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**THE EXPERIENCE OF BEING A PARENT OF A CHILD
WHO STUTTERS AND SUBSEQUENT INVOLVEMENT IN
SUPPORT GROUPS: A NARRATIVE STUDY**

by

KATLYN FERGUSON

**B.S., COMMUNICATIONS SCIENCES AND DISORDERS
MARYVILLE UNIVERSITY OF ST. LOUIS, 2018**

THESIS

Submitted in Partial Fulfillment of the
Requirements for the Degree of

**Master of Science
Speech-Language Pathology**

The University of New Mexico
Albuquerque, New Mexico

July 2020

DEDICATION

For my family—past, present, and future

Dulcius Ex Asperis

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My sincere thanks to those who participated in this study. It has been an honor to know your story and a privilege to pass it on to others.

In recognition of my committee: Dr. Arenas, thank you for guiding me through this process, for your genuine enthusiasm for exploration, and for fostering my interest in this area. Dr. Binger, thank you for always pushing me to push myself, think critically, and ask questions that leave no stone unturned. Mary, thank you for your wisdom and for your unconditional support, care, and kindness. Your passion for life and for others is admirable.

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To my best friend, thank you for your encouragement and patience. I am thankful for your ability to ground me back in reality while still lifting me up.

Finally, I have endless gratitude for my family. Thank you for your advice, for sharing your experiences, and for being the voices of both reassurance and reason. Thank you for reminding me of life's simple joys, for your lighthearted humor, and the sharp wit that keeps me on my toes. Thank you for showing me the value of perseverance, balance, and passion, and for always reminding me how far I have come. Nearly everything I am is because of you.

**THE EXPERIENCE OF BEING A PARENT OF A CHILD WHO STUTTERS AND
SUBSEQUENT INVOLVEMENT IN SUPPORT GROUPS: A NARRATIVE STUDY**

by

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ABSTRACT

INTRODUCTION: Developmental stuttering generally begins after a period of typical fluency and is highly variable in its presentation and persistence. This variability along with the lack of a definitive cause and social stigma often negatively impact both children who stutter (CWS) and their caregivers. However, research on the specific effects of stuttering on the caregiver is quite sparse compared to research into the caregiver experience in other disorders. Additionally, although social support has been identified as a primary protective factor for other caregivers, little evidence exists to show how support groups benefit caregivers of CWS.

METHOD: Five parents participated in narrative interviews where they were asked

to describe their involvement in support groups as well as their overall experience as a parent of a CWS. Interviews were analyzed using a modified version of Carol Gilligan's Listening Guide.

RESULTS: Parents shared many commonalities including their approach to their child's stutter, therapy experiences, and support group benefits. Support groups provided connection, reduced feelings of isolation, fostered acceptance, and encouraged a shift in parental mindset and attitude away from a focus on fluency toward a focus on communication.

IMPLICATIONS: Therapists should support the family alongside the child by providing resources, encouraging and providing social supports, and involving the family in treatment decisions. Therapy should seek to address the social-emotional aspects of stuttering and support effective communication regardless of fluency.

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INTRODUCTION

Developmental stuttering is a communication disorder that typically begins between the ages of two and four and is usually preceded by a typical degree of fluency. An estimated 75% or more of children who begin to stutter will “outgrow” it within 24 months of onset, but the remaining are at increased risk of stuttering throughout their lives (Bloodstein & Ratner, 2008). Despite decades of research, stuttering is still a bit of an enigma. Due to its high variability and lack of physical visibility (i.e., invisibility), common misconceptions and misinformation continue to fuel social stigma, putting those who persist in stuttering at an elevated risk of experiencing negative socioemotional effects. Such effects can be seen as early as preschool and persist throughout adolescence and adulthood impacting daily participation, perceptions of oneself, academic and vocational success, social relationships, and overall quality of life (Corcoran & Stewart, 1998; Crichton-Smith, 2002; Erickson & Block, 2013; Hugh-Jones & Smith, 1999; Klompas & Ross, 2004; Langevin, Packman, & Onslow, 2010). Fortunately, research regarding protective factors such as social support and treatment is plentiful (Boyle, 2015; Boyle et al., 2018; Corcoran & Stewart, 1998; Craig et al., 2011; Crichton-Smith, 2002). While research is pushing to understand the experiences of people who stutter (PWS) and the role of social support as a protective factor, the experiences of the people who provide these supports are still largely overlooked.

Impact of Other Disorders on Caregivers and Families

Although research on the experiences of caregivers of PWS is currently lacking, research on caregivers in other disorder areas offers a preliminary look into the roles and experiences of these individuals. All caregivers must balance the everyday needs of those in their family, external commitments such as work, and their own needs including self-care and personal relationships. Caregivers of a child with a disability must also factor in the specialized needs of that child. Studies on chronic physical conditions (Pinquart, 2018), intellectual disabilities (Cramm & Nieboer, 2011), behavioral disorders (Cronin, 2004; Kelso et al., 2005; Roper et al., 2014), and multiple disabilities (Roper et al., 2014) indicate higher levels of parenting stress, increases in perceived caregiver burden, and a decrease in overall

caregiver wellbeing. The most common stressors are perceived lack of social support— from family, friends, professionals, or the community— and family issues. These two stressors, especially when compounded together, often result in feelings of isolation (Cramm & Nieboer, 2011; Cronin, 2004; Kelso et al., 2005; Piquart, 2018; Roper et al., 2014). Regarding family issues, caregivers report unequal division of labor and balancing relationships with other family members the most (Kelso et al., 2005; Piquart, 2018; Roper et al., 2014). In some families, the need for specialized care skills—and the time and cost involved with training others in those areas—can be a barrier to family flexibility (Kelso et al., 2005). Another study discussed perceived sibling relationships within these families. Some families report more positive sibling relationships than families with typically developing children; however, higher levels of perceived caregiver burden correlate with more negative perceptions of sibling relationships (Roper et al., 2014). Challenges regarding access to and availability of services, difficulty navigating health care and education systems, strained interactions with professionals, and difficulty finding information are commonly reported service-related stressors. Additional service-related stressors include lack of inclusion in treatment decisions and stress surrounding the diagnostic and treatment processes as a whole.

For some caregivers, the specific skills needed to manage their child’s disability and maintain daily routines along with social reactions and judgements are significant stressors (Cronin, 2004; Kelso et al., 2005). For instance, for caregivers of children with invisible disabilities, particularly those that are highly variable (e.g., attention deficit hyperactivity disorder), social perceptions and judgements are a significant point of stress. Caregivers report pressure due to social controversies surrounding the existence of the disorder and its etiology, diagnosis, and treatment. Parents often comment on fears of being labeled a “bad parent” due to a lack of understanding from the community regarding their child’s behaviors and the pressure put on being “normal.” Parents also report a lack of support from health professionals and more difficulty getting a diagnosis and services (Cronin, 2004; Kelso et al., 2005). Finally, regardless of visibility or the type of disability, maintaining personal wellbeing can be a challenge; stress and caregiver burden are noted as having a negative

impact on personal wellbeing (Cramm & Nieboer, 2011; Cronin, 2004; Kelso et al. 2005; Pinquart, 2018; Roper et al., 2014). The cyclical relationship between these aspects and many others creates a complex network of both internal and external factors that affect caregivers of children with disabilities across all aspects of their life.

Support for Caregivers of Children with Other Disorders

Fortunately, although these factors present unique challenges for each caregiver and their family, a number of supportive mechanisms have also been identified. Just as lack of social support has been identified as a primary stressor and contributor to decreased caregiver wellbeing, ample social support has been identified as a significant protective factor for these individuals (Bull, 2003; Kelso et al., 2005; Solomon et al., 2011). Caregivers often seek informal support from family, friends, church groups, and other personal social groups. Many also seek formal support from government services, non-profit organizations, teachers, health professionals, and support groups (Kelso et al., 2005). Some caregivers seek a support group as a source of information such as education strategies, management suggestions, coping strategies, relevant organizations and contacts, and steps to navigating complex systems of care (Bull, 2003). Others seek these groups for emotional support as these groups often create a sense of community and belonging, support friendships between members, and increase self-esteem, confidence, and a sense of agency in the individual's larger community (Bull, 2003; Kelso et al., 2005; Solomon et al., 2011). Beyond seeking social support, several other emotion- and problem-focused strategies have been observed: acknowledging personal successes, avoiding stressful situations and limiting competing demands, cognitive reappraisal and working towards acceptance of the diagnosis, learning new skills, seeking out more information, releasing emotion through crying, and using humor and relaxation techniques (Kelso et al., 2005).

Like caregivers of children with other disorders, caregivers of children who stutter experience a complex interaction of external and internal factors; however, factors specific to this group must also be discussed due to the inherent difference of stuttering as a communication disorder rather than a physical, intellectual, or behavioral disorder.

Impact of Stuttering on Caregivers & Family

Research specific to the experiences of caregivers of children who stutter, as opposed to other types of disabilities as discussed above, is a fairly recent endeavor, but common themes have begun to emerge. Potentially due to the often-sudden onset of stuttering after a period of typical fluency, feelings of confusion are common in the initial stages. Parents are unsure if the stuttering will persist, how to respond, and whether or not they should talk about stuttering at home or with their child. Parents also frequently report uncertainty about the disorder itself. Parents report high levels of dissatisfaction regarding their knowledge of the cause of stuttering, how it presents, and how to address it (Plexico & Burrus, 2012). Additionally, a 2010 study (Langevin et al., 2010), showed approximately 90% of parents feel they had been affected in some way by their child's stutter, with 71% of parents indicating they feel emotionally affected. Although less than 5% report their relationship with their child had been affected, approximately half feel it affects their communication with their child, and 36% report not knowing how to respond to their child when they stutter (Langevin et al., 2010). Parents often report giving the child undivided attention when speaking, encouraging them to continue speaking when frustrated, simply waiting for the child to finish speaking, and modifying one's own speech (e.g., slowing down). Parents also try to always remain calm despite potential frustrations or difficulty understanding their child. These are explained as attempts to reduce the pressure on their child (Langevin et al., 2010; Plexico & Burrus, 2012). Many parents also report asking the child to modify their speech, such as asking them to slow down and take a deep breath first (Langevin et al., 2010).

Parents of CWS frequently report feelings of anxiety, concern, uncertainty, self-blame or guilt, worry, sadness, frustration, feeling generally upset, and feeling overwhelmed (Langevin et al., 2010; Plexico & Burrus, 2012). Similar feelings of anxiety are often discussed when parents speak about their child's future. Parents are concerned others will react negatively to their child or underestimate their child's intelligence. Parents also worry their child might lose self-confidence and self-esteem, withdraw and miss out on social opportunities, struggle to have satisfying personal relationships, be hesitant or not pursue

their goals, or struggle in school (Langevin et al., 2010, Plexico & Burrus, 2012; Erickson & Block, 2013). To combat this, parents report a strong desire to help their child and often discuss the importance of building up their child's self-esteem and confidence by always encouraging participation and offering both verbal and nonverbal support as much as possible. Some parents who are also PWS report discussing stuttering in the home and emphasize the importance of making sure their child knows it is okay to stutter (Plexico & Burrus, 2012). Frustration comes mostly from difficulty understanding their child or from seeing their child struggle, particularly with peers. Some parents report they become upset when they see other children walk away from their child (Langevin et al., 2010). Others report frustration with not being able to help or fix the problem rather than frustration with their child. For many, their child's distress causes a deep sense of frustration and sometimes sadness (Langevin et al., 2010; Erickson & Block, 2013).

Some evidence suggests that having a CWS affects family dynamics as well. Erickson and Block (2013) found that 69% of parents feel stuttering has at least a moderate impact on their family. Emotional strain, difficulty mitigating their child's frustrations, and some family conflict have been noted but largely attributed to the impact of stuttering on the child rather than from any frustration with the child. Beilby et al. (2012) explored the particular experiences of children who have a sibling who stutters and found these children respond in highly variable ways. All siblings demonstrated a level of acceptance of their sibling's stutter and most sibling pairs reported a closer relationship than fluent sibling pairs. Many siblings reported being involved in their sibling's treatment and approximately 50% of fluent siblings even reported taking on a "protector" role. However, every child also reported at least one negative feeling about having a sibling who stutters. Additionally, these sibling pairs demonstrated higher levels of conflict and significant status disparity between them. It was suggested these differences may be due in large part to a whole-family focus on the CWS with little focus on the feelings of the fluent sibling. Furthermore, parent partiality to the CWS was observed in 2/3 of families, with fluent siblings commenting on the different levels of attention and communication given to their sibling versus themselves (Beilby et al., 2012).

Overall, although caregivers often appear to bear the brunt of disorder-related stress and strain, in reality the entire family system can be uniquely impacted at all levels.

Support for Caregivers of CWS

Fortunately, similar to caregivers in other disorder areas, caregivers of CWS also benefit from various protective factors. Humeniuk and Tarkowski (2016) reported on coping styles of parents of CWS using the Lazarus and Folkman Process Model of Coping. Overall, fathers use more task-oriented coping strategies whereas mothers use more avoidance-oriented strategies. Plexico and Burrus (2012) found that parents often use an emotion-focused coping style in the beginning and more problem-focused coping strategies as time goes on. Seeking social support was noted as an effective problem-focused coping strategy; however, parents still report a desire for more support outside of friends and family such as formal support from a support group (Plexico & Burrus, 2012). Klein, Jackson, and Caggiano (2015) have been credited as the first study specifically on parents of children who stutter attending support groups. Participants attending an annual conference for children who stutter completed a questionnaire at the end of the three-day conference about their feelings and attitudes as well as why they attended the conference. These parents reported similar feelings as previous studies regarding the impact of stuttering on them and their child, their hopes and fears for their child, and specific areas of stress (e.g., lack of information or knowledge about stuttering). When asked why they attended the conference, a desire for more knowledge and information was the second most common theme. The most common theme, with 31 of 45 parents including it in their response, was social support. Of those 31 parents, 11 directly included social support for themselves and their child. Differences between first-time attendees and returning parents were also observed. Most notably, parents who had attended more than one conference were significantly more comfortable discussing the causes of stuttering than first-time parents; however, overall, parents generally reported they were comfortable and knowledgeable about stuttering (Klein et al., 2015).

PURPOSE OF THE STUDY

Caregivers and families with CWS seem to share similar experiences as those with other disorders. These shared experiences include challenges, but also similar protective factors that are reported to lessen the burdens. Two protective factors that stand out from the limited research with parents of CWS are changes in coping strategies over time (Plexico & Burros, 2012) and social support (Klein et al., 2015). Although the information gathered by Klein et al. provides some foundational information about the benefits of support groups, the participants represent a select group and questionnaires were collected at the end of the 3-day conference resulting in both an inherent bias for support groups and a measure of only current thoughts and feelings. The purpose of the current study was to capture the process of change and evolution of attitudes, beliefs, and coping strategies of parents of CWS.

A qualitative narrative approach was used (Creswell, 2013). By employing open-ended questions, participants were able to describe their experience—or their story—and the influence of support groups in an open but detailed way. This approach also lends itself to chronicling these experiences as the narrative develops and encourages discussion about both direct events and the underlying experiences of those events over time. Understanding these experiences and the factors that influence them helps to inform decisions made by professionals working with this population. Though these professionals typically work mainly with the CWS, because those who stutter benefit from social support, understanding how to support caregivers ultimately supports the child as well. To do this, five parents who have attended support groups were recruited to answer the following questions:

1. What are the stories parents tell about their experiences having a child who stutters and how did the plots in these stories develop?
2. What influence does a support group have in the development of these stories and how did these influences operate?

METHOD

Participants

Participants were recruited using a convenience sample from FRIENDS, a U.S. organization dedicated to supporting young people who stutter and their families. Dr. Richard Arenas announced the study at the end of a keynote presentation at the 2019 FRIENDS annual convention, and afterward recruitment emails were sent to parents who expressed interest in participating. Additionally, the executive director of FRIENDS aided in recruitment by letting parents who were not able to attend the 2019 convention know about the study. Inclusion criteria included the following: (a) parent or caregiver of at least one CWS; (b) a minimum age of 10 years for the CWS; (c) parent has participated in at least one FRIENDS conference. Five participants were interviewed for this study. All completed all phases of the study. Participants included three women and two men ranging from 49 to 71 years of age (avg. 58.4 years). Two couples were included but interviewed separately. Participant 1 (P1) and Participant 5 (P5) each discussed their experience with their son. Participant 2 (P2) discussed her daughter. Participant 3 (P3) and Participant 4 (P4) discussed their son. Participants reported attending FRIENDS for 3-10 years (avg. 6.4 years). At the time of the interview, all participants were currently active within FRIENDS. Family history refers to the participant’s personal family history of stuttering. Ages reported are that of the participant and their child at the time of the interview. Region reported is where the participant resided at the time of the interview. Demographic data is presented in Table 1.

Table 1								
<i>Participant demographic data</i>								
#	Age	Sex	Ethnicity	Maternal Education	Region	FRIENDS Experience	Family History	Age of Child
P1*	71	Male	White		Northeast	10 years	No	29
P2*	61	Female	White	Advanced degree ^a	Northeast	5 years	Yes	21
P3*	49	Female	White	Bachelor’s degree ^b	Midwest	4 years	No	18
P4*	49	Male	White		Midwest	4 years	No	18
P5*	62	Female	White	Advanced degree ^c	Northeast	10-11 years	Yes	29

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

**Participant’s spouse participated as well*

^a Ph.D., ^b Bachelor of Science degree in nursing, ^c Graduate degree in social work

Researcher Characteristics

Katlyn Ferguson (female) and Dr. Richard Arenas Ph.D. (male) were the two primary members of the research team. Dr. Arenas is an associate professor at the University of New Mexico, whose primary area of research is in the area of developmental stuttering. He has been researching this topic for 16 years and has interacted with many people who stutter over those years both personally and professionally, including leading a local stuttering support group. His personal experience as a person who stutters along with his professional experience with stuttering provided important insights but also potential biases that were reflected upon. Katlyn is a graduate student at the University of New Mexico who has taken a graduate level course on stuttering and has had minimal experience working clinically with people who stutter. Due to Katlyn's relative inexperience with stuttering, she provided a less biased view of participants' experiences. During the analysis phase, both investigators reflected on their possible biases and individual perspectives surrounding the research topic. Katlyn conducted all of the interviews with the participants after reviewing a book on qualitative research approaches that included narrative designs (Creswell, 2012), other interview-based studies with caregivers and PWS that described their general interview process (Corcoran & Stewart, 1998; Crichton-Smith, 2002; Cronin, 2004; Plexico & Burrus, 2012), and several articles describing the specific methodology used here (particularly the Listening Guide; Doucet & Mauthner, 2008; Gilligan, 2015; Gilligan & Eddy, 2017; O'Dwyer et al., 2018). Katlyn also completed a full practice narrative interview with Dr. Arenas about his experiences being a parent of a child who stutters. Katlyn and Dr. Arenas reflected on the interview to identify its strengths and weaknesses.

Researcher Relationship with Participants

Dr. Arenas has known the founder and executive director of the FRIENDS organization, who facilitated some of the recruitment efforts, for several years. Dr. Arenas had also previously spoken with one participant who had been a guest speaker for his graduate fluency class on two occasions prior to the interview. Katlyn did not have a previous relationship with any of the participants in this study. Participants were informed

Katlyn was a graduate thesis student and were welcome to ask questions about the project, her role in the study, and the reasons for her interest in the topic.

Data Collection

A biographical narrative approach (Creswell, 2013) was used to gain a more detailed understanding of the process of change that involvement in support groups facilitates for parents of CWS including both major events and underlying experiences. According to Creswell, a biographical study is a “form of narrative study in which the researcher writes and records the experiences of another person’s life” (Creswell, 2013). Narrative studies are effective for capturing detailed stories or experiences from small groups or individual people but may be analyzed for larger themes as well. Information may be collected and framed within the participants overall personal contexts, community, culture, and other historical details such as time and place (Creswell, 2013).

Interviews were semi-structured with broad questions used as needed to explore the participant's experience and perspectives over time as it related to being a parent of a child who stutters. Participants were encouraged to speak about their experience in a narrative fashion and connect specific stories or experiences back to the support group’s role and overall process of change.

The interviewer initially prompted the participant with the following structured request aimed at addressing the first research question:

I am interested in hearing your story about being a parent of a child who stutters. Start wherever you wish, but you could begin when you first noticed your child’s stuttering. If you would prefer to start in another way, please feel free to do so.

The interviewer used a second structured request, aimed at addressing the second research question, toward the middle of the interview if the interviewee did not already mention the sub-narrative related to the support group:

I am also interested to hear your story about your participation in the stuttering support group FRIENDS. Start wherever you wish, but you could begin when you first heard about the group, or when you first attended a meeting. If you would prefer to start in another way, please feel free to do so.

In addition to the structured questions, the interviewer employed requests such as “Tell me more about that” to encourage greater elaboration from interviewees who needed more encouragement to continue. Interviewees who were giving short responses were asked additional open-ended questions, specifically if they were not talking about particular areas related to parenting, like “How did your response to the stuttering impact your relationship with your child?”. Paraphrasing responses back to the participant was also used to clarify and ensure the interviewer understood the participants’ experiences and emotions.

All interviews were conducted via Zoom, a video conferencing software, with only the interviewer and participant present and both were in private rooms. Each participant completed one interview, ranging from 38 to 78 minutes (avg. 55 minutes). All interviews were audio recorded using the Zoom recording function. Reliability of the transcriptions was accomplished by having one undergraduate assistant and the thesis student separately transcribe audio recordings of the interviews. The thesis student then compared the transcripts for accuracy. Any discrepancy between the transcriptions was resolved by reviewing the audio recording. Identifying information was removed from the transcripts prior to analysis. Validity was ensured through member checking, using procedures recommended by Creswell (2013). Although transcripts and full analysis were not returned to each participant, main themes from each interview were summarized. Three participants responded to the email request to validate the accuracy of their summary and requested their document be sent via email. Each summary was sent as an encrypted document. After reviewing the summaries, the participants were asked to rate their degree of agreement with how well the summary represented their experiences as they were expressed in the interview using a 7-point scale. They were also asked to provide any comments or clarifications to add to or correct any information in the summaries. The three participants who offered feedback represent two families. Both parents in one couple, P1 and P5, and the mother from the second couple, P3, responded. P1 and P3 indicated agreement ratings of seven (strongly agree) and did not provide additional comments. P5 initially rated their summary a 6 (agree) and provided clarifying comments. For example, the participant explained that when she said, “I know lots of wonderful speech therapists, but...”, she was referring to private speech

therapists only. This clarification was helpful in gaining a more detailed understanding of her experience with therapists; however, her comments did not change the overall outcome of the analysis. With these edits, the participant changed her agreement rating to 7 (strongly agree).

Data Analysis

Data derived from participants were analyzed using a modified version of Carol Gilligan’s Listening Guide approach (Doucet & Mauthner, 2008). This version of the Listening Guide approach includes four successive “listening” with each focusing on different aspects of the participant's narrative. Both researchers worked through one transcript in order to discuss the specific parameters of each listening and create a procedure for analyzing each transcript in a way that was consistent but also accounted for the natural variability between participants. The thesis student then analyzed each transcript in-depth using the set guidelines. This was similar to other qualitative, narrative studies discussed by Syed & Nelson (2015) where a single-analyst approach was appropriate due to the amount of detailed information collected by one researcher and the emphasis on careful self-reflection throughout data collection and analysis. Once each transcript was fully analyzed, Dr. Arenas was then able to review the analyses from a more objective position due to his relative distance from the participants and their narratives as compared to the interviewer similarly to one study where the analyst consulted with “knowledgeable outsiders” (Syed & Nelson, 2015) regarding her interpretation of the narratives. Both researchers then discussed overarching themes across the group based on the analyses.

Listening 1

The first listening—also referred to as “listening for the plot” (Gilligan & Eddy, 2017), — had a general focus on understanding the story the participant was telling about their experience. Throughout the listening questions like “How did this story begin?”, “How did it evolve over time?”, “Who are the most important characters?”, and “What is my reaction to their story?” were guides to establish a timeline of events, identify both primary and secondary people involved, and identify recurring words and themes. As each

participant described their narrative arc—that is, their storyline—common events arose that became the structure of participant timelines. All participant timelines were created based on three main events: onset, treatment, and involvement with FRIENDS. The researcher then filled in participant-specific details such as age of onset, age when parents began seeking a professional, age when therapy began, years of therapy received, gaps in therapy, time of first FRIENDS conference, and current involvement in FRIENDS. A therapy timeline was also created for participants that reported seeing several therapists over time. Therapists were noted as school-based speech language pathologists (SLPs), private SLPs, or fluency specialists. Word frequencies were then counted using online software. Interviewer responses were removed prior to count. Recurring words were grouped into the following categories: pronouns, nouns (people, places, and groups), main verbs, feelings/emotions, descriptors, other, and topic specific. Words that fell into more than one category were grouped based on the context in which they were used by the participant. Frequently recurring words that did not fit into a category were noted in their own group. Topic specific words were also grouped based on emerging themes from the listening (e.g., stutter, fluency, therapy, communication, FRIENDS, support etc.).

This listening also includes a focus on researcher reflexivity (Doucet & Mauthner, 2008, p. 405); that is the researcher identifies ways in which their personal experiences may be influencing their perception and understanding of the participant’s narrative. The researcher reflected on potential biases throughout the interview and analysis processes and noted reactions or thoughts that arose when reviewing transcripts and throughout each listening. Table 2 provides an example of a reflexive response to Participant 5 describing her experience with her son.

Table 2	
<i>Listening 1 - Researcher's Reflexivity</i>	
Participant 5's Words	Researcher's Reaction to The Story
<p>Um, so, I think he struggled with friendships. He struggled in the classroom. He did all the things you're supposed to do, like making presentations. I would sometimes call up teachers ahead of time so that they knew he stutters. Um, I can remember times when parents, um, would think he was crank-calling and would hang up on him or yell at him. Um, yea it was really something. Um, and he has such an amazing heart. He just keeps on going. But, there's a huge price. I'm going to start crying. It's so hard for him and he, he just keeps on going. Just pulls himself together. But I know he has a lot of anxiety. Excuse me... So. Anyway, he xx his field. He has a great job now. He got through college. He, he's on his second job doing really well. But it's not easy for him.</p>	<p>I notice P5 starts by speaking about her son's experience at school before moving into her own. Her desire to make his teachers aware of his stutter beforehand leads me to think she is worried his teacher will mistake his stutter as nervousness and is trying to protect him from being penalized in any way in the classroom because of it. As she moves away from school and tells me about other parents hanging up or yelling at her son, I feel surprised and a bit upset. It frustrates me that this seemed to happen more than once and that it came from other parents. I think about how this means her son struggled with both peers and adults. I wonder about P5's response to these incidents. As she continues, I notice more emotion in her voice. She comments she's going to start crying. She continues on to describe her son to me and I imagine him as big-hearted and resilient. It seems P5 views him this way as well but is upset that others have not given him the chance to show this. Though she is speaking about her son, it is clear how close to home and emotional this experience still is for her even after many years. She pauses for a moment to regroup, and I'm happy to have a minute too. She then switches relatively quickly to how her son is doing well despite some remaining challenges. I feel like her shift in tone is a cue to move on, so I wait to see where she will go next.</p>

Listening 2

The second listening focuses on the narrator—that is, the participant—and how they speak about themselves and their world. Previously referred to as “listening for the ‘I’” (Gilligan & Eddy, 2017), each instance where the participant used “I” or other first-person singular pronouns was noted. Tracking the participant’s use of “I” allows the researcher to trace the participant’s presentation of themselves and their self-identified role throughout their experience. This also helps the researcher identify moments where the “I” shifts to

another pronoun which may be suggestive of a different experience or perception of self (e.g., “we” or “them”) (Doucet & Mauthner, 2008). Statements that began with “I” were extracted. Statements that began with “you” were also pulled if “you” could be replaced with “I” and maintain the same meaning. “We” and “our” statements were also noted. When sentences contained several parts, only the first complete thought was collected. When necessary, context was included alongside the selected statement. The “I” statements were categorized by feelings, thoughts, actions, and relationships, and then sorted into the story timeline by major events or themes. Table 3 shows selected “I” statements and how they were coded (feeling, thought, action, relationship) and significant events in their timeline.

Table 3		
<i>Listening 2 - Use of "I" From an Important Event - Stuttering Onset</i>		
Coding Category	Extracted “I” Statements	Excerpt from Participant 2 with “I” Highlighted
Thought	I thought maybe it was just a regular developmental stuttering that she might grow out of	When she first began, uh, started to stutter, I thought that...Okay good, so when she first started to, to stutter at three, I thought maybe it was just a regular developmental stuttering that she might grow out of, and then, um, uh, so, uh, you know, we did uh techniques at home, like environmental modifications, the way that we spoke to her, the way that we xxx not interrupting her, not finishing her sentences, so that was, um, and then, uh, as she got a little older, she’s six, now she’s seven, um, I realized that she was going to, uh, have a stuttering, uh, disorder for a much longer time and maybe, uh, lifetime... after three, when she started going to school, four, five, um, she was, I had an, um, an IEP for her in school, but she did not want to be singled out in school, so I always kind of honored where she was, so I had just a speech therapist consult with the teachers, and, um, I got a private speech therapist who was a fluency specialist, so, um, at that point, uh, she was in therapy for, ‘til, like, age nine, and through her development, we did the same thing. We listened to her and didn’t interrupt her and slowed, uh, speech down. I think my speech is still slow because of, um, doing it for, uh, so many years, um, and we tried to encourage her to, uh, communicate, so, um, I had some, you know, good support in terms of not doing things for her, so she made her own phone calls, she always ordered
Action	I always kind of honored where she was, so I had just a speech therapist consult with the teachers, and, um, I got a private speech therapist who was a fluency specialist	

Table 3 (cont.)

Action	We listened to her and didn't interrupt her and slowed, uh, speech down	her own meals, she, um, from when she was very very young, uh, I would have her, um, uh, go to the store. There were like local little stores where they knew her, so they knew what she was gonna ask for, so she was pretty good in terms of, um, speaking, uh, not, uh, not, you know, uh, being so quiet, except when she was in, I guess, uh, kindergarten, she said to me, um, she got a report card, and it, and it wasn't very good, so I said, 'Well, the reason why it's not good is because you're not talking in school, and you have to make a decision. Do you want to be known as the quiet little girl in the back, um, whom, who doesn't do well in school, or do you want to know, uh, be known as the person who, who, who talks and shares her great ideas but sometimes is not, um, has 'bumpy speech,' as we called it at that time, and, and then at that point, after kindergarten, she started talking in school as well, so I kind of, um, I was really okay with, with, with her stuttering,
Feeling	I kind of, um, I was really okay with, with, with her stuttering	

Listening 3

The third listening focuses on the participant's social connections and relationships. It is rooted in the idea that "all narrated subjects are understood as intrinsically relational and as part of networks of relations" (Doucet & Mauthner, 2008, p. 403). Essentially, this listening aims to frame the participant's experiences within their social network. Due to the focus of this study, a formal model of classifying relationships such as Blackstone's "Circles of Communication Partners" (Blackstone, 1991) was not explicitly used. In Blackstone's model, five concentric circles are used to illustrate one's social network. People in the individual's life are sorted into these circles starting with the innermost circle—those closest to the person (e.g., family)— and moving outward to include members of the community (e.g., unfamiliar partners) (Blackstone, 1991). In the current study, a broader structure was used where the researcher sorted relationships into primary and secondary groups based on their degree of influence. By sorting relationships based on influence rather than closeness or intimacy, relationships that are often considered to be more distant were able to carry more weight (e.g., other parents and CWS). Additionally, this approach allowed for more

flexibility to tease out and explore individual relationships within a group. For example, rather than grouping all “therapists” or “professionals” together, long-term therapists were separated from short-term therapists. The researcher first noted all relationships discussed by the participant as they detailed their experience and then determined primary and secondary groups based on a combination of typical relationships (e.g., family) and those included by all participants (e.g., therapists, other parents). Primary relationships included the participant’s relationships with their child, spouse, other involved family members, other members of the support group, and long-term therapists. Secondary relationships included those with other professionals, short-term or minimally discussed therapists, and less involved or extended family. Table 4 provides excerpts that demonstrate the relationships with minor and major characters of their story.

Table 4	
<i>Listening 3 – Participants’ Relationships with Others</i>	
Character/ Relationship	Excerpts
Child who stutters (P1)	I mean a lot of it has been very tough love, you know, with our feeling, it has always been, um, uh, ‘We love you. There’s nothing that you can do that, you know, will take that away,’ um,
Child who stutters (P4)	I probably talk to him more about those types of things then say [wife], [wife] does, so he maybe confides in me probably a little bit more just based on our relationship... I think ultimately, you, you know, in it’s weird way, [son] and I are probably closer, ‘cause there are times that he needs to talk to somebody. Um, and, you know, I probably, just as a father and son, we do things together, I coached him, his basketball team for nine years and, so I know all his friends, or if we go fishing
Spouse (P5)	but I’m not sure the stuttering- I, uh, I don’t know if it changed the relationship. I think, um, just being parents of kids and being too busy at those times in our lives probably impacted us more than the stuttering itself. Um, so, I, I would say the brunt of the work fell to me, but we would talk, you know, after the kids went to bed, and you know ‘how are we going to handle this or that’, or, um, ‘[therapist] says to do this or that’, um, that’d be his therapist, um, so, I, I guess not a lot.

Table 4 (cont.)

Extended family (P2)	You know, it bothered me, um, and even, even if I said to them, you know, '[Daughter] is likely to be a lifelong stutterer, and it'll, you know, it will come and it will go,' um, uh, that attitude of them wanting her to be fluent and commenting on her fluency persisted, you know, and, and sometimes they, it's not persisting as much because I guess after 20 years of telling them, maybe they've gotten it
Therapist (P2)	I had a very nice, a wonderful fluency specialist when she was, you know, between the ages of four and nine... you know, in the beginning of course when she's stuttering, you read stuff, you know, uh, it could've been emotional, you could've messed her up, you know, you' all this, kind of, things, and um, uh, you know... I worked through that fairly quickly, um, well not, well, quicker... I mean, I don't have it now at all, um, but the speech therapist, like, kind of helped me with that.
Other parents from FRIENDS Convention (P3)	I just, it was just a sense of relief to know that other people are going through the same thing. I mean you hear it over and over and over again, the same types of questions and scenarios and, and, you know, some people are definitely way above, ahead of the game, but, um, for the most part, it just, I don't know, just to know that you weren't in it alone.

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Listening 4

The final listening is meant to connect and frame the individual's narrative within a broader social context: "structured power relations and dominant ideologies that frame narratives" (Doucet & Mauthner, 2008, p. 406). By noting connections made by the participant to larger structures such as prominent social influences, work life, and other external factors such as healthcare and education systems, the researcher may better understand how the participant's larger, societal culture may have influenced their experience. This study also noted connections participants made to their personal cultures and backgrounds such as previous family experiences, beliefs, and family-specific events. This created an additional layer that took into consideration the participant's own personal worldview in addition to external influences and relationships. Excerpts in Table 5 demonstrate how P2 was influenced to push her daughter into therapy based on the

recommendation from the pediatrician, a person in a position of significant social influence. She then reflects back on how she regrets being influenced by him.

Table 5

Listening 4 - Power Relationships – Participant 2 Feeling Influenced by a Pediatrician

I guess it was probably when she was about 13, I took her to the pediatrician, and he was giving me a hard time, ‘Why isn’t she still in speech therapy? You need to put her in speech therapy,’ so I found the speech therapists, you know, close by, ‘cause it was hard for her, when she was in high school, she stayed after, and, um, she went for a year, and she looked at me, and she said, ‘Mom, this is not what I need,’ so I said, ‘Okay, you can, you can quit,’ you know, but that was the only time when I kind of forced her to do something, not forced her, but like, I guess strongly suggested, because the pediatrician felt it was, and, um, I guess, I guess I went, um, I didn’t listen to my, my inner voice. I should’ve just let her, uh, you know, do what she needed to do, so I let her quit. It was, you know, the therapist had her, uh, reading from passages and pausing and, you know, whatever, and she was, you know, rolling her eyes every time she left the session, so I said, ‘Okay, that’s, that’s enough,’ you know?

Using the Four Listeners

Though each of the four listenings focused on different aspects of the participants’ stories, together they provided a structured and systematic way of analyzing each participant’s experience. Listening 1 clearly identified main events and people, and recurring words and phrases offered a more objective view of the overall tone of the interview. Listening 2 provided a first-person account of the parents’ experiences and clearly showed ways in which parents talked about themselves compared to others. Listening 3 framed the participants’ experiences within their social relationships and networks allowing for a deeper understanding of how each parent was influenced by those around them. Listening 4 identified broader and more pervasive internal and external influences and how they each impacted the parents’ thoughts, feelings, and actions. Because of this organization and how the listenings progressed from identifying the plot of the story to identifying more abstract influences, early listenings were able to support and inform later listenings. For example, part of Listening 1 was to create a list of all the people identified by the participant and begin differentiating between those who were highly influential and those who played more of a peripheral role. These lists then informed which relationships became the focus of Listening

3. Additionally, by homing in on these different pieces, it became easier to compare participants' experiences. Common themes as well as differences arose and became much clearer and more detailed than what initially stood out from the interviews.

RESULTS

The interviews revealed that parents' narratives about their experiences having a CWS shared many commonalities, particularly main events like stuttering onset, early treatment, and seeking structured outside support. The narratives also included distinct differences, mostly with regard to influencing factors and how they shaped each parents' thoughts, feelings and actions. Despite these differences, a common theme of making meaning of their experience through giving back and active involvement in support groups arose.

Note that results pertaining directly to the experiences of the children (e.g. amount of therapy) are based on only three CWS. Even though five parents participated, two sets of married couples were included, resulting in only three unique CWS discussed across the interviews. When discussing each family or couple, participant pairs will be referred to together as follows: Participant 1 and Participant 5 (P1/P5), Participant 3 and Participant 4 (P3/P4). Participant 2 (P2) will continue to be referred to as P2.

The arc of the narratives

All five participants described their parental journey in a relatively similar and linear nature but with several mini-narratives and anecdotes interwoven. Throughout their retelling, they each expressed a range of thoughts, feelings, and actions. A mix of past and present tense in the retellings provided insight into current thoughts and feelings and how past events may have influenced or changed their feelings or perspectives.

Stuttering Onset

For all participants, the onset of stuttering was noted between ages one to three, when the child first began speaking or when they began putting words together. All participants initially believed their child would outgrow their stutter, with three parents commenting on being "hopeful" their child's stutter was temporary. This belief was supported by others telling them their child would grow out of it, sometimes even several years post-onset. This comment came from family members, those in the community, and professionals including

SLPs and pediatricians. In one case, parents delayed starting treatment after an SLP assured them their son would outgrow stuttering. Despite this uncertainty about persistence, parents seemed to be optimistic. They were hopeful their child would outgrow it or that they would be able to take their child to someone who could address everything. Parents also tended to worry less early on because their children were not yet experiencing social difficulty. Interestingly, this uncertainty about persistence and ultimate hope that the stutter would resolve was expressed not only by parents for whom this was new, but by parents with a clear family history of stuttering as well.

While waiting to see if their child's stutter would persist, parents researched on their own and practiced behavioral techniques at home such as slowing their speech and waiting for their child to finish speaking rather than providing words or finishing their sentences. As it became clear the child's stuttering may persist and school approached, parents typically began searching for more formal services. They also increased their focus on educating and explaining to others that their child's stutter would likely be lifelong, but that stuttering remained only one aspect of their child. Emphasis was placed on encouraging the child to communicate and speak up just like their siblings did even if it was difficult or took longer. Children were not allowed to defer to the parent to speak for them at home or in public. For instance, P3/P4 always encouraged their son to order his own food at restaurants despite the difficulty and occasionally negative reactions. For P2, this approach appeared slightly easier. She described how she was able to send her daughter to the store where they were already aware of her stutter and what she was going to ask for. This goal of not making their child's stutter the focus of everything was observed across all parents, regardless of the degree of community support, and continued even beyond the years surrounding onset. Table 6 provides quotes that exemplify some of the thoughts, feelings, and actions of parents following stuttering onset of their children along with relevant external influences.

Table 6	
<i>Narrative Elements Close to Stuttering Onset</i>	
Category	Excerpts
Thought	<p>[Wife]’s father stuttered when he was younger and still stutters ever so slightly... so he said, ‘Well, I used to stutter,’ and I think [we] were somewhat expecting and hoping that, with growing up, it would just somehow disappear, and it never did. (P1)</p> <p>I think when we first noticed that [child] started stuttering, especially not knowing anyone who stutters, I think for many many years we thought it was a passing thing. That he would ultimately wake up one day and practically stop stuttering. I don’t think we ever realized that it could or would be a long-term, life thing. (P4)</p>
Feeling	<p>I think we held onto that hope for many many years. (P4)</p> <p>Really confusing... and really not having a sense of what it meant. I think I went into it sort of like, ‘Okay, we’ve got to deal with this, and we’ll take him to someone, and this will get fixed.’ So not a lot of worry. For years not a lot of worry, because when he was young—until maybe fourth grade—he had friends. He seemed to be managing okay. It was when that all began to change that it became harder. (P5)</p>
Action	<p>We did techniques at home, like environmental modifications, the way that we spoke to her... not interrupting her, not finishing her sentences. (P2)</p> <p>... the one thing we never did with [child] is allow him to defer to us. He had to order from the own menu. Okay, so it takes a little bit longer... it’s frustrating at times and I think it’s uncomfortable for people to listen to a stutterer if they don’t know any. (P4)</p> <p>...when we realized that it was more him, we didn’t want that to be the focus. (P3)</p>
External Influences:	<p>...people all around us were telling us, ‘Oh, kids will grow out of it’ you know... even as he was getting into middle school, I still had people, ‘Don’t worry, he’ll grow out.’ (P3)</p>
Others	<p>...part of it was from pediatricians telling us that with speech therapy a high percentage of children who stutter often—whatever connections happen, and all is well. (P4)</p>

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Therapy

Overview of Services

Though only one child received early intervention services, all parents sought services through the schools. Two families, P1/P5 and P3/P4, worked with at least one school-based SLP and P2 had an SLP consult with the classroom teacher. All families also received private services outside of the school. P1/P5 tried different therapists until they found someone long-term; their son worked with this therapist from elementary through high school. The other two families tried different therapists until their children decided to stop therapy. P2's daughter eventually researched on her own and found a therapist. P3/P4's son became tired of therapy as a whole and stopped. P1/P5 and P3/P4 worked with at least one therapist who stuttered. P2 did not comment; however, she was the only one who discussed working with fluency specialists. Overall, over the course of their child's school years, all three families tried a minimum of three therapists total.

Challenges and Stressors

Regardless of whether the family was seeking a school-based SLP or a private one, the most common service-related challenge was difficulty finding a therapist who was both qualified to work with stuttering and who was accessible. Even P2, who was able to work with two fluency specialists, commented on the lack of qualified professionals in her area. Not only was there a lack of certified fluency specialists in the area, these parents also discussed how they quickly found that general SLPs varied widely in their knowledge and skill regarding stuttering. All parents entered therapy with the belief that all SLPs are as knowledgeable about stuttering as they are other disorder areas, but soon found this was not the case. Challenges continued even if families were able to find qualified therapists. For instance, P3 discussed the challenges of balancing after school therapy for her son with a knowledgeable SLP with the needs and schedules of her other younger children. Finances were also discussed by three participants. Although P4 commented he felt fortunate their family was able to try different therapists and approaches, the cost of private services and the lack of financial support for therapy were still noted. Additionally, P3 and P4 both expressed

frustration about spending upwards of \$1,000 on a device recommended by an SLP that ultimately was not functional or natural for their son.

Because of these external barriers, feelings of frustration and disappointment were pervasive across all parents. These emotions were particularly poignant when discussing therapy services received in the schools. P2 was the only parent to report a relatively positive experience with the schools; however, she was also the only parent whose child did not receive direct services. P2 and her daughter also likely benefitted from a series of social factors. P2's daughter remained in the same school throughout elementary and middle school with the same peers, did not experience teasing or bullying, and had the support of her two siblings. These supports helped P2 feel less anxious about her child and likely contributed to a more positive school experience. The other two families had more variability in the schools attended and additional factors such as behavioral difficulties with their child. For these families, school-based services were much more stressful. Even P3, who reported her son only received direct school services for a brief time, discussed how the quality of services was unsatisfactory. They pulled their son from school therapy shortly after starting because he was being treated in a group working on articulation; after this, they had an individualized education plan (IEP) for him for additional academic support but only used outside therapists. P1/P5 tried a number of therapists through the school but were highly dissatisfied and stopped once they found a qualified private SLP. Both P1 and P5 discussed the lack of knowledge therapists had about stuttering and P1 also expressed disappointment in the lack of support provided by the school as a whole. He felt that although classroom teachers tried to help, there was still an overwhelming lack of understanding of stuttering. Overall, frustration with the schools stemmed from the lack of understanding and knowledge their school therapists had about the treatment of stuttering along with the lack of individualized treatment.

Overall Therapy Experience

Overall, though experiences with school-based therapy were typically stressful and disappointing, experiences with private therapy varied widely. P1/P5 and P2 reported positive therapy experiences when working with a long term private SLP who was not only

qualified to work with stuttering, but who also focused on involving and supporting the family alongside the child’s communication. Parents were typically more involved in treatment with private therapists as they were either brought into sessions or provided techniques to help their child practice at home. P2 reported being highly involved in her daughter’s therapy particularly when working with a fluency specialist. She was invited into sessions regularly and learned about stuttering and techniques alongside her daughter. P2 even discussed how, in retrospect, receiving such early, qualified support created a strong positive foundation for her and her daughter. P1 and P5 also commented on being brought into sessions by their long-term therapist. These long-term therapists also seemed to focus more on supporting communication rather than prioritizing fluency. In contrast, short-term therapists and those who were not specialists in this area focused mainly on decreasing the number of disfluencies. One exception was a private therapist who worked with P3/P4 for a few years. This therapist specialized in teaching the Lidcombe Program, a specialized fluency program focused on gradually decreasing the number of disfluencies in an individual’s speech. Overall, P3/P4 appeared to have a more divided experience with private SLPs. Fortunately, they were able to work with a small handful of private therapists who they felt were knowledgeable and supportive, particularly those therapists who were also people who stuttered. However, this family was typically unable to stay with these therapists long term, and they encountered a series of SLPs they felt were much less effective throughout their years trying therapy. Table 7 provides quotes that exemplify some of the thoughts, feelings, and actions of parents regarding therapy for their children along with relevant external influences.

Table 7	
<i>Narrative Elements Related to Child’s Therapy</i>	
Category	Excerpts
Thought	...we didn’t also understand as parents that most speech pathologists know nothing about stuttering. We assumed, unfortunately, that if they took a class—it was one class, and he would be treated with everyone else who has some type of young speech impediment, whether they can’t say their s’s or t’s... which was completely useless with knowing to treat what he had... (P4)

Table 7 (cont.)

Feeling	<p>...we tried several different therapists. First the school therapist, who was useless and misleading and knew nothing about stuttering... I think we made the mistake of trusting the school and we never felt the school give us any support. We still are kind of bitter about the school system as a result... we're quite bitter about their feeling was their therapist was fine and, in hindsight, clearly their therapist was not fine. (P1)</p>
Action	<p>I think we've stopped it a couple times and tried to restart, but I think ultimately, totally stopped, um, in 2013, January of 2013, where he was absolutely not cooperating, had no interest in it. (P3)</p> <p>I had just a speech therapist consult with the teachers and I got a private speech therapist who was a fluency specialist. (P2)</p>
External Influences: Others	<p>...we tried I think one therapist who was okay and then, just by happenstance, we discovered somebody who was fabulous. And to this day we're still in contact. (P1)</p> <p>I think it was great that she was probably the first person that [child] met that actually stuttered as well, and so that was really great for him and great for us. She really had a different kind of understanding. (P3)</p> <p>[Re: early support from specialist] It was wonderful, actually. Wonderful... she's had really terrific help and support. Top-notch, really, support. (P2)</p>
Range of experiences with therapist and different therapies	<p>...we've had a speech therapist here as well that also stuttered, um, and I really liked her a lot, but she was, you know, driving in New York, and she was farther out East, and it was stressful. It really was, because we would have to wait after school, and then you're in busy traffic, and I have the other kids, and it was just really stressful. (P3)</p> <p>...it's fortunate we do have the resources to try many many different things, whatever therapies, earpieces to wear, and spend the whatever money... (P4)</p> <p>...she brought up the speech-easy device to us. And so, I have to say, don't love it. What a crack. Really, a lot of money... but we sort of felt we had to give him the chance to try it. (P3)</p> <p>...that was tough to actually have people say they would treat him and then to find out they had no idea what they were doing. None... sometimes that would be only because I asked to sit in on a session six months in... And I've had them turn to me and say, 'I don't really know if this is what I should be doing. This is an articulation exercise'. Why are you doing this then? So that, I think, was pretty universally a bad experience for us. [Son] has had probably... four speech therapists—and [therapist], who was there all along, was the only one who really helped. (P5)</p>

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Support Group Involvement

Pre-FRIENDS

Along with therapist support, and prior to becoming involved with FRIENDS, P2, P3, and P5 all described supports outside of therapy. P5 commented on personal support the most; she described making friends with other parents of children who were on her son's baseball team or in his band. These friends were a positive source of social support. P5 also had some contact with another mother of a CWS for a couple of years. Outside of these two supports, all forms of support discussed by these three parents were directed either entirely or mostly toward the child. Both P3 and P5 were able to try a one-time group hosted by a local therapist for CWS and their families. Unfortunately, in the group P3 tried, the children were too far apart in age to really connect and the group never truly solidified. There were similar challenges in P5's group. P5 discussed how she periodically contacted local therapists looking for a group for her son and even tried creating one; unfortunately, it was difficult to find enough other children and parents to get a group off the ground. Finally, P2 reported trying a 1-day stuttering conference, but this along with finding another CWS were directed towards supporting her daughter. The 1-day conference was also not presented as a support group, but rather a workshop to learn more about stuttering. Overall, support options for both the CWS and the parents were notably lacking.

FRIENDS

Each family was introduced to FRIENDS as their children got older. Families attended their first FRIENDS conference when the child was between 10-15 years old. P2 attended because her daughter found and became interested in the group, and she wanted to continue being involved in her daughter's journey with stuttering. P1/P5 started attending FRIENDS with their son after their therapist, someone they respected and trusted to help support them and their son, recommended it and due to the proximity of the conference, they could commute each day. P3/P4 found out about FRIENDS by chance through P4's job and decided to try it in an attempt to help their son—who no longer felt therapy was beneficial and was unwilling to try another therapist—and because the conference was being hosted in their city that year. P3 commuted while P4 was able to stay with their son at the conference.

For this family, having other younger children appeared to influence the decision to have one parent commute. For these two families, P1/P5 and P3/P4, the conference being held in their area made attending more feasible. Only P2 traveled out of their area for their first conference. Regardless of how each family found FRIENDS, when they started, or the distance they traveled, the root reason for attending was to help their child.

The decision to commute or stay appeared to impact how much the parent felt they and their child initially connected with other attendees. For instance, P1 described how returning home each night kept the conference from becoming an all-encompassing experience and how connecting with other attendees outside of workshops was difficult. For P3, after commuting to meet her son and husband at the conference each day explained how she wished she had found someone to stay with their other children; she felt she missed out on some of the experiences her son and husband were having. Despite this initial difficulty connecting, four parents still felt their first conference was incredibly beneficial for both them and their child. P2 noted the first year was the most emotionally powerful. P3 described how emotional it was to see so many other PWS. Three of these parents also discussed how their child responded to being around other CWS. Overall, these benefits did not stop after the first conference. Not only did they extend well into the following years, but parents were also able to connect more with other parents and PWS each year they returned. For the participants who commuted the first year, staying in the hotel for the second conference made a notable difference in their feeling of connection. P1 explained how staying allowed them to participate in evening activities and interact with other attendees creating a more round-the-clock experience.

Two families commented on bringing their other children to later conferences. For P1/P5, attending FRIENDS became an important family event where everyone had the opportunity to connect and reconnect with other families and learn more about stuttering and its impact. P3/P4's other children were also able to connect with other CWS and gain a better understanding of what their brother was experiencing. P3 even explained how she does not believe its coincidence that her daughter is now interested in becoming an SLP.

Shared FRIENDS Experiences

Overall, there were five aspects of FRIENDS that were repeatedly discussed regarding each parent's experience. The impacts included: (a) being around other parents who shared similar experiences, stories, and challenges; (b) having a place to receive support while also supporting others; (c) connecting and building relationships of their own despite having initially attended for their child; (d) seeing other successful PWS and learning about their experiences; and (e) learning more about stuttering and gaining a better understanding of their child.

Safe Place to Share Experiences, Stories, and Challenges: Every parent spoke about the impact of being around other parents of CWS who shared the same stories and challenges. This experience was described as “freeing”, “emotional”, “therapeutic”, and “helpful”. One parent explained how it gave her a sense of relief to know others were going through the same things and helped her feel less alone. Another explained how ‘things just kind of flowed out’ and the parent groups were a safe place to ‘verbalize and discharge’ feelings. Even after several years, parents continue returning to these groups because they still feel they benefit from being reminded they are not the only ones who have struggled.

Reciprocal Support: Knowing other parents shared their experiences created an environment of safety and support. Parents were able to share and get support, but they were also able to support others. This reciprocal support was discussed by each parent especially when they talked about later conferences. One parent described the feeling of realizing something she said may have helped another parent and how it reminds her she “still has things to offer.” Another explained how they are able to help other parents prepare for challenges that may arise as their child progresses through school, much as other parents were able to do for him.

Connecting and Building Relationships of Their Own: This reciprocal support extended beyond FRIENDS for some parents. Two parents have become involved with the organization and another commented on keeping in touch with a couple of other fathers between conferences. For these parents, it has been beneficial to maintain some connection

with other parents throughout the year. Then, just as the children return to reunite with the same group of kids each year, the parents reconnect as well. Despite having started with FRIENDS to find support for their child, each parent was given the opportunity to build personal relationships as well. As one parent explained, they did not attend with the intention of connecting, but they are glad they did.

Seeing Successful PWS and Learning About Their Experiences: Connecting with other parents was not the only benefit noted. Parents also described the impact of seeing other children and people who stutter, learning about their experiences, and seeing how they are being successful. Parents who were concerned about employment options commented on the power of seeing adults who stutter in a wide range of jobs and positions. Parents were able to see other PWS in leadership positions with successful personal and social lives. This was described as being a very hopeful and powerful situation that showed parents their child can pursue anything and can have successful relationships. Parents who brought other children also commented on how they benefited. One parent explained how her daughter benefited from meeting other girls her age with a stutter and how it helped her understanding of what her brother was going through in a way that she could not have otherwise. For some parents, seeing other PWS influenced the way they viewed their own child's stutter. One parent described how seeing such a range of severities helped him re-gauge how severe he thought his son's stutter was. This parent also commented on how other PWS helped him understand that severity does not necessarily correlate to social-emotional wellbeing, success, or quality of life.

Learning More About Stuttering and Gaining a Better Understanding of Their Child: Other children and adults who stutter helped with this in the aforementioned ways, but they were also able to articulate experiences to parents that their own children could not. For example, several parents discussed learning about how tiring and effortful it is to use fluency techniques all the time. One parent explained how he had never realized how much mental energy it takes to think about every word before you say it, and once he found someone who was able to explain that, he felt he had a better understanding of his son.

Parents also learned more about the true social-emotional impacts of stuttering and how they can better support their children. For P3 and P4, this deepened understanding along with their overall involvement in the group encouraged them to seek one more form of support for their son: a mentor. This person was able to help their son develop important skills that were likely impacted early on by the negative implications of his stutter. P4 explained how he believes his son was receptive to this despite turning away therapy because of the success they found with FRIENDS. Table 8 provides quotes that exemplify some of the thoughts, feelings, and actions of parents along with external influences regarding their involvement in support groups.

Table 8	
<i>Narrative Elements Related to Support Group Involvement</i>	
Category	Excerpts
Thought	<p>... it definitely was an incredible support to us and to [son]. I think our whole family benefited, even my daughter for the years that she came... it helped her sort of slow down and have an appreciation that she wasn't as willing to hear from her parents, but when it came from other people and peers, I think it was very helpful to her too. (P5)</p> <p>...it's helped us think through the situation differently, I think. And not try and make things better or, you know, it's a mind-set shift that helped us. Helped us with speaking to him, as well as to help us understand some of the things he's going through. (P4)</p> <p>Yeah, I wish there, there to my knowledge were not support groups, um, for [son] as a kid or for me as an adult, as a parent, um, when he was growing up. (P5)</p> <p>...when [child] would say, 'You don't understand,' the fact of the matter is he's right. I don't understand. And we didn't have anyone to go to to help us understand either. (P4)</p> <p>...when we started to understand some of the stuff that he was going through better, it certainly helped his relationship with, certainly with me. (P4)</p>

Table 8 (cont.)

Feeling	<p>I walked in with [child] that first time, and we were greeted by someone in their twenties that stuttered, and, I mean, I almost broke down into tears to think, ‘Oh my gosh, we’re meeting this person that stutters’. We’ve never been surrounded by that many people that stutter. That was so good for [child] but it was equally as good for me. (P3)</p> <p>All of these kinds of things just kind of flowed out. It was a really safe place to verbalize and discharge a lot of these feelings, and most of the people had similar feelings. So, that was very freeing. I think the first conference was the most emotionally powerful for me. (P2)</p> <p>...it was just a sense of relief to know that other people are going through the same thing. I mean you hear it over and over and over again, the same types of questions and scenarios. And, you know, some people are definitely way above, ahead of the game. But for the most part it just, I don’t know, just to know that you weren’t in it alone. (P3)</p> <p>It was transformative, the experience for us as a family...we brought his sister, too. We really enjoyed it as a family. (P1)</p> <p>...we were gonna do whatever we could to help him, so it didn’t matter if we were connecting, but it certainly was wonderful that we did... we feel like we had some wonderful friends and still do in FRIENDS, because we went year after year after year. Really look forward to it... [Husband] and I go back even though [son] is an adult. Still great. Because the challenges are still there... it’s sort of a highlight for us each year, to go to FRIENDS. (P5)</p> <p>...it just continues to be helpful to us... to go there and talk about ‘how was our year, and how was your year’, and what successes the kids had and what was tough. It’s a really safe place to do that. (P5)</p>
Action	<p>[Son]’s speech therapist told us that there was a group and they were coming to Boston that year... So, I said great. I signed [son] and me up, just having no idea what it was. (P5)</p> <p>...even though I go, and I love the support I get, I think that we have made that switch to try to give back... every year we offer to help, and we do help in one way or another. It can sometimes be like running or co-running a group or a workshop. But just outside of that, really making an effort to connect with new parents. To say, ‘Come back’... I think we definitely want to be doing as much of that as we can. Helping other parents. It helps us too. (P5)</p>

Table 8 (cont.)

Others	<p>...I know a lot now about stuttering and sort of the experience from my own child... And that's helpful to someone who's at the start... So you feel—because you don't know what their struggles might be—but just to say, 'We're here. We're here the other parts of the year too.' Just reminds me that I do have something to offer. (P5)</p> <p>Another thing about FRIENDS is that, when you're a parent of a child who has fluency issues, you're wondering, 'How is this fluency going to affect my child's ability to reach the goals, or are they gonna reset their goals because of the fluency? How is it gonna impact, hold them back in any way?' And then you see these young adults that have come back to FRIENDS... they're in their twenties, and they're standing up there, and they're saying, 'I'm doing this, I'm doing that, I decided to do this, I'm not gonna shy away from that,' and you see all of these people who did not let fluency get in the way... That is very powerful. That is very powerful for parents to see that, because they see, right there, these people who still have fluency issues, but are successful, are happy, are married, are funny, are wonderful, are brilliant, are compassionate and kind. So, that takes away the fear. So, that's a really good thing for parents. (P2)</p>
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Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Influencing Factors

Family Dynamics

Although each family approached their child's stutter in similar ways and tried to make sure it was not the focus, each child's response significantly differed which required parents and siblings to respond differently as well. Parents still felt their family was affected, though typically by the social-emotional effects of the child's stutter rather than the child or the stutter itself. For example, P1 and P5 both discussed how they believe their son was significantly impacted by his stutter and used alcohol as a way to cope with the social and emotional challenges he was facing. P3/P4's son also struggled, and though his response to his stutter was different, parents still reported a 'dark period' where he struggled with anxiety and depression. For both families, although the stutter was at the root of everything, it was the secondary issues that impacted everyday life and interactions between family members.

Along with discussing some of these larger family influences, several parents

described what they felt their role as a parent should be. Regardless of how the child responded to their stutter or how other family was impacted, all parents discussed ways in which they tried to support their child. Overall, it appeared that most parents wanted to help their child by minimizing challenges when possible and creating spaces where their child felt supported and involved (see Table 9).

Table 9
<i>Family Dynamics – Family Approach</i>
...the strategy that we have always followed... is that you don't need to feel ashamed... The number one issue is are you a good person? If you are, you will have friends. Be honest with yourself and allow stuttering to be part of you... and then the question can be how can you best communicate given that you do stutter. (P1)
The struggle of speech stuttering can seem so huge and, relatively speaking, it isn't. People have kids who have a far worse disability, but that's not what worries you as a parent. What worries you as a parent is your own kids. (P1)
...it impacted our entire family, definitely. I mean, everything revolved around [child] and what would be the best, what would [child] want, what's the best for [child], you know? Maybe not so obvious that way but... And if he was having a bad day, nobody had their friends over. Like I said, my other three are very social kids, and how much could we let them do if [child] is not doing it, you know. Oh gosh, yeah it impacted all of the time... because every child needs something different. They don't see it that way, but every child needs something different. (P3)
...from a parent perspective, anything that your child is struggling through, I think people would do whatever it would take, and that just happened to be stuttering at this point. (P4)

Note: P1 = Participant 1, P3 = Participant 3, P4 = Participant 4

Regarding more specific relationships within each family, all parents discussed their observations of how their children interacted with each other. Like most siblings, these relationships and interactions appeared to change over time. Overall, sibling relationships were relatively positive and appeared minimally influenced by one child having a stutter. Similarly to the entire family dynamic, in cases where the relationship was affected, it appeared to be due to the social implications and challenges from the stutter rather than any impact from the stutter itself (see Table 10).

Table 10

Family Dynamics – Sibling Relationships

I would say she [daughter who does not stutter] has varied in how she's reacted to it. Certainly, she played the protector role at times—especially when she was younger. But once [son] started using alcohol to sort of medicate the anxiety and the depression around it, there were years where she was really sort of impatient. (P5)

Now [daughter who does not stutter] has been very supportive. When we were in elementary school, well, when they were in elementary school, I can remember every once in a while she would kind of look out for him, and she would get angry, and talk to other kids who she thought might be, um, you know, taunting [son] a little bit. She would see it, 'cause she was only two grades ahead. Uh, and they weren't always in the same school. I mean, she was in high school and he was in middle school like normal, but, um, she was always very, very protective. They are, they are not that close. (P1)

They were all so close in age, um, but the kids always looked up to [son who stutters]. I mean, always, and I'd know that he didn't necessarily see that all the time, but even to this day, like, everybody, and he's, and now, he has such a great relationship with all of them. (P3)

I think when you go away to school for the first time, you realize that home isn't actually a perfect place, and so he [son who stutters], he has longer conversations with, uh, [wife] or, uh, you know, or his siblings more so now than he ever had. (P4)

She [daughter who stutters] has, uh, she's one of triplets, so she has two brothers who were there who were very protective and, you know, it was really like a family situation. (P2)

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Parent-child relationships also appeared minimally impacted throughout. In two families, parents agreed the child was generally closer to one parent in part because of how each parent addressed the stutter and its impact. In P1/P5's family, P5 (mother) was described as emotionally closer to their son. She tended to talk with him more about what was going on in his life while P1 (father) was more likely to just ask what he could do to help. For P3/P4, the father (P4) was noted to be closer to the child. P4 suggested this may be because he and his son share more activities and interests which leads his son to share and open up more to him about what he's going through. Overall, the child's stutter did not impact the parent-child relationship as much as it influenced the ways in which parents tried

to support that child. Like most parents, these parents encouraged their child to pursue their interests and hobbies and tried to be aware of difficulties their child was having. More specifically to stuttering, all parents tried to give their child at least some control over their own therapy, encouraged communication despite fluency, and sought additional support from groups for CWS (see Table 11).

Table 11
<i>Family Dynamics – Parent-Child Relationship</i>
<p>...when she was about nine she said to me, ‘Mom, I need a break from speech therapy.’ So I said, ‘Okay, you can have a break from speech therapy, not a problem.’ I wanted to kind of give her some control over her therapy. (P2)</p> <p>[Wife] is probably much closer in work than I with [son]. You know, she’s the mom, I’m the dad, and so it’s, you know, uh, somewhat more traditional, um, a way, you know, I don’t necessarily have deep, heavy conversations with [son]. Occasionally, but not, not, not that often, whereas [wife] will. (P1)</p> <p>She is, is, um, much more, like, will have direct, good conversations with [son] than I will, whereas I will be more, ‘What can I do to help?’ (P1)</p> <p>you know, we’re also...[husband] and [son] have a very special relationship, and I think that’s, you know, helps the father and son, but they have a lot of similar interests and likes, and that’s, um, you know, he was always, I mean, he was great. Always there for [son], and I was always there, but it was just something about that dad and son kind of bonding, I guess. (P3)</p> <p>I mean, [son], I think he knows, and he can come to us with, you know, talk to us at any point in time. It’s just, um, he seems to reach out to [husband], would be his first pick. I would be his second if he can’t reach him, but, that’s fine, you know, just as long as he has someone to, to reach out to, and talk to about what’s going on in his life, because, you know, I keep saying he’s, he’s on the upswing, but I’m not saying it can’t go down again. (P3)</p>

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3

Beyond the CWS, parental relationships with their spouses were minimally impacted. Even when P3 (mother) and P5 (mother) commented on taking on more of the daily workload in their respective households, parents still appeared to make all decisions regarding their child together. P5 suggested that if the relationship was impacted at all, it was due to the inherent nature of additional stress on the family from having a child that has

more specific needs rather than the stutter (see Table 12).

<p>Table 12</p> <p><i>Family Dynamics – Parent-Parent Relationship</i></p> <p>I think when you have a child who needs extra help, it puts stress on the family... and I think as the mom I was the one running the kids around a lot, so it was just a little extra going on. But I'm not sure the stuttering- I don't know if it changed the relationship. I think just being parents of kids and being too busy at those times in our lives probably impacted us more than the stuttering itself. I would say the brunt of the work fell to me, but we would talk after the kids went to bed... 'how are we going to handle this or that' or, '[Therapist] says to do this or that'... I guess not a lot. (P5)</p>

Note: P5 = Participant 5

Beyond the immediate family, extended family was discussed by all parents as well. There was variability in how extended family members responded both between families and within them. For instance, in P1/P5's family, P1's family did not make it a focus whereas P5's family was more concerned with lessening the child's stutter. P2's family was also concerned about her daughter's stutter and progress in therapy. Both P2 and P5 reported this pressure from family has continued though to a lesser degree than at onset. In the third family, P3/P4, neither side seemed to focus on the stutter. Interestingly, the families that were more concerned with lessening the child's stutter were also the ones with a history of stuttering. The three groups of extended family who did not react did not have a known family history. For these families, questions and misconceptions appeared to be addressed early on and then did not continue. All parents, however, regardless of their family's responses discussed how they have tried to answer questions and educate their family about their child's stutter (see Table 13).

Table 13

Family Dynamics – Extended Family

...and so [son]'s just one of the bunch, and, uh, um, his cousins have never really said much about stuttering, it's just, well that's [son]. He stutters, and I think that's probably the best approach. Our feeling was always we don't make it a big focus, and, you know, [son] should just be [son], and, uh, you know when I think back on it now, I don't think we, I, I don't, it seemed very natural. (P1)

My mother was very xx [interested?] and wanted to know when he would finally be fixed. That was a theme, forever. (P5)

I think people, even my dad would be like 'well I stopped stuttering in high school, why hasn't [son]', uh, there was a lot of pressure to fix him and 'why haven't you fixed him' and, uh, 'you must not be doing the right things', um, that kind of thing. (P5)

You know, it bothered me, um, and even, even if I said to them, you know, 'X is likely to be a lifelong stutterer, and it'll, you know, it will come and it will go,' um, uh, that attitude of them wanting her to be fluent and commenting on her fluency persisted, you know, and, and sometimes they, it's not persisting as much because I guess after 20 years of telling them, maybe they've gotten it, you know. (P2)

No, the family's been great with it all the time, where I have to say I'm an only child, so it was just you know, and I have some extended family but it was never, ever, ever, ever an issue for our family, and everybody was very patient with him growing up and stuff. (P3)

...and so, um, no, they, you know, my, my family [not pulled], eight, um, when I would talk about Y's stuttering, and we would let them know, 'Listen, you know, Y stutters,' and, I was, we were very, they, they, they knew that don't finish his sentences, don't, and so, they don't really get, they honestly, my family and his cousins, uh, honestly, they know he stutters, and they really don't care. (P4)

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Fears and Worries About Child

Across all parents, fears and worries about the child were typically discussed in regard to three main areas: the child's participation, their behaviors, and their peer relationships. P2 and P5 commented on their children's participation at school, such as giving presentations and joining clubs. P2 explained how her daughter did not appear to have significant difficulty with this whereas P5 described how her son struggled in school

and ways in which she tried to help. P5 reported she tried to make teachers aware of his stutter early on and tried to make sure he had activities and hobbies that he enjoyed that were unaffected by stuttering. Regarding behaviors, P1/P5 discussed the behavioral challenges their son had in school such as fighting or acting out in the classroom as well as his challenges outside the classroom with alcohol. In contrast, P3/P4 described their son as quieter and more withdrawn at school than at home. P2 did not report any behavioral concerns with her daughter. Despite the three widely different presentations across these families, all parents described feelings of worry or anxiety surrounding their child's peer relationships at least once. For P2, this worry appeared to subside fairly quickly since her daughter demonstrated little to no difficulty engaging with peers and at school. The other two families reported more long-lasting anxiety surrounding peer relationships. Overall, parents struggled seeing their child not fit in with peers and struggle with making and keeping friendships. P3 also talked about seeing other children become impatient with her son as they got older, and P1 talked about how he and his wife still worry about their 29-year-old son's social relationships even today (see Table 14).

Table 14
<i>Fears and Worries About Child</i>
<p>...but she was pretty good, because when she first started high school, she, she came, um, home, and I said, 'Oh, did you join any clubs?' and she said, 'Yeah, I joined speech and debate.' I almost, I went, 'Wow, speech and debate.' I was, like, shocked, that she would join speech and debate. (P2)</p> <p>And then she was going to high school, so I said, 'Oh, I hope she's gonna do alright.' The speech therapist had said sometimes people who stutter transition to new environments they could have setbacks where the stuttering would interfere more with their ability to communicate. But she didn't seem to have that... she didn't have it in high school, I didn't worry about it in college. (P2)</p> <p>I think it was we didn't know what else to do besides bring him to speech therapy [and] make sure teachers and parents knew. (P5)</p> <p>And then you just carry on. We made sure that he had things that he did love, that were not hard... things he could excel at that his stuttering didn't impact, so that was nice. (P5)</p>

Table 14 (cont.)

...so he had a great deal of difficulty that he was the only one, you know, in the school that stuttered. He never saw anybody else stutter, uh, and, uh, he would get teased by the kids about stuttering, and, um, you know, xxx fights. (P1)

I think [son] had a very hard time in school, and I had a hard time with his school. They were not supportive of doing anything. He acted out. He would swear—not surprising—would occasionally get himself into trouble sort of doing class clown kinds of things. (P5)

...he started—did the typical thing I guess with smoking pot while he was in high school and we found out pretty quickly. Then he shifted to drinking. He ended up having a real drinking problem. It kind of took over and it became a much bigger problem than the stuttering in terms of what we as parents had to deal with. (P5)

...we discovered in high school that it wasn't drugs, it was alcohol... We struggled with issues I'm sure were related to stuttering, but from a family point of view it was, 'What do we do with somebody who is 16-years-old and abusing alcohol?' (P1)

...there were some darker times that it certainly would've impacted the family because I think, based on what was going on in [child]'s life, he acted out in ways. Never outside the home... he never got in trouble at school, and he never got in trouble with the law... maybe a little bit of a silver lining that he never—he would avoid situations, so he didn't go to parties... we did not have drugs or alcohol that we had a deal with, even though his friends did. (P4)

...but when he would be at home, and if he was having a bad day... when he was younger, middle school maybe, probably high school, he would bring that bad day home. (P4)

It was hard to see him not quite fit in. (P3)

I don't know if it's all kids, but I think socially he struggled a little bit, too, but the, um, the stuttering, of course, we always feel that that was a, a problem. (P3)

...he was busy doing things because of these groups, but he wasn't necessarily making friends, and then, or new friends. He stayed very tight with a few boys that he had from grade school... (P3)

...but as he got older, it was, especially when we moved here, it was so clear that kids didn't want to give him the time of day, they didn't want to wait for him. (P3)

...he's doing very well... his number one issue for the last few years is always his lifestyle, friendships... he had roommates in college, he's got roommates now. We worry all the time about what would happen if he lost his friends. (P1)

Note: P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

Societal Views About Stuttering and Importance of Fluency

Not only did each parent discuss the social implications of stuttering on their child, but a unique set of expectations extended to the parent as well. Each parent commented on instances where they recognized social pressure to address their child's stutter. Pressure showed both explicitly and implicitly. For instance, P5's family was an explicit influence, as was P2's pediatrician. P3 and P4 commented on more implicit pressures, such as getting looks at restaurants when their son ordered. Whether from family, professionals, or people in the community, social pressure to address the child's stutter presented in each parent's story. As their stories continued, and they became involved with FRIENDS, each parent discussed experiencing a shift in their thoughts and feelings about their child's stutter. Overall, parents started off by seeking services, practicing behavioral techniques, and feeling pressure from others to 'deal with' the stutter, but involvement in these groups pushed them towards acceptance and focusing on effective communication over fluency. P2 explained how important this shift was for her, and how it helped her realize that focusing on fluency restricts people who stutter and does not help desensitize the community. P4 and P5 also commented on thoughts they had about what jobs their sons would be able to do. This concern about the impact of stuttering on one's occupation appeared to be influenced by this same idea that fluency is the gold standard. After seeing other adults who stutter in leadership positions and holding a wide variety of jobs, they both commented on how their child really can pursue any career and that being an effective communicator and a good person is what should be prioritized (see Table 15).

Table 15
<i>Societal Views About Stuttering</i>
I think [daughter] was better because she got a lot of good feedback when she was younger, um, you know, talking, and people responding to her and being patient, and she had good treatment, so she was really really really, um, blessed, um, with, uh, that, and I know that other people that I've spoken to, their situations are so very much different, you know, um, heartbreakingly different, you know, so, um, um, so I guess that's it. (P2)

Table 15 (cont.)

...and then of course, you know, you hate to project, but, um, you know, clearly there's jobs that you can't do with stuttering, or, or, you know, you'd be really challenged to do. Public speaking was always, um, a concern, and it certainly was a concern in grade school for [son], but, um, now, um, that changed in high school, um, and he, we got him accommodations in college. (P3)

...but, like, little things, going in to order at a restaurant, or, you know, um, the look, you know, of, you know, this, this lady's in a hurry, like, you know, 'I've got to get your order and get to the next table,' or whatever, like, and I saw it, I saw the looks, I hope, I know he saw the looks a lot more than he let on seeing the looks. (P3)

Um, and, you know, and trying to teach people, um, you know, what stuttering is and what it isn't, and it's not just a um, you know, when people are nervous, 'cause a lot of people stutter when they're nervous, they're on stage and hate being on stage, and, you know, and they freeze up, that's not stuttering. (P4)

Um, and I think that's probably the case in, in some, I think some people truly don't want to talk to him because they don't want to listen xx they don't know how to react to him. (P4)

...this is a town where there's a lot of pressure to do well. A lot of parents have advanced degrees and run businesses and make lots of money so there was always pressure to sort of be doing great. And so those were kids who, it was hard to keep up. He couldn't. (P5)

I think there came a point where it was pretty clear that what I needed to do to be a good parent to [son] was really different from what other parents in this town were doing... it just became clearer that we have a different package [situation**]... (P5)

I kinda understood, also, how when we focus on fluency, people who stutter only talk when they feel they can be fluent, and that doesn't desensitize the, the community to different patterns of speech. And it makes it harder for people who stutter. Instead of making it easier, it makes it harder. There was a lot of things that... my perspectives really changed on so many levels, so that was really important. (P2)

...but even going off to college this year, we had an encounter on move-in, and I said, 'People just don't understand. They have never, you know, come encounter, encountered this, and people don't understand typically what they're hearing or what's happening, so to be an advocate. (P3)

Note: P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5

*** Feedback given from participant*

Final Thoughts and Insights

At the end of each interview, parents were asked to summarize their main takeaways from their experiences with their child and with FRIENDS. Each parent was then asked to share what they felt was the most important aspect of therapy now that they have been through this process of change. Responses fell into four main categories. Parents commented on the importance of acceptance and prioritizing communication over fluency, teaching fluency techniques as tools rather than solutions, the importance of learning to treat stuttering specifically, and the importance of exploring the underlying social-emotional impacts of stuttering (see Table 16).

Table 16
<i>Final Thoughts and Insights</i>
...we're of similar mind now, with... especially these people that... have the same philosophy about... communication, and these are the important things, and that fluency is not on the top of that list of the treatment with stuttering. (P2)
My daughter has a lot of tools, but in the same way... we say, you get dressed up for work; you have a three-piece suit, a tie, shoes on, and the first thing you wanna do when you get home is take all that off. Take all your tools off, because using tools is so stressful. You have them when you need to be an effective communicator, but otherwise, why are you using them? Why are you exhausting yourself, you know? (P2)
...so that was, there was a real switch, right? If you wanna call, 'Fire fire, everybody out of the building, there's a fire,' you might have to use your tools—in an emergency or if you need to communicate something, but not all the time. And that was always the focus, and I feel sad about that... so I think when parents realize that, it changes everything. And especially for fluency that's up and down, 'Oh, he's doing good. Oh, he's not doing good. He's doing good.' All of that, it's so disruptive to the child. Having that end goal as to be fluent instead of to be an effective communicator. (P2)
[Re: takeaways] I think the thing of acceptance and just really not the focus on fluency. And the support. The support was so important. (P2)
...everyone knew from the day he met everyone, and he stuttered, but it was no big thing. But as those middle school years and high school years wore on, it became a much bigger iceberg underneath the water... from that perspective is—certainly try to help the child understand the techniques—but get down to what's really going on and help them deal with the rest of the iceberg... That's what I think FRIENDS has helped do, is deal with what's underneath the water and not just what's visible. (P4)

Table 16 (cont.)

...it's not about being fluent, it's about being able to get your thoughts out. Where you can live and go into society with more confidence. (P4)

[Re: experience with school therapists] I wish those speech therapists had been willing to stand up to their management and say, 'This is something that requires a specialty. I don't know enough about this.' I would have appreciated that in a speech therapist. And that's a lot to ask because there can be a lot of pressure to just deliver services and save the school system money. But I think that was damaging to [son]... there's no shame in saying, 'I'm not sure I can do this for you'. I think the shame [is in not] representing yourself—in an area, specialty areas for people to be able to qualify. (P5)

Note: P2 = Participant 2, P4 = Participant 4, P5 = Participant 5

DISCUSSION

Though each parent's story was unique, many experiences were shared across participants as well as with those included in previous research on caregivers of both CWS and individuals with other disorders. Participant stories followed similar timelines including stuttering onset, therapy, and involvement with FRIENDS and were impacted by various external influences along the way.

Timeline Summary

Similar to findings reported by Plexico & Burrus (2012), the onset of stuttering for these families was generally accompanied by feelings of uncertainty surrounding persistence of the stutter. For the parents included here, a sense of hope and optimism that the child would outgrow their stutter was also present, particularly in the beginning before the child began demonstrating any social difficulty. This additional response may be due to others—including professionals—continually reassuring parents that stuttering often resolves on its own. While waiting, parents searched for more information and used behavioral techniques, two strategies that have also been previously reported in stuttering research by Langevin et al., (2010) and Plexico & Burrus (2012).

As each family began therapy, service-related stressors commonly seen in other disorder research were observed including a lack of access and availability of services, strained interactions with professionals, difficulty finding information, and not being included in treatment decisions. Stress surrounding the diagnosis and treatment processes has also been observed in previous research, particularly for caregivers of individuals with other invisible disorders due to controversy surrounding the disorder (Cronin, 2004; Kelso et al., 2005). This type of treatment-related stress was apparent for this group of parents as well. More specifically, for these parents especially, variability in therapist qualifications and lack of family involvement in treatment became primary stressors. This was particularly true for school-based services. Overall, the focus of treatment (e.g., fluency vs. communication), the qualifications of the therapist, whether the therapist was long-term or short-term, and the degree to which therapists involved the family all notably impacted

parents' therapy experiences. Communication focused therapy, qualified and long-term therapists, and therapy where the family was highly involved appeared to be mitigating factors for treatment-related stress for these parents.

Unfortunately, as observed by Cronin (2004) and Kelso et al., (2005) with caregivers of those with other invisible disorders, there was an overarching lack of community and professional support for these parents as well. FRIENDS, then, appeared to be a welcome opportunity to find more information and support. These were the two biggest reasons for attending and returning to the group. Attending stuttering support groups for information and for emotional support was noted in Klein et al., (2015) as well. Though families initially attended FRIENDS to better support their children, all parents experienced additional personal benefits that are still present today.

Influencing Factors Summary

As each parent's story unfolded, along with common experiences, common influences arose as well. Often regardless of point in time, family relationships, fears and worries, and social perceptions influenced parents' actions, thoughts, and feelings. Though most parents felt their families were affected, this was mainly due to secondary effects of the child's stutter. This is similar to Langevin et al., (2010) and Erickson & Block (2013) who both reported factors such as difficulty mitigating the child's frustrations and parental frustration from seeing others react negatively to their child's stutter were more impactful. Also, like Langevin et al., (2010), individual relationships within the family were minimally impacted by the child's stutter. In the current study, parents reported they felt like their relationship with their child was largely unaffected, but they did modify their communication with their child. Sibling relationships were relatively positive as seen in those discussed by Beilby et al. (2012). Additionally, responses from extended family varied within and between families.

For parents, a variety of emotions also arose. Most notably, feelings of uncertainty, anxiety, worry, and frustration appeared pervasive and notably influenced parent concerns and their responses. These emotions parallel those reported by parents of children who stutter in Langevin et al., (2010) and Plexico & Burrus, (2012). However, the feelings of

guilt and self-blame that are commonly reported in stuttering research were not prominent here. Parents were most commonly concerned about their child's participation and social relationships. This concern, and attempts to alleviate it, were similar to those seen in previous stuttering literature (Langevin et al., 2010; Plexico & Burrus, 2012; Erickson & Block, 2013), where parents worried their child may lose self-esteem, withdraw, be reluctant to pursue goals, struggle in school, and struggle with social relationships; this anxiety is particularly prevalent when discussing their child's future. Parents tried to make sure their children continued to participate in preferred activities. P5 specifically commented on making sure her son had activities he enjoyed that stuttering would not impact. Two families had additional concerns about personal and behavioral challenges specific to the child.

In keeping with previous stuttering research (Langevin et al., 2010; Plexico & Burrus, 2012; Erickson & Block, 2013), social stressors were common for parents in the current study. Social pressure to address the stutter compounded with inconsistent information about the etiology and treatment of stuttering was noted as a stressor for some parents, as were fears about others' reactions to the child. Though these pressures pushed parents to seek treatment for their child early on, parent attitudes and beliefs about stuttering and its treatment shifted over time due to therapy experiences, education, and involvement in FRIENDS.

Clinical Implications

From a clinical perspective, the variability in therapy experiences and deeply rooted emotions associated with different approaches is particularly illuminating. Parents often spoke about the lack of training and understanding their SLPs had of stuttering and of their child. This finding is even more salient when considering the reality that this is not an unfounded impression. For many SLPs, diagnosing and treating stuttering is a daunting task. A 2013 study surveyed 141 school-based SLPs to explore their training, experience, and comfort level with treating stuttering. 47.5% of participants reported they did not have an undergraduate class dedicated to stuttering and 10% reported they did not have one in graduate school (Gabel, 2013). This lack of exposure was even more noticeable when examining treatment experience where just over half of the participants reported no

experience (i.e., 0 hours) diagnosing or treating stuttering during their clinical fellowship year. Consider this in comparison to a study exploring SLP experience and comfort with written language disorders. Of 599 school-based SLPs, 60% reported working with a child with a written language disorder weekly or even daily. Most respondents stated they felt “somewhat confident” in diagnosing and treating these disorders despite limited clinical training likely because 63% received on-the-job training instead (Blood et al., 2010).

This disparity in training and everyday experience with stuttering as compared to other speech and language disorders shows up in many different ways. As was observed in the current study, this lack of training can become apparent to parents resulting in feelings of mistrust and frustration. Uncertainty about how to approach stuttering may lead to many CWS being placed in groups and treated the same as children with articulation disorders. One 2020 study even suggested that the lack of confidence many SLPs have in their knowledge of stuttering resulted in therapists being reluctant to even use the term “stuttering” when discussing diagnoses with families (Byrd, 2020). Suggestions have been made for how to improve SLP training and experience with stuttering such as increasing opportunities for continuing education and introducing fluency disorders earlier on in undergraduate classes (Gabel, 2013). More clinical experience and knowing people who stutter have also been identified as predictors of increased therapist comfort (Byrd, 2020). However, speaking with the parents and family is not always included in these suggestions, despite the importance of involving family in providing effective evidence-based practice.

Variability in the Experiences of Being a Parent of a CWS

Although the parents in the current study shared many emotions and experiences with each other and with parents in other studies, and all parents benefitted in similar ways from FRIENDS, the ways in which these factors interacted differed for each family. Across just three families, a range of experiences emerged. The child’s response to their stutter, the subsequent response from the family, and personal and professional supports available to parents all contributed to each parent’s overall experience. Only by talking with families can clinicians truly begin to understand the unique set of factors contributing to that family’s experience, needs, and life. Consider each family.

P2 generally reported a fairly positive experience; she reported relatively few worries about her daughter as she did not appear to have many of the challenges often seen in CWS. P2 reported her daughter struggled briefly in kindergarten because she was not talking at school; however, P2 addressed this with her daughter quickly and directly. In addition, both P2 and her daughter had strong therapist and community support. P2 remained active in her daughter's therapy and continued to encourage her to participate in preferred activities. As a result, this difficulty resolved fairly quickly, and the child continued to do well socially throughout school.

P3/P4 described a mixed experience where challenges gradually increased as their son got older but have since begun to improve. Growing up, P3/P4's son experienced more social-emotional difficulty which seemed to be exacerbated when the family moved during grade school. Parents reported he did well in school but was notably quieter and more withdrawn than when he was at home. He also struggled with anxiety and depression in his early teenage years. For this family, concerns about their child's participation and relationships were more prominent. As a result, P3/P4 made more direct efforts to find ways to help their son through different therapists and encouraging his interests and hobbies at home and school. Though this family did not have as consistent therapist support as P2, both sides of the family were very supportive. They were also able to find their son a personal mentor at the end of high school who provided additional supports outside of stuttering.

P1/P5 described a more challenging experience overall. Like P3/P4's son, P1/P5's son also had more social-emotional difficulty, but for this child, these challenges did show up in school. Parent's reported difficulty with friendships, fighting, and 'class clown' behaviors. Though this family had consistent therapist support, as their son got a little older, their focus shifted away from the stutter and involvement in FRIENDS for several years in favor of addressing his struggles with alcohol use. Their son has since returned to FRIENDS and has tried speech therapy again. However, P1 discussed how they still have some social concerns and would be very concerned if their son lost his current friends.

The variability observed in just a handful of parent experiences demonstrates the complex interplay of factors often seen with CWS and their families. Consider P2's daughter

and P1/P5's son. Both families were able to connect with a qualified therapist close to the time of onset and both families attempted to address the stutter in similar ways, but both children still responded to their stutter in drastically different ways. Another example is clear when comparing P3/P4's son and P1/P5's son. Both children experienced social-emotional difficulties likely resulting from their stutter, but this difficulty manifested behaviorally in different ways. Though it is tempting to quantify parent experiences based on a set of events and a select few influencing factors, it is important to remember that these parents and their families are influenced by much more. Furthermore, parent priorities and what they want from therapists also varies between families and may likely change over time within them.

Parent Advice and Recommendations

Fortunately, the parents in the current study offered a preliminary set of recommendations and requests for therapy. In general, parents typically responded more positively to communication-focused therapy over fluency-focused therapy, and to therapists who were specialists or who had more clear competence in this area. Significant dissatisfaction with school-based services was present due to lack of qualifications and individualized treatment. When asked what they would have wanted from therapy or what they want SLPs to know, parents discussed wanting therapy that (a) focuses on effective communication over fluency, (b) teaches fluency techniques as tools to be used when necessary rather than all the time, (c) attends to the social and emotional impacts of stuttering and supports the child through these, (d) is specialized and individualized to the child rather than treating stuttering the same as an articulation disorder, and (e) prioritizes acceptance. Along with acceptance-oriented therapy—such as those that include mindfulness exercises (Boyle, 2011), cognitive behavioral therapy (Nnamani et al., 2019), acceptance and commitment therapy (Beilby & Yaruss, 2018), or a combination of approaches (Freud et al., 2019)—parents wanted therapists who focused on and actively practiced acceptance as well. They also discussed the importance of therapists who work to connect with the child on a personal level while incorporating the family, and therapists who put in the effort to learn more about the treatment of stuttering or who will accurately represent their qualifications, or lack thereof, and advocate for a referral to someone more qualified when necessary.

Ultimately, effective and holistic family support will come from combining SLP knowledge and continuing education, knowledge of common stressors and protective factors for CWS and their parents, and the goals, priorities, and experiences of each individual family.

Limitations

Because of the sampling method, the narratives collected represent a very specific subset of the population of parents with CWS, namely White, highly educated, middle-class families with the time and technological and financial resources to take advantage of organizations such as FRIENDS. A relatively small sample size was used; two couples and one single parent which resulted in only three different children who stutter. However, each parent was interviewed separately and encouraged to speak on their own lived experience. Interviewing couples provides some insight into how these experiences can be different between parents. Participants were longtime FRIENDS attendees resulting in a potentially biased sample; parents who attended FRIENDS once and then did not return because they did not find it helpful are not represented. Parents and families who have not attended or sought support groups are also un-represented here. Though the current study was focused on families who have had experience with support groups, it is highly likely that more families would seek these groups if other barriers were not present. Financial constraints, limited time, distance from and lack of access to any therapy services, family culture and support, and the needs of other children or family members are just some of the socioeconomic factors that may be at play. These families should be included in future research to better understand the barriers to support that they experience in addition to the stuttering-related challenges discussed in this study. Convenience sampling was used as well. Future research should try to recruit randomly from a pool of first-time attendees or a mixed group of first-time and returning parents.

Conclusion

From the time of onset, these parents were impacted by their child's stutter. They experienced feelings of confusion, hopes of recovery, and a myriad of other emotions and

concerns all the way through their child's development. For these parents, the stress of balancing the everyday needs of themselves, their child who stutters, and other family members was compounded by a pervasive lack of community and professional support. Difficulty finding qualified and accessible therapists, community resources, and personal supports resulted in often profound feelings of dissatisfaction, frustration, and irritation. Furthermore, for some parents, though the degree of impact may have decreased, many of these concerns and emotions are still present even today. To combat this, parents worked—and continue to work—to find the best ways to support their child through each stage of their life. Throughout this process, all parents have found involvement in support groups to be highly beneficial. This kind of social support not only encouraged parents to shift their views of stuttering away from prioritizing fluency and towards actively accepting their child and their stutter, but these groups also created a sense of connection between parents and provided a safe place for parents to share their stories, concerns, and advice. Finally, support groups helped give these parents the support they needed in order to support their child. This system of reciprocal and cyclical support is crucial to the effective treatment and wellbeing of those who stutter and their families. In light of this, those working with CWS must involve the family and take into consideration the type of therapy they are seeking in order to provide the best care.

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