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Quality of life of people who stutter

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A Thesis

entitled

Quality of Life of People who Stutter

by

Emily Figliomeni

Submitted to the Graduate Faculty as partial fulfillment of the requirements for the

Master of Arts Degree in

Speech Language Pathology

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May 2015

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An Abstract of
Quality of Life of People who Stutter

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Stuttering is a communication disorder that can impact a person's life. The purpose of this study was to qualitatively explore the impact of stuttering on quality of life (QOL), and the differences between the beliefs of people who stutter (PWS) and the speech-language pathologist (SLP) regarding this issue. Individual experiences were obtained through the process of open-ended interviews with six PWS, and six SLPs who work with PWS. Major recurring themes included: 1) restriction, 2) identity, 3) positivity, 4) control, and 5) therapy impact. Similar beliefs were shared among individuals in both groups of participants, and were reflected in additional minor themes including therapy impact on QOL, physical impact, empowerment, acceptance, authenticity, and restriction regarding occupation and personal relationships. Different beliefs were also identified between individuals in both groups of participants, and were reflected in minor themes regarding happiness, unpredictability, avoidance, responsibility, good and bad therapy, advocacy, the individual, and restriction of education. Further research is recommended to continue the process of understanding the similarities and differences between how PWS and SLPs believe QOL should be involved in therapeutic practices.

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Table of Contents

Abstract	iii
Acknowledgements	iv
Table of Contents	v
List of Tables	ix
List of Figures	x
List of Abbreviations	xi
Preface	xii
I. Literature Review	1
A. Definition of Stuttering	1
B. Prevalence and Etiology	2
C. Stigma	3
D. Psychosocial Characteristics	5
E. Perspectives of People who Stutter	6
F. Quality of Life	8
G. International Classification of Functioning (ICF)	10
a. Impairments in Body Function	11
b. Impairments in Body Structures	12
c. Personal Contextual Factors	13
d. Environmental Contextual Factors	13
e. Activity Limitations and Participation Restrictions	14
H. Therapy for People who Stutter	15
I. Statement of the Problem	19

J. Purpose	20
II. Methods	21
A. Qualitative Research	21
B. Participants	24
C. Procedures	30
D. Analysis	31
E. Credibility	33
III. Results	35
A. Introduction	35
B. Participation Information	35
C. Qualitative Data	36
a. Restriction	39
i. Restriction Regarding Occupation	39
ii. Restriction Regarding Personal Relationships	40
iii. Restriction Regarding Education	42
iv. No Restriction	43
b. Identity	45
i. The Individual	45
ii. Advocacy	46
iii. Acceptance	47
iv. Authenticity	48
c. Positivity	49
i. Happiness	49

ii. Empowerment	50
d. Control	52
i. Unpredictability	52
ii. Avoidance	54
iii. Responsibility	55
iv. Physical Impact	56
e. Therapy Impact	58
i. “Good” Therapy	58
ii. “Bad” Therapy	60
iii. Therapy Impact on QOL	61
IV. Discussion	63
A. Impact of Stuttering	65
B. Definition of QOL	69
C. Impact of Stuttering on QOL	70
D. Beliefs of PWS and SLPs	72
V. Conclusion	75
A. Limitations	75
B. Implications for Further Research	76
References	78
Appendices	96
A. Permission by University of Toledo Social, Behavioral, and Educational Institutional Review Board from the Department for Human Research Protections	96
B. Contact Email/Flyer for Quality of Life Study	97

C. Contact Email/Flyer for Quality of Life Study-From Emily to Schedule	98
D. Adult Research Subject – Informed Consent Form	99
E. Demographic Questionnaire for Speech-Language Pathologists	102
F. Demographic Questionnaire for Individuals who Stutter	103
G. Questions for Interviews of SLPs Working with Individuals who Stutter	104
H. Questions for Interviews of Individuals who Stutter	105

List of Tables

Table 1	People who Stutter (PWS) Demographic Information	25
Table 2	Therapy Experiences of People who Stutter (PWS)	26
Table 3	Speech Language Pathologist (SLP) Demographic Information	28
Table 4	Major and Minor Theme Structure	37

List of Figures

Figure 1	Theme differentiation according to participant occurrence	38
Figure 2	Theme differentiation according to research question.....	64

List of Abbreviations

ASHA.....	American Speech-Language-Hearing Association
CCC	Certificate of Clinical Competence
ICF	International Classification of Functioning
N/A	Not Applicable
OASES.....	Overall Assessment of the Speaker's Experience of Stuttering
OASES-S	Overall Assessment of the Speaker's Experience of Stuttering – School Age
PWDS	People Who Don't Stutter
PWS	People Who Stutter
Ph.D.	Doctor of Philosophy
SLP.....	Speech Language Pathologist
SSI.....	Stuttering Severity Instrument
SIG	Special Interest Group

Preface

Stuttering is a communication disorder that affects nearly one in every one hundred people, and can genuinely impact many aspects of a person's life (Guitar & Conture, 2006). Despite the abundance of research that has been devoted to stuttering as a disorder, comparatively less research describes how stuttering impacts a person's life. Some researchers suggest that quality of life (QOL) of people who stutter (PWS) is greatly affected by their stuttering (Craig, Blumgart, & Tran, 2009; Markham, 2009; Yaruss, 2010; Yaruss & Quesal, 2004). Not only is QOL important for researchers to recognize, it is vital for speech-language pathologists (SLPs) to understand how meaningful it is for these individuals.

Extensive literature documents that healthcare professionals, including SLPs, believe that understanding the outcome of treatment should include measuring the impact of the condition on QOL (e.g., Johnson, Beitchman, & Brownlie, 2010; Manning, 2010; Moyson & Roeyers, 2012; Theofilou, 2013; Van Riper, 1973; Yaruss, 2010; Yaruss & Quesal, 2004). To date, quantitative studies have utilized questionnaires that were not developed for use with PWS (e.g., Bombardier, Tugwell, Patel-Sneider, Germanson, & Corey, 1983; Theofilou, 2013; Woodend, Nair, & Tang, 1997). Qualitative studies have asked questions related to QOL (e.g., Moyson & Roeyers, 2011; Yaruss, 2010), but very few have fully explored the impact of stuttering on QOL (e.g., Craig, Blumgart, & Tran, 2009), particularly the differences between the beliefs of PWS and the clinicians regarding this issue.

In contrast to the lack of qualitative research regarding how a communication disorder affects an individual, many quantitative studies have explored the relationship

between people with communication disorders and QOL issues. For example, surveys have been used to compare patient, physician, and family QOL perspectives on persons with health disorders (Bombardier, Tugwell, Patel-Sneider, Germanson, & Corey, 1983; Woodend, Nair, & Tang, 1997). Questionnaires have been used to investigate the relationship between personality characteristics of PWS and the impact of stuttering on everyday life (Bleek, 2012) as well as its impact on academic experiences (Crowe & Walton, 1981; Yeakle & Cooper, 1986). Differential scales have been used with college students and university professors to rate hypothetical PWS with particular personality traits (Dorsey & Guenther, 2000). Other experimental modalities have been used to compare PWS with people who do not stutter (PWDS) (Davis, Howell, & Cooke, 2002; Franck, Jackson, Pimentel, & Greenwood, 2003). All of these studies investigate how key aspects of a person's life, like personality and academic success, can affect their overall QOL living through quantitative modalities.

Although QOL of PWS has been explored quantitatively, little to no research has been done to qualitatively study the beliefs of PWS and SLPs about the impact of stuttering on QOL. Therefore, the following chapter will review the available literature related to QOL, psychosocial characteristics of stuttering, and the role of the SLP when measuring therapy outcomes with PWS. The literature review will be divided into sections that include: 1) a review of research on psychosocial impact of stuttering; 2) an exploration of the impact of stuttering on an individual; 3) literature related to the importance of QOL and communication disorders; and 4) the role of health-care professionals and SLPs in regards to QOL.

Chapter One

Literature Review

Definition of Stuttering

Stuttering can be identified as both a speech event and a disorder (Yairi & Seery, 2015). As a speech event, stuttering is an involuntary disruption of the smooth execution of a speaker's intentional speech act (Yairi & Seery, 2015). Overt speech characteristics are the most obvious outward aspects of stuttering, and these characteristics are what define stuttering as a speech event. Interruptions are displayed by PWS in the normal flow of speech in their respiratory, articulatory, and phonatory levels, and they also demonstrate repetitions, prolongations, or blocking of sounds and/or syllables (Yairi & Seery, 2015). While many PWDS demonstrate interruptions in their speech, it is important to differentiate between PWS and PWDS. A major aspect of differentiating between the speech of PWS and PWDS is often provided by the listener. Yairi and Ambrose (2005) considered the fact that because normally fluent speakers sometimes produce disfluent speech, defining stuttering is often based on the statistical probability that certain speech patterns will be perceived by listeners as stuttering.

Stuttering is a complex disorder, and has consistently been identified as a multidimensional communication disorder throughout the literature (Yairi & Seery, 2015). When considering stuttering as a multidimensional disorder, many other characteristics and dimensions that are debilitating to PWS are considered beyond speech disfluency. Yairi & Seery (2011) identify stuttering dimensions that include overt speech characteristics (e.g., repetitions, prolongations, cessations, etc.), physical concomitants (e.g., tense body movements in the head and neck regions, poor eye contact, etc.), and

abnormal physiological activity (dilated pupils, changes in blood flow, brainwave activity, etc.). Additional dimensions of a stuttering disorder include heightened affective reactions to speech disruptions (Miller & Watson, 1992; Yairi & Seery, 2015; Yaruss & Quesal, 2004), limiting cognitive processes (Boyle, 2011; Craig, Blumgart, & Train, 2009; Yairi & Seery, 2015), and a negative impact on interpersonal and social dynamics (Murphy, Yaruss, & Quesal, 2007; Yairi & Seery, 2015; Yaruss & Quesal, 2004).

Prevalence and Etiology

The etiology of stuttering remains a mystery. However, the hallmark of the development of stuttering is that there is variability in most suspected causes. Information about the prevalence and incidence of stuttering with respect to factors such as gender, age, and/or different subpopulations (e.g., those with phonological disorders/delays), has direct implications for understanding the dynamics and causation of stuttering (Yairi & Seery, 2015). Andrews & Harris (1964) did a longitudinal study reporting both the prevalence and incidence of this stuttering disorder. They surveyed one thousand children over a period of fifteen years, and determined that forty-five children had stuttering that lasted any duration, and ten of these children were still stuttering after fifteen years. According to this study, the incidence of stuttering is about 4.5% and the prevalence is approximately 1%. In general, estimates of the lifetime incidence of stuttering in the United States and Western Europe vary greatly (Bloodstein, 1995), but the central tendencies of the various reports indicate that 5% of the general population has ever stuttered, and 1% of the population stutters today.

Changes in the prevalence of stuttering with age, gender, subpopulations, and the influence of the rate and timing of natural recovery from stuttering are considered when

interpreting incidence and prevalence (Yairi & Seery, 2015). For example, a lower incidence of stuttering was identified in deaf people (Backus, 1938), and a higher incidence of stuttering was identified in people with Down's syndrome (Preus, 1973). Differences in subpopulations such as auditory processing, chromosomal abnormality, low intelligence levels, discrepancies in language skills, and low muscle tone may prove to be possible influences on stuttering (Yairi & Seery, 2015). Trends in familiarity have also been seen in PWS. While 10% of normally fluent people had family members who stuttered, according to studies by Yairi, Ambrose, and Cox (1996), the majority of studies reported between 30% and 60% of PWS had a familial incidence. Additional evidence indicates a potential genetic component to stuttering (Kidd, 1984; Suresh et al., 2006).

Stigma

Frequently, PWS are viewed as being more anxious than PWDS (Craig, 1990) and as being depressed (Costa, 1983; Costa, Antoniac, Bergheanu & Marinescu, 1986; Khavin, 1985). Literature has shown that PWDS hold a stuttering stereotype in which PWS are viewed as being guarded, nervous, self-conscious, tense, sensitive, hesitant, introverted, and insecure (Davis, Howell, & Cooke, 2002; Kalinowski, Lerman, & Watt, 1987; Woods & Williams, 1976).

Bricker-Katz, Lincoln, and Cummings (2013) qualitatively explored the impact of stuttering on the work lives for adults who stutter. Several adult participants indicated that stigmatizing attitudes in the workplace limited their work experience. Two stigmas were evident: 1) a self-stigma from the adult who stutters and 2) a perceived public stigma from coworkers. Many of the adults who stutter expressed "fear of others doubting their competence," and being perceived as "not normal," ultimately impacting

their self-confidence by circulating “bad thoughts” throughout the workday. Even though judgments were perceived to be a reflection on how competent these adults who stutter were in their work role, very few participants actually reported receiving negative feedback about their performance, indicating a possibility of dramatic thoughts and excessive focus on a public stigma that may not even exist to the extent at which they perceive it. The intensity of emotion that is evidently attached to these adults’ fear of negative evaluation about their stutter could arise from years of exposure to the public stuttering stereotype (Betz, Blood, & Blood, 2008; MacKinnon et al., 2007), diminishing self-esteem and restraining possibilities for occupational goal setting (Bricker-Katz, Lincoln, & Cummings, 2013).

Boyle (2013) conducted a study that assessed self-stigma of PWS, and ways to measure its impact. Nearly 300 adults who stutter were presented with an experimental scale call the Self-Stigma of Stuttering Scale (4S) in order to measure different levels of self-stigma these individuals perceived. The scale included questions related to confidence, self-efficacy, and overall life satisfaction. Results of the study indicated that the scale was able to reveal crucial components supporting a multidimensional model of stigma. Stereotype-agreement and stigma awareness were negatively correlated with life satisfaction, self-confidence, and self-efficacy, indicating that the 4S has strong construct validity and is recommended for SLPs to use when working with PWS. Boyle’s 4S can help proactively identify and combat stigma in therapy to alternate negative beliefs and help reduce the possibility of relapse. Additionally, the study corroborates existing evidence that stigma is a powerful self-abrasive perception that can negatively impact a

person's QOL (Corrigan, Larson, & Kuwabara, 2010; Major & O'Brien, 2005; Steele, 1997; Steele & Aronson, 1995).

Psychosocial Characteristics

Many researchers used to believe that stuttering was a product of anxiety (Johnson, 1942). However, anxiety is simply another affective response to how stuttering intrudes on a person's everyday life. Researchers know now that stuttering is a multifaceted disorder involving primary speech characteristics and secondary reactions, including anxiety, negative attitudes, and emotions (Cooper, 1993; Manning, 2001; Yaruss & Quesal, 2004). These primary and especially secondary characteristics can affect a person's overall QOL.

According to Craig, Blumgart, and Tran (2009), anxiety and negative attitudes may not always be towards stuttering, but towards their dependence on therapy. In their study, they used the Medical Outcomes Study Short Form-36 (SF-36; Ware & Gandek, 1998; Ware et al., 1993), to assess the impact of stuttering in adults who stutter. Using the domains of this test as a reference, they found that stuttering in this population of adults impacts mental health status, vitality, and emotional and social functioning. These results are indicative of additional clinical resources to be invested in treating adults who stutter. Additionally, this study found that adults who stutter and seek treatment would stutter more severely than adults who stutter whom do not seek treatment, and that perhaps, as a consequence, those who seek treatment will have elevated anxiety levels (Craig, Hancock, et. al., 2003; Craig, Tran, & Craig 2003).

A similar study by Chun, Mendes, Yaruss, & Quesal (2010) investigated how stuttering affects the QOL of children and adolescents who stutter while using the Overall

Assessment of the Speaker's Experience of Stuttering – School-Age (OASES-S). Results indicated over 71% of these children and adolescents felt “very bad” for being called stutterers. Further quantitative analysis in this study found that there is a tendency toward a positive correlation between severity of stuttering and impact of stuttering on QOL, meaning that to younger people, the more severe their stutter is, the more it may affect their QOL. Regardless, a better understanding of the impact of stuttering in these age groups provides a needed guide for ways to create better stuttering treatments to improve outcomes.

Perspectives of People who Stutter

In order to understand a clinician's perspective of different PWS, it is necessary to explore how people use perspective to define themselves. Barofsky (2012) examined how people identify themselves by exploring the idea of how differing perspectives can define this identification. Self is something that emerges from a relational process: individuality is created by and through others (Bakhtin, 1990; Mead, 1934). The self is not something completely new; instead, it is derived from an integration and an elaboration of past experiences in the here and now of the interaction in which people are involved (Barofsky, 2012). In previous qualitative studies, PWS reported negative effects of self-stigma from PWDS in a workplace environment (Bricker-Katz, Lincoln, & Cummings, 2013). This implies that people define themselves, in part, by how others perceive them. The challenge for this perspective is thus to account for an individual's uniqueness without adopting an individualistic lens and to stress how a dynamic conception of the self is the result of interaction between stability and change (Salgado & Goncalves,

2007). Barofsky (2012) concluded that gaining perspective seems to be a promising tool for the analysis of the negotiation of identities in conversation.

Daniels & Gabel (2004) took the concept of identity further, and said that when identity is considered as a social construction, it becomes an extremely important concept in understanding PWS. These authors argued that for PWS, constructing a positive identity can be very difficult because of the effect that stuttering may have on communication and social interactions, as well as the scarcity of role models and peers who stutter. Most researchers exploring perceptions of PWS have found that all listener groups surveyed have reported negative perceptions and/or stereotypes about PWS (Daniels & Gabel, 2004); these studies included the perceptions of SLPs (Cooper & Cooper, 1996; Turnbaugh, Guitar, & Hoffman, 1979). This study by Daniels & Gabel (2004) provides support for suggesting that PWS can provide insight about identity that may vary from the usual ways that the disorder is categorized.

Other studies provide valuable insight into parental perceptions of their child's QOL, but little evidence reports perception from the children themselves (Glogowska et al, 2001; Markham & Dean, 2006), which again reiterates the importance of clinical perspective in relation to therapy outcomes. Markham & Dean (2006) quantitatively examined perceptions of parents who had children with communication needs. Markham, van Laar, Gibbard, & Dean (2009) further studied this concept by qualitatively describing experiences as reported by children. They studied a group of children between 6 and 18 years of age who had a variety of communication needs and were all receiving speech therapy. Results of this study concluded that many children with speech-language

difficulties have a higher incidence of psychosocial, educational, and emotional problems than their non-impaired peers.

The most interesting findings from this study, however, were the similarities and differences between what parents identified as affecting their children's QOL compared to what the child identified as affecting their QOL. Similarities between perceptions of parents and children included the need for the child with the communication impairment to live independent lives if they are to have an increased QOL, and that a quiet, calm and structured learning environment positively assists their lives in school (Markham, van Laar, Gibbard, & Dean, 2009). Differences between perceptions of parents and children included children, unlike their parents, feel that relaxation, friendship, and a sense of achievement contribute to their QOL. These differences indicated a need for targeted change in therapy so that children and adolescents may have greater value in life rather than increased linguistic outcomes.

Quality of Life

QOL and its importance to understanding our lives has been debated since the time of Aristotle and yet it still remains a universally undefined term (Rapley, 2003). QOL has been viewed as a multidimensional concept emphasizing the self-perceptions of an individual's current state of mind (Bonomi, Patrick, Bushnell, & Martin, 2000), but even the American Society for Quality acknowledges difficulties with the term by stating that "quality" is a "subjective term for which each person has his or her own definition" (see Barofsky, 2012, pg. 626). However, many researchers have attempted to use QOL measurements in order to assess how large external factors (e.g., terminal illnesses, surgery) are impacting a person's life. QOL can be defined not by describing what has

occurred, but how something has occurred. A single global item, such as the Self-Assessed Health Status (SAHS), can be useful for research on quality of life (Barofsky, 2012).

A trend in how “life quality” is defined has been observed. Positive terms rather than negative terms have been used to define “life quality.” Instead of measuring how negative their life quality is, people tend to measure how positive their life quality is by measuring “goodness” and “well-being” (Theofilou, 2013). This implies that QOL is measured by what needs to be done so that a person is happy, more so than what needs to be done so that a person is not unhappy. Regardless, both positive and negative affect influences a personal sense of one’s QOL (Diener, et. al., 1999).

The measurement of psychosocial issues in addition to biomedical measures has been shown to play an important role in ensuring positive patient outcomes from both a clinician’s and patient’s perspective, and it is an important outcome measure when evaluating treatment (Theofilou, 2013). It has been suggested that there may be a distinction between observable objective measures of health status, such as in a clinical profile and an individual’s perception about the quality of his/her life (Mathers & Douglas, 1998). This is why it is important to use QOL assessments appropriately and respectfully with individual clients. After all, the validity of an instrument is the degree an instrument measures what it was intended to measure (O’Connor, 2004).

Ultimately, QOL measurement provides a holistic understanding of an individual’s condition and therefore a greater number of alternatives to manage the condition (Bowling, 1997). Unbiased qualitative research is advocated by researchers of QOL who recognize that health care providers and clients often disagree on the important

issues impacting a client's life (e.g., Slevin et al., 1988). QOL assessments must emerge from the individual of interest rather than from the interested observers of that person. Many domains can impact QOL, but previous literature seems to indicate that personal relationships (e.g., family, spouse, classmate), work relationships (e.g., coworkers, supervisors, etc.), personality (e.g., introverted, extroverted, etc.), education (e.g., career path, class participation, etc.), and physical health (e.g., stress, facial or laryngeal tension) are possible contributing factors to the QOL of PWS (see Bleek, et al. 2012; Corcoran & Stewart, 1998; Craig, Blumgart, & Tran, 2009; Crichton-Smith, 2002; Yaruss & Quesal, 2006).

International Classification of Functioning (ICF)

The World Health Organization (WHO) presents meaningful, comparable information on health system performance, and explains variations of key factors that strengthen scientific foundations of health policies across the world (Murray & Frenk, 1999). It provides an operational framework for assessing health system performance (Murray & Frenk, 1999). The environment and contextual factors that affect an individual's health and overall functioning fall under distinct categories, and can have varying impacts on an individual. The WHO describes QOL as a person's unique perception of their position in life in the context of the individual culture and value systems where they live in relation to their expectations, standards, concerns, and goals (WHOQOL, 1998a).

The International Classification of Functioning (ICF) is enveloped within the WHO framework, measuring health and disability of large populations and of the individual (WHO, 2014). Ultimately, the ICF models how to assess the impact of

functioning of an individual based on environmental and other contextual factors (WHO, 2014). The ICF model incorporates environmental and personal factors to describe how an individual person could react to their health condition. This model also takes into account the listener's reaction to a person's health condition as well, which is particularly relevant to PWS (Yaruss & Quesal, 2004). These reactions may be helpful or harmful, but either way, measuring a person's reactions to his/her health disorder helps identify the person's overall life experience in relation to the disorder.

The ICF identifies impairments, limitations, and restrictions in two main categories: 1) body function and structure, and 2) activities and participation. Impairments describe difficulties that arise with how the body forms and functions in relation to the disorder (body function and structure), while limitations and restrictions describe difficulties with participating in the natural activities of daily living (activities and participation.) Although it may not be realistic to create a complete list of every adverse effect that all PWS could experience in their lives, the ICF provides a framework that accounts for most of these effects (Yaruss, 2010). A summary below will explain how the ICF Model can provide a specific framework describing the external parameters of stuttering.

Impairments in Body Function. This ICF parameter refers to difficulty with producing speech, including observable disfluencies (e.g., blocks, part-word repetitions, etc.) that may be perceived by the listener or the speaker who stutters (Yaruss, 2007). Riley (2009) developed the Stuttering Severity Instrument – Fourth Edition (SSI-4) as a valid and reliable norm-referenced assessment of an individual's speech and fluency behaviors. Speech behaviors include frequency, duration, physical concomitants, and

naturalness of the person's speech. The SSI-4 was normed on sixty adults, as well as one hundred and thirty-nine school-aged children and seventy-two preschool-aged children. This assessment provides evidence that PWS have significantly different speech behaviors (e.g., blocks, part-word repetitions, etc.) when compared to typical peers. In addition to Riley's assessment, other extensive literature discusses how stuttering can impair body function (see Boehmler, 1958; Conture, 2001; Johnson, 1961; Johnson, Darley, & Spriestersbach, 1963; Williams & Kent, 1958; Yaruss, 1997; Yairi & Ambrose, 1992).

Impairments in Body Structure. This ICF parameter refers to underlying neuro-anatomical differences in PWS relative to PWDS (Yaruss, 2007). Many studies have explored the details of neuroanatomical differences between PWS and PWDS. Sommer, et al. (2002) found that developmental stuttering results from an uncoordinated activation timing of important areas in the brain relevant to speech. Sommer, et al. further suggests that when the left hemisphere does not adequately function for speech, the right hemisphere's simultaneous overactivation may indicate the existence of a compensatory mechanism, indicating that the right hemisphere may be functioning more than it is inherently designed for. Other researchers, like Beal, Gracco, Lafaille, & DeNil (2007) even suggest neuro-anatomical differences throughout the cortical network for speech motor control and limitations in structures such as the corpus callosum, superior temporal gyrus, bilateral inferior frontal gyri, left putamen, and right Rolandic operculum; additionally they discuss the unnatural proportion of grey matter in speech relevant brain regions. Additional literature documents further neuro-anatomical differences in PWS,

ultimately identifying impairments in PWS' body structure (e.g., Foundas et al., 2003; Foundas, Bollich, Corey, Hurley, & Heilman, 2001; Chang et al., 2008).

Personal Contextual Factors. This ICF parameter refers to the speaker's affective, behavioral, and cognitive reactions (ABC reactions). Reactions may include embarrassment, low self-confidence, shame, tension and struggle (Yaruss, 2007). Watson (1988) looked at communication attitudes between PWS and PWDS by using a scale that reflected behavioral, affective, and cognitive components of speech. Affective components refer to the way a person feels, or the way a person is affected by their speech. Behavioral components refer to the way a person acts, or behaves as a reaction to their speech. Cognitive components refer to how a person thinks, or cognitively processes their speech. Results of Watson's study revealed that PWS and PWDS had similar and different ratings regarding speaking situations. More recent researchers, including Yaruss (2010) and Manning (2010) indicate that the ABC's of stuttering are personal contextual factors that impact therapy outcomes. Additional literature discusses how stuttering can impact personal contextual factors (see Watson, 1988; Van Riper, 1982; Starkweather & Givens-Ackerman, 1997; Sheehan, 1970; Shapiro, 1999; Murphy, 1999; Manning, 1999; Cooper, 1993).

Environmental Contextual Factors. This ICF parameter refers to reactions from people in the speaker's environment based on stereotypes, myths, or discriminations (Yaruss, 2007). Craig, Tran, & Craig (2003) recognized the importance of assessing community stereotypes about PWS from people who have never spoken with a person who stuttered in their entire life. Interviews were given to random participants over the phone with questions regarding their beliefs about PWS *after* they had already been given

a description of stuttering and an introduction of their research. Results indicate that many PWDS believe that PWS are shy, anxious, self-conscious, and have low self-esteem. Many participants also believed that PWS have typical intelligence, and were capable of maintaining responsible employment positions. A large portion of society continues to know very little about stuttering as a speech disorder, making environmental discrimination a factor that can impact PWS' QOL (see Doody, Kalinowsky, Armson, & Stuart, 1993; Mackinnon, Hall & MacIntyre, 2007; White & Collins, 1984, Crowe & Walton, 1981; Klassen, 2001; Woods & Williams, 1976; Gabel et al., 2004; Klein & Hood, 2004; Bricker-Katz, Lincoln, & Cumming, 2013).

Activity Limitations and Participation Restrictions. This ICF parameter refers to difficulty performing daily activities involving communication, social interaction, or vocational responsibilities (e.g., talking on the telephone, giving a speech at work, participating in religious events, engaging in educational advances, etc.) (Yaruss, 2007). Yaruss and Quesal (2006) examined the link between reactions to impairment of body function in stuttering and resulting negative consequences. They discuss that PWS' reactions to their impairments, in personal contexts, body contexts, and structural contexts, are largely controlled by the speaker's reactions to their stuttering (the ABC's of stuttering). Negative reactions to stereotypes, low feelings about having a speech disorder, or frustration with the tension in their speech has been shown to lead some PWS to participate less in daily living. This is ultimately why the ICF model is important when considering QOL in therapy with PWS. Other literature discusses further how the speakers' reactions to their stuttering can mediate therapy outcomes and limit their participation in daily life (see Brutten & Shoemaker, 1974; Erickson, 1969; Ornstein &

Manning, 1985; Woolf, 1967; Write & Ayre, 2000; Yaruss & Quesal, 2006; Yaruss et al., 2002; Ahlback & Benson, 1994; Bobrick, 1995; Carlisle, 1985; Hood, 1998; Jezer, 2003; Johnson, 1930; Manning, 1999; Shapiro, 1999; St.Louis, 2001; Daniels & Gabel, 2004).

Therapy for People who Stutter

Research has consistently shown a weak relationship between patients' reports of their sense of well-being and objective measures of disease state (e.g., Locker & Slade, 1994; Lomas, et al., 1987; Strauss, 2001; Woodend, Nair, & Tang, 1997). This lack of one-to-one correspondence between healthcare professional and client reports of QOL and disorders has provided much of the motivation to include client-centered reports of life participation and QOL when planning treatment and measuring outcomes.

Woodend, Nair, & Tang (1997) compared perceptions of QOL among cardiac outpatients, the patients' families, and the patients' physicians. They also investigated factors that were perceived by the three groups to optimize QOL. The patients and their families seemed to provide similar scores more so than patients and physicians, or families and physicians. Overall, family and staff members differed in their ratings of the importance of most of the elements to the quality of their daily living. More importantly, the elements of the survey that seemed most important to the patients and their families were positive aspects of life; it was very important to them to have a high self-esteem, a high satisfaction with their lives, and a lot of confidence. These aspects were more important than not feeling depressed or anxious.

Clients' and clinicians' relationships play a significant role in therapy outcomes (Asay & Lambert, 1999; Bernstein Ratner, 2005; Franken, Kielstra-Van der Schaik & Boelens, 2005; Lambert & Bergin, 1994). Hayhow, Cray, and Enderby (2002) used a

questionnaire to examine the views of adults who stutter concerning the effect of stuttering on their lives and the speech therapy they received. Patient surveys have been used to improve those aspects of care that are the direct responsibility of managerial staff, and hospitals and family doctors have made use of surveys to identify improvements that are needed in service delivery (Fitzpatrick, 1993; Hayhow, Cray, & Enderby, 2002). Hayhow et al. discovered that patients feel most satisfied with their treatment when the views they hold concerning their illness and its management are consistent with those held by the relevant health care professional; for example, a study of clinicians and their patients with multiple sclerosis found that both groups agreed on the assessment of their physical disability but failed to agree on health-related QOL issues (Rothwell, McDowell, Wong, & Dorman, 1997). For this reason, interviewing is generally accepted as a satisfactory way of exploring peoples' beliefs and expectations (Abbott & Sapaford, 1998). Most people in this study felt positively about the therapy they had received, even though no single speech and language therapy approach was singled out as being particularly helpful.

Improving PWS' QOL is a primary role of a SLP. According to the American Speech-Language-Hearing Association (ASHA), "Speech-language pathologists work to improve QOL by reducing impairments of body functions and structures, activity limitations, participation restrictions, and barriers created by contextual factors" (2007, pg. 4). These responsibilities are discussed within the ICF Model regarding structural and physiological difficulty. But counseling is another clinical service within an SLP's scope of practice, in that SLPs are tasked with "counseling individuals, families, coworkers, educators, and other persons in the community regarding acceptance,

adaptation, and decision making about communication and swallowing” (ASHA, 2007, pg. 7). An SLP’s responsibility to counsel is supported within the ICF Model regarding personal contextual factors that might cause difficulty just as significantly as physiological factors.

Because stuttering is a multi-faceted communication disorder, treatment approaches are varied. There are many variable targets that could be chosen, depending on the individual’s priority and goals. Some approaches seek to decrease negative consequences of stuttering behavior, or even eliminate them completely in addition to reducing speech disruptions observed by the listener (e.g., Breitenfeldt & Lorenz, 2000; Manning, 2010; Shapiro, 1999; Van Riper, 1973; Yaruss, 2010). Other approaches may focus on primarily decreasing the stuttering behavior itself (e.g., Ingham, 1984; Neilson & Andrews, 1993; Onslow, et al., 1996; Ryan, 1979; Webster, 1980; Yaruss, 2010). There are many options for treatment, so it is important to consider each speaker’s individual experience with stuttering, and how it can relate to their overall lives beyond the therapy room.

Little consideration is given to broader consequences of stuttering, as compared to how therapy can change observable characteristics of the disorder (see Andrews, Guitar, & Howie 1980; Bothe, et al., 2006; Cordes, 1998; Prins & Ingham, 2009; Thomas & Howell, 2001; Yaruss, 2010). It is easy for therapy to gravitate towards the outward characteristics since the listener, including the SLP, most easily observes these. But the literature suggests that when adults who stutter are asked about why they are in therapy, they often respond with answers beyond their speaking condition (Yaruss et al., 2002).

As mentioned, there is a general lack of focus on QOL, and patients' responses to stuttering treatment. While there are many tools that can qualitatively measure a person's reaction to his or her stuttering in varying situations, such as the "S-Scale" (Erickson, 1969), the S-24 adaptation (Andrews & Cutler, 1974), or the Inventory of Communication Attitudes (ICA, Watson, 1988), these instruments have not been widely used in treatment research (Yaruss, 2010). There are some exceptions. Some instruments have been used throughout therapy, but these instruments were used to measure change over time (e.g., Blomgren et al., 2005; Boberg & Kully, 1994; Montgomery, 2006), or to allow comparison of relative effects of other various conditions on peoples' lives for other research purposes (e.g., Medical Outcomes Study Short-Form 36-Item Health Survey, or SF-36; Ware & Gandek, 1998; Ware et al., 1993). Many general QOL instruments have been used to assess PWS's response to their stuttering, but these instruments tend to contain information irrelevant to stuttering, and do not generally report difficulties in many of the domains. For example, most PWS do not report any negativity with physical pain, general health, vitality, or sexual function. Domains in which they do report negative experiences include social interactions or the ability to pursue educational or vocational opportunities, or other aspects that are not mentioned on the instruments at all, such as identity issues (Gabel, Blood, Tellis, & Althouse, 2004; Hood, 1998; Klein & Hood, 2004; McClure, 2009; St. Louis, 2001; Yaruss et al., 2002).

Researchers and therapists should direct their assessment protocols based on what speakers experience in their daily life in relation to their stuttering. Yaruss (2010) said it best: "If clinicians and researchers wish to know whether a treatment yields an

improvement in a speaker's life experience (and not just in speech fluency), then direct assessment of that life experience is needed" (pg. 192). This consideration in therapy could directly improve the speaker's overall QOL. If instruments are used for examining QOL of an individual as a therapy tool, a disorder-specific instrument should be used (Yaruss, 2010), particularly with a multifaceted communication disorder like stuttering, so that all domains are appropriately assessed and involved in therapy. Fortunately, researchers have suggested using the ICF Model for creating an ideal framework to evaluate the experiences of PWS. Eventually, the Overall Assessment of the Speaker's Experience of Stuttering (OASES) (Yaruss, Quesal, & Coleman, 2010) instrument was derived from this model, and is now used throughout therapy interventions for PWS.

Statement of the Problem

Researchers have continually identified that stuttering is a communication disorder involving a complex array of characteristics, both primary and secondary, cognitive and physiological, individually and holistically. The idea that stuttering is a multidimensional communication disorder involving many negative feelings including shame, embarrassment, and anxiety in addition to difficulty communicating is not a new concept (e.g., Ahlback & Benson, 1994; Bobrick, 1995; Carlisle, 1985; Corcoran & Stewart, 1998; Craig, Blumgart & Tran, 2009; Hood, 1998; Jezer, 2003; Johnson, 1930; Klompas & Ross, 2004; Manning, 1999; Manning, 2010; Shapiro, 1999; St.Louis, 2001; Yaruss & Quesal, 2006; Yaruss et al., 2002). Although very little has been done to understand the importance of QOL for PWS, QOL is consistently used as a measure in many healthcare professions to monitor how, and to what extent, clients enjoy their life based on hardships that are out of their control (Theofilou, 2013). However, the extent

of the reactions that PWS have to their stuttering may or may not be accurately perceived by the SLPs who treat them. Many PWS in National Stuttering Association (NSA) support groups have stated that their satisfaction with speech therapy strongly correlates with PWS' judgments of their clinicians' competence, suggesting that SLPs should redirect their focus in therapy (Yaruss, et al., 2002).

Many therapy approaches for PWS involve reducing stuttering behaviors, reducing negative consequences of the disorder, or both. The outcome of these treatments, however, is hindered when the SLP does not fully understand the severity of the individual's situation. Therefore, it is necessary to qualitatively explore the impact of stuttering on QOL, and the differences between the beliefs of PWS and SLPs regarding this issue.

Purpose

Additional research is needed to explore the beliefs of SLPs and PWS on QOL perspectives regarding stuttering as a communication disorder. This exploration is intended to provide further qualitative information in order to help researchers and clinicians more fully understand the impact of stuttering on QOL. To do this, the following research questions were proposed:

- 1) How do PWS and SLPs describe the impact of stuttering?
- 2) How do PWS and SLPs define quality of life?
- 3) How do PWS and SLPs describe the impact of stuttering on QOL?
- 4) How do PWS and SLPs differ in their reports regarding the impact of stuttering on QOL?

Chapter Two

Methods

Qualitative Approach

The QOL of PWS has become an area of focus over the past decade (Craig, Blumgart, & Tran, 2009; Franic & Bothe, 2008; Klompas & Ross, 2004; Yaruss & Quesal, 2006). Researchers have utilized a variety of questionnaires, including but not limited to the Medical Outcomes Study Short Form-36 (SF-36; Ware & Gandek, 1998; Ware et al., 1993), the Lifestyle Appraisal Questionnaire (LAQ; Craig, Hancock & Craig, 1996), and the Overall Assessment of the Speaker's Experience of Stuttering (OASES; Yaruss & Quesal, 2006, 2009). Additionally, interview studies derived from phenomenological frameworks have explored QOL (e.g., Bricker-Katz, Lincoln, & Cumming, 2013; Crichton-Smith, 2002; Johnson, Beitchman, & Brownlie, 2010; Markham, van Laar, Gibbard, & Dean, 2009; Moyson & Roeyers, 2012; Plexico, Manning, DiLollo, 2005). Though QOL has not been the focus of any one qualitative study, QOL has been an important theme found in several qualitative studies (Klompas & Ross, 2004).

The demand to explore QOL in PWS requires researchers' attention to various approaches of data collection, particularly qualitative analysis, in order to more fully understand how PWS experience stuttering, (Craig, Blumgart, & Tran, 2009; Patton, 2002a). Qualitative studies in the past have asked questions related to QOL, but few have fully explored the impact of stuttering on QOL, especially the differences between the beliefs of PWS and SLPs.

Qualitative research designs are used to investigate a holistic view of a phenomenon, such as stuttering, based on various perspectives of individuals and thematic structures of perceptions in different realities (Patton, 2002a; Maxwell, 2005). It is rooted in the philosophy of constructivism, requiring the researcher to explore the concept that multiple realities exist in various contexts (Creswell, 1998; Glesne, 2006; Kvale, 1996; Lincoln & Guba, 1985). Contexts in this type of research relate to the personal experiences of PWS. These experiences have been explored through use of semi-structured, open-ended interviews and surveys that are qualitatively analyzed for theme structures (i.e., Moyson & Roeyers, 2011; Yaruss, 2010).

Though questionnaire studies have been utilized quite effectively, there are some limitations to survey research. One thing to consider is that most questionnaires measuring QOL tend to reflect the point-of-view of the clinician or researcher, while the use of the qualitative interviews might allow for an understanding of the perspective of PWS. There needs to be a focus on understanding the beliefs of PWS and their QOL along with the beliefs of SLPs and how they perceive PWS' QOL because this will have an impact on measuring treatment outcomes. A qualitative research method a) allows all participants to specify issues of importance, b) minimizes the bias of the investigators, and therefore c) increases the face validity of the information that is obtained (Patton, 2002a). Interviews are kept open, encouraging the researcher and participant to engage in a dialogue (Patton, 2002a) while simultaneously illuminating perspective areas that were previously not properly understood (Parr, Byng, Gilpin, & Ireland, 1997; Crichton-Smith, 2002). Providing a natural communication environment, additionally, promotes the participants to provide a detailed and credible response during the interviews

(Moyson & Roeyers, 2012). This method was useful in developing an understanding of how SLPs and PWS might differ in their definitions of QOL and the impact of stuttering on QOL.

Other researchers have demonstrated how stuttering is a multifaceted disorder (Cooper, 1993; Manning, 2001). These researchers suggest that therapy for PWS should focus not only on speech characteristics, but also on secondary characteristics of the speech disorder. Secondary characteristics include negative attitudes and emotions, and cumbersome lifestyle adjustments that become a by-product of living with the disorder (Yaruss & Quesal, 2004). This is why therapists and researchers believe QOL can be impacted by a person's disorder (Yaruss & Quesal, 2004) and why exploring QOL directly will provide important information on how psychosocial aspects of the disorder may lead to difficulties related to living their life.

A phenomenological approach is a method that appropriately explores how QOL is affected by psychosocial and additional secondary characteristics of stuttering. "Phenomenological analysis seeks to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people" (Patton, 2002b, pg. 482), in this case, PWS. A phenomenological study focuses on descriptions of what people experience and how they experience it (Patton, 2002c). The only way to really understand another person's experiences is to experience the phenomenon as directly as possible. This leads to the importance of participant observations during in depth interviewing and personal communicative exchange (Balestra, 2012; Patton, 2002a).

Interviewing is generally accepted as a satisfactory way of exploring people's beliefs and expectations (Abbott & Sapaford, 1998). Qualitative research in stuttering has yielded deep insights into the stuttering experience (Bricker-Katz, Lincoln & McCabe, 2010; Corcoran & Stewart, 1998; Crichton-Smith, 2002; Klompas & Ross, 2004). There is an interaction between interactive communicative situations and the multiplicity of self expressions, and this is characteristic of what Barofsky (2012) calls positioning, or the idea that sharing personal concepts, thoughts, and ideas with other individuals allows perspective to be gained from both speaker and listener. Therefore, allowing discussion in an interview enabled the participants to provide a significant amount of information regarding QOL and other topics, and encouraged them to discuss their own personal experiences.

Participants

This study was reviewed and granted permission by the University of Toledo Social, Behavioral and Educational Institutional Review Board from the Department for Human Research Protections (see Appendix A). A population of six PWS and six SLPs who do not stutter, but work with individuals who stutter, were included this study. All participants, both PWS and SLPs, were over 18 years of age. None of the participants had other disabilities, communication disorders, or neurological conditions aside from stuttering. No plans were made to exclude any ethnic groups, and no vulnerable populations (e.g., elderly, UT students, pregnant women, etc.) were targeted. None of the participants received compensation for their participation. Participants were under no obligations and could have withdrawn from the study at any time. All participants were recruited via email (see Appendix B and C) from email contacts of the advisor for this

project (R.M. Gabel). Already existing data (demographic questionnaires and narratives) from four participants who stutter were gathered previously by the advisor. Thus, the primary researcher interviewed two PWS, while four PWS were previously interviewed from this prior project.

All participants were randomly assigned a pseudonym in order to respect the privacy of each participant. The PWS included three women – Anna, Lily, and Rita – and three men – Simon, Dan, and Eddy. The SLPs also included three women – Jane, Jackie, and Molly – and three men – Carl, Frank, and Sam. The participants who stutter are identified by their pseudonyms, and described in further detail, below (see Table 1).

Table 1

People who Stutter (PWS) Demographic Information

	<u>#1 Anna</u>	<u>#2 Eddy</u>	<u>#3 Lily</u>	<u>#4 Rita</u>	<u>#5 Simon</u>	<u>#6 Dan</u>
Age	18	33	46	19	35	20
Gender	Female	Male	Female	Female	Male	Male
Ethnicity	White	White	White	White	White	White
Marital Status	Single	Single	Married	Single	Married	Single
Present employment status	Student	Full-Time	Full-Time	Student	Part-Time	Student
Stuttering severity	Mild	Severe	Moderate	Mild	Moderate	Severe
Presently receiving therapy	Yes	No	Yes	No	Yes	Yes
Previously received therapy	Yes	Yes	Yes	Yes	Yes	Yes
Years spent in therapy	4	12	5	1	20	10
Therapy success rating	Successful	Somewhat Successful	Positive	Successful	Very Successful	Moderately Successful

Additional information regarding past therapy experiences from each participant who stutters can be observed in Table 2.

Table 2

Therapy Experiences of People who Stutter (PWS)

	<u>#1 Anna</u>	<u>#2 Eddy</u>	<u>#3 Lily</u>	<u>#4 Rita</u>	<u>#5 Simon</u>	<u>#6 Dan</u>
Stuttering Modification	Successful	Successful	Successful	N/A	Successful	Successful
Counseling	Successful	Not Successful	Successful	N/A	Successful	N/A
Fluency Shaping	Successful	Successful	Successful	Successful	N/A	Successful
Eclectic Approach	N/A	Successful	Successful	N/A	N/A	N/A
Drug Therapy	N/A	Not Successful	N/A	N/A	N/A	N/A
Assistive Device	N/A	Not Successful	N/A	N/A	Not Successful	Not Successful

Anna was an eighteen-year-old woman who was a full-time student. She described herself as a “mild” stutterer, and said that she had previously received four years of speech therapy for her stuttering throughout her life. Anna reported that her therapy experiences had been successful, involving stuttering modification, counseling, and fluency shaping techniques. Lily was a forty-six year old married woman who was working full-time in the medical field. She described herself as a “moderate” stutterer, and said that she had previously received five years of speech therapy for her stuttering throughout her life. Lily reported her therapy experiences had also been successful, involving stuttering modification, counseling, fluency shaping techniques, and other eclectic approaches. Rita was a nineteen-year-old woman who was a full-time student. She described herself as a “mild” stutterer, and said that she had previously received one year of speech therapy for her stuttering. Rita reported her therapy experiences had been successful, involving fluency shaping techniques.

Simon was a thirty-five year old married man who worked part-time as an auxiliary officer. He described himself as a “moderate” stutterer, and said that he had

previously received twenty years of speech therapy for his stuttering throughout his life. Simon reported his therapy experiences had been “very successful,” and involved stuttering modification and counseling strategies. Dan was a twenty-year-old man and was a full-time student. He described himself as a “severe” stutterer, and said that he had previously received ten years of speech therapy for his stuttering throughout his life. Dan reported his therapy experiences had been “moderately successful,” and involved stuttering modification strategies, fluency shaping techniques, and assistive devices. Lastly, Eddy was a thirty-three year old man who, during the time of his interview, was a recent graduate of a master’s program in speech-language pathology, and he had just begun his career as an SLP. While Eddy is a person who stutters and was also an SLP, his participation in this study was justified due to his valid beliefs and experiences strictly as a person who stutters. He described himself as a “severe” stutterer, and said that he had previously received twelve years of speech therapy for his stuttering. Eddy reported that his therapy experiences had been “somewhat successful.” He shared that stuttering modification, fluency shaping, and other eclectic approaches were more successful than counseling, drug therapy, and assistive devices.

The SLP participants are identified by their pseudonyms, and described in further detail, below (see Table 3).

Table 3

Speech Language Pathologist (SLP) Demographic Information

	<u>#1</u>	<u>#2</u>	<u>#3</u>	<u>#4</u>	<u>#5</u>	<u>#6</u>
	<u>Carl</u>	<u>Frank</u>	<u>Jane</u>	<u>Jackie</u>	<u>Molly</u>	<u>Sam</u>
Age	38	31	28	31	29	46
Gender	Male	Female	Female	Female	Female	Male
Ethnicity	White	Asian	White	White	White	White
I have a communication disorder	No	No	No	No	No	No
Number of years working as an SLP	15	6	4	7	5	23
Number of years in present position	3	4	4	< 1	1	15
Highest degree attained	M.A.	Ph.D.	M.A.	Ph.D.	M.S.	Ph.D.
I hold the CCC	Yes	Yes	Yes	Yes	Yes	Yes
I am a member of an ASHA SIG	4, 18	4	4	4	4	4
I am a recognized specialist in fluency disorders	Yes	No	No	No	No	Yes
Number of individuals on my present caseload	15	5	40	30	7	15
Number of individuals on my caseload who stutter	15	5	20	0	7	15

Jane was a twenty-eight year old woman who had been working for four years as an SLP. She has her master’s degree in speech-language pathology, and worked in an outpatient clinic in a city hospital. She was a member of the American Speech-Language and Hearing Association’s (ASHA) Special Interest Division (SIG) 4, Fluency and Fluency Disorders, but she was not a recognized specialist in fluency disorders. Jane worked with forty individuals on her caseload, while twenty of them stuttered. Jackie was a thirty-one year old woman who had been working for seven years as an SLP. She has her Ph.D. and was an assistant professor at a university. She was a member of the ASHA SIG 4, but she was not a recognized specialist in fluency disorders. Jackie worked with thirty individuals on her caseload, while none of them stutter. Molly was a twenty-nine year old woman who had been working for five years as an SLP. She has her master’s degree in speech-language pathology, and was working towards her doctorate degree. She was a member of the ASHA SIG 4, but she was not a recognized

specialist in fluency disorders. Molly worked with seven individuals on her caseload, while all seven of these individuals stuttered.

Carl was a thirty-eight year old man who had been working for fifteen years as an SLP. He had his master's degree in speech-language pathology, and was an assistant professor at a university. He was a member of both the ASHA SIG 4, and SIG 18, Telepractice, and he is a recognized specialist in fluency disorders. Carl worked with fifteen individuals on his caseload, and all fifteen of these individuals stuttered. Frank was a thirty-one year old man who had been working for six years as an SLP. He has his Ph.D., and was an assistant professor at a university. He was a member of the ASHA SIG 4, but he was not a recognized specialist in fluency disorders. Frank worked with five individuals on his caseload, and all five of these individuals stuttered. Sam was a forty-six year old man who had been working for twenty-three years as an SLP. He has his Ph.D., and was an ASHA Fellow and an associate professor at a university. He was a member of the ASHA SIG 4, and he is also a recognized specialist in fluency disorders. Sam worked with fifteen individuals on his caseload, and all fifteen of these individuals stuttered.

As one may observe, all participants varied in age, gender, race, education, and other factors. According to Corcoran and Stewart (1998), “themes derived from a maximally varied sample are more likely to be related to the topic under study, because there exists less chance that the themes are related to a secondary common factor” (pg. 249).

Procedures

The advisor approached potential participants and asked whether they would be interested in participating in the study. If they expressed an interest in participating in the study, the primary researcher then contacted the participants to set up an appointment time and place for the interview. Once the participants were contacted, they were sent the consent document (see Appendix D). They were asked to sign and return this document via US mail or as a .pdf file. All the participants provided informed consent before participating.

The interview and demographic questionnaire were completed in a place that was comfortable for the participant (see Appendix E and F). Participants were interviewed using videoconferencing (Scopia or Facetime) if they did not live within a reasonable distance of the researcher. The length of participation was between 45 and 60 minutes. Interviews and questionnaires were completed individually, and at no point were the participants expected to share any identifying information. All email addresses and other contact information were kept confidential and not reported. Only the primary researcher and the advisor had access to the data. All records were stored in a locked research lab in the University of Toledo Speech Language & Hearing Clinic. When the research was completed, all data was destroyed.

The advisor knew all the SLP participants, and all PWS were current or past clients of the advisor. The advisor had no contact with the participants nor did he view any of the recorded interviews during the study. He had access to all written data, but without any information to identify the participants. There was no undue pressure for the

participants to participate in the study, and the advisor did contact them, at any point, during the study.

The six SLPs were interviewed to gather information pertinent to the overall aims of this study. The questions that were asked involved inquiries about a) their perspectives on the clients they work with who stutter, b) how they believe stuttering affects a person's life, c) how they would describe quality of life, d) how they believe stuttering affects quality of life, and e) their experiences providing therapy (See Appendix G).

Similarly, the six PWS were interviewed to gather information pertinent to the overall aims of this study. Questions covered topics such as a) stuttering as a communication disorder, b) their life as a person who stutters, c) their description of quality of life, d) how they believe stuttering affects their quality of life, and e) experiences receiving previous therapy (see Appendix H).

Analysis

The data gathered from the open-ended interviews and questionnaires were analyzed using a qualitative, thematic approach by means of three steps: 1) individual notes from the interviews, 2) open coding, and 3) axial coding.

The first step in data analysis was to review the primary researcher and advisor's individual notes from the interviews. These field notes allowed the primary researcher to gather initial thoughts on important themes from the interviews and helped identify points of discussion between the primary researcher and the advisor (Patton, 2002a). The primary researcher stayed in contact with the advisor throughout the data gathering process, and they conversed about the data as it was gathered. These conversations

provided initial opportunities to identify potential core themes, and attempted to remove bias from the analysis, thus addressing credibility. All interviews were then transcribed verbatim, and these transcriptions were the primary data source of this study. Reading each transcript in its entirety allowed the primary researcher to become familiar with the data prior to coding, and also assured that the data was credible.

Through the process of immersion, each researcher read and analyzed each line of the interview data independently (Patton, 2002a) using open coding (Strauss, 1987). In this procedure, each researcher reviewed through several iterations of reading the data line-by-line, independently refining, adding, deleting themes as they re-read the transcripts. Core themes of the participants' responses were identified through this process. After independently arriving at a set of core themes, the researchers discussed their findings and attempted to reach consensus on the important themes of the study.

Lastly, axial coding was completed (Strauss, 1987). During this step of the analysis, each phrase included on the transcript was scrutinized for its importance and relationship to the core major themes. Each line of the transcript was given a code representing the core theme in which it related, and secondary minor themes were identified. Care was taken to allow the identification of new themes and subcategories.

Following the completion of this rigorous review of the transcripts, these responses were put into thematically related categories, including core major themes and the related secondary minor themes. Ultimately, themes identifying important concepts related to QOL of PWS and perceptions of SLPs in therapy came from this analysis.

Credibility

Qualitative research does not lend itself to the usual expectations of quantitative designs, especially related to objectivity measures such as reliability and validity (Patton & Westby, 1992; Taylor & Bogdan, 1998). Qualitative studies attempt to obtain some measure of objectivity in analysis by utilizing the concept of credibility through various measures (Patton & Westby, 1992). Credibility findings were enhanced in this study through four methods derived primarily from Corcoran & Stewart (1998), Cresswell (1998), Lincoln & Guba (1985), and Patton (2002a).

1. The interviews were recorded and transcribed verbatim.
2. Biases of all researchers involved were discussed in great detail at the beginning of data collection and during the process of data analysis. This is a method called bracketing, a technique encouraging investigators to eliminate the effect that prior experiences and biases play on data analysis (McCracken, 1988; Patton, 2002a). At all times during the data analysis, biases were taken into account to assure that a true understanding of the participants' responses was attained. This technique allowed the researchers to grasp and elucidate the meaning, structure, and essence of the lived experience of the phenomenon of each individual participant (Patton, 2002b, pg 482). Different investigators' backgrounds reduced the likelihood of the researchers' bias regarding the experience of stuttering (Corcoran & Stewart, 1998). The primary researcher in this study is a fluent speaker with no history of stuttering, has a bachelor's degree in speech-language pathology, and is a student enrolled in a master's degree program. The secondary researcher, the advisor, is a Board-Certified Specialist in Fluency Disorders (BCS-F) with a Ph.D. in speech-

language pathology, has been working with fluency clients for over eighteen years, and is a person who stutters.

3. Additionally, triangulation was used to enhance credibility (Kuzel & Like, 1991). This process allowed the phenomenon to be viewed from more than one point of view (Plexico, Manning, & DiLollo, 2005). After all the transcripts from the interviews were separately reviewed, the researchers identified emerging themes and key utterances, and discussed their results until discrepancies were discovered and consensus regarding each theme was reached.
4. After major themes were established, second interviews were scheduled with the participants so that the researchers could share their findings with each individual. This process, called member checking, ensured that a valid interpretation of statements was gathered in the transcripts, and that the themes derived from the narratives were consistent with the individual's responses (Kuzel & Like, 1991).

Chapter Three

Results

Introduction

This study focused on four research questions. Specifically, these research questions asked how PWS and SLPs describe the impact of stuttering, how PWS and SLPs define QOL, how PWS and SLPs describe the impact of stuttering on QOL, and how PWS and SLPs differ in their beliefs regarding the impact of stuttering on QOL. This information was collected through a qualitative process using a phenomenological approach in order to learn the most about the experiences related to the phenomenon being studied (stuttering) and how this phenomenon can be interpreted into a reality for others who do not otherwise experience stuttering as a communication disorder.

Participant Information

As mentioned above, specific criteria were used to acquire six SLPs and six PWS to participate in this study. All PWS were over the age of eighteen, and all SLPs had been working with PWS for at least five years. Many PWS were full-time students, but some worked full-time or part-time jobs. All PWS had received speech therapy in the past, but not all were receiving therapy at the time the interviews took place. All SLPs had their Certificate of Clinical Competence (CCCs) and were members of the ASHA SIG 4. Some SLPs had their Ph.D., but others held a Master of Arts or a Master of Science degree.

Qualitative Data

This section reports the data and analysis gathered from the interviews of PWS and SLPs. Following the coding procedure for the interview transcripts, supporting minor themes emerged that contributed to the formation of five major themes (see Table 4). Major theme 1 consisted of the concept of restriction, with four minor themes: restriction regarding occupation, restriction regarding personal relationships, restriction regarding education, and no restrictions regarding daily living activities. Major theme 2 consisted of the concept of identity, with four minor themes: the individual, advocacy, acceptance, and authenticity. The third major theme consisted of the concept of positivity. Two minor themes contributed to this major theme, including: happiness, and empowerment. The fourth major theme consisted of the concept of control. Four minor themes contribute to this major theme, including: unpredictability, avoidance, responsibility, and physical impact. The fifth and final major theme describes the overall impact of therapy. Three minor themes added to this major theme, including: good therapy, bad therapy, and therapy's impact on QOL.

Table 4

Major and Minor Theme Structure

Major Theme 1 – Restriction

Restriction regarding occupation
Restriction regarding personal relationships
Restriction regarding education
No restrictions

Major Theme 2 – Identity

The Individual
Advocacy
Acceptance
Authenticity

Major Theme 3 – Positivity

Happiness
Empowerment

Major Theme 4 – Control

Unpredictability
Avoidance
Responsibility
Physical Impact

Major Theme 5 - Therapy Impact

"Good" therapy
"Bad" therapy
Therapy impact on QOL

Further explanations of the major and minor themes are outlined in Figure 1.

Each theme was determined when two or more participants in a group discussed a similar belief. Some themes were apparent among participants in the same group, and some themes were apparent between participants in different groups.

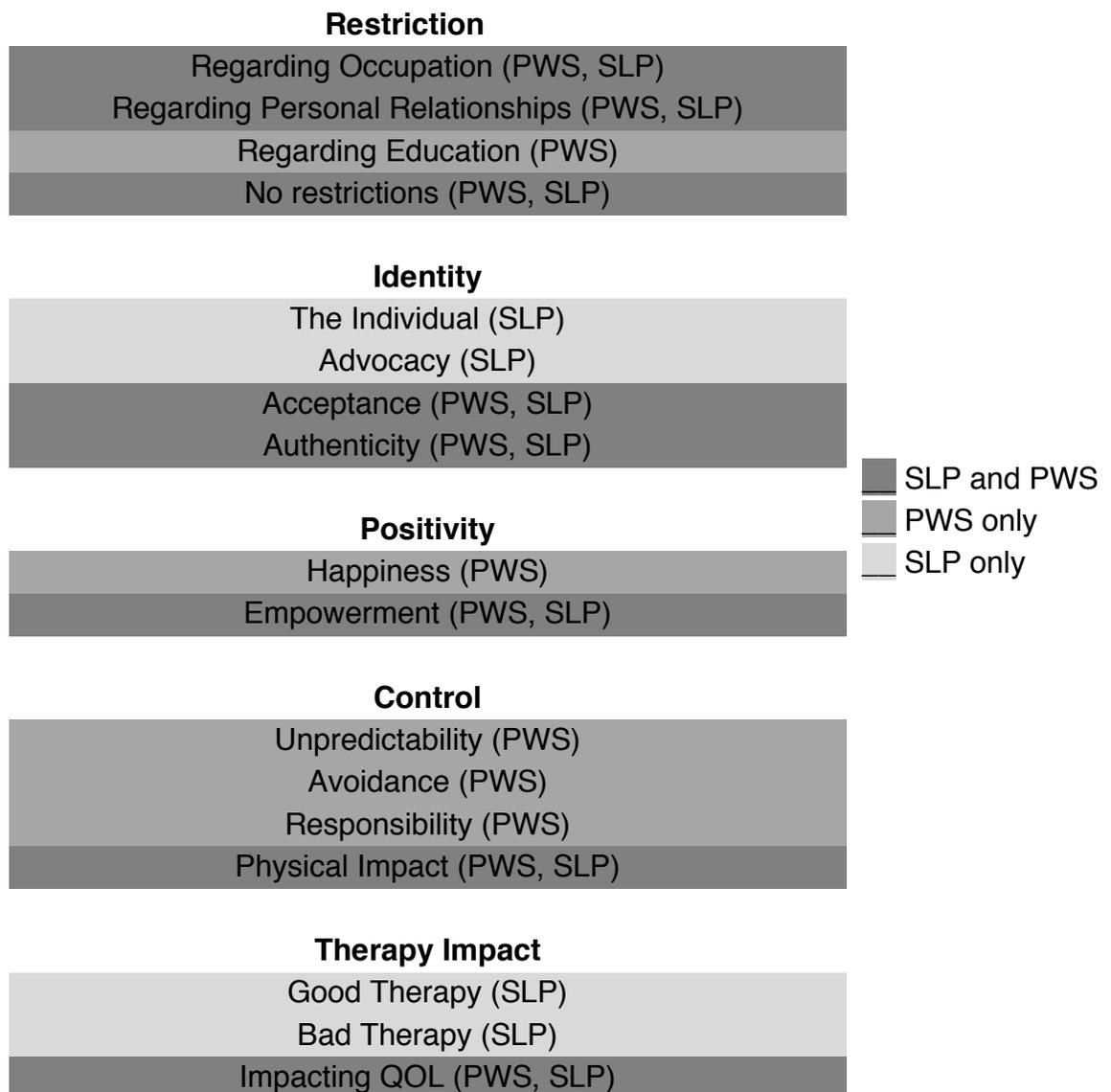


Figure 1. Theme differentiation according to participant occurrence

Restriction. The first major theme describes restriction, referring to a limitation on the use or enjoyment of some aspect of life. In this case, restriction is identified with PWS when they are presented with limitations as a result of their stuttering. Both groups of participants discussed restriction throughout the interviews. Depending on the context of discussion, a sense of restriction was communicated differently by PWS as compared to SLPs. The four minor themes that contributed to the development of this major theme are discussed below.

Restriction regarding occupation. Restriction regarding occupation refers to feeling held back from an activity, or prevented from fully participating in an activity that is oftentimes the principal business of one's life (Merriam-Webster, 2015). Both SLPs and PWS commented on how stuttering can have an impact on feeling restricted in the workplace, or the limitation of the work that a person does.

Feelings of defeat, acceptance, and discouragement were expressed by many PWS when discussing restrictions in their occupations. Anna talked about how stuttering prevents her from working jobs in retail:

I just see that the current positions that are open to me in terms of the workforce, you know, the ones that a typical 20-year-old would have access to, is very limited to me because of my speech. I'd have to fight a bit harder to get the position.

Two other participants who stutter talked about how stuttering has restricted them from the opportunity to earn their dream job. Simon seemed to accept the fact that he was told he was incapable of performing the job: "It has prevented me from becoming a police officer, but that's how it is, right?" Dan was not so convinced this restriction was appropriately deserved:

I tried to join the army. I went to take my physical, and I passed everything but my speech and so I was unable to join the army. At the time, I was a bit upset, but I was told that I was able to fix it, and I just had to talk to some people and do some stuff and I could still sign up. So I tried for six months to still get back in. I even went through the senator, and they still didn't accept me.

Some SLP participants talked about how stuttering can impact a person's ability to perform certain responsibilities at particular jobs. For example, Carl said, "I think it could affect their ability to perform their job to some degree, depending on what their job is, if they're not willing to say certain things or participate in certain things." Another SLP, Jackie, talked about how restrictions in the workplace might be due to ill-informed employers, "I think a lack of education in the workplace for people who are ignorant to what stuttering is, that can just be detrimental." Frank commented similarly: "I think there can be a little bit of discrimination going on and a lot of misconception going on."

Other SLP participants used current clients as examples of how stuttering can impact a person's occupational opportunities. Jane noted:

I actually evaluated a 49-year-old woman who's never had therapy ever for stuttering, and she's a social worker and she's super successful, and she said, 'You know I've been stuttering my whole life and it's never bothered me.' Now she's in this leadership position being asked to give a lot of presentations, and she's like, 'All of a sudden I realized I can't, I won't do this.'

Restriction regarding personal relationships. Feeling restricted in personal relationships can be defined as people having difficulty with the way in which two or more people talk, behave, and deal with each other, or the way in which two or more people are connected (Merriam-Webster, 2015). Both SLPs and PWS believed that

stuttering largely impacts how a person can be restricted from developing intimate connections with other people.

One participant who stutters, Eddy, talked about how stuttering has impacted romantic relationships, family relationships, first impressions, and friendships:

It made dating impossible... it's the initial getting-to-know somebody that made it very difficult. I isolated myself from my friends and family because I was so ashamed of my speech, I didn't want to talk, I didn't want to see them have to see my stutter so it was easier to be myself and not talk to anybody. It [stuttering] affects your first impressions that you make with people. It made it hard to meet strangers. I couldn't always tell my friends everything I wanted to. I used to be able to do that. I was uncomfortable with how my friends felt around me because I stutter so badly.

Another participant who stutters, Rita, talked about what it is like simply being a person who stutters: "I felt very alone, helpless, like no one understood me." Her relationship with her mother was hostile for a long time due to her stuttering. Her mother would call her and say, "Oh your speech is sounding so bad!" And the participant said that she would hang up. During the interview, the participant went on and said, "I wasn't going to put up with that. She [mom] has this thing where she wants to help, and I know she cares, but she's going about it in all the wrong ways." Rita also talked about her relationships with other people, aside from her mother:

I always feel like I'm stereotyped as having some other mental disability or something like that. They just have no idea what I'm feeling. And just the fact that a person could say or think, 'Oh, you're trying to think of what you're saying,' that just blows my mind. Obviously they have no idea....

Almost all SLP participants acknowledged that stuttering could impact how PWS develop and maintain personal relationships. Carl said, "I think [stuttering] could affect

the ability to talk in front of groups, and I think it would affect their ability to have personal relationships with people in terms of getting to know people on a personal level.” Jackie talked about how PWS might have a negative view of themselves, and this negative self-reflection can impact personal relationships involving other people:

Communication is a huge factor of relationships and for an individual who stutters, they might have a narrow view of themselves as a communicator and that might impact a relationship and their partner might go along with it because that’s just how they perceive stuttering, the impact of this type of diagnosis or label or whatever.

Other SLPs used their clients as examples to describe how stuttering can restrict a person from developing personal relationships. Sam explained:

There’s a man who just left my office here, he’s a sports writer, he’s a young guy, he’s in his twenties, he stutters, and experiences adverse impact in his life for example doing his job, interacting with other people. He’s quieter than he wants to be, he’s more withdrawn than he wants to be. He has difficulty introducing himself and engaging with people.

Restriction regarding education. Restriction regarding education refers to a limitation regarding the process of teaching or someone, learning something, or making decisions based on academic successes. This minor theme was discussed among multiple PWS, while SLPs did not share beliefs that stuttering largely impacted how a person can be restricted from educational opportunities.

Many PWS discussed how stuttering has restricted them from participating in a quality education. Eddy talked about how stuttering has impacted his college education:

After undergrad, I was still having trouble with my speech. When I went to grad school in Colorado, I didn’t know anybody and it put a lot of pressure on my speech again, and I kind of felt like I was held back. I put off taking my clinical practicum a whole semester. I’m glad they let me put it off, because I would have quit if they wouldn’t. I was just not ready. My stuttering really affected me a lot, in grad school even.

Dan talked about presentations in class being impacted by his stuttering:

If I have to give a speech in class and stuff, and I have to be under a certain time, I'm unable to continue on because it's happened to me. Because I had a speech that was really good and everything, but I was unable to complete it, because it would have taken me so long to speak and stuff. So at some points it's held me back, but just when I have to speak to others or do speeches.

Anna talked about being restricted from participating in campus leadership opportunities because of her stuttering:

You had to audition and they said I was perfectly qualified, they just didn't think I could get through the material in the time slot that I needed. I really wanted to prove them wrong. I wanted to basically slap them in the face and prove that I could do it, but I also had that feeling that it is possible that I couldn't.

Although every experience is unique, each experience suggests that PWS can be very limited in school, and limited regarding the types of experiences they receive as a result of earning an education. These experiences are specific to stuttering, and would therefore not typically be experienced by those who do not stutter.

No restrictions. Both SLPs and PWS believed that having a choice, and not feeling restrictions regarding life decisions, is an important aspect of a good QOL. When participants in each group were asked how they would define QOL, many of them responded in a way that indicated what a good QOL might look like.

All PWS commented on the power of choice, and freedom from restriction when asked about QOL. One participant who stutters, Lily, said, "A good quality of life is to be who you choose to be – be healthy, be positive." Eddy spoke similarly, and talked about the sanctity of "freedom":

A really important factor in quality of life is a sense of peace and feeling that you're free, that you can do whatever you want to do, and that you have no limits. For me, when I can talk fluently, I feel like I can do anything, and there's nothing that can really hold me back.

Dan described that a good QOL, for anyone, is...

...to be happy with who they are, and if they aren't happy with who they are to change it. Because I've always felt that if you aren't happy with something then change it, because it's your choice to be who you want to be.

Every SLP participant commented on similar factors that contribute to QOL. Carl described a good QOL as:

Doing what you want to do in life – within reason, of course – but to not letting outside influences or things that you have affect your overall life.... I think it [a bad quality of life] would be having something that would affect your ability to make decisions on a day-to-day basis....

Frank spoke about the concept of freedom, and said, "My personal description and understanding of quality of life, just for myself and any person in general, would be living my life to the fullest doing everything I want to do without the need to restrict myself."

Jane commented similarly:

I would define quality of life as the ability of someone, someone's ability to do what they want. So I think that everyone has goals, and I think the ability to work toward those goals would improve a person's quality of life.

Jackie talked about how important it is for people to have the freedom to fulfill life responsibilities:

I would define quality of life as the day-to-day realities... the daily decision making process as well as the long term impact, the big picture

impact... And someone who can ‘do’ for themselves in many ways, who can accept help when necessary.

Other SLPs talked about a how they might define a bad quality of life. Sam said, “A poor quality of life, and quality of life that is affected by stuttering, is when a person is either dissatisfied with their communication or their communication experiences – the things that they want to be able to say, or when they’re held back from doing things.” Another SLP, Molly, said that a poor quality of life is “when people feel so limited, or feel that they have to be something that they’re not... so limited but anything external due to something that is beyond their control, or within their control.” Regardless of context, all participants discussed the idea that having no restrictions positively contributes to a good QOL.

Identity. The second major theme refers to identity as a distinguishing character or personality of an individual (Merriam-Webster, 2015). Both groups of participants discussed the concept of identity throughout the interviews, especially when asked to describe the impact of stuttering on a person’s life. The concept of personal identity was decidedly a recurring topic that was discussed, since many PWS consider their stuttering as a component to who they are as a person. The four minor themes that contributed to the development of this major theme are discussed below.

The individual. Being an individual refers to existing as a distinct entity (Merriam-Webster, 2015). This theme was only relevant among SLP participants, who talked often about how the impact of stuttering pertains to the individual, and also how therapy is shaped toward the individual depending on how their stuttering impacts their life. Frank said, “I think... people who stutter are a very heterogeneous population, you

can't really apply every single person every single component of it." When asked to describe the clients he works with, Carl explained:

Stuttering is really highly individualized and everybody that comes through your door is a little bit different. So, I don't know if there's one broad experience you can paint of working with someone who stutters.... I've met some people who stutter but don't really have any difficulties with it, and they're completely fine with it and they do very well. I think on the other side of the spectrum I've met people who stutter who won't leave their house because they stutter. So it's a very broad spectrum I think, in that regard.

Advocacy. Advocacy refers to defending or maintaining a cause of proposal, or supporting and promoting a personal interest (Merriam-Webster, 2015). This theme was only observed among SLP participants, and most of the discussion regarding advocacy involved the importance of advocating in the workplace. Advocacy, the SLPs said, is an important ability to demonstrate and a necessary skill to teach in therapy so that co-workers in the workplace can identify PWS's strengths and weaknesses beyond the fact that they stutter. One SLP participant, Frank, mentioned the impact of stuttering in the workplace, and how important it is for PWS to advocate for themselves and their ability to perform:

This is where I feel sometimes discrimination can come in where an employer might not trust that a person can execute a certain task because of their stuttering. To some extent, I feel like an employer's concern could be valid because – if there's a private business they want to make sure they are getting the best results – but in therapy, it's important we are teaching our clients the importance of advocating for themselves, and work with employers and raising more awareness about stuttering.

Jackie expressed similar beliefs, but described how advocacy is the responsibility of the person who stutters: "I think that a person's level of advocacy for self and the

ability to educate others... can impact them in a positive or negative way in the workplace.”

Jane talked about a particular client who stutters whom was receiving comments from his employer about his stuttering at his place of employment:

I feel like employers... like, if the client said, ‘Hey I’m in therapy,’ they have this expectation that their stuttering is going to lessen. They think they are going to make that go away. So I think that’s a very important conversation to have.

Overall, each SLP participant talked about how educating others and feeling the necessity to accurately represent their ultimate potential is an expectation for PWS, perhaps even more so than PWDS.

Acceptance. Acceptance refers to receiving something willingly, giving admittance or approval, and enduring without protest (Merriam-Webster, 2015). Both PWS and SLP participants believed that accepting stuttering as a part of individual identity is important to consider when discussing the impact of stuttering.

As a participant who stutters, Anna said, “It’s who I am, and it [stuttering] plays a part in who and how I became who I am. Honestly, I would love to be suddenly fluent, but I’m accepting of the fact that isn’t going to happen, and this is who I am, and I’m going to stutter.”

When Dan was asked what it felt like to be a person who stutters, he explained that at this point in his life, he hasn’t taken the interest in helping himself to overcome it, since he’s already come to terms that it isn’t going away: “I’m not too into, ‘I want help with this,’ because I know that I can’t really stop it.” This participant has already accepted that stuttering is a part of who he is, which is an example of how stuttering can impact a person who stutters’ identity of themselves.

When SLP participants mentioned acceptance as an impact of stuttering, unlike PWS, most tended to refer to it as a result of therapy. Stuttering can impact a person in different ways depending on how much a person accepts their stuttering, and how different therapy might be for clients depending on their “acceptance process,” according to Molly:

I see a lot of people who stutter who are in the process of accepting, so they’re not quite there in the treatment period where we’re really working on acceptance and identifying themselves as a person who stutters – at that point, you see a huge life impact in terms of willingness to speak, the quality of those social interactions, and just overall motivation to communicate.

Jane, however, did not mention therapy at all when talking about acceptance:

I think that for a lot of teens and adults, it really comes to the comfort with who they are, acceptance of the stuttering, not necessarily liking it, but accepting it, and really figuring out what that means for them.

Authenticity. Authenticity refers to being true to one’s own personality, spirit, or character (Merriam-Webster, 2015). Both groups of participants commented on the relevance of having the freedom to be authentic as the answer to embracing a good QOL.

When PWS were asked how stuttering has impacted their quality of life, they tended to respond with negative reactions. Lily said, “I think it [stuttering] didn’t let me be the person I think I could have been,” suggesting that her ability to be herself was skewed, and it became difficult to present herself as the person she truly was. Eddy also talked about the challenges of staying authentic:

I wouldn’t talk to strangers, and I was held back, and I wasn’t expressing myself. I was being somebody else and that’s not fair to myself. I just saw myself as a stutterer. I hated myself, hated my stuttering. I had a very low quality of life.

When one SLP, Molly, was asked how stuttering might impact a person's quality of life, she said, "I think people who stutter... their quality of life might be impacted if they believe that stuttering has to influence who their true identity is, or what they really want to do in life." Jackie talked about how the impact of stuttering can distort a person's concept of personal authenticity:

I think it [stuttering] can affect that process of self, that thought process of reactivity that might occur, reactivity with how you deal with a situation, beating yourself up over something, or shifting your perceptions of self based on an incident. So, impacting your character traits, when it should be something that you just move through, you feel and let go. Thought sometimes can be something that you not only feel, but you harbor.

Positivity. Both groups of participants discussed positivity in their interview discussions as a result of the impact of stuttering. Positivity refers to an entity that is good or useful; good qualities of someone or something; thinking that a good result will happen; hopeful or optimistic (Merriam-Webster, 2015). Both SLPs and PWS discussed topics that developed a theme regarding positivity, since some of the experiences described positive impacts of stuttering rather than negative impacts. The two minor themes contributing to the development of this major theme are discussed below.

Happiness. Happiness refers to a state of well-being and contentment; a pleasurable or satisfying experience (Merriam-Webster, 2015). Participants who stutter discussed happiness when asked how to define QOL. Anna explained how she might define a good QOL: "Quality of life to me is being happy and being able to care for yourself... If you're happy with the things you have, then you have a good quality of life." Rita shared a similar definition: "I think to me, quality of life would just mean your

ability to be happy and to enjoy your life... the ability to be happy with yourself and have a fulfilling life.”

Another participant who stutters, Lily, explained how she might define a poor QOL: “Somebody who is not healthy, who’s not happy, that type of person, is pissed off all the time, not taking care of themselves.”

Empowerment. Empowerment refers to the act of promoting a self-actualization or influence of something else based on a positive experience (Merriam-Webster, 2015). Both PWS and SLP participants shared their thoughts about the impact of stuttering on QOL regarding feelings of empowerment, however, from two different perspectives. PWS tended to talk about how they are empowered by their stuttering, while SLPs tended to talk about how PWS have empowered them as clinicians.

Several participants who stutter talked about stuttering as an “eye-opening” experience that has empowered them to feel strong and positive towards other aspects of their life as a result of the fact that they stutter. For example, Anna said:

I definitely have been able to see people who are true and will stick with me, and who can appreciate the things that I do without looking at how I speak.... it [stuttering] has helped me weed out people. So it’s good in the sense that it’s a filter of some sorts.

Rita talked about how stuttering has actually increased her overall motivation to be successful:

I think stuttering played a part in me becoming such an over-achieving student. Because of that I was able to go to college, and now I’m able to go to grad school, and because of that I’ll be able to get a job. So being a good student has allowed me to reach my goals, and I believe that stuttering played a big part of that. I’ve said before that I think feeling empathy toward people who are different, that’s an important quality to have and stuttering has helped me have that.

Dan explained that stuttering has empowered him to become creative in ways that help himself and others be happy:

It just made me be happy, because if I can't speak than I want others to be happy. I've got to do what I can to make my life happy, because speech brings it down and I have to do other things to make up for it... I would prefer not to have my speech stuttering from now on, but I don't think I would take it back if I was in grade school, because it's helped me in other ways that I don't want to change.

The SLP participants talked a lot about how PWS have empowered them to be better clinicians. Four out of the six SLP participants discussed how stuttering can positively impact QOL through ways of empowering the individual and people around them. For example, Jane said:

I think people who stutter teach us a lot. I think that my clients have taught me a lot about listening – for sure – and for being courageous and for taking those risks like I talk with them a lot about, things that I ask them to do in therapy – you know – I have to do that first and then a lot of those things are tricky for me. Here they are, you know, going out there and taking these chances and I think that a lot of people recognize that, especially as they get older.

Another SLP, Jackie talked about “positive elements of the quality of life in feeling empowered that you took something on, and empowered that you're not letting stuttering get in the way, empowered that you're being true to yourself, feeling and knowing that you're an equal and that you have a voice.” Molly came full circle when describing the experience of stuttering as an empowering and sustainable aspect of self:

I think through that acceptance process and identification as a person who stutters, I think that stuttering can be used as a tool. It can empower people to advocate for, you know, really anything... being who they truly want to be. I think they can use their experience as a person who stutters to promote authenticity.

Control. Both groups of participants discussed control in their interview discussions regarding the impact of stuttering and how stuttering impacts QOL. Control refers to the concept of exercising or directing influence over something else; to have power over; to reduce the incidence or severity of something else (Merriam-Webster, 2015). Many participants from both groups discussed aspects of how stuttering has elicited some sort of unpleasant control over life experiences. Four minor themes contributing to the formation of a sense of control (or lack, thereof) are discussed below in more detail.

Unpredictability. Unpredictability refers to the deprivation of the ability to foretell an experience. People are physiologically wired to “plan ahead,” due to the functions of the frontal lobe in the brain (Myers, 2013). Having this innate ability comes naturally to most people, and if people are inhibited from the ability to do something that would otherwise come naturally, or if people are suddenly found not in control of their ability to predict and plan ahead, it can have a negative impact. All participants who stutter discussed how the unpredictable nature of stuttering has negatively impacted his or her lives.

As a participant who stutters, Lily talked about how she has been challenged her whole life with moments that were out of her control, and how stuttering contributed to this challenge. She used the interview as an opportunity to elaborate: “I’ve stuttered as long as I’ve known. I have no idea why I stutter, that’s a big question for me, is why? If I knew what you were going to say [in this interview], I could change things, and I’d probably say what you’d want me to say.” This participant’s desire to have control over

situations in her life is overwhelming, and because the nature of stuttering is so unpredictable, the impact of stuttering on her life is great.

When other participants who stutter were asked to describe their stuttering as a communication disorder, many of them went into detail about how stuttering has impacted different stages of their life. Rita said, “I’ve stuttered ever since I can remember.” She talked about her stuttering when she was a toddler, then into fifth and sixth grade being very fluent. Rita went on to say that in seventh grade she began to stutter more severely, and that she learned to hide it in her life after that. She continued hiding it until she started receiving therapy in college, and now she accepts her stuttering and copes more effectively with it now than she ever has. But the severity throughout Rita’s life has shown that stuttering is undeniably unpredictable, and it can impact an individual at different degrees at different life stages, at times when it is impossible to plan for, and difficult to adjust to.

Another participant who stutters, Simon told his story:

All right well, I think it started at the age of seven and when it first happened, I didn’t want to talk to anyone, I didn’t want to say anything, I just wanted to stay in my shell. And then I had speech therapy in the States and that helped a lot. I was getting better and better, I was almost fluent. Then after high school, all the stress hit of me – like school and all that, being away from home – my stuttering went downhill again. Then I attended this other speech clinic that really sucked and it didn’t help at all. Then I attended the clinic down in Ohio and it helped. And right now I’m at the point there are days that I have awesome days, and that I have horrible days.”

A different participant who stutters, Dan, told his story:

I started when I was in the second grade. And I didn’t notice until a month or two ago what I think actually caused it. In second grade I got an exchange student, and I’m thinking that was it, you know? Because I

don't know how it would affect me, but that was the big event that happened when I was in second grade.... We had her for a whole school year. And I don't know if it was just about me, because I was like seven at the time, and she was sixteen. So it was someone I new who was like a sister who was cool, and I wanted to be just like her or something. So I kind of think that's what caused it. One day I just woke up and it happened.... It just came out of nowhere. I went to sleep one night and I woke up the next day, and I've had it ever since.... At first it was a bit worse than it is now, and after that I got really, really bad. It got horrible. And then slowly over time it got to where it was, but it got there slowly.... I've been about the same way now for about all through high school, I would say, to the point where it wasn't so bad any more....

Despite some PWS talking about their experiences in therapy during times when their stuttering was out of their control, they still seemed to round back to the concept that stuttering remained an unpredictable disorder that impacts their lives in some way, no matter what. Anna admits:

You know, I think having speech therapy and simply getting older boosted my confidence, because as I was younger, I hated having to speak. I just hated to talk. In high school I really got confident and so really, I did see an improvement. So out of high school therapy stopped, I'm two years into college, and I have definitely seen my fluency slipping.

Avoidance. Avoidance refers to the act of withdrawing from something; it refers to emptying, vacating, or clearing away from something that is, oftentimes, undesirable (Merriam-Webster, 2015). In the case of this study, the theme of avoidance has contributed to the major theme of control in that avoidance is a reaction that many PWS experienced as a result of encountering something beyond their control. Many participants who stutter spoke about avoidance in many contexts.

When talking about stuttering having an impact on his education, Simon said, "I think there are certain times I was asked a question, and I had an answer but I didn't want to say it because I thought I'd stutter." Lily described her stuttering by saying, "I try to

hide it.” Lily then went on to talk about stuttering impacted her personal relationships, admitting that her husband didn’t know she stuttered until after they were married, indicating that she avoided this conversation until it absolutely felt relevant to identify it as a part of who she was.

Eddy discussed how stuttering has impacted him throughout different times in his life, saying:

I was really good at changing my words around what I was saying so that I would try to hide it from people. Then around my senior year, I would still change my words, try to hide it from people, but I didn’t think or worry about it that much.

Eddy chose to avoid the words he used, rather than social situations. Nonetheless, the experience of avoidance is a theme that represents the lack of control that PWS might experience as a result of their stuttering.

Responsibility. Responsibility refers to a task that a person should do because they are expected to do it, because it is morally right, or legally required (Merriam-Webster, 2015). In the context of the interviews with participants who stutter, responsibility is a theme that was uncovered when participants talked about how stuttering impacts QOL. Lily, as a person who stutters, reported how she learned she had a responsibility to take control over the quality of her own life, because of her stuttering:

I’m trying to accept it more. I’m not saying I like it, I’m not proud of it, I don’t want to embrace it – although there are some people who do that. I don’t like it. I’m not happy about it, but I’m trying to cope with it more and deal with it more, make it more than me just saying, ‘that other things,’ because it’s more a ‘whole’ and not an alter-ego.

Rita explained that stuttering has impacted the quality of her life so much that she finally had to step up and take responsibility for where this life was taking her. She

thought: “I can’t continue to go on like this.’ It was a realization for myself that something needs to be done.”

Physical Impact. As previous literature has shown, stuttering is a multi-factorial communication disorder, with there being evidence that there is a physiological basis (Yairi & Seery, 2015). The current literature documents neuro-anatomical differences in PWS, ultimately identifying impairments in PWS’ body structure (e.g., Foundas et al., 2003; Foundas, Bollich, Corey, Hurley, & Heilman, 2001; Chang et al., 2008). The ICF Model identifies a physiological impact that stuttering can have on an individual, as it may interrupt activities of daily living. Many PWS and SLPs commented on their beliefs regarding the physical impact of stuttering on a person’s life.

When asked how it feels to stutter, two participants who stutter responded that they both feel tense, and described stuttering as an “exhausting” and “frustrating” experience. Eddy went into more detail, saying stuttering feels... “...tense when I get into a block, but my head, my neck, my chest gets tense, and tenseness will linger several minutes after the blocks and the more blocks I have consecutively the worse I’m going to feel.” Anna shared her experience of what stuttering feels like:

The one thing I really hate is that when I do have a stutter, it can get hard to breathe. I feel a tightness and it worries me a bit. I grew up in a smoking environment. I didn’t smoke, but every other person in the family has. And that concerns me a bit. And simply the fact that I can feel the tightness, it gets hard to breathe. If I stutter my saliva increases and that really is a bit of a concern because I don’t want to have spit at the corners of my lips, but...there are some physical things with it, and they bother me. But I don’t think they’re going to be trouble to my health. I would love to be able to have this tightness in my throat just leave.

Many SLP participants acknowledged the emotional impact of stuttering and also agreed that there can be a physical impact, as well. Frank explained that the impact of

stuttering on physical health varies between individuals, since the stuttering population is very “heterogeneous,” but that stuttering... “definitely could have an impact on physical health, especially if someone has a very severe behavioral component that results in excessive muscle tension in a moment of stuttering, that could impact physical health.”

Two SLP talked about the connection between emotional health and physical stress. Jane said:

I strongly believe that the way that we react emotionally to things can impact us physically. So I think that if there’s a lot of stress and worry, that definitely causes someone to be more run down, to not have much energy for some things.

Jackie explained:

I do [believe stuttering impacts physical health] in the ways that stress impacts health. So, the whole personality thing, the whole ‘not saying what you want to say when you want to say it’ *chronically*, having a negative feeling going through your mind *chronically*, I think all of that builds up to an amount of stress, and I think we all know enough about stress now to say that stress is more than just mental. It physically affects us.

Sam had similar beliefs about physical health and emotional health, and referred to a current client as an example:

There is a significant amount of stress that they feel with their stuttering, significant amount of anxiety, even depression. So the relation there to stuttering is not a direct one; it’s stuttering that has an impact on their mental health, their mental health has an impact on their physical health. But it also can be fairly direct, I’ve worked with people who have experienced a very high degree of physical tension in the breathing mechanism. I’ve got one guy who’s always speaking on the end of his breath stream, his expiration, and he’s just filled with physical tension, and that affects him all during the day. He carries a lot of excess tension in his body. I think that that has an impact on his physical well-being. It’s not a direct relationship, typically. I think that the stuttering is maybe an underlying cause but there’s probably some other mediator... like the high

anxiety and the depression, that ultimately leads to the impact of physical well-being.

Therapy impact. Therapy impact refers to conversations that occurred among interviews with both groups of participants regarding the treatment of stuttering as it relates to the impact on a person's life, and how therapy has been involved in these experiences. The impact of therapy was often discussed as an indirect impact on a person's life, since many participants who stutter talked about the impact of therapy for their stuttering, rather than the stuttering, itself. SLP participants talked about the impact of therapy as a contribution to how stuttering can impact a person who stutters. No matter which way each participants brought it up, the impact of therapy on an individual oftentimes was referred to as providing a negative impact – “bad” therapy – or a positive impact – “good” therapy. Discussions between both groups of participants are discussed below in more detail.

“Good” therapy. For this theme, the term “good” refers to something that is of high quality, correct, proper, favorable, suitable, agreeable, pleasant, well-founded, adequate, and satisfactory. “Good” therapy is discussed as what might be considered high quality treatment for PWS. The term “good” indicates that the SLP participants talked about the positive aspects of therapy, bringing up topics regarding how it can lead to impacting a person's overall QOL.

Molly talked about how QOL can improve if people are encouraged by SLPs to explore their stuttering in different ways:

I've seen them [people who stutter] start to see things in a different way and start to see them taking risks, and I've seen that in one on one too. They start to take communication risks...and you can see doors starting to open up for them, and they kind of become empowered in that way.

Jackie talked about how PWS who receive “good” therapy could have an improved QOL if the therapy involved an approach that focused directly on improving the person’s QOL, itself:

Good therapy is based on the person in front of your and based on an assessment that has looked at all ICF elements, all ABCs of stuttering, so looking at that Affective-Behavioral-Cognitive, to say, ‘Oh well at this point in this person’s life, it is only behavioral. Let’s just work on behavioral techniques.’ But you can say that after having assessed what this person’s emotions and reactions are, and avoidances, and how it’s impacting their quality of life.

Jane talked about how the impact of stuttering on a person’s QOL can change based on the client-clinician relationships that develop as a result of receiving “good” therapy: “I think that a strong therapy alliance where the client really feels empowered and recognizes that they can do everything that everyone else can, and they feel very supported, I think can definitely improve quality of life.”

Carl talked about the importance that perspective can have not only on the impact of a person’s stuttering on their QOL, but also on the SLP who is providing the therapy to get to that point:

My quality of life, whether I am 10% disfluent, might not change at all. We don’t know that. But if you’re just looking at disfluency rate in terms of success in therapy, it doesn’t tell you anything about the person as a whole. In my mind, good therapy focuses on the whole person and focuses on the overall impact of stuttering on their life.

Molly talked about how she felt responsibility to provide “good” therapy that focused on increasing QOL of PQA, and to do this, the focus in therapy needed to shift appropriately: “I think it’s our responsibility and our duty as speech-language

pathologists to target the quality of life of people who stutter and not just fluency, which, I feel like we're in that forward way of thinking."

Overall, most SLPs considered "good" therapy as an approach that involved a bigger picture than simply focusing on disfluent patterns in a person's speech. This idea of therapy as a holistic approach appeared to be an agreed-upon concept among all SLP participants.

"Bad" therapy. For this theme, the term "bad" refers to something that is of poor quality, incorrect, unfavorable, objectionable, disagreeable, faulty, unpleasant, and invalid. "Bad" therapy is discussed as what might be considered poor quality treatment for PWS. The term "bad" indicates that the SLP participants talked about the negative aspects of therapy, discussing topics regarding how it can lead to impacting a person's overall QOL.

Carl said, "Bad therapy focuses on just trying to make them more fluent." PWS will often go to speech therapy to help manage their stuttering. Sam talked about how therapy impacts QOL since the reason PWS are receiving therapy initially, is because they stutter. Therefore, stuttering impacts a person's QOL, in this sense, in a negative way if they do not receive "good" therapy:

Therapy comes as more scary for me because, generally, therapy is based heavily on fluency skills, and not stuttering management, I've found has the potential to create fear of stuttering. So these clients do whatever it is that they possibly can to NOT stutter.

Jackie talked about the importance of pertaining to the individual in therapy, and if SLPs do not consider each person who stutters as an individual, SLPs are using what she called "prescriptionistic therapy, which is not geared toward the person in front of you; it's this 'one size fits all.'"

Jane shared her beliefs on the difference between what might be considered “good” and “bad” therapy, and how this relates to the individual’s QOL:

Bad therapy is therapy that is 100% about making stuttering go away. No, if I have a client whose goal really is to work on making talking easier, then that’s obviously something that we work on and I think that’s phrased very differently.

Therapy impact on quality of life. While both groups of participants discussed their beliefs regarding “good” and “bad” therapy, only SLP participants’ responses were agreed upon, while the responses from participants who stutter varied widely. There did not seem to be any solidifying definition of “good” or “bad” therapy for PWS according to the interviews. However, many participants in each group did talk about how therapy can impact a person’s QOL.

Most participants who stutter talked about the impact of therapy providing a positive reaction, and therefore improving their QOL. Eddy had just recently been discharged from therapy, and commented on his experience:

I feel like a much-improved person [after speech therapy] I feel like the person I always thought I could be but couldn’t be. I feel like I have a higher quality of life because I’m not held back by any situation now and I’m free to do what I want to do and my speech can actually be an asset to me and not a liability, and that’s a huge change.

Rita spoke similarly:

Speech therapy was successful because we not only worked on techniques but we also talked about how we felt and more of counseling, sort of. I got to meet other people who stuttered so I didn’t feel as helpless and alone.

Most SLPs discussed how therapy – whether it’s therapy they’ve provided, or therapy that was provided for their clients previously – had impacted a person who stutters’ QOL. For example, Jane said: “I really do feel like the therapy for the most part,

I think helps with quality of life.” She also commented on what it’s like being an SLP working with PWS while trying to improve their QOL:

I think it forces you to be a good counselor at times, or be a better counselor because so much of what you’re doing working with a person who stutters is on counseling. It’s a big part of what we do.

Sam believes that the only reason he sees people who stutter as clients is because their QOL is impacted, and this is why improving QOL in therapy is a primary focal point for his clients:

I see them [people who stutter] because there is adverse impact on their quality of life, that’s the deciding factor for me in therapy. That would be why they come to therapy. A person who just stutters and has no impact on their quality of life probably isn’t going to benefit much from therapy.

Molly uses a client as an example of how therapy can impact quality of life:

The adults that I know [who stutter], I think some of them have had really crappy therapy unfortunately and it hasn’t been until early adulthood that they really started to identify that and say, ‘Now I need for myself to find quality of life despite the fact that I stutter.

Chapter 4

Discussion

The purpose of this study was to explore the beliefs of SLPs and PWS about QOL and their perspectives regarding the impact of stuttering. More specifically, this study sought to better understand how PWS and SLPs describe the impact of stuttering on an individual, and whether these relational impacts are subsequently impacting a person's overall QOL. Additionally, this study explored the beliefs of how SLPs and PWS define QOL as it relates to stuttering, and also as it relates to others who do not stutter. Lastly, this study explored the differences between the beliefs of SLPs and PWS regarding these issues.

In order to answer these questions, qualitative data was collected from six PWS and six SLPs. This data collection consisted of open-ended semi-structured interviews where participants from each group shared their experiences related to their beliefs regarding the impact of stuttering and QOL issues. Along with the interviews, participants completed demographic questionnaires to identify their present situation and status regarding stuttering as a communication disorder. The results of this qualitative data were analyzed and common themes were compared as the conclusion of the study.

The following sections discuss the beliefs of participants regarding the impact of stuttering (research question 1) definitions of QOL (research question 2), the impact of stuttering on QOL (research question 3), and the differences between PWS and SLPs involving these issues (research question 4). The sequential organization of this discussion is outlined in Figure 2.

WHAT IS THE IMPACT OF STUTTERING?

SLP	PWS
The Individual Advocacy	Positivity Restriction Regarding Education Unpredictability Avoidance
SLP and PWS	
Physical Impact Acceptance Identity Restriction Regarding Occupation Restriction Regarding Relationships	

WHAT IS THE DEFINITION OF “QUALITY OF LIFE?”

SLP	PWS
Perspective	Happiness
SLP and PWS	
Authenticity No Restrictions	

WHAT IS THE IMPACT OF STUTTERING ON QUALITY OF LIFE?

SLP	PWS
Therapy Impact Regarding Good Therapy Therapy Impact Regarding Bad Therapy	Responsibility
SLP and PWS	
Therapy Impact Regarding Quality of Life Restriction Authenticity Empowerment	

Figure 2. Theme differentiation according to research question

Impact of Stuttering

Interviews with both groups of participants involved a great amount of discussion of how stuttering can impact a person. Some themes were identified only among SLPs, some themes were identified only among PWS, and some themes were found between both groups.

Many PWS talked about positive aspects of how stuttering impacts them. Multiple participants shared how stuttering has shown them who their true friends are, and it's brought out their best qualities as a person since they realize that stuttering might be something that restricts them in other areas where people who don't stutter may not be otherwise restricted. SLPs did not mention any thoughts regarding how stuttering can impact a person in a positive way, which is synonymous to already existing literature that investigated various SLP perceptions of PWS (Cooper & Cooper, 1996; Turnbaugh, Guitar, & Hoffman, 1979).

Many PWS also talked about how their stuttering can restrict their education in a sense that it made them feel like they were at a disadvantage when they were competing against others who do not stutter for participation points, or campus involvement roles. Some PWS even said that if they didn't stutter, they would have chosen a completely different career choice than what they had right now. While SLPs talked about stuttering restricting PWS from occupational opportunities and personal relationships, SLPs did not tend to discuss how stuttering might impact PWS's education in the same way that PWS did.

Every participant who stutters talked about the unpredictable nature of stuttering and how this can impact a person's life. When asked to describe their stuttering, all

PWS had a story to share. Their stories reflected the “ups and downs” of stuttering throughout their lifetime, and how stuttering has impacted their lives more or less at different times. Nearly all PWS expressed frustration regarding this unpredictable nature of stuttering as a disorder, and how it is a life-long challenge to live their lives with stuttering. No SLP participants spoke about the unpredictability of stuttering as an impacting factor in the same way that PWS did.

Lastly, avoidance was a common theme talked about among PWS. While some SLPs discussed avoidance as a common reaction to stuttering, SLPs spoke about avoidance in a sense that PWS avoid talking. The PWS in this study, however, talked about not only avoiding talking, but avoiding conversation topics with people they love, or avoiding the responsibility to “do something about” their stuttering, or avoiding the urge to express entire thoughts in class or among groups of friends. Avoidance for PWS appeared to be a much larger concept when compared to avoidance discussed among SLPs.

Many SLPs spoke often about the individual when they were asked to describe their stuttering clients. Most of them found they could not generalize a definitive answer when describing their clients who stutter because all of their clients are so different from one another. The SLPs expressed that they believe PWS might sometimes face similar challenges, dependent on context, personality, or other aspects of situations surrounding them. In this sense, SLPs valued that a person who stutters encompasses an individuality that sets them apart from one another, and SLPs believed that stuttering has an impact on how PWS have shaped their identity as a person. Most PWS did not discuss individuality in relation to stuttering.

SLPs also spoke of how stuttering can require PWS to develop a desire to advocate for themselves, particularly in the workplace. SLPs spoke about how many people in most occupations are uneducated regarding stuttering and the impact it can have on a person, and therefore PWS are expected to advocate for themselves in environments where most people who don't stutter would not have to. Most SLPs used clients' examples to explain the necessity of advocacy based on how much their clients were impacted by unfair restrictions at their jobs. PWS did not mention advocacy as an impact of stuttering.

Many SLPs and PWS discussed similar themes regarding the impact of stuttering. Five out of the six participants from each group spoke strongly about the physical impact of stuttering, and how this can impact a person. Most PWS talked about physical tension when they were explaining the actual speech act, and how they feel "tense," "tight," and "exhausted." Most SLPs talked about the physical tension as a result of stress from social experiences many PWS go through every day as a reaction of their stuttering in social situations. Regardless, both groups demonstrated strong beliefs that physical tension is an impact of stuttering.

Acceptance is another theme that both SLPs and PWS discussed when talking about the impact of stuttering. Many SLPs expressed their beliefs that accepting stuttering is an essential aspect of therapy, and how many PWS will see a "huge life impact" once they accept their communication disorder. Many PWS discussed moments of when they finally realized that they need to accept their stuttering, or moments when they already accepted their stuttering, and how this has had a positive impact on their life.

In this sense, both groups of participants shared the same belief that stuttering has an impact on how PWS develop an acceptance of who they are.

Both SLPs and PWS discussed beliefs regarding restriction in the workplace. They talked about the fact that many employers are ill informed about stuttering as a communication disorder, and oftentimes this leads to inevitable discrimination and misconception about the performance ability of a person who stutters. Many comments and stories from PWS seemed to follow up with the SLPs comments when they shared their experiences in the workplace. Most PWS had a story that involved how they felt they need to “prove themselves” at work because of their stuttering, not because of their inability to do a job that was asked of them. Many PWS were even restricted from being offered the position they wanted in the first place.

Both groups also discussed beliefs regarding restriction regarding personal relationships. Many SLPs talked about their beliefs when referencing how many PWS carry shame as a reaction of their stuttering, and how this shame can negatively impact relationships they have with other people. Participants who stutter did not discuss shame as a group, but they spoke about how stuttering can complicate different relationships, including romantic relationships, family relationships, first impressions, and friendships. PWS indicated that they have to work a little harder to accurately demonstrate who they are, because they tend to feel like their stuttering is louder than their identity. Both SLPs and PWS believed that the impact of stuttering includes restrictions in the workplace and within personal relationships.

Definition of QOL

Interviews between both groups of participants involved defining “quality of life.” As previously mentioned, the term “quality of life” has been difficult to define by many researchers and health professionals (Rapley, 2003). “Quality” is a “subjective term for which each person has his or her own definition” (Barofsky, 2012, pg. 626). Asking SLPs and PWS how they might define QOL gives insight on how to relate overall QOL to therapeutic approaches for people with communication disorders, particularly stuttering. Previous research has documented that both positive and negative affect influences a personal sense of one’s QOL (Diener, et. al., 1999). Definitions from the participants in this study also give information on how QOL is perceived and addressed today. Some themes were identified only among SLPs, only among PWS, and some themes were identified for both groups.

Participants who stutter spoke primarily about a person’s happiness. They said QOL is about being happy with who you are, happy with where you are in your life, happy with your career, and happy with the people you surround yourself with. Most SLPs did not directly address the concept of happiness in their definitions. Instead, SLPs discussed a person’s perspective. Many SLPs used situational examples to explain their beliefs, including what they think a “bad” QOL might look like versus what a “good” QOL might look like. Ultimately, SLPs believed that a person’s QOL depended on how they perceive the world around themselves, regardless of how other people perceive the world around them. This overall theme illustrates the importance of the individual, and how one person’s QOL on one scale might look completely different to another person’s QOL on the same scale. This is synonymous with what Mathers & Douglas (1998)

suggest, in that there may be a distinction between observable objective measures of an individual's perception about the quality of his/her life. These different definitions provide indication for further research to quantify the definition of QOL, particularly among people with communication disorders. Since most PWS believe that QOL is a result of happiness, however, perhaps happiness itself needs to be addressed in therapeutic objectives.

Participants in both groups discussed authenticity, and freedom as crucial components to a "good" QOL. Being authentic is something that people should be able to "embrace," according to SLPs. Not feeling like you're as good as you want to be, and feeling like you aren't being "true to yourself" is something that contributes to a "poor" QOL, according to PWS. Therefore, having the freedom to be who you choose to be without restrictions on your identity as a person is what might define QOL, as reported by both PWS and SLPs.

Impact of Stuttering on QOL

Existing literature documents that many domains can impact QOL, but other literature indicates that personal relationships (e.g., family, spouse, classmate), work relationships (e.g., coworkers, supervisors, etc.), personality (e.g., introverted, extroverted, etc.), education (e.g., career path, class participation, etc.), and physical health (e.g., stress, facial or laryngeal tension) are possible contributing factors to the QOL of PWS (see Bleek, et al. 2012; Corcoran & Stewart, 1998; Craig, Blumgart, & Tran, 2009; Crichton-Smith, 2002; Yaruss & Quesal, 2006). But for this study, new and different themes were identified to describe the impact of stuttering on QOL.

More than one participant who stuttered shared an experience related to the concept, or theme, of responsibility. During the interview, they explained a time when they realized for themselves that they could not be in complete control over their speech at that moment, and that they needed to do something about it. Oftentimes, this meant they would begin going to therapy. Regardless, this experience shared by participants who stutter indicated that stuttering had impacted their QOL so much that they finally had to step up and take responsibility for this life direction, which was being inappropriately led by their stuttering. SLPs did not share beliefs that PWS experienced the realization of taking responsibility, but SLPs discussed their beliefs regarding how “good” and “bad” therapy can directly have an impact of the QOL of a person who stutters.

Most SLPs agreed that “good” therapy embodied the concept of addressing the whole person, and the experience of stuttering; likewise, most SLPs agreed that “bad” therapy embodied the concept of strictly addressing the stuttering behavior, or the stuttering disfluencies, and nothing else. Many SLPs shared the belief that the type of therapy approach provided for PWS directly impacts the QOL of PWS. While the theme discussing the SLPs beliefs of “good” and “bad” therapy is evident, it is important to realize that if SLPs have the intention to do therapy in a particular way but they do not understand the experience (i.e., the impact of stuttering) that is being treated, then there is still a gap in treatment effectiveness that needs to be closed, in order to provide the most effective treatment for PWS.

Participants in both groups talked about therapy having an impact on QOL. Most participants who stutter shared a therapy experience that shifted their overall QOL in a

positive direction, but their stories were shared from their point of view in a sense that they were the ones in therapy who shifted this impact as a result of therapy. On the other hand, SLPs spoke about the therapy impact on QOL in a sense that they had the responsibility to provide that for their clients by recognizing the individual, incorporating counseling techniques in therapy, and allowing QOL improvement to be the ultimate treatment goal.

Lastly, participants in both groups shared similar beliefs when they discussed that stuttering has a negative impact on QOL when restrictions or limitations were in place as a result of stuttering. The SLPs referred to restriction in this sense by referencing times when past clients have allowed their stuttering to make decisions for them in social situations, ultimately restricting them or limiting them from an experience that they otherwise would have participated in if they did not stutter. Participants who stutter referred to restriction by sharing experiences when they put blame on their stuttering during times when they chose not to do something, ultimately restricting themselves or limiting themselves from an activity that they otherwise would have participated in if they did not stutter.

Beliefs of PWS and SLPs

Participants in both groups made similar comments regarding the definition of QOL, the impact of stuttering, the impact of stuttering on QOL, and their beliefs and experiences regarding therapy's impact on QOL. The major similarities were reflected in themes regarding therapy impact on QOL, physical impact, empowerment, acceptance, authenticity, and restriction regarding occupation and personal relationships. The major differences were reflected in themes regarding happiness, unpredictability, avoidance,

responsibility, good and bad therapy, advocacy, the individual, and restriction of education. Each previous research question and the participants' responses are discussed below.

To explore the initial impact of stuttering, both groups of participants discussed how stuttering can be experienced with physical tension, how acceptance is an inevitable process of self-identity, and how PWS can experience restrictions or limitations at their jobs or in personal relationships with other people. However, only SLPs talked about how PWS need to be identified as individuals in therapy so that the impact of their stuttering is decreased, and how advocacy is an essential life skill that PWS must learn in order to lessen the impact of stuttering in their life. Many PWS discussed positive impacts of stuttering, restrictions in their educational journeys, the challenges of unpredictable moments of stuttering, and their struggles with avoidance in certain situations occurring as a direct impact of stuttering.

To explore the definition of QOL, participants in both groups discussed how a good QOL involves a person who is able to be who they choose to be (authenticity) and choose what they choose to do (have no restrictions.) However, only SLPs expressed the concept of "perspective," and how QOL truly depends on the person's perception of their own experiences. All participants who stutter talked about "happiness" as an essential aspect of a good QOL.

When exploring the overall impact of stuttering on QOL, participants in both groups talked about their positive experience with therapy and how therapy can improve QOL, how stuttering has provided a sense of empowerment – either for the person who stutters, or for the SLPs who assists them in therapy – and lastly how feeling restricted

and the inability to be authentic might lead to a poor QOL. The SLPs tended to talk about their role in improving or worsening PWS' QOL in therapy, and talked about how important providing "good" therapy is for PWS. Participants who stutter, on the other hand, discussed their responsibility in taking control of their own QOL in ways that only they could figure out for themselves.

Chapter 5

Conclusion

There are many similarities and many differences in the beliefs of the participants who stutter and the SLPs regarding the impact of stuttering, how to define QOL, and the impact of stuttering on QOL. This study provides an exploration of how some SLPs might be addressing key aspects in therapy, but there are still some aspects that SLPs might need to focus more on so that they are providing the most effective treatment for PWS.

The concept of phenomenology is to provide an opportunity for subjects to share their personal experiences of a particular phenomenon. In this case, the phenomenon was stuttering. While PWS in this study could share their experience directly, since they are people who stutter, SLPs could only share their experiences indirectly, since they are people who do not stutter. The gaps in beliefs between the participants in both groups indicate there is still need for further study towards understanding the impact of stuttering on QOL. Further discussion regarding limitations of the study and implications for further research are discussed below.

Limitations

Participant sampling presented some limitations to this study. The sample size in this qualitative study was small, so it is difficult to generalize this data to the wider populations of SLPs and PWS (Meline, 2006). All SLPs had worked with PWS for at least five years and had experience working with PWS, so future studies should involve a larger sample size with other SLPs who have less experience working with PWS, in order to better represent the general population. All PWS had a previous relationship with the

advisor of the study, so it is suggested that future studies randomly acquire a sample of PWS with no relationship to the researchers to further eliminate bias. Lastly, a stricter participant requirement should be established in order to improve internal validity (Meline, 2006).

Implications for Further Research

Though this study summarizes the beliefs of PWS and SLPs regarding the impact of stuttering on QOL, there are still many aspects of stuttering as a communication disorder that are not addressed in therapy between PWS and SLPs who treat them (e.g., avoidance behaviors, restriction regarding education). Eddy was a participant who stutters, but was also an SLP. While Eddy's beliefs regarding the impact of stuttering and QOL were valid for the purpose of this study, themes developed from his independently generated responses could be a starting point for further research. While there are limited studies on the perspective of SLPs regarding QOL issues, the literature is even more limited regarding the perspective of health professionals with communication disorders. Additional research should explore the phenomenon of SLPs with communication disorders and how this might impact their role as a health professional.

Counseling was a concept mentioned by SLP participants sporadically throughout the interview in different contexts, and was also a concept mentioned by participants who stutter in a sense that they had previously experienced therapy addressing their "self-esteem." Counseling is in the SLPs' scope of practice and it should therefore be expected that all SLPs be comfortable delivering counseling aspects of therapy for people with all

communication disorders, not just PWS. Therefore, questions suggested for further research include:

- 1) How can the gap be closed between the beliefs of SLPs and PWS regarding QOL issues as an impact of stuttering?
- 2) Should SLPs feel responsible for PWS' QOL in therapy?
- 3) If SLPs were trained in counseling throughout their initial education as graduate students and continuing education as professionals, would therapy for PWS be more effective?

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Appendix A

Permission by University of Toledo Social, Behavioral, and Educational Institutional Review Board from the Department for Human Research Protections



The University of Toledo
Department for Human Research Protections
Social, Behavioral & Educational Institutional Review Board
Office of Research, Rm. 2300, University Hall
2801 West Bancroft Street, Mail Stop 944
Toledo, Ohio 43606-3390
Phone: 419-530-2844 Fax: 419-530-2841
(FWA00010686)

To: Rodney Gabel, Ph.D., and Emily Figliomeni
Department of Rehabilitation Sciences, SLP Program

From: Barbara K. Chesney, Ph.D., Chair
Mary Ellen Edwards, Ph.D., Vice Chair
Walter Edinger, Ph.D., Chair Designee
Lee Ann Pizzimenti, J.D., Chair Designee

Signed: B.K. Chesney **Date:** 03/17/14

Subject: IRB #200102
Protocol Title: *Quality of Life of People who Stutter*

On 03/17/14, the Protocol listed below was reviewed and approved by the Chair and Chair Designee of the University of Toledo (UT) **Social Behavioral & Educational** Institutional Review Board (IRB) via the expedited process. The Chair and Chair Designee noted that signed and dated consent is required prior to an individual taking part in this research. This action will be reported to the committee at its next scheduled meeting.

Items Reviewed:

- IRB Application Requesting Expedited Review
- Current IRB Approved Assessments (version date 03/17/14)
- Current IRB Approved Consent Form(s) (version date 03/17/14)
- Current IRB Recruitment Email(s) (version date 03/17/14)

This protocol approval is in effect until the expiration date listed below, unless the IRB notifies you otherwise.

Only the most recent IRB approved Consent/Assent form(s) listed above may be used when enrolling participants into this research.

Approval Date: 03/17/14 Expiration Date: 03/16/15

Number of Subjects Approved: 50

Please read the following attachment detailing Principal Investigator responsibilities.

Appendix B

Contact Emily/Flyer for Quality of Life Study

Hello _____,

I hope you are doing well. I wanted to contact you today to see if you might be interested in participating in a study that I am doing with one of my students, Emily Figliomeni. She is doing this project to complete her master's thesis.

This study is designed to evaluate the quality of life of individuals who stutter and other issues. Besides getting your perspective on your own quality of life, we are interested in learning how speech therapy impacted your quality of life, either positively or negatively. As a group leader, we would also like you to consider asking your group members (through email, phone, or at a meeting) to participate.

To participate, you will be asked to complete a short questionnaire. You will then be asked to participate in a short interview. It is expected that it will take you 40-60 minutes of your time to complete this study.

Thank you for considering participating in this study. If you are interested or if you have any questions; please contact me by email. Your participation will help the field of communication disorders gain a better understanding of the experience of stuttering and to develop more effective therapies for people who stutter.

Sincerely,

Rodney Gabel, Ph.D., CCC-SLP, BCS-F
Department of Rehabilitation Sciences, SLP Program
The University of Toledo, MS 119
Toledo, OH 43606
Rodney.Gabel@utoledo.edu
419-530-6682
https://www.utoledo.edu/healthsciences/depts/rehab_sciences/speech/shutteringclinic.html

Appendix C

Contact Emily/Flyer for Quality of Life Study-From Emily to Schedule

Hello _____,

Dr. Gabel shared that you are interested in participating in our study. Thank you very much. At this point, I want to attempt to schedule an appointment with you to complete the study. We can set this up at your convenience, either meeting in person (if possible) or through video conferencing. As Dr. Gabel shared, this meeting will include both the completion of a short questionnaire and an interview. We will also review your rights as a research participant. This should take no longer than 45-60 minutes.

At this point, could you email me back to confirm that you are still interested in participating in the study? If you are still interested, you and I can get this meeting scheduled at your convenience. Thank you again for your interest in this study.

Emily Figliomeni, Graduate Student in SLP

Appendix D

Adult Research Subject – Informed Consent Form



Rehabilitation Sciences
2801 Bancroft Street, MS119
Toledo, Ohio 43606
419-530-6670
419.530.4780

ADULT RESEARCH SUBJECT - INFORMED CONSENT FORM
Quality of Life and People Who Stutter

Principal Investigator: Rodney Gabel, Ph.D., CCC-SLP, BRS-FD, Associate Professor, 419-530-6682; Emily Figliomeni, BA, Graduate Student

Purpose: You have been asked to participate in this research study, which has been explained to you by. This study is being conducted by Emily Figliomeni and Rodney M. Gabel Speech, Language Pathology Program at the University of Toledo. The title of the study is: Quality of Life and People Who Stutter. The purpose of this study is to learn more about the beliefs the adults who stutter and speech-language pathologists report regarding the impact of stuttering on quality of life.

Description of Procedures: To participate, you are being asked to complete a survey and participate in an interview. The questionnaire will ask you to share some basic demographic information such as your age, occupation, and historical information about your stuttering. The interview will ask you to respond, in detail, to questions regarding your stuttering, your quality of life, and your experiences with therapy. This interview will be video and audio recorded. Your participation in this project will take approximately 40-60 minutes. This interview can be scheduled at a time and place that is convenient for you. If you wish, we can do this via videoconferencing. The interview will be audio recorded. Will you permit the researcher to {audio record/video record} during this research procedure?

Form with YES/NO checkboxes and lines for 'Here' and 'Initial Here'.

After you have completed your participation, the research team will debrief you about the data, theory and research area under study and answer any questions you may have about the research.

Potential Risks: There are no more than minimal risks to participation in this study, including loss of confidentiality.

Potential Benefits: You may not receive any direct benefit from this study. The knowledge gained from this study may eventually benefit others. This experience may also be a learning experience for you.

Confidentiality: Any information about you that is obtained as a result of your participation in this research will be kept as confidential as legally possible. In addition, there are certain instances where the researcher may be legally required to give information to the appropriate authorities. These would include mandatory reporting of infectious diseases, mandatory reporting of information about behavior that is imminently dangerous to your child or to others, such as suicide, child abuse, etc.

Audio and/or video recordings will be kept on a computer in a locked research laboratory (HSHS 1200) and will be destroyed as soon as possible after the research is finished. In any publications that result from this research, neither your name nor any information from which you might be identified will be published without your consent.

Voluntary Participation: Participation in this study is voluntary. You are free to withdraw your consent to participate in this study at any time. Refusal to participate or withdrawal will involve no penalty to you and, if you are a student, will not affect your class standing or grades. Refusal to participate or withdrawal will not affect your future care, or your employee status at University of Toledo.

In the event new information becomes available that may affect your willingness to participate in this study, this information will be given to you so that you can make an informed decision about whether or not to continue your participation. You have been given the opportunity to ask questions about the research, and you have received answers concerning areas you did not understand.

Upon signing this form, you will receive a copy. If you are doing the interview by teleconference, the copy will be sent to you as a PDF document shortly after the interview is completed.

Contact Information: If you have any questions or feel any discomfort about this study, please do not hesitate to contact Emily Figliomeni by phone 419-343-9805 or emfiglio@gmail.com. You can also contact Rodney Gabel, Ph.D., CCC-SLP, BCS-F by phone (419) 530-6682 or Rodney.Gabel@utoledo.edu. If you have any questions about your participation in this research, you can also contact the Social, Behavioral and Educational Institutional Review Board at the University of Toledo by phone 419-530-2844. You will be given a copy of this form to keep.

SIGNATURE SECTION – Please read carefully

You are making a decision whether or not to participate in this research study. Your signature indicates that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research.

The date you sign this document to enroll in this study, that is, today's date must fall between the dates indicated at the bottom of the page.

Name of Subject (please print)	Signature	Date
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Name of Person Obtaining Consent	Signature	Date
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This Adult Research Informed Consent document has been reviewed and approved by the University of Toledo Social, Behavioral and Educational IRB for the period of time specified in the box below.

Approved Number of Subjects: 50

Appendix E

Demographic Questionnaire for Speech Language Pathologists

1. Your age: _____
2. Gender: ____ male ____ female
3. Do you have a communication disorder? ____ yes ____ no IF YES, please describe:

4. Ethnicity: _____ (African-American, Hispanic etc.)
5. Number of years working as an SLP: _____
6. Number of years in your present position: _____
7. Highest degree attained: _____
8. Do you hold the CCC? ____ yes ____ no
9. Are you a member of any ASHA Special Interest Divisions? ____ yes ____ no
IF YES, please list:

10. Are you a recognized specialist in fluency disorders:
12. How many individuals are on your present caseload? _____
13. How many people on your caseload stutter:

Appendix F

Demographic Questionnaire for Individuals who Stutter

1. Your age: _____
2. Gender: ____ male ____ female
3. Ethnicity: _____ (African-American, Hispanic etc.)
4. Marital Status: ____ Married ____ Single ____ Divorced ____ Widowed
5. What is your present employment status?
____ Retired ____ Unemployed ____ Disabled ____ Student
____ Homemaker ____ Full-time ____ Part-time
6. Currently, how severe would you rate your stuttering?
____ mild ____ moderate ____ severe
7. Are you presently receiving therapy? ____ yes ____ no
8. Have you had therapy in the past? ____ yes ____ no
9. In your opinion, how successful has your speech therapy been? _____
10. Please share with us which of the following modes of therapy have you participated and your perceptions of how successful each one was for you:

____ Stuttering Modification	____ Successful	____ Not successful
____ Counseling	____ Successful	____ Not successful
____ Fluency shaping	____ Successful	____ Not successful
____ Eclectic Approach	____ Successful	____ Not successful
____ Drug therapy	____ Successful	____ Not successful
____ Assistive Device	____ Successful	____ Not successful
11. In your life, how many years have you spent in therapy? _____

Appendix G

Questions for Interviews of SLPs Working with Individuals who Stutter

1. Tell me about the individuals you work with in therapy.
 - a. Describe them.
 - b. What difficulties do they have?
 - c. What sorts of things are they able to do?
 - d. What are their major limitations?

2. How does stuttering affect a person's life?
 - a. Personal relationships.
 - b. Work relationships.
 - c. Personality.
 - d. Education.
 - e. Physical health.

3. How would you describe quality of life?
 - a. A good quality of life?
 - b. A poor quality of life?

4. How does stuttering affect quality of life?
 - a. Positive aspects.
 - b. Negative aspects.
 - c. How would things be different if your clients did not stutter?

5. Could you describe your therapy experiences with your clients?
 - a. Bad therapy.
 - b. Good therapy.

6. How does therapy impact your clients?

7. How has therapy impacted your clients' quality of life?

8. How does therapy impact you?

Appendix H

Questions for Interviews of Individuals who Stutter

2. Tell me about your stuttering.
 - a. When did it start?
 - b. What does it feel like?
 - c. How well are you understood?
 - d. How do you communicate?

3. What is it like to be a person with a stuttering?
 - a. When you were young?
 - b. When it first started?
 - c. During adulthood?
 - d. How do others perceive you?

4. How has the stuttering affected your life?
 - a. Personal relationships.
 - b. Work relationships.
 - c. Personality.
 - d. Education.
 - e. Physical health.

5. How would you describe quality of life?
 - a. A good quality of life?
 - b. A poor quality of life?

6. How has stuttering affected your quality of life?
 - a. Positive aspects.
 - b. Negative aspects.
 - c. How would things be different if you did not have a CDIS?

7. Could you describe your therapy experiences?
 - a. Bad therapy.
 - b. Good therapy.

8. How has therapy impacted you?

9. How has therapy impacted your quality of life?