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Life Partner Perceptions of the Emotional Impact of Stuttering

Athanasia Svenning
University of Central Florida

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LIFE PARTNER PERCEPTIONS OF THE EMOTIONAL IMPACT OF STUTTERING

by

ATHANASIA SVENNING

B.S., University of Central Florida, 2016

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ABSTRACT

The aim of the present study is to investigate the extent to which life partners understand the emotional impact stuttering has on their loved one who stutters. This was accomplished by administering the Speech Situation Checklist - Emotional Reaction (SSC-ER), a subtest of the Behavior Assessment Battery (BAB; Vanryckeghem & Brutten, 2018) via Qualtrics, an online survey software, to the participants who stutter and a modified version of the SSC-ER to their life partner. No significant differences and a positive correlation were observed between groups (people who stutter (PWS) and their life partner (LP) as it relates to total score on the SSC-ER. Gender, age, and duration of relationship, overall, were not confounding variables that affected the total score. Internal reliability was high across both the SSC-ER and its modified version. All items on the test correlated significantly with the total score with the exception of items 8 and 13 for PWS and items 6, 13, and 36 for LPs. Between-group item analysis revealed that the majority of test items did not differ significantly with the exception of six items: 3, 4, 13, 19, 26, and 27. The aforementioned items follow the construct pertaining to fixed sounds and/or words. The findings in this investigation provide evidence that LPs have a general understanding of the anxiety levels their partner who stutters experiences as it relates to communication situations.

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Writing a graduate thesis has allowed me the opportunity to delve further not only into the realm of fluency disorders, but it has also provided me a chance to learn about myself. Having this experience has taught me the value of persistence and hard work. This project serves as a reminder that all good things take time, and nothing is impossible without the support of many.

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LIST OF ABBREVIATIONS

BAB	Behavior Assessment Battery
LP	Life Partner
PWNS	People who do not Stutter
PWS	People who Stutter
QoL	Quality of Life
SLP	Speech-Language Pathologist
SSC	Speech Situation Checklist
SSC-ER	Speech Situation Checklist-Emotional Reaction
SSC-SD	Speech Situation Checklist-Speech Disruption

CHAPTER ONE: INTRODUCTION

1.1. Stuttering

Stuttering, a multidimensional speech disorder, has been defined as an uncontrollable disruption in an attempt to produce a spoken utterance (Perkins, 1990). It is agreed upon by researchers and clinicians alike that stuttering is characterized by specific overt stuttering behaviors, and that the age of stuttering onset lies between the ages of two and six (Bloodstein & Bernstein Ratner, 2008). Of all fluency disorders, stuttering is most common (Cummins, 2010) with an overall prevalence of this disorder being around 1% (Craig, Blumgart, & Tran, 2009) and the lifetime incidence around 5% (Mansson, 2000). Stuttering incidence is four times greater in males compared to females (Bloodstein & Bernstein Ratner, 2008).

Those diagnosed with stuttering exhibit differences in physiological, emotional, cognitive, and behavioral reactions when compared to “fluent” speakers as a result of an interruption in the forward flow of speech (Bleek, et al., 2012), making stuttering a multidimensional disorder. These differences seen in the life of a person who stutters (PWS) as it relates to the Affective, Behavioral, and Cognitive components, also known as the “ABCs” of stuttering, are atypical reactions to speech when compared to a “fluent” speaker. The ABCs consider an individual’s emotional reactions to his or her speech (A), speech disruptive behaviors and behaviors used to avoid or escape speech disruption (B), and speech-related attitudinal reactions (C; Vanryckeghem & Brutten, 2018). Some characterize stuttering as a unidimensional disorder and focus predominantly on a disruption of speech. Many PWS, however, not only experience dysfluencies, but often undergo feelings of frustration, anger, shame, and self-consciousness, as evidenced through the “A” component of the ABCs (Bleek et al., 2012;

Ginsberg, 2000; Klompas, M. & Ross, E., 2004; Vanryckeghem, Matthews & Xu, 2017).

Additionally, Vanryckeghem and Brutten (2011, 2012) found that PWS, as a group, have a significantly more negative attitude about their own speech compared to people who do not stutter (PWNS). Further, PWS often exhibit concomitant behaviors, manifesting themselves as avoidance or escape behaviors related to speech situations and/or the use of coping behaviors as an attempt to mitigate stuttering behaviors (Vanryckeghem & Brutten, 2018; Vanryckeghem, Brutten, Van Borsel, & Uddin, 2004).

Ginsberg and Wexler (2000) discuss three behavioral components of stuttering specific to the consequences associated with the disorder: difficulty speaking, avoidance of situations that induce dysfluencies, and expectancy of speech struggle. In reference to stuttering, *struggle* denotes physical strain, tension, and effort when speaking. These struggle behaviors can manifest themselves at the articulatory, phonatory, and/or respiratory levels. *Avoidance* behavior refers to an effort to evade situations, words, and/or sounds that can induce dysfluencies. This type of behavior associated with stuttering is ever-changing and represents different periods of development within a PWS. For instance, children rarely avoid the opportunity to talk, but self-consciousness increases as one gets older, thus increasing the utilization of avoidance behaviors. Avoidance, in particular, impinges on one's ability to engage in specific relationships (Ginsberg & Wexler, 2000). The last stuttering-associated behavior, as defined by Ginsberg and Wexler (2000), is expectancy. *Expectancy* refers to one's anticipations about the ability to verbally communicate. The expectation of stuttering may induce concomitant behaviors that accompany the speech-related struggle. In addition, these hindrances experienced by PWS can be worsened by fluent speakers' misconceptions and negative attitudes toward stuttering in general (Ginsberg

& Wexler, 2000). These misunderstandings include, but are not limited to, assuming that PWS are less intelligent than others and believing that stuttering is a consequence of fast speech rate. Further, Collins and Blood (1990) found that perceptions of individuals who openly disclose their stuttering are thought of more negatively by others as opposed to PWS who do not disclose to others about their speech impediment. It is not unlikely that PWS are faced with negative reactions specific to intelligence, personality, and even appearance due to their speech impediment. As one can anticipate, the effects associated with stuttering can greatly impact one's quality of life (QoL), specifically in the areas of emotional functioning, mental health, and social functioning (Craig et al, 2009).

As a result of PWS' interviews, Corcoran and Stewart (1998) found that *suffering* was the primary theme among the individuals. This feeling of suffering is rooted from experiences of being obstructed in making efforts to speak. Participants in the study explained experiencing suffering through accounts of nightmares, humiliation, dread, isolation, and thoughts of suicide; had feelings of helplessness, shame, fear, and used avoidances (Corcoran & Stewart, 1998). Helplessness originates from not feeling in control of the direction of one's life, whether it be socially or professionally. Further, according to the participants, the involuntary nature of the disorder contributes to a feeling of a lack of autonomy. This lack of self-governance is found to be a factor in prompting suicidal thoughts. Additionally, in regards to shame, PWS reported that whatever positive characteristics they identify with, are overshadowed by their speech impediment, as they feel that their stutter is what captures conversational partners' attention and becomes the primary focus of an interaction. Moreover, there were reports in reference to the insensitivity of listeners during a conversation, inducing stronger feelings of shame in addition to

guilt and pain (Corcoran & Stewart, 1998). As would be expected, the aforementioned feelings of helplessness, shame, guilt, and pain, in turn, cause fear of communicating in general. Consequently, avoidance behaviors are exhibited as a means to avoid communicative acts.

Overall, Corcoran and Stewart (1998) found that the participants' reports of their experiences are similar to Cassell's (1991) definition of suffering: "the state of severe distress associated with events that threaten the intactness of the person" (p.33). Cassell also writes that individuals experiencing pain often report suffering from agony when they feel there is a *loss of control*, when pain is *overwhelming*, when the source of the distress is *unknown*, when the meaning of the ache is *dire*, or when the discomfort is perceived as *endless*. These elements discussed by Cassell correlate with the description of the PWS' experiences in Corcoran and Stewart's study (1998). Feelings of suffering contribute to lower social and emotional functioning, all of which result in a negative impact on one's QoL (Craig et al., 2009). QoL heavily relies on many factors, including physical, psychological, and vocational aspects (Craig et al., 2009). Speech disruptions, in conjunction with an individual's various reactions to it, can hinder everyday communication and have significant consequences in one's daily life, as negative speech-related responses can be linked to particular situations, sounds, and/or words. With that, there is an increased chance of the development of various mental health issues in PWS, including negative affective responses as well as generalized and social anxiety disorder (Bleek et al., 2012; Blumgart, Tran, & Craig, 2010), all of which can have a negative impact on QoL.

1.2. Social Anxiety Disorder

Social anxiety disorder, also referred to as social phobia, is defined as being characterized by a marked, persistent fear of “one or more social situations in which the individual is exposed to possible scrutiny by others” (Diagnostic and Statistical Manual of Mental Disorders; DSM-5; American Psychiatric Association, 2013a, p. 202). Social phobia is one of the most prevalent mental health disorders affecting between 8% and 13% of the general population (Kessler et al., 2005; Ruscio et al., 2008). The fear experienced by those diagnosed with social anxiety disorder can be debilitating as it impinges on daily interactions and situations such as meeting new people, talking on the phone, and speaking with authority figures. In severe cases, this may lead to avoidance behaviors, social isolation, and failure to partake in activities, whether occupationally, socially, or interpersonally related (American Psychiatric Association, 2013). Not all situations can be avoided, so it is not uncommon for those living with social anxiety disorder to experience extreme discomfort and/or distress in unavoidable social interactions or performance-related situations (American Psychiatric Association, 2013). These types of situations can include exposure to certain speech settings and one’s communicative expression in general (Vanryckeghem, Matthews, & Xu, 2017).

Anxiety may express itself in physiological symptoms such as blushing, trembling, sweating, increased heart rate, and abnormal breathing patterns (Craig & Tran, 2006). The feeling of anxiety is associated with making a bad impression, in turn, increasing the fear of negative evaluation (Helbig-Lang & Petermann, 2010). Social, educational, and occupational situations that are perceived as intimidating are typically avoided in light of negative social outcomes by those living with social anxiety disorder (Iverach & Rapee, 2014) since the majority

of the aforementioned physical symptoms can be easily seen by others (Bogels et al., 2010). Provided that those who present with social anxiety disorder may be characterized as overestimating threat and underestimating their own coping capabilities (Rachman & Richard, 1988), they result to safety behaviors as a way to manage their anxiety. These avoidance behaviors can impose on one's academic achievement, work-related performance, social interaction, relationships, and overall QoL (Iverach & Rapee, 2014). Social aspects are additionally considered in evaluating QoL, something that presents with great difficulty for those living with social anxiety disorder. The impact that this type of anxiety disorder has socially on those living with it, includes the hardship of fostering and preserving relationships with others.

Individuals living with social phobia have issues in creating and maintaining healthy social relationships due to their reluctance to self-disclose to others (Green, Wilhelmson, Wilmots, Dodd, & Quinn, 2016). Revealing personal information contributes to feelings of closeness and intimacy in friendships and romantic relationships as one becomes more transparent and open with someone else. People experiencing social anxiety tend to avoid negative social consequences and may utilize self-protective behaviors in order to prevent disapproval from others. These self-protective behaviors may take the form of avoiding social interactions, possibly leading to decreased general self-disclosure (Green et al., 2016). While socially anxious individuals may evade from particular social interactions, there is still as much a desire for social contact similar to those who are not diagnosed with social phobia (Myers, Kaheneman, Diener, & Schwarz, 1999). It is expected that PWS have the same wants: to partake in interpersonal interaction and connect with individuals at an intimate level. However, it is not

uncommon for some PWS to have similar reactions to social situations as persons living with social anxiety disorder.

1.3. Stuttering and Social Anxiety Disorder

Generally speaking, stuttering can be associated with a variety of mental health problems.

Among these, the most prevalent is social anxiety disorder (Lowe et al., 2017). With that, social anxiety can be a secondary symptom of stuttering. A study conducted by Craig and Tran (2006) revealed persistent levels of anxiety experienced by PWS and their subsequent fear and avoidance of social interactions (Beilby, Byrnes, Meagher, & Yaruss, 2013). Approximately 40% of individuals diagnosed as having a stutter meet the criteria for social anxiety disorder (Blumgart et al., 2010; Craig & Tran, 2014), as opposed to the general population (8-13%; Iverach & Rapee, 2014).

Ezrati-Vinacour and Levin (2004) believe that the relationship between stuttering and anxiety can be explained in one of two ways: anxiety that is specific to speech communication, or the anxiety of PWS which originates from a general stress trait. Trait anxiety refers to stable anxiety attributes in an individual as opposed to contextual differences in anxiety (state anxiety; Craig, Hancock, Tran, & Craig, 2003). Craig and colleagues (2003) have conducted research supporting the notion that anxiety is a personality trait of PWS, especially if stuttering is chronic. Trait anxiety is multidimensional in that the effects of a generalized anxiety characteristic differ among individuals (Ezrati-Vinacour & Levin, 2004). PWS may exhibit higher levels of state anxiety as opposed to fluent speakers as well. However, the degree of state anxiety present is

relative to stuttering severity (Ezrati-Vinacour & Levin, 2004). With that, there are a variety of reasons to expect that stuttering may be correlated with social anxiety disorder, provided the state and trait anxiety findings in recent research. As one can imagine, the impact that anxiety has on a PWS can pose as debilitating. These aforementioned effects can have negative outcomes when it comes to an individual's daily life and future well-being.

The combination of stuttering and social phobia can affect QoL as harmfully as life threatening conditions such as neurotrauma and coronary heart disease (Iverach & Rapee, 2014). Further, suicidal thoughts and suicide have been documented with adults who stutter (Iverach & Rapee, 2014). Research supports this notion as PWS have higher locus of control scores than PWNS (Andrews & Craig, 1988). Higher locus of control scores indicate that individuals' perceived life outcomes are less likely to be controlled by personal efforts and ability, but rather by luck, chance, or power (Craig, Franklin, & Andrews, 1984). With that, focusing on "luck" as opposed to "efforts" can greatly impact how a PWS approaches life in general. This outlook can come as a result of negative experiences one has in daily life, relative to speech in this particular case.

Stuttering can be accompanied by several negative consequences across the lifespan, potentially increasing susceptibility to social and psychological hardships (Iverach & Rapee, 2014). "Negative consequences" can begin early in childhood with those who experience bullying, exclusion, teasing, and general negative peer reactions. Given that childhood and adolescence are crucial periods in one's life in which identity and self-concept are developed (Tatum, 1999), it is hypothesized that the relationship between stuttering and poor self-concept begins in childhood. As a result, occurrences of exclusion and victimization experienced during

childhood can have lasting effects and lead to social anxiety and low self-esteem (Cummins, 2010). As one ages, these negative consequences are intensified as the demands for social interaction and public speaking increase, further instilling a negative identity. Not only can these instances impact the morale of an individual, but it can also induce shame, embarrassment, and withdrawal. In a qualitative analysis studying the effects of stuttering on students aged from kindergarten to 12th grade, Daniels, Gabel, and Hughes (2012) found a variety of effects that are impacted/induced in PWS: coping strategies (physical, linguistic, and social-interactional), physiological (e.g. tension, illness, etc.) and psychological consequences (negative self-concept), potential limitations on relationships, and post-educational costs (e.g. continued fear of speaking situations, personal identity/reflections/observations, etc.). These aforementioned components, especially the post-educational consequences, correlate with common features of social anxiety disorder that are typically seen in PWS: fear of negative evaluation, expectancies of poor social outcomes, negative thoughts and attitudes, attentional biases, evasion, and safety behaviors (Iverach & Rapee, 2014).

One of the hallmarks of social anxiety disorder is fear of negative evaluation (Iverach & Rapee, 2014). Negative evaluations and cognitions (e.g. *“No one will like me if I stutter”*, *“I stutter all the time”*, and *“I will always stutter”*) can lead to a lack of confidence in PWS, generally resulting in a poor overall self-concept, even potentially affecting one’s personality (Bleek et al., 2012). In addition, negative thoughts can induce self-identification as a “stutterer” rather than a “speaker” (Linn & Caruso, 1998). Persistent negative thinking may play a significant role in maintaining fear of negative evaluation and associated social anxiety (Iverach & Rapee, 2014). The majority of participants in Fuse and Landham’s (2016) research self-

reported that they experience reduced confidence levels due to stuttering, further validating these conclusions. Lack of confidence may induce heightened anxiety, thus increasing stuttering severity and vice versa (Ezrati-Vinacour & Levin, 2004). Due to low self-esteem, it is not unusual for PWS to exhibit avoidance behaviors in an attempt to evade situations that can induce anxiety and embarrassment.

Coping behaviors are typically exhibited by PWS as behaviors secondary to the expectation and/or occurrence of speech difficulty. Concomitant characteristics such as these are specific to an individual and may alter how one functions in everyday life, effecting one's QoL and general social interaction. Participants in Fuse and Landham's (2016) study showed that the five most common situations participants avoided were phone calls with a stranger (65%), presentations in front of a group (61%), answering questions in class (54%), reading aloud to others (54%), and meeting strangers (41%). Safety behaviors can manifest themselves externally (emerging as avoidance or escape behaviors from situations, topics, and specific words, mentally rehearsing sentences before speaking, and/or avoidance of eye contact) and/or internally (the escape or avoidance of particular thoughts and/or emotions), sometimes called restorative safety behaviors (Helbig-Lang & Petermann, 2010). Restorative behaviors mainly aim to reduce bodily symptoms as it relates to anxiety (e.g. shortness of breath, sweating) or to reduce the perceived likeliness of feared consequences (e.g. embarrassment and/or bringing harm to oneself or others; Helbig-Lang & Petermann, 2010).

In observing the use of safety behaviors in PWS, Lowe and colleagues (2017) found that the most frequent behaviors exhibited by their participants are skipping unnecessary talking when having a bad day, avoiding topics that induce anxiety, and keeping answers short. These

behaviors can pose as a sign of social anxiety disorder as it relates to stuttering in an attempt to avoid negative outcomes. While the intent of safety behaviors is to lower speech-related anxiety levels, cognitive theorists suggest that those living with social anxiety disorder and present with these behaviors prevent fear extinction and, as a result, maintain anxiety rather than depress it (Clark, 1999; Rapee & Heimberg, 1997; Salkovskis, 1991). This is hypothesized because safety behaviors do not allow an individual to notice anxiety-disconfirming information from the environment, thus maintaining anxiety (Helbig-Lang & Petermann, 2010). Attempts to control symptoms of anxiety are found to be associated with increased anxiety levels and avoidance behaviors (Helbig-Lang & Petermann, 2010). These effects typically go unnoticed, however, in those living with any type of anxiety. In conclusion, the utilization of safety behaviors has been found to be counterproductive.

Additionally, Lowe and colleagues (2017) found that the use of coping behaviors correlates with fear of negative evaluation as well as negative cognitions related to one's own speech. The escape or avoidance behaviors exhibited by PWS are associated with anxiety maintenance and non-significant outcomes in treatment as they prevent fear extinction in the individual (Lowe et al., 2017). These data reinforce the impact that stuttering may have on one's decision to partake in social interactions, thus creating difficulty in developing intimate relationships with others.

It has been noted by Ginsberg and Wexler (2000) that some PWS would rather be lonely instead of experiencing the pain and discomfort in attempting to communicate with a stranger. As a result, they exhibit self-defeating avoidance behaviors that impinge on the formation and maintenance of relationships. Considering this, for PWS, dysfluencies contribute to difficulty in

daily living social adjustment (Prins, 1972; Wingate, 1962). The creation and conservation of interpersonal relationships can pose as a hardship for PWS due to lack of self-presentational confidence. Speaking situations may be viewed as negative, stressful, and/or threatening to PWS for a variety of reasons (Linn & Caruso, 1998), causing extreme uneasiness and lack of verbal communication. Speech disruptions may frustrate not only the speaker, but the listener as well. As an attempt to avoid negative outcomes of interaction, PWS may not speak due to dysfluency or anxieties about talking, thus hindering the creation of long-term relationships (Beilby et al., 2013).

In previous research, others' perceptions toward PWS from the perspective of teachers, students, professionals, parents, employers, and peers have been investigated (Crowe & Cooper, 1977; Crowe & Walton, 1981; Dorsey & Guenther, 2000; Lass et al., 1992; St Louis & Lass, 1981; Yeakle & Cooper, 1986). The impact that stuttering potentially poses on various aspects of one's life has also been reviewed from the viewpoint of Speech Language Pathologists (SLPs), vocational rehabilitation counselors, special educators, relatives, and family members (Cooper, 1985; Cooper & Cooper, 1996;; Doody, Kalinowski, & Armson 1993; Guntupalli, Kalinowski, Nanjundeswaran, Saltuklaroglu, & Everhart, 2006; Hurst, 1983; Kalinowski, Armson, Stuart, & Lerman, 1993; Lass & Ruscello, 1989; Turnbaugh, Guitar, & Hoffman, 1979; Yairi & Williams, 1970; Zhang, Saltuklaroglu, Hough, & Kalinowski, 2009). Despite the abundant body of research regarding others' perception of stuttering, the perceptions of PWS' significant others remain relatively unexplored (Beilby et al., 2013). Although issues related to disability, stuttering, and intimacy have been researched (Linn & Caruso, 1998), there is a dearth within the literature exploring how PWS' life partners (LPs) understand their loved one, specifically related

to their speech-associated emotional reactions. In order to aid in the counseling aspect of treatment, it is imperative that PWS have familial support and understanding, especially from a life partner as he or she plays an essential role as an agent in their partner's fluency intervention (Beilby et al., 2013; Boberg & Kully, 1985), acting as primary facilitators warranting the success of their partner's interactions (Hughes, Gabel, Irani, & Schlagheck, 2010).

1.4. Assessment and Diagnosis of PWS

Typically, a variety of areas are assessed when evaluating a PWS, including one's general, non-speech-specific emotional state, speech-specific emotional reactions, the type and frequency of dysfluencies and concomitant behaviors, speech-related attitude, among others. These factors aid SLPs in differential diagnosis as it relates to fluency disorders.

Assessment might encompass clinical observation as well as the administration of self-report tests. Clinical observations can include documentation of the type and frequency of speech interruptions and the notation of voluntary behaviors that are used as a means to avoid, escape, or hide speech dysfluencies. Self-report measures provide valuable insight to the SLP as they assess specific dimensions that characterize the PWS and typically include affective, behavioral, cognitive, physical, and social components. The results gathered from self-reports complement the qualitative and quantitative external observations made by the clinician. These findings provide the professional information as to what will eventually require his or her therapeutic attention relative to negative emotional reaction, speech disruption, negative speech-related attitude, and the use of behaviors secondary to stuttering.

Given the definition of “stuttering” as an involuntary disorganization of speech, Perkins (1990) concluded that dysfluency occurrence can only be accurately measured by the PWS since it is only the individual who can detect when stuttering has occurred. The Behavior Assessment Battery (BAB; Vanryckeghem & Brutten, 2018) supports this ideology as a standardized self-report instrument that evaluates attitudinal, emotional, situational, and behavioral factors surrounding stuttering, in conjunction with additional quantitative and qualitative measures obtained by the SLP specific to type and frequency of dysfluency. A variety of subtests encompassing the BAB, measure the “ABC” components present in the PWS. Further, this assessment tool fits into the International Classification of Functioning, Disability and Health (ICF, WHO, 2001) terminology and ideology (Vanryckeghem & Brutten, 2018). The BAB is suitable within this nomenclature as it reviews a person’s daily activity and participation, challenging interpersonal speech interactions specific to the client, the “ABCs”, and associated consequences of stuttering, as well as the overall impact of the disorder on the individual’s QoL (Vanryckeghem & Brutten, 2018). Assessing the multidimensional aspects of stuttering through the BAB further validates that there is more to being a PWS than the overt dysfluencies that are characteristic of the disorder and visible to the observer. Data collected from the BAB make it possible to see the relationship between speech-associated attitude, negative emotion, speech disruption, and coping behaviors. The subtests that encompass the BAB provide the clinician valid and reliable information that are relevant to everyday clinical practice. They help in the differential diagnosis of fluency disorders, allowing the clinician to examine whether the client’s responses to the self-report questionnaires are within or beyond what is typically considered in a “normally fluent” person, are like those of PWS, or might be characteristic of a different kind of

fluency disorder. Noting this distinction aids the clinician in avoiding false positive or negative diagnoses (Vanryckeghem & Brutten, 2018). The results obtained from these measures not only assist in differential diagnosis, but also in the determination of treatment targets. Goals that are specific to the client can easily be created based on the tests' outcomes.

Little is known about how PWS' significant others perceive stuttering. Even less is known about how PWS' life partners understand the debilitating nature of the fluency disorder specific to their significant other. Research has shown that familial inclusion in speech therapy for young children who stutter facilitates treatment success through consultation and counseling (Unger & Berg, 2013) as well as through specific interventions such as parent-child interaction therapy (PCIT; Millard, Nicholas, & Cook, 2008). As one ages, what would be considered "familial support" shifts from having the support of a parent, to having the support of a significant other. While there are data to warrant family-centered consultation and counseling in treatment in early childhood stuttering, there is limited information corroborating this conclusion as it relates to life partners. Limitations such as these lead to the present study which aims to investigate how PWS' significant others perceive their loved one's speech-associated emotional reactions to dysfluencies relative to particular situations. Based on this information, the ultimate goal is to aid in the facilitation and outcome of fluency treatment through family inclusion.

CHAPTER TWO: METHODOLOGY

2.1. Participants

All of the participants were required to be at least 25 years old, have been in a committed relationship that has existed for over one year, and had to be able to understand and read English. English language proficiency was determined via inquiry as part of the demographic questionnaire (0-5; 0: not very comfortable, 5: very comfortable; Appendix A). Every participant involved in this study indicated that he/she was “very comfortable” with his/her ability to read and understand English.

Participants who stutter had to have been diagnosed as a PWS by a Board-Certified Fluency Specialist or Speech-Language Pathologist. Individuals who had additional speech and/or language disorders were not included as part of the sample. The participants of this investigation were 23 adults who stuttered and their life partners who did not stutter. The age range was 25 to 63 for the PWS and 25 to 68 for the significant others. The average age was 35 for the PWS and 34 for the life partners. Seventy-three percent (74%; $n=17$) of the PWS were male and 26% ($n=6$) were female. For the significant others, 26% ($n=6$) were male and 74% ($n=17$) were female.

The participants in both of the subject groups are considered to be a representative sample of the population as they were gathered from 12 different states within the United States of America (Colorado, Connecticut, Florida, Georgia, Illinois, Massachusetts, Nevada, New Jersey, New York, Pennsylvania, Texas, Virginia). Participants were recruited via Board Certified Fluency Specialists, Speech-Language Pathologists, and National Stuttering Association chapters across the country.

Participants were asked to document his/her own/partner's perception of stuttering severity via Likert scale (very mild, mild, moderate, severe, very severe). Seventeen percent (17%) of stuttering participants considered their stutter to be very mild, 26% indicated their stuttering severity to be mild, 48% perceived their stuttering to be at a moderate severity level, 9% considered their stutter to be severe and 0% thought their stutter to be very severe. Perception of stuttering severity ranged among life partners' awareness of how their significant other who stutters views his/her stutter from very mild (4%), mild (39%), moderate (48%), severe (9%), to very severe (0%).

One hundred percent (100%) of the participants who stutter had been enrolled in speech therapy targeting their stutter specifically. Thirty percent (30%) of the participants who stutter are currently receiving fluency treatment. The PWS specified the types of therapy they had been exposed to as desensitization/anxiety reduction (most frequently listed), followed by attitude change, and a tie between stuttering modification, fluency shaping/reinforcement, and other (unspecified). Seventy percent (70%) of respondents who stutter were members of at least one fluency support group.

Time in which couples had been involved ranged from 1 year to 21 years with an average of 8.4 years ($SD=6.3$). Data related to participants who stutter and their life partner's age, education, and profession can be found in Tables 1 and 2, respectively.

Table 1: Demographic Information Related to Age, Education, and Profession of Participants Who Stutter

Age	<i>N</i>	Highest Level of Education	<i>N</i>	Profession	<i>N</i>
25	3	Associate's	1	speech-language pathologist	4
26	1	Bachelor of Arts	1	student	3
27	1	Bachelor of Science	5	engineer	3
28	1	Bachelor's (unspecified)	3	computer programmer	1
29	1	Master of Arts	1	crime analyst	1
32	3	Master of Science	2	financial services	1
33	2	Master's (unspecified)	8	general manager	1
34	1	Master of Business Administration	1	human resources	1
36	2	Doctor of Philosophy	1	investment banker	1
38	2			IT security	1
42	3			marketing	1
44	1			professional poker player	1
48	1			social science researcher	1
63	1			social services provider/musician	1
				special education teacher	1
				web developer	1

Table 2: Demographic Information Related to Age, Education, and Profession of Life Partners

Age	<i>N</i>	Highest Level of Education	<i>N</i>	Profession	<i>N</i>
25	1	High School	1	consultant	2
26	2	Associate's	1	nurse	2
27	3	Bachelor of Arts	1	scientist	2
28	1	Bachelor of Science	3	speech-language pathologist	2
29	3	Bachelor's (unspecified)	6	teacher	2
30	1	Master of Science	1	advertising	1
31	1	Master's (unspecified)	9	college administrator	1
32	1	Master of Business Administration	1	criminal justice	1
34	1			director of creative services	1
35	1			engineer	1
36	1			event planner	1
37	2			instructional design	1
39	1			personal trainer	1
46	1			philanthropist	1
47	2			student	1
68	1			tour guide	1
				unemployed	1
				realtor	1

2.2. Materials

2.2.1. *Speech Situation Checklist (SSC)*

All participants in this study were administered the Speech Situation Checklist (SSC; Vanryckeghem & Brutten, 2018). The SSC, one of the BAB subtests, is divided into two measures: Speech Situation Checklist – Emotional Reaction (SSC-ER) and Speech Situation Checklist – Speech Disruption (SSC-SD). These measures evaluate a client’s negative emotional reaction and degree of dysfluency, respectively, across a variety of different speech situations. The SSC-ER contains descriptions of different speech situations that a client rates according to the strength of association between negative emotional reaction (i.e. anxiety, fear, worry) and the listed speech situations. In other words, the Affective component of the stuttering syndrome is being investigated (Vanryckeghem, Matthews, Xu, 2017). The SSC-SD measures the degree to which the same situations as the ones described in the SSC-ER are viewed by the client as being associated with speech breakdown, or stuttering (Behavioral component; Vanryckeghem et al., 2017). Responses are rated on a five-point Likert scale, “1” signifying “not at all” to “5” indicating “very much” presence of speech-related emotional reaction and speech dysfluency in each of the 38 speech situations described. Scores are obtained by adding the individual’s responses based upon the self-severity rating. For the purpose of this study, the researchers will only be observing scores of PWS and their significant others on the SSC-ER.

While collecting normative data for the SSC, Vanryckeghem et al. (2017) found that the SSC presents with promising internal reliability, content validity, as well as construct validity. Factor analysis broke down the SSC items into seven factors. Situations in which speakers cannot avoid certain sounds or words (e.g., reading aloud) accounted for most anxiety (15.20%).

The second factor was related to interpersonal communication (e.g., asking specific questions or information; 13.88%). Criticism, being rushed or teased, and using specific sounds accounted for 11.25%. Factor 4 related to circumstances in which personal or specific information needs to be obtained and conditions where one needs to make an appointment or phone call, talk to a stranger, or be interviewed for a job (10.69%). The fifth factor induced limited concern for the participants and included speaking with friends (7.74%). Conditions such as public speaking (Factor 6) accounted for 6.82% and speaking with someone of the opposite gender (Factor 7) accounted for 4.89%.

These findings confirm earlier investigations by Brutton and Janssen (1981) assessing the validity and reliability of the SSC across Dutch and American PWS. Results indicated similarities between the two demographic groups with the top three situations that caused the most negative emotional reactions being the same, on average: speaking in front of a group of people, giving a prepared speech, and being rushed when talking.

Further, using a stepwise discriminant analysis, Hanson, Gronhovd, and Rice (1981) found the SSC items to have a significant discriminative power in differentiating PWS from PWNS. Specifically, the SSC was identified by the researchers as a helpful screening tool that is effective in detecting atypical speech-related anxiety. This statistically significant between-group difference was confirmed by Vanryckeghem et al. (2017). While both the SSC-ER and SSC-SD provide useful information in the differentiation between PWS and PWNS, the SSC-ER proved to be the most helpful in differential diagnosis (Vanryckeghem et al., 2017). Ten of the SSC-ER items proved to be the most telling as it relates to the differentiation between PWS and PWNS. Through the utilization of the discriminant equation, these aforementioned items correctly

identified 88.37% of PWS and 100% of the PWNS. This confirmed Bakker's (1995) data that the SSC-ER evidenced to be the most telling in regards to whether treatment is being generalized for a PWS.

2.3. Procedure

Participants in this investigation were given a consent form approved by the University of Central Florida Institutional Review Board (confirmation number: SBE-17-13586). Individuals involved in this study were told the purpose of the investigation as well as their need to complete questions via the Qualtrics Survey Software. The participants who stutter were provided the SSC-ER and their partners were given a modified version of the SSC-ER as it relates to his or her partner who stutters. Both groups were asked to complete the online self-report tests on an individual basis without consulting their life partner. Completing the SSC-ER generally took 10-15 minutes.

2.4. Data Analysis

Total as well as item scores were entered into IBM SPSS Statistic V25 software for statistical analysis. In order to see whether or not the answers of the two participant groups to the SSC-ER differ to a statistically significant extent, total score analyses were performed via *t* tests and a pre-set significance level of .05. Additionally, potential between-group gender and age differences were determined. Between-group data was obtained specific to duration of

relationships and analyzed by means of an analysis of variance (ANOVA). Within-group item score analysis was performed in order to determine Cronbach alpha internal reliability, as well as item-total score consistency. In addition, between-group analysis explored the extent to which items were answered in a same or a different way.

CHAPTER THREE: RESULTS

3.1. Total Score Analyses

As Table 3 and Figure 1 indicate, the minimum score on the SSC-ER for PWS was 44 (possible minimum is 38) and the maximum was 148 (possible maximum is 190). The median and mode were 92 and 69, respectively. For the life partners, the minimum score on the modified SSC-ER was 39 and the maximum score was 131. The median and mode were both 75.

The average SSC-ER score for the PWS ($M=92.91$; $SD=29.72$) was descriptively higher than that of their life partners ($M=80.65$, $SD=22.92$). However, this difference was not statistically significant ($t=1.567$, $p=.124$). A Pearson Correlation analysis between the groups' (PWS and LPs) revealed a significant moderate correlation of $.55$ ($p=.006$).

Table 3: Measures of Central Tendency and Variation for PWS and their Life Partners on the SSC-ER and Modified Version of the SSC-ER

Central Tendency	PWS	LP
Mean	92.91	80.65
Standard Deviation	29.72	22.92
Median	92	75
Mode	69	75
Minimum	44	39
Maximum	148	131

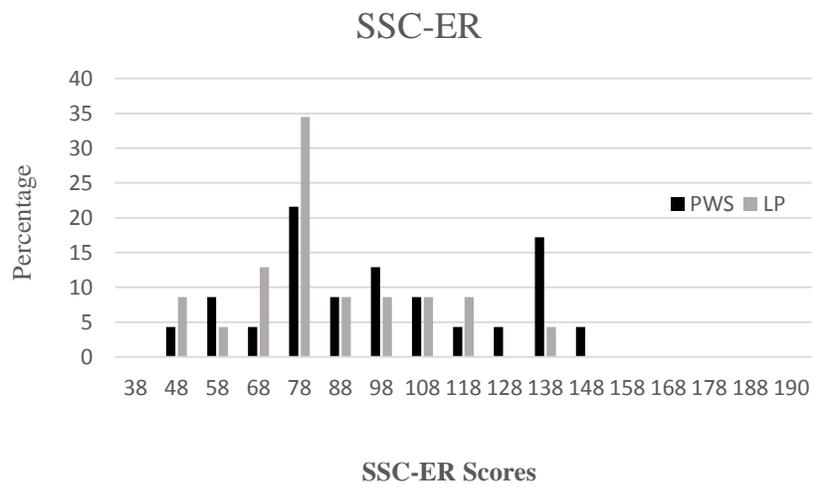


Figure 1: Distribution of SSC-ER Scores for PWS and LP

3.1.1. Gender Effect

The effect of gender on the SSC-ER scores revealed a mean of 91.18 ($SD=28.7$) for the 17 (74%) males and 97.83 ($SD=34.82$) for the 6 (26%) females in the group of PWS. This difference was not statistically significant ($t=-.463$, $p=.648$). The LP group consisted of 6 males (26%) and 17 females (74%). Their average scores were 91.18 ($SD=28.70$) and 97.3 ($SD=34.82$), respectively. This difference in scores was not significant ($t=-.059$, $p=.954$).

3.1.2. Age Effect

In order to investigate a possible age effect, the participants were split into two age groups: those aged 25 to 35 and those aged older than 35. For the PWS sample, the “younger” group (61%) scored on average 29.3 ($SD=3.47$) on the SSC-ER, whereas the “older” group (39%) had an average score of 42.9 ($SD=8.00$). This difference was not statistically significant ($t=.172$; $p=.865$). The “younger” participants in the group of LP (57%) scored 29.08 on average ($SD=3.01$), and the “older” individuals’ (43%) SSC-ER score was 44.63 ($SD=10.57$). This upward trend in scores with age did not prove to be statistically significant ($t=-.059$, $p=.954$).

3.1.3. Effect of the Relationship Duration on SSC-ER Score Agreement

The possible differential effect of the relationship duration on the agreement of the SSC-ER scores between PWS and LP was determined via ANOVA, which revealed a non-significant

effect ($F=.751, p=.698$), indicating that duration of the relationship does not affect the agreement of SSC-ER scores between PWS and their LP.

3.2. Item Score Analyses

Item score analysis was performed in order to investigate the SSC-ER and its modified partner version's internal reliability. The Cronbach Alpha correlation was high and significant for both groups (PWS=.97; LP=.95).

Item-total score consistency determination revealed that, for the sample of PWS, all items, except two, correlated significantly with the total score. They were items 8, "Are you anxious, concerned, or worried about your speech when you are chatting with friends" and 13, "Are you anxious, concerned, or worried about your speech when you are reading fixed material aloud?". For the LP sample, all but three items correlated significantly with the total score. They were items 6, "Is your partner anxious, concerned, or worried about his/her speech when he/she is talking with a close friend?", 13, "Is your partner anxious, concerned, or worried about his/her speech when he/she is reading fixed material aloud?", and 36, "Is your partner anxious, concerned, or worried about his/her speech when he/she is giving a telephone number?".

When comparing the SSC-ER item scores of PWS and their LP, all but six were in agreement and did not differ significantly. The item scores that were not in agreement and significantly differentiated the two groups were items 3, 4, 13, 19, 26, and 27. They relate to: saying one's name, saying a sound or word that previously has been troublesome, reading fixed

material aloud, and making introductions. PWS reported higher levels of negative emotional reactions compared to their LP on these aforementioned questions.

CHAPTER FOUR: DISCUSSION

4.1. Interpretation of PWS Results

When comparing the current SSC-ER results of PWS with other investigations of this self-report test (Vanryckeghem et al., 2017), it was observed that the average scores from the 2017 investigation were higher ($M=115.34$, $SD=28.62$) compared to the present data. It needs to be kept in mind, however, that the current data are based on a much lower sample size compared to the Vanryckeghem et al. (2017) data (88 PWS).

The SSC-ER scores for PWS were not differentially affected by gender or age. Also, in the Vanryckeghem, Matthews, and Xu (2017) study, males and females' scores did not differ to a significant extent. In contrast, in the Belgian study by Brutton and Vanryckeghem (2003), the female PWS scored statistically significantly higher on the ER portion of the SSC. Thus, as it relates to gender, the data systematically point to higher scores among females compared to males. However, this difference in scores is not always significant.

The current investigation did not find a significant age effect among PWS, although descriptively, the older participants had a higher SSC-ER score. These results are in agreement with the Brutton and Vanryckeghem (2003) data where numerically (though not significantly) higher scores were obtained among the older adults. Vanryckeghem and colleagues (2017) divided their sample into age groups 18 to 30 and 31 to 60. In contrast to the current, and Brutton and Vanryckeghem (2003) results, they found that the average SSC-ER score of the younger group ($M=116.62$; $SD=29.56$) was higher than the older group ($M=111.37$; $SD=26.54$), a difference that was not statistically significant. It can, thus, be concluded that age does not affect the SSC-ER scores of PWS to a statistically significant extent.

The SSC-ER Cronbach Alpha value indicates high internal reliability, meaning that the test's items correlate well with one another. These findings corroborate with the high internal reliability value of .96 found by Vanryckeghem et al. (2017) for PWS. In addition, item-total score consistency indicated that the vast majority of items correlate significantly with the total score, and, thus, contribute to the totality of the test. In the Vanryckeghem et al. (2017) study, all of the items correlated significantly with the total score and were able to successfully identify PWS based on their responses to the items.

In general, it can be stated that the SSC-ER is an internally reliable measure that can be used in identifying negative emotional reaction in individuals who stutter. Although gender and age contribute to the total score, they do not do so to a statistically significant extent.

4.2. Interpretation of LP Results

Provided that there have not been any studies analyzing life partner's perceptions on the emotional impact that stuttering has on their significant other, the present study's conclusions cannot be compared to previous investigations. Similar to the PWS group, the SSC-ER scores for LP were found not to be differentially affected by gender or age. In addition, the modified LP SSC-ER version indicated a high internal reliability and item-total score consistency, demonstrating that items correlate well with one another and the total score.

4.3. Between-Partners Data

The differences in the average SSC-ER scores between PWS and their LP indicate that LPs, to some extent, underestimate the emotional impact that stuttering has on their loved ones overall, but not to a significant extent. Also, the correlation between the two groups' scores was moderate and significant, suggesting that there is a general understanding on the LP's behalf of the emotional impact that stuttering has on their life partner who stutters. Related to this, it was important to note that length of the relationship did not have a significant effect on the agreement between the SSC-ER scores of the two groups. These data indicate that duration of relationship, whether it be 1 year or 21 years, does not affect the agreement of the negative emotional reaction perceptions between PWS and their LP.

SSC-ER item score comparison between groups revealed that all but six items were answered in a way that was not significantly different. Those situations that led to a different scoring by the members of the two groups all revolved around one construct in particular: situations in which words/sounds cannot be easily substituted or changed. They dealt with stating your name, introducing oneself and reading, which might be situations that are less obvious to the LP in terms of being anxiety provoking. Specifically, the items related to being unable to switch/substitute fixed words/sounds, speech situations in which the PWS has to give his/her name, reading fixed material aloud, and make introductions --- all of which include "fixed" words to some extent (e.g. one's name cannot be changed upon meeting someone, neither can changing words when reading aloud). Additionally, saying a sound or word that has previously been troublesome was an item that differed to a significant extent between the groups. Provided that words can easily be circumlocuted or substituted by the PWS, it might be possible that the

LP is not aware of any overt struggle, especially if their loved one is proficient in navigating/manipulating words and terminology when speaking. These aforementioned differences between groups are miniscule when considering every construct this test assesses. PWS and their LP agree in terms of perception of what the partner who stutters experiences relative to situations that involve interpersonal stress (e.g. asking specific questions/information), situations in which personal and/or specific information needs to be provided (e.g. making appointments), talking to friends, and situations that include public speaking.

In summary, provided the significant, moderate correlation between the PWS and LP SSC-ER scores, and the lack of a significant between-group difference in the scores, it can be concluded that PWS communicate their speech-associated emotional reaction relative to particular speech situations at least to some extent. In addition, only six of the 38 SSC-ER items were answered in a significantly different way between the two groups, indicating, again, that the LPs' perception of how their loved one feels in certain communication situations is quite accurate.

4.4. Including Life Partners in Treatment

When undergoing fluency treatment, it is imperative that support, whether it be from someone the client is related to, friends with, or involved with, is incorporated in therapy (Bloodstein & Bernstein Ratner, 2008). Having a life partner accurately perceive the emotional reactions of a loved one who stutters may attribute to attained fluency for a client. In studies revolving around parental involvement in children who stutter, the inclusion of loved ones in fluency treatment has

been highly encouraged. There are multiple ways in which parents can be involved in their child's treatment, whether it be through active participation such as in the Lidcombe Program of Early Stuttering (verbal response contingent stimulation; Onslow & Millard, 2012; Onslow, Packman, & Harrison, 2003) or the Palin Parent Child Interaction stuttering program (family-oriented therapy; Onslow & Millard, 2012). The therapist can also support the parents by providing education relative to stuttering (Ramig & Dodge, 2005), or indirectly via general guidance, or established treatment programs such as the Demands and Capacities Model (manipulation of environment so as not to induce dysfluencies; Sonnevile-Koedoot, Adams, Stolk, & Franken, 2015).

It is encouraged that PWS' significant others are active participants in fluency treatment (Ramig, 1993). Ramig suggests that loved ones initially begin by observing sessions. After this initial step, it is recommended that they are active participants in treatment, becoming part of the activities and helping to reinforce strategies presented in therapy. This type of inclusion will increase the likelihood of positive reactions outside of the therapy room, due to increased levels of sympathy. In turn, this involvement might be expected to reduce the PWS' negative emotional reactions and negative attitude toward dysfluencies. It can be hypothesized that incorporating loved ones into treatment will, overall, increase their level of knowledge toward stuttering, allowing them to further understand client-specific environmental factors that can aid or hinder fluency in everyday life. Examples of situations that may impede fluency include, but are not limited to, speaking to the individual with a fast speech rate, having unrealistic fluency expectations, and negatively reacting to dysfluencies.

It is not uncommon that people's attempts to help PWS result in being detrimental and unhelpful to the individual, overall exacerbating the stutter (Ramig & Dodge, 2005). Sayings such as "Take a deep breath", "Slow down", or simply ignoring dysfluencies can be considered as "negative" reactions to dysfluent speakers. These reactions are believed by some to instill fear and avoidance behaviors in PWS (Ramig & Dodge, 2005). Responses to stuttering that are encouraged are comments such as "That was a hard word. Take your time, though, I will always wait for you to finish what you would like to say". Additional strategies include lessening interruptions in conversation, speaking with a slower speech rate, and respecting silence in interactions. Providing appropriate reactions and responses to a stutter can benefit the communicative environment for a PWS, thus improving attained fluency, whether it be for a child or an adult who stutters (Ramig & Dodge, 2005). Considering these conclusions, with education, life partners will be more likely to facilitate and support positive speech-associated emotional reactions from their loved one who stutters if he/she reacts and responds appropriately to dysfluencies and the PWS' reactions to them.

4.5. Treating the Client, Not Only the Stutter

As mentioned previously, the SSC-ER can provide helpful information as it relates to differential diagnosis between PWS and PWNS, or individuals with other fluency failures. Considering this, knowledge gathered from the SSC-ER can help guide treatment to meet a client's individual therapeutic needs specific to communicative emotional reactions (Vanryckeghem et al., 2017). Not only could fluency enhancing strategies be used as a means to improve a client's fluency,

but, as a result, also his/her confidence. Counseling techniques may be found helpful to an individual when attempting to increase confidence levels. Counseling has been found to be very effective in working with clients who stutter in terms of addressing the emotional aspects surrounding stuttering. In order for counseling to make an impact, the therapist must be educated not only about the speech impediment itself, but also be aware of the client-specific speech-related struggle and avoidance behaviors he/she is faced with on a daily basis (Ginsberg, 2000; Ginsberg & Wexler, 2000). Researchers have shown that there are positive effects on attained fluency in those who stutter when provided with sympathy and compassion by a clinician (Ginsberg, 2000). Having this mutual understanding extend beyond the therapy room would be expected to have lasting effects, due to the increased level of support at an intimate level, especially from a life partner. When interactions and environments outside of therapy are paralleled with those in effective treatment, chances of attained fluency will increase as a result (Ramig & Dodge, 2005).

In their investigation of successful stuttering management, Plexico, Manning, and DiLollo (2005) found that what differentiated “unsuccessful management” from “successful management” of stuttering were support, effective therapy, self-reflection and behavior change, and attitudinal change. The aforementioned factors can result from successful counseling and specific cognitive-behavioral treatment procedures. Positive feelings can be induced by a competent clinician and would be expected to be even stronger if a loved one is provided with insight into the communication-related emotional reactions specific to his or her partner who stutters.

CHAPTER FIVE: INVESTIGATION LIMITATIONS

At the conclusion of this study, the data were based on a small sample, which is considered a limitation in terms of generalizability of the results. However, given that this study is part of a larger ongoing investigation about the relationship between PWS and LP's feelings, thoughts, and speech perceptions relative to the partner's stuttering, data will systematically be added to the totality of data collection.

CHAPTER SIX: CONCLUSION

LPs have a general understanding of the situation-specific emotional impact that stuttering has on their loved one. The PWS and LPs' scores on the SSC-ER and its modified version did not differ significantly and the relationship between the total scores was moderate and significant. Further analyses confirmed that age and gender of the participants did not significantly affect the SSC-ER scores. Both the original SSC-ER and the partner version proved to be internally valid. Comparison of the item scores of the PWS and their LP, revealed that both partners are, to a large extent, in agreement as it relates to their perception of the situation-specific emotional reaction. The six items that the partners did not agree upon related to specific sounds and words.

Stuttering therapy that is multi-dimensional not only consists of the introduction of strategies that modify stuttering or enhance fluency, but also addresses the cognitive and emotional impact stuttering has on an individual. The importance of counseling and incorporating the partner in fluency treatment is part of the more holistic approach to treatment of the individual who stutters. The results of the present investigation can help guide fluency treatment in incorporating a significant other in therapy and creating talking points between partners, ultimately strengthening the union between the PWS and his/her LP.

**APPENDIX A:
UNIVERSITY OF CENTRAL FLORIDA INSTITUTIONAL REVIEW BOARD
APPROVAL LETTER**



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Determination of Exempt Human Research

From: **UCF Institutional Review Board #1
FWA00000351, IRB00001138**

To: **Athanasia Svenning**

Date: **December 04, 2017**

Dear Researcher:

On 12/04/2017, the IRB reviewed the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination, Category 2
Project Title: Life partners' perceptions of emotional, behavioral, and cognitive impact of stuttering
Investigator: Athanasia Svenning
IRB Number: SBE-17-13586
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

This letter is signed by:

A handwritten signature in cursive script that reads "Renea Carver".

Signature applied by Renea C Carver on 12/04/2017 01:33:57 PM EST

Designated Reviewer

**APPENDIX B:
ENGLISH LANGUAGE PROFICIENCY MEASURE FOR PWS AND LP**

Is English your first language? Yes No

If not, what is your mother-tongue?

How well do you understand English? (0 = not at all; 5 = near native proficiency)

0 1 2 3 4 5

How well do you read English? (0 = not at all; 5 = near native proficiency)

0 1 2 3 4 5

How comfortable do you feel in your ability to understand English? (0 = not comfortable at all; 5 = very comfortable)

0 1 2 3 4 5

How comfortable about do you feel when reading English? (0 = not comfortable at all; 5 = very comfortable)

0 1 2 3 4 5

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