. Examples of responses are presented below.

P(40): "*When* a block occurs. *Anytime* that the person is unable to clearly speak."

P(362): "A black hole *where time stands still* until the word(s) get verbalized."

P(35): "*When* I'm trying to push through and can't. *It's a few seconds but it's also an eternity*. *When* muscles are frozen or trembling."

P(25): "*A terrifying time* of feeling out of control and humiliated."

3.2 Speakers' Definition of the term "Stuttering"

Iterative analysis yielded 6 over-arching themes refined from the 28 initial categories: (a) *Loss of Control/Sensation of Being Stuck,* (b) *Affective/Emotional Reactions*, (c) *Behavioral Reactions,* (d) *Cognitive Reactions,* (e) *Limitations and Impact,* and (f) *Perceived Influence of Listeners and Conversation Partners.* Various sub-themes arose within the larger themes. For example, the theme of *Loss of Control/Being Stuck* contained the sub-themes of motor-linguistic control and pragmatic control.

3.2.1 Loss of Control/Sensation of Being Stuck

Participants described the experience of stuttering as a perception of a "loss of control," or the inability to speak the way they want to speak—a disconnect between intention and execution. Many speakers used the terms *stuck* or *unable to proceed* to juxtapose what they wish to do, but are unable to do. The terms were more specifically used in two ways: referring to motor-linguistic execution and referring to a social-pragmatic difficulty. This distinction is consistent with prior qualitative work in this area (see Tichenor & Yaruss, 2018).

P(2): "*Stuckness. Being unable to move ahead in speech* and all the difficulties that leads to, both physically and socially."

P(371): "*Getting stuck on a word or not being able to speak a word*."

P(213): "A block in speech. *Feeling unable to move forward*…"

P(11): "A *loss of control* when talking..."

P(187): "…The ability to know exactly what you want to say, when you want to say it , and how you want to say it, but having little to no *control* on how it will come out"

3.2.1.1 Motor-Linguistic Control

Speakers discussed this sensation of a loss of control as a disconnect between what they want to say and what they are able to say.

P(291): "*When your brain thinks faster than your mouth can speak*."

P(334): "*Getting stuck like a needle on a record.*"

P(5): "An involuntary short in the wire... *an interruption* in my speech."

3.2.1.2 Pragmatic Control

Speakers discussed the sensation of a loss of control in a pragmatic sense that juxtaposed their perceptions of others in relation to themselves. This sense of the word *control* was discussed in terms of some unachieved standard or trait that others possess but they do not. This sense of control was interpreted by respondents to relate to their identity and the social aspects of their interactions with others.

> P(105): "*Not be able to speak like everyone else,* the ability to just transfer thoughts to words at any point."

> P(121): "The *inability to normally voice* my ideas by speech."

> P(332): "*The inability to communicate like a human*— knowing what you want to say but having a rebellious body that throws up roadblocks."

> P(231): "*The momentary loss of control over one's ability to speak with what is considered to be 'standard fluency'*."

3.2.2 Affective/Emotional Reactions

Respondents described the word *stuttering* by discussing various affective/emotional reactions, including shame, guilt, worry, anxiety, embarrassment, emotional pain, hopelessness, emotional exhaustion, and fear. These were discussed as reactions to the underlying sensation of being stuck or unable to communicate in the manner a person wanted. These affective reactions

were often discussed as being so deeply ingrained that they had become a central component in the experience of stuttering that followed thoughts and lead to behaviors.

> P(363): "Word repetition, hesitation and repletion at the beginning of words, blocks, *anxiety of speaking*, *fear of above*, avoidance of certain words, substitution of feared words, avoidance of speaking situations."
>
> P(7): "Non-desired interruption in the forward flow of speech, marked by prolongations, repetitions, and/or tense blocks; as well as the behavioral and psychological *responses of fear, anxiety… anger, shame*."
>
> P(139): "Blocking and halting in the flow of speech accompanied by anticipatory and post thoughts and *feelings about the experience."*
>
> P(216): "Inability to speak when I want to. *Getting tired fighting* trying to get a whole sentence out."
>
> P(201): "Profound resistance in moving forward in speaking words, phrases and sentences… *and fear.*
>
> P(154): [an inability] to say certain words or sounds, or a repetition of certain words or sounds that is difficult to control, *producing anxiety*.

3.2.3 Behavioral Reactions

Participants often described the word *stuttering* in terms of behaviors. This included behaviors that a listener or observer might see, behaviors that may only be perceptible to speakers, and behaviors they perceive to be reactions to a previous event or state. Experiences relating to physical tension, effort, movement, or struggle were also common reactions. Again, these reactions were discussed as being so deeply ingrained that speakers often discussed them as central and often debilitating aspects of stuttering that co-occurred with affective/emotional and cognitive reactions.

3.2.3.1 Overt Behaviors

Many speakers discussed overt behaviors such as prolongations, repetitions, and blocks. Some speakers mentioned all three, but most mentioned only one or two of these behaviors, in addition to other affective/cognitive responses or covert behaviors.

> P(167): "*Stuttering is manifested in our reaction to it. This reaction to the stuttering may involve overt moments of stuttering, like repetitions, prolongations and blocks,* as well as an assortment of secondary behaviors*.*"
>
> P(168): "*Blocking or making repetitive sounds at the beginning or in the middle of pronouncing certain words.*"
>
> P(37): "*Repeating the same sound in a word over and over again* and being unable to say what you want to say."

3.2.3.2 Covert Behaviors

Many speakers specifically referenced covert or more-hidden behaviors. These included choosing not to speak, removing themselves from a situation, substituting feared sounds or words, or other methods used to hide or avoid detection by conversation partners.

> P(68): "A break in fluency characterized by repetitions, prolongations, and/or blocks. *The break may not be seen, however, if the person who stutters exhibits covert behaviors such as substituting words, avoiding situations, or not talking*."
>
> P(242): "I consider stuttering when I can't get the word out, or feel stuck when speaking, or *not even speaking at all because I am scared to stutter*."
>
> P(353): "Stuttering to me is the way you talk and the way you might put in fillers *to hide it,* so no one knows you stutter."
>
> P(434): "Someone that has difficulty speaking or saying certain words [and] *often has to change their word choice to an alternative word that is easier to say*."

3.2.3.3 Physical Tension, Struggle, Movement

Other behavioral reactions were often discussed by speakers. Common experiences included physical tension, struggle, or bodily movements. Many speakers discussed these aspects as deeply ingrained experiences that occur with the sensation of being stuck or out of control. They also discussed them occurring in conjunction with other affective states.

P(45): "The inability to fluently express oneself due to *uncontrollable muscle tensions in the mouth, throat, chest, and belly area*."

P(66): "Having a difficulty to pronounce a word spontaneously and fluently or *without unnecessary tension*."

P(95): "Impulses in the brain forces the *muscles in the lips, tongue, palate, and other facial muscles to tighten and to feel locked in place*."

P(339): "…my speech is interrupted by repetitions, blocks or spasms, or prolongations of sounds or syllables, *sometimes accompanied by contortions of the face and body*."

P(213): "…Feeling unable to move forward and locked in a *painful moment of tension and struggle*."

P(227): "Unable to speak fluently at will; *physical difficulties* trying to say what I want; *struggling to release words*, with uneven speech, repeating words..."

3.2.4 Cognitive Reactions

Thoughts were often discussed by respondents when describing the term stuttering. These thoughts occurred in the form of reactions to the sensation of being stuck or out of control (e.g. anticipation). They could also be more meta-cognitive in nature, such as relating to identity or sense of self.

3.2.4.1 Identity, Sense of Self, and Self-Esteem

The term stuttering was often defined in terms of how speakers viewed themselves and how stuttering affected their self-esteem and identity. Alternatively, some respondents discussed their identity independent of stuttering, suggesting that stuttering was something that happens to them but does not define them.

P(111): "Stuttering is a block in speech that may last for a few seconds. *It happens when I talk, but it is not who I am.*"

P(309): "It impacts social relationships, *attitudes and feelings about self and speaking,* and can really impact all aspects of a person's identity and experience."

P(332): "*The inability to communicate like a human*— knowing what you want to say but having a rebellious body that throws up roadblocks."

> P(188): "Externally: pauses, blocks, repetitions in speech. Internally: in response and in anticipation of those speaking struggles, feelings such as shame and embarrassment *negatively impacting self-esteem."*

3.2.4.2 Anticipation

Anticipation is often considered to be the thought that stuttering might soon occur. Respondents discussed anticipation as a central cognitive reaction that they experience that often leads to affective/emotional and behavioral reactions.

> P(348): "For me, it's that moment of actually physically stuttering but *it can also be the anxiety and the feeling of "build up" to actually stuttering. Sometimes, I can almost feel it coming and sometimes it's very sudden*."

> P(16): "When you can feel a stutter coming *and are anxious/worried about it* in addition to the actual stuttering episode itself."

> P(5): "*The feeling when a stutter is coming on*."

> P(46): "*The feeling that arises* when you know you are not going to be able to complete the word."

> P(159): "…w*hen you anticipate*."

3.2.5 Limitations and Real-World Impact of Stuttering

Participants discussed various limitations they experience as a consequence of either not being able to say what they want to say or as a result of their affective, behavioral, and cognitive reactions. The limitations could vary in type—from not being able to say what they want to say in a conversation, to forming social relationships, to being denied or limited larger life opportunities (e.g. employment or educational choices).

> P(171): "The inability to *speak fluently at will*."

> P(11): "…*It impacts social relationships, attitudes and feelings about self and speaking, and can really impact all aspects of a person's identity and experience*."

> P(449): "*It is the biggest challenge in my life, especially occupationally. I cannot talk on the telephone…Which is probably why I have always steered towards auto mechanics*

> *and construction as a career. It has limited many aspects of my life...It has caused some self-esteem issues that still affect me to this day… I wouldn't wish this curse on anybody."*

> P(51): "Disfluency to an extent that is *detrimental/noticeable in general conversation*."

> P(57): "Not being able to communicate in the manner with which I want to communicate. *It can change/stop how I was going to communicate*."

3.2.6 Perceived Influence of Listeners and Conversation Partners

When describing the impact of stuttering, many participants also described the often-negative influence of listeners or observers. This suggests that how a person who stutters conceptualizes *stuttering* is dynamic and subject to the influences of conversation partners or observers.

> P(244): "*Stuttering [involves] fending off the desire to negatively perceive how our listeners might react to the disfluent speech*."

> P(305): "Having issues within, and not able to express them *for the fear of being judged*."

> P(353): "Stuttering to me is the way you talk and the way you might put in fillers to hide it, *so no one knows you stutter*."

> P(189): "To me stuttering is the abnormal behaviors that we do out of *fear or shame of making speaking imperfectly*, *being judged by how we talk or the content or our speech*, etc."

3.3 Summary

Adults who stutter experience *stuttering* as a tightly inter-related constellation of behavioral, cognitive, affective/emotional, and social experiences. Underlyingly, speakers experience stuttering as a sensation of loss of control/feeling stuck. Behaviorally, speakers experience stuttering as involving overt behaviors (repetitions, prolongations, and blocks), covert behaviors (hiding, choosing not to speak, and avoiding sounds, words, or situations), and behaviors that are more typically thought of as reactions to the sensation of being stuck (physical tension, struggle, and extra movements). Previous speaking difficulties may lead a person to

develop deeply ingrained cognitive and behavioral habits, such as anticipation, pushing, and struggling. These thought processes and speaking patterns are central components to the experience of stuttering. These reactions feed off each other and interact, with thoughts leading to feelings, leading to behaviors, and so on. People also experience stuttering in terms of the impact that it has on their lives—the negative emotions, the limitations, and the real-word effects that negatively impact quality of life and their ability to participate in life activities. Each of these components is as important or central to the experience of stuttering as other aspects of the constellation.

This multi-dimensional chain can be seen in the following quotes from participants in this study:

> P(9): "Stuttering is difficulty moving forward with a smooth flow of speech. Importantly, stuttering includes secondary behaviors such as escape and avoidance. Stuttering can have a great impact on a person's educational, social, and vocational experiences and overall quality of life."
>
> P(33): "It's the incapacity to produce a sound or to pronounce a word which either create a stop in the middle of a sentence or prevent the beginning of a sentence when speaking. For some people, it's also the unwanted repetition of words, sounds or syllables."
>
> P(167): "Stuttering is something intangible that occurs while speaking…Stuttering is manifested in our reaction to it. This reaction to the stuttering may involve overt moments of stuttering, like repetitions, prolongations and blocks, as well as an assortment of secondary behaviors. Stuttering may also be occurring when we are avoiding overtly showing signs of stuttering or secondary behaviors."
>
> P(390): "As he or she speaks, a person who stutters is aware of a difficult upcoming speech situation caused by specific words, audience, time or other situational aspects. What the person does to deal with this situation is called stuttering."
>
> P(233): "…For me, it's a conflict of intentions. Part wanting to express myself, and part wanting to hold back for many possible reasons. Two examples are not wanting to come across too strongly, another is the fear of stuttering itself.

Thus, the term *stuttering* indicates a sensation of being stuck or out of control when speaking, a behavior a person might or might not outwardly show, and various affective or

cognitive reactions a person experiences. *Stuttering* often leads to real-world negative consequences, which are influenced by speakers' perceptions of their listeners' reactions.

4.0 Discussion

For decades, researchers have debated about how to define stuttering (for examples, see Bloodstein, 1990; Ingham, 1990; Martin & Haroldson, 1986; Wingate, 1964, 2001; Yairi, 2013). Fewer discussions have approached this issue *from the perspective of people who stutter* (Jackson et al., 2012; Perkins, 1983, 1984, 1990; Quesal, 2010). Data from this large-scale qualitative study provide evidence that, to adults who stutter, the term *stuttering* encompasses numerous components: the underlying sensation of being stuck or losing control; the affective/emotional, behavioral, and cognitive reactions that they might have in response to that sensation; the ways in which other people, such as conversational partners, might react to the observable behaviors; and the life limitations and adverse impact that may result.

Yaruss (1998a) and Yaruss and Quesal (2004) adapted the World Health Organization's *International Classification of Impairments, Disabilities, and Handicaps* (WHO, 1980, 1993) and *International Classification of Functioning, Disability, and Health* (ICF; WHO, 2001) to the study of stuttering to show how various aspects of the overall stuttering disorder interact in creating the overall experience of stuttering (see also Yaruss, 2007; Yaruss & Quesal, 2006). The original frameworks were developed based on prior research on stuttering, which, as noted above, is largely based on the perspectives of listeners. Data in this study from adults who stutter, ascertained through bottom-up qualitative analysis principles, show that the ICF framework does indeed capture the perceptions and experiences described by adults who stutter, as well.

Importantly, however, there are some subtle differences from previous instantiations of the ICF framework for stuttering that can be identified based on the lived experiences of adults who stutter analyzed in this study. Specifically: The primary impairment in stuttering can be described not as the overt behaviors that listeners may observe but rather as an internal sensation of being stuck or losing control (for discussion of impairment vs. adaptation symptoms, see Tichenor & Yaruss, 2018). This underlying sensation may lead to various affective, behavioral, and cognitive reactions, as people cope with not being able to communicate the way they wish. Importantly, many overt behaviors, including repetitions and prolongations, are experienced by adults who stutter as *reactions* to the underlying sensation of being stuck. These reactions can become deeply ingrained, to the point where they may even seem to an observer to be the moment of stuttering itself. Still, adults who stutter still report that they *use* these behaviors in reaction to the perception of present or impending loss of control, either as an attempt to prevent themselves from losing control to regain control, or to hold the conversational floor while they attempt to continue speaking (Tichenor & Yaruss, 2018).

Based on these insights obtained through the responses of adults who stutter, the present authors have updated the Yaruss and Quesal (2004) ICF model as adapted to stuttering. The revised framework, which is presented in Figure 1, describes the overall experience of stuttering as follows: For underlying genetic and neurological reasons (*etiology*), people who stutter experience a disruption in planning and/or executing what they want to say (*primary impairment in body function or structure*). They experience this as a sensation of losing control or of being unable to move forward in their speech (*primary symptom*). This sensation may lead them to experience and exhibit certain *personal reactions*. These can be described as (a) affective reactions, including emotions such as embarrassment, anxiety, and shame; behavioral reactions,

including covert and overt behaviors such as disruptions in speech (i.e., speech disfluencies), as well as tension and struggle, or avoidance, and (c) cognitive reactions, including a sense of anticipation and feelings of low self-confidence or self-esteem. These personal reactions often interact and co-occur with one another; and, ultimately lead to *limitations in performing daily activities* that involve talking, as well as *restrictions in the ability to participate* in life areas, such as social interaction, education, or employment. *Environmental influences*, including listener reactions, may also negatively affect all of these factors. Taken together, the model shows that, "Stuttering is more than just stuttering" (Yaruss, 2007, p. 314), meaning that the experience of the stuttering disorder, as lived by people who stutter, involves more than just observable disruptions in speech, as perceived by listeners.

Note that this conceptualization of stuttering, and the data from adults who stutter upon which it is based, are not in conflict with the observations of SLPs. The conceptualization of so-called "stuttering" or "stutter-like" behaviors (repetitions, prolongations, and blocks) as *reactions* may seem like a significant change. Still, many clinicians and researchers over many years have recognized the dual nature of the experience of stuttering as reflecting both something observable to the listener *and* something that is internal to the speaker (E. B. Cooper, 1977; W. Johnson et al., 1963; Perkins, 1984, 1990; Sheehan, 1951, 1953, 1970). The updated ICF model refines this viewpoint by identifying specific aspects of both the stuttering behavior and the experience that reflect the reality of the lived experiences of adults who stutter, as well as current scientific understandings of the underlying nature of stuttering.

In addition to describing various aspects of the experience of stuttering, this model also helps to account for the variations and differences between and among individuals who stutter. Each person who stutters exhibits a unique and individualized constellation of behaviors and

reactions as compared to someone else who stutters. These behaviors and reactions develop based on each person's individual experiences and tendencies. All of these individuals are *stuttering,* even though there may be seemingly great differences in the presentations of stuttering. For example, many people who stutter exhibit so-called stuttering or stutter-like behaviors that can easily be observed by listeners. Importantly, however, other people may engage in behaviors to hide stuttering, such as avoiding sounds or words, switching words, or choosing not to talk as a response to the underlying sensation of being stuck (Tichenor & Yaruss, 2019). According to this framework, such individuals would also be considered to be *stuttering,* even though they do not demonstrate overt stuttering behaviors that listeners might perceive. Thus, just as there are many aspects of this stuttering constellation, there are many phenotypes of stuttering, as past models have theorized (see Yaruss & Quesal, 2004).

The updated ICF model in Figure 1 allows for the numerous forms that stuttering can take, based on the interactions between and among the underlying etiology, the impairments/symptoms, the personal reactions, the adverse impact, and the influence of environmental factors. By accounting for these various aspects of stuttering, clinicians and researchers can understand how the different components of stuttering relate to one another. They can also better understand what leads people who stutter to do what they do and experience what they experience. It is important to recognize that the intent of this framework is to describe the *experience* of stuttering, in order to account for the myriad forms that stuttering may take. The term "experience" was selected intentionally, instead of the word "disorder," to allow for individual differences in how stuttering affects people's lives. Certainly, many people who stutter do experience stuttering as a *disorder*, a phenotype involving negative feelings/thoughts that lead to real-world limitations. Yet, not every person who stutters experiences stuttering as a

disorder (see discussion in Constantino, 2018). Thus, it is important to describe stuttering in broader and more inclusive terms that more accurately reflect the varying phenotypes of stuttering reported by individuals living with the condition.

Ongoing research endeavors continue to elucidate the neural (see, Etchell, Civier, Ballard, & Sowman, 2017) and genetic (see, Kraft & Yairi, 2012) etiology of the stuttering condition. These research efforts are aimed at clarifying how the stuttering genotype is inherited, what the underlying impairment in body function or structure might be, and how the phenotype of stuttering is expressed. Yet, an understanding of person-centered factors is critical for determining how stuttering is expressed and experienced in people's lives. By accounting for the views, experiences, and perspectives of people who stutter in explorations of stuttering, a better understanding of the full range of stuttering phenotypes can be ascertained. It is hoped that such improvements in the conceptualization of stuttering will help to address current common misunderstandings about the condition by clinicians (E. B. Cooper & Cooper, 1985, 1996; Quesal, 2010; Tellis, Bressler, & Emerick, 2008), individuals who stutter, and the public at large (Boyle, 2017; St. Louis, 2011; Yaruss, Quesal, & Murphy, 2002). Such a broader focus may also offer hope to those people who receive unidimensional treatment that focuses primarily or exclusively on behavioral aspects of stuttering rather than the whole constellation of the experience of stuttering (Yaruss, Quesal, Reeves, et al., 2002; Yaruss, Quesal, & Murphy, 2002).

4.1 Clinical and Research Applications

Data from this study and the updated ICF model for stuttering (see Figure 1) highlight important clinical considerations. First, the diagnosis of stuttering is frequently made by clinical observation of stuttering behaviors. In fact, the *Stuttering Severity Instrument*—a commonly used evaluation protocol —assesses stuttering based solely on how often behaviors happen as

observed by the listener, how long in duration those observable behaviors are, how distracting these behaviors are to the listener, and how natural a person's speech sounds to the listener (SSI-4, Riley, 2009). Data from this study show that a person may experience stuttering and self-report to be a person who stutters (even severely), *regardless* of whether or not they exhibit such behaviors or whether a listener can perceive them. Other research evidence suggests that covert stuttering behaviors may be relatively common across the population of people who stutter (Constantino et al., 2017; Douglass et al., 2018; Tichenor & Yaruss, 2019). Thus, in order to accurately diagnose a person who stutters, or to appropriately include a person in a research sample of people who stutter, clinicians and researchers must account for the many and varied ways that the stuttering phenotype can be expressed. To continue to assess stuttering by virtue of how often certain behaviors happen likely underestimates the prevalence of stuttering and may lead to a higher likelihood of rejecting someone from services when they actually need them, discharging someone from therapy when they should not be, or considering someone recovered when they are actually still experiencing stuttering (Franken et al., 2018).

Data from this study also support more comprehensive view of treatment. To adults who stutter, stuttering includes many different components, so treatment of the stuttering disorder should account for *all* of these aspects on an individual basis (Yaruss, Coleman, & Quesal, 2012a). Such a view is consistent with the scope of practice for speech-language pathologists as defined by the American Speech-Language-Hearing Association, which states "the role of the SLP in the counseling process includes interactions related to emotional reactions, thoughts, feelings, and behaviors that result from living with the communication disorder" (ASHA, 2016). A person may or may not demonstrate stuttering behaviors but still qualify for and benefit from therapy *if adverse impact is present*. In a like manner, researchers who base their inclusion

criteria solely on how often a speaker exhibits certain overt behaviors that are perceptible to a listener may increase measurement error. Certain authors in the field have long known this (E. B. Cooper, 1977; W. Johnson, 1961; Sheehan, 1951, 1953, 1970), and many treatment approaches have accounted for this (Beilby, Byrnes, & Yaruss, 2012; Boyle, 2011; Cheasman, 2013; Harley, 2018; Kelman & Wheeler, 2015; Palasik & Hannan, 2013; Plexico & Sandage, 2011; Van Riper, 1973; Yaruss, 2010; Yaruss, Coleman, & Quesal, 2012b; Yaruss & Pelczarski, 2007; Yaruss & Quesal, 2007). The present findings provide data from a large sample of adults who stutter to confirm the appropriateness of viewing and treating stuttering in a comprehensive manner.

4.2 Limitations and Future Directions

This study explored the experiences of adults who stutter using qualitative methods. Although the study includes a very large number of responses from adults who stutter, it is still possible that this sample does not account for all of the heterogeneity within the population. For example, most of the respondents in this study had a history of therapy. Many also had participated in self-help/support. Both of these experiences may contribute to how a person conceptualizes stuttering (Tichenor & Yaruss, 2019); this should be explored in future research. Care should also be taken in applying the present results to those from non-American/European backgrounds, given that the sample skewed towards those populations. Future research may explore how certain therapy experiences influence the conception of stuttering and whether this is related to nationality or regional background. It is also possible that some participants did not fully express themselves in their written responses, though the large sample counteracts this threat to some extent. This could be addressed in future work through additional in-person follow-up session to ensure that participants have the opportunity to fully describe their experiences. Future research should also investigate the experiences of children or adolescents,

to learn more about how a person's definition of stuttering develops or evolves over time. Finally, in accordance with qualitative research principles, and because the purpose of this study was not to ascertain frequency but meaning (Creswell, 2013), the frequency of themes was not presented in this paper to limit the likelihood of misrepresenting the data (Sandelowski, 2001). Based on the findings from this study, future research should operationalize these themes and sub-themes and explore frequently they are experienced by those who stutter.

4.3 Summary

This study provides data on how adults who stutter define the term *stuttering*. To adults who stutter, the term connotes an entire constellation of behaviors and experiences, including a sensation of being stuck, out of control, or unable to say what they intend; the affective/emotional, behavioral, and cognitive reactions to that sensation; the real-world limitations that people who stutter so often experience; and, the impact that the environment may have on a person's experiences. Accounting for this person-centered definition of stuttering holds promise for increasing our understanding of the varying phenotypes of stuttering, thereby supporting improvements in both clinical work and research endeavors.

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Figure Captions

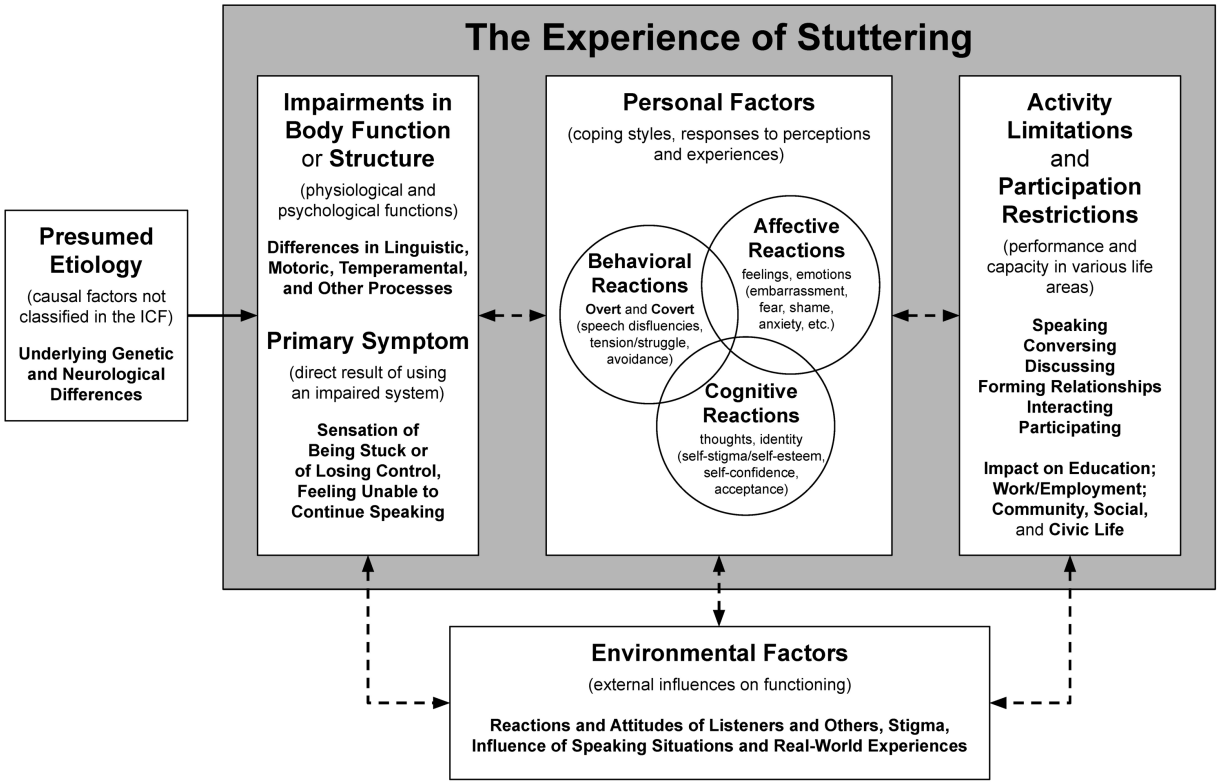
Figure 1. Update of Yaruss & Quesal's (2004) representation of how the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) can be applied to stuttering.

Table 1. Demographic Data

Demographic Variable	% or M (SD), Range
Age	38.6(15.54), Range (18-85)
Sex	
Female	27.4%
Male	55.1%
Prefer not to say/Missing Data	15.9%
Ethnicity	
American Indian or Alaskan Native	0.0%
Asian American	4.4%
Black or African American	4.8%
Native Hawaiian or other Pacific Islande	0.0%
Caucasian	68.7%
Other	4.7%
Prefer not to say/Missing Data	17.4%
History of stuttering therapy	
Yes	92.6%
No	7.4%
Prefer not to say/Missing Data	<1%
History of self-help or support	
Yes	64.0%
No	32.6%
Prefer not to say/Missing Data	3.4%
High education experiences (having college or post-graduate degree)	
Yes	65.3%
No	17.4%
Prefer not to say/Missing Data	19.6%
Country/Continent of Origin	
United States of America	68.1%
North America (Not USA)	<1%
Europe	9.5%
South America	<1%
Asia	1.2%
Africa	<1%
Australia (or Oceania)	1.4%
Prefer not to say/Missing Data	14.5%

Table 2. Themes & Sub-themes

Loss of Control/Sensation of Being Stuck
Motor-Linguistic Control
Pragmatic Control
Affective/Emotional Reactions
Behavioral Reactions
Overt Behaviors
Covert Behaviors
Physical Tension, Struggle, & Movement
Cognitive Reactions
Identity, Sense of Self, and Self-Esteem
Anticipation
Limitations and Real World Impact of Stuttering
Perceived Influence of Listeners and Conversation Partners


The Experience of Stuttering
Presumed Etiology
(causal factors not classified in the ICF)
Underlying Genetic and Neurological Differences
Impairments in Body Function or Structure
(physiological and psychological functions)
Differences in Linguistic, Motoric, Temperamental, and Other Processes
Primary Symptom
(direct result of using an impaired system)
Sensation of Being Stuck or of Losing Control, Feeling Unable to Continue Speaking
Personal Factors
(coping styles, responses to perceptions and experiences)
Behavioral Reactions
Overt and Covert
(speech disfluencies, tension/struggle, avoidance)
Affective Reactions
feelings, emotions (embarrassment, fear, shame, anxiety, etc.)
Cognitive Reactions
thoughts, identity (self-stigma/self-esteem, self-confidence, acceptance)
Activity Limitations and Participation Restrictions
(performance and capacity in various life areas)
Speaking
Conversing
Discussing
Forming Relationships
Interacting
Participating
Impact on Education; Work/Employment; Community, Social, and Civic Life
Environmental Factors
(external influences on functioning)
Reactions and Attitudes of Listeners and Others, Stigma, Influence of Speaking Situations and Real-World Experiences