AN INVESTIGATION OF FAMILY RELATIONSHIPS FOR PEOPLE WHO STUTTER

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ABSTRACT

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      The purpose of this study was to explore the impact that family relationships have had on people who stutter (PWS). A qualitative framework was applied in order to obtain the experiences that seven PWS have had with their family. Themes included a description of support participants received along with their desire for positive stuttering role models. Barriers to receiving meaningful, deep support for these participants included lack of communication, along with misguided information from speech-language pathologists (SLPs) and families. In addition, participants felt pressure in general along with the pressure to be fluent with their families. It is recommended that families and PWS attend support groups to alleviate lack of communication. Also, family education and meaningful involvement in therapy can help encourage positive communication and alleviate pressure that PWS experience in their families. Finally, SLP education in regard to the treatment of PWS would be beneficial.

This study is dedicated to people who stutter and their families.

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TABLE OF CONTENTS

INTRODUCTION

Stuttering is a disorder that encompasses much more than speech disfluencies. Stuttering not only affects the forward flow of speech, but is an impairment that has additional psychological and social effects (Guitar, 2006). A definition of stuttering was forwarded by Guitar (2006), who described stuttering as being "characterized by an abnormally high frequency and/or duration of stoppages in the forward flow of speech. These stoppages usually take the form of (1) repetitions of sounds, syllables, or one syllable words, (2) prolongations of sounds, or (3) 'blocks' of airflow or voicing in speech" (p. 13). Wingate (1988) further states that the person who stutters does not readily control these disruptions. These definitions only encompass speech, but other researchers also suggest that stuttering involves feelings, associated movements, and beliefs (Bennett, 2006). Clinicians need to take into consideration all three of these areas not only when working with the person who stutters, but also when working with their family.

Speech is an essential tool for social communication. Relationships are established through people successfully communicating their thoughts and feelings with others. Since stuttering can profoundly impact communication, a person who stutters may have trouble with social interactions, and they may therefore have trouble building relationships (Daniels & Gabel, 2004). Many factors will contribute to a person who stutters' ability to manage and cope with their stuttering in social situations. Among these factors is the ability for the person who stutters to cope with emotional reactions to their perceived communication failure (Bennett, 2006). Another factor is the family of people who stutter (PWS). The family and other important supportive relationships may provide support or delay the ability of the person who stutters to cope with and manage their stuttering effectively (Yaruss & Quesal, 2004).

Due to the multifactorial nature of stuttering, speech-language pathologists (SLP) have advocated the inclusion of significant others in the treatment of PWS (Guitar, 2006). In addition, it has been noted that other members in the environment (e.g., family) of PWS have a direct impact on their development (Kelly, 1995). Therefore, family oriented therapy programs have been developed to involve family members into the therapy process for a person who stutters (Guitar, 2006). The rationale for including family members is to help facilitate effective communication for the person who stutters in the home environment. It does appear that family involvement in therapy, along with transfer activities, proves to be an effective tool in achieving communication success (Mallard, 1998).

In order to accurately and successfully involve family members into the treatment of a person who stutters, one needs to understand the experiences that PWS have had with their families. Unfortunately, very little research has explored the experiences that PWS have had with their families. In addition, little research has explored the perceptions PWS have regarding the benefits that their family has on therapy. More research is necessary in order to fully understand the relationship that PWS have had with their families.

The purpose of this literature review is to explore the perceptions and experiences that PWS have had with their family, especially family involvement in speech therapy. Thus, this chapter is divided into three sections. These sections consist of: (1) describing the development and multidimensional nature of stuttering; (2) discussing family involvement in therapy for PWS; and (3) reviewing the investigations of the experiences of PWS.

CHAPTER I: THE NATURE OF STUTTERING

It is important in normal human development that individuals construct a strong personal identity. Daniels and Gabel (2004) examined the importance of identity construction and how it relates to PWS. The authors stated that although constructing one's identity is a life long process, there is an emphasis on identity construction in the late childhood and early adolescent years, a time that is widely considered a milestone for changes not only physically, but also socially. In addition, the authors state that PWS may have difficulty establishing a positive identity due to their perceived communication failure in social situations. Often times, how a person who stutters copes with this perceived failure is based on the listener's response (Daniels & Gabel, 2004). This proves to be detrimental because many people that a person who stutters encounters will carry existing stereotypes and beliefs about stuttering, most of which are not accurate (Gabel, Blood, Tellis, & Althouse, 2004).

Effectively coping with stuttering involves many factors. One of these essential factors is a support network. Yaruss and Quesal (2004) analyzed the multidimensional nature of the International Classification of Functioning, Disability, and Health (ICF) presented by the World Health Organization (WHO) as it relates to stuttering. The authors stated that the ICF, when adapted, is an effective tool when looking at stuttering because it takes into consideration factors that are beyond the observable characteristics of the impairment. Beyond the physiological deficits of stuttering, personal factors, environmental factors, and the individual's performance in life activities can all be applied to describe the effects of stuttering. In addition, the model focuses in on intermingling personal factors and environmental factors and the model demonstrates how these two areas have an effect on the individual's ability to perform in regard to their speech. The framework that Yaruss and Quesal (2004) present indicates the

strong relationship that the environment has on a person who stutters' ability to perform effectively. This model also emphasizes that the support networks and relationships that PWS have will greatly affect their ability to function in the real world.

The family can be seen as a support network and be viewed as forming the first relationships that people will experience. The family, through their reactions and relationships with a person who stutters, can either have a positive impact, providing support and positive guidance in teaching the person who stutters to manage and cope with their stuttering, or can have a negative impact, hindering the person who stutters' development of positive management techniques and their self-identification as a person who stutters.

In order to examine an individual's stuttering, one cannot ignore the positive or negative effect that the home environment plays in the development of the disorder. Yairi (1997) reviewed the research that has been done regarding the home environment and parent child interactions in childhood stuttering. His interpretations of the research indicated that clinicians need to become more accustomed to the home environment of the child that stutters. In addition, Yairi stated that the home environment contains potential difficulties for the child who stutters. These difficulties are personal and social in nature and they can affect the development of the child. Due to the importance that the family plays in the child's development, it is critical that clinicians understand the dynamics that family interactions have on PWS.

Crowe and Cooper (1977) studied the attitudes toward stuttering reported by parents whose children stuttered compared to parents whose children did not stutter. These researchers studied 50 parents of PWS and 50 parents of people who do not stutter. Participants were administered the <u>Parental Attitudes Towards Stuttering Inventory</u> and the <u>Alabama Stuttering Knowledge Test</u>. Results indicated that parents of PWS displayed more undesirable attitudes

towards stuttering than parents of people who do not stutter (Crowe & Cooper, 1977). This study provides an argument that the negative attitude demonstrated by parents of people who stutter may have a significant impact on the home environment of a person who stutters and may hinder their ability to develop positive management skills for their stuttering.

Stuttering can also interact with the family dynamic. Bergstrom (2001) discussed the importance of family dynamic on stuttering. Additionally, the author discussed how to investigate the environment of a child who stutters (CWS) and ways to modify the organization of the family in order to produce positive change. The author wrote, "We cannot isolate the individual from his environment when we discuss stuttering and we need to observe the interaction between the stuttering child and his family in order to understand how the problem develops and manifests itself and how it is affected by and affects the family" (Bergstrom, 2001, p. 141). Additionally, Bergstrom (2001) advocated that clinicians need to view the entire family unit when assessing the child that stutters. Also, families who have a child that stutters need to feel as if they can express emotions and their diversity within the family without losing its sense of cohesiveness. Bergstrom (2001) concluded that clinicians may not be able to change the speech of the child that stutters, but they can change the environment in which the child is raised in so that positive changes can be made to better help them with their stuttering (Bergstrom, 2001).

Shuman and Mallard (2001) explored the interaction patterns of families of CWS and families of children who do not stutter. The researchers specifically examined the number of turns in a conversation, the number of turns with questions, number of interruptions, and total negotiation time during a negotiation task. The two experimental groups included two sets of 10 families, one set of 10 families had a child who stuttered and the other set had a child who did

not stutter. Both groups were asked to discuss, as a family, what they would do if they had two

thousands dollars to spend on a vacation. Overall, there were no significant differences that

existed between the total number interruptions, turns, turns with questions, or negotiation time.

However, fathers of CWS interacted differently with their family, exhibiting more interruptions

than any other family member (Shuman & Mallard, 2001).

This study provided quantifiable data in regard to interaction patterns, however it did not

use follow-up questions to inquire why the fathers of CWS produced more interruptions. Nor did

they ask the child who stuttered how he or she felt about the interaction style with their family.

Additionally, the study focused on the responses that parents exhibited, but did not elaborate on

sibling interaction styles. More research is needed to understand the entire family dynamic

during negotiation tasks as it relates to a person who stutters.

Family relationships can be seen as the first interactions that a PWS may have socially,

even before entering preschool. The beliefs that family members have regarding stuttering may

greatly reinforce or hinder a person who stutters' ability to construct a positive social identity.

Incorporating family members into the therapy process is an important area for treatment,

however it is crucial that clinicians have an accurate understanding of the experiences that a

person who stutters has had with their family in order to appropriately involve family members

into the treatment process.

CHAPTER II: THE IMPORTANCE OF FAMILIES IN STUTTERING TREATMENT

Clinicians have discussed the importance of incorporating family members into therapy for a PWS. Kelly (1995) advocated for incorporating not only one parent, but both parents into the treatment process for children who stutter. She stated that mothers and fathers demonstrate variability in their interactions with their child. Treatment must take into account these variables as well as the unique context that each child who stutters comes from. Additionally, it is recommended that therapy address goals specific to the father and mother and or anyone else that plays a significant role in the child's development. The author reinforced that clinicians must understand that there are other individuals in a child's environment that have an impact on their development (Kelly, 1995).

Mallard (1998) developed a therapy program that emphasized problem solving procedures that families could utilize in helping PWS manage their speech. In addition, social skills were also a part of the therapy program. At the end of the therapy program, each family developed strategies that were specifically molded to the individual that stuttered. The parents addressed areas in which they believed to be most important in dealing with their child that stuttered. Results indicated that 82% of the 28 families who participated did not need further treatment for their child that stuttered for at least one year after therapy (Mallard, 1998).

From Mallard (1998), it appears as though parental involvement is critical for increasing the effectiveness of therapy for elementary-aged children who stutter. This program involved families in the therapy process, by gaining an understanding of what stuttering was and learning techniques to help their child with their stuttering. Transferring this knowledge into the home environment of the child who stutters is vital for effective coping and management of their stuttering. One limitation of the study is that it only explored the perspective of the parent. It is

possible that the perspectives of the child would add valuable information that would help guide parent-child interaction while in therapy. Learning what the child that stutters experiences in their home environment may greatly contribute to the therapy success of involving families into stuttering intervention.

The Lidcombe Program is a classic example of how parents are involved in the treatment of stuttering (Onslow & Packman, 1999). In this program, parents administer therapy, collect speech samples throughout the week, and meet weekly with the SLP for consultation regarding their child's speech. The authors developed this program to integrate the SLP, child, and the parents as players in helping the child's stuttering. Procedures within the program were behavioral in nature. The parents praised stutter free speech and corrected speech that was deemed to be stuttered. Along with the behavioral aspect to the therapy, there was a cognitive component. Parents were instructed to change their old behaviors and alter the environment so that they would be able to praise the child's speech and offer rewards for fluent speech. Long term outcome data from the Lidcombe program indicates that the majority of participants were demonstrating stuttering frequency below 1% seven years post treatment. In addition, no cases of relapse had occurred. Onslow and Packman (1999) in the development of the Lidcombe program stress the importance of the parents in the child's development. By incorporating parents into the treatment process this program had a good success rate (Onslow & Packman, 1999). The Lidcombe program uses parents in the therapy process; however, the program does not mention the inclusion of other family members that play an important role in the child's development. The inclusion of other significant people in the child's environment into the therapy process may lead to higher success versus only including parents. In addition, no studies have explored the child's perspectives on involvement in therapy.

Early intervention programs for CWS are seen as an effective way to combat stuttering early in the child's life. Gottwald and Starkweather (1995) provided a framework for constructing an early intervention program for CWS, their teachers, and their families. The authors proposed that teachers and families reduce the environmental demands that are placed on the child. Additionally, the researchers stated that teachers and parents will need to make behavioral changes in the form of speaking rate reduction, and increasing the opportunity for turn taking in conversations, as to increase the child's capacity for fluency. Adaptations are not only made in the home environment, but in the classroom as well (Gottwald & Starkweather, 1995).

This early intervention program stresses the importance that family members have on CWS. By family members reducing the demands that are placed upon the child, the child's capacity for fluency would increase. A further investigation in terms of the experiences that a person who stutters has had with their family would educate family members in how to further reduce environmental demands.

CHAPTER III: THE EXPERIENCES OF PEOPLE WHO STUTTER

To date, little research has explored the experiences PWS report related to their family and therapy. Qualitative methods are often utilized in extracting lived experiences from PWS. By gaining an understanding of the experiences of a person who stutters clinicians may be better equipped to address the concerns that a person who stutters has.

Damico and Simmons-Mackie (2003) discussed the benefits that qualitative research has on the field of speech-language pathology. Damico and Simmons-Mackie (2003) defined qualitative research as, "a variety of analytic procedures designed to systematically collect and describe authentic, contextualized social phenomena with the goal of interpretative adequacy" (p. 132). In addition, Damico and Simmons-Mackie (2003) stated that there is an increasing need to address the complexities of communication disorders in addition to how these disorders occur in a variety of contexts. Also, the field is taking a hard look at efficacy issues in the treatment of people who have communication disorders, in particular the impact that treatment has on communication settings outside of the therapy room. In addition, therapy should take into consideration that clients come from a variety of social contexts. The authors stated that a qualitative approach is an excellent research design to accommodate the demands of the diversity of the clients seeking speech-language therapy. Qualitative research can be viewed as a multidimensional approach to speech-language therapy research (Damico & Simmons-Mackie, 2003).

Stuttering is multidimensional in nature, consisting of affective, behavioral, and cognitive variables (Bennett, 2006). One could therefore conclude that qualitative research would be appropriate for accurately describing the complexities of stuttering. There are many advantages that qualitative designs can provide to stuttering research. Tetnowski and Damico (2001)

provided justification for the use of qualitative methods in stuttering research. The authors suggested that experimental research has provided the area of stuttering with substantial and valuable information; however the designs did not take into consideration the complexities of stuttering. Also, in an experimental design some of the variables that have an impact on stuttering may be omitted. In addition, the authors stated that experimental designs are difficult to replicate. Finally, Tetnowski and Damico (2001) explained that the data collected in an experimental environment may not be an accurate picture of a person who stutters' performance in a natural setting. The authors concluded that there are advantages to gaining the perspective of the disorder through the person who is actually experiencing the disorder. Also, researchers will obtain a deeper understanding of how a person who stutters operates in social contexts (Tetnowski & Damico, 2001).

By gaining this understanding, clinicians would be able to work with people who stutter more effectively in overcoming difficulties experienced in the real world. In order to fully understand stuttering, one cannot put the disorder into a "one size fits all" design. Multiple designs are necessary in order to fully understand and explain the complexities of stuttering accurately.

Much of stuttering research has been dedicated to the physiological aspects of the disorder. However, Quesal (1989) discussed reasons for why this approach may be harmful to stuttering research by emphasizing the importance of using psychological and psychosocial perspectives when researching and treating stuttering. Clinicians who work with PWS deal with more than just the speech behaviors; they deal with the individual experiences that a person who stutters brings with them to therapy. Clinicians must address the issues that are of importance to the person who stutters. Quesal (1989) argued that the experiences from PWS suggested that

psychological and psychosocial aspects were extremely important. In the past, researchers have said that it is difficult to quantify the reported experiences of emotions, beliefs, and attitudes. Thus, qualitative procedures may be helpful in understanding the psychological aspects of stuttering. Quesal (1989) concluded by suggesting that professionals need to adopt a variety of perspectives when examining PWS. Additionally, the author advocated for researchers to examine how physiological and psychological aspects of the disorder interact, that knowledge about all areas of stuttering should be the goal of researchers. Thus, exploring family relationships and experiences that a PWS has had would be an important area for researchers to investigate.

The qualitative research exploring the experiences of PWS has focused on recovery, management, the effects of therapy, and general life experiences of PWS. Corcoran and Stewart (1995) investigated the therapeutic experiences of PWS by focusing on the experiences in the therapy process that were either helpful or negative in the process of modifying their stuttering. To do this, the researchers utilized a semi-structured, qualitative interview with seven adults who stuttered, and from this interview important themes describing the participants' experiences were identified. The participants felt successful in the therapy experience by gaining a clearer understanding of the nature of stuttering and by gaining an understanding of their own experiences with stuttering. Participants stated they were able to make positive changes in the wake of nurturing relationships with others. Participants also spoke of relationships that were beneficial or detrimental to the therapy process. Participants characterized a beneficial relationship as one in which there was shared knowledge with other people who stutter. In addition, participants said they felt a sense of hope and support as a result of this sharing in addition to a feeling of not being alone. Relationships that were negative to the therapy process

were characterized by a lack of understanding from the parent, teacher at school, or the speech

therapist. Some participants indicated that their parents did not know what to do about their

stuttering and as a result remained silent. As a result, participants felt that parents did not

recognize their need for assistance with their stuttering (Corcoran & Stewart, 1995). When the

person who stutters feels that they cannot form an understanding relationship with their parent,

teacher, or therapist they are left alone to cope with their own experiences.

Corcoran and Stewart (1995) concluded that three elements played a crucial role in the

improvement of stuttering, these being an understanding of stuttering and their own personal

experience, ability to develop positive coping strategies, and access to supportive relationships.

Parental relationships had a significant impact on the therapy experience for PWS. These

authors addressed the issue of the relationship that PWS had with their parents, however, they

did not investigate the entire family dynamic. The relationships that a person who stutters

develops with their siblings can also have an effect on how they view themselves and form

positive coping strategies.

In a second study, Corcoran and Stewart (1998) conducted a qualitative interview with

eight PWS. The participants in this study discussed their experiences as a person who stuttered.

The researchers found that suffering was the main theme that appeared upon analysis of the

transcripts. In addition, the authors found four fundamental themes of living with stuttering:

shame, helplessness, fear, and avoidance. The authors concluded that the relief of suffering

should be a main goal in stuttering therapy. Findings in this study highlighted the importance of

a supportive relationship in the therapy process for PWS (Corcoran & Stewart, 1998). Though

the authors concentrated on the relationship that the person who stutters has with the clinician,

the study did not explore the relationship that the person who stuttered had with their family. It

may be that the relationships with family members might not allow PWS to discuss their experiences. More research is needed in order to understand the relationship that PWS have had with their family (parents and siblings) to understand why such an understanding relationship is not being created.

Crichton-Smith (2002) utilized a qualitative approach to study the different ways that PWS communicate on a regular basis. Additionally, the author explored the variety of communication strategies individuals used in order to manage their stuttering. The author conducted semi structured interviews with 14 PWS. There were four strategies mentioned in regard to the way participants coped with, and managed, their stuttering. These strategies included "no change", which indicated speaking without prior planning, "intuitive changes", which designated the use of techniques not taught in therapy, but created by the person who stuttered, "taught change", which were techniques that were learned in therapy, and finally "highlighting", which included discussing stuttering openly with others. An area of note in this study was that all participants indicated that during childhood they received negative reactions to their stuttering, usually from a teacher or a parent. Also, the majority of participants indicated that they were comfortable stuttering at home or with friends rather than in their work environment (Crichton-Smith, 2002). The authors suggested that participants reported this feeling due to the sense of a supportive relationship that existed in their home environment and with friends that was not present in their place of employment.

Anderson and Felsenfeld (2003) conducted a qualitative interview with six individuals who had self reported recovery from stuttering after the age of 10. Participants retold their stories of recovery and the authors identified three themes that emerged from the transcripts. These themes consisted of increased confidence, increased motivation, and the ability to make

direct speech changes. The authors noted some limitations to the study. One limitation in particular addressed the fact that participants identified factors they perceived helped them in the recovery process. However, the factors mentioned may not have been the true factors that helped participants on the road to recovery. Upon review of the topics that were covered in the semi-structured interview, it was noted that Anderson and Felsenfeld (2003) did not probe, nor include, the aspect of family relationships or reactions into the interview. Participants may have not been given the opportunity to reflect on their personal family dynamic to see if it was a contributing factor into their recovery. A study exploring the impact of family relationships on recovery from stuttering would provide critical insight into how family relationships may be a vital factor in recovery and management of stuttering.

Plexico, Manning, and DiLollo (2005) explored the aspects of successful management in stuttering. The researchers interviewed seven PWS regarding how they were able to manage their stuttering effectively. Results indicated that successful management was due to many factors. The themes that arose included successful therapy and high levels of motivation. In addition, the past experiences of participants were important in identifying gradual awareness and identifying negative emotions and avoidance. Participants reported that stuttering continued to be successfully managed. An important theme that arose in the interviews was the concept of support networks. The family unit can be seen as a support network not only for stuttering, but for all life aspects (Plexico, Manning, & DiLollo, 2005). If PWS identified support as a theme to successful management of stuttering, then appropriate analysis of the experience that a person who stutters has with their family is necessary in order to better facilitate this family support network.

Klompas and Ross (2004) investigated the life experiences of 16 PWS from South Africa and specifically looked at the impact their stuttering had on their quality of life. The authors conducted interviews that targeted several topics. The topics included the impact that stuttering had in their education, employment, social life, speech therapy, family and marital status, identity, beliefs, and emotions. The authors stated that, for the majority of the participants, stuttering affected their academic performance at school and relationships between teachers and classmates. In regard to the overall impact on family life, participants reported mixed views on how stuttering had an influence on family or marital life. Specifically, looking at the category of family life, 7 out of the 16 participants reported that stuttering did have an effect on their relationship with their parents. Lack of understanding, impatience, and completion of sentences were common themes shared by these participants. Themes that arose for the rest of the group indicated that stuttering did not have an effect on their relationship with their parents. In regard to relationships with siblings, 8 of the 16 participants indicated that their stuttering had only positive effects, while the remaining 8 indicated that stuttering had both positive and negative effects. Positive effects included patience, understanding, support, and encouragement. Negatives effects included jealousy, impatience, and lack of understanding, embarrassment, and suggestions given regarding speech were just some of the themes found (Klompas & Ross 2004).

Klompas & Ross (2004) provides a picture into the life experiences of PWS. However, the area of family life was not explored deeply in this study, because it was only one of several parts of quality of life explored. Klompas and Ross (2004) explored a broad topic of general life experiences and the impact these experiences had on quality of life. More exploration is needed to gain a clearer understanding of the impact that stuttering has on family relationships. By

gaining an understanding of what PWS have experienced, clinicians can more accurately include family members into the therapy process.

Statement of Purpose

Currently, there is no research study that has focused specifically on the impact that family relationships have on a person who stutters, although many therapy programs have reported success when family members are involved in the therapy process (Kelley, 1995; Mallard, 1998; Onslow & Packman, 1999). Despite the continued advocating of family members being a part of stuttering therapy (Bennett, 2006; Bergstrom, 2001; Guitar, 2006; Rustin, Cook, & Spence, 1995), little is known from the perspective of the person who stutters of the impact that family relationships have had on their ability to manage their stuttering. As a result, an exploratory investigation of the significance that family relationships have on a person who stutters is necessary in order to appropriately and accurately include others into the therapy process.

Therefore, the purpose of this study is to explore the impact that family relationships have had on a person who stutters. A qualitative framework will be applied in order to obtain the experiences that PWS have had with their family. The current study applies a phenomenological framework, with the understanding from the literature review that families have a significant impact on a person who stutters. In the spirit of qualitative research, the experimenter will conduct a semi-structured interview, allowing participants the flexibility that is needed to account their personal experiences in regard to the extent of their family relationships. The findings from the current study will contribute and help facilitate the inclusion of family members into the therapy process for PWS.

The following questions will be applied in order to understand the impact that family relationships have on a PWS:

1. How does stuttering affect family relationships? Since stuttering can have a profound impact on communication, PWS may have difficult constructing positive social identity in relation to other people in their environment (Daniels & Gabel, 2004).

2. How did family relationships affect stuttering? Investigating how family support networks are utilized for PWS would provide valuable insight toward the inner workings of families of PWS.

3. How has therapy impacted the family relationships of PWS? In particular, do PWS report that they are able to communicate better after therapy with their family.

4. Finally, how have family relationships impacted therapy experiences for PWS? Have families been utilized appropriately in therapy and if family members were involved how did PWS feel about their involvement in their therapy process.

CHAPTER IV: METHODOLGY

General Approach and Procedures

The methods completed for this study were derived from a qualitative framework. A qualitative approach is descriptive in nature, and attempts to understand how a phenomenon occurs, instead of exploring cause-effect relationships (Creswell, 2003). In addition, a phenomenological strategy was implemented in the study to understand the life experiences of the participants. The application of a phenomenological approach enables the researcher to understand how the social phenomenon occurred from the participant's perspective (Patton, 2002). A semi-structured interview was the specific procedure used in the study. This approach is done to allow participants to answer questions as freely as possible during natural conversation. The researcher utilized open-ended questions in an attempt to extract the participants' personal stories regarding stuttering, experiences with their family, and the interplay between family relationships, stuttering, and therapy. When necessary, planned prompts were applied to responses that the researcher deemed interesting and important for the study (Creswell, 2003). To guide the interview, seven questions were used (Appendix A). These questions were adapted from other qualitative studies in stuttering (Klompas & Ross, 2004; Plexico et al., 2005), but were altered to meet the specific purpose of this study. The open ended questions used in this study allowed participants to convey their personal stories of stuttering with an emphasis on how stuttering related to their family experiences.

The interviewer (first author) met each participant at a location that was most comfortable for them. The interviewer offered to travel to each participant's home, or a location specified by the participant (personal office, a room in a speech and hearing clinic, a research lab, or other private place). The participant was seated in a chair and the interviewer was seated

directly across from them, so they were facing each other. A table or desk separated the

interviewer and the participant. The only item that was on the table was an audio- recorder. The

interviewer took field notes during the interview. These field notes will be used to supplement

all analyses.

Prior to the interview, participants provided their consent to participate in the study.

After the consent process was complete, each participant completed a demographic questionnaire

(Appendix B). The questionnaire obtained information regarding the participants' age,

background, family history, stuttering, and therapy experiences. The information obtained from

these questionnaires contributed to the qualitative analysis and described the participants. After

the completion of the consent form and the demographic questionnaire, the interviewer greeted

the participants and described the nature of the study.

Type of Sampling and Participants

Participants were identified using purposeful sampling (Patton, 2002). In this type of

sampling procedure, individual cases are identified as participants, based on their characteristics.

Those individuals who were asked to participate were chosen based on how their experiences or

shared stories would contribute to the phenomenon of interest. Thus, the population that was

interviewed consisted of adults who stutter, as these individuals were able to reflect on their

childhood experiences of stuttering as it related to their family relationships and therapy. There

were seven participants in the study. This number falls within the 7-10 participant range that is

recommended as a sample size when conducting a qualitative semi-structured interview

(Cresswell, 2003). Also, participants   had some form of treatment for their stuttering at some

point in their life. This is because the study was partially focused on the perceptions of the

participants' experiences in therapy as it related to their families.

Participants were recruited from the Northwest Ohio area. The researcher contacted the

National Stuttering Association (NSA) support group chapters in Northwest Ohio and in

Southeast Michigan, as well as speech and hearing clinics in those areas. Support group leaders

and clinicians were asked to assist in identifying appropriate individuals to participate in the

study. Once these individuals were identified, the researcher contacted these individuals to

schedule a time and place to conduct the interview. A description of the participants is provided

in the table below:

Table 1: Participant characteristics

Participant #	Age	Gender	Current self-rating of stuttering severity	Family Description
#1	34	Male	Moderate	Oldest sibling in his immediate family has younger brother who he reported stutters mildly and a younger sister. Also, has older step-brother and older step-sister. Grew up with both his parents.
#2	32	Male	Moderate	Youngest sibling in his family. Has an older brother and grew up with both his parents.
#3	30	Male	Mild	Oldest in his immediate family. Has a younger sister who stutters and grew up with his mother and father.
#4	24	Male	Severe	Youngest in his immediate family also has older brother who stutters mildly. Parents were divorced and he lived primarily with his mother.
#5	22	Female	Moderate	Youngest in her family. Has an older sister and grew up with both her parents.
#6	53	Male	Moderate	Three brothers and three sisters in his immediate family and was the oldest out of the boys. Also, grew up with both his parents until the age of 20 when they got a divorce.
#7	30	Female	Mild	The oldest of six children, grew up with both of her parents.

Analysis

The analysis process of the current study involved several steps. First, the primary researcher transcribed the interview verbatim and typed up any field notes that were taken throughout the interview. A coding process was then performed where the researcher "chunks" the information and examined the transcripts for major themes that emerged (Creswell, 2003). Then, the primary researcher advanced the central themes generated into descriptions in order to generate a qualitative narrative. These narratives took the form of chronological events or themes that emerged during the course of the interview. Finally, after the narrative was established, the researcher made an interpretation from the major themes generated in the transcripts.

Credibility

Credibility is a term used to assure that the results obtained are accurate from the perspective of the participants, researcher, and the readers of the study (Creswell & Miller, 2000). Credibility, also described as truthfulness, is similar to concepts such as validity and reliability often sought in quantitative designs. The researcher followed certain steps in order to guarantee that credible information was obtained and analyzed.

1) Each semi-structured interview was audio recorded and transcribed verbatim. The researcher then was able to reflect on each interview in its entirety.

2) The primary interviewer was a graduate student in speech-language pathology as well as a person who stutters. As a result, it was important that the researcher was aware of professional and personal biases before the interviewing process was initiated. To accomplish this task, the primary researcher participated in a 60-minute interview regarding the impact that family relationships had on his life as a person who stutters.

The interview was transcribed and analyzed for major themes. The primary researcher conducted this analysis, which made him aware of his potential biases. The primary researcher conducted his own analysis because it was important that he know potential biases to ensure that the analyses of the participants' data were unbiased.

3) A reliability check was also conducted in order to gain multiple perspectives on the transcribed interviews. Two individuals were involved in the analysis of the interviews, the primary researcher and an individual with a background in stuttering and experience with qualitative research. Both these interpretations were compared in order to establish consistency when analyzing the transcripts.

4) Finally, credibility was ascertained by a process known as member-checking (Creswell, 2003). Member-checking has been used in stuttering research as a method to verify results with the participant (Plexico et al., 2005). In addition, member-checking is documented in the literature as being an effective strategy to authenticate findings with the participants involved in qualitative research studies (Corcoran & Stewart, 1998). The primary investigator met with five of the participants following analysis of the data and discussed the findings. The perceptions that the participants had of the themes were added into the final interpretation of the data. Lastly, the primary researcher mailed final copies of the results to each participant and requested feedback.

CHAPTER V: RESULTS

A number of themes were identified using well-accepted qualitative research techniques (Creswell, 2003). Each theme was created through a series of steps. First, the interviews from the 7 participants were transcribed, and the examiner derived themes from each interview. Then, the examiner re-met with 5 of the 7 participants to ask the participant for their opinions on the themes (member checking). Based on the original thematic analysis and the input of the participants themselves, a number of themes arose from the data. The themes described below are themes that occurred in a majority of the participants, and themes that the participants verified during the member checking process.

Based on the thematic analysis described above, there were two groups of themes that arose from the data. The first group was related to support and desires and included 3 themes. Specifically, participants described their perception of receiving support from their families (Support Received). In addition, they discussed their desire for receiving deeper, more meaningful support (Support Desired). Along with these two themes, participants discussed their desire for positive stuttering role models (Role Models).

A second group included themes related to pressures and barriers. This group consists of 6 themes. Participants felt pressure to be fluent with their families (Pressure for fluent speech), along with general pressure in their families (Pressure unrelated to stuttering). Barriers to receiving meaningful, deep support for these participants included lack of communication (Lack of Communication regarding stuttering and Lack of Communication regarding speech therapy), and misguided information/help (Misguided help from speech-language pathologists and Misguided Help from family members).

Themes Related to Support and Desires

Support Received

All participants reported receiving a type of "surface support" from their family. This type of support typically did not address emotions or feelings that were specifically related to stuttering. Some examples of the types of support included in this theme are school-related support for things like extracurricular activities, along with support for traveling to stuttering therapy and paying for stuttering therapy.

Six of the seven participants indicated that their family supported them in areas of their lives not related to stuttering such as school and extracurricular activities. For example, participant P2 spoke about the surface support he received, "My parents always provided for me. They were always there for school functions and everything. They supported me all throughout school and all throughout my life."

In addition to support for functions such as school, all seven participants indicated that family members provided financial support for speech therapy. P1 discussed his mother's involvement in speech therapy, "I mean my Mom was a little pro-active with stuttering and like she got information about it." He went on to discuss his family's involvement in providing financial support with his speech therapy, "They were always real supportive and pretty much do anything that I needed. They even helped me pay for some of my speech therapy."

P6 reinforced how family members played a role in transportation to and from therapy in attempts to help them with their stuttering. In addition to stuttering therapy, this participant reported that his mother brought him to other types of therapy in attempts to help him with his stuttering, "I think mostly my mothers doing is that she sent me to therapy and she didn't know

they didn't know anything. She sent me to a therapist. I went to therapies, I went to psychologists."

Even though the surface support participants received from families typically did not include deep emotional support, participants were grateful for this type of family support. P3 expressed his gratitude for the support he received from his family, "I would say that it was good, my parents always provided for me, they were always there for school functions and everything. They supported me all throughout school." Participants indicated that along with the support they received they also desired deeper levels of support from their families.

Support Desired

Throughout the interviews, participants mentioned "wishes" they had regarding support from their family. Participants had a desire for what the primary researcher has defined as "deep support" (regarding emotions, feelings regarding stuttering, etc.). Even though participants did report receiving a significant amount of surface support from their families, many participants reported wanting a different type of support. This type of support can be characterized by a desire to also discuss emotional aspects of stuttering openly with family members.

Four participants expressed a sincere desire to discuss stuttering openly with their families. P2 indicated that he wanted to feel comfortable discussing the topic of stuttering with the rest of his family in addition to his feelings of frustration,
 "I wished that it was comfortable to just talk to them about stuttering, about what I was feeling about frustration, about stuttering."

P1 reinforced this desire for deeper support in the home. He discussed his wishes that his parents would have communicated openly about stuttering. In particular, he wanted his family to

understand how to listen to him, and he wanted them to look past the stuttering and listen to the

content of his message.

> I just I think that would've really helped if they would've known how to listen to me and
> you know maybe would've told me you know we know that you stutter but we don't care
> you can stutter as much as you want but we just care about what you have to tell us.

Participants desired for family members to understand their needs and approach them

regarding the topic of stuttering. Finally, participants felt it was important for family members to

learn how to listen to them, and to discuss the feelings that were associated with stuttering.

Role Models

As part of wishes for deeper support, some participants discussed a desire for a role

model. Specifically, participants wished they would have come in contact with more individuals

who stuttered, in particular a role model who also stuttered and who understood their everyday

experiences as PWS. Five participants indicated that they had a lack of exposure to PWS.   In

addition, these participants indicated that they desired to know someone who understood the

problems of stuttering. Similarly, several participants had not encountered PWS in professions

involving an emphasis on communication.

P6 commented on the importance of how PWS need someone to guide them through life

decisions. He said, "I think rather than just stuttering therapy, stutterers would be much better

off with like a life counselor, somebody who knew the problem of stutterers."

P4 commented on not being exposed to other people who stutter. More specifically, this

participant felt the need to see more PWS in positions where their stuttering was visible for all to

see, as in jobs that place an emphasis on oral communication, "I hadn't been familiar and hadn't been in contact with people who stuttered who were teachers or doctors or any of those professions that put an emphasis on speaking and communication."

P3 also emphasized the idea of not having someone to guide him through the "ups and downs" of his stuttering. He noted how difficult it was for him as a child growing up with no exposure to a role model who stutters, let alone anyone else who stutters.

> So, I think if I had a model, like a role model, an example to follow in the footsteps of, it would've made it very easy. It's like driving down the freeway with no signs, you're kind of wandering aimlessly, there's no one to guide you, you're just figuring things out on your own, which is hard to do as a child.

Overall, participants had a desire to be around other PWS. More specifically, participants shared a desire to have stuttering role models. These role models could have helped participants receive deeper support, especially if these role models were holding communication-related jobs.

<div align="center">Themes Related to Pressures and Barriers</div>

<div align="center">*Pressure to be Fluent with Family Members*</div>

Participants reported pressure that was related to speaking fluently. This type of pressure was concerned solely with their ability to speak fluently around their selected family members. Four participants felt as if they could not stutter around certain family members. In some cases, attending speech therapy seemed to contribute to this pressure.

Participant P2 described constant pressure to not stutter around his family, because family members would correct his speech, "I didn't talk to them as much. I always felt under pressure. I always felt as if I could not stutter."   In addition, two participants reported perceived

pressure for fluent speech around a certain family member due to either that family member's

role in speech therapy or for a desire to satisfy a family member. P4 reported feelings of

expectations for fluent speech when he was in the presence of his mother.

> I felt like I couldn't just come out and talk and stutter simply because she (mother) was always the one whom I felt that I had to be in control of my speech around simply because she was taking me to speech therapy.

P1 reinforced this desire to satisfy a family member. He felt the need to be fluent when he was

around his father, "I always wanted to please my Dad and so I felt like if I stuttered around him

that I wasn't pleasing him."

Pressure within Family in General

Participants reported feelings of pressure that were related to expectations within their

family unrelated to fluent speech. This type of pressure involved the roles and expectations for

responsibility that participants felt the need to meet in their respective families.

The majority of participants (with the exception of P6) were the oldest or youngest in

their family and commented on this fact during the interviews. For example, P1 stated, "So, I

was the oldest child and I felt for some reason responsible to keep the place up and so felt this

need of responsibility for whatever reason." In addition, P7 also discussed the feelings of

pressure, "I kind of had that added pressure just kind of my whole life to be the leader and be

responsible and to help the younger kids and those kind of things." Along with feelings of

responsibility and leadership, the expectation to fit a certain role within the family emerged. P3

noted that he felt that his stuttering took away from the image of being a strong figure within his

family, "So, because I stuttered and because I was very sensitive I felt like that took away from the image that I was expected to uphold in my family growing up."

Participants felt pressure within their families to fit certain roles or expectations. These responsibilities and expectations that participants reported within their families were significant enough to comment on during the interviews. In some cases (P3) stuttering took away from that role or image that participants felt they needed to occupy in their family.

Lack of Communication in Families – Regarding Stuttering

Many participants discussed the fact that there was a lack of communication regarding their stuttering. Participants felt that stuttering was not an open topic that could be discussed in their homes. In addition, participants stated that feelings or emotions they felt associated with stuttering were not discussed.

Four participants reported that family members chose not to acknowledge that stuttering behavior was happening or decided to not make stuttering a topic of discussion in the home environment. P4 described how he did not even discuss stuttering with his brother who also stuttered, "I don't think I talked to my parents or my brother about my stuttering. I think it's always been this 'hush, hush' kind of issue and I just put up the front that everything's fantastic." Another participant (P2) indicated that everyone knew about his stuttering, but no one ever discussed it with him.

"It felt like one of those things that everybody knows about, but you just don't talk about. What's the psychological metaphor, the purple dinosaur in the middle of the living room, everybody sees it but no one talks about it."

P6 had a similar experience, including an avoidance of the actual word "stuttering".

>They didn't talk about it much. When I was older and having a little bit of trouble, my mother did mention it you know once, was it about your stuttering? Is it about your stuttering? I don't remember my Dad ever mentioning it, other than, 'let's go to therapy, we're going to take you downtown.' I don't ever remember him even saying the word stuttering.

The lack of communication related to stuttering was evident in the household of four participants. If the family members were aware of the struggles the participants were going through, they did not directly comment on it with the participants.

Lack of Communication in Families – Regarding Speech Therapy

Participants and their families rarely discussed what was happening in speech therapy. When speech therapy was discussed it was with occasional friends and selected family members. In addition, family members may have been only aware of the surface level of participants' speech therapy (homework assignments, descriptions of fluency principles)

Six participants reported that speech therapy was seldom discussed within their families. P3 commented on his dialogue with his family regarding his speech therapy.

>I never discussed what was happening in therapy with my parents. I discussed it with friends that I had in school. But, as far as my family we didn't. It was just not something we discussed or talked about, it was just an unspoken topic.

Participant P5 discussed a lack of communication with her father, regarding her stuttering therapy. She stated, "I'm sure that my Dad knew that I was going to therapy because I'm sure that my Mom had told him but we had never talked about it face to face at all." P7 also reported a similar experience, "My Mom would every once and awhile ask me how's therapy going or

whatever, and I'd be like 'oh it's good' and it would kind of be this brushed off thing. But, we really didn't discuss it."

Participants indicated that family members were aware of their attendance in speech therapy and knew a small portion of what happened in therapy, but any further communication seemed to be absent. Also, for some participants a certain family member took the role of knowing more about therapy than other family members.

Misguided Information – from Speech-Language Pathologists

Participants reported that the information and help that speech-language pathologists (SLPs) provided to them was sometimes not helpful, and seemed inappropriate in helping them cope and manage their stuttering.

Four participants were exposed to therapy approaches that they felt were not beneficial to them in their long term recovery. P7 described her experience with one of her speech therapy approaches, "They told me if I felt comfortable twirling my hair that I could twirl my hair if I was feeling uncomfortable and obviously those are secondary characteristics that you don't want to develop." P6 also commented on a speech therapy, describing what was done in an attempt to correct his breathing.

> As I talked she punched me, I mean she didn't punch me like that, she put her fist in my stomach, I remember this really clearly, now that I think about it I was either 8 or 9 and as I, every time I would block, she would punch me a little and her conclusion was that I wasn't breathing or something and she was going to push out the air.

Participants were exposed to SLPs who were misinformed regarding stuttering therapy. The participants felt that the therapy approaches that these SLPs utilized were not beneficial in

assisting them with their stuttering. Although the SLPs may have been well-intentioned in their therapy, participants reported that their therapy was not always effective.

<center>*Misguided Help – from Family Members*</center>

In an attempt to help the participants, family members provided assistance that was not beneficial to positive stuttering management. This type of help was sometimes due to advice families received from SLPs, but in some cases it was self generated. Participants reported that in some cases the help they received from family members made their stuttering and their feelings associated with stuttering worse.

Four participants indicated that family members "didn't know any better" and that the help they were giving them was well intentioned, but, in the end, proved to be ineffective. P2 stated,

> I don't blame them because that's what they were taught but they definitely hindered it by not being comfortable enough to talk about it on both sides of the coin and like telling me to stop and stuff and slow down. It definitely made my emotions a lot worse but then again I don't blame them.

P5 indicated her frustration when her mother would attempt to help her with her speech, "If I was in a hard stuttering moment, she would go, 'say it again, take your time, slow down' and so that would frustrate me so much and it would just end up in this whole screaming fit."
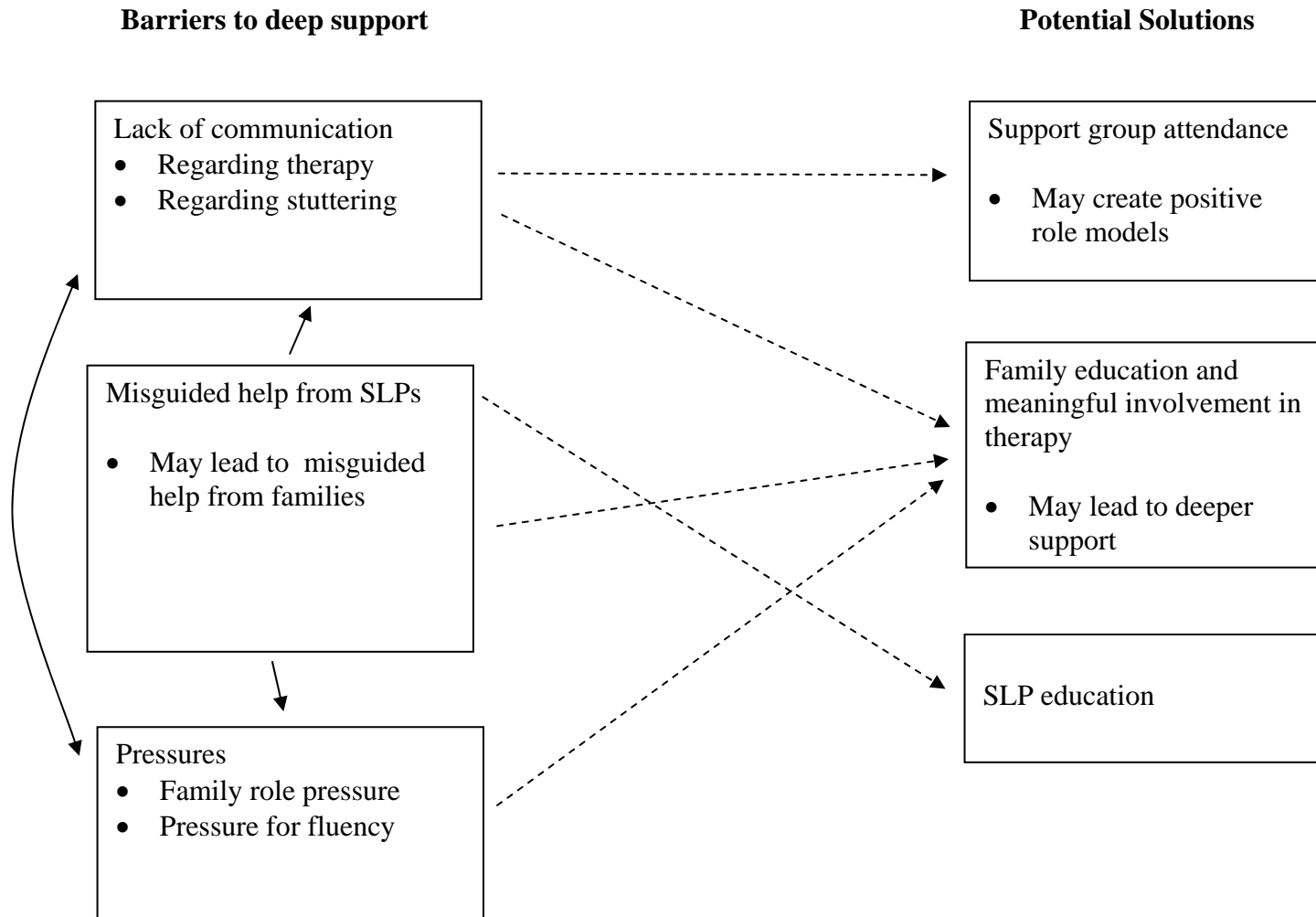
In an attempt to alleviate the difficulties that stuttering can present, family members attempted to provide help that was either taught to them or was self-generated. Participants reported that the help they received from their family was with good intentions. However, the

assistance participants were exposed to did not help them manage their stuttering in a positive

manner.

CHAPTER VI: DISCUSSION

The intent of this study was to explore the impact of family relationships on people who

stutter. In addition, this study intended to investigate how stuttering and family relationships

affect one another. Some of the themes identified in this study matched previous themes found

for individuals who stutter and their families. However, a number of themes were unique to this

study. Figure 1 shows the themes from the current study. Some of the themes within this figure

represent barriers to support that were experienced by the participants. In addition to this,

potential solutions to these barriers are presented in the figure and discussed below. Along with

Figure 1 there will be a discussion of the themes, including similarities and differences compared

to previous literature. There will also be a discussion of some participant opinions that did not

end up becoming themes, along with a discussion of how this current data can lead to

improvements in future research.

Figure 1: Participant experiences with barriers to deep support along with potential solutions.

Barriers to deep support   **Potential Solutions**

Lack of communication
- Regarding therapy
- Regarding stuttering

Support group attendance

- May create positive role models

Misguided help from SLPs

- May lead to misguided help from families

Family education and meaningful involvement in therapy

- May lead to deeper support

Pressures
- Family role pressure
- Pressure for fluency

SLP education

Support and Desire for Role Models

A majority of participants indicated that they received support from their families, and that this "surface support" was not related to their feelings or emotions regarding their stuttering. In addition to the support the participants received, a majority of participants had wished for deeper, more emotional support from their families. As part of this desire for deeper support a number of participants shared a desire to have a positive role model who stuttered.

In previous stuttering literature, support has been acknowledged as a critical component in helping people manage their stuttering. Yaruss and Quesal (2004) stated that the environment plays a critical role in how PWS are able to cope effectively with their stuttering. The researchers emphasized the importance of support networks in this process of effective coping. However, the term support as used in the Yaruss and Quesal (2004) study is generalized and does not necessarily take into consideration different levels that support can take. Bertera (2005) stated that social support is multidimensional, and that family support can help to decrease anxiety of individuals with anxiety and mood disorders. The current study also found that support was multidimensional, finding that there was a difference between the levels of support received and the levels of support desired.

In contrast to the current findings, some researchers have suggested that PWS did establish supportive relationships in their home environment. Crichton-Smith (2002) investigated strategies individuals used in order to manage their stuttering. Results indicated that participants felt more comfortable stuttering openly when at home or with friends as opposed to stuttering at their place of employment. This is in contradiction with some of the current data. Four participants in the current study stated that they did not feel comfortable stuttering at home due to a feeling of pressure to be fluent. Crichton-Smith (2002) suggested the participants in their

particular study may have felt comfortable due to supportive relationships that were established in the home environment and with friends. This also somewhat contradicts the current data, as the participants in the current study reported receiving some support at home, but desiring more. Upon closer examination of both studies there may be some methodological differences that would explain the disparity of findings. Crichton-Smith (2002) reported that the mean age for the participants was 56 years old (the current study age mean was 32). In addition, Crichton-Smith's participants were asked to discuss their current experience with stuttering and were not asked to reflect on their experiences growing up. As a result, the home environment their participants were describing may have been very different than what the participants in the current study were depicting.

As mentioned previously, a majority of participants in the current study reported a desire for deeper support related to emotional coping with their stuttering. However, some participants did receive some positive, meaningful deep support. For example, P1 described the desire for deeper support overall, reporting that he wished his family knew how to listen to him. However, this participant also described receiving some meaningful support from one family member. He stated, "I think my younger brother helped me the most because he stuttered too, so we're kind of going through similar things." P1 went on to report that he would confide in his younger brother regarding his feelings and emotions related to his stuttering.

Participant P1 talked about receiving meaningful support from his brother (who also was a person who stuttered), but other participants had different experiences. Upon closer examination of the transcripts, two participants reported that stuttering was not discussed in depth with their siblings who also stuttered. This variability of opinions is notable, given the relatively small sample size of the current study. A majority of participants felt they wanted

more support, while at least one participant reportedly received meaningful support from a sibling.

One possible way to fulfill the participants' desire for role models who stutter is through attendance at support groups. Previous literature has made reference to the importance of support groups for people who stutter. Ramig (1993) found that self-help meetings improved the feelings that PWS had regarding their speech. In addition, Ramig advocated strongly for the inclusion of support groups for PWS. Along with self-help groups, Manning (2001) provides information regarding group therapy for PWS and the benefits it can have on their feelings and speech.

The Effect of Supportive Relationships on Stuttering

Previous research indicates the importance of supportive relationships in helping people cope with stuttering. Corcoran and Stewart (1995) explored the therapeutic experiences of people who stutter. The researchers discovered that participants described a supportive relationship as one in which there was shared knowledge with other PWS. In addition, participants reported that there feelings of isolation decreased when they came in contact with other PWS.

These findings by Corcoran and Stewart (1995) are consistent with the current study as they support participants' desire to be affiliated with other PWS. It is an important point however that the current participants made reference to a desire for a role model who understood stuttering. No previous research has examined the effects of role models for PWS. The current findings regarding support have several implications for researchers, clinicians, PWS, and the families of PWS.

It is recommended that future research investigate support for PWS as a multidimensional system, taking into consideration the different components of surface support and deep support. Since the current study is unique in reporting on multiple levels of support for individuals who stutter, future research should verify these findings on a larger sample size. Also, the concept of role models for PWS should be further explored. The implications of these findings for people who stutter and for SLPs are similar. The current study reinforces the clinical importance for PWS to attend support groups. This may provide the positive role models needed for individuals who stutter, and help individuals feel that they are being supported.

Pressures in the Home

Participants reported feelings of pressure associated with the need to fit a certain role within their family. This pressure within their family may or may not have contributed to the pressure some participants perceived for fluent speech when in the presence of family members.

Sheehan (1970, 1975) wrote about children who stutter and indicated that a child who has begun to stutter probably has too many demands placed upon them with too little support. Starkweather (1987) reinforced this line of thought by introducing the capacities and demand theory of stuttering, stating that if the demands in a child's internal and external environment exceed their capacity for fluent speech, then stuttering will occur. These findings are consistent with pressure within families and for fluent speech the current participants reported. The argument could be made that the pressure the participants were experiencing contributed to their stuttering.

During the analysis of the transcripts, it was noted that six of seven participants were either the oldest or youngest in their family. Guitar (2006) indicates that other family members,

such as siblings, are factors in an individual's social and emotional development. The family position that participants occupied may have impacted their stuttering. The observations of the current participants' family position are consistent with earlier research that has examined family structure as it relates to stuttering. Rotter (1939) surveyed 522 people who stuttered and discovered that fewer middle children stuttered when compared to older and younger siblings (Rotter, 1939). Similar results were found by Johnson (1959) when he revealed statistically significant results that stuttering was more predominant in "oldest" and "only" children.

However, some researchers have found no relationship between family position and stuttering. Andrews and Harris (1964) concluded that being the oldest or only child was not related to stuttering. A possible reason for this difference might be that Andrews and Harris surveyed individuals in English households where although the family environment is similar to that of the United States, the differential tradition of the home environment may have been a factor. In addition, the difference in results may have been a result of a generational difference where stuttering was viewed differently during the time of their study compared to the current study.

In the current study, 3 of the participants were the oldest child in their family (P6 oldest male in his family), and 3 other participants were the youngest. Previous research has addressed the issue of the oldest or only child within families (Rotter, 1939; Johnson, 1959), but no research has extensively investigated the issue of the youngest member of a family stuttering.

The findings of this study present several ramifications. Participants experienced pressure to be responsible and to fit a role within their family, along with pressure to be fluent. These two types of pressure may have indirectly affected one another and contributed to the participants' stuttering. Future research should take into consideration the different forms

pressure can take within families of PWS. In addition, it is recommended that clinicians take into consideration both kind of pressure within families and address these issues when appropriate in therapy. Moreover, families of people who stutter need to understand that people who stutter may feel the need to fit certain roles within a family and in the quest to achieve those roles their stuttering may become exacerbated. Families need to be sensitive to these issues when attempting to understand the impact that stuttering is having on their family member who stutters.

Lack of Communication within Families

All seven participants indicated that they did not discuss stuttering extensively with their families. Four participants indicated that it was never discussed in their household. Along with the absent dialogue related to stuttering, there were six participants who indicated that there was little communication regarding speech therapy. Family members would sometimes help with homework; however that was the extent of their involvement in speech therapy.

Communication about Stuttering

Lack of communication has been noted in previous stuttering research. Corcoran and Stewart (1995) indicated that participants in their study reported that their parents were unsure as to how to help them regarding their stuttering. As a result, participants indicated that their parents did not communicate with them concerning their stuttering or how to help them with their speech (Corcoran & Stewart, 1995). These findings indicate that lack of communication in regard to stuttering is real for participants as it relates to their parents. The current study

revealed that participants not only had decreased communication with parents in concern to stuttering, but also with other family members.

Alternatively, some research has indicated that parents *have* discussed stuttering with their children. Johnson et al. (1959) reported that the majority of parents discussed stuttering with their child to a certain degree. However, these discussions only dealt with suggestions that parents were giving their child to assist them to not stutter. In the Johnson et al. (1959) study, parents were not particularly discussing the emotions related to stuttering; rather they were more interested in correcting their child's speech. Lack of communication regarding stuttering and the emotions related to it appear to be very real not only in the current study, but also in previous literature.

Communication about Therapy

Lack of communication within families as it pertains to stuttering therapy is rarely discussed in stuttering research, however, there has been research into the effect of including families in stuttering therapy. Mallard (1998) indicated that including family members into the therapy process is an effective way to improve an individual's fluency. However, it appears participants in the current study were reluctant to discuss what was being done in speech therapy with their family. In addition to Mallard (1998), the Lidcombe Program is a classic example of illustrating how parents are directly involved in their child's stuttering therapy (Onslow & Packman, 1999). The Lidcombe Program deals with only correcting stuttered speech and does not address the feelings the child may be having related to having their parents as an integral role in their therapy. Despite this, Woods, Shearsby, Onslow, and Bumham, (2002) investigated the psychological impact the Lidcombe Program can potentially have on the children involved. The

researchers utilized the Child Behavior Checklist (CBCL) with 8 preschool children. The CBCL

was intended to measure post-treatment behavioral changes within the children such as

depression, aggression, and withdrawal. Results revealed that children did not report any

depression, aggression, and withdrawal. In addition, it was noted that children did not report any

changes in the quality of their relationship with their mother (Woods et al., 2002).

The findings of Woods et al. (2002) indicate there were no negative psychological effects

as a result of including family members in stuttering speech therapy. However, these researchers

utilized a behavior checklist which may have limited the scope of the results. A more extensive

investigation may have yielded alternative emotions that the child was feeling.

Based on previous literature, it appears that involving family members in the therapy

process for PWS is beneficial. However, in the current study participants reported not discussing

speech therapy in detail with their families. It was unclear why participants and family members

did not discuss speech therapy. It is possible that this topic was not discussed within the family

because the family was not included in the actual provision of therapy.

Two of the participants had interesting comments regarding their speech therapy. It

appears as for a small portion of participants (P6, P7) there was a sense of independence and

autonomy involved in going to therapy by themselves. P7 discussed positive feelings related to

attending therapy independently at a different location as opposed to the speech therapy she

received in school.

> That was a lot better experience just emotionally for me because my Mom would drop
> me off at the front of the hospital and let me walk up all the way up to the three floors to
> the elevator and up by myself, and I kind of felt cool even going into the hospital.

In addition, P6 also felt a sense of independence by attending speech therapy on his own. He goes on to describe how his mother discovered how he got himself to therapy, "I used to go up and hitchhike there and one time she saw, she saw me hitchhike to the therapist… maybe I was trying to be independent I don't even think I was asking her for a ride." It is possible that participants may have not wanted to discuss speech therapy with their parents because they felt a need to be independent in helping themselves in relation to their stuttering.

Researchers need to investigate the lack of communication in families as it pertains to speech therapy and emotions related to stuttering. Also, the findings of the above themes have clinical implications for the SLPs. Clinicians should be aware that lack of communication concerning stuttering is present in families. In addition, discussing speech therapy with families may not be enough. Clinicians need to encourage family members to discuss other feelings associated with stuttering, as these feelings might be related to how PWS view and feel about their speech therapy. Finally, families need to sensitive to feelings associated with attending speech therapy and be open to discussing all levels of stuttering with their children.

Misguided Information/Help – from Speech-Language Pathologists and Families

It has been noted throughout the history of stuttering therapy that individuals have been exposed to what is now known as unhelpful therapy (Bennett, 2005; Guitar, 2006). Four participants in the present study were exposed to therapy approaches that did not address their needs to cope with their stuttering in an effective manner. Participants also reported frustration when these techniques failed to help their stuttering.

Previous literature has made reference to stereotypes that clinicians hold regarding PWS and appropriate treatment. Cooper and Cooper (1996) surveyed a large sample of clinicians and

results indicated that these professionals continued to hold negative stereotypical beliefs in

relation to the parents of PWS, personality of people who stutter, and the usefulness of early

treatment for CWS. While the researchers noted that stereotypical views by SLPs towards

people who stutter have improved over time, clinicians continue to hold false beliefs regarding

the treatment and general characteristics of PWS (Cooper & Copper, 1996).

It is evident that some of the current participants were exposed to clinicians who held

negative stereotypes regarding stuttering as noted in Cooper and Cooper (1996). This led to

frustration among the current participants. This frustration was best illustrated in the comments

P6 reported regarding his speech therapy,

> I'm really down on the speech therapy in general. I think they made money off of a lot of
> stutterers, they always, like I told you, they always told me that it was up to me. I think
> they should have told you at the beginning, listen we don't know anything about this. I
> mean we can try and try, but we haven't had a lot of success. We haven't even measured
> our success, so we don't know if we've had any success.

In addition to the misguided information speech therapists were giving the participants, it

was also reported that misguided assistance was given by family members. Very little research

has explored the area of assistance that family members have provided to people who stutter. In

their study of 150 CWS, Johnson et al. (1959) indicated that the most common suggestions

parents made to their children were to slow down, stop and start over again, or to take it easy.

These suggestions that Johnson (1959) reported were consistent with the advice that participants

were given from their family in the current study. In general, there is lack of research

concerning the topic of help that family members provide people who stutter.

The majority of the current participants indicated that they received misguided assistance

from their family regarding their stuttering. However, P7 had a slightly different experience

regarding the help she received from her family. She reported that her mother and father were supportive in their own ways in helping her cope with her stuttering,

> I would come home from school and sing to her, sing whatever it was that I needed to express to her because otherwise I couldn't get it out so and she would sing to me too … it was just our little coping skill that we made up because you know when you sing you don't stutter, so she was supportive in her own way, and then I think my dad was there when I got emotional.

Clinicians need to be aware that misguided assistance can occur in the home environment that may hinder people who stutters' ability to cope with their stuttering effectively. Also, more research is needed to investigate the guidance and assistance that family members provide people who stutter. Finally, the information in this study can provide families with valuable information regarding what type of assistance to provide their family member who stutters.

Impact of Stuttering on Family Relationships

Participants were diverse in their response to the question "How did stuttering affect family relationships?" As a result of this diversity, no themes arose. However, individual participant data and opinions are relevant.

A wide range of experiences were reported by participants in respect to family relationships and stuttering. All participants indicated that growing up with stuttering was a difficult experience to deal with. However, stuttering appeared to have both positive and negative affects on family relationships. Some participants reported that stuttering made it difficult to establish solid family relationships. For example, P4 spoke regarding his relationships with his family,

> I think that it sort of was a dividing point simply because of how I handled myself and at the same time the severity of my speech caused me to distance myself and not talk about anything too personal or too emotional or too important.

It was difficult for some participants to converse with certain family members because of their stuttering. P3 discussed how stuttering impacted not only his relationship with his father, but also with certain males within his family due to his feelings of having to live up to a certain image.

> So, I didn't really bond a whole lot with them just because I didn't feel like I lived up to the image that you know that they expected me to live up to. So, I guess as far as how it affected my family relationships the men in my family were very hard to talk to.

P5 described the effect that stuttering had on her relationship with her mother, "I think it's caused a lot of tension between my Mom… it's something that I feel is a part of me that she is never going to understand."

Some participants, however, found that stuttering had an overall positive effect on their family relationships, identifying that it was something that brought them and their family closer together. P7 spoke about her interactions with her family and her stuttering, "Maybe it made us closer because you know they knew that I needed help with some things and it would have to do with stuttering and speech and talking to people."

Overall, P1 also thought his stuttering strengthened his family interactions, even despite feeling like he could not stutter around his father. In addition, he highlighted the understanding his family had regarding what it was like to live with stuttering.

I think if anything it's made them stronger I think. I just have a real supportive family and you know I think they realize that growing up with stuttering and living with stuttering isn't easy and I think they really respect that.

One of the participants (P6) was not clear if stuttering had a negative affect on his relationship with his family, however, he made reference to feelings of frustration towards family members, "I'm not sure if it did have much effect on, although I used to fight with my brothers, I used to tease them all the time, maybe I felt frustrated so I took it out on them." When asked if stuttering had an effect on his relationships with his parents he responded, "I don't think so, my father, like I said wasn't around that much and my mother tried to help in some ways."

The current results indicate that stuttering can have varied effects in respect to family relationships. These current findings are consistent with Klompas and Ross (2004) who investigated the impact that stuttering had on quality of life for their participants. These researchers found that stuttering had both positive and negative effects in respect to family relationships.

With the exception of Klompas and Ross (2004) no previous research has specifically investigated the impact that family relationships and stuttering have had on one another. The current findings contribute valuable information to family relationships as they relate to stuttering by stating that stuttering can have both positive and negative effects. Not only can stuttering have both positive and negative implications to family relationships, but these effects can be seen in the entire family or just focused on selected family members.

Future research should explore further what contributes to a positive relationship with family members as well as the experiences that constitute a negative relationship. By gaining a

deeper understanding of PWS and their family, clinicians would be able to include family members more appropriately into therapy. In addition, clinicians could become aware that the quality of relationships within families may differ from each family member in respect to stuttering. Lastly, this research is valuable to family members of PWS by providing insight into positive and negative relationships with PWS.

Education of Participants

An area that should be considered in interpretation of the current results is the education of some of the participants. Three participants were educated as SLPs. This education and background may have played a role in their perceptions of their experiences with their family. Future research may need to take into consideration the background of participants and attempt to examine a more diverse group of participants.

Gender

An area that should to be mentioned in this current study is related to the gender of the participants. It has been documented in the stuttering literature that male to female ratio of PWS is 3:1 (Guitar, 2006). However, some researcher suggests this ratio increases as CWS get older (Bloodstein, 1995; Kloth, 1999). The ratio of male to female participants (5 males, 2 females) in the current study is consistent with this published ratio. It is possible that males and females in the current study may have been exposed to different interaction styles from their parents.   One participant (P3) mentioned the impact that gender had on him in relation to his stuttering,

You're supposed to be a guy, you're tough… fluent speech is a part of that, and so we (PWS) don't have that then it sort of makes you look like you're weak and it makes you look like you're not strong enough…I just didn't always feel like I was man enough.

Hutson (1983) reported that fathers act differently towards their sons compared to their daughters. As a result, the behavior may contribute to a distinction between genders. Also, Baumrind (1989) stated that parents typically allow males more freedom than females. In addition, males and females occupy different roles growing up, such as females being assigned baby-sitting responsibilities. The differences in the way the participants were raised according to their gender may have had an impact on the pressures that were reported.

Gender may also have been a factor in how participants perceived support from their family. In an examination of anxiety and mood disorders, Bertera (2005) indicated that female participants reported more positive social support than male participants. The participants in the present study may have received different types of support for their stuttering based upon their gender. Future research should examine the effect of gender on social support for PWS.

CHAPTER VII: CONCLUSION

Based upon the results of the current study, it is evident that there are many factors that contribute to the support that people who stutter receive from their families and SLPs. There are barriers that prevent people who stutter from accessing the support in which they desire. In order to alleviate these barriers possible solutions are suggested.

Barriers: Misguided information provided by SLPs was one barrier discussed by participants. This misguided information can and sometimes does give rise to misguided help from family members. This misguided information / help together may contribute lack of communication regarding stuttering and speech therapy, along with increased pressure for the PWS. In addition to all of these connections, lack of communication and pressures also may influence each other. Since stuttering was often not discussed in the home, it is unknown whether family members shared the expectation of fluency reported by the participants.

Solutions: A number of potential solutions / recommendations are presented based on examination of literature related to each theme. In order to break the silence of the lack of communication regarding stuttering and speech therapy, families of PWS could encourage attendance at support groups. This attendance at support groups would meet the desire that participants expressed to be affiliated with other people who stutter, in addition to the possibility of a creation of a positive stuttering role model. Also, lack of communication and pressure that people who stutter experience in their families could be lessened by family education and their meaningful involvement in stuttering therapy. This education and meaningful participation may lead participants to the deeper support they desired. Finally, misguided information that SLPs are providing to people who stutter and their families would be lessened with the inclusion of educational programs in regard to the treatment of PWS.

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Appendix A

Script for the Interviews

Before we begin, I just wanted to let you know that I am a person who stutters, as well as a Masters student completing a thesis at BGSU. Because of my academic and personal experiences, I am interested in investigating the importance of family relationships and stuttering.

1. To begin with, I would like to know about your family, can you please describe your family? (Research questions 1 & 2)

       a) How were these relationships with your family growing up?
       b) How are these relationships now?

2. Now, I would like to ask you about your stuttering. Can you tell me more about your stuttering? (Research question 3)
       a) How severe?
       b) How has it changed over time?
       c) What was it like as a child, adolescent, and an adult?

3. Now, can you tell me more about how stuttering has impacted your life? (Research question 1 & 2)

       a) As a child
       b) As an adolescent
       c) As an adult
       d) Positive vs. negatives.

4. Describe for me how you would cope with your stuttering?

       a) Can you tell me about your speech therapy?
       b) Have any of your important life choices been altered by stuttering?

5. Describe for me what role your family played in your ability to cope with your stuttering. (Research questions 1 & 2)

       a) What about your Father?
       b) Mother
       c) Siblings
       d) Were there any other family or other important supportive relationships that helped you?

6. Now, I want to discuss your family's involvement in speech therapy. Tell me about any involvement your family had in your therapy. (Research question 3 & 4)

7. Please describe for me how stuttering affected your family relationships, if any? (Research questions 1 &2)

Appendix B

Demographic Questionnaire

1. Age:_____

2. Gender: Male   Female

3. Employment: _____

4. Highest education completed: _____

5. Ethnic background:_____

6. How would you describe your stuttering severity?

   As a child: Mild   Moderate   Severe

   Adolescent: Mild   Moderate   Severe

   Adult: Mild   Moderate   Severe

   Currently: Mild   Moderate   Severe

7. How has your stuttering changed over time?_____

   _____

8. Do you have a family history of stuttering? If so, who?

   _____

   _____

9. Describe your therapy? (Amount of therapy, types of therapy and duration of therapy)

   _____

   _____

10. Did therapy change your stuttering? (Better, worse, etc.)

   _____

   _____