

■ Family Experiences of People who Stutter

■ Expériences familiales de personnes qui bégaiant

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Abstract

This study utilized a qualitative approach to explore the family experiences of seven adults who stutter. These family experiences were examined with respect to family interactions and coping with stuttering and speech therapy, along with an investigation of how the family interactions affected speech therapy and the ability of participants to manage their stuttering. The thematic analysis of semi-structured interviews revealed three major themes. The first major theme was the support participants desired from their families, which included a desire for role models as well as additional emotional support. The second major theme was support received by participants. In general, few participants perceived helpful support from their families regarding their stuttering. The third major theme was the perceived barriers to the support desired by participants, which included the pressure to be fluent, a lack of communication regarding stuttering and speech, and the good but often misguided intentions of family members. Suggestions for the continued study of family experiences of people who stutter are made.

Abrégé

Cette étude a utilisé une approche qualitative pour analyser les expériences familiales de sept adultes qui bégaiant. Dans cette étude, nous avons observé : les interactions de la famille, comment fait-elle face au bégaiement et comment participe-t-elle aux traitements d'orthophonie. Une recherche sur la façon dont les interactions de la famille ont influencé les traitements d'orthophonie et la capacité des participants à gérer leur bégaiement a aussi été effectuée. L'analyse thématique des entrevues semi-structurées a révélé trois thèmes principaux. Le premier grand thème est l'appui que les participants souhaitent recevoir de leur famille, incluant un désir d'avoir des modèles ainsi que davantage de soutien affectif. Le deuxième grand thème est l'appui reçu par les participants. En général, peu de participants avaient l'impression que l'appui de leur famille en ce qui concerne leur bégaiement était utile. Le troisième grand thème est les obstacles perçus à l'appui désiré par les participants, dont la pression d'être fluent, un manque de communication concernant le bégaiement et la parole ainsi que les intentions de la famille, certes bonnes, mais souvent peu judicieuses. Des suggestions pour l'étude des expériences familiales de personnes qui bégaiant sont formulées.

Key words: qualitative, stuttering, therapy, and family.

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There is general agreement that stuttering is more than a disorder of speech fluency, as it also involves emotions, associated movements and beliefs (Johnson et al., 1959; Van Riper, 1982). Recently, Yaruss and Quesal (2004) demonstrated how the World Health Organization's international classification of functioning, disability, and health (ICF) model could be applied to describe the impact of stuttering. The ICF model demonstrates how environmental factors, such as support and relationships, can have a significant impact on the quality of life for people who stutter (PWS). Oftentimes, PWS have difficulties with social interaction and establishing relationships (Daniels & Gabel, 2004; Van Riper, 1982). This difficulty with establishing social relationships is problematic because supportive relationships with others, especially family, can be critical to the successful management of stuttering. In particular, the lack of support from others, including family, can lead to negative social, educational and economic barriers for PWS (Yaruss & Quesal, 2004).

Yairi (1997) summarized and reviewed the classic research related to the home environment of children who stutter (CWS). He argues that the home environment of CWS was critical to their successful development and recovery from stuttering. Additionally, the home environment may contain potential difficulties for CWS. These difficulties may include problematic speaking behaviors and conversational styles that are modeled by parents (Kelly, 1995; Savelkoul, Zebrowski, Feldstein, & Cole-Harding, 2007; Weiss, 2002; Yaruss & Conture, 1995) and parents' negative beliefs and reactions toward stuttering (Crowe & Cooper, 1977). These studies indicate that changing the family's reaction to stuttering and teaching communication behaviors that can facilitate fluency are important in stuttering therapy.

Due to the critical need for family support, many clinicians and researchers advocate for the inclusion of parents in therapy (Guitar, 2006; Mallard, 1998; Onslow & Packman, 1999). A well-accepted example of involving parents in the therapy process is the Lidcombe program (Guitar, 2006; Onslow & Packman, 1999). In this program, parents administer therapy, collect speech samples, and meet weekly with speech-language pathologists (S-LPs) for consultation regarding their child's speech. Mallard (1998) described a therapy program in which S-LPs assist parents in helping their children manage their stuttering by teaching families techniques to deal with communication breakdowns, limit environmental pressures, and increase fluency. At the end of the therapy program, each family develops a set of strategies for helping their child manage his or her stuttering. Similarly, Gottwald and Starkweather (1995) provide a framework for constructing early intervention programs for CWS, their families and teachers. The program focuses on reducing environmental demands or stressors that are placed on the child. Millard, Nicholas and Cook (2008) discussed parent-child interaction therapy with CWS. This indirect therapy approach is flexible and the purpose is to assist parents in developing strategies

to assist their child in achieving fluency. In addition, parents are asked to discuss stuttering with their child and acknowledge when stuttering is occurring.

Overall, outcome data suggests that parental and family involvement in stuttering therapy is beneficial. In particular, the Lidcombe program has proven to be successful in eliminating stuttering behaviors (Jones et al., 2005; Onslow, 2003). While the role of parents in the Lidcombe program can be viewed as beneficial, it is not known whether parental involvement is the sole factor in determining its success (Bernstein Ratner & Guitar, 2006). Mallard (1998) showed that 82% of families participating in a stuttering management program did not require further stuttering therapy. Other therapy programs have reported success with incorporating strategies focusing on parental reactions and acknowledgment of stuttering (Yaruss, Coleman, & Hammer, 2006; Millard, Nicholas, & Cook, 2008).

Incorporating parents and families into stuttering therapy appears beneficial, but little is known about how PWS perceive, and are affected by, their families' reactions to stuttering. Little research has addressed the experiences of PWS with their families related to stuttering therapy. Understanding the family experiences of PWS in addition to their perceptions of childhood speech therapy will provide important information related to the impact of stuttering within a family.

Qualitative Research and Stuttering

In recent years, qualitative methodologies have been utilized to explore the life experiences of PWS (Anderson & Felsenfeld, 2003; Corcoran & Stewart, 1995, 1998; Crichton-Smith, 2002; Klompas & Ross, 2004; Plexico, Manning, & DiLollo, 2005; Plexico, Manning, & Levitt, 2009a, 2009b). Stuttering is a multidimensional problem (Smith, 1999; Smith & Kelly, 1997) and one in which knowledge of the personal experiences of those who stutter can contribute to better treatment and understanding of the problem (Quesal, 1989). Thus, qualitative methodologies can help researchers gain a better understanding of experiences related to stuttering and the issues that affect PWS (Tetnowski & Damico, 2001).

To date, qualitative studies exploring the life experiences of PWS have focused on living with stuttering (Corcoran & Stewart, 1998; Crichton-Smith, 2002; Plexico, Manning, & Levitt, 2009a, 2009b), long-term recovery (Anderson & Felsenfeld; 2003; Plexico et al., 2005), and therapy experiences of adults and adolescents who stutter (Corcoran & Stewart, 1995; Hearne, Packman, Onslow, & Quine, 2008). For example, Klompas and Ross (2004) interviewed 16 adults to learn how stuttering affected their education, employment, social life, speech therapy, family, marital status, identity, beliefs and emotions. For most of the participants, stuttering had a marked impact on all aspects of life. Seven of the 16 participants reported that stuttering affected their relationship with their parents. A lack of understanding, impatience, and completion of sentences

by family members were common themes among the participants. Crichton-Smith (2002) investigated strategies individuals used in order to manage their stuttering. Her results indicated that most of the participants felt more comfortable stuttering at home or with friends as opposed to stuttering at their place of employment. Hearne et al. (2008) explored the therapy experiences of adolescents who stutter. One of the major findings of their study was a perceived lack of awareness of stuttering by parents.

Though researchers and clinicians underline the importance of the family in understanding and providing stuttering therapy for children, little is known about the experiences that PWS have with their families and the impact that the family has on their ability to manage stuttering. The purpose of this study was to explore the family experiences of PWS related to their interactions with their family, experiences with speech therapy, and ability to cope and manage their stuttering during their childhood and adolescent years.

Methods

Participants

Keeping with the standards of qualitative research design, participants were identified using purposeful sampling (Patton, 2002). Individuals who were asked to participate were chosen based on how their experiences would contribute to understanding the phenomenon of interest. Therefore, the population consisted of adults who stutter, as these individuals were able to reflect on their family experiences during their childhood and adolescent years as it related to their stuttering. The seven participants in the study were within the participant range that is recommended as a sample size when conducting qualitative research (Patton, 2002). All participants had received treatment for their stuttering at some point in their life. Participants were recruited from the National Stuttering Association (NSA) support group chapters and speech and hearing clinics in the Midwestern region of the United States. Members of the NSA have been used as participants in many studies of stuttering (e.g., Plexico et al., 2009a,b; Yaruss & Quesal, 2004). Though one might argue that using members of support groups might lead to a biased sample, the current individuals had varied life experiences related to stuttering during their lives. Support group leaders and clinicians were asked to assist in identifying adults who were willing to participate in the study. Once these individuals were identified, the first author contacted each participant to schedule a time and place to conduct the interview. The recruitment procedure continued until no new themes emerged from the participants' stories, a process consistent with qualitative methodologies. Rubin and Rubin (1995) referred to this process as the principle of completeness in which participants are recruited for the study until a "saturation point" has been reached. A description of the participants is provided in Table 1.

Procedures

Because the intent of the current study was to describe the family experiences of PWS as they related to stuttering, a phenomenological approach to qualitative research was chosen. The phenomenological approach, explained by Creswell (2007, p. 57), "describes the meaning for several individuals of their *lived experiences* of a concept or a phenomenon." To record these lived experiences, semi-structured interviews were conducted with each participant. This approach was used to allow participants to answer questions as freely as possible during natural conversation. To guide the interview, seven questions were used (see Appendix A). These questions were adapted from other qualitative studies in stuttering (Corcoran & Stewart, 1995; Klompas & Ross, 2004; Plexico et al., 2005), but were rephrased to meet the specific purpose of this study. The researcher utilized open-ended questions in an attempt to guide the participants in sharing their stories regarding stuttering, experiences with their family, and the interplay between family interactions, stuttering, and speech therapy (Appendix A). Each interview lasted between 60 and 90 minutes. When necessary, planned prompts were applied to responses that the researcher deemed interesting and important for the study (Creswell, 2003).

The interviewer (first author) met each participant at a location that was most comfortable for them. Prior to the interview, participants provided their consent to participate in the study and completed a demographic questionnaire. The questionnaire obtained information regarding participants' age, background, family history, stuttering and therapy experiences. The information obtained from these questionnaires contributed to the qualitative analysis and description of the participants. Each interview began with the first author stating the purpose of the research study. The first author took field notes following each interview in addition to audio recording the interviews. These field notes provided additional observations about the participants' experiences and contributed to the formation of themes.

Analysis

The analysis process of the current study involved three steps:

The first author transcribed the interview verbatim and typed up any field notes that were taken throughout the interview.

Following the transcription of each narrative, the first and fourth authors read each line of the transcript individually and generated a list of significant statements. These lists of statements reflected how participants experienced the phenomenon (Creswell, 2007). For example, "LOC" was utilized as a code for "lack of communication," and "PRE" was used for "pressure." These abbreviated codes were written in the margins of the transcripts.

Significant statements were then organized and grouped into meaningful units, referred to as themes (Creswell, 2007). A constant comparative method was used to compare

Table 1
Description of Participants

Participant	Age	Gender	Education Completed	Stuttering Severity	Speech Therapy Description	Family Description
#1	34	Male	Graduate degree	As a child: mild As an adolescent: severe	Stuttering modification and fluency shaping until age of 18. Some work on attitudes and emotions related to stuttering.	Oldest sibling in his immediate family; has younger brother who he reported stutters mildly and a younger sister. Grew up with both parents.
#2	32	Male	Graduate degree	As a child: moderate As an adolescent: moderate	At 8 years old "I read out-loud". 18-20 years of age worked on attitudes. Then, 20-25 years old participated in individual therapy.	Youngest sibling in his family. Has an older brother and grew up with both parents.
#3	30	Male	Graduate degree	As a child: moderate As an adolescent: moderate	Integrated approach to stuttering therapy for two summers at a university clinic during college years.	Oldest in his immediate family. Has a younger sister who stutters and grew up with both parents.
#4	24	Male	3 years of college	As a child: moderate As an adolescent: severe	Speech therapy since grade school. Continued therapy during college years and focused on emotional aspects to stuttering.	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	High School	As a child: moderate As an adolescent: moderate	Speech therapy in grade school and intensive therapy in high school and college.	Youngest in her family. Has an older sister and grew up with both parents.
#6	53	Male	1 year of college	As a child: moderate As an adolescent: severe	Speech therapy beginning in grade school, continued until adulthood.	Three brothers and three sisters. Oldest of the boys.
#7	30	Female	Bachelors Degree	As a child: severe As an adolescent: moderate	Stuttering modification and fluency shaping. Private and school therapy.	The oldest of six children; grew up with both parents.

codes, so that those codes that were relevant conveyed a specific meaning. Once codes were established, the first author reviewed all the codes in order to determine major and minor themes. All of the themes were self-generated, meaning that they reflected the data and did not reflect a predetermined system of codes. Major themes included those elements that permeated most aspects of the participants' experiences, and were judged to be meaningful. Minor themes included those elements that were present in the interviews, but were judged to be contributing to, and providing a deeper description of, each of the major themes.

Credibility

Credibility reflects the methods used to ensure that the results obtained are accurate from the perspective of the participants, researchers, and readers of the study (Creswell & Miller, 2000). Credibility is similar to concepts such as validity and reliability, which are often sought in experimental designs. The authors utilized the following steps in order to ensure that credible information was obtained and analyzed:

As described earlier, each semi-structured interview was audio recorded and transcribed verbatim. The first author then was able to reflect on each interview in its entirety.

At the time of the study, 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 his family experiences with stuttering. The interview was transcribed and analyzed for major themes. The first author conducted his own analysis because it was important that he know potential biases to ensure that the analyses of the participants' data were unbiased. Following this analysis, the researcher shared his own biases, or findings from analyzing his narrative, with the other co-authors.

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 first author and the fourth author, an individual with a background in stuttering and experience with qualitative research. Once the interviews were transcribed verbatim, both authors reviewed them and progressed through the analysis steps independently. After themes were generated independently, their interpretations were compared and discussed until a consensus was reached (Corcoran & Stewart, 1998; Plexico et al., 2005).

Lastly, 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; Tetzowski

Table 2

A summary of the major themes and minor themes identified

Themes

Major theme 1 - Support Desired

Minor theme 1 - Desire for "deep" support (4 participants)

Minor theme 2 – Role Models (6 participants)

Major theme 2- Support Received from Family (7 participants)

Major theme 3 – Perceived Barriers to Support Desired

Minor theme 1- Pressure to be Fluent (4 participants)

Minor theme 2- Lack of communication regarding stuttering (4 participants) and speech therapy (6 participants)

Minor theme 3- Unhelpful Assistance for Stuttering(4 participants)

& Franklin, 2003). In addition, member-checking is documented in literature as being an effective strategy to authenticate findings with the participants involved in qualitative research studies (Corcoran & Stewart, 1998). The first author met and discussed the findings with five of the seven participants following analysis of the data. The perceptions that the participants had of the themes were added into the final interpretation of the data. Furthermore, the first author mailed final copies of the results to each participant. All seven participants corresponded with the first author regarding the final copies of the results either by phone, email or in person. In this correspondence with the first author, none of the participants identified any areas of revision and all participants felt the conclusions of the authors represented their experiences. As a result, there were no disagreements between the conclusions drawn by the authors and the perceptions of the participants.

Results

Based on the thematic analysis of the participants' narratives and the researcher's field notes, three major themes were identified. The first major theme was related to support desired by participants. Two minor themes contributed to the formation of this theme and consisted of statements pertaining to the desire to have role models and to receive emotional support for stuttering. The second major theme was related to support received from the family. In this theme, participants described their perceptions of receiving support from their families in general and related to their stuttering. The third major theme was related to perceived barriers to the support participants desired. Three minor themes contributed to the formation of this theme and consisted of statements related to pressure to be fluent, lack of communication about stuttering and speech therapy, and unhelpful assistance for stuttering. Table 2 summarizes this theme structure.

Support Desired from Family

Throughout the interviews, participants reported "wishes" they had regarding support from their families.

One of these wishes was the desire for support concerning the emotional aspects of stuttering. In addition, participants mentioned the wish for role models in the area of stuttering.

Desire for “Deeper” Support

Participants had a desire for what the first author defined as “deep support.” This type of support represents the emotions and feelings related to stuttering. Even though participants did report receiving some support from their families, four participants specifically reported a desire to also openly discuss their feelings associated with stuttering. These feelings consisted of isolation, embarrassment, guilt and frustration.

P2 indicated that he wanted to feel comfortable discussing the topic of stuttering and his with the rest of his family: “I wished that it was comfortable to just talk to them about stuttering, about what I was feeling about frustration, about stuttering.” P1 discussed his wish that his parents would understand how to listen to him, as he wanted them to look past the stuttering and listen to the content of his message:

I just I think that [it] would've really helped if they would've known how to listen to me and you know maybe would've told me, '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.

Four participants desired for family members to understand their needs and approach them regarding the topic of stuttering. Also, participants felt it was important for family members to learn how to listen to them, and to discuss emotional reactions that were associated with their stuttering. Moreover, these participants reported a desire to communicate openly about stuttering with their family.

In contrast, 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. But this participant also described receiving meaningful support from his brother who also stuttered. 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.

The Desire for Role Models in Stuttering

Six of the seven participants expressed their wishes for positive role models concerning stuttering when they were younger. Each believed that knowing an older child or adult who had overcome their stuttering, or someone who was more knowledgeable regarding stuttering, would have helped them cope more effectively with their speech. For example, P3 stated this desire:

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. Because it was like driving down the freeway with no signs...you're just figuring things out on your own which is hard to do as a child.

P6 reported that access to another person who knew about stuttering to guide him with decisions regarding his education would have been beneficial: “I think rather than just stuttering therapy, a life counselor, somebody who knew the problem of stutterers and maybe say...so you want to get an education, what are the problems that you have?”

The statements associated with this theme indicate that the majority of the participants felt a need to identify with others who stutter, or individuals who knew about stuttering, in order to obtain support that was not provided by their family. In many instances, to paraphrase P3, participants reported “figuring things out” for themselves. Furthermore, participants believed the presence of role models would have been helpful in dealing with stuttering.

Support Received from Family

All seven participants reported a generally supportive environment in their families. Participants went on to describe this support as relating to school and extracurricular activities. For example, P3 spoke about this general supportive environment by stating: “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 terms of support for stuttering, families of participants assisted them in finding speech therapists, provided transportation to treatment sessions, and paid for stuttering therapy. This general support typically did not address emotions or feelings that were related to stuttering. P1 discussed how his family provided financial assistance for his stuttering therapy:

They were always real supportive and pretty much [did] anything that I needed. They even helped me pay for some of my speech therapy.

Despite indicating desires for “deeper” support with stuttering, participants reported a general supportive home environment in other areas of their lives. In particular, participants felt supported by their families in school and with extracurricular activities. When asked about how their family provided support related to stuttering, participants stated that family members provided assistance locating speech therapists to provide stuttering therapy, as well as providing transportation and financial assistance for stuttering therapy.

Perceived Barriers to Support Desired

The majority of participants reported various barriers that prevented them from receiving the help they desired from their family in dealing with their stuttering. One of these barriers was a feeling of pressure to be fluent around certain family members. Furthermore, a lack of communication was reported not only in terms of stuttering, but also stuttering therapy. Finally, participants described how assistance from family members and S-LPs, although provided in the best intentions, was ultimately unhelpful in assisting them dealing effectively with their stuttering.

Pressures

Participants reported feeling pressure from family members to speak fluently. Four participants felt as if they could not stutter around family members because of reactions to their stuttering. The reactions from family members were at times subtle, as some participants perceived such reactions like tone of voice, facial expressions and body language as communicating to them that stuttering was not acceptable. Other participants reported overt family reactions to their stuttering such as “slow down” or “take a breath” when stuttering occurred. In some cases, participants reported the influence of speech therapy on family reactions to stuttering, as family members overemphasized certain speech techniques being used in therapy. P2 described the constant pressure that he felt to be fluent around his family, referring to the influence of a “stop, think, breathe” technique he was taught in speech therapy:

I heard the stop, think, breathe, from when I was eight years old until I was eighteen years old and that came from my mother, father and brother... I always felt under pressure. I always felt as if I could not stutter.

Two participants cited specific family members where they felt pressure to produce only fluent speech. P1 went on to describe the facial expressions of his father when he stuttered and how he interpreted these reactions as his father not being accepting of him when he stuttered. For P4, it was the role of his mother in speech therapy that contributed to his feelings of pressure to be fluent, as his mother was the one who took him to speech therapy and communicated with the S-LP regarding his progress. P4 described this feeling of pressure to be fluent with his mother:

I felt like I couldn't just come out and talk and stutter simply because she 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 and I felt she was almost looking over [my speech] in a way.

The experiences of four participants revealed feelings of pressure to be fluent around their family. This “pressure to be fluent” feeling appeared to be the result of subtle and overt family reactions that indicated to the participants that stuttering was unacceptable. These reactions from family members appeared to be associated with their knowledge of participants’ speech therapy. At times, this pressure to be fluent was generated by the entire family but for two participants it was specific to certain family members.

Lack of Communication Regarding Stuttering and Therapy

Four participants shared that their stuttering was seldom discussed with their families. These participants believed that stuttering was not a topic that could be discussed openly in their homes. In addition, participants stated that their feelings or emotions associated with stuttering were not discussed. If the family members were aware of the struggles the participants were going through,

they did not directly comment on it with them. P4 reported on the lack of communication about his stuttering: “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.”

Speech therapy was seldom discussed in the families of six participants. When speech therapy was discussed, it was with select family members and friends. In addition, family members were only aware of the surface level of the participants’ therapy (homework assignments, descriptions of fluency principles), but not of the broader context (nature of stuttering, why certain aspects of therapy were important). P3 commented on the lack of discussion 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.

Overall, participants experienced a lack of communication in their families about their stuttering and what occurred in speech therapy. Four participants believed stuttering was not an acceptable topic to talk about with their family. Furthermore, participants shared that, in the rare instance that their stuttering was discussed, the extent of the impact of their stuttering, as well as the emotional components to their stuttering, were not mentioned. The family members of six participants were aware of their attendance in speech therapy, and knew some details of what happened in therapy. However, no further communication took place.

Unhelpful Assistance for Stuttering

Participants reported that the assistance provided by S-LPs and family members, although well-meaning, was ultimately not helpful and did not assist them with their stuttering. Four participants were exposed to stuttering treatments that they felt were not beneficial to their long-term recovery. These approaches consisted of compensatory strategies to avoid or postpone stuttering. Furthermore, some participants reported that S-LPs they encountered appeared ill-prepared in providing stuttering therapy. For example, P7 described her experience by saying:

Every time that I would go into a stuttering block they wanted me to clench my fist... They told me if I felt comfortable twirling my hair, you know, that I could twirl my hair if I was feeling uncomfortable and obviously those are secondary characteristics that you don't want to develop. Later I had to start to break those [secondary behaviours] off one at a time and that was a lot of work to try and do.

Similarly, the participants reported that the therapy approaches they learned when they were children were not beneficial in assisting them with their stuttering. The participants reported their stuttering remaining the same, or in some cases increased in severity, despite following through with speech therapy recommendations. This led

to frustration and was best illustrated in the comments made by P6 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.

In an attempt to help the participants with their stuttering, family members provided assistance that ultimately was not perceived as beneficial. This type of help was sometimes due to advice families received from S-LPs, but in the majority of cases was self-generated. Four participants indicated that family members “didn’t know any better” and that the help they were giving them was well intentioned but ineffective. Examples of family assistance with stuttering consisted of instructing participants to concentrate on their breathing or slowing down when they spoke. P5 reported her frustration when her mother would attempt to help 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.”

Though the majority of comments made by the current participants indicated that they received misguided assistance from their family regarding their stuttering, P7 had a slightly different experience regarding the help she received from family members:

I would come home from school and sing to [my mother], 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.

Four participants perceived the assistance provided by family members and S-LPs as well-intentioned but unhelpful to managing their stuttering. They perceived family and S-LPs as ignorant of stuttering (“didn’t know any better”). However, one participant (P7) perceived the help provided by her family as beneficial for coping with stuttering. Nevertheless, the majority of participants experienced unhelpful assistance with their stuttering from families and S-LPs.

Discussion

The purpose of this study was to explore the family experiences of PWS related to their interactions with family members, speech therapy and stuttering management. In general, there appeared to be a complex interaction among the family experiences of participants related to these variables. Though some participants reported receiving some family support for their stuttering in the form of seeking out and providing financial assistance for stuttering therapy, many participants reported a desire for deeper support that would have assisted them in coping with the emotional and attitudinal aspects of stuttering.

Many participants reported pressure to be fluent, lack of communication about stuttering and speech therapy, and unhelpful assistance as barriers to the emotional support they desired from their families.

The majority of participants indicated that stuttering and speech therapy were rarely discussed in their household. These findings are similar to other research that has reported a lack of communication about stuttering between parents and PWS (Corcoran & Stewart, 1995; Hearne et al., 2008). Hearne et al. (2008), in their investigation of the perceptions of adolescents who stutter regarding stuttering and speech therapy, found that stuttering was neither discussed in the home environment nor talked about with friends. However, Johnson et al. (1959) reported that the majority of parents *had* 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 did not report discussing the emotions related to stuttering. Rather, they were more interested in correcting their child’s speech.

Many of the family members knew little about how to address stuttering, but were still willing to provide advice about how stuttering could be eliminated or greatly reduced. Very little research has explored the assistance that family members provide to PWS. Johnson et al. (1959) found that the most common suggestions parents made to children were to slow down, stop and start over again, or to take it easy. Other authors have argued that parents and significant others may offer advice that actually leads to negative coping (i.e. avoidance and secondary behaviors; Guitar, 2006; Manning, 2010). The participants recalled similar suggestions and reported on the negative impact of the advice they received from family members, especially related to techniques employed to enhance fluency.

Perhaps the most troubling themes found were those related to the participants’ perceptions of therapy experiences and the advice received from clinicians. Four of the seven participants were exposed to therapy approaches that they felt did not address their needs to effectively cope with their stuttering. Participants also reported frustration when these techniques failed to help their stuttering. It has been reported that some S-LPs are uncomfortable and feel they lack the training necessary to work with PWS (Brisk, Healey, & Hux, 1997; Cooper & Cooper, 1996; Yaruss & Quesal, 2002). This appears to have led to frustration among the participants of the current study.

Though little research has explored the extent to which parents and family members discuss stuttering and therapy, many therapy programs suggest that therapy for CWS should include parents (Gottwald & Starkweather, 1995; Mallard, 1998; Onslow & Packman, 1999, Yaruss et al., 2006). Few studies have explored the psychological and social impact that these therapy programs might have on the family. Woods, Shearsby, Onslow and Bumham (2002) investigated the psychological impact the Lidcombe Program can potentially have on the children involved. Results revealed that children did not report any depression,

aggression, or withdrawal following therapy. 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).

As part of their desire for deeper support, a number of participants wished to have a positive role model who stuttered, or who knew about stuttering. One possible way to fulfill this desire for role models is through attendance at support groups. Previous literature has documented the importance of support groups for PWS. Several authors have suggested that self-help meetings can improve the feelings that PWS have regarding their speech because they allow contact between individuals who have had similar experiences (Ramig, 1993; Trichon, Tentnowski, & Rentschler, 2007). Past studies have also reported the importance of support groups for PWS, indicating that participating in these groups had a positive effect on self image and acceptance of stuttering (Yaruss et al., 2002). Other authors have provided information regarding group therapy for PWS and the potential benefits it can have on their feelings and speech fluency (Manning, 2010; Ramig & Bennett, 1997). Corcoran and Stewart (1995) found that PWS described a supportive relationship as one in which there was shared knowledge with other PWS. These findings support the participants' desire for a role model who understood stuttering.

In contrast to the findings of the present study, some researchers have suggested that PWS establish "deep" support in the form of supportive relationships in their home environment. These findings are supported by Crichton-Smith (2002), who found that her participants were comfortable stuttering openly at home. Crichton-Smith suggested the participants in her study felt comfortable due to the supportive environment that was established in the home and with friends. In contrast, four participants in the current study stated that they *did not* feel comfortable stuttering at home due to pressure to be fluent. Methodological differences may explain the disparity of these findings. Crichton-Smith (2002) reported that the mean age for the participants was 56 years old whereas the current study age mean was 32. The older participants might have had a different perspective regarding their experiences with their stuttering. In addition, Crichton-Smith's study did not focus on the home environment as the central issue of the interview. As a result, this may have impacted the amount of information and types of experiences shared on this topic when compared to our findings.

In general, more research is needed to understand the family experiences of PWS. In particular, it is recommended that future researchers examine the type of support that families provide to PWS, as well as how stuttering is discussed in their households. Researchers should also explore the existence of role models for PWS and whether or not the themes in the current study exist in a larger population of PWS.

The current findings need to be interpreted with caution, as several limitations exist. The study was

retrospective in nature and dependent upon the memories of participants. Furthermore, this study investigated a select group of PWS, as the majority of participants were recruited through the NSA. Finally, a natural limitation of qualitative research is its limited ability to generalize to larger populations.

Clinical Implications

The results from this study have several clinical implications. It is important for professionals in speech therapy to be aware that PWS may seek deeper support (empathy, understanding, decreased isolation, etc.) for their stuttering. Moreover, PWS who are looking for this support may find this assistance in support groups and group therapy. In addition, PWS may find support from an understanding and empathetic clinician (Manning, 2010).

The results provide support for the involvement of parents and family members in the treatment process. By including family members in the therapy process for stuttering, they will be more knowledgeable regarding the speech therapy process, as well as the rationale for certain treatment approaches. Clinicians should be aware that misguided assistance can occur in the home environment and may hinder the ability of PWS to cope with their stuttering effectively.

S-LPs should encourage families to make stuttering an acceptable topic for conversation, not just in terms of what is occurring in speech therapy, but also in terms of the affective and cognitive components related to stuttering. It is important for S-LPs to be aware of this potential lack of discussion about stuttering in families, and how this may be interpreted by the PWS. The last word on the matter is left to P7 who summarizes the discussion of stuttering more in the home environment:

We need to stop whispering about stuttering, or making stuttering a closet issue and I think that starts in the home and its going to grow from there. We need to be able to talk about it, and learn about it, and know the facts, and dismiss the myths about stuttering...I just think it starts in the home.

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Appendix A

1. To begin with, I would like to know about your family. Can you please describe your family?
 - How were these relationships with your family growing up?
 - How are these relationships now?

2. Now, I would like to ask you about your stuttering. Can you tell me more about your stuttering?
 - 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?
 - As a child
 - As an adolescent
 - As an adult
 - Positive vs. negatives

4. Describe for me how you would cope with your stuttering.
 - Can you tell me about your speech therapy?
 - 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.
 - What about your Father?
 - Mother?
 - Siblings?
 - 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.

7. Please describe for me how stuttering affected your family relationships, if at all.