Clients' Experiences with, and Perceptions of, Psychological Counseling to

Augment Stuttering Therapy

by

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Abstract

Introduction: Stuttering impacts almost every aspect of life, stimulating fear and speaking avoidances, anxiety, frustration, anger, guilt, and/or shame in those affected. Because stuttering triggers anxiety and other psychological and emotional reactions and limits participation in society, it follows that psychological counseling could enhance stuttering treatment outcomes. The Comprehensive Stuttering Program (CSP; Boberg & Kully, 1985; Kully, Langevin, & Lomheim, 2007) offered at the Institute for Stuttering Treatment and Research (ISTAR) uses speech restructuring and stuttering modification methods to reduce stuttering, and cognitive behavioral techniques to address the psychoemotional and social consequences of stuttering. However, in addition to the CSP, clients are provided the option to participate in psychological counseling offered by a resident Registered Psychologist. Despite the potential for counseling to enhance stuttering treatment outcomes in the CSP and other stuttering treatment programs, no research has been published to date on clients' experiences with, or views toward, adjunct psychological counseling services.

Research Question: The purpose of this study was to gain an understanding of clients' experiences with, and perceptions of, psychological counseling as an adjunct to the speech therapy for stuttering.

Method: Participants were adults or young adults between the ages of 13 to 38 years of age who stuttered. Six of the participants took part in psychological counseling at ISTAR, whereas three chose not to do so. Semi-structured

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interviews were used to gather data. Following data collection, interviews were transcribed and data was analyzed using grounded theory as a guiding framework. **Results:** Three central themes emerged from the data. The first was 'Participation decisions as determined within the context of clients' life stories, personal experiences, perceptions of counseling, and the way that the counseling service was promoted at ISTAR.' Decisions to participate (or not) involved factors that have been associated with help-seeking in related fields (e.g., perception of benefits, presence of negative life events) as well as novel factors (e.g., 'why not' mentality, seeing the service as a 'limited resource'). The second theme was 'Counseling as a necessary optional component in stuttering treatment,' as illustrated by the experiences and opinions of those who participated in counseling, and the surmised benefits of the service according to those who did not participate. The final theme was 'Counseling as a great service that begs wider promotion and enhancement.' Participants made suggestions for enhancing the counseling service at ISTAR, but grappled with, and discussed, barriers to modifying the service that are relevant to ISTAR and to other centers providing stuttering treatment. Inherent in the three core themes was the belief that clients at ISTAR would, or could, benefit from psychological counseling with a mental health professional who is specifically trained to deal with emotional and psychological issues; however, participants indicated that counseling needs to remain an optional component despite being an integral part of a treatment program.

Preface

The research conducted for this thesis was a collaboration between Alanna M. Lindsay and supervisor, Dr. Marilyn Langevin. Alanna Lindsay was responsible for the proposal, ethics application, data collection, data analysis, and manuscript production. Dr. Langevin advised about the project during the proposal stage. She contributed to the ethics application and to data analysis. She also advised about, and edited, the final manuscript.

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Chapter 1: Introduction

For the majority of the population, fluent and rapid speech is fundamental to surviving and thriving in every day human life and interaction. However, for individuals who stutter, fluent speech does not come easily. Stuttering can impact almost every aspect of life (Kalinkowski & Saltuklaroglu, 2006), leading to a variety of negative affective reactions, such as frustration (Bloodstein & Bernstein Ratner, 2008), anger, guilt, and shame (Daniels & Gabel, 2004). Stuttering can influence identity development and can negatively impact social interactions throughout the lifespan (Daniels & Gabel, 2004; Kully & Langevin, 1999; Langevin, Bortnick, Hammer, & Weibe, 1998; Langevin, Packman, & Onslow, 2009b; Yairi & Seery, 2011).

Since the psychological, emotional, and social consequences of stuttering can be profound, psychological counseling services, such as those that are currently being implemented at the Institute of Stuttering Treatment and Research (ISTAR) in Edmonton, Alberta, might serve as a helpful adjunct to speech therapy for stuttering. To date, no research has been published on clients' perceptions of, or experiences with, counseling programs to augment stuttering treatment.

In the remainder of this introduction, literature on stuttering will be reviewed, with emphasis on the consequences of this fluency disorder for the individuals affected. Next, various clinical techniques that have been proposed and implemented for the treatment of stuttering, including techniques that are being utilized at the ISTAR clinic, will be highlighted. Finally, a discussion of factors

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that may influence clients' decisions regarding whether to access counseling services will be presented.

Stuttering

What is Stuttering?

Stuttering is a disruption in fluency. Guitar (2014) refers to stuttering as "an abnormally high frequency and/or duration of stoppages in the forward flow of speech," that may take the form of "repetitions of sounds, syllables, or one syllable words," "prolongations of sounds," or "blocks' of airflow or voicing in speech" (p. 7). Stuttering is involuntary, and exists outside of the speaker's control (Kalinkowski & Saltuklaroglu, 2006; Yairi & Seery, 2011).

Stuttering typically begins between the ages of 2-5 years. The incidence of stuttering, or percentage of people that show signs of stuttering at some point during their lives, is reported to be approximately 5% in childhood (Guitar, 2014; Mansson, 2000). The prevalence of stuttering, or the percentage of people who stutter in a given population, varies over time and between cultures (Bloodstein & Bernstein Ratner, 2008). In general, at a given time in cultures such as the United States and Europe, the prevalence rate has been found to be about 1%, meaning that about 1% of the population in these areas stutter (Bloodstein & Bernstein Ratner, 2008). Some studies have found the prevalence of stuttering in the normal population to be as high as 2.4% in kindergarten children, decreasing to 1% in school-aged children, and decreasing again to less than 1% in adult populations (Guitar, 2014).

Stuttering has been theorized to be a disorder of brain organization, timing of neural processes involved in speech, and language production, a physiological

tremor, a reduced capacity for internal modeling (Guitar, 2014), a breakdown of speech under pressure, a belief that speech will be difficult, and as a conflict between brain hemispheres (Bloodstein & Bernstein Ratner, 2008). Recent research has shown that, in comparison to typically fluent speakers, individuals who stutter show a high degree of right-hemisphere activation when performing activities such as processing speech (Bloodstein & Bernstein Ratner, 2008; Guitar, 2014).

There is strong evidence that stuttering has a genetic basis (Guitar, 2014) and that it often occurs alongside stressors that become present in children's lives (Guitar, 2014). According to Guitar (2014), "life events can deliver a blow to a child's stability and security...children who are predisposed to stutter often show the effects of such events in their speech" (p. 70). Physical and psychological traumas may be associated with childhood stuttering, as well as with the onset of stuttering in adulthood (Guitar, 2014; Yairi & Seery, 2011). Age may also be related to stuttering, as the majority of stuttering cases emerge during the preschool period (Yairi & Seery, 2011). Additionally, gender may be an associated factor; stuttering has been found to be more prevalent in males than females (Guitar, 2014; Yairi & Seery, 2011).

It has also been posited that stuttering is a symptom of a personality disorder (for which there is no conclusive evidence; see Manning & Beck, 2013). Many researchers have asked whether stuttering may be caused by nervousness, or other types of psychological issues (Yairi & Seery, 2011). Studies show that individuals who stutter also report high levels of anxiety (Ezrati-Vinacour & Levin, 2004; Mulcahy, Hennessey, Beilby, and Byrnes, 2008; Yairi & Seery, 2011), however, there is no evidence that nervousness is a root cause of the onset of stuttering. Instead, individuals who stutter may demonstrate conditioned physiological anxiety responses in speaking situations (Alm, 2004).

Stuttering often incorporates secondary behaviors, including escape behaviors, or attempts to terminate the stutter, such as blinking, nodding, or verbalizing extra sounds, as well as avoidance behaviors, which are learned when the speaker anticipates, and uses behaviors to avoid, stuttering. Avoidance behaviors may also include blinking and vocalizing extra sounds (Guitar, 2014).

Psychological, Emotional, and Social Consequences of Stuttering Across the Lifespan

The consequences of stuttering begin in early childhood and continue across the lifespan. Stuttering is characterized by emotional, behavioral, and cognitive consequences that may affect social interaction, and numerous aspects of social life (Altholz & Golensky, 2004). In addition to feelings of anxiety, stuttering may lead to emotions such as fear, guilt, shame, and stress. Stuttering may also be accompanied by a sense of helplessness to control one's speech productions (Altholz & Golensky, 2004).

For older children, adolescents, and adults who stutter, an 'iceberg metaphor' illustrates that overt stuttering, the observable stuttering behaviors, are just one aspect of the disorder, and many other aspects of stuttering exist below the surface (Sheehan, 1970). Underlying components of stuttering may include negative emotions, such as frustration and anxiety (Bloodstein & Bernstein Ratner, 2008; Kalinkowski & Saltuklaroglu, 2006). Yairi and Seery (2011) suggest that stuttering may be classified as a disorder based on six dimensions: overt speech characteristics, physical or tense body movements, changes in physiological activity, affective states/emotional reactions, cognitive processes (such as the selection, planning, and execution of speech, as well as level of awareness and beliefs about stuttering), and social effects. The revised International Classification of Functioning (ICF) model further suggests that a broad range of participation activities might be indirectly or directly affected by fluency disorders, depending upon the severity of the stutter, and the influence of individual and contextual factors (Yaruss & Quesal, 2004). Aspects of the environment, such as negative social perceptions, may limit the participation of people who stutter in society (Yaruss & Quesal, 2004).

Consequences of stuttering in early childhood. From a young age, a majority of children who stutter are aware of their fluency disorder and experience negative social consequences (Boey et al., 2009; Ezrati-Vinacour, Platzky, & Yairi, 2001, Langevin, Packman, & Onslow, 2009). Langevin et al. (2009b) found that although the majority of peer comments towards preschoolers who stuttered during free play were neutral or positive, peers interrupted, mocked, ignored, and walked away from the children when they were in the act of stuttering. In addition, some children who stuttered had difficulty leading play and conveying their thoughts (Langevin et al., 2009b). Likewise, Ezrati-Vinacour et al. (2001) found that, by the age of 4 years, study participants were significantly more likely to choose a fluent puppet as a 'friend' over a non-fluent one. By the

age of 5 years, children often reported choosing the fluent puppet for speechrelated reasons. Finally, survey measures reveal that the parents of children with fluency disorders have perceived stuttering to negatively affect their children, and have reported experiencing emotional distress as a result of their children's fluency disorders (Langevin, Packman, & Onslow, 2010b).

Consequences of stuttering in older children and adolescents. Older children and adolescents also experience negative social consequences as a result of stuttering, including bullying (Langevin et al., 1998), lower levels of selfesteem and optimism (Blood et al., 2011), difficulty with peer interaction (Kully & Langevin, 1999), and challenges with identity development (Daniels & Gabel, 2004). For instance, types of bullying experienced by adolescents who stutter include social alienation, verbal aggression (Kully & Langevin, 1999), physical aggression/intimidation (Langevin et al., 1998), or imitation of stuttering (Langevin et al., 1998). In a survey study with non-stuttering children in grades 3 to 6, Langevin, Kleitman, Packman, and Onslow (2009a) found that about one fifth of participants demonstrated scores that reflected neutral to very negative attitudes towards peers who stuttered. Additionally, Kully and Langevin (1999) indicated that adolescents and teens who stutter report believing that their peers feel uncomfortable around them. Also, Daniels and Gabel (2004) suggest that late childhood to early adulthood reflects a time of self-discovery, and that the anger, guilt, and shame that often accompany stuttering may serve as barriers to identity construction (Daniels & Gabel, 2004). Langevin et al. (1998) caution that if stuttering is left untreated, children may avoid a variety of speaking activities,

including reading out loud and answering questions. These avoidance behaviors might be particularly detrimental to performance in the classroom.

Consequences of stuttering in adults. Adults with fluency disorders continue to experience negative consequences, such as feelings of helplessness, fear, shame, and avoidance (Daniels & Gabel, 2004), lower self-reported vitality (Craig, Blumgart, & Tran, 2009), and fear of negative evaluation (Bricker-Katz, Lincoln, & Mccabe, 2009), throughout their lives. For instance, Craig, Blumgart, and Tran (2009) conducted interviews and administered psychological and quality of life surveys and found that adults who stuttered reported significantly lower social, emotional, and mental health/functioning when compared to control participants.

Stuttering may also be associated with individuals' employment and educational opportunities (Klein & Hood, 2004; O'Brian, Jones, Packman, Menzies, & Onslow, 2011). In a survey of the effect of stuttering on employment, promotion, and overall job performance, Klein and Hood (2004) found that over 70% of participants felt that stuttering affected their chances of getting a job, and 69% felt that stuttering had impacted their job performance at some point. Furthermore, O'Brian, Jones, Packman, Menzies, and Onslow (2011) explored the relationship between adult participants' highest attained educational level, and self-reported severity of stuttering in various situations (for example, 'while ordering food or drink'). A significant negative correlation was found between highest education level attained and self-reported stuttering severity. In contrast, a longitudinal study of a British birth cohort by McAllister, Collier, and Shepstone (2012) compared individuals whose parents reported that they stuttered by age 16, and individuals with no history of fluency disorders by age 16. No significant differences between the groups were found for educational outcomes throughout the lifespan. However, stuttering was associated with lower-status jobs at age 50. This study suggests that stuttering may shape the life and employment experiences of adults who stutter; McAllister et al. (2012) speculated that individuals who stutter may choose lower-status jobs because these jobs may not require, or depend upon, good communication abilities.

Social anxiety and stuttering. Social anxiety may be one of the most common anxiety disorders experienced by individuals who stutter (Iverach et al., 2009a). Negative experiences throughout childhood may lead to the development of social phobia later in life (Iverach et al., 2009a); adolescents who stutter talk about the fear and anxiety they feel before, during, and after communication (Kully & Langevin, 1999), and also report fear of negative evaluation (Mulcahy et al., 2008). Stuttering has been associated with both reduced heart-rate and greater reported levels of anxiety; based on negative past experiences with speaking, individuals who stutter may respond with anticipatory anxiety and a physiological type of 'freezing response' in speech-related situations (Alm, 2004).

While 'normal' social discomfort may be felt by any individual during a situation in which people are watching and scrutinizing him/her, social anxiety disorder is a more extreme fear that performance or interaction will be judged as inadequate (den Boer, 2000). Social anxiety disorder ultimately leads individuals to feel acute discomfort in social environments, or to avoid social environments all together (den Boer, 2000).

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Increased levels of anxiety may only be a reality for certain individuals who stutter. Kraaimaat, Janssen, and Van Dam-Baggen (1991) compared adults who stuttered to adults with social phobia and control participants on measures of social anxiety, and found that while participants who stuttered scored significantly higher than controls on measures of social anxiety, they also scored significantly lower than participants with social phobia. As a group, individuals who stutter have shown a normal distribution on scores of social anxiety, suggesting that social anxiety may vary within groups of individuals who stutter (Kraaimaat et al., 1991). Hence, not all individuals who stutter report high levels of social anxiety (Kraaimaat, Vanryckeghem, & Van Dam-Baggen, 2002).

Evidence regarding the types of anxiety experienced by individuals who stutter, and the domains in which anxiety is experienced, remains inconclusive. Trait anxiety has been described as inherent to the individual, whereas state anxiety has been described as situation specific (Ezrati-Vinacour & Levin, 2004). Ezrati-Vinacour and Levin (2004) found that a group of individuals who stuttered reported significantly higher levels of trait anxiety than a group of fluent speakers, and reported higher levels of state anxiety in social communication situations as their stuttering severity increased. In a review, Craig et al. (2005) suggested that those who stutter may develop higher levels of trait anxiety as they age.

While some sources suggest that, for individuals who stutter, anxiety may be associated with speech-related situations alone (Alm, 2004; Messenger, Onslow, Packman, & Menzies, 2004), others propose that anxiety may affect multiple aspects of life, beyond social situations (Iverach et al., 2009b; Tran, Blumgart, & Craig, 2011). Messenger et al. (2004) found that participants who stuttered reported experiencing anxiety in social domains, but not in areas such as 'physical danger,' or 'daily routines.' In contrast, Iverach et al. (2009b) found that stuttering was associated with a significantly greater likelihood of participants meeting the diagnostic criteria for a range of anxiety disorders, including social phobia, generalized anxiety disorder, and panic disorder. In particular, the association of stuttering with generalized anxiety disorder, as found by Iverach et al. (2009b), suggests that the anxiety experienced by some individuals who stutter may extend past communication issues, and into other areas of every day life, including the realms of psychological health and well-being.

While some literature still suggests that personality disorders are common among clients who stutter, other research suggests that personality disorders occur at about the same rate for clients who stutter, and that psychological issues (such as anxiety and stress) experienced by clients who stutter may be natural reactions to fluency disorders (Manning and Beck, 2013). For example, Manning and Beck (2013) found that forty-five out of fifty participants seeking treatment for stuttering did not meet criteria for any personality disorders on the Assessment of DSM-IV Personality Disorders. The rate of observed personality disorders in this study was comparable to past rates observed in the general population.

In summary, children, adolescents, and adults who stutter may experience a variety of negative consequences associated with their fluency disorders. Limited ease of participation in social situations, as well as feelings of helplessness and anxiety in realms of communication, are just some of the many common social, emotional, and psychological consequences of stuttering. It follows that in addition to treating the physical aspects of stuttering, the social, emotional, and psychological factors associated with stuttering, including anxiety management (Craig et al., 2005) all need to be considered when designing treatment programs (Altholz & Golensky, 2004). It is possible that individuals with high anxiety or associated mental health issues may not benefit from typical stuttering treatment approaches alone, so combining stuttering treatment with psychological counseling services may improve post-treatment gains for these individuals. Iverach et al. (2009a) assessed participants for mental health disorders prior to entering a stuttering therapy program that addressed reduction of disfluencies. Post-treatment outcomes were worse when individuals had been identified as also having a mental health disorder. Although this study was correlational in nature, it suggests that counseling may be especially helpful for individuals who stutter and also have mental health disorders.

Stuttering Treatment Approaches

Fluency Management Treatments

Stuttering reduction and management treatments typically include a variety of different forms of desensitization, operant conditioning, including the punishment of stuttering and reinforcement of fluency, and aiming for stutter-free speech (Bloodstein & Bernstein Ratner, 2008). Prins and Ingham (2009) described two types of behavioral management treatments; the first, fluency shaping, has a goal of establishing stutter-free speech, whereas the second, stuttering management, teaches people who stutter to respond to disfluencies calmly, in order to reduce

unnecessary effort. Fluency shaping and stuttering management are not mutually exclusive, may be used together, and both incorporate modeling and self-management (Prins & Ingham, 2009).

Cognitive-Behavioral Therapy

Cognitive-behavioral therapy is also presently used as a stuttering treatment approach, and may lead to gains, specifically in anxiety reduction and reduced social avoidance, for individuals who stutter (Menzies et al., 2008; Menzies, Onslow, Packman, & O'Brian, 2009). Cognitive-behavioral therapy aims to deal with emotional-attitudinal aspects of stuttering (Langevin et al., 2010; Menzies et al., 2009). Menzies et al. (2008) found that cognitive-behavioral therapy led to the elimination of social phobia, and reduced levels of anxiety and avoidance, for clients who were previously diagnosed with social phobia. Menzies and colleagues also found that speech restructuring techniques alone did not reduce social phobia; however cognitive-behavioral therapy in isolation did not result in significant stuttering reduction post-treatment, which suggests that cognitivebehavioral therapy and fluency shaping/stuttering management techniques might be combined to maximize client treatment outcomes.

Integrated Treatment Approaches

Increasingly, present-day stuttering treatments integrate components of both fluency shaping (speech restructuring) and cognitive behavioral therapy (Bloodstein & Bernstein Ratner, 2008). The Comprehensive Stuttering Program, (Kully, Langevin, & Lomheim, 2007; Langevin, Kully, Teshima, Hagler, &

Prasad, 2010), or CSP, offered at ISTAR is one example of an integrated treatment approach that employs fluency shaping, stuttering modification, and cognitive-behavioral methods. Although cognitive-behavioral therapy alone has been shown to lead to gains in anxiety reduction (Menzies et al., 2008), the possibility exists that counseling services, provided by a mental health professional, might further enhance therapy by more explicitly addressing the complex social, emotional, and psychological consequences that often accompany fluency disorders. For instance, Beilby, Byrnes, and Yaruss (2012) found that clients who participated in group therapeutic sessions using an Acceptance and Commitment Therapy approach, led by a speech-language pathologist and a clinical psychologist, demonstrated statistically significant improvements in both fluency, and multiple areas of psychosocial functioning. Although acceptance of stuttering is an important aspect of the cognitive-behavioral component of the CSP, which is delivered solely by speech-language pathologists at ISTAR, its developers added counseling with a registered psychologist as an optional component to their program.

The Comprehensive Stuttering Program (CSP)

The Comprehensive Stuttering Program (CSP) addresses the overt and covert aspects of stuttering, including speech (i.e., fluency, stuttering management), emotional-attitudinal consequences of stuttering (i.e., reduced avoidance, management of fear and anxiety), self-management (i.e., self-monitoring, practice, problem solving), and environmental aspects of stuttering (i.e., parental and family understanding and support) throughout the treatment process (Kully et al., 2007; Langevin et al., 2010). There are three treatment phases. In the acquisition phase of treatment, clients focus on developing fluency through use of fluency shaping (e.g., starting the voice easily and gently, using a controlled rate of speech achieved by prolonging vowels during speech production) and stuttering management techniques (e.g., reducing oral tension to ease out of a stutter). Clients simultaneously learn to use cognitive-behavioral skills, including self-talk, to achieve acceptance of stuttering and to relieve or manage the negative affects of stuttering, such as guilt and shame (see 'Cognitive behavioral therapy component' below). In the second phase of therapy, clients learn to transfer their newly acquired skills to situations outside of clinic. That is, clients learn to generalize these skills beyond therapy, into the 'real world.' In the third phase of therapy, clients continue to use the fluency skills in their natural environments, engage in self-designed transfer activities, and continue to use cognitivebehavioral techniques to manage their feelings and emotions associated with stuttering and using fluency skills. During the maintenance phase, clients engage in self-generated practice; however, during this time they may also engage with an ISTAR clinician for weekly maintenance treatment sessions, and may attend scheduled 2 day, 3 day, or 1 week refresher treatment programs.

The evidence base for the CSP is well established. Langevin, et al. (2010a) conducted a longitudinal study to investigate the durability and stability of treatment outcomes at ISTAR over a five-year period. At five years post-treatment, the majority of clients maintained significant reductions in stuttering, and improvements in speech-related attitudes. Langevin et al. (2006) also found

the CSP to be effective in both Dutch and Canadian cultures. Both Dutch and Canadian groups demonstrated reductions in stuttering and improvements in speech-related attitudes at 2 years post-treatment.

Cognitive-behavioral therapy component. As mentioned above, the CSP includes a cognitive-behavioral therapy component. This component focuses on teaching clients awareness of self-talk, and fostering effective, as opposed to ineffective, self-talk in every day situations in order to reduce avoidances, manage feelings and emotions associated with stuttering, and to support use of fluency targets. It also includes modified behavioral experiments in which clients use stuttering management skills, including easing out of a stutter, when challenging beliefs and fears about listener reactions (e.g., that listeners may respond negatively to, or judge, a person who stutters). In addition, the cognitive behavioral therapy component of the CSP includes some aspects of mindfulness (Boyle, 2011), such as sustaining attention and focusing on breathing.

Psychological counseling component. Recognizing that clients may derive additional benefit from stuttering treatment that is augmented by psychological counseling, CSP developers added the opportunity for clients to seek psychological counseling services during or after their treatment programs. As such, a registered psychologist and/or students being supervised by the psychologist, offer counseling services at ISTAR to help clients cope with anxiety, difficulty speaking, or other individual challenges (Institute of Stuttering Treatment and Research, 2012). This interdisciplinary practice that is taking place at ISTAR is relatively novel, and research is needed to learn more about the benefits or effectiveness of psychological counseling for individuals who stutter.

Rationale for Inclusion of Counseling in Stuttering Treatment

In the past, diseases and disorders were primarily defined in terms of impairment, handicap, and disability (Yaruss & Quesal, 2004). In contrast, today the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) model recognizes that individual health consists of a combination of body structure/function, activities and participation, and personal and environmental factors. Thomas (2004) provides a social relational definition of disability, and argues that although impairments may cause some activity restrictions, many activity restrictions are actually socially imposed. Thomas (2012) discusses 'disablism' as the "social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorized as 'impaired'" (p. 211), and 'impairment effects' as the "direct and unavoidable impacts that 'impairments'... have on individuals' embodied functioning in the social world" (p. 211). It is evident that the consequences of stuttering include impairment effects (such as the inability to physically produce certain words when the person who stutters wants to do so) and disabilism (for example, compromised educational and employment opportunities). In summary, today we recognize that 'being well' means more than living without physical impairment. When individuals live well, they are able to participate in social life and daily activities, to the extent that they desire, without insurmountable barriers, regardless of whether these barriers are imposed by impairments, social

constraints, and/or other personal or environmental factors.

If health/wellness consists of more than just body structure, then therapy, too, must address factors beyond physical impairment. Therapy must consider the extent to which clients' impairments impact their life activities, the ways in which clients may be socially restricted from engagement, and the individual and environmental factors that are relevant to clients. For clients who stutter, therapy should address not only fluency, but should work towards helping clients to 'live well.' One method of enhancing clients' quality of life might be addressing, through adjunct counseling services, the social, emotional, and psychological consequences of stuttering that affect each client in unique ways, and that may require intervention beyond the scope of the cognitive-behavioral methods that are typically included in integrated treatment programs, such as the CSP.

Counseling is known to be a critical part of stuttering therapy, which has traditionally been provided by speech-language pathologists. For instance, Fourie (2009) conducted a grounded theory study in order to explore clients' perceptions of their therapeutic relationships with their speech-language pathologists. A theory of 'restorative poise' arose from Fourie's (2009) study. Participants reported that therapists used therapeutic actions, such as empowering the client, as well as particular qualities, such as 'being understanding,' and 'being gracious.' As mentioned previously, counseling is often integrated into stuttering treatment through components of cognitive-behavioral therapy.

While counseling has typically been assumed to fall within the speech language pathologist's scope of practice, with ever-increasing interdisciplinary practice today, other professionals, such as psychologists, might benefit stuttering treatment teams. Particular support for this approach comes from Iverach et al. (2009b), who found that adults seeking treatment for stuttering demonstrated higher odds for meeting diagnoses of anxiety disorder, social phobia, generalized anxiety disorder, and panic disorder, than a control group. Upon reporting these findings, Iverach et al. (2009b) emphasized the need for anxiety management techniques in stuttering therapy, and suggested that psychologists and psychiatrists might be of great value in the implementation of these services. Altholz and Golensky (2004) argue that speech-language pathologists often include counseling in treatment of fluency disorders, but rarely refer clients to mental health professionals (such as psychologists and social workers), as these professionals are perceived to know very little about fluency disorders.

Although the current state of the literature does not explicitly include any studies on clients' perceptions of the involvement of trained mental health professionals in stuttering treatment, Plexico, Manning, and DiLollo (2005) interviewed seven participants about their experiences managing their stuttering. One participant mentioned that he had worked with a counseling psychologist, and described this experience as very helpful in his own stuttering management. Beilby et al. (2012) provide further evidence that including mental health professionals in stuttering therapy, and addressing psychosocial functioning alongside fluency treatment, might contribute to treatment gains for those who stutter. Clients who participated in Beilby and associates' Acceptance and Commitment Therapy (ACT) demonstrated reduced stuttering frequency, reduced perception of the adverse impact of stuttering on their lives, increased readiness for change scores, and an improvement in mindfulness skills; gains were maintained three months post-treatment. Research is needed to determine if clients who have participated in integrated stuttering treatment programs, such as the CSP, perceive psychological counseling services provided by trained mental health professionals to be a valuable and/or necessary component of stuttering treatment.

Facilitators and Barriers to Accessing Psychological Counseling

In this section, a discussion of facilitators and barriers to accessing psychological services outside the field of communication disorders will be presented. A summary of the limited research on barriers and facilitators to accessing such services within the field of communication disorders will follow.

General Facilitators and Barriers

Some facilitators to, or factors associated with, help-seeking may include success with seeking help in the past (Gulliver, Griffiths, & Christensen, 2010; Vogel & Wester, 2003), gender (with females being more likely to seek help; Rickwood & Braithwaite, 1994), willingness to disclose (Kelly & Achter, 1995; Rickwood & Braithwaite, 1994; Vogel & Wester, 2003), anticipating benefits of help-seeking (Shaffer, Vogel, & Wei, 2006), having open relationships, knowing others who have sought help in the past (Rickwood & Braithwaite, 1994), and experiencing more life events/stressors, and/or impairments (Rosen et al., 2011; Schoffield & Khan, 2008). In contrast, some barriers to, or factors associated with avoiding help-seeking may include high anticipated risks of help-seeking (Shaffer et al., 2006; Vogel, Wester, Wei, & Boysen, 2005), a lack of willingness to disclose (Kelly & Achter, 1995; Rickwood & Braithwaite, 1994, Vogel & Wester, 2003), gender (with males being less likely to seek help; Rickwood & Braithwaite, 1994), attachment avoidance, (Shaffer et al., 2006), stigmatizing attitudes (Aisbett, Boyd, Francis, Newnham, & Newnham, 2007; Gulliver et al., 2010; Ludwikowski, Vogel, & Armstrong, 2009; Schofield & Khan, 2008; Vogel, Wade, & Hackler, 2007), accessibility issues (Aisbett et al., 2007; Gulliver et al., 2010), especially in rural communities, concerns about confidentiality and trust, difficulty recognizing symptoms, concerns about the service provider, lack of knowledge about services, fear/stress about seeking help (Gulliver et al., 2010), the perception that help is not needed, a preference for self-management, or a lack of time (Czyz, Horwitz, Eisenberg, Kramer, and King, 2013).

A variety of factors may come together to determine help-seeking behaviors. For instance, Schofield and Khan (2008) found that women between the ages of 50 to 55 who sought counseling reported more life events and stressors in the past year, higher life satisfaction, higher perceived control, and lower levels of optimism. Furthermore, Pederson and Vogel (2007) argue that for male students, between the ages of 18 and 40, the relationship between gender role conflict and willingness to seek counseling may be mediated by factors such as tendency to disclose, self-stigma about seeking counseling, and attitudes towards seeking counseling. Additionally, every individual may consider unique factors when weighing the decision about whether or not to enter into therapy. For example, Shaffer et al. (2006) found that undergraduate students who reported high levels of attachment avoidance also reported higher anticipated risks of seeking counseling, and that those who reported attachment anxiety anticipated both great benefits and great risks to therapy. When participants anticipated more benefits, they also reported increased intentions to seek help.

Public and self-stigma (regarding help-seeking) may also serve as barriers to accessing professional services (Ludwikowski, Vogel, & Armstrong, 2009; Schofield & Khan, 2008; Vogel, Wade, & Hackler, 2007); however, the perceived importance of these factors may vary between groups. For example, Loya, Reddy, and Hinshaw (2010) found that South Asian participants reported increased reluctance to seek psychological counseling, and increased stigma towards those with mental health problems when compared to Caucasian participants.

Furthermore, public and self-stigma may increase or decrease in significance when compared to other factors, such as degree of impairment (Rosen et al., 2011). Rosen et al. (2011) found that veterans (from ages 18 to 69) who had been diagnosed with Post Traumatic Stress Disorder did not report negative attitudes towards seeking mental health services. Rosen et al.'s (2011) study suggests that individuals may be more likely to initiate treatment if they are more impaired, regardless of their stigma towards help-seeking.

Facilitators and Barriers Within the Area of Stuttering Treatment

Although little is known about factors that may serve as barriers or facilitators to accessing counseling services for stuttering, Kully and Langevin (1999) make mention of factors that may determine whether an intensive program is a good fit for adolescents. One such factor is desire for change. A reluctance to undergo therapy for stuttering may also arise from doubts about the effectiveness of therapy, a reluctance to acknowledge that the problem is present in the first place, or a reluctance to talk about negative feelings such as shame and humiliation (Kully & Langevin, 1999). These types of beliefs, in the area of stuttering treatment and management for adolescents, may also apply to adults, and to the process of accessing counseling for issues related to stuttering. Altholz and Golensky (2004) also suggest that individuals who stutter may distrust mental health professionals, such as social workers and therapists, because of their apparent lack of knowledge about stuttering.

In summary, it is possible that facilitators and barriers to accessing mental health services in other fields may also apply to accessing counseling services to augment stuttering therapy. For instance, factors such as accessibility, perceived stigma, and lack of knowledge (about services and their benefits) may serve as barriers to accessing counseling services alongside stuttering treatment. Although psychological counseling at ISTAR is made available, it is possible that clients choose to not access therapy because they have concerns about anonymity, because they perceive stigma about help-seeking, because they feel stressed about attending counseling, or because of unique, individual factors, that have yet to be explored and documented.

Research Question

The purpose of this study was to gain an understanding of clients' experiences with, and perceptions of, psychological counseling services that address consequences associated with stuttering. In particular we were interested in

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whether, and if so, how, clients who accessed counseling to augment their stuttering treatment perceived the service to be a beneficial addition to the CSP, how clients made their decision to participate, and whether clients perceived any barriers or facilitators to participation. We were also interested in learning about potential ways to enhance the counseling experience. For clients who did not participate in counseling, we were interested in how these clients made the decision not to access counseling, whether they perceived any barriers or facilitators to participation, and whether they could offer any suggestions to ISTAR regarding the counseling service.

Chapter 2: Methodology

Justification for Methodology

Qualitative research methods were used to obtain and analyze data in this study. Qualitative research allows for participant-generated meanings to be heard, and encourages the emergence of new conceptual categories of meaning, drawn from participants' experiences (Willig, 2008). Finn and Felsenfeld (2004) suggest that qualitative research values individual opinions, gives unique insight into group membership, is useful for exploring subjective meaning, and may be used to explore topics or problems that have yet to be analyzed. As such, qualitative methods fit with the overall purpose of this study, which was to gain an understanding of clients' experiences with, and perceptions of, psychological counseling to augment speech therapy for stuttering.

Research Design

The guiding qualitative method was grounded theory, which was originally developed by sociologists Glaser and Strauss (Charmaz, 2006). Consistent with Glaser and Strauss' original method, simultaneous data collection and analysis was utilized, codes/categories were constructed from data (not from preconceived hypotheses), constant comparative methods were considered, memo writing was employed to elaborate upon categories, and sampling aimed towards theory construction (as opposed to focusing on representativeness through random sampling; Charmaz, 2006) was used. The present study deviated from Glaser and Strauss' original method in that the literature review was constructed prior to data collection (for the purpose of graduate thesis preparation).

Since its origins, grounded theory has been further developed by a number of researchers, including Charmaz (2006). In line with Charmaz's constructivist approach, we assumed that researchers do not objectively discover theories. Instead, researchers construct grounded theory through their "past and present involvements and interactions with people, perspectives, and research practices" (Charmaz, 2006, p. 10). Grounded theory has been used to explore many topics in the field of communication disorders (Bruce, Parker, & Renfrew, 2006; Fourie, 2009; Graves, 2007; Pickl, 2011), including fluency disorders (Plexico, Manning, & Levitt, 2009b).

Participants

The current study employed purposive sampling in order to intentionally select individuals who could address the topic of interest (Liamputtong, 2009). To

address maximal variation (Patton, 1990), all clients who participated in stuttering treatment at ISTAR during 2012 were invited to participate. By considering maximum variation, researchers hoped to enhance the potential generalizability of the study. Nine adult and young adult clients (ages 13-38) agreed to participate. Eight clients were male, and one was female. Six of the participants accessed psychological counseling services at ISTAR when given the opportunity to do so, and three did not access such services. All clients took part in at least one treatment program at ISTAR. Six of the interviews took place in person, and three took place either through videoconferencing, or over the telephone, at the request of the participants.

The number of participants selected for grounded theory studies in the field of communication disorders has ranged from approximately 5 (Bruce et al., 2006) to 35 (Pickl, 2011). However, in line with theoretical sampling, data should be collected until categories are 'saturated,' or until "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of...core theoretical categories" (Charmaz, 2006, p. 113). Guest, Bunce, and Johnson (2006) suggest that while reaching theoretical saturation is a common justification for sample size in qualitative methods, the notion of theoretical saturation remains conceptual, and does not provide researchers with a reliable way of estimating sample size prior to data collection. Guest et al. (2006) conducted 60 interviews in order to assess the degree of saturation that took place throughout the grounded theory coding process. Saturation occurred after coding 12 interviews, and major themes

were evident after coding 6 interviews. The number of clients who agreed to participate in this study, 9, falls within the guidelines reflected in this research.

According to Willig (2008), although we cannot automatically generalize from small-scale qualitative research samples, it can be argued that if a given experience is possible, it has the potential to be shared by others. As a result, although this sample may be relatively small (specifically, compared to quantitative studies with hundreds of participants), it provides an important starting point for understanding the role of psychological counseling in treatment for a group of clients who stutter.

Recruitment

Approval was obtained from the Human Research Ethic Board 1 (REB 1) at the University of Alberta campus. The pool of potential participants was generated based on participation in the 2012 stuttering treatment programs at ISTAR. An initial letter of invitation (see Appendix A), and an information sheet (see Appendix B) were sent to each client in the 2012 treatment group via e-mail. A second, follow-up e-mail was sent two weeks later. A few days following the second e-mail, phone calls were placed to clients who had not yet responded. A second phone call was made a week after the first if clients could not be reached with the first phone call. After this point, no further contact was attempted. Those clients who agreed to participate spoke with the study investigator to set up an interview over video-conferencing, the telephone, or in person.

Consent

Prior to the interviews, participants were given an overview of the study, and written consent was obtained (see Appendix C). One participant was under the age of 18; therefore, this client's guardian was asked to sign a modified version of the consent form (see Appendix D). This client also received a modified information sheet and assent form (see Appendix E). When the interviews took place over the phone or via videoconferencing, participants e-mailed or faxed their consent form to the study investigator prior to the interview, and had an opportunity to ask questions and to verbally confirm their consent before the interview began.

Confidentiality

Participants in this study were identified by a pseudonym. Only the primary investigator was aware of the identity of the participants and their pseudonyms. The list of pseudonyms was stored in a locked cabinet in Dr. Langevin's lab, separate from other project materials. During transcription, any identifying information was anonymized (e.g., details about clients' lives, including their hometowns, job titles, family members' names, and friends' names, were removed or assigned pseudonyms). Audio files and transcripts were encrypted and password protected to ensure that only the researchers involved in the study had access to these files.

Procedures

Semi-structured interviews were used to collect data. The interviews were guided by a few main research questions (see Appendix F), which allowed for a

balance between maintaining control of the interview and allowing theinterviewee "the space to redefine the topic under investigation" (Willig, 2008, p.24). Probes were used to encourage participants to elaborate upon, clarify, andcomplete their accounts (King & Horrocks, 2010).

The interview began with a general question that allowed the interviewer to build rapport with participants, and provided a broad scope for the participant to share stories about their experiences with stuttering and adjunct psychological counseling (or the lack thereof). The interview ended by asking participants to share anything else that they felt was important or necessary. General questions are typically considered good practice for wrapping up qualitative research (King & Horrocks, 2010). Interviews were recorded for later transcription and analysis. Field notes were taken throughout the interviews, in order to allow for written reminders about important concepts that were generated (King & Horrocks, 2010).

Following the interview, participants were asked to complete a brief demographic form (see Appendix G) that enabled a demographic description of the sample. Lastly, clients were debriefed (see Appendix H) and thanked for their participation. Participants also filled out an honorarium form to receive compensation for their time.

Rigor

Throughout this study, researchers emphasized the features of transparency, maximal validity, maximal reliability, comparativeness, and reflexivity (Saumure & Given, 2008). In adhering to transparency, researchers clearly described the methodology for the current study, in order to allow for future replication

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(Saumure & Given, 2008). In terms of maintaining validity, researchers aimed to include all participants' voices in the final paper, whether or not clients reported positive views towards the counseling process. Both clients who did, and did not, access psychological counseling were interviewed. Codes were discussed within the research team in order to enhance reliability. To ensure comparativeness, sets of data were continually checked against each other, and summed to ensure that the results reflected all participants' experiences. Finally, in order to be reflexive, researchers reflected upon their biases and perspectives. The investigator attempted to suspend these biases as much as possible by avoiding leading comments in interviews, and the research team only applied codes believed to accurately reflect participants' experiences. At the end of data analysis, researchers displayed reflexivity by discussing the strengths and limitations of the study (Liamputtong, 2009).

Chapter 3: Data Analysis

Grounded Theory Coding

Following data collection, the audio-recorded interviews were transcribed, and the transcripts were coded. Two main stages of coding were used: initial and focused coding (Charmaz, 2006). Initial coding can be described as a method of remaining open to whatever theoretical possibilities can be discerned from the data. During this stage, coding should stick closely to the data. Constant comparative methods, used at this point, help in avoiding redundancy (Charmaz, 2006). During initial coding, data is conceptualized with a label that serves as an "abstract representation of an event, object, or action/interaction that a researcher identifies as being significant in the data" (Strauss & Corbin, 1998, p. 103). Next, focused coding can be understood as a process by which a researcher takes a limited set of significant or frequent codes, and applies them to large amounts of data (Charmaz, 1994; Charmaz, 2006) in order to allow a theory to emerge from the data.

Consistent with these definitions, researchers first engaged in initial coding. Specifically, researchers moved through the transcribed interviews, and assigned one code to each concept that could be identified in the interviews. Constant comparative methods were utilized by applying the same codes to concepts that were similar or identical throughout the transcripts. Next, researchers began focused coding by arranging the data around higher-order categories. At this point, researchers moved through the master list of codes, arranging the codes by common concepts (which serve as higher order categories). Throughout this process, the central, or selective categories began to emerge from the data. The central categories represent the main themes of the research, and have the ability to pull other categories together to form an explanatory whole (Strauss & Corbin, 1998).

Memo writing. Memos, also known as "written elaborations of ideas about the data and the coded categories" (Charmaz, 1994, p. 106), were used throughout this study as a tool for assisting researchers in capturing comparisons and connections, and crystallizing questions and directions to pursue (Charmaz, 2006). Memos reflect what a code is about; and, therefore, memo writing helps researchers to further develop categories. Charmaz (2006) suggests that memos
are often spontaneous, written in unofficial language for personal use, and are designed in order to allow the researcher to explore ideas as they come to him/her (Charmaz, 2006). Memo writing can be helpful at all stages of the research process, however, Charmaz stresses that memo writing is "the pivotal intermediate step between data collection and writing drafts of papers" (Charmaz, 2006, p. 72).

Chapter 4: Results

Central Categories

Three central themes emerged from the data. The first was 'Participation decisions as determined within the context of participants' life stories, personal experiences, perceptions of counseling, and the way that counseling was promoted at ISTAR.' The second theme was 'Counseling as a necessary optional component in stuttering treatment.' The final theme was 'Counseling as a great service that begs wider promotion and enhancement.' Each of the central themes, and their respective subthemes, are discussed in detail below.

Participation Decisions as Determined Within the Context of Participants' Life Stories, Personal Experiences, Perceptions of Counseling, and the way that Counseling was Promoted at ISTAR

Participants began their interviews by talking about their life stories, including the history and nature of their fluency disorder, personal consequences of stuttering, individual factors or life challenges, previous treatment, and how the combination of these factors contributed to their decision to take part in treatment at ISTAR. Since stuttering treatment at ISTAR was the context in which the counseling service was offered, each of the participants spent a significant amount of time describing their ISTAR experience. To present a complete picture of participation decisions, in clients' own words, a brief account of treatment experiences at ISTAR will be detailed below.

Stuttering Treatment Experiences at ISTAR

Participants revealed some challenges involved in treatment at ISTAR, for example they described how controlling/changing speech can feel stressful and overwhelming, that treatment can be very demanding, and that maintaining gains requires practice. However, all participants described their treatment experience at ISTAR as overwhelmingly positive, whether treatment took place in person, or through telehealth services. Participants reported that stuttering treatment at ISTAR was helpful, and provided them with useful skills. One participant, Michael, used a metaphor to describe the way that ISTAR teaches skills for fluency shaping and stuttering management:

-at the end of the day you're learning skills and tools that you unfortunately did not get when you were a kid. It's like you're trying to fix a car with like a- oryou know, like a- with a toothbrush and ISTAR says no no no no, it's not a toothbrush, you need to use like a- like a key or, you know, like a- a wrench.

That's what ISTAR is doing, really... this is how you do it."

Participants described positive speech outcomes in terms of reductions in stuttering, or better stuttering management, post-treatment. They also reported increased self-esteem and self-confidence upon leaving ISTAR, and described ISTAR staff as "wonderful" and "all amazing." Alexander called ISTAR "kind of like a perfect system," and Michael described ISTAR as "fantastic, they're 10/10 in my book." According to Mark, the open environment at ISTAR facilitates treatment progress:

And a bit part of it I think is because it's like a comforting environment, like you feel you don't have to hide the stutter, people are going to be patient with you, and everyone knows like what- what's going on, right.

Participants also discussed the aspects of stuttering treatment that they perceived to be most beneficial. Specifically, Bob suggested that the transfer activities were the most helpful part of treatment for him; talking to others was difficult at first, but really boosted his self-confidence in the long-run. Alexander also enjoyed transfer activities, and viewed them as a 'stepping stone:'

Uh, the best part- the funnest part was probably pres- like when I was able to go up in an audience and talk and read that was probably the funnest part I just felt happy it was like a stepping stone.

Finally, Roger spoke about the cognitive-behavioral therapy/self-talk component of treatment, and his belief that it encourages reflection, acceptance, and stuttering management.

Decision To Access, or Not Access, Counseling Services at ISTAR

Following discussion of treatment at ISTAR, participants went on to describe how their life stories, personal experiences (including past treatment experiences), perceptions of counseling, and the promotion of counseling at ISTAR, ultimately influenced their decision to participate, or not, in the counseling service. Eight of the participants reported that the counseling service was offered to them by a clinician at ISTAR. One participant could not directly remember the offer, and speculated that counseling hadn't been offered to him because clinicians may have perceived that he didn't need it. One participant reported that he couldn't remember the offer clearly, as he tuned it out due to lack of interest.

Those who participated. Six of the nine participants chose to access the counseling service. Shared reasons for participation included a belief that counseling would be useful or helpful, seeing value in an opportunity to talk to a professional or specialist, viewing counseling as a 'good venting outlet,' having an open attitude, and seeking stress reduction. Below, Steve describes the counseling service at ISTAR as an opportunity to talk to a professional, instead of seeking other 'venting outlets:'

Yes, exactly right, I mean, um, suppose there was family right, I mean, theythey aren't trained speech pathologists right, so- so- so I mean they- they can't um, uh, relate, uh, to my- to my feelings right, but a psychologist, specifically trained in- in um, human feelings, can- can be oh this is actually something that is happening right, or like these- these are, uh, solutions, maybe, right. So yeah. That's about it. I was...happy actually....

Jack also reported that his decision to participate was also influenced by "wanting some sort of, like, professional venting outlet."

A number of the participants displayed a 'why not' mentality, recognizing that the service was available, that it 'couldn't hurt,' and that it would most likely help them throughout their stuttering treatment. For example, when discussing his decision to participate, Mark reported that when he was offered the opportunity to participate in counseling, he thought "...I may as well use it, right." Likewise, Robert displayed a 'why not' attitude, and a willingness to try anything that might be beneficial during his time at ISTAR:

Well, I figured I might as well try everything, like- like I figured it wasanything that could help, I'm not opposed to it, right. I figured it's being offered so why turn it down I thought. I- I had never actually seen a psychologist so maybe I'd find something out.

Clients also had individual factors, related to their life stories and personal experiences, that motivated them to participate. Steve moved to his current location as a young adult, and didn't have any other reliable 'venting outlets.' As a result, during his stuttering treatment, he was interested in participating in the counseling service:

Well, uh, I- as you may kn- other people have- have different, um, reasons, bubut I basically came to [current city], um, um, [when I was young] actually, and there wasn't any family up in [new country] right, so I was a student by myself basically right, and then um, I started this [a few years ago] and- and treatment it- it um, it sort of changes um- someone's um, way of speaking basically, right, and, um, at first, um, that whole process, um, seemed- seemed, um, extremely sort of stressful and like, um, strange actually to me right, and like it seemed extremely difficult actually and- and there wasn't any family who I could speak to, right. And since, um, I saw that at least as an opportunity to speak to somebody about it. Right, so um, um, I guess I signed up sselfishly I guess, if that's- yeah. Right. Another participant received a recent mental health diagnosis, and was curious about its' relationship to stuttering:

Mark: I kinda wanted to ask [the counselor] a few questions about, like, what do you think that means, is there any kind of issues that should be- that I should know about that- you know, are kind of specific to someone like me, that's kind of those two things [mental health diagnosis and fluency disorder] happening at the same- same time.

Finally, two of the participants had personal, family challenges, and felt that counseling might help to address these challenges. Isabella did not discuss her family challenges in detail, but indicated that talking about these challenges in counseling helped to improve her speech. Mark's family did not agree with his decision to access stuttering treatment, and preferred not to discuss his fluency disorder. As a result, Mark wanted to discuss his family interactions with the counselor:

Yeah, and I guess now that you mention it, one of the big topics that I talked about with the [counselor] was how to, um, kinda stick with my game plan for, uh, you know being fluent when I'm interacting with [my family] right, because going back to that kind of- those people where, you know, those conversations happen where I was arguing, you know, [stuttering] is a real problem they're saying no it isn't, now I go back for Thanksgiving, Christmas dinner, and those kind of old feelings come up, and, you know, just- how do I kinda like deal with that, right, so I talked through a few things with [the counselor] about that as well... I had a very targeted kind of goal for part of

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my time with [the counselor] where I wanted to figure out, like, how should I deal with my [family] when I go home for Christmas and [they convey that they don't think stuttering is a real problem]. So I just really wanted to get like, kind of a- like [the counselor's] like thoughts on how I should best handle that, right and [the counselor] gave me some pretty good tips so I was happy with that for sure.

Those who participated in counseling identified reasons why other clients may not likewise participate. Participants surmised that others may have received insufficient information about the service, and may have been unaware of the benefits:

Mark: - you know, they haven't really had any, uh, time where they've talked to a counselor or somebody before, right, so they don't really know, like why would you go to talk to someone, right, like what is that service really gonna do for me.

Steve indicated he did not feel that ISTAR provided sufficient information about the service, as there was no discussion of what to expect during counseling.

Participants also hypothesized that others may have felt uncomfortable 'opening up' in counseling. Mark suggested that it is especially difficult for men to express their feelings in counseling. Roger suggested that for some, opening up can be viewed as a sign of weakness. Isabella suggested that others may not participate in counseling due to fear of judgment: "I think that would probably be why you wouldn't because you think that everyone's gonna be like that's a dumb issue, what's your problem?" Alexander expressed that being too young (and therefore, not emotionally ready for the service) can also be a barrier to participating in, or benefitting from, counseling. Steve agreed that the high degree of self-reflection involved in stuttering treatment, and in adjunct counseling, might be too overwhelming for younger clients.

Additionally, the way that the service was presented, as a volunteer role, was perceived as a significant barrier to participation. A number of participants reported that clinicians described the counseling service as run by volunteers. Taking advantage of a volunteer-run service made many of the participants feel hesitant or uncomfortable:

Mark: Well, I think if the counseling service was, uh, maybe like marketed a little bit better to clients when they first come to the institute, that might be helpful. Um, I think, um, it would not be- it's not really an easy thing to- to do well, but I definitely kind of felt like [the counselor] just kind of gives time to free to the institute, right, and some people- like I definitely felt a little bit awkward, kinda like getting that free service, right, like there's other people that have maybe much more serious problems that [the counselor could be] helping, right, so I kinda felt a little bit awkward about it cuz like the way that they, uh, explained it to you when you go to the institute is that okay we have [this person] that is part of our staff kinda, but really [they] just give [their] time for free to help so if you want [the counselor] can come and talk to you, right. So if it was kind of expressed a little bit differently perhaps clients might feel a little bit more comfortable using that.

Finally, time/scheduling challenges, associated expenses, and having other outlets (such as a spouse or parents) to talk with were identified as reasons why others may choose not to participate.

Those who did not participate. Three of the nine participants chose not to take part in the counseling service. Common reasons for not accessing the service were viewing stuttering treatment as sufficient without the addition of counseling, and having a desire to focus primarily on the 'speech' aspect of treatment. Bob reported that stuttering was his "main concern" at the time of his stuttering treatment, and Michael described his desire to deal with his speech before pursuing any additional mental health services if necessary:

Michael: I did think about it a lot because I knew that s- stuttering is not just a speech thing, there's a lot of psychological- psychological damage, uh, that has to be repaired, so I was very wary about that concept and I told my parents about it and my parents said well why don't you, uh, take counseling, you know, in adjacent to this... but I thought well let me get over this hurdle, and-which is like speech, and maybe that's something that I do after.

Beyond these common reasons for not accessing counseling, participants' accounts were unique, diverse, and based in the context of their life stories. As a result, participants' accounts will be discussed separately.

Michael had been seeing a counselor outside of ISTAR before his stuttering treatment. When given the opportunity to participate in counseling at ISTAR, Michael perceived that he already had someone to go back to if the need arose (although he didn't really like his previous counselor). He compared this situation to a romantic relationship:

I had a psychologist who I talked with, um, but I had stopped maybe like two, three months before ISTAR. So I thought, you know what, I might as well go back to that guy who I know but I didn't like that guy. So I was like a little bit confused myself, like, you know they have that option and maybe I should go back to this guy cuz he was a little bit pushy about going back to him. Feels like- uh, like a boyfriend or something. [laughs] But I mean I felt like, um, you know, just that I had an issue with him personally that, I mean, you know, if I wanted to take counseling I would go back to my counselor but I didn't like him.

Michael also perceived that counseling at ISTAR would be offered infrequently because the service was 'run by volunteers.' Michael felt that an infrequent service would not be sufficient to meet his needs if he later required counseling services. Like Mark who, as described above, was concerned about the counselor being a volunteer, Michael also expressed concern that the counseling service was a volunteer-run, 'limited resource;' he didn't want to take advantage of this service when others 'might need it more' than he did. In addition, Michael indicated that he did not want to divert energy from his focus on acquiring the fluency skills needed to directly manage his stuttering. He described how he had reached the stage of being truly ready for speech therapy; he was ready to focus all of his energy on his speech, and didn't want, or need, his attention to be divided between the CSP and counseling. Further, Michael felt that his needs

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were met at ISTAR without the addition of the counseling service. Below, he describes how he anticipated that stuttering treatment would address the psychological aspects of his fluency disorder, and how his expectations were met:

So I- I thought maybe on some level they cover that, which they do. In somebut not to the extent that a psychologist or counseling would cover, but I felt that you know what, I'm sure they're going to cover something, and after a few sessions [the clinician] did touch on, uh, lots of those topics. And I felt a lot better."

Although Roger did not explicitly recall the offer to participate in counseling, he indicated that he was in a good place in his life when he arrived for stuttering treatment at ISTAR. Roger stated that he never let his stuttering hold him back, and that clinicians may have perceived this, and therefore not offered the service during his initial treatment, or during the refreshers programs that he later attended. Roger also indicated that he had developed other outlets for dealing with the psychological consequences of stuttering, including weekly phone calls with friends he originally met at ISTAR, with whom he continues to maintain contact. As a result of these additional 'outlets,' or support systems in his life, Roger did not feel that counseling was necessary.

Bob perceived that counseling wasn't worth his time. He had had a previous, negative experience with a counselor, and expressed that his view of counselors was 'spoiled by a rotten egg:'

Yeah, uh, when I was, uh, [younger] I experienced some pretty heavy bullying and such in, uh, middle school, and my parents took me to a local counselor, this was back [in my hometown] and [the counselor] really wasn't helpful at all and actually kind of further damaged my self-esteem...[the counselor was] pretty harsh and, uh, didn't listen well. I think [the counselor] might have been better if I'd been an adult, but as I was a child at the time it really felt like [the counselor] was constantly talking down to me, and, uh, that kind of spoiled my, uh, my whole image of counselors.

Bob also discussed negative stereotypes about counseling, including the assumption that participation in counseling implies mental illness. He indicated that these stereotypes might influence a person's decision to take part in psychological counseling. Bob reflected on the negative portrayals of counselors that exist in the media, and suggested that counselors are often portrayed as 'manipulative.' Bob indicated that for himself, and for others, negative personal experiences with counselors, and negative perceptions of counseling, can be very difficult to overcome. Bob also stated that speech was his main concern during his treatment at ISTAR. Much like Roger, stuttering treatment at ISTAR (without the addition of a counseling service) was sufficient to meet Bob's needs. However, subsequent to his treatment at ISTAR, Bob decided to access a counseling service at another facility. Bob's positive experience with that counseling service helped to reframe his attitude towards mental health professionals:

-[recently] when I had, uh, I had some [mental health challenges] and I decided it was time to get some help and, uh, I had two very good, very helpful, uh, counselors, one of whom was a psychiatrist, the other one was a, like, counselor, psychologist, kind of deal, and that's kind of brought my, uh,

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opinion back around but yeah, for quite awhile I was pretty, uh- I didn't really like the idea of talking to counselors.

As a result, Bob became open to the possibility of future counseling (if the need were to arise). At the time of his interview, he reported that he would take part in counseling at ISTAR if given the opportunity again because it 'couldn't hurt,' and might help.

In addition to the accounts of Michael, Bob, and Roger who did not participate in counseling at ISTAR, another client, Mark, who attended ISTAR for two stuttering treatment programs, described why he did not participate in counseling the first time he was at ISTAR. Mark reported that during his first treatment at ISTAR, he was uncomfortable opening up. Mark described how in his first treatment program, he wanted a physical, 'surgical' cure for his fluency disorder. At that time, he did not want to address the feelings associated with stuttering. Instead, he wanted to use his fluency skills to mask his stuttering. When he experienced a desire to open up, and to explore his feelings, Mark chose to take advantage of the counseling service.

Counseling as Necessary Optional Component in Stuttering Treatment

Study participants unanimously agreed that the counseling service at ISTAR is component of stuttering treatment that can prove helpful and necessary for some, if not all, clients with fluency disorders. The challenge of integrating psychological counseling into an already overwhelming treatment program was recognized. For instance, Alexander participated in the counseling service at ISTAR, but was the only client who revealed that he would not do so again if given another opportunity. Alexander found the service to be overwhelming due to his young age, and also suggested that leaving ISTAR felt like a progress milestone for him:

Mm, I don't think I would do it exactly like that like counseling at ISTAR, but maybe somewhere else- yeah, if I ever felt, um, like I needed help again, probably...when I finished my, um, lessons it was kind of like I was really happy cuz I could speak better not perfect, but better I could kind of leave there and it was kind of like a point of moving on, so I wouldn't really wanna

go back to there because then it would feel like I have to start all over again. Alexander's account speaks to the program intensity of the CSP; this intensity requires dedication on the part of clinicians and clients, and allows clients to experience changes in their speech, thoughts, and attitudes.

Participants also perceived that not all clients would want, or need, to access the counseling service, so the importance of having the service as an optional component was recognized.

Clients who participated in the counseling service described a number of direct benefits of the experience. They perceived that counseling was necessary for a number of reasons, but specifically, because stuttering and stuttering treatment involve a psychological component that may not otherwise be adequately addressed in therapy. Participants indicated that counseling can help clients to explore and address 'self-created' barriers to stuttering treatment, and can help clients to 'get on track with the program.' For example, Michael discussed counseling's role in the stuttering treatment process as follows: Cuz if you think the program works, it will really help you, but if you're not that- if you're not there yet, the counseling can be like hey listen, this is tricky,

you know what i- what is, um, impeding you from focusing on- on ISTAR? Steve also indicated that he took the opportunity to talk to the counselor at ISTAR about his speech, speech-related scenarios (like talking on the phone or talking to others at the grocery store), and "self-created barriers...to accepting treatment [at ISTAR]."

Even when clients did not participate in the counseling service themselves, they surmised that counseling could be helpful for others in many situations. When clients chose not to participate in counseling, they often recognized, in hindsight, that counseling "couldn't have hurt," and some clients reported that they would make the decision to participate in counseling today, if given a second opportunity.

Expectations

Those who took part in counseling reported minimal expectations prior to their counseling experience. Instead, most participants arrived at counseling with an open mind. Some participants revealed that they were initially unsure what would take place. Reported expectations included a 'good venting outlet,' a beneficial service, advice for interacting with others, clarification of problems, discussion of speech concerns, and tips for personal life challenges. One client reported an expectation that counseling might solve problems that he wasn't previously aware of:

Steve: And, uh, there weren't really like any s- set expectations like by- by

October I shall have this solved or, right. So um, I don't think there were any expectations other than, uh, they are- they are providing this as this will be beneficial so I should, uh, um, sign up for it. Right. So- so um, I guess in that sense the expectation is that this would, um- um, solve any um, problems that I didn't even know that were there right. I mean I didn't really have anything set [expectations] or anything.

All participants reported that their expectations were met. For instance, Jack indicated that he was looking for "someone to like- uh- to sort of like spit my neuroses back at me in like a clarifying way, and I definitely got that for sure." Isabella described her expectations, and the outcome of her counseling experience, as follows:

Um, I don't think I had any expectations I just thought it would just be like I could just speak with [the counselor] like once or whatever, um, they were met for sure."

Isabella further indicated that she continued to take part in counseling because her expectations were met.

Direct Benefits

Clients identified a number of distinct benefits to taking part in the counseling service at ISTAR. Many clients reported that counseling was helpful in general. For example, one client described counseling as a basic process that works: Jack: That's a- not really, I- I mean it's pretty- it's- it's like pretty rudimentary process anyway, you just like set up [an appointment] and talk to them and then you wait for another week or so and then that's- that's all it is, and- and it works.

Several participants indicated that counseling served as a 'venting outlet' for them. Isabella captured the relief that often comes from having this type of outlet: "It's definitely a big help. Just to be able to be like okay, blah [sound of blowing out air]." Jack reported that he "talked to the [counselor several times]...and found that to be like a good, uh, venting outlet kinda thing some good like suggestions and whatever." Robert also suggested that counseling was especially helpful because it provided an opportunity to 'open up:'

Just get to kinda talk to somebody about it and be totally- don't have to worry about anything you just kinda tell- tell them exactly- yeah- what you've been feeling and that kind of thing.

Participants reported that during counseling, they could talk through both challenges and happier moments/milestones in their lives. For instance, Isabella described counseling as a service that helps to reduce the burden that typically hangs over her:

I was thinking like by being able to speak about things that are bothering me with them and you know other things in my life it would help my speech, and it does help my speech actually. It helps my speech a lot because I don't have this like burden hanging over me kind of. Um, yeah, so that's why I participated just so I can get off some of that additional stress or whatever.

Jack suggested that although opening up can be a painful process, "the relief you feel certainly overrides any initial pangs of pain." For many participants, this process of 'opening up' helped them to deal with the emotions surrounding

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stuttering, and/or helped to improve their speech. Not having to censor oneself, or worry about judgment, was also highlighted as a notable benefit of participation.

Many participants indicated that they valued the opportunity to talk to a professional or specialist. Jack reported that his counselor at ISTAR broke down the issues he was facing into manageable components. Isabella agreed that counseling helped to put issues into perspective. Alexander indicated that he learned breathing exercises and mental imagery that helped him to achieve a more relaxed state of being.

One participant, Isabella, identified helpful qualities that she perceived her counselor at ISTAR to possess. She described her counselor as "amazing...the best person...so kind." Isabella reported that she continued with counseling because of the excellent counselor she met at ISTAR.

One client took part in counseling through telehealth services, and reported that there were no barriers to this service, other than feeling slightly less fluent over the telephone. He suggested that one advantage of the counseling service at ISTAR is its availability, through telehealth, for clients in distant locations.

Additionally, Mark, also valued the privacy that counseling offered. He indicated that talking individually to a counselor was much easier for him than talking about his personal challenges in the group setting (where clients are learning cognitive-behavioral techniques to help them manage the psychological, social, and emotional consequences of stuttering) that is an integral part of the Comprehensive Stuttering Program (CSP) at ISTAR. Mark talked about how difficult it can be for clients who stutter mildly to share their emotional challenges in the group setting and to feel that their emotional responses are valid when other group members stutter so severely that they can hardly get a sentence out. He also indicated that he likes the development of fluency skills and the provision of counseling to be separate components of his therapy:

-so, um- I think- I felt more comfortable talking one-on-one with [the counselor] than I would have been with someone who was also teaching me those fluency skills like someone kinda separate from that right.

Surmised Benefits

Clients who did not access counseling at ISTAR thought that counseling could be valuable for addressing speech and life issues, and for providing others with extra support. Participants described stuttering and other issues as intertwined, and reported that it's very difficult to "treat one without the other." Bob, whose stuttering started later in life, suggested that those with a life-long history of stuttering would probably benefit the most from counseling services.

Those who did not participate in counseling suggested that counseling service could address diverse issues, including social skills, self-esteem, relationship problems, and daily situations from phone calls to shopping. Michael emphasized the role that counseling could play in helping clients to 'advertise,' or tell others, including employers or colleagues, about their stutter. He also suggested that counseling could be helpful for initiating relationships, which is often very difficult for clients with fluency disorders:

-but that's issues w- with counseling- the- the main thing for me I'd say is relationships. Is talking to the opposite sex, I- I mean you're dealing, as- as a guy you're being rejected anyways, you know- you know without really doing much, uh, a person who doesn't stutter. But, uh, when you have that- you know, it just makes you feel like oh my god, you know, dammit, I can't even like say my name, you know- like in class, ugh, h- how am I gonna go, you know, like to a bar or to a girl I wanna talk to. Just like, I mean normal people with like no stuttering have issues...Yeah so you- just think you know what, the hell with humanity, I'm gonna be, uh- I dunno, you know, I'm- I'm just gonna be there. On my own. So the- so there's that social aspect to it.

Michael had a number of other ideas for how counseling might supplement, and/or play an integral role in, the stuttering treatment process. He highlighted client commitment to using treatment techniques such as slow rate of speech as a psychological issue, and suggested that these types of challenges could be discussed with a mental health professional. He also suggested that counseling could help clients to 'take control' of their stutter. Finally, Michael surmised that counseling could be helpful for answering parent questions, particularly questions that arise over and above what can be addressed by a clinician. For instance, counseling could address family goals and expectations for therapy.

Roger surmised that while other outlets do exist, other clients may value the opportunity to talk to a professional or specialist:

I think too if you're prepared to talk about it too you can talk to your family or friends and other people as well, um, it might be hard to find a person who would be as understanding or knowledgeable [as a counselor] though.

Counseling as a Great Service that Begs Wider Promotion and Enhancement

Participants expressed very positive views towards incorporating counseling services into stuttering treatment programs. Participants also shared a number of ideas for promoting and expanding the counseling service at ISTAR in order to educate clients about service benefits, to improve opportunities for accessing the service, and to further tailor the service towards clients' needs.

Promotion

Participants indicated that it would be helpful to receive more information about the counseling service at ISTAR, including information about how the service works, and the benefits of participation. For example, Isabella stressed that clients should know "that this is beneficial and it is confidential and thereand there aren't any judgments about your issues." Both clients who did and did not participate in counseling stated that being advised of statistics about service effectiveness would be valuable; for example, statistics on how many clients access counseling, what type of issues have been addressed in counseling, and how many clients find counseling to be beneficial. In essence, they suggested advising clients of the evidence base for the service.

Michael stated that ISTAR should be clear about what will happen in counseling, and how counseling is related to stuttering treatment at the institute. Participants felt that more in-depth information sharing would help other clients to overcome any stereotypes or assumptions about the counseling service. While brochures or follow up e-mails might be used to inform clients about the counseling service, overall, participants thought that personal, face-to-face accounts would be the best way to advise clients about the counseling service. Participants overwhelmingly enjoyed hearing, and giving, former client talks, and suggested that former client talks could be adapted to include information on counseling at ISTAR. In this sense, former clients could serve as 'practical examples' of the value of counseling. Bob suggested anonymous client testimonies, or a video montage about clients' experiences as an alternative, should former clients be unavailable to discuss their experiences.

In addition, participants mentioned that the counselor, as part of the ISTAR team, might most effectively get the message across about the benefits of counseling:

Mark: Well, I think one thing that might help is that if, um, whoever's gonna be offering the service can visit a group of clients when they're coming in through the- through the start of a session, right. So if it's a 3 week or a 1 week clinic, they can come in at the start and [the counselor] can just kind of say hi and talk to them for a couple minutes and say this is who I am, this is what I do, I'm, you know, able to come here at these times, right. I think just that little kind of face-to-face meeting might make people feel more comfortable following up, right.

Other participants agreed that during this time, the counselor could introduce themselves, or, as Steve put it, "break the ice," explain their role, highlight possible topics for discussion in counseling, help clients understand what to expect throughout the counseling process, and provide their availability. Steve suggested that the counselor should not be the only member of the ISTAR team involved in promotion of the counseling service. He recommended that while meeting the counselor would be valuable, speech-language pathologists at ISTAR should be the ones to present information about the benefits and statistics related to counseling, due to their pre-existing relationship, and established trust, with the clients.

Sign-Up

One participant, Mark, suggested that the sign-up process for counseling may serve as a barrier to participation. Mark revealed that notifying a clinician of personal interest in counseling can be a very difficult leap for clients to make:

-but I definitely re- remember, um, you know, like the first time that I went to the clinic when it was over on the other building, there was a group of about 5 or 6 of us that were in that [clinic], and, you know, they just kind of mentioned near the start of that time that we have this [person] and [they] will be willing to come here for free and chat with you guys if you want, so if you're interested like come talk to me...so, I don't really think that a lot of stutterers, like for me certainly when I was that age, right, and with all the unhealthy kinda baggage that I had associated with it, I didn't really feel comfortable kinda taking that leap, right. If they could kind of find a way to make that leap a little bit easier for you to take, I think that would be helpful, right.

Mark suggested that clients could be given written options for their treatment program at ISTAR. These options could include 'opting in' or 'opting out' of counseling, and providing the counseling service as a transfer activity in the same

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way that phone calls, shopping, and speeches are possible transfer activities at ISTAR.

Service Delivery

Participants suggested that counseling should be integrated more fully into the stuttering treatment process, but recognized that this integration would be challenging, and grappled with exactly what 'integration' should look like. For instance, participants talked about barriers to modifying service promotion/education, including the cost and time commitment of having a mental health professional present to speak to clients at each stuttering treatment session:

Bob: -I mean the counselors have got to be busy, as is, so taking the time out of their schedule to, uh, deliver a pep-talk about the whole counseling thing, uh, you might be hard to find time for that, but I do think it would probably help a lot.

Michael cautioned that counseling should be built into stuttering treatment, as opposed to existing as an adjunct service that could take away from stuttering treatment:

So that is uh- is a component that you have to deal with, I don't know you'd do it but, um, to kinda make sure that it doesn't take away from this, and it's anit's an- it's an organic thing. Cuz it's gotta be an organic thing from ISTAR,

it's gotta be something embraced by ISTAR, not something added to ISTAR. Michael further elaborated that counseling could be incorporated as a module within stuttering treatment, and that if counseling isn't directly incorporated into treatment, it should at least be highly recommended by clinicians, because stuttering has a psychological component. Steve also felt that counseling should be incorporated into stuttering treatment, but debated the ethics of telling, or not telling clients about this facet of the program beforehand:

So, um, maybe just, uh- um, make them feel they are signing up for a session but like have it split into like half and half secretly, I'm- I'm not sure that's fair to them, but- but that's what I think.

On the other hand, Michael suggested notifying clients from the beginning that counseling is one facet of the program. Other participants agreed that everyone could try counseling, but these participants also saw value in presenting counseling as a choice, and suggested an 'opt-out' option for clients who really do not need or want counseling.

A few clients proposed enhancements for the counseling service itself. Based on her experience, Isabella recommended that counseling services should be offered more frequently, ideally every 2 weeks. Additionally, Alexander shared his personal experience of counseling as a young adult, and suggested that counseling sessions can feel awkward:

But the only problem was I thought- I think [the counselor] um, thought a little bit too much cuz there would be awkward periods when [the counselor] would just like sit there and yeah, that's about it I think...and [the counselor] couldn't really come up with anything, so I knew [the counselor] was trying [their] best but I also think at that time I wasn't really mature enough for something like that so we couldn't really come up with a solution together. Alexander also described the counseling environment as 'gloomy' and the sessions as long. Alexander provided suggestions for tailoring the counseling service to younger clients: make treatment more energetic, schedule sessions on weekends, during daytime hours, create a relaxing environment with comfortable furniture, and provide stress balls or fidget toys to allow clients to take their mind off the session occasionally. He also recommended reducing the intensity of treatment sessions for very young clients so that counseling is not perceived as overwhelming.

Chapter 5: Discussion

Participants in this study agreed that the majority of individuals seeking treatment for stuttering would, or could, benefit from psychological counseling with a mental health professional who is specifically trained to deal with emotional and psychological issues; however, they also agreed that a counseling service needed to remain an optional component, despite being an integral part of a treatment program. Reasons for deciding to access or not access counseling with psychologists at ISTAR ranged from novel, previously unexplored help-seeking factors, to typical facilitators or barriers to help-seeking found in the literature outside the field of communication disorders. Benefits ranged from those that were intimately related to stuttering to those that were more distantly related. Participants also recognized that there would be challenges to integrating psychological counseling options more robustly into the CSP at ISTAR; some of these challenges are relevant for other treatment programs. Nonetheless, participants provided many suggestions for enhancing and promoting the

counseling service. Further explication of these major findings and their clinical implications follow.

Facilitators and Barriers to Help-Seeking

The present study suggests that many of the factors that have influenced helpseeking in other fields also influenced participants who accessed counseling at ISTAR. However, findings also suggest novel reasons for participating in counseling, including a 'why not' attitude, and the nature of pre-existing therapeutic alliances. The current study also revealed barriers to help-seeking that aligned with barriers previously identified in the literature. Additionally, participants discussed previously unexplored barriers to participating in counseling that may extend past research findings, including perception of the counseling service as 'limited,' and perception of the CSP at ISTAR as intensive.

Facilitators to help-seeking. Previously reported facilitators to help-seeking, that influenced participants' decisions to access counseling, included anticipating benefits, wanting a means to vent, being open to the idea of disclosure, and seeking help when experiencing more stressors in life. Like participants in Shaffer, Vogel, and Wei (2006), participants in the current study anticipated that they would benefit from counseling. In particular, they expected that the counseling services could help their speech, or could compliment, or support them during, their stuttering treatment. Participants anticipated that counseling could provide a 'venting outlet.' Counseling as a 'venting outlet' has been discussed in areas such as cancer patient caregiver support (Gilbar, 1997) and art therapy or group sessions for grieving children (Davis, 1989). Similar to findings of Kelly and

Achter (1995), Rickwood and Braithwaite (1994), and Vogel and Wester (2003) participants in the current study who chose to take part in the counseling service at ISTAR also felt open to the idea of disclosure. They were ready and willing to talk about the consequences of their fluency disorder, their personal life situations, their stuttering treatment, and other issues. Finally, just as Rosen et al., (2011) and Schofield and Khan (2008) found, participants in this study were more likely to seek help when their life challenges were perceived to be great, or when their impairments were perceived to be severe. Some participants in this study chose to take part in counseling services when they perceived the psychological, social, and emotional consequences of their stuttering to be severe, and/or when they experienced more life challenges or stressors. Some clients experienced significant psychosocial consequences related to stuttering (e.g., anxiety, bullying, low self-esteem) at some point in their lives, and felt that counseling might help them deal with these issues. One participant had a co-occurring mental health disorder, and was interested in learning about its' relationship to, and interaction with, stuttering. Furthermore, participants' diverse accounts suggested that every individual considers unique factors, such as personal life challenges, or family difficulties, when making a participation decision. This finding is consistent with previous studies, which indicate that many unique factors may overlap to predict help-seeking behaviors (Pederson & Vogel, 2007; Schofield & Khan 2008; Shaffer et al., 2006).

Results also suggested some novel reasons why clients participated in counseling at ISTAR. Clients who chose to participate often discussed a 'why not'

attitude towards counseling. In some instances, these clients were not aware of specific benefits of counseling, and did not always have specific reasons for participating. Instead, they saw that the service was available, heard about the service through clinicians whom they trusted at ISTAR, and decided to advantage of the service. In Fourie's (2009) grounded theory study, participants discussed therapist actions and qualities that defined an effective therapeutic relationship between clients and speech-language pathologists. Participants discussed important therapist actions, such as Being Confident, and therapist qualities, such as Being Erudite, or knowledgeable; participants in the current study perceived these, and other helpful qualities, to apply to the speech-language pathologists at ISTAR. Participants described the speech-language pathologists at ISTAR as knowledgeable, kind, and trustworthy. As a result, many participants valued their therapist's opinion, and accepted the offer to participate in psychological counseling. These findings suggest that a strong therapeutic alliance, based in trust and mutual respect, may be a crucial factor in clients' decisions to participate in counseling with a psychologist or other mental health practitioner whom they have not previously met.

Barriers to help-seeking. Consistent with existing research, barriers to helpseeking discussed by participants in this study included unwillingness to disclose, anticipated risks, and stigmatized attitudes toward of help-seeking.

Similar to findings of Kelly and Achter (1995), Rickwood and Braithwaite, (1994), and Vogel and Wester, (2003), Mark was one client who initially chose not to participate due to discomfort with disclosure. However, he later

participated in counseling when he felt more willing to 'open up.' In the area of stuttering treatment, this finding also overlaps with Kully and Langevin's (1999) suggestion that a treatment program may not be a good fit for clients if they are reluctant to discuss negative feelings. Another participant, Bob, chose not to participate in counseling due to his concerns about mental health professionals (due to a previous negative experience). Similarly, Gulliver et al., (2010) found that concerns about mental health professionals were negatively associated with help-seeking. Interestingly, although Gulliver et al. (2010) found that concerns about confidentiality were also negatively associated with help-seeking, none of the participants in the current study discussed concerns about confidentiality, even when they chose not to access ISTAR's counseling service.

When participants who did not access counseling were asked why others might choose to not access counseling, their reasons were similar to other commonly reported barriers. They surmised that others may not participate due to lack of awareness of the counseling service, or a lack of awareness of potential benefits. Lack of knowledge about services has been negatively associated with helpseeking in previous studies (Gulliver et al., 2010). Some participants also surmised that it can be particularly difficult for men to 'open up' in the counseling process. This is consistent with findings that male gender negatively predicts help-seeking behaviors (Rickwood & Braithwaite, 1994)

Participants in this study also had some novel, previously unexplored reasons for not participating in counseling themselves, and perceptions of why others may not participate. For instance, Mark and Michael saw the counseling service as a

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'limited resource,' and expressed concerns about depriving other clients (who may be in 'greater need') of this service. This barrier has not previously been discussed in the help-seeking literature. As indicated above, help-seeking has been associated with more negative life events, or severe impairments (Rosen et al., 2011; Schofield & Khan 2008); however, Kleinberg, Aluoja, and Vasar, (2013) have reported that although available services exist, help-seeking rates for mental health disorders remain low. They found, in a cross-sectional study, that only 1/3 of depressed individuals accessed counseling, and most often did so when their health was poor and when their depression was severe. However, results of the current study indicate that although some clients may be experiencing severe impairment (or, in this case, severe consequences related to their stuttering), they may not seek help if they perceive their impairment to be less severe than that of someone else. Program developers in the field of communication disorders, and in the area of stuttering treatment, in particular, should consider potential concerns about service allocation when promoting counseling services. If clients feel guilty, or diminish the severity of their psychological needs and interpret counseling as a 'limited service, run by volunteers,' they may be less likely to seek mental health services to accompany their treatment. As Dr. Langevin (personal communication, April 6, 2014) indicates, when ISTAR speech-language pathologists or speech-language pathologists in others settings talk about the availability of individual psychological counseling in the future, it will be important to emphasize that each person is affected by their stuttering in unique ways, and that there is not a one-toone relationship between the severity of stuttering and its psychological, emotional, or social consequences; a person who has mild overt stuttering can be equally or even more profoundly affected than an individual who has severe overt stuttering. Although Dr. Langevin advises that this idea of uniquely individual experiences, needs, and progress through therapy is routinely discussed at the beginning of treatment programs at ISTAR, study results indicate that these concepts warrant repetition.

Lastly, some participants also spoke to the intensive (and often overwhelming) nature of the stuttering treatment program at ISTAR, and expressed a desire to invest all of their time in stuttering treatment, as opposed to dividing their cognitive resources between stuttering treatment and counseling. This barrier to help-seeking is specific to clients undertaking the CSP at ISTAR, but may also apply to similar stuttering treatment centers and programs.

Counseling With a Trained Mental Health Professional – A Necessary Option

Study results revealed that participants clearly supported the option to access additional psychological counseling services at ISTAR. They discussed stuttering as being inseparable from its consequences in all aspects of life. As a result, there was no doubt among participants that stuttering treatment programs need to address psychological, emotional, and social consequences of fluency disorders. Counseling often helped clients to relieve the burden of stuttering. Clients indicated that an opportunity to vent to a professional/specialist was especially valuable. Counseling also played an important role in the stuttering treatment process for clients who did not have any other outlets, due to factors such as their living situations, and having no access to others who truly understand stuttering.

The consequences of fluency disorders might be addressed as an integrated part of stuttering treatment, or as an additional component, depending on clients' personal readiness for, and need for, such counseling services. In the current study, some participants valued counseling as a separate component of their stuttering treatment. For example, Michael did not choose to access counseling, and wanted to focus solely on his speech/fluency skills during his time at ISTAR. Additionally, Mark, who did access counseling, expressed a desire for counseling and fluency skills to be separate components of therapy; he appreciated that the psychological counseling service at ISTAR gave him an opportunity to talk to a mental health professional one-on-one. On the other hand, some participants expressed that further integrating psychological counseling into stuttering treatment might encourage more clients to access, and benefit from, the service.

Overall, findings suggest that stuttering treatment programs (including those that already integrate fluency enhancing speech skills and CBT) might further enhance functional outcomes, at least for some clients, by introducing psychological counseling as an integral component to the delivery of the program, as Beilby, Byrnes, and Yaruss (2012) have done with Acceptance and Commitment Therapy, or as an integrated, but optional component as did Kully, Langevin, and Lomheim, developers of the CSP. Study participants agreed that the option to talk to a 'professional' or 'specialist' for mental health issues is valuable throughout stuttering treatment. This finding supports the notion that mental health professionals can contribute to the stuttering treatment process, beyond the counseling and CBT that is already provided by speech language pathologists (Altholz & Golensky, 2004). Ideally, speech-language pathologists could work on interdisciplinary teams with counseling psychologists, and/or other mental health professionals, who have an understanding of fluency disorders, in order to determine how to best tailor services to clients' needs, and in order to maximize clients' treatment experiences and outcomes.

Promotion and Enhancement of Counseling Services

As indicated above, participants valued counseling as a worthwhile and important time/resource investment. They provided specific recommendations for promoting and enhancing the service at ISTAR that may be relevant to other treatment centers; however, they grappled with some barriers to incorporating their ideas.

Service promotion. Suggestions for modifying the counseling service in terms of promotion included presenting statistics, being explicit about the benefits of counseling, thoroughly explaining the counseling process, dispelling myths about counseling, and establishing rapport between counselor and clients. Participants in both groups talked about the importance of presenting evidence of the benefits of participating in counseling with a psychologist or other mental health provider who is trained to help clients deal with emotions. This result fits with the climate of evidence-based practice that has been a cornerstone of the CSP, and addresses a gap in the literature in terms of clients' perceptions of the value of psychological counseling. Findings also provide support for a program of future research dedicated to elucidating whether counseling supports outcomes of integrated treatment programs, provides added value, or can replace some of the counselingbased components of integrated treatment programs such as the CSP.

Service delivery. Participants also made a number of suggestions for how the counseling service could be delivered. Although some participants suggested that counseling could be added as a module, it was clear that counseling should not be presented as adjunct, but, rather, as an 'organic,' completely integrated, but still optional component in the CSP. Although, overwhelmingly, participants felt that all clients could benefit from additional counseling services as a complement to the CSP, they debated the ethics of 'requiring' clients to take part in psychological counseling, and ultimately agreed that counseling should be presented as an optional, but strongly recommended, component of stuttering treatment. They stressed that any further integration of counseling into the CSP should not 'take away' from the emphasis on, and dedication required for, developing and enhancing fluency and stuttering modification skills. The CSP was perceived as an overwhelming and intensive program as is, without the addition of individual counseling sessions. As a result, program developers at ISTAR, and other stuttering treatment centers, should carefully consider how counseling services may be presented in an integrated way, without further overwhelming clients during their treatment.

Participants also discussed barriers such as cost of services, and scheduling/management of clinician and client time, as applicable to the psychological counseling service at ISTAR. 'Not having enough time' has been identified as a client barrier to accessing counseling services in other fields (Czyz et al., 2013). Challenges such as cost and time-investment may be relevant for any stuttering institute or public health service seeking to incorporate counseling into treatment options for clients with fluency disorders. Hiring a resident psychologist and/or establishing an interdisciplinary team that includes a psychologist may not be feasible in all settings due to these challenges. Where this type of interdisciplinary practice is not possible, collaboration might still be established between speech-language pathologists and mental health professionals. For example, local psychologists, with an awareness of fluency disorders (perhaps established through in-services or additional training sessions led by speechlanguage pathologists, and to receive fluency-related client referrals, whenever possible.

Study Limitations

Qualitative research, such as the current investigation, does not aim to generalize, but aims to gather extensive data from a small number of participants in order to explore complex human experiences. In the current study, attempts were made, throughout the recruitment process, to interview participants who were as diverse as possible. However, out of the 9 participants, 8 were male, and only 1 participant was under the age of 18. None of the participants were over the age of 38. Additionally, all of the clients took part in stuttering treatment at ISTAR within a consistent time frame (during 2012). In order to determine whether the results apply to other clients who stutter (such as children or teens),

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similar studies could be done with individuals of a variety of ages. More female participants could be recruited (however, it is important to note that there are typically more males than females who stutter; Guitar, 2014; Yairi & Seery, 2011). Additionally, this study is specific to the stuttering treatment program and counseling service offered at ISTAR, and the applicability of the study results to other institutes and public health services may vary depending on the nature of these services. In order to explore the value of, and challenges to implementing, counseling services in diverse stuttering treatment programs, similar studies should be replicated in other locations and institutes.

A further limitation of the generalizability of findings is that the resident certified psychologist at ISTAR has many years of experience working with clients who stutter, and a thorough understanding of how the CSP works. This psychologist has, with students, reviewed the CBT component in the past (Marilyn Langevin, personal communication, March 30, 2014). Students who provide counseling at ISTAR benefit from the resident certified psychologist's experience. This level of knowledge about stuttering is likely only representative of psychologists, or other mental health professionals, who have close association with stuttering treatment programs. Whether or not this level of stuttering knowledge is needed has yet to be determined, particularly in view of previous literature that has suggested that, although social workers or other mental health professionals could play a very important role in counseling clients with fluency disorders, their lack of knowledge about stuttering may serve as a barrier to effective service delivery (Altholz & Golensky, 2004).

Future Directions

In the present study, participants made a number of suggestions for promoting and enhancing the counseling service at ISTAR. Should any modifications to the counseling service be carried out in the future, further research should follow up with clients, using survey, or other methods, to assess client satisfaction with the information presented about counseling services, and with the counseling experience itself.

Many participants pointed out the importance of providing clients with statistics about the benefits of counseling. Unfortunately, very little research has been carried out to date on clients' experiences with these types of services. The current study is a step towards establishing the benefits of counseling services for clients at ISTAR. In the future, research could move towards quantifying these benefits, perhaps using survey methods to compare treatment outcomes (for measures such as mental health, anxiety, adjustment, self-esteem, fluency, and so on) between groups of clients who did, and did not, participate in counseling as part of their stuttering treatment program. Additional research in this area would help to establish the evidence base for including a counseling component in stuttering treatment, and would allow clinicians to provide their clients with a more accurate picture of how and why counseling can be helpful. If benefits of counseling within the area of fluency disorders continue to be revealed, clinicians can have greater confidence in the recommendation that clients consider participation.

In the present study, only three out of nine participants did not participate in counseling services at ISTAR when given the opportunity. One of these three participants indicated that, although he perceived that the counseling service could be useful for others, he did not have a need for counseling because he 'never let his stuttering hold him back.' While this study established that barriers may prevent clients in need from accessing psychological counseling (e.g., desire to focus on speech, unwillingness to 'open up,' concern for resource allocation), further research is needed to explore the reasons why a wider range of clients may not want, or need, counseling as part of their stuttering treatment. The perception of not needing counseling services has been identified as a barrier to help-seeking in other fields. For example, Czyz et al. (2013) recently conducted a study with students who were at elevated risk for suicide; self-reported answers to openended questions revealed that the most common barrier to seeking counseling was personal perception that treatment wasn't needed. Another common barrier was a preference for self-management of symptoms. To determine why some clients perceive that counseling is not needed as part of stuttering treatment, theoretical sampling of clients who did not take part in counseling (when given the opportunity) might explore personal factors (e.g., high self-efficacy, extroversion, beliefs) or relational factors (e.g., close support network, peers who also stutter) that are associated with the decision not to participate. The prevalence of clients who do participate, versus those who do not, may also be explored, in order to determine the number of mental health professionals, or the extent of services, that should be available at various stuttering treatment institutes.

Furthermore, in the current study, only one participant was under the age of 18. This participant discussed the unique challenges involved in applying counseling services to younger clients, and made a number of suggestions for modifying counseling services to better suit younger clients' needs. This client's experience differed significantly from the experiences of older, adult clients, at ISTAR, and, as a result, we cannot assume that young adults experience counseling services the same way that older adults do within the field of communication disorders. In order to determine whether counseling services presently address the psychosocial consequences of stuttering for youth or young adults in stuttering treatment centers and public health centers, more research needs to be carried out in this area.

Conclusion

In the current study, clients chose to access, or not to access, counseling for a variety, and combination of, individual reasons, including willingness to disclose, severity of consequences of stuttering, severity of life issues, perception of benefits, degree of awareness of service/benefits, perceptions of mental health professionals, and the need for a 'venting outlet' in the form of a mental health professional. These factors have been associated with help-seeking behaviors in previous fields; results indicate that these factors may also be relevant for clients seeking counseling as a component of their stuttering treatment. However, the current study identified several additional factors that may predict the help-seeking behaviors of clients who stutter. These factors include a 'why not' attitude aimed at taking advantage of available services, the existence, and nature of, the

relationship with the professional who offers the service, the perception of counseling as a 'limited resource,' and the nature of the treatment program in question, including client perceptions of program intensity. All of these factors need to be taken into consideration by program organizers when contemplating the implementation of counseling services into a stuttering treatment program.

Results of this study revealed that the CSP met (and exceeded) some clients' needs and expectations without the addition of a counseling service, whereas other clients perceived the counseling service offered by mental health professionals at ISTAR to be a critical aspect of stuttering treatment. Participants in the current study agreed that counseling was a necessary and beneficial part of stuttering treatment, either for themselves personally, or for other clients, because stuttering can result in many negative psychosocial consequences for those affected, and because stuttering treatment has a psychological component (i.e., reframing one's thoughts about speech, or recovering from a life-time of ostracization). As a result, including a counseling component in stuttering treatment may be a worthwhile and important time/resource investment for other treatment institutes, and public health centers.

Lastly, clients proposed suggestions for how counseling services might be promoted and delivered at ISTAR. They suggested that service promotion should address benefits and dispel myths about counseling, and should focus on rapport building between the counselor and clients. They also stressed that any servicedelivery modifications should present counseling as an organic, integrated, and optional component of the stuttering treatment process, in order to best meet clients' needs. These recommendations, for service promotion and delivery, may be relevant to any stuttering treatment programs or public health centers considering the implementation of psychological counseling services for clients who stutter.

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Appendix A

Letter of Invitation

Title of Research Study:	ISTAR Clients' Experiences With, and Perceptions of, Psychological Counseling to Augment Stuttering Therapy
Principal Investigator:	Alanna Lindsay, BA, Graduate Student, Department of Speech Pathology and Audiology, University of Alberta
Co-Investigators:	Marilyn Langevin, PhD, Assistant Professor, Department of Speech Pathology and Audiology and Institute for Stuttering Treatment & Research

Date

Dear (name of client),

We are inviting you to consider participating in a research project. This project aims to explore ISTAR client's experiences with, and views towards, the counseling service that is offered at ISTAR. We would like to obtain opinions of both those who did and did not participate in the psychological counseling service. The investigation is being conducted by Alanna Lindsay, under the supervision of Dr. Langevin.

An information sheet and a copy of the consent are attached for you to review in the event that you are interested in participating. Participants will be offered compensation for time and travel expenses incurred.

As explained in the information sheets, your participation in this study is completely voluntary. If you decline to participate, or if your participation is withdrawn at any time, this will in no way affect your relationship with ISTAR or your present or future treatment.

If you have any questions, please do not hesitate to contact Dr. Langevin or Alanna Lindsay. You may call Dr. Langevin at (780-492-2619) or you may leave a message for Alanna Lindsay at the ISTAR main office (780-492-2619) and she will return your call. You may also contact Dr. Langevin or Alanna Lindsay through e-mail, at marilyn.langevin@ualberta.ca or amlindsa@ualberta.ca

Thank-you for taking the time to review this invitation.

Yours sincerely,

Alanna Lindsay, BA, Graduate Student, University of Alberta Marilyn Langevin, PhD, R.SLP, S-LP(C), CCC-SLP Assistant Professor (Research)

Appendix B

Information Sheet-Adults		
Title of Research Study:	ISTAR Clients' Experiences With, and Perceptions of, Psychological Counseling to Augment Stuttering Therapy	
Principal Investigator:	Alanna Lindsay, BA, Graduate Student, Department of Speech Pathology and Audiology, University of Alberta Contact: (780) 492-2619 amlindsa@ualberta.ca	
Co-Investigators:	Marilyn Langevin, PhD, Assistant Professor, Department of Speech Pathology and Audiology and Institute for Stuttering Treatment & Research Contact: (780) 492-2619 marilyn.langevin@ualberta.ca	

<u>**Purpose</u>**: The purpose of this study is to gain an understanding of ISTAR clients' experiences with, and views towards, the psychological counseling service that is offered as optional component of speech therapy for stuttering.</u>

Background: Currently, researchers don't know very much about clients' experiences with, or views towards, counseling services as part of stuttering therapy. Alanna Lindsay, a graduate student at the University of Alberta, is conducting this research under the supervision of Dr. Langevin in the Department of Speech Pathology and Audiology.

Eligibility: You are eligible to take part in this study if you have if you have participated in one or more stuttering treatment clinics at ISTAR, and **whether or not** you chose to access psychological counseling at ISTAR when given the opportunity.

Procedures: If you agree to participate in this study, you will complete an interview with Alanna Lindsay. Prior to the interview, you will have an opportunity to ask questions about the study, and you will be asked to sign an informed consent form. During the interview, you will be asked some open-ended questions about your experiences with, and/or views towards, the counseling service that is provided at ISTAR and why you chose to participate or not participate in the counseling. The interview will be audio-recorded to allow for later transcription and analysis. You will also be asked to fill out a brief demographic form.

Confidentiality: Your personal information will be kept confidential. Only the investigators listed on this information sheet will have access to your data. Your name, and the names of others that you may mention in the interview, will be replaced with pseudonyms by Alanna Lindsay, before the other investigator, Dr. Langevin, has access to the data. This means that the information that you share will not be identifiable. The interview data will be analyzed in conjunction with multiple other interviews. The aggregate findings may be presented at research conferences and published in research publications (e.g., academic journals). During the study, your electronic information (e.g.,

transcripts, audio-recordings) will be securely stored on a password protected computer and hard copy data (i.e., hard copy transcripts) will be stored in a locked filing cabinet in Dr. Langevin's laboratory. Following completion of the study, your information will be securely stored in Dr. Langevin's laboratory, after which, it will be destroyed.

Possible Benefits and Risks: Participating in the study may benefit you in several ways. You will have the chance to share your story, and to reflect on your own therapy, beliefs, and personal development. We expect that there are no risks other than those encountered in every day life. However, if you experience emotional upset, we will advise you to seek counseling services at ISTAR, or to contact the University of Alberta Hospital Clinical Psychology Department at 780-407-6896.

Voluntary Participation: Participation in this study is voluntary. If you decide to participate in this study, you may withdraw your participation at any time during or following the study, up until the point of data analysis. Once in the data analysis stage, you can withdraw consent to use quotes. Your decision to withdraw will not affect your relationship with the Institute for Stuttering Treatment and Research.

Location of Study: The interview will take place at Corbett Hall or another mutually agreed upon University location. If you are currently residing away from the Edmonton area, the interview may take place through video messaging.

<u>**Compensation for time**</u>: As compensation for the time and travel expenses that you will incur in participating in this study, you will receive an honorarium of \$50.

If you have any questions or concerns about this study, or would like to set up an interview, please leave a message for Alanna Lindsay at (780) 492-2619 or e-mail Alanna at <u>amlindsa@ualberta.ca</u>. You also may contact Dr. Marilyn Langevin at (780) 492-2619 or at <u>marilyn.langevin@ualberta.ca</u>.

If you have concerns about your rights or any aspect of this study, you may contact Charmaine Kabatoff with the Health Research Ethics Board. She can be reached at (780) 492-0302. This office has no affiliation with the investigators.

Appendix C

Informed Consent Form

Title: ISTAR Clients' Experiences With, and Perceptions of, Psychological Counseling to Augment Stuttering Therapy Principal Investigator(s): Alanna Lindsay Co-Investigator(s): Dr. Marilyn Langevin

To be completed by the research participant or guardian:

Do you understand that you have/your child has been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you and/or your child had the opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you and your child are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your present and/or future treatment at, or relationship with, ISTAR.	Yes	No
Has the issue of confidentiality been explained to you and your child? Do you understand who will have access to your records?	Yes	No
This study was explained to me by:		
I agree to take part in this study.		
Signature of Research Participant/Guardian Printed Name Date		

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee

Date

Appendix D

Youth Information Sheet and Assent Form

Title of Research Study:	ISTAR Clients' Experiences With, and Perceptions of, Psychological Counseling to Augment Stuttering Therapy
Principal Investigator:	Alanna Lindsay, BA, Graduate Student, Department of Speech Pathology and Audiology, University of Alberta Contact: (780) 492-2619 amlindsa@ualberta.ca
Co-Investigators:	Marilyn Langevin, PhD, Assistant Professor, Department of Speech Pathology and Audiology and Institute for Stuttering Treatment & Research Contact: (780) 492-2619 marilyn.langevin@ualberta.ca

In this study, we want to learn about what clients think about the counseling service that is offered at ISTAR.

<u>Purpose</u>: The purpose of this study is to learn about clients' experiences with, and what they think of, psychological counseling that is offered as optional component of speech therapy for stuttering.

We would like to talk with clients who participated in the counseling and those who did not participate.

What will you do?

If you take part in this study, you will come to an interview with Alanna Lindsay. Alanna is a student at the University of Alberta. The interview will take place at location on the University campus, or another place that we agree on. If you participated in the counseling, the interview will be a conversation about what it was like for you to take part in counseling at ISTAR. If you did not participate in the counseling, the interview will be a conversation about why you chose to not participate in the counseling and what you think about counseling. The interview will take about half an hour. When you come for the interview, you will be asked to sign this form. Alanna Lindsay will then ask you some questions. She will record your responses so that she can listen to them and analyze them later.

Will you get anything out of it?

By being in the study, you will help us learn about what clients at ISTAR think of the counseling service that ISTAR provides. You will have a chance to talk about

your experiences. You will also receive \$50 as a thank-you for participating in the study.

Can you quit?

You don't have to be in this study if you don't want to. You can stop at any time, and that is okay. You just need to tell us that you want to stop and we will do that.

Will your name be used in the study?

Your name will not be used in anything that we write about the study. Only Alanna Lindsay will know who takes part in the study. Instead of using your name to identify the information that you share, Alanna will use a fake name that you will choose.

Do you have more questions?

If you have more questions, you can talk to Dr. Marilyn Langevin who is supervising the study. Her phone number is (780) 492-2619. You can email her at marilyn.langevin@ualberta.ca.

Your signature:

If you want to be in the study you will need to sign your name below. Your parent or guardian also needs to sign a form that says that they will allow you be in the study.

I agree to be in the study.

(Your signature) (Da

(Date)

(Signature of investigator)

(Date)

Appendix E

Semi-Structured Interview Questions

Thanks for coming in to participate in an interview today. Your participation will help me to learn about what ISTAR clients think about the counseling service offered at ISTAR. I want to let you know that I will be audio-recording your interview today so that I can listen to it, and type it out later. I also want to remind you that anything you say in this interview will be kept confidential. I will be keeping the interview anonymous by using a fake name in place of your real name in the data. I will be removing your real name from the data before my supervisor, Dr. Langevin, from ISTAR, has an opportunity to see the data. I will ask you to fill out a form now that includes your age, gender, and the pseudonym, or fake name, that you would like me to use instead of your own name.

Before we begin, I also want to remind you that anything you say in this interview will not affect your relationship with ISTAR, or your treatment at ISTAR, in any way. I am interested in learning about your opinions, and what you truly think about the counseling service at ISTAR. Please feel free to share your thoughts and perspectives with me. Do you have any questions?

For Those Who Did Participate In Counseling

1. To begin, I'm interested in learning about you and some of your past experiences. Can you tell me a little about your story, the history of your fluency disorder, how you came to ISTAR, and how you ended up in the counseling session(s). *Probes:* Did you take part in other therapy before coming to ISTAR? How did you first hear about ISTAR?

2. I'm interested in what influenced you to participate in counseling at ISTAR when participation was optional. When you were given the opportunity, what was it that made you decide to participate in the counseling?

Probes: What were some of the most important reasons why you decided to participate in counseling? Were your reasons more to do with stuttering, or with other life issues? Did you decide right away to participate in counseling, or did you have to think about it for a while? Can you walk me through your thought process when you decided to take part in counseling?

3. What were your expectations for counseling, and were these expectations met?

Probes: Were there any specific aspects of counseling that wereespecially helpful? Are you glad that you participated incounseling? Would you participate in psychological counselingagain, if you had the chance? Can you think of ways thatpsychological counseling could be made more helpful for clients?

4. Why do you think that other clients who stutter might choose to take part, or not to take part in counseling?

Probes: Do you think that others decide to take part in counseling for the same reasons you did? Do you think their reasons would

have more to do with stuttering, or with other life issues? Would you recommend that others take part in counseling?

5. Is there anything else that you would like to tell me about your experience with stuttering treatment or counseling, or about your views towards psychological counseling? Anything that you think I've missed that you think might be important for me to know?

For Those Who Did Not Participate in Counseling:

1. To begin, I'm interested in learning about you and some of your past experiences. Can you tell me a little about your story, the history of your fluency disorder, and how you came to ISTAR?

Probes: Did you take part in other therapy before coming to ISTAR? How did you first hear about ISTAR?

2. I'm interested in what influenced you to NOT participate in counseling it was offered. When you were given the opportunity, what was it that made you decide to NOT participate in the counseling?

Probes: Did you decide right away not to participate in counseling, or did you have to think about it for a while? Can you walk me through your thought process when you decided not to take part in counseling? Are there issues in your life that could be addressed in psychological counseling? Do those issues have more to do with stuttering, or with other parts of your life? Were you happy with your decision not to participate? Would you make the same

decision if you had another opportunity to participate in counseling?

3. Why do you think that other clients who stutter choose to participate, or not to participate, in psychological counseling?

Probes: Do you think that counseling could be helpful for others who stutter? Do you think some people who stutter are more or less likely than others to participate in counseling? Do you think that the issues they might address in counseling would have more to do with stuttering, or with other parts of their life?

4. Can you think of any things that might make clients at ISTAR more likely to participate in psychological counseling services?

Probes: Is there anything that would have made you more likely to participate in counseling? If you could give ISTAR some suggestions about counseling services, what would they be?

5. Is there anything else that you would like to tell me about your experience with stuttering treatment, or about your views towards psychological counseling? Anything that you think I've missed that you think would be important for me to know?

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Appendix F

Information Form

Please Indicate Your:

- Name:
- Age:
- Gender:

The name I would like you to use instead of my own name is:

Appendix G

Debriefing Form

This debriefing form will be read to participants at the end of each interview:

Thank you for your participation in this interview. Your interview will
help researchers to determine if counseling at ISTAR is helpful, and if
there are any ways that it could be made more helpful for clients. If you
have any questions or concerns about the study, please feel free to contact
Dr. Langevin, the supervisor of this study; her contact information is on
your copy of the information sheet. If you should feel any distress after
participating in this study, counseling service information is also on the
informed consent form. Thanks again for your time and participation.