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A Phenomenological Analysis of the Experience of Stuttering

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Abstract

Purpose: Stuttering behaviors and moments of stuttering are typically defined by what a listener perceives. This study evaluated participants' perceptions of their own experience of moments of stuttering.

Method: Thirteen adults who stutter participated in a phenomenological qualitative study examining their experience of moments of stuttering. Analysis yielded several common themes and sub-themes culminating in an *essential structure* describing the shared experience.

Results: Speakers experience anticipation and react in action and non-action ways. Many speakers experience a *loss of control* that relates to a lack of a well-formed speech plan or agency. The experience of moments of stuttering changes through therapy, over time, with self-help, and across situations. Many speakers experience so-called typical stuttering behaviors as *reactions* rather than direct consequences of trying to speak. Interactions with listeners can affect the experience of stuttering.

Conclusion: While research recognizes that the experience of the stuttering *disorder* involves more than just speech behaviors, people who stutter experience stuttering behaviors in time as involving more than just the disruption in speech. This finding has implications for both the theoretical understanding of stuttering and the clinical evaluation and treatment of the stuttering disorder.

Keywords: Stuttering, Fluency, Fluency Disorders

1.0 Introduction & Background

For as long as stuttering has been observed, people have sought to define it. Johnson, Darley, & Spriestersbach (1963) described three ways that the term *stuttering* has been used: (1) as a name for a behavior, (2) as a name for a problem that a person might have, and (3) as a name for a category of a behavior that a listener might identify. These various uses of the word *stuttering* underscore some of the apparent confusion in the literature about what the term *stuttering* means and how it should be identified. The *stuttering disorder* has been shown to include environmental, personal, and physiological factors that can negatively affect and impact the life of a person who stutters (Yaruss & Quesal, 2004). *Stuttering behaviors* are the overt disfluencies that a speaker experiences and a listener hears and judges to be stuttering. Numerous classifications of *stuttering behaviors* have been proposed (Conture, 1990; Cordes & Ingham, 1995; Gregory, 1986; Teesson, Packman, & Onslow, 2003; Wingate, 1964; Yairi & Ambrose, 1992). Many behavioral classifications appear to be based on the assumption that disruptions in fluency, such as repetitions, prolongations, or blocks, are the direct result of underlying deficits in motor production (Civier, Bullock, Max, & Guenther, 2013; Civier, Tasko, & Guenther, 2010; Max, 2004; Max, Guenther, Gracco, Ghosh, & Wallace, 2004; Olander, Smith, & Zelaznik, 2010; Van Lieshout, Hulstijn, & Peters, 2004; Walsh, Mettel, & Smith, 2015), linguistic formulation (Howell & Au-Yeung, 2002; Postma & Kolk, 1993), temperamental or cognitive influences (Alm, 2014; Conture, Kelly, & Walden, 2013; Jones, Conture, & Walden, 2014; Vasic & Wijnen, 2005), or the interaction of multiple processes (Conture, 2001; Smith & Kelly, 1997; Smith & Weber, 2017; Starkweather & Gottwald, 1990). In these views, the primary impairment, disfluent speech, is seen as the

direct result of using an impaired system. This view is consistent with work elsewhere in the field of communication science and disorders, for example, where manifestations of certain disorders such as dysarthria are seen as the direct result of damage to direct or indirect activation pathways (Duffy, 2005).

Another way of viewing stuttering behaviors is to consider the surface speech disruptions as a speaker's *adaptation* to an underlying impairment. In this view, repetitions, prolongations, blocks, and other behaviors may reflect the speaker attempts to recover from or cope with an underlying disruption in language formulation or motor planning (Brocklehurst, Lickley, & Corley, 2013; Conture, 1990b; Johnson, 1967; Kolk, 1990, 1991; Perkins, Kent, & Curlee, 1991). In addition to adaptations due to linguistic-motor deficits, adaptation behaviors can also be conscious (e.g. avoiding, word-switching). The concept of adaptation can be seen in other physical domains, as well, including walking and other movements. For example, a person may widen their gait pattern while walking on a slippery surface due to a perceived imbalance, even when a slip does not actually occur (Nutt, 2013). A widened gait pattern in this case is an adaptation behavior because no true deficit in ambulation exists. Rather, the gait pattern is adopted by the walker consciously or unconsciously to prevent a fall.

Certainly, some behaviors exhibited by people who stutter are already thought of as adaptation behaviors (Williams, 1957). For example, physical tension and other non-speech behaviors (so-called secondary behaviors) are usually thought of as either being a speaker's attempt to prevent, avoid, or cope with moments of stuttering or as an attempt to maintain fluency once it is established (Johnson, 1961, 1967; Starkweather, 1987; Wingate, 1964). Still, it is unclear if so-called *core* behaviors of stuttering, including

repetitions, prolongations, or blocks, reflect the primary symptom of an impaired speech and language system or if they result from the speaker's adaptations to that impaired system.

The differentiation of whether observable stuttering behaviors reflect an underlying impairment or an adaptation to that impairment is not merely semantic. Understanding the underlying nature of surface stuttering behavior has consequences for interpreting other aspects of the stuttering disorder, such as anticipation (Jackson, Yaruss, Quesal, Terranova, & Whalen, 2015), covert stuttering (Constantino, Manning, & Nordstrom, 2017; Murphy, Quesal, & Gulker, 2007), variability (Arenas & Zebrowski, 2017; Constantino, Leslie, Quesal, & Yaruss, 2016; Yaruss, 1997), why observed fluency may not correlate with fluency as perceived by the speaker (Riley, Riley, & Maguire, 2004), and why severity as perceived by speakers is often more negative than listener perceptions (James, Brumfitt, & Cowell, 2009). In other words, better understanding the nature of stuttering behaviors may improve our understanding of long-standing observations and paradoxical questions regarding them.

In order to differentiate between behaviors that result directly from a primary impairment or result as an adaptation to an impairment, more information is needed about moments of stuttering. Of course, countless studies over many years have examined moments of stuttering from many acoustic, linguistic, motoric, and cognitive perspectives. Interestingly, the vast majority of these inquiries have focused on the observable or surface features of the stuttering behavior—that is, what a *listener* might perceive. Indeed, Bloodstein & Bernstein Ratner (2008, p. 9) suggested that the “best

definition” of stuttering behaviors that can be given is, “whatever is perceived as stuttering by a reliable observer who has relatively good agreement with others.”

Importantly, people who stutter have used different words to describe their experience of stuttering behaviors and moments of stuttering. Although no prior study has sought to explicitly capture the reports of those who stutter, popular press books and other personal stories have provided narrative reports of the experience of stuttering (see Ahlback & Benson, 1994; Hood, 1998; Preston, 2013; Reitzes & Reitzes, 2012; St. Louis, 2001). Individuals who stutter do not describe their speech in terms of binary distinctions between “stuttered” and “nonstuttered” disfluencies, as researchers and clinicians have sought to do. Instead, they reflect on their sense of *internal* experience of moments of stuttering itself, as well as the cognitive and affective effort that is required to control their stuttering. For example:

For fifteen years of my life I passed as fluent. I hid my identity as a person who stutters from everyone, including my closest friends, parents, and sister. Through avoidance, word switching, and silence, I tricked my listeners. That was my one goal (MacIntyre, 2012, p. 25).

Thus, this individual maintained control by avoiding, changing words, etc. Other people who stutter have discussed control in different ways: “The harder we try to be fluent, the greater is our tension and struggle” (Klein, 2012, p. 40). The hidden costs of fluency necessitate a paradoxical choice by the speaker, to accept the price or not. On the one hand, the sensation of control is appealing to a person who stutters. “We’re in control of our mouths. [The] ability to control a coordinating system is inspiring” (Dell, 1994, p. 102). Yet, the hidden cost of control is a steep price to pay. “I had spent much of my life

controlling myself, controlling when I spoke, who I spoke to, and how I responded to the reactions I saw” (Preston, 2013, p. 187). Other people who stutter opt for so-called *open* or *clean* stuttering free of tricks or techniques to mask, avoid, or control overt disfluency. “My first radical task in therapy was to get rid of the controls and get back my core stuttering pattern: no modifications, no tricks, no holding back” (Schuff, 2012, p. 11). The snippets of insight into the experiences of people who stutter that these popular press books give suggests that Johnson may have been at least partially correct when he said, “Stuttering...is what the stutterer does trying not to stutter” (Johnson, 1961, p. 68), in that in attempting to effect control over one’s speech may induce more struggle, disfluency, and severity of the behaviors.

Though these anecdotes give some insights into the experience of moments as experienced by speakers, no systematic evaluation of speakers’ perspectives of moments of stuttering exists. A few experimental studies have used speaker self-reports of moments of stuttering (see Brocklehurst & Corley, 2011; Martin & Haroldson, 1986; Postma & Kolk, 1992), but the experience of moments of stuttering as a phenomenon by people who stutter has yet to be explored in detail. Few, if any, studies have asked speakers about *their* experience associated with the speech disruption. No study has yet explored situations where a speaker may appear or sound fluent to a listener yet feel like they are stuttering under the surface or compensating for stuttering by changing words or using other avoidance strategies. Moreover, no study has asked what speakers experience or perceive during moments that may be perceptibly fluent to a listener but still seem disrupted to the speaker.

In the early 1980s, Perkins began to explore a speaker-based definition of moments of stuttering he called the *loss of control* (see Perkins, 1983, 1984, 1990). In referencing the experiences of people who stutter, he said, “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). Martin and Haroldson (1986) attempted to quantify the loss of control by comparing speaker and listener judgments of moments of stuttering. Speakers were asked to press a switch when they were experiencing a “loss of speech control” during a series of speech tasks (Martin & Haroldson, 1986, p. 187). Minimal correspondence was found between listeners’ ratings of stuttering and speakers’ rating of the loss of control. Martin and Haroldson interpreted this finding as “a lack of *internal* consistency in identifying stuttering” (Martin & Haroldson, 1986, p. 189). In other words, Martin and Haroldson viewed the *listeners’* judgments to be the gold standard in determining whether stuttering actually occurred, rather than the speakers’ judgments. More recent research has cited this study as evidence that the loss of control is not “reliably associated with a stuttering event” (Bainbridge et al., 2015; Ingham, Ingham, & Bothe, 2012, p. 270). The assumption in Martin & Haroldson’s 1986 study was that what observers perceive defined whether or not stuttering has occurred. Rather than considering the notion that listener perceptions may not adequately match the speakers’ reality, researchers have insisted that the problem of identification lies with the speakers and that listener judgments must be the gold-standard to which stuttering behaviors are defined. For example,

Interestingly, self-perception of stuttering, just like its opposite, namely objective measures of stuttering, share the desire to bypass listeners’ identification. But, the

reality is that both types of measures must be validated against listeners' judgments...If two judges perceive a person's speech as stuttered and the person denies it, would any scientist assign him/her to the control group of people who do not stutter? Negative answers are most likely (Yairi, 2013, pp. 295–296).

The anecdotal reports of those who stutter challenges this thinking, for it appears that there are aspects about moments of stuttering for speakers that are not adequately captured by the perceptions of listeners (Jackson, Yaruss, Quesal, Terranova, & Whalen, 2015; Riley et al., 2004; Tichenor, Leslie, Shaiman, & Yaruss, 2017).

Inherent in this discussion of the differences between speakers' and listeners' perceptions of stuttering is the question of whether stuttering results directly from an underlying impairment or whether stuttering behaviors reflect an adaptation to an underlying impairment. If more so-called core, typical, or stuttering-like behaviors are adaptation symptoms rather than impairment symptoms, examining the experiences of speakers may give crucial insights into not only how stuttering behaviors manifest but what speakers do in response to the underlying impairment, whatever that may be. To address these issues, more information is needed about moments of stuttering *from the speaker's perspective*. A speaker may experience and sense some type of underlying disruption (an impairment in speech or language formulation). This underlying impairment might directly lead to a disruption in speech production that might be identified by a listener as *stuttering*. Alternately, a speaker might experience an underlying disruption and, subsequently, react or adapt to it in ways that might not be identified by a listener as *stuttering*. It may be impossible for a listener to distinguish impairment behaviors and adaptation behaviors as an observer; however, people who

stutter themselves may be able to provide insights into whether their experience involves a primary impairment that results in disrupted speech or whether their disrupted speech behavior reflects their attempts to cope with an underlying impairment. As such, the primary purpose of this study is to explore the perception of moments of stuttering as experienced by people who stutter.

2.0 Methods

2.1 Participants

Participants were 13 adults who stutter (8 male, 5 female), ranging in age from 22 to 65 years (mean age = 34.9 years, SD = 13.0 years). Participants were recruited from research registries from previous studies, flyers, personal contacts of the authors, and word-of-mouth. All self-identified as people who stutter.

Participants completed a demographic questionnaire where questions relating to self-identifying as person who stutter, age of onset, therapy history, and self-help participation were asked. No minimum overt severity or quality of life impact was required for participation in this study to allow for the broadest range of experiences possible. All but one participant reported that stuttering started in early childhood (mean age of onset for 12 participants = 4.29; SD = 2.05); the remaining participant reported an age of onset of 18 years, though this participant's experiences with respect to stuttering were judged by the first author, a licensed and certified SLP specializing in stuttering, to be consistent with those of other people who stutter. All participants reported no co-occurring speech, language or hearing deficits, though one participant reported a diagnosis of ADHD as a child. Ten participants reported past or current membership in self-help groups such as the National Stuttering Association, SAY: The Stuttering

Association for the Young, or Friends: The National Association of Young People Who Stutter. All reported a history of stuttering therapy, and two participants were actively receiving therapy at the time of this study. Past and current therapy experiences were varied. Some participants indicated participation in recent intensive therapy programs, while others indicated long breaks from therapy. The participants' perceptions of their therapy experiences differed greatly. Participants generally discussed therapy experiences focusing on *acceptance* as positive while indicating more negative experiences with therapy only focusing on managing overt speech disruptions. When asked to describe their therapy experiences, participants described various techniques, including but not limited to fluency shaping, stuttering modification, acceptance, and cognitive-behavioral therapy approaches. Overall, these therapy and support experiences were consistent with those reported by other people who stutter (Yaruss et al., 2002). Additional demographic data about the participants are presented in Table 1.

All participants completed the *Stuttering Severity Instrument*, 4th edition (Riley, 2009), and the *Overall Assessment of the Speaker's Experience of Stuttering* (Yaruss & Quesal, 2016) to assess observable severity and adverse impact. Table 1 contains specific SSI-4 and OASES results. Interviews were conducted in person in a research laboratory or via video-conferencing to allow for the widest inclusion of participants possible and the most representative sample of people who stutter. When interviews took place via video-conferencing, only audio data were recorded to limit the potential loss of confidentiality. The University IRB approved all aspects of this study.

2.2 Phenomenological Research

Because this study aimed to understand the experiences of a group that shares a common experience, a phenomenological approach was used. Phenomenology “describes the common meaning for several individuals of their lived experiences of a concept or phenomenon” (Creswell, 2013, p. 76). Recent studies in stuttering have used phenomenology to explore the experiences of people who stutter. Jackson et al. (2015) used phenomenology to evaluate the experience of anticipation in people who stutter and what people who stutter do in response to anticipation. The authors found that people who stutter use avoidance, management, and approach strategies in both action and non-action ways in response to the anticipation of stuttering. Plexico, Manning, and DiLollo (2010) used phenomenology to explore the experience of the therapeutic alliances between people who stutter and clinicians. The authors found that bad therapeutic alliances were based on clinicians who could not convey trust, acceptance, and understanding. They found that good therapeutic alliances were based on clinicians who took a more holistic approach to understanding the entire disorder. Because the moment of stuttering is a phenomenon experienced by people who stutter, phenomenology is well-suited for exploring the nature of that experience.

2.3 Data Collection

Participants completed an open interview where they were prompted for their experience of moments of stuttering. Principles of phenomenology were strictly adhered to during data collection. No word or phrase was used by the first author when speaking with a participant before first having been used by that same participant. All were first asked “What is your experience of the moment of stuttering?” Follow-up clarification questions using the participant’s own language were asked as needed to ensure

understanding by the first author and to ensure a rich description of the experience. For example, if a participant stated, “I want control of my speech in this situation” the interviewer asked, “What do you mean by control?” No specific follow-up questions were included in the study; rather, clarifying questions alone were asked when necessary to ensure understanding on the part of the first author.

2.4 Data Analysis

Data analysis followed previous phenomenological studies in stuttering (see Bricker-Katz, Lincoln, & Cumming, 2013; Jackson et al., 2015; Plexico, Manning, & DiLollo, 2010; Tetnowski & Damico, 2001). The steps below are also consistent with the steps outlined by (Creswell, 2013). The first author began by describing his experience of the phenomenon in an attempt to acknowledge, set aside, and account for his own personal experiences so as not to confound interpretation of the subjects’ experiences. Participants responses were transcribed verbatim and reviewed for accuracy. Verbatim transcripts were saved as plain text files and imported into RQDA (Huang, 2016), a qualitative analysis package developed for the R project for the statistical computing package R (R Core Team, 2014). The first author then read each for a broad understanding. Through subsequent readings, significant statements comprised of sentences or quotes that highlight the experience of the subjects were collected. A list of significant statements was collected, grouped, and clustered into meaning units and themes using RQDA. These meaning units and themes with significant statements were discussed with the second author who performed a reliability check on the data and analyzed the categories for concurrence. A consensus was formed on the minimal points of disagreement when they occurred. A re-organization of one theme and sub-theme was

made (see *Relationship with listeners*). Textual and structural description was followed by a composite description of the phenomenon, which is “the essence of the experience and represents the culminating aspect of a phenomenological study” (Creswell, 2013, p. 194). Demographic data were analyzed using lmerTest (Kuznetsova, Brockhoff, & Christensen, 2015), a statistical package for R (R Core Team, 2014).

2.5 Credibility

Data collection continued until saturation of themes was reached. Data saturation occurs when “there is enough information to replicate the study, when the ability to obtain additional new information has been attained, and when further coding is no longer possible” (Fusch & Ness, 2015, p. 1408). In this study, the first author collected and analyzed data until these criteria were met. When no new additional information via themes and subthemes was found, the authors collected data from one additional subject. This occurred with recruitment of a 14th subject. Analysis of data from this subject again yielded no new information, so saturation was reached.

Credibility procedures followed the steps outlined in previous phenomenological studies in stuttering (see Jackson et al., 2015; Plexico et al., 2010). The essence of the experience collected by the authors was sent to all participants for validation. Participants were asked to read the essence of the experience and responded on a 7-point Likert scale how accurately the essence corresponded to their experience and to provide feedback. Of the thirteen participants, nine (69%) responded with a mean agreement of 6.44 out of 7 with a standard deviation of .46 (See Table 1).

3.0 Results

All participants spoke about their experience both *before* the moments of stuttering and *during* moments of stuttering, indicating that the experience includes pre-speech components as well as components that occur during the time when an observer might be able to identify stuttering. The collected meaning units created 31 main categories. A list of themes and sub-themes is shown in Table 2. The following sections review the specific themes and sub-themes that were identified. Quotes provided below represent examples of statements within specific themes and sub-themes. Not every instance of a statement supporting a theme or sub-theme is included due to space limitations; rather, specific quotes are used to “bring in the voice of the participants” and provide concrete evidence in support of themes (Creswell, 2013, p. 219).

3.1 Anticipation of Stuttering

Participants discussed their experience of anticipation, or the sensation or feeling that they are about to stutter. The theme of anticipation was described using both action and non-action language. Action responses included voluntary and non-voluntary reactions to feelings of anticipation that the speaker either *did* to their speech system while non-action responses included behavioral, affective, and cognitive *states* that the speaker experienced. Actions often followed states.

3.1.1 Action Responses

Participants discussed voluntary and non-voluntary reactions they experienced in response to anticipation of moments of stuttering. Participants discussed scripting, avoiding or changing words, tensing, and avoiding situations in this sub-theme.

Participant 2 (P02): If I knew a word was coming that I couldn't pronounce, I would change the word. I would change the sentence...add little bits to the story to make it easier... just trying to create time for myself to get through a stutter.

P06: I prefer email to phone conversations... If it's planned out, I will modify what I'm going to say. For instance, if a menu has numbers on it I will always say the number so and so because that's easier.

P08: I could feel the tension before I got to the restaurant to order food, or an hour before I met the person I'm going to meet... Years back, even before a conversation started, even before I walked in the room, I could feel the muscles tighten and the airflow get less and less.

P13: I knew I was going to stutter and so... I would avoid speaking.

3.1.2 Non-Action States

Participants described non-action states they experienced before moments of stuttering. These states included feelings of anxiety, tension, uncertainty, a lack of confidence, and fear.

P05: A little bit before I have to say the word I will [sense the fear]...

P12: It does feel a lot like that stressful feeling you have before a big sporting event or a big test. It feels like that big stress building up inside of you. You know elevated heart rate kind of thing where it's just like generalized anxiety or anticipation. But, as you speak... [it becomes] localized in various parts of your speaking mechanism.

3.2 The Loss of Control

Participants described their experience of stuttering in terms of *control*. When discussing this theme as a group, participants used the word "control" in two meanings: a physical sensation of motor-linguistic control and a cognitive-conversational sense of control that related to the social aspects of speech. To some participants, the loss of control included both aspects, while others discussed the loss of control in terms of only aspect.

3.2.1 Physical, Motor, Linguistic Control

Participants spoke about control in terms of being *stuck*. They spoke about how they knew what they wanted to say, what speech movements they wanted to execute, but could not. Speakers illustrated that how they reacted to this sensation, dictated how much they struggled and how the stuttering behavior developed.

P01: The loss of control feels like a blip in the system where there's like a brief instant where whatever plans that are occurring are interrupted. And, it's kind of like a moment that feels like there's no roadmap for it. You're kind of in a freeze frame. It's just kind of like a delay. If you're playing an old record, it's like a skip. You don't know how long the skip is going to last when you are playing that record.

P03: I think the loss of control is the sensation of not being able to get out what you want to say, like being in a moment of stuttering and knowing where you want your mouth, lips, and tongue to move and knowing how you want it to sound and literally not being able to produce that word.

P12: It feels like it [the word] is stuck the ground or something, and as you go to say it there is a bit of struggle with it. Depending on how much struggle determines how the stutter is going to manifest.

3.2.2 Pragmatic Control

Participants spoke about control in larger pragmatic, social, or conversational terms. They often juxtaposed their feeling of loss of control with skills that a conversation partner had such as fluency, agency, the ability to express themselves, and make their needs, wants, and wishes known effectively.

P02: I don't think of myself as someone who wants a lot of control when they speak. But, there are situations where [I do]...I want to feel like I have agency when I speak. That I'm the one who is choosing to engage in that conversation without the power being lost to a fluent speaker...

P09: I think control is simply the idea [that]... if you're in a situation, can you get out of it? Can you move through it? Can you handle it? Or is it going to be a total disaster and you're going to be stuck? Can I feel somewhat effective? Can I survive it?

P13: It's a physical feeling of loss of control but it's accompanied by emotional arousal.

3.2.3 Degrees of Loss of Control

Participants discussed degrees of control and how the sensation of loss of control differed among stuttering behaviors.

P07: I feel less in control when I block because I feel like that the perception of the person that I'm talking to, when I block, is different. At least there is always a sound coming out of my mouth when I do my normal stuttering with the repetition. But with a block, the person I'm talking to is confused as to what's happening...

P13: I think there's probably some loss of control [with repetitions]... the idea is like if you were truly in control you wouldn't be stuttering, the speech would just flow. So, I think that the notion there is that it's sort of a more minor sort of a thing. You're trucking a long and you feel a little bit of that catch in your speech but it's not the stuck, it's not the sort of stuck feeling because again you can keep moving on in your speech.

3.2.4 Reaction to the Loss of Control

Participants discussed their reactions to the loss of control sensation. These reactions included both physical acts such as pushing and struggling, as well as non-action states such as fear and panic. Speakers discussed a continuum beginning with non-action states that then led to physical responses. When discussing both types of reactions, speakers directly discussed how their reactions affected overt disfluencies.

P03: I think that the panic can almost lead to more of a loss of control or exacerbate it. The more panic there is the more out of control I feel or the more, or the less likely I'm able to move through the word and the more stuck and the more loss of control I experience. I think the pushing almost comes as a response to the loss of control. Like once I'm experiencing the loss of control, one of the options, often the easiest option, is just to push.

P12: It's like you have a choice of how you want to react to it. Within that split second when you react to ... that feeling, that's when you run into most of your problems. I think the best plan of action is to react as least amount as possible but that's kind of counterintuitive and difficult...you might react to it very much and have a hard block.

3.3 Variability

Participants discussed aspects of their experience of moments of stuttering that vary across time and situation.

3.3.1 Variability Over Time

Aspects that vary across time include tension, struggle, amount of stuttering, ease of speaking, management strategies, negative thoughts and feelings, etc. Speakers discussed these changes not in linear terms suggestive of slow steady change. Rather, speakers spoke about how dynamically these aspects varied from day to day and from year to year.

P05: Well, even a few years [back], I had a lot more high tension [at] times. Actually, I think my stutter has changed a lot throughout all the years. I've picked up habits and gotten rid of habits, picked up different ones, and gotten rid of them again and stuff like that... [There are days] the variability still annoys me so much.

P09: It's certainly is not anywhere close to the intense experience that it has been in the past... I think that's the sort of thing, the experience of not having it be like a total disaster or car crash every time I stutter. I think when I was a kid and wasn't handling it quite so well. Every time I stuttered it was like the worst thing that could happen verses now it's just a thing. It happens, and I get through it. I don't give it a ton of thought and I just move on.

3.3.2 Variability Across Situations

Similar aspects of participants' experiences were discussed to vary across situations. Participants consistently spoke about how some situations were easier than others, but these hierarchies were different across individuals.

P05: The thing with my stuttering is that the experience is so different depending on where I am. Like right here I'm speaking decently well, and there might be stutters, and blocks, and repetitions, and stuff; but I do have a fair amount of tension but overall, it's not a big deal. There are sometimes I'm with my family and I'm fluent the whole night but there are times when at work or school and I'm stuttering up a storm and that is completely a different experience from the others. It's all very different, very dependent on where I am and what my mind frame is.

P06: So, really it depends on the situation. Sometimes I am able to slow down, like when I'm talking one on one with somebody, especially somebody I'm

comfortable with in a social setting. Or, if I'm anxious like with my boss...I will try and get the words out as fast as possible. It really depends.

P11: My experience of the moment of stuttering is that it really varies based on context. And, both my physical reaction to it, my proprioceptive feelings, and my emotional response to it can all vary based on who I'm talking to and what type of situation, like what other types of physical stress or emotional stress I'm under.

3.4 Physical, Emotional, and Cognitive Experience

Participants discussed their experience of moments of stuttering using language that reflected physical, emotional, and cognitive reactions, which often differed for different stuttering behaviors. The physical, emotional, and cognitive aspects of the experiences were intertwined with each other and not separate experiences, so they are represented as a single theme. Some speakers discussed moments of stuttering as a trauma they suffer, feeling an out of body experience while it occurs.

P04: I have a lot of secondary characteristics. And, I guess I push through it and that pushing through it turns into the physical, the secondary characteristics, so that little progression of thoughts, feelings, and expectations which takes a millisecond. That's... how I feel that the stutter happens.

P07: I still tend to get hot in the face when I stutter. And, a lot of times I will have like a secondary action that I'll do, like I will close my eyes or look down. I tend to look down more now than [have] my eyes closed. I've been working on trying to reduce those. Instead of closing my eyes, I just now kind of look down instead to move towards not having anything at all. So those are my big three things, my face gets hot, I look down or I close my eyes.

P09: ...It was almost like a traumatic experience where I almost felt like I would not be inside my body when I stuttered. I would sort of be watching so I was sort of distanced.

P11: I think that when I think about my most severe instances of stuttering, I feel a lot of tension, and it becomes exhausting. There is a little bit of embarrassment there still...

P12: I described it that my speech was sticky, it's like I was walking or speaking through mud or something. Each word I had to fight for. I don't know if any of them came out normally fluent. I might not have blocked on them all, but they were all sort of effortful and struggle-filled to varying degrees...I still definitely

have that sensation of sort of effortful speech in general where every word is sort of not tough anymore, but it doesn't come out easily and has the threat of turning into a block or something...

3.5 Stuttering Behaviors as Reactions

Participants spoke about the manifestation of their stuttering behaviors. They often spoke about tension as the essential experience but contrasted how the overt manifestation of the behavior depended on their reaction to the internal struggle or loss of control.

P01: I don't agree with the definition that [disfluencies] being termed core behaviors because I don't believe that they are core. I think that they are just the by-product. But I think that my experience with them is that they fall along a continuum [of struggle]. The more you try not to do it, the more you enact more fight, and that fight is the core behavior in my mind... They [stuttering behaviors] are like what you're trying to do to get un-stuck and out of the loss of control to be in control again. It's your attempt to control that's actually what a lot of what the listener sees as your stuttering.

P02: I had a lot of blocks. My parents used to tell me if I was going to stutter, "Stop!" So, what ended up happening is, I think I developed blocks as a response to that, because I would want to move through the sounds "da da da" where you repeat the sound, but my parents would tell me to not [do that]. And, just to stop, because it made them uncomfortable and embarrassed... I just changed the repetitions of sound kind of stuttering. I'm sure there's a word for it where you kind of "ka ka ka ka," when you repeat the sound you're stuck on, because I was instructed to not do that. That I think eventually my stutter turned into blocking, because I would say, "Oh, here it comes—the stutter," and I would just like, I wouldn't even try to make the sound because of how unacceptable it was to do that. I think, in retrospect I think I literally said "Ok, here comes a stutter. I'm not going to make the sounds, but I can't stop the stutter so I'm just not going to say anything."

P05: Sometimes I will just say "um" before a word that I'm going to stutter on. And then like that helps me move through the word. But that's a habit.

P08: With airflow, I can keep the sound moving [simulated this behavior]... For a while if I felt like I was going to block, I just kept making noise, kept making sounds [demonstrated a prolongation on a sound]... It's better to be forced and sound bad than be speaking and have no air coming out at all.

P10: If I'm placing an order or asking a person for directions and I have a block, they would tend to ignore me in a sense because I'm having a block and can't get the word out. But, I've realized that if I do go like "ca ca car," for example, the person sees that I'm trying to speak...

P12: If I really wanted to, I could grab on to a hot pan, but my initial reaction is going to be to let go of that pan. And, I can overpower that but that requires a lot of practice grabbing hot pans or something. As an observer, what do you see differently? I think what you observe, all you're observing is my reaction to it [being stuck]... You might react by not wanting to stutter and wanting to clamp down on that and push it out and I think that's what a block is. You not wanting to audibly stutter... I think the more you try to control that stutter the more you want it to come out a certain perfect way. That's when you get sort of these classical stuttering behaviors like prolongations and repetitions. It's almost like you trying to not stutter in an unacceptable fashion. And, I think the less you react to it, sort of the more easy the stutter can come out.

P13: I think avoidance is as much of a stuttering behavior as are a repetition or a prolongation.

3.6 Management

Participants discussed how they manage moments of stuttering or the loss of control. All participants discussed management in both action and non-action ways.

3.6.1 Action Response

Management included actions that the speakers performed proactively. These included techniques such as avoidance, speech strategies, increased effort, advertising (Breitenfeldt & Lorenz, 2000), or more attention to fluency.

P03: When I'm in a moment of stuttering, a lot of my focus or attention is on where in my body the word or sound feels stuck...and then figuring out how to move my articulators or reduce the physical tension that's in my throat or in my tongue to ease out of that block or repetition or...using speech tools like voluntary stuttering...I don't know if avoid the loss of control is fair? But like proactively putting them in so I never get to that out of control place.

P07: [I try] to be more proactive about understanding my response being in a high-stakes situation. I know I'm going into a meeting with the CEO, before I go in, I tell myself the first word I say is going to be a pseudostutter.

P10: I've used easy-onset. I'm not sure how to describe it, it's when if you're going to begin a sentence you tend to ease into the first syllable. So, if I'm saying the car is awesome I would say the car is awesome (demonstrated the technique), where you make the first syllable drag out slightly. I tend to use that quite a bit if I'm going to block on the first word of the sentence...I tend to advertise in places where it's an important spot. When I had my internship and had to give the presentation, I did advertise prior to that.

P11: There are times when I am actively increasing my attention to how I'm saying things in order to use strategies to not stutter. It is a behavioral choice to shift my attention to focus on how I'm saying what I'm saying in order to reduce tension, slow down... that's often when I close my eyes more, because I focus, I'm limiting the amount of incoming sensory information kind of helps me.

3.6.2 Non-Action States

Management also included non-action states acceptance and spontaneity.

Speakers discussed these aspects as overarching constructs or goals to which they aspire.

P02: So, I think for me when I'm saying "stuttering freely" I'm able to say what I actually want to say without having to use the machine. It's real artificial. Everything is very scripted. I know I can say this so I'm going to say this. Stuttering freely is freedom because I can say what I want. I can use whatever word I want in whatever order I want.

P04: I think I was more fluent when I was younger. I didn't really know or care about society's expectations or their perception of stuttering. When I was a kid, I just talked. I was more soulful. I didn't really care as much.

3.7 Relationship with Listeners

Participants discussed how the influence of speaking partners, conversation partners, or listeners can influence moments of stuttering in negative ways.

P06: I find especially when I'm in a multiple person social situation that the conversation is moving very fast. I have to try and keep up with it or else lose my turn to speak. And that you know is very frustrating.

P11: But, when I do stutter, and I want to impress the person, it's almost as if that in the moment I do regard it [stuttering] as a momentary failure but I don't let that feeling last. I wish I hadn't stuttered. I feel like it's more because that my attempt to communicate was less effective...

P13: And then that's usually when the listener starts giving me the look, why is this person not saying anything? And I know that I'm doing something. I'm trying to get my speech moving again but the listener is kind of sitting there looking at you and thinking what's this guy's problem?

3.7.1 Reactions to the Listener

Participants discussed ways in which they improve this speaker-listener relationship through active strategies including self-disclosure, advertising (see Breitenfeldt & Lorenz, 2000), and education.

P01: We have to know they know. We have to know [that] they get it and understand the nuances and the tricks and paradoxes of stuttering... We've got to do something to handle that relationship with the listener. And I think that's why a lot of people talk about advertising as being very powerful. But I think it goes beyond advertising I think even you have to know that they're pretty educated on stuttering and that they are not thinking of all these myths and stereotypes.

3.8 The Essential structure

Based on the results above, an essential structure of the experience of moments of stuttering *from the perspective of those who stutter*, was developed:

Moments of stuttering include more than the speech disruptions that may be perceived by an observer.

Even before moments of stuttering are observable, speakers may have an awareness (often referred to as a sense of anticipation) that some difficulty in speaking will occur. Speakers may react to this awareness with behaviors (e.g. avoiding words or situations, scripting) or emotional states (e.g. tension, anxiety, fear). The specific way in which speakers react develops based on past experiences and perceived communication stressors. The experience of anticipation can vary depending on the situation, the conversation partner, and other factors.

Many speakers experience what they describe as a "loss of control" prior to or during moments of stuttering. This loss of control can relate to a lack of agency during a conversation or to a sense of being "stuck" and unable to move forward in speech. The ways in which speakers react or attempt to regain control determine what conversational partners observe.

The loss of agency occurs when stuttering interferes with people's ability to express themselves, be understood, or participate in social interactions. The

relationship between speakers and their listeners can influence how they experience moments of stuttering and how they perceive themselves. Speakers may be able to improve their relationship with their listeners through proactive strategies such as educating others about stuttering or being open about stuttering.

The sensation of being stuck occurs when speakers know what they want to say but are unable to say it. This sensation does not directly correspond to the behaviors that listeners may observe (e.g., repetitions, prolongations, and blocks). Rather, speakers may react to the sensation of being stuck with tension or struggle, and these behaviors might be observable. They might also experience being stuck without observable reaction until the sensation passes. Other possible reactions include: attempting to restart speaking, prolonging or repeating a sound to hold the conversational floor, avoiding sounds or words, changing words or the message in an attempt to postpone or prevent stuttering, or holding the conversational floor through other conversational means (e.g., starter or filler words). Speakers may also respond by using speaking strategies (e.g., reducing tension) through methods learned in treatment or independently. They may also respond by focusing on acceptance or spontaneity.

The experience of moments of stuttering, the sensation of loss of control, and speakers' reactions can vary significantly depending upon the situation, the relationship between speakers and their conversational partners, and the ways in which listeners react. These aspects of stuttering can also change over time, with age, through self-help, and with treatment.

4.0 Discussion

Participants in this study described their experience of stuttering in ways that are consistent with prior research; but, also expand knowledge about the phenomenon. As reported by Jackson et al. (2015), anticipation is a very common aspect of the experience of stuttering. This anticipation can lead people to react with actions (e.g., avoiding words, changing words, scripting, tension, and avoiding situations) and non-action states (e.g., anxiety and fear). Importantly, participants in this study reported that anticipation is not an independent phenomenon but rather part of moments of stuttering itself—something which occurs before the disruption in speech but still a part of the experience of those moments. Anticipation was described as both a long-term build-up that could begin

minutes, hours, or days prior to a speaking situation as well as a sensation someone experiences as they begin to formulate an utterance. People who stutter reported experiencing physical and emotional arousal during moments of stuttering in a similar manner. For example, P13 said, “It’s not just being stuck, being stuck by itself would be fine. But, it’s being stuck and then being [in] the emotional discomfort that accompanies being stuck [that’s bad].” Participants also described various forms of managing moments of stuttering, including using speech and stuttering modification techniques, as well as focusing on cognitive states such as acceptance (De Nardo, Gabel, Tetnowski, & Swartz, 2016) and spontaneity (Constantino & Manning, 2015).

Novel themes identified in this study related specifically to the speakers’ experiences immediately before and during stuttering behaviors themselves. Many participants discussed what they called a *loss of control* as being central to their experience of moments of stuttering. Speakers discussed two aspects of control. The first was a motoric or linguistic sense where speakers knew what they wanted to say but could not execute the necessary speech movements. This feeling of being stuck was an inability to stop or escape the sensation. For example, P01 said, “In a moment of typical disfluency I can stop doing that [being disfluent].” Yet, when experiencing a loss of control, “the awareness triggers and I know you’re going to stutter and it’s not that ability to just decide I want to stop it when I want to.” The second sense of control was more conversational and pragmatic. Speakers discussed wanting control of their space in the conversation to make their thoughts heard and to give themselves a voice. For example, P09 said, “Control is...Can you get out of it? Can you move through it? Can you handle it? Or is it going to be a total disaster and you’re going to be stuck?” Speakers also

discussed variability over time and situation, physical experience, and emotional reactions as common characteristics of moments of stuttering. The physical and emotional sensations were often different for different stuttering behaviors and across situations. Interestingly, the physical, emotional, and cognitive aspects of the experiences were described as being intertwined with each other, rather than being seen as separate experiences. This suggests that these aspects of stuttering co-occur.

Further novel themes in this study relate to how stuttering behaviors manifest. Participants often talked about tension, struggle, or loss of control as central to their experience of stuttering behavior, but they also highlighted that the manner in which they react to this sensation determined how those overt behaviors would appear. For example, many participants discussed how they might *volitionally* use prolongations or repetitions rather than blocks because of the impact that blocks might have on their ability to hold the conversational floor or because of the negative reactions they may receive from listeners when they block. Conversely, other people spoke about how they might choose to remain silent so that overt stuttering behaviors do not occur. This avoids the pain of enduring the negative reactions of listeners (or themselves). For example, P02 said, “In retrospect I think I literally said, okay, here comes a stutter. I’m not going to make the sounds, but I can’t stop the stutter, so I’m just not going to say anything.”

These results raise questions about the distinctions between stuttering behaviors that might arise directly from an underlying impairment and those might be better viewed as adaptations. Certainly, some behaviors commonly associated with stuttering are commonly thought to be adaptation behaviors (e.g. avoiding words, situations, increased tension). Results from this study suggest that, at least to some people who stutter, overt

stuttering behaviors such as repetitions and prolongations are not the direct result of speaking with an impaired system as is commonly assumed. Rather, to at least some people who stutter they too are adaptation behaviors. The only difference is the choice the speaker makes in terms of the manifestation of the disruption. Data from this study support this claim. For example, P10 stated, “[The conversation partner] would tend to ignore me...I’m having a block and can’t get the word out. But, I’ve realized that if I do go like “ca ca car,” for example, the person sees that I’m trying to speak.” This blurred line between impairment and adaptation directly reflects the distinction raised by Perkins (1990) in his proposal that stuttering might best be viewed as having occurred only when a speaker experiences the sensation of “loss of control.” Although the specific name for the phenomenon can be debated (Jackson, Quesal, & Yaruss, 2012; Quesal, 2010), the essence of the loss of control definition is that speakers experience something underlying moments of stuttering and that the observable behaviors that listeners perceive come about only in response to that underlying experience. In this view, the true occurrence of moments of stuttering would not be defined by whether a speech disruption occurs on the surface but whether the sensation of loss of control (whatever that may be neurologically) is *experienced* by the speaker (Quesal, 2010). The presence of this underlying feeling does not necessarily correlate with the occurrence of overt behaviors that listeners might typically define as stuttering behavior. Put differently, a conversational partner may or may not observe moments of stuttering because overt speech disruptions may or may not be present. Regardless, if the sensation of being stuck is experienced by a speaker, then the speaker would say that a moment of stuttering has indeed occurred. As revealed through the responses of participants in this study, definitions of stuttering that are based

on observable behaviors do not encompass all of the ways in which people who stutter themselves actually experience moments of stuttering. These results further indicate that it is not sufficient to simply categorize non-observable behaviors as part of a speaker's learned reactions to stuttering, for participants reported that the loss of control sensation can occur independently from the production of observable speech disfluencies.

Present findings suggest that listener-based definitions of stuttering based on surface behaviors may lead to evaluation protocols and treatment approaches that are too narrow (i.e., focused only on observable speech behaviors). Jackson et al. (2012) stated that "a surface definition de-emphasizes the experience of the individual;" the reports of the participants in this study support this view. Moments of stuttering involve more than the just the behaviors that can be identified by listeners. These results provide the first qualitative support that directly support other theoretical accounts of surface stuttering behaviors as involving a reaction to an underlying disruption that is perceivable only to the speaker (see Brocklehurst et al., 2013; Guntupalli, Kalinowski, & Saltuklaroglu, 2006; Perkins, 1983, 1984, 1990). Furthermore, the fact that speakers in this study themselves validated the essential structure of the experience of moments of stuttering with a high degree of agreement supports that it captures their collective experience.

When Perkins proposed the idea of a loss of control, various researchers in the field expressed concern of the lack of validity of such a non-observable definition of stuttering that a listener cannot quantify (see Bloodstein, 1990; Ingham, 1990; Smith, 1990). It may be that future research will help to identify more objective factors that relate to the speaker's internal experience of stuttering. For example, a growing body of research using neuroimaging and other neural processing techniques is exploring possible

impairments underlying stuttering behavior. This research continues to show that persistent stuttering results from aberrant neural structural and connectivity in speech and language networks (Cai et al., 2014; Chang et al., 2017; Chang, Zhu, Choo, & Angstadt, 2015; Cieslak, Ingham, Ingham, & Grafton, 2015; Connally, Ward, Howell, & Watkins, 2014) resulting in different cortical dynamics in people who stutter compared to those who do not (Sengupta, Shah, Gore, Loucks, & Nasir, 2016; Sengupta et al., 2017). Such research may ultimately provide a means for correlating the so-called *loss of control* sensation perceived by speakers to more objective neural phenomena. More research is needed to explore what speakers are sensing and to what they are reacting.

4.1 Clinical Implications

Aligning the definition of stuttering behavior with the experiences of individuals who stutter has significant clinical implications for improving diagnostic and therapeutic outcomes. Because some participants discussed using so-called typical stuttering behaviors (e.g. repetitions and prolongations) as well as more covert behaviors (e.g. avoidance and scripting) as reactions to the sensation, it may be more accurate to expand the definition of stuttering behaviors to include behaviors such as avoidance and scripting rather than relying simply on categorizations of “stuttered” (or “stutter-like”) and non-stuttered disfluencies. A person may react to the sensation of being stuck by struggling, tensing, switching words, using a prolongation or a repetition, remaining silent, or any of a wide range of other behaviors that may or may not fall into the traditional listener-based definitions of stuttered vs. non-stuttered speech. Speakers may even use so-called non-stuttered or typical disfluencies as they react to the underlying disruption. From the perspective of the speaker, these behaviors should still be considered “stuttering,” even if

they do not take the form of the typical types of behaviors that listeners judge to be stuttering. Such a re-definition of stuttering behaviors may also help to reconcile covert stuttering (Constantino et al., 2017; Murphy et al., 2007) and so-called typical stuttering, in that the compensations or adaptations a person may employ in response to the sensation of losing control or being stuck includes changing words, staying silent, or using any of the other strategies reported by those who stutter covertly. Counting or recording less-observable behaviors, either by broader observation of through the self-report of the person who stutters (see Guntupalli et al., 2006), may yield meaningful information that can help to increase the accuracy of observational data, both for diagnosis and treatment outcomes evaluations.

Presently, the standard criteria for determining that an individual has recovered from stuttering are based on the percent stuttered syllables or the severity of stuttering as perceived by clinicians and parents (Yairi & Ambrose, 2005). Likewise, current research designed to predict persistence and recovery uses such listener-based criteria (see Smith & Weber, 2017). Findings from this study suggest that that a broader view of what constitutes recovery may need to be considered. If some individuals feel as if they are stuttering even if they do not exhibit overt speech behaviors that may be judged by listeners to be *stutter-like* (as the participants in this study reported), then estimates of recovery or persistence may need to be adjusted. Evaluating less-observable stuttering behaviors alongside conventional stuttering-like behaviors may help to more accurately describe the broad range of behaviors and experiences reported by those who stutter.

4.2 Limitations and Future Directions

One strength of this study was the varied composition of the participants who stutter from different occupations, ages, history of treatment, perceptions of treatment, and outlooks on stuttering that give support to the consistency of the findings. There are, however, potential limitations that need to be addressed. For example, most of the participants had experience with self-help in addition to treatment. Research has shown that people who participate in stuttering self-help are quite varied in terms of the life experiences, knowledge about stuttering, and other factors (Yaruss et al., 2002), their participation in self-help may have caused there to be some homogeneity among the participants. It may have primed participants to use terms such as *loss of control* to describe their experiences. The sample size (n=13) was relatively large for a face-to-face conversation-based phenomenological study in stuttering, though future research should follow up on these findings with survey studies to explore how common the identified themes are across large groups of people who stutter—including children and adolescents, who may experience moments of stuttering differently. Exploring the experiences of younger participants who stutter may also offer insights into the how perceptions of moments of stuttering start, and how they change over time. Future research should explore the relationship between adaptation behaviors and therapeutic approaches, such as voluntary stuttering and stuttering modification.

4.3 Summary

According to individuals who stutter, moments of stuttering include more than just overt speech behaviors that listeners may (or may not) see and hear. Commonly observed stuttering behaviors (e.g. repetitions and prolongations) may actually reflect a reaction or adaptation to an underlying sensation of being stuck (termed by some

speakers as a “loss of control”) to some people who stutter rather than a direct reflection of an impaired speech or language system. Researchers and clinicians should account for this broader view of moments of stuttering to ensure that they are considering moments of stuttering as perceived by those who stutter, and future research should explore the potential neural underpinnings of this experience to improve the definition (and, ultimately, the evaluation and treatment) of stuttering.

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Table 1.

Participant Demographics

Participant	Age	Gender	Occupation	Self-Help	SSI		OASES-A		
					Total Score	Severity	Overall Impact	Severity	Credibility
1	30	Female	Speech-Language Pathologist	Yes	11	Very Mild	1.42	Mild	7
2	25	Female	Research Coordinator	No	8	Very Mild	1.99	Mild/Moderate	6
3	29	Female	PhD Student	Yes	18	Mild	1.31	Mild	6.5
4	30	Male	Engineer	Yes	8	Very Mild	3.02	Moderate/Severe	
5	28	Female	Medical Doctor	Yes	27	Moderate	2.69	Moderate	
6	34	Male	IT Specialist	Yes	20	Mild	3.24	Moderate/Severe	
7	24	Female	Data Analyst	Yes	9	Very Mild	2.26	Moderate	6
8	56	Male	Property Manager	Yes	37	Very Severe	2.11	Mild/Moderate	7
9	47	Male	College Professor	No	11	Very Mild	1.37	Mild	7
10	22	Male	Undergraduate Student	Yes	34	Severe	3.61	Moderate/Severe	
11	34	Male	Post-Doctoral Student	No	9	Very Mild	1.7	Mild/Moderate	6
12	30	Male	Speech-Language Pathologist	Yes	10	Very Mild	1.57	Mild/Moderate	6
13	65	Male	Retired College Professor	Yes	13	Very Mild	1.57	Mild/Moderate	6.5

Table 2.

Themes	Sub-Themes
Anticipation of Stuttering	Action Response Non-Action States
The Loss of Control	Physical, Motor, Linguistic Control Pragmatic Control Degrees of Loss of Control Reaction to the Loss of Control
Variability	Variability Over Time Variability Across Situations
Physical, Emotional, and Cognitive Experience	
Stuttering Behaviors as Reactions	
Management	Action Response Non-Action States
Relationship with Listeners	Reactions to Listeners